Mercury Disability Board Reform Expert Panel
Final Report

Submitted to the Parties

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Table of contents

List of Tables

List of Figures

Message from the Expert Panel

Since the Mercury Disability Board (MDB) was established in the mid-eighties, there have been important advances in knowledge on the health effects of mercury exposure. Over this same period, the critical role of cultural sensitivity for better understanding the health and rights of Indigenous people has evolved. The mandate of the MDB Expert Panel was to update the examinations and processes of the MDB within the context of current knowledge and best practices.

The Expert Panel thanks all the people interviewed. We learned much from the communities and from individuals currently or previously involved with the MDB. Their input allowed us to contextualize our scientific knowledge with the reality of the situation.

We began our work with visits to the two communities. They expressed significant concerns for their health, well-being, and future of their people. The Elders have tremendous concern for their children, who live with learning, behavioural and health problems. The young adults and Elders also have significant, life-impairing health conditions, and feel that they are aging faster than their parents and grandparents.

Our visits to the communities demonstrated that the health facilities are inadequate to provide care and therapeutic interventions for persons with mercury poisoning. Within local school programming, there is no formal recognition of the need for adapted learning or other interventions to counteract the known effects of mercury on the developing brain. It is the opinion of the Expert Panel members that adequate individual and community-based therapies and counselling would reduce the number of persons requiring individual compensation.

We heard from many people, including community members, physicians, as well as current and former MDB members, that the current process is unfair. Many of them told us that the communities, as a whole, deserve compensation. While this is beyond our mandate, we would like to go on record that we agree with this statement.

The MDB was born out of a negotiated settlement in the mid-eighties and reflected the beliefs and knowledge of the time. The Honourable David Crombie, Progressive Conservative Minister of Indian Affairs and Northern Development presented the Bill that set up the MDB to the House of Commons on May 21, 1986, and noted that it had taken 16 years from the knowledge of the disaster to the settlement[1]. He hoped that the Bill constituted *"the last page of the bad old way on the matter of Grassy Narrows and Whitedog."* and that "*…it is the first page for a new future for both these bands".* He further mentioned that *"we will never be able to rectify what was done*" and indicated

[1] Honourable David Crombie, Progressive Conservative, Minister of Indian Affairs and Northern Development: presentation of the Grassy Narrows and Islington Bands Mercury Pollution Claims Settlement Act. House of Commons Debates 33rd Parliament Volume IX, May 21, 1986, p. 13496.

that although the negotiations were difficult, *"the next 20 years will be the most difficult for these communities."*

When the MDB was established, the general belief was that *"the delayed effects of mercury ingestion will not appear as late as ten years after cessation of mercury-contaminated fish"*[2]. Science has shown this assumption to be incorrect. Current MDB procedures and examinations must be updated to reflect present-day knowledge and understandings.

The following key drivers guided the Expert Panel's work:

- Canadian decision makers and the public recognize that systemic racism has inequitably affected many decisions concerning Indigenous peoples.
- There is an increasing recognition among health authorities that Indigenous concepts of health and well-being are different from non-Indigenous approaches.
- Best practices in compensation have evolved over time.
- There is a greater understanding of the breadth of chronic and long-term health effects of methyl mercury exposure.
- Diagnostic tools and protocols for neurotoxicity have been refined.
- Assessments of quality of life have been shown to be relevant indicators of well-being and functional disability.
- There is a wealth of information on historic biomarkers of mercury in the two communities.

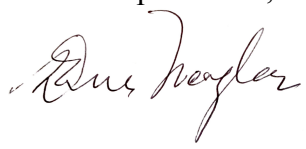
The Plan Document requires that points be used to summarize an individual's impairment due to *"signs and symptoms consistent with mercury poisoning."* We had great difficulty with reducing an individual's life and hardships to a score. Conceptually, this score reflects the personal physical and mental health consequences of an environmental disaster that eliminated the communities' livelihood and health, deprived them of the fish and wildlife central to their cultural traditions and nutrition, and left them with few Elders.

[2] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-exposed Indians of the Grassy Narrows and White Dog Reserves: Report and Recommendations, 13 pp.

When the settlement was passed into law, Mr. Crombie stated in his concluding remarks[3]: *"Anyone who has had experience with the episode of mercury poisoning in the English and the Wabigoon Rivers and how it affected the communities will know that, in a way, we will never rectify what was done."* Mr. Keith Penner, Liberal Party member for Cochrane-Superior added[4]: *"I want to indicate that the compensation package for these Indian people is only a very humble attempt to correct a wrong. It seems that all we can do is offer money… However, let the House know that in no way can we heal all the wounds or undo the harm"*.

In our recommendations to update the MDB examinations and procedures, we did our best to respect both the individual, the community and the requirements set up by law.

For the Expert Panel,



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[3] Honourable David Crombie, Minister of Indian Affairs and Northern Development: presentation of the Grassy Narrows and Islington Bands Mercury Pollution Claims Settlement Act. House of Commons Debates 33rd Parliament Volume IX, May 21, 1986, p. 13496.
[4] Mr. Keith Penner, Liberal Party member for Cochrane-Superior. House of Commons Debates 33rd Parliament Volume IX, May 21, 1986, p. 13497.

Executive Summary

Between 1962 and 1975, a chlor-alkali plant discharged approximately 10,000 kg of mercury into the English-Wabigoon River System, depriving the First Nation communities, for whom fish was central to their cultural heritage, of their livelihood, their health and their dietary mainstay[5]. A 1978 preliminary "Memorandum of Understanding" produced by the government of Canada stated that *"the Indian Bands residing on Whitedog and Grassy Narrows Reserves are experiencing adverse effects on their social, health, cultural, environmental well-being, as well as their economic opportunities by reason of damage to resources on which they relied for the viability of their communities."* [6]

In 1985, a Memorandum of Agreement was signed between the plaintiffs Asubpeeschoseewagong Netum Anishinabek ("ANA"), also known as Grassy Narrows, the Wabaseemoong Independent Nations ("WIN", formerly known as Islington Band) and the defendants: Reed Limited, Dryden Chemicals Limited, Dryden Paper Company Limited, Reed Incorporated, Great Lake Forest Products Limited, Her Majesty the Queen in the Right of the Province of Ontario. This agreement, mediated by Justice Emmett Hall, included the establishment of the Grassy Narrows and Islington Bands Mercury Disability Board (henceforth referred to as MDB). It is useful to recall that the Mercury Disability compensation constitutes the major benefit for which *"all existing and future rights of action of a Band, and of every past, present and future member of a Band, and of the estates thereof, in respect of any of the claims or causes of action that are the subject of the Agreement are hereby abolished."*[7]

In 1986, the Ontario parliament adopted the English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act c23 (henceforth referred to as the Act), which established the MDB.

In January 2019, the four parties, ANA, WIN, Canada and Ontario, set up an independent Expert Panel, the MDB Reform Expert Panel ("Expert Panel") to *"determine and report on whether, in addition to the existing Known Conditions, there are other observable*

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[5] Canada-Ontario Steering Committee. 1983. Mercury Pollution in the Wabigoon-English River system of Northwestern Ontario, and Possible Remedial Measures. Summary of the Technical Report. 18 pp.
[6] Vecsey C. 1987. Grassy Narrows Reserve: Mercury Pollution, Social Disruption, and Natural Resources: A Question of Autonomy. American Indian Quarterly 11: 287-314.
[7] Hall E. 1986. Affidavit. In the Supreme Court of Canada between Isaac Mandamin (and others) and on behalf of all members of the Islington Band of Indians and Simon Roy Fobister (and others) on the on their own behalf and on behalf of all members of the Grassy Narrows Band of Indians (numerous other names) plaintiffs and Reed Limited, Dryden Chemicals Limited, Reed Inc., Great Lakes Forest Products, Her Majesty the Queen in the right of the province of Ontario, Defendants.

medical symptoms, signs or conditions (or combination thereof) that are reasonably consistent with mercury poisoning and capable of significantly impairing the quality of life or limiting the activities of an applicant… and any corresponding additions to the Grading Guidelines in the Plan Document, or any related MDB documents, policies or procedures."[8]

Members of the Expert Panel include the following specialists, with expertise in environmental health:

Donna Mergler PhD: Chair, Neurophysiology

David Bellinger PhD: Neuropsychology

Jane Hightower MD: Internal Medicine

Bruce Lanphear MD: Children's environmental health

Katherine Lippel LL.M : Compensation Law

Brad Racette MD: Neurology

Chantelle Richmond PhD: Indigenous Health

A brief summary of the expertise of each member is presented in Appendix 1.

The scope of work assigned to the Expert Panel was to:

i. Determine whether further conditions should be added to the Known Conditions, listed in Appendix III of the Plan Document;
ii. Update the grading guide;
iii. Align policies and procedures to changes in the examinations and grading.

The work of the Expert Panel began with community-organized visits to ANA and WIN, where assemblies, focus groups and individual encounters told their stories of experiences with the MDB process. The take-away message was the need for cultural safety, policy and decision-making transparency, and counselling. School personnel stressed children's learning disabilities, behavioural problems and special education needs. In addition to input from the communities, Expert Panel members established a fruitful dialogue with the MDB, and consulted with former and present MDB members and physicians, as well as with outside experts in different fields.

[8] Mercury Disability Board Reform Expert Panel ANA-WIN-Canada-Ontario [Without Prejudice] Terms of reference. January 2, 2019.

To carry out its mandate, the Expert Panel developed a multi-tiered framework (Figure 1) to: i) review the documentation provided by the parties; ii) critically examine the breadth of scientific knowledge since the mid-eighties; and, iii) identify gaps in the current assessment processes. Using this framework, a total of 51 evidence-based recommendations were formulated. A first set of 13 recommendations addresses the cross-cutting issues of cultural safety and best practices in compensation, that form the context for appropriate examinations and accompanying processes. These recommendations are core to the work of the MDB.

In conformity with the Act and the Plan Document, the Expert Panel updated Known Conditions and recommends the addition of Further Conditions and Other Material. A total of 11 recommendations, based on current state of the art protocols and tools, focus on updating the assessment of the Known Conditions for the adult examination. In keeping with the current scientific evidence of the effects of prenatal, childhood and adult exposure to mercury on the nervous system, the Expert Committee recommends that addition of two Further Conditions: Neuropsychological Deficits and Neuropsychiatric Disorders. Seven recommendations address these Further Conditions.

In keeping with Section 10 (d) of the Act[9] that indicates that the MDB can prescribe *"other material"* for the application and Section 27 that states that: "*The Board shall consider any information, advice, report, evidence or other material or matter which, in its sole discretion, it deems useful for the purpose of deciding any matter including whether it may be appropriate to make or vary any award or awards...",* the Expert Panel proposes the category 'Other Material', which groups elements that do not fall under Known or Further Conditions (5 recommendations). The elements within this category serve to inform the MDB and, in specific circumstances, qualify for additional points. Under 'Other Material' to be submitted to the MDB, we include the general examinations and medical and personal histories, previously part of the neurologic adult and pediatric examinations, and diagnosed non-neurologic chronic health conditions *"reasonably consistent with mercury poisoning and capable of impairing the quality of life or limiting the activities of an applicant",* as well as a questionnaire that addresses the loss of quality of life and activity limitations. Finally, we consider historic biomarker information (umbilical cord blood, blood and hair) and formulate 5 recommendations on how this information would be used in the grading system for adults.

For children's assessment, the same cross-cutting issues apply; the multi-tiered framework for the children's clinical examination is presented below (Figure 2) Six recommendations address the children's examination and four recommendations address the grading system.

[9] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, 1986, Statutes of Ontario, 1986, c.23 p. 275.

Figure 1. Multi-tiered Framework : Adult

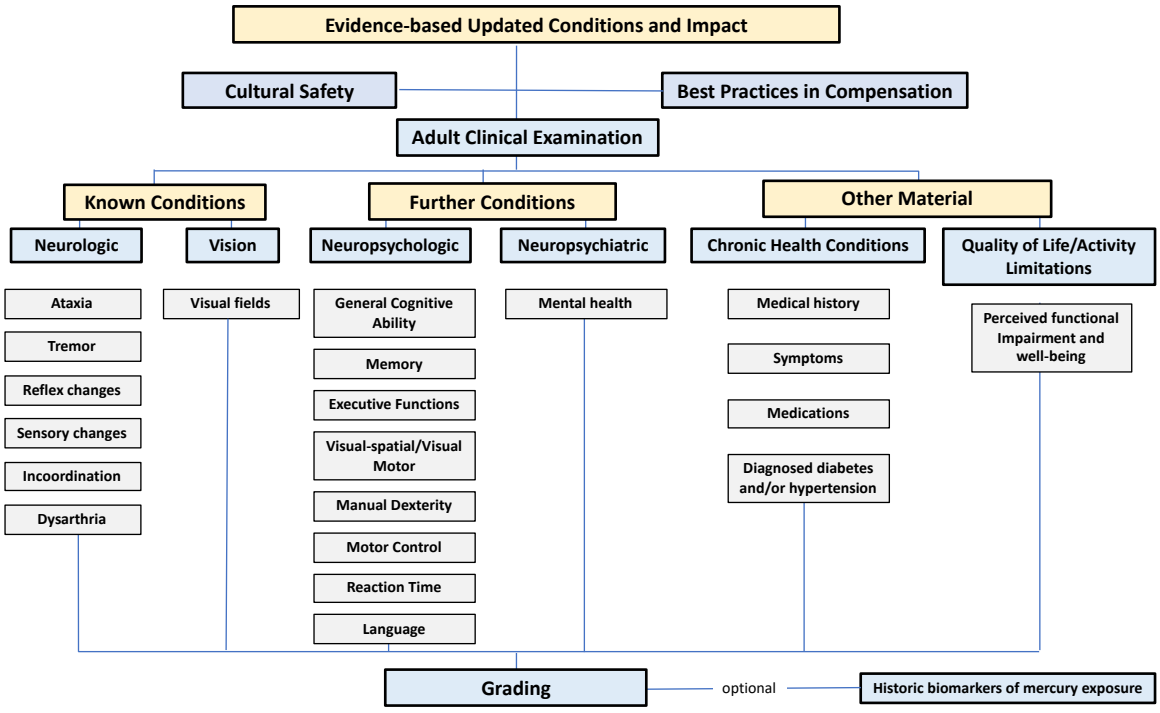
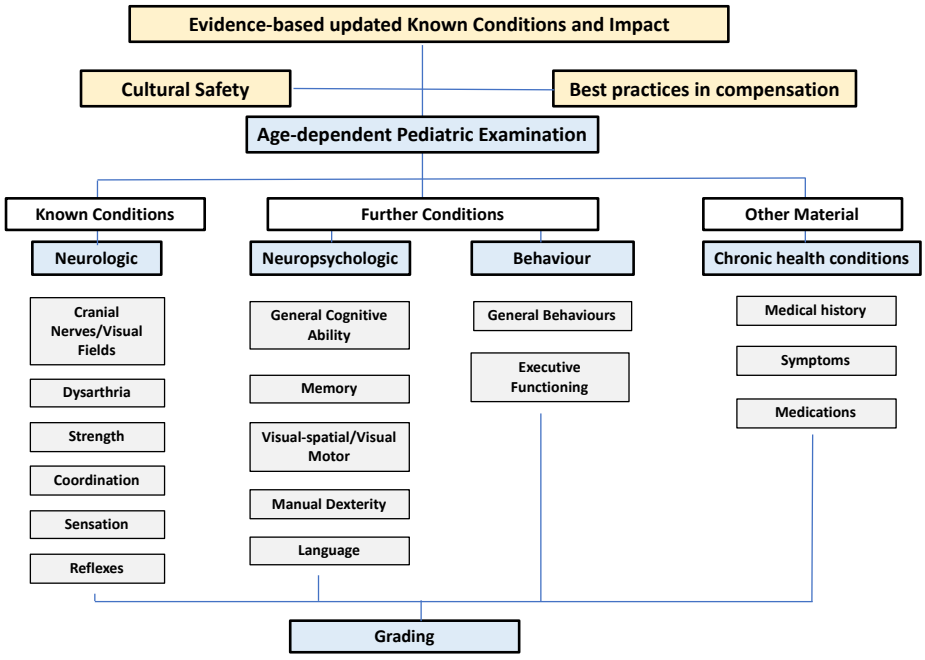


Figure 2. Multi-tiered Framework : Children



Each element in blue of the framework constitutes a chapter of the present report, with a discussion of the background, a summary of the current scientific literature, recommendations for best practices and examination protocols, required personnel,

concluding with a summary of the rationale and recommendations, outlined below. The final chapters address the issue of historic biomarker data and present a decision-tree grading system, in conformity with the existing distribution of points. The concluding chapter presents an operationalized overview of the elements of the framework, with overarching considerations.

Rationale and Recommendations

Cultural Safety

Given the moral obligation to be culturally sensitive in the currently strengthening climate of cultural equity and reconciliation,

We recommend that:

1. Every individual involved in any capacity with the MDB and/or mandated to interact with the actual or potential claimants, receive specific training on ANA and WIN culture, history and experiences with mercury.

2. The professionals, recruited by the MDB to carry out the examinations, be required to complete a program on Indigenous Cultural Safety.

Given the perception and testimonies of poor communication, mistrust and distance between the community members and the MDB,

We recommend that:

3. The MDB enhance their outreach strategies, including appropriate communication tools, website architecture and content, integration of cultural rituals in opening and closing of meetings, and co-learning through face-to-face activities.

4. The hiring of a Community Support Worker for each community, with a contractual relation with the MDB, to ensure that claimants meaningfully participate in, and benefit from, the mandate of the MDB.

Given the inequality of training on legal and health issues between representatives of the communities and representatives from government and other MDB appointees,

We recommend that:

5. Community members on the MDB be provided with the financial support to hire consultants when they consider it necessary.

Best Practices in Compensation

Given the legal and ethical concerns that may arise from the medical evaluator's role and the need to ensure a trustful and culturally safe climate,

Given the evidence from the Community Health Assessment that contradicts the voiced suspicion on the part of several of the persons involved with the MDB of wide-scale malingering by claimants,

Given the difficulties in recruitment of professionals,

Given that section 1 of the Act defines "authorized physician" as "*a physician entitled to practice medicine in any jurisdiction in Canada or the United States of America and designated as an authorized physician by the Board,",*

We recommend that:

6. The MDB recruit culturally sensitive, authorized specialists from any jurisdiction in Canada or the United States of America.

Given the perception of procedural complexity,

We recommend that:

7. The Community Support Workers (see recommendation 4) inform and assist potential and current claimants through the process, from eligibility to application, to decision-making interpretation, re-application and review, as needed.

Given procedural fairness requirements,

We recommend that:

8. Acceptance and denial letters include detailed justifications of the decisions.

9. Claimants have access to their files including, but not limited to, the evidence provided by the specialists who undertake the evaluation at the behest of MDB.

Given that the right to be present when one's claim is heard and the right to review are clearly laid out in the Act,

We recommend that:

10. All claimants should be invited to attend the meeting when their claim is on the agenda.

11. Claimants whose initial applications or reapplications are denied, or who receive, by the decision, a lower level of benefits than they expected, be informed of their right to review.

12. All claimants should be informed of the reapplication process when they receive their decision.

13. When requested, financial support should be provided to cover fees of counsel and/or access to a second medical opinion, for claimants seeking review.

Adult Clinical Examination

Given that the adult examination, carried out by the MDB, is based on the Prichard and McIntyre report, using data from examinations conducted between 1976-1979;

Given that the belief, at the time of the Act, that delayed effects of mercury would not appear as late as 10 years after cessation of exposure, has been proven incorrect;

Given that there is scientific evidence that neuropsychological deficits and neuropsychiatric symptoms can result from methylmercury exposure;

Given the extensive literature on the neurodevelopmental toxicity of prenatal exposure to mercury exposure and that almost all claimants, born in 1962 and after, were exposed *in utero*.

Given the growing evidence that methylmercury exposure can contribute to non-neurologic chronic health conditions,

Given that according to Section 10 (d) of the Act, the MDB can prescribe "other material" for the application,

We recommend that:

14. The clinical examination for Known Conditions be updated to current best practices.

15. The examination be expanded to include documented Further Conditions.

16. Relevant elements, not included in Known or Further Conditions, be included in Other Material prescribed by the MDB.

Given that the medical history, nervous system complaints, personal history and general examination included in the current Clinical Adult Neurologic Examination Protocol is cursory;

Given that one of the major complaints of claimants is a feeling of being short-shifted and that the story of their symptoms is overlooked;

Given the need for a good medical history that includes symptoms that are consistent with mercury poisoning and sometimes sporadic, as is the case for other neurological conditions;

Given that some claimants may have undergone clinical neurological and/or psychological examinations through referral by their primary clinician or in the context of research projects;

Given the need for a "safe place" where the claimants can relate the history of their health problems in their own words;

Given that according to Section 10 (d) of the Act, the MDB can prescribe "other material" for the application,

We recommend that:

17. The general examination be eliminated from the neurologist's examination.

18. A medical history, including current symptoms, and a general examination be performed by an authorized, specially trained nurse practitioner and the report be included in Other Material to be submitted with the application.

19. If the claimant so wishes, information from previous clinical neurological and/or psychological examinations, carried out by referral to specialists or as part of a clinical research project, be provided to the nurse practitioner and included in Other Material.

Neurologic Examination

Given that the Known Conditions included in the current neurologic examination are still relevant;

Given that current best practices in neurology include validated, anchored protocols, ensuring better consistency, precision of application and reproducibility;

Given that the current visual examination is not sufficiently sensitive to assess ophthalmological impairments;

Given that the current examination of visual functions in the neurologic examination serves solely to determine whether the claimant should be referred for visual field examination,

We recommend that:

20. Specific rating protocols be adopted for tremor and ataxia (encompassing incoordination and dysarthria) and sensory loss.

21. Vision loss be removed from the neurologic examination and assessed by an optometrist, within the context of the visual field examination.

Visual Field Examination

Given that the visual system (retinal and cortical) is a well-known target for methylmercury;

Given that visual field loss is included in the Known Conditions for mercury poisoning;

Given that visual field analysers quantify the sensitivity of peripheral vision;

Given that persons with mercury-poisoning may have deficits that affect their ability to adequately follow the testing procedure for visual field loss,

We recommend that:

22. All claimants undergo a visual field examination.

23. The visual field examination be performed using a Humphrey Visual Field Analyser (HFA) with gaze tracking capability, with the 30-2 Swedish Interactive Thresholding Algorithm (SITA).

24. The scoring procedure to assess visual field constriction be adapted to possible neurocognitive deficits.

Neuropsychological Assessment

Given that it is well recognized that methylmercury exposure, even at very low levels, is associated with neurocognitive disorders;

Given that the analysis of MDB data shows that a large number of adult claimants and in all probability future claimants were exposed *in utero* and/or in early childhood;

Given that the developing brain is the most sensitive target for methylmercury toxicity;

Given the evidence of neurocognitive deficits associated with cerebellar lesions;

Given the scientific literature showing that neurodevelopmental deficits affect future functional capacities;

Given that neuropsychological test batteries provide a quantified assessment of brain functions;

Given that nervous system disruption caused by toxic exposures may not be detectable without neuropsychological testing,

We recommend that:

25. Neuropsychological deficits be included as Further Conditions.

26. All claimants undergo an examination of neurocognitive status, using validated neuropsychological tools for the following domains: Cognitive ability, Memory, Executive functioning, Visuo-spatial/Visual-motor ability, Manual dexterity, Attention/vigilance and Language.

27. The neuropsychological test battery be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist trained in the administration and interpretation of neuropsychological tests.

Given that the neuropsychological test battery is lengthy and time-consuming;

Given that we expect a pattern of deficits, with some brain areas more affected compared to others,

We recommend that:

28. The results of a first cohort of 60 consenting persons[10], be analyzed to identify domains with the greatest and least deficits, with a view to refining the battery and reducing the time required to administer the tests.

Neuropsychiatric Assessment

Given that psychiatric symptoms are known to be associated with methylmercury poisoning;

Given that psychiatric symptoms affect functional capacities and quality of life;

[10] This number was ascertained using power calculations from a Pilot Project with 11 adults from Grassy Narrows.

Given that there are validated, normed questionnaires to assess neuropsychiatric symptoms;

Given that the SCL-90-R has been validated in First Nation communities and shown to have a high internal consistency,

We recommend that:

29. Neuropsychiatric disorders be included as a Further Condition**.**

30. All claimants be screened for neuropsychiatric symptoms, using the SCL-90-R, which includes 3 Global Scores and the following dimensions: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticism.

31. The neuropsychiatric questionnaire be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist.

Non-neurologic chronic health conditions

Given that many studies indicate that mercury may play a role in the etiology and/or course of several multifactorial chronic health conditions;

Given that the strongest evidence points to diabetes, including diabetic co-morbidity (peripheral neuropathy, vision), and hypertension;

Given that the claimant's quality of life can be further affected by these conditions,

We recommend that:

32. Diagnosed diabetes and hypertension, verified by the nurse practitioner, be included within Other Material that the claimant can provide to the MDB and included, when appropriate, in the final scoring.

Quality of Life/Activity Limitations

Given that significant impairment to the quality of life or limitations in activities are important aspects of the compensation process;

Given that the *Neurological Grading Guidelines and Cultural Illustrations of Functional Impairments* in the Plan Document refers primarily to traditional activities, many of which were halted due to the contamination;

Given that there is no consideration in the current guidelines of the potential impact of mercury poisoning on the physical and mental requirements for today's jobs, training, education and daily activities;

Given that clinical rating schedules for compensation are considered inadequate to assess the impact of an impairment on an individual's earnings capacity;

Given that in Section 1 Act defines a condition as *"capable of significantly impairing the quality of life or limiting the activities of an applicant.";*

Given that since the adoption of the Act, a very large number of questionnaires have been developed and validated to assess quality of life and limitations of activities,

We recommend that:

33. A questionnaire with good psychometric properties, Canadian normative data and validated with a First Nation population (Medical Outcomes SF-36v2), serve to assess a claimant's quality of life and limitations of activities.

34. The questionnaire be administered by the nurse practitioner and the results be included in Other Material.

Biomarkers of Mercury Exposure

Given that individual's umbilical cord blood, hair and blood biomarker data collected by Canadian and Ontario ministries and agencies are available on written request;

Given that Section 10 of the Act states that the MDB may consider any **Other Material**, it *"deems useful for the purpose of deciding any matter including whether it may be appropriate to make or vary any award or awards…";*

Given that biomarker data represents the situation at the time of sampling and that mercury exposure varied throughout the year and with the type of fish recently consumed and the size of the fish,

We recommend that:

35. If the claimant so wishes, biomarkers of past mercury exposure be included in the Other Material submitted to the MDB.

36. High exposures be presumptive of mercury poisoning, but low values not be disqualifying.

Adult Grading System

Given our mandate to assign appropriate points to the Further Conditions, in conformity with the distribution of points in effect for the Known Conditions,

We recommend that:

37. A core grading schedule include both the original Known Conditions and Further Conditions for neuropsychological and neuropsychiatric dysfunction, with points based on recommended validated protocols.

38. For persons whose score is equal to or greater than 6 (the minimum number of points for compensation), further points be attributed if they have been diagnosed with diabetes and/or hypertension.

39. For persons whose score is equal to or greater than 6 (the minimum points for compensation), further points be attributed for severity of impairment to the quality of life and limitations of activities.

40. A sliding scale be used for point attribution for historic biomarker data that recognizes potential damage caused by moderate, high and very high exposure to mercury.

41. The Known Conditions, Further Conditions and Other Material be considered in accordance with the Recommended Grading Scale for Adults.

Pediatric Examination

Given that the neurologic pediatric protocol was modified in 1999 to improve and better quantify the examination;

Given the absence of neuropsychological and behavioral assessment in the current examination, despite the wealth of knowledge on the harmful effects of prenatal and early childhood mercury exposure on children's neurodevelopment and behaviour;

Given the importance of allotting adequate time for the medical history of pregnancy and childhood, the general examination, the parent or care-givers and child's impressions of development and behaviour,

We recommend that:

42. The current revised pediatric neurologic examination be maintained for the examination of cranial nerves, strength, tone, involuntary movements, reflexes, motor coordination and sensation.

43. The current assessment of developmental status, orientation to time, recent and remote memory, language and knowledge be replaced by a neuropsychological test battery composed of tests widely used in both clinical and research settings.

44. Neuropsychological deficits, including the following domains: General Cognitive Ability, Memory, Visual-Spatial/Visual-Motor functions, Manual Dexterity and Language, be included as Further Conditions.

45. Behaviours be included as Further Conditions and assessed using validated rating scales for behavioural problems, adaptive functioning and executive functioning.

46. The neuropsychological and behavioural tests be administered and interpreted by a pediatric neuropsychologist.

47. A nurse practitioner perform the general examination and record medical, developmental and behavioural history.

Pediatric Grading System

Given that the pediatric neurologic examination was revised in 1999 and contains a grading protocol for its components;

Given that the assessment of neurodevelopment and behaviour does not use validated, standardized test batteries;

We recommend:

48. The current grading system for Cranial nerves/Visual Fields, Dysarthria, Strength, Coordination, Sensation and Reflexes, be maintained.

49. Points be attributed with respect to the scores obtained on the pediatric neuropsychological test battery, with respect to severity of impairment.

50. Points be attributed in relation to the scores obtained on the validated behaviour questionnaires.

51. The physicians on the MDB consider all of the above, as well as the qualitative report from the nurse practitioner.

Overarching Considerations

Keeping in mind that scientific knowledge and awareness of the short and long-term effects of *in utero*, child and adult exposure to mercury is constantly and rapidly evolving,

- We urge the parties to establish a regular revision schedule of the MDB process and Further Conditions if and when new scientific data is available, with a maximum of every 5 years.

- We deem appropriate that current claimants be informed of the modification and update in the examination process and that they be invited to re-apply if they so wish.

In keeping with Cosway's suggestion[11] to carry out statistical analysis of data from the examinations, which could at the same time provide valuable information on the understanding of the health of people in these communities, and serve to optimize the examination strategy and possibly reduce time and cost,

- We urge the parties to regularly conduct a scientifically sound analysis of the results of the examinations.

In the spirit of the report Royal Commission on Health Services, tabled by Justice Emmett Hall in 1964[12], and in keeping with Health Canada's current commitment to ensures access to high-quality health services;

And, considering that the information, collected during the examination process, can be useful for further treatment, referrals and follow-up,

- We believe that the examination results should be transferred to the primary care provider or a specialist designated by the claimant, subject to his/her written permission, compensated or not.

In keeping with the MDB statistics on the age of death of claimants, coupled to the recent evidence that long-term mercury exposure among persons from Grassy Narrows is

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[11] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986 – 2001 (3 volumes) prepared for the Grassy Narrows and Islington Band Mercury Disability Board, October. p.167.

[12] Ford AB. 1964. Royal Commission on Health Services, Vol I. JAMA. 190:1138.

associated with an increased prevalence of reduced longevity and dying before 60 years[13],

And, in keeping with best practices in compensation,

- We encourage the parties to consider including a provision for compensation to families of claimants who were receiving benefits at the time of their death.

While we often associate health and well-being solely with the health system, there are many consequences of *'signs and symptoms consistent with mercury poisoning'* on other facets of life, notably the school and welfare systems. During the Expert Panel's visits to the communities, we learned of the difficulties faced by the schools, thus,

- We urge the parties to ensure that 'benefits' go beyond the financial aspects and adopt a more holistic approach that includes adequate support for schooling and therapeutic measures.

We recognize that implementing our recommendations will entail human and financial resources, thus,

- We advise the parties to ensure that the MDB staffing, funding and project allocation be adequate to this purpose.

A listing of the recommendations is provided in Appendix 2.

[13] Philibert et al. 2020. Mercury exposure and premature mortality in the Grassy Narrows First Nation community: a retrospective longitudinal study. Lancet Planetary Health 4: 141-148.

Chapter 1 Mandate and Methods

1.1 Context

Between 1962 and 1975, a chlor-alkali plant discharged approximately 10,000 kg of mercury into the English-Wabigoon River System, depriving the First Nation communities, for whom fish was central to their cultural heritage, of their livelihood, their health and their dietary mainstay[14]. The Mercury Disability Board was established following a series of negotiations and mediation efforts, which began in the mid to late seventies, between the two First Nation communities, as plaintiffs, and the companies involved and the Ontario government, as defendants. A 1978 preliminary "Memorandum of Understanding" produced by the government of Canada stated that *"the Indian Bands residing on Whitedog and Grassy Narrows Reserves are experiencing adverse effects on their social, health, cultural, environmental well-being, as well as their economic opportunities by reason of damage to resources on which they relied for the viability of their communities."*[15] In 1985, a Memorandum of Agreement was signed between the plaintiffs Asubpeeschoseewagong Netum Anishinabek ("ANA"), also known as Grassy Narrows, the Wabaseemoong Independent Nations ("WIN", formerly known as Islington Band) and the defendants: Reed Limited, Dryden Chemicals Limited, Dryden Paper Company Limited, Reed Incorporated, Great Lake Forest Products Limited, Her Majesty the Queen in the Right of the Province of Ontario. This agreement, mediated by Justice Emmett Hall, included the establishment of the Grassy Narrows and Islington Bands Mercury Disability Board (henceforth referred to as MDB).

In Justice Hall's affidavit to the Supreme Court of Ontario, he notes that the Mercury Disability compensation constitutes the major benefit for which *"all existing and future rights of action of a Band, and of every past, present and future member of a Band, and of the estates thereof, in respect of any of the claims or causes of action that are the subject of the Agreement are hereby abolished."*[16]

In 1986, the Ontario parliament adopted the English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act c23 (henceforth referred to as the

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[14] Canada-Ontario Steering Committee. 1983. Mercury Pollution in the Wabigoon-English River system of Northwestern Ontario, and Possible Remedial Measures. Summary of the Technical Report. 18 pp.
[15] Vecsey C. 1987. Grassy Narrows Reserve: Mercury Pollution, Social Disruption, and Natural Resources: A Question of Autonomy. American Indian Quarterly 11: 287-314.
[16] Hall E. 1986. Affidavit. In the Supreme Court of Ontario between Isaac Mandamin (and others) and on behalf of all members of the Islington Band of Indians and Simon Roy Fobister (and others) on the on their own behalf and on behalf of all members of the Grassy Narrows Band of Indians (numerous other names) plaintiffs and Reed Limited, Dryden Chemicals Limited, Reed Inc., Great Lakes Forest Products, Her Majesty the Queen in the right of the province of Ontario, Defendants.

Act), which established the MDB. In his analysis of this mediated settlement, West, writing in the journal of Environmental Law[17], states the following:

> *"On June 26, 1986, a unique and complex environmental settlement agreement finally resolved nine years of controversy and negotiations between the Objibway Indians of the Grassy Narrows and White Dog reserves of Northwestern Ontario and Reed Paper Company of Dryden, Ontario"… "The agreement and the events leading up to the settlement illustrate the limitations of the Canadian legal system's ability to deal with and redress environmental wrongs".*

In January 2019, the four parties, ANA, WIN, Canada and Ontario, set up an independent Expert Panel, the MDB Reform Expert Panel ("Expert Panel"). The Terms of Reference that established the Expert Panel's mandate were defined within the context of the Act:

"Consistent with the Ontario Act, the Expert Panel's mandate will be to determine and report on whether, in addition to the existing Known Conditions, there are other observable medical symptoms, signs or conditions (or combination thereof) that are reasonably consistent with mercury poisoning and capable of significantly impairing the quality of life or limiting the activities of an applicant" … "and any corresponding additions to the Grading Guidelines in the Plan Document, or any related MDB documents, policies or procedures.

The Expert Panel's report containing recommendations are to be submitted to the Parties and the MDB, to be considered in determining whether such further conditions, for both adults and children, should be included in Appendix III, along with an "assign[ment of] points in conformity with the existing distribution of points" (Ontario Act, s. 22(2)), and any corresponding additions to the Grading Guidelines in the Plan Document, or any related MDB documents, policies or procedures."[18]

Our scope of work covered the following: i) Determine whether further conditions "reasonably consistent with mercury poisoning and capable of significantly impairing the quality of life or limiting the activities of an applicant" should be added to the Known Conditions, listed in Appendix III of the Plan Document; ii) Update the grading guide; iii) Align policies and procedures to changes in the examinations and grading.

We used a multi-tiered approach to complete our mandate. Specifically:

- We examined the original documents provided by the parties.

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[17] West L. 1987. Mediated Settlement of Environmental Disputes: Grassy Narrows and White Dog Revisited, Environmental Law 18: 131-150.

[18] Mercury Disability Board Reform Expert Panel ANA-WIN-Canada-Ontario [Without Prejudice] Terms of reference. January 2, 2019.

- We met with the MDB at one of their statutory meetings and interviewed the past and current interim Chair.
- We met with the two communities and interviewed individual community members.
- We met with physicians who have been involved with the MDB and consulted scientists and physicians with expertise in mercury poisoning.
- We analyzed the anonymized claimant data that we obtained from the MDB.
- We derived a multi-tiered conceptual framework for evidence-based updates.
- For each element of the framework, we reviewed the current literature on health effects of mercury exposure, loss of quality of life, compensation policies and procedures, and culturally sensitive practices with First Nation communities.
- We formulated recommendations to update the current protocols and practices.
- As per our mandate, we proposed an accompanying point system.

1.2 Documents Provided by the Parties and the MDB

The parties provided the Expert Panel with a series of documents, which we classified into the following categories: i. Documents establishing the MDB; ii. Information on the MDB; iii. Reviews of Methyl Mercury in Canada; iv. Studies on ANA and WIN and literature reviews produced for the MDB or the parties.

Documents establishing the MDB
We used these original documents to identify elements relevant to our mandate:

a. Affidavit of Justice Emmett Hall, retired Justice of the Supreme Court of Canada, to the Supreme Court of Ontario, 1985[19].
b. Memorandum of agreement (MOA)/settlement 1985-1986.
c. English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, Statutes of Ontario, 1986, c.23.

[19] Justice Emmett Hall indicates in the affidavit, signed on June 18, 1985 that he was "appointed by the Honourable David Crombie, Minister of Indian and Northern Affairs Canada to serve as his personal representative to participate in negotiations for the purpose of arriving at a Settlement Agreement involving the Plaintiffs (The Islington Band of Indians and the Grassy Narrows Band of Indians) and the Defendants (Reed Ltd, Dryden Chemicals Ltd, Dryden Paper Company Ltd, Reed Inc, Great Lakes Forest Products Ltd and her Majesty the Queen in the right of the Province of Ontario)".

d. The Services Agreement Plan Document (1987), signed by Great-West Life Insurance, the designated administrator, and the Grassy Narrows and Islington Bands MDB.

- **Definition of a 'Known Condition'**: In the list of definitions in Schedule A of the MOA, *"a known condition means an observable medical symptom, sign or condition, or combination of related medical symptoms, signs or conditions which*
  i) Is a known condition, or
  ii) Has been determined by the Board to constitute a condition on the basis that it is reasonably consistent with mercury poisoning and capable of significantly impairing the quality of life or limiting the activities of an applicant."

- **The list of 'Known Conditions'**: The MOA lists: Ataxia, Tremor, Reflex changes, Sensory changes, Visual fields, Psychosis and Dysarthria. The inclusion of psychosis in the list was conditioned in paragraph 2.1.4(b) of the MOA as a *"known condition yet to be determined"*. In Appendix III of the Plan Document, "incoordination" replaces "psychosis". For children, the Plan Document included two conditions as *"known conditions"*: mental retardation and cerebral palsy.

- **The point system:** The initial point system had 5 categories of impairment for each of the 'known conditions' with mild classified as 0, whereas the Plan Document had 4 categories, with scores listed for each condition: none (0) mild (none, 1 or 2), moderate (1, 2 or 4) and severe (4 and 8). The entitlement score is 6, the maximum entitlement score is 16 and the maximum score is 52. The point system for children included 4 categories (none (0), mild (2), moderate (4) and severe (8)). The entitlement score is 4 and the maximum entitlement score is 8. The maximum score is 16.

- **The Neurological Guidelines and Cultural Illustrations of Functional Impairments:** This section of Appendix III of the Plan Document includes a list of what is considered *"culturally appropriate functional impairments"* for each of the disability categories of the *"known conditions"*. The Plan Document contains a protocol for the neurologic examination.

- **Adjudication:** In the Plan Document, Great-West Life Insurance was responsible for the initial adjudication of claims.

- **Authorized physicians:** Authorized physicians are defined in section 1 the Act: *" a physician entitled to practice medicine in any jurisdiction in Canada or the United States of America and designated as an authorized physician by the Board."*

Relevant to our work is also the scientific basis for the clinical examinations to determine eligibility compensation. The Prichard and McIntyre report, *Neurologic Findings in Mercury-Exposed Indians of the Grassy Narrows and White Dog reserves: Report and*

Recommendations provides this information[20]. It is an unpublished, non-peer-reviewed report. In the 2001 report by Cosway[21] describes the report's background and detail; she lists it in her references as 1985, unpublished and includes a third author (J.G. Stopps). She relates that Dr. John Stobo Prichard was a professor at the University of Toronto and a physician at the Hospital for Sick Children. After his death in the mid-eighties, Dr. Lynn McIntyre, a consultant for the Ontario Ministry of the Attorney General completed the reports and recommendations. Dr, Gordon Stopps, who was Dr. McIntyre's residency supervisor, had been employed in the 1970's by the Ministry of Health and was a member of the Province of Ontario Mercury Task Force.

- The report contains the **findings of 3 medical teams** that had visited Grassy Narrows and White Dog at the request of Health and Welfare, Canada in April 1976, November 1977 and May 1979, using a "standard protocol".
- For the adults, **seven categories** are suggested: Tremor, Ataxia, Incoordination, Dysarthria, Absent reflexes, Sensory abnormality and Visual field constriction.
- With respect to **Psychosis/dementia**, the authors recommended that it not be included "because it is a late and severe effect of organic mercury intoxication which would appear only in an individual who also had deficits in the other neurologic categories and who would thereby also be eligible for maximum compensation."
- The proposed **entitlement scores** are different from those that are in Appendix III of the Plan Document and one can assume that this document was produced between the MOU (1985-1986) and the Plan Document (1987).
- For children, the document suggests that **children's IQ** should be tested. While the authors note that the testing of the intelligence quotient is culturally sensitive and that no "culturally fair" IQ test is available, they recommend tests that were currently in use at that time.
- **No references** are included in this document.

Information about the MDB

The parties initially provided only the Table of Contents of the historical report produced by Cosway in 2001[22]. During our work, we requested the complete document, which was provided to us by the MDB. The overall report provided the Expert Panel with a wealth of information essential to understanding the work and evolution of the MDB between 1986 and 2001. In 2006, the MDB published a synthesis of Cosway's work, prepared by Len Manko. It is available on the web at http://www.mercurydisabilityboard.com/.

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[20] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-exposed Indians of the Grassy Narrows and White Dog Reserves: Report and Recommendations, pp.15.

[21] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986-2001, P1. p. 60.

[22] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986 – 2001 (3 volumes) prepared for the Grassy Narrows and Islington Band Mercury Disability Board, October. pp. 249.

We were likewise provided with documents, prepared at request of the MDB by Dr. Laurie Chan and Dr. Donna Mergler in 2009[23] and by Dr. Alan Jackson in 2013[24]. The first contained a review of the literature on methylmercury and an analysis of Dr. Harada's studies and the second reported on the MDB's neurological examination for mercury poisoning.

The Expert Panel was also provided with the submissions from ANA and WIN to the MDB Review in 2017 and the Revised Draft Summary of the Collection of Information: ANA and WIN Experiences with the MDB prepared by Kathleen Lickers. These were useful for our understanding of the way in which the communities view the MDB and the type of changes that they propose, particularly as concerns procedure and policy.

Further documents provided by the parties
The parties likewise provided the Expert Panel with the following documents:

- An expert Report entitled *Grassy Narrows' General Mercury and Health Facts* by Dr. Donna Mergler, which was presented to Ontario Superior Court of Justice by the Canadian Environmental Law Association (2015).

- A preliminary report on research results for Minamata Disease in First Nations Groups in Canada prepared by Dr. Masanori Hanada (2014).

- The document Lessons from Minamata Disease and Mercury Management in Japan, prepared by Ministry of Environment, Japan (2013).

- The three volumes of Methylmercury in Canada from 1979, 1984 and 1999.

- Four articles/reports produced by Dr. Masazumi Harada and his team:

    - Harada et al. 1976. Epidemiological and clinical study and historical background of mercury pollution on Indian Reservations in Northwestern Ontario, Canad Bull. Inst. Costit Med. 26: 169-184.

    - Harada et al. 2005. Long-term study on the effects of mercury contamination on two indigenous communities in Canada (1975-2004) in *Research on Environmental Disruption* vol 34 (translated from Japanese).

    - Harada et al. 2011. Mercury poisoning in First Nations Groups in Ontario, Canada: 35 years of Minamata Disease in Canada.

[23] Chan L and Mergler D. 2009. Literature Review: A Review of the Current Understanding of Mercury Poisoning, commissioned by the Mercury Disability Board, September 21. pp. 51.
[24] Jackson A. 2013. Mercury Disability Board Report. January 23. pp. 8.

- Takaoka et al. 2014. Signs and symptoms of methylmercury contamination in a First Nations community in Northwestern Ontario, Canada. Science of the Total Environment 468-469: 950-958.

- Asubpeeschoseewagong Netum Anishinabek Community Health Assessment (ANA-CHA) Report (May 2018).

- Asubpeeschoseewagong Netum Anishinabek Community Health Assessment (ANA-CHA) Report Part 2: Children and Youth Report (December 2018).

1.3 Consultations

Visits to the communities
Two visits were organized to each community to discuss the MDB examinations and processes. The first was on April 10 – 11, 2019, for adults and the second, on May 1-2 to discuss child claims. In both communities, community organizers advertised the meetings and coordinated the activities.

Appendix 3 contains the meeting notes from the 4 meetings. In both communities, we heard dissatisfaction and lack of confidence with the process and the medical examination. Community members were knowledgeable and asked very good questions.

Meetings with the Mercury Disability Board
Expert Panel members Donna Mergler and Katherine Lippel were received by the MDB during a statutory meeting on March 26, 2019. We learned about their procedures, successes and barriers to carrying out their mandate (Meeting notes of visits with the MDB are available on request). Further direct and e-mail discussions with Ms. Evelyn Baxter, Chair of the MDB and Ms. Chris Smith, administrator, provided clarification of some of the issues.

On August 19, 2019, three Expert Panel members, Chantelle Richmond, Katherine Lippel and Donna Mergler held a telephone conference with Ms. Margaret Wanlin, interim and past Chair of the MDB. At Ms. Wanlin's request, we prepared a series of questions. The questions and responses are available on request.

Subsequent to the meetings, we asked for and received the various forms that are used for claim application and re-application, the examination protocols and the scoring process. We verified that we had the current neurological and/or medical assessment forms that are used by the authorized physicians, and the template(s) for medical reports that authorized physicians complete and submit to the MDB, and any other related documents.

We requested and received the acceptance and refusal letters sent to the claimants by Great West Life Assurance Company, following the initial evaluation, and by the MDB following the pre-application. We likewise learned that the MDB had commissioned Dr. William Turk and Dr. Ian Clark to carry out an extensive ophthalmological examination on 14

claimants in 2018 and were provided with the summary report[25]. We followed up with Dr. Clark, who informed us that Dr. Jeremy Levi had further information. We contacted Dr. Levi, who provided us with a more complete presentation of the findings[26].

We were initially provided with a summary of the MDB outcomes until March 30, 2016. We later obtained the anonymized data from the MDB up until March 30, 2019, which we analyzed.

Other consultations
The list of consultations with physicians previously or currently involved with the MBD and professionals familiar with mercury poisonings or the communities is presented in Appendix 4.

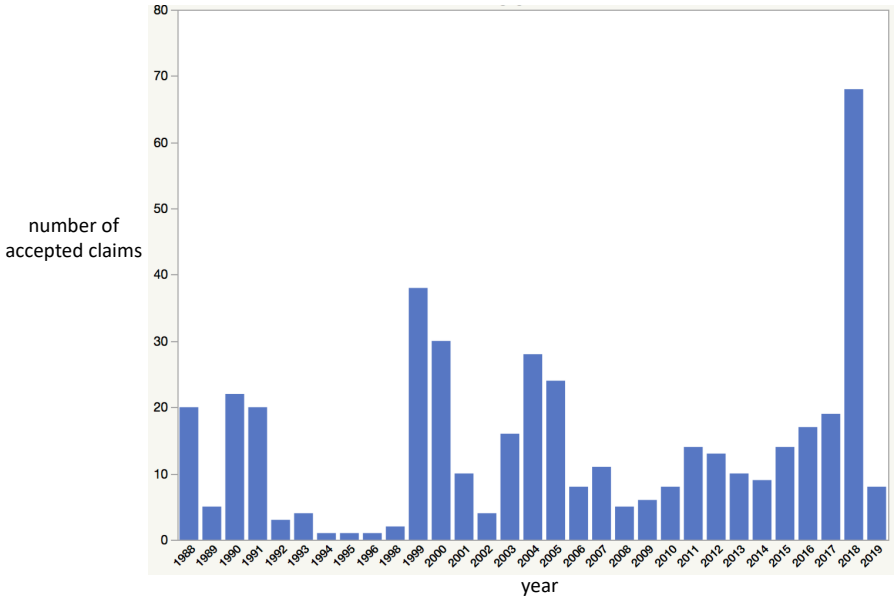
Expert Panel members' meetings
Following our initial Expert Panel Skype meetings, where we discussed the history of the MDB and the terms of reference, each Panel member was attributed responsibility for a section of the report. Exchanges between Panel members mainly took place in small group Skype meetings and e-mails. Appendix 5 contains a log of the Expert Panel members' meetings. As the report progressed, draft texts were sent back and forth until we reached a final draft proposal.

1.4 Analysis of MDB Data

Between 1988, when claims began and March 31, 2019, initial claims were received for 1054 adults and 199 children (n = 1253), of which 364 adults (35%) and 75 children (38%) were approved for compensation, either at the initial claim or following a review or re-application. The yearly distribution of accepted claims is presented in Figure 3.

[25] Turk W and Clark I. 2018. Mercury Toxicity and Vision: summary report to the Mercury Board September 12. pp.6.
[26] Levi J. 2019. Mercury Risen: Final Data from Grassy Narrows and Wabaseemoong Study. Presentation May 17.

Figure 3. Number of accepted claims over time



The average age at approval for compensation for adults was 50 years of age (25th – 75th percentile: 42-59 years of age) and 8 years of age for children (25th – 75th percentile: 5-12 years of age).

A total of 168 persons (45% of the total number of accepted adult claimants) and 4 persons whose claims were accepted as children, have died since receiving compensation.

- For deceased adults who had received compensation:
    - Payments were received for an average of 12 years (25th – 75th percentile: 7-16 years).
    - The average age of death was 65 years.
    - 55 (34%) had died before the age of 60 years; 130 (77%) died before 75 years of age, considered as the cut-off for premature mortality in Canada[27].

We did not have information on gender for those who died, but for those whose claims were accepted as adults and were alive on March 31, 2019, 54% are women and 46% are men. Among children, the proportion of boys is higher than that of girls (61% and 39%, respectively). Gender differences for mercury toxicity has been reported for children,

[27] Statistics Canada. Premature and potentially avoidable mortality, Canada, provinces and territories. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310074401 (accessed 2020-06-09).

with respect to mercury exposure[28]. There is no gender difference between the age of acceptance for adult or child claims.

Since *in utero* and early childhood exposure is known to be more toxic than adult exposure[29,30] we looked at the profile of recipients, who were born in 1960 or later. A total of 147 adults (41% of all adults) and all of the children were born since this time.

- Among the adults born in this period, 28 (19%) have since died; their average age at death is 45 years (25^{th} – 75^{th} percentile: 37-53 years).

We retained the following aspects for consideration in our work:

- Premature mortality (<60 years of age) is high among the recipients; there are no benefits for the family following the death of a recepient [31].
- On average, persons receive compensation over a relatively short period of time.
- *In utero* exposure, even in recent years, may be predicting later life signs and symptoms consistent with mercury poisoning (accepted claims).
- Neurological signs and symptoms in children born since 2001 are consistent with the findings of the ANA-CHA Part 2[32] that reported a positive association between neurological and behavioral problems and mothers' fish consumption during pregnancy.
- Gendered analyses suggest that young boys may be more susceptible to mercury poisoning compared to young girls, but that remains to be confirmed.

1.5 Framework

In keeping with today's scientific knowledge and best practices, the Expert Panel developed a multi-tiered framework to lay out the rationale for updates and formulate

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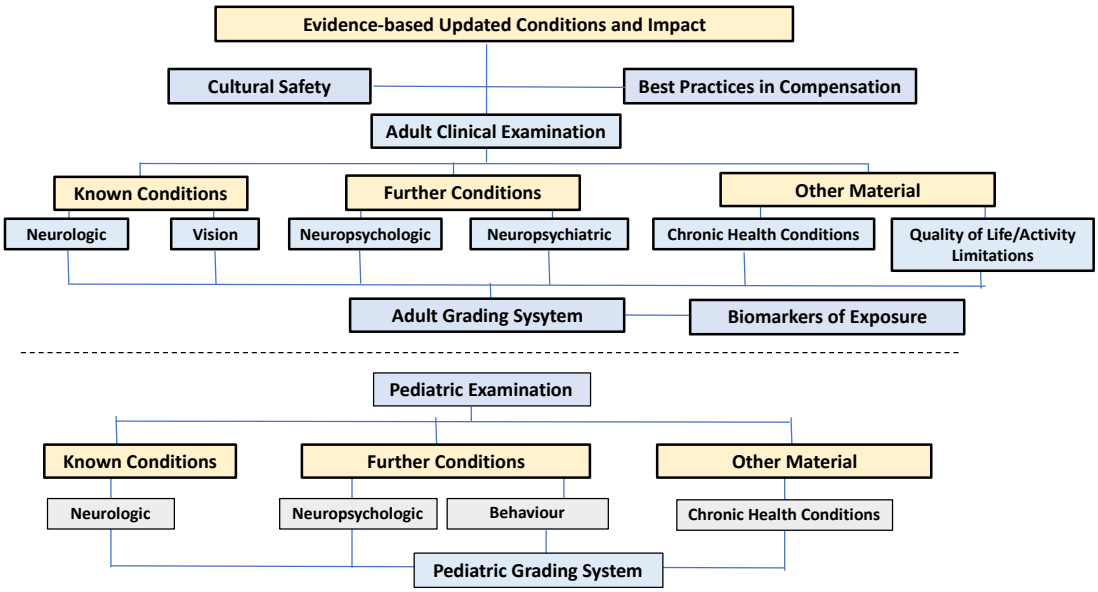
[28] Castoldi AF et al. 2008. Human developmental neurotoxicity of methylmercury: Impact of variables and risk modifiers. Regulatory Toxicology and Pharmacology 51:201-214.
[29] Karagas MR et al. 2012. Evidence on the human health effects of low-level methylmercury exposure. Environmental Health Perspectives. 120:799-806.
[30] Mergler D et al. 2007. Methylmercury exposure and health effects in humans: a worldwide concern. Ambio 36:3-11.
[31] Contrary to the protections provided to survivors of injured workers under s. 48 of the Workplace Safety and Insurance Act, 1997, S.O. 1997, c. 16, sch A (WSIA).
[32] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report. Part 2 2018. Children and Youth; November, pp. 94.

recommendations (Figure 1 and 2). The chapters (in blue), in Figure 4, address each of aspect of the framework.

Figure 4. Chapter organisation within the multi-tiered framework



Chapter 2 Cultural Safety

2.1 Background

Cultural considerations for communities affected by mercury

In recent years, it has become common practice among Canadian institutions and governments to perform Indigenous Land Acknowledgements at the start of meetings. The purpose of a Land Acknowledgement is to pay respect to the Original Peoples of the territory upon which you meet. This Acknowledgment recognizes the role and responsibilities of Indigenous peoples as the original inhabitants to the place we now call Canada. Through this act, we recognize the dispossession of Indigenous people from their lands and resources, which has been regulated through federal policy to the highest degree. The negative impacts of systemic racism and lacking cultural safety, as they pertain to Indigenous health care and policy, are well demonstrated[33,34].

Land Acknowledgements are also an important way to declare our commitment to building relationships with and responsibilities to Indigenous communities. Our mandate to update functional impairment and quality of life limitations starts with an understanding of what happened to the people of Asubpeeschoseewagong Netum Anishinabek (ANA), also known as Grassy Narrows First Nation, and Wabaseemoong Independent First Nation (WIN). This is a prerequisite for any person who is involved in any capacity with the MDB.

Among Indigenous people, the land is centrally important for health and overall well-being as it provides the place upon which Indigenous Knowledge is conceived and practiced[35,36]. In 1994, LaDuke[37] described Indigenous Knowledge as "the culturally and spiritually based way in which Indigenous peoples *relate to their ecosystems and with one another*" (127: emphasis added). This knowledge has formed the basis of relationships between humans, the land, and the spiritual, thereby forming the foundation for Indigenous ways of living that are healthful, nurturing and sustainable[38].

Among the Anishinaabe people, these relationships are central for living "the good life" or *mino biimadisiwin. Mino biimadisiwin* is an Anishinaabe philosophy about living in the world and relating in a good way with people, animals, medicines and the

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[33] Allan B and Smylie J. 2015. First peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. Toronto, On. The Wellesley Institute, pp. 17.
[34] Loppie C. 2018. Racism as a social determinant for health for indigenous people. https://bcpsqc.ca/wp-content/uploads/2019/08/FNHA-BCPSQC-Webinar-8.pdf (accessed February 15, 2020).
[35] McGregor D. 2004. Coming Full Circle: Indigenous Knowledge, Environment and Our Future. American Indian Quarterly 28:385-410.
[36] Berkes F. 2012. *Sacred Ecology*. New York: Routledge, pp. 392.
[37] LaDuke W. 1994. Traditional Ecological Knowledge and Environmental Futures. Colorado Journal of International Environmental Law and Policy 5:127-148.
[38] Shaw et al. 2006. Encountering Indigeneity: Re-imagining and decolonizing geography. Geografiska Annaler: Series B Human Geography 88:267-276.

spiritual[39,40,41]. It is a way of living that understands and respects the idea that Creator has provided the gifts needed for the Anishinaabe to live in a healthy, contented way. Anishinaabe identity, morals and every-day practices are shaped in important ways by these connections and obligations.

For the communities of ANA and WIN, the English River ecosystem forms the cornerstone of their Indigenous Knowledge system, and is a critical piece of their collective cultural identity. Not only does this River system form an abundant means of food and medicines and other resources required to be healthy, sustaining people, its network of narrows and lakes has enabled safe transport of people for ceremonial and familial obligations. Their subsistence needs were met through a host of fish, waterfowl, large mammals, berries, wild rice and other medicines. Among these communities, the River is viewed not as a resource to be used and exploited, but as a relative. Maintaining a healthy relationship with the River occurred through principles of reciprocity, interconnection and minimal waste.

With the onset of white trappers in the region in the 1600's, and the signing of Treaty 3 in 1873, the delicate relationship between the Anishinaabe people and the land began its slow decline, which was accelerated with the introduction of the commercial fishery. The communities adjusted to these changes, and were able to support a way of life that balanced Indigenous knowledge and market-based systems of interacting with the River. This led to a thriving commercial and sport fishery, and the development of a guide-fishery where the men and women of ANA and WIN were able to draw from their Indigenous Knowledge systems to boost the local economy. In the early 1960's, it is estimated that employment rates in ANA were as high as 95%[42].

In the 1960's it was discovered that the River was contaminated with methylmercury[43]. Because of the distinct importance of the River for maintaining the knowledge systems and cultural well-being (including their food source) of ANA and WIN, the discovery of methylmercury was devastating. It was not long before the people of ANA and WIN began to show the health effects of mercury poisoning, and many died. But contamination did not only pose significant risks for physical health, it presented risks to the health of local economies as well. The commercial fishery was shut down, and it was advised by federal and provincial scientists that residents stop consuming fish.

Mercury contamination has had devastating impacts in both communities. Community members experienced unparalleled disruption of lifestyle and eating patterns, and a range

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[39] Borrows J. 2016. Seven Gifts: Revitalizing Living Laws Through Indigenous Legal Practice. Lakehead Law Journal 2:2-14.
[40] McGuire PD. 2013. Anishinaabe Giikeedaasiwin–Indigenous knowledge: An exploration of resilience (Doctoral dissertation, University of Saskatchewan) pp. 276
[41] Debassige B. 2010. Re-conceptualizing Anishinaabe mino-bimaadiziwin (the good life) as research methodology: A spirit-centered way in Anishinaabe research. Canadian Journal of Native Education 33:11.
[42] Vescey C. 1987. Grassy Narrows Reserve: Mercury Pollution, Social Disruption, and Natural Resources: A Question of Autonomy. American Indian Quarterly 19:287-314.
[43] Fimreite N and Reynolds L. 1973. Mercury Contamination of Fish in Northwestern Ontario. The Journal of Wildlife Management 37:62-68.

of socio-cultural and economic processes[44]. Because mercury was not visible in the waterways or fish, its presence caused significant vulnerability for Indigenous Knowledge systems, which led people to distrust the ways of knowing and interacting with the land that had always sustained them.

In 2019, many of the direct and indirect effects of mercury poisoning continue to affect ANA and WIN. As discussed repeatedly by local people however, the reality of "living with mercury" has become a normalized and expected feature of daily life. With regard to the normalization of mercury, and all of the complicated intergenerational consequences, perhaps more troubling is the profound structural indifference among physicians and policy makers with respect to this highly inequitable circumstance.

Among Canada's leading scholars, there is agreement that considerations of Indigenous peoples' health must be contextualized against a broader set of structural and holistic determinants[45], including historic and on-going experiences of dispossession and colonialism. Adopting this structural framing is critical for understanding how Anishinaabe experiences of mercury exposure – or even mercury in the environment – has interconnected and intergenerational impacts that extend broadly across perceptions of health, connection to the land, and various other aspects of daily life[46]. This holistic framing of health differs drastically from a biomedical perspective that often forces dichotomies of health and well-being (e.g. diseased or not, mobile or not, depressed or not[47]). It is precisely these philosophic differences about *what health means* that can form tension among and between health care providers and Indigenous patients[48], particularly in the diagnosis of health conditions and coinciding delivery of care.

The Settlement: A Context of Distrust

During our time in both communities, community members spoke about the MDB with a great deal of mistrust and suspicion. Community members talked about experiences of racism and perception of a double standard. Despite the existence of a process put into place to support and compensate them for health effects experienced as a result of external environmental contamination, they expressed frustration that they are required "to continually beg" for what should be rightfully theirs. In the interactions with the MDB, several community members mentioned that they are treated with a lack of respect and routinely humiliated.

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[44] Wheatley B and Wheatley M. 2000. Methylmercury and the health of indigenous peoples: a risk management challenge for physical and social sciences for public health policy. The Science of the Total Environment 259:23-29.

[45] Reading C. 2015. Structural Determinants of Aboriginal Peoples' Health. In M. Greenwood, S. de Leeuw, N. M. Lindsay, & C. Reading (Eds.), *Determinants of Indigenous Peoples' Health in Canada: Beyond the Social* (p.3-24). Canadian Scholars' Press Toronto pp. 279.

[46] Richmond CA and Ross NA. 2009. The determinants of First Nation and Inuit health: A critical population health approach. Health & Place 15:403-411.

[47] Durie M. 2005. Indigenous knowledge within a global perspective. Higher Education Policy 18:301-312.

[48] Little Bear L. 2000. "Jagged Worldviews Colliding" In *Reclaiming Indigenous Voice and Vision*, Marie Battiste (Eds.), Vancouver: UBC Press. Ontario Legislation p.77–85.

It is noteworthy that at the time of enactment of the Act, indexation of injured workers' compensation was adopted for Ontario workers. It was not until 2018 that the disability payments for MDB recipients were indexed. Many had since died. When introducing the Bill for injured workers' compensation in 1985, the Ontario Minister of Labour, the Honourable William Wrye, Liberal MP[49] said these words:

> *"The measures being proposed by the present government will* en*sure that injured workers will no longer have to worry about whether and to what extent their benefits will be adjusted.... The pain, the loss, the disruption and the disorientation caused to a worker and his or her family by a disabling injury is suffering enough. We should never add to this suffering the indignity of having to come cap in hand to the steps of the Legislature angrily demanding merely the protection of compensation benefits from the annual rate of inflation. From this day forward, injured workers will never again be in that humiliating position."*

Moreover, section 7 of the Act contains clauses authorizing the MDB the right to deny or reduce claims where the Board considers that, after the date of the settlement, *"the conduct of an applicant has contributed and is contributing to the continuation or exacerbation of a disability."* There are no similar clauses in workers compensation in Ontario. While Expert Panel members were told that this has never been used, it sets a tone for what is acceptable and inacceptable conduct.

The descriptions of the *"Cultural illustrations of functional impairment*" contained in the Plan Document and used today in the *Neurological Grading Guidelines and Cultural Illustrations of Functional Impairments* – adult assume a very stereotypic and mostly masculine loss of capacities. At the time that they were written, the fisheries and fishing lodges had been closed down and the claimants had lost their jobs in these industries. Since that time, community members (men and women) require and have developed new skills to provide for their families. No mention is made of the consequences of loss of the capacity to read, to learn, to use a computer, to manage human resources, to work in the building trade, etc. During the Expert Panel's visits, we met with an artist who had lost the capacity to draw straight lines; he could no longer live up to the standards that he had previously achieved.

Recommendations for improved assessment of functional impairment and quality of life are presented in Chapter 10.

Environmental Racism and Power Imbalance

Environmental racism refers to *"racial discrimination in environmental policy-making and enforcement of regulations and laws, the deliberate targeting of communities of colour for toxic waste facilities, the official sanctioning of the presence of life-threatening poisons and pollutants for communities of colour, and the history of excluding people of*

[49] 33rd Parliament, 1st session, Hansard Transcripts, Ontario. December 17, 1985.

colour from the leadership of the environmental movement"[50] . In broader terms, many minority groups are subjected to environmental hazards that are detrimental to their health by way of systemic discrimination, *"which can be described as patterns of behaviour, policies or practices that are part of the structures of an organization, and which create or perpetuate disadvantage for racialized persons."* [51] This is an issue that many communities around the globe are faced with, and one deserving of attention in the context of Indigenous health inequities. Hazardous operations, such as waste facilities, are more likely to be located in or near communities of colour, and especially Indigenous communities. Indigenous experiences of environmental racism reflect a broad-scale failure to acknowledge issues of Indigenous sovereignty and treaty rights[52,53], as well as the physical and spiritual needs of Indigenous communities. Systemic discrimination in Canada means that Indigenous peoples are actively and purposefully excluded from environmental legislation and decision-making processes, thus making them subject to environmental degradation, and leading to direct and indirect negative effects on their health.

Mercury contamination in Grassy Narrows and Wabaseemoong has led to early mortality[54] and a range of social, cultural and economic sufferings among affected individuals and their families[55,56]. The MDB was created to provide economic settlements to affected persons, yet the perception of community members is that its process is mired with complications that deprive potential claimants of a fair process.

2.2 Towards cultural safety

The 4Rs

Acting on Indigenous cultural safety means acknowledging and addressing power imbalances in systems that have inequitably marginalized and silenced Indigenous peoples' voices, ideas and experiences. During our time in the communities, we heard a repeated frustration about the current claims process, which the community perceived to

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[50] Holifield R. 2001. Defining environmental justice and environmental racism. Urban Geography 22:78-90.

[51] Ontario Human Rights Commission. http://www.ohrc.on.ca/en/racism-and-racial-discrimination-systemic-discrimination-fact-sheet (accessed July 13, 2020).

[52] Westra L. 1999. Environmental racism and the First Nations of Canada: Terrorism at Oka. Journal of Social Philosophy 30:103-124.

[53] Waldron IR. 2018. *There's something in the water: Environmental racism in Indigenous and black communities*. Winnipeg: Fernwood Publishing pp. 184.

[54] Philibert et al. 2020. Mercury exposure and premature mortality in the Grassy Narrows First Nation community: a retrospective longitudinal study. Lancet Planetary Health 4:141-148.

[55] IIyniak N. 2014. Mercury Poisoning in Grassy Narrows: Environmental Injustice, Colonialism, and Capitalist Expansion in Canada McGill Sociological Review, Volume 4:43-66.

[56] Vescey C. 1987. Grassy Narrows Reserve: Mercury Pollution, Social Disruption, and Natural Resources: A Question of Autonomy. American Indian Quarterly 19:287-314.

be "stacked against them", echoing the findings of the Lickers report[57]. The Expert Panel is of the opinion that more can be done to support the communities of Grassy Narrows and Wabaseemoong to ensure that they meaningfully participate in, and benefit from, the mandate of the MDB.

The Expert Panel views the MDB as a system that serves the communities, recognizing their context and realities. A holistic worldview, consistent with the cultural and moral perspectives of the communities of Grassy Narrows and Wabaseemoong, is reflected in the philosophy of the 4Rs [58] (Respect, Relevance, Reciprocal relations, Responsibility through participation), which should guide the work of the MDB:

1. **Respect**: Respect for the distinct cultural knowledge, traditions, and values inherent to the communities of Grassy Narrows and Wabaseemoong.

2. **Relevance**: Attentiveness to the cultural integrity of Grassy Narrows and Wabaseemoong, including consideration for Indigenous Knowledge and actions that are conscious of the communities' daily realities and knowledge systems.

3. **Reciprocal Relationships**: Bridging specialized knowledge and community experience through reciprocal learning to build stronger relationships and decrease power imbalances and cultural disconnection.

4. **Responsibility Through Participation**: Ensuring that MDB community members can more fully participate in decision-making.

2.3 Proposals for action

The Expert Panel considered several concrete actions that can be taken to ensure that the MDB provides cultural safety for the examinations and decision process.

Knowledge mobilisation

There is extensive information on what has happened to the communities of Grassy Narrows and Wabaseemoong, including scientific articles, informative reports, book chapters, government documents and web-based interviews. CBC archives, available on the web, contain important historic documentaries from as early as the 1970's. However,

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[57] Lickers K. 2017. Revised Draft Summary of the Collection of Information re: Asubpeeschoseewagong Netum Anishinabek (ANA) and Wabaseemoong Independent Nations (WIN) Experiences with the Mercury Disability Board (document provided by the parties).

[58] The 4R's were originally published by Kirkness, V. J., & Barnhardt, R. 1991). First Nations and higher education: The four R's—respect, relevance, reciprocity, responsibility. Journal of American Indian Education 1-15. Kirkness & Barnhardt wrote this piece in response to the severe underrepresentation among Indigenous people in higher Education. We borrow and adapt the 4R's as supporting or guiding principles of cultural safety for the MDB.

many of the persons involved with the MDB are unfamiliar with the history of the two communities that they serve, their culture and tradition or how to provide a safe environment for clinical examinations.

- The MDB should make available a list of informative documents for all persons that are involved in decision-making or examinations. The website could be updated with links to relevant documents.

- Clinicians should be required to complete a program on Indigenous Cultural Safety, such as the *San'yas: Indigenous Cultural Safety Training* program accredited by the Family Physicians of Canada.

Community Support

Despite the important role the community representatives play in supporting the MDB process, the Expert Panel heard repeated messages from individuals in both communities about the lack of community-level support with regard to the practical and technical aspects of filling the MDB forms. Most claimants were unaware that they were entitled to review (see chapter 3: Best Practices in Compensation).

The Expert Panel is of the opinion that a Community Support Worker in each community would serve to improve the understanding of the application/examination and decision-making process and increase the capability of community members to access, and successfully complete, the MDB applications and procedures.

The Community Support workers should receive training about the context and history of mercury exposure and the MDB mandate; their responsibilities could include:

- Identify individuals in the community who may be eligible to make a claim;
- Supply forms and support individuals with form-filling;
- Provide support in obtaining Other Material for their claims, such as biomarker data and letters from primary care providers and/or specialists;
- Identify Elders to perform translations as necessary (pay for translation);
- Work with the MDB Executive Director to organize appointments for claimants' examinations;
- Help claimants with understanding and interpreting MDB decisions and seeking review, when necessary;
- Support individuals with reapplications if their condition deteriorates;
- Organize Non-Insured Health Benefits (NIHB) travel for individuals travelling for appointments related to MDB claim or review;
- If the community agrees, annually host at least one statutory meeting of the MDB in each community.

The two Community Support Workers would be housed in their communities, at the health clinic or some other community space where the worker will have access to a private meeting space with desk, chair and additional seating for potential claimants, a

computer with MS Office and the latest version of Adobe Acrobat program, highspeed internet, a printer, photocopier and fax machine.

Training for the Community Support Workers would involve learning about the following: the impact of mercury on health; the history of the contamination of the English-Wabigoon River and ecosystem; the history, development, structure and evolution of the MDB; the MDB application processes for first application, re-application and review; the meaning of technical terms used in decisions or documents provided; any necessary administrative training that the candidate(s) require.

Support for MDB representatives from the community
The MDB currently includes representatives from WIN and ANA.

Addressing complex health problems requires collaborative teams that bear diversity of knowledge, skill and shared commitment to addressing inequality[59]. This collaborative approach requires the creation of culturally safe spaces and sharing of knowledge. The community representatives on the MDB hold a high level of community and local knowledge. They are expected to contribute to the discussion with the others who, for the most part, have at least one university degree and are accustomed to debate and decision-making in an administrative setting. In contrast to the representatives from Ontario and Canada, the WIN and ANA representatives do not have free of cost access to professional opinions.

Cultural safety is about recognizing the differences in power that exist among actors and equalizing these power dynamics[60], in such a way that MDB representatives receive support and claimants receive dignified and competent care.

2.4 Summary of Rationale and Recommendations

Given the moral obligation to be culturally sensitive in the currently strengthening climate of cultural equity and reconciliation,

We recommend that:

- Every individual involved in any capacity with the MDB and/or mandated to interact with the actual or potential claimants receive specific training on ANA and WIN culture, history and experiences with mercury.

- The professionals, recruited by the MDB to carry out the examinations, be required to complete a program on Indigenous Cultural Safety.

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[59] Richmond CA and Cook C. 2016. Creating conditions for Canadian aboriginal health equity: the promise of healthy public policy. Public Health Reviews 37:2.
[60] Cote-Meek S. 2014. Colonized classrooms: Racism, trauma, and resistance in post-secondary education. Fernwood Publishing pp. 198.

Given the perception and testimonies of poor communication, mistrust and distance between the community members and the MDB,

We recommend that:

- The MDB enhance their outreach strategies, including appropriate communication tools, website architecture and content, integration of cultural rituals in opening and closing of meetings, and co-learning through face-to-face activities.

- The hiring of a Community Support Worker for each community, with a contractual relation with the MDB, to ensure that claimants meaningfully participate in, and benefit from, the mandate of the MDB.

Given the inequality of training on legal and health issues between representatives of the communities and representatives from government and other MDB appointees,

We recommend that:

- Community members on the MDB be provided with the financial support to hire consultants when they consider it necessary.

Chapter 3 Best Practices in Compensation

Effective implementation of updated measures of disability and recommendations for best practices in evaluating mercury poisoning in adults and children requires an adequate understanding of key components of the compensation process. We reviewed the compensation practices of the MDB and its mandate, as defined by the regulatory framework, to ensure that the compensation processes that feed the MDB decision-making can appropriately apply the Expert Panel's recommendations.

This chapter includes a description of the specificity of the role of Independent Medical Evaluators (IMEs) in the context of compensation, the consequences of misunderstanding the IME-claimant relationship and challenges to the credibility of the claimants by the use of malingering labels. It also addresses procedural issues including review and re-application procedures.

3.1 The Independent Medical Evaluator

MDB claims adjudication is based on the assessment of an independent medical evaluator, a third-party physician. Since independent medical evaluators (IME) are retained by the requesting party, their relationship with the claimant is different from the relationship in the traditional physician–patient model.

The difference in role between an IME and a physician that a person consults himself or herself, is not necessarily understood. Because the primary responsibility of the independent medical evaluator is to provide a service for the hiring third party and not for the patient, legal and ethical concerns may arise during an IME examination that would not typically arise within the context of a standard physician–patient relationship. Particularly challenging and controversial issues are duty of care within the evaluator–examinee relationship, disclosure of important medical findings, and the right of the examinee to access the IME's report, which could include working notes[61]. Some Canadian courts have held that independent medical evaluators have a responsibility to disclose to the examinee medical problems uncovered during the examination[62] .

[61] Ebrahim et al. 2014. Ethics and legalities associated with independent medical examinations Canadian Medical Association Journal 186:248-249.
[62] Baum K. 2005. Independent medical examinations: an expanding source of physician liability. Annals of Internal Medicine 142 (12 Pt 1):974–978.

The Canadian Medical Protective Association (CMPA) has complied common complaints received by the College of Physicians about IME[63] :

- *"the doctor's demeanour, (e.g., rudeness such as "He questioned me as if he was a policeman.") or a "rough" physical examination;*
- *the duration of the evaluation (alleged to be too short);*
- *the type of evaluation (alleged to be incomplete);*
- *the conclusion (alleged to be unfair)."*

The CMPA note that complaints have been brought to the Human Rights Commission, the Privacy Commissioner and through Civil litigation alleging battery, defamation and/or breach of the standard of care.

During our visits to the communities, the Expert Panel heard every one of the above complaints repeatedly from members of the two communities. Furthermore, for MDB applicants, the nature of these complaints is compounded by their perceptions of racism. The 2017 Licker's report on Asubpeeschoseewagong Netum Anishinabek (ANA) and Wabaseemoong Independent Nations (WIN) Experiences with the Mercury Disability Board[64] contains similar complaints and notes that *"Members are frustrated - they thought this process was set up to help them and instead they feel that they have to defend themselves."*

Cultural safety, referred to in the previous chapter, is critical in the context of compensation claims. The CMPA website provides an overview of IME specificity and indicates that *"... it is important to ensure that both the individual being evaluated as well as the party referring the individual are dealt with equitably"*[65].

3.2 Critical Cultural Challenges in Independent Medical Evaluation

The misunderstanding of roles not only affects the claimants, but also the examiner. In a recent article on procedural justice in workers' compensation, a similar situation to the MDB compensation process, Kilgour and co-authors[66] write that independent medical evaluations are not designed to serve a therapeutic purpose and often result in denied claims. The authors indicate that this can lead to misunderstanding and mistrust on the part of the patient/applicant and can affect the behavior of the examining physician as

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[63] CMPA-ACPM https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2000/independent-medical-evaluations-be-prepared: document revised July 2011, accessed August 1, 2019.

[64] Lickers K. 2017. Revised Draft Summary of the Collection of Information re: Asubpeeschoseewagong Netum Anishinabek (ANA) and Wabaseemoong Independent Nations (WIN) Experiences with the Mercury Disability Board. p. 11

[65] CMPA-ACPM *ibid*

[66] Kilgour E et al. 2015. Procedural justice and the use of Independent Medical Evaluations in workers' compensation. Psychological Injury and Law 8:153-168.

well. They stress the importance of both patient/applicant and examining physician understanding the process and the dynamic, and recommend that the physicians be appropriately sensitized to the population they are serving. They go on to say that the process will go more smoothly, even if it results in a denied claim, if the applicant believes that he or she has received *"procedural justice"*, that is, that he or she has been respected and permitted to express his or her feelings or views.

"Perceived fairness" in the compensation process has been shown to correlate with better health outcomes, and medical assessments were among the variables identified as important in the perception of fairness by the claimants involved in motor vehicle accidents in two Australian states, one which resorted to medical assessments (IMEs) earlier on and more often than the other[67].

Stereotyping and discrimination based on race, ethnicity or language[68] are known problems in health care and IME[69,70]. In an article on stereotyping of medical disability claimants, van Riijsen and colleagues[71] report that stereotyping, that is, assuming common characteristics within identifiable classes of individuals, can save time and help the practitioner adjust his or her style to the cultural and educational norms of the patient, but is fraught with danger and can lead to inappropriate and unjust outcomes. As mentioned in the previous chapter, there is a long history of systemic racism towards First Nation communities in the Canadian health care system[72].

The misunderstandings and difficulties described above not only lead to discord between the MDB, their physicians and the communities, but also to problems in recruiting neurologists to carry out assessments as IME[73].

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[67] Elbers et al. 2016. Differences in perceived fairness and health outcomes in two injury compensation systems: a comparative study. BMC Public Health 16:658.
[68] Premji S. Barriers to Return-to-Work for Linguistic Minorities in Ontario: An Analysis of Narratives from Appeal Decisions. 2015. Journal of Occupational Rehabilitation. 25:357-367.
[69] Burgess DJ et al. 2006. Understanding the Provider Contribution to Race/Ethnicity Disparities in Pain Treatment: Insights from Dual Process Models of Stereotyping. Pain Medicine 7: 119-134;
[70] Stone J and Moskowitz GB. 2011. Non-conscious bias in medical decision making: what can be done to reduce it? Med. Educ. 45: 768-776.
[71] van Rijjsen HJ et al. 2010. Stereotyping of medical disability claimants' communication behaviour by physicians: towards more focused education for social insurance physicians. BMC Public Health 10:666.
[72] Allan B and Smylie J. 2015. First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. Toronto, ON: the Wellesley Institute p.17.
[73] Interviews with E. Baxter [March 26th 2019] and M. Wanlin August 9th 2019.

3.3 Challenging the Credibility of Claimants

The distrust of claimants and the numbing of experts' sensitivity to claimants are documented[74]. For example, van Rijssen and co-authors[75] studied insurance physicians in the Netherlands. These IME providers benefited from ongoing training and monthly meetings with colleagues and were required to evaluate 10 patients a week, conditions far more favourable than those in which IME providers evaluate claimants for the MDB. Nonetheless in this Dutch study, stereotyping was pervasive. Among the "advantages" of stereotyping, identified by physician participants in the study, was their contribution to the rapidity of evaluations in a context where time pressure was important. The IME physicians in this study were highly trained in medico-legal evaluations and nonetheless the authors recommend that training courses include strategies to *"increase awareness of the potential influence of stereotyping"*. They also conclude that stereotyping increases when there are strong time constraints placed on the insurance physician and that «attention should be paid to the time limitations and information overload» that some insurance physicians experience.

In our interviews with different parties involved with the MDB, we heard several times that *"everyone reports symptoms of numbness and tingling in hands and feet because they know that it is a symptom of mercury poisoning"*. Indeed, some persons associated with the MDB, openly suggested that applicants lie about numbness and tingling because they wish to receive benefits. On the other hand, community members complain that *"the MDB physicians do not listen to us and think that we are being dishonest and are just there to get some money. This is insulting to us."*

We examined this question using data from the ANA Community Health Assessment (ANA-CHA)[76]. Among the 50 questions on symptoms, the survey included the following: *Do your hands (feet) feel numb?* and *Do you have a tingling feeling in your hands (feet)?* The choice of answers was: *never, rarely, from time to time, often, always.* Tingling and numbness in hands/or feet are indeed the symptoms the most often reported. Figure 5 presents the results of the answers to these questions, with respect to the answer to a question about whether the person had made a claim to the MDB. Each point represents a person's response score. A total of 336 adult Band members (18 – 80 years) answered both questions.

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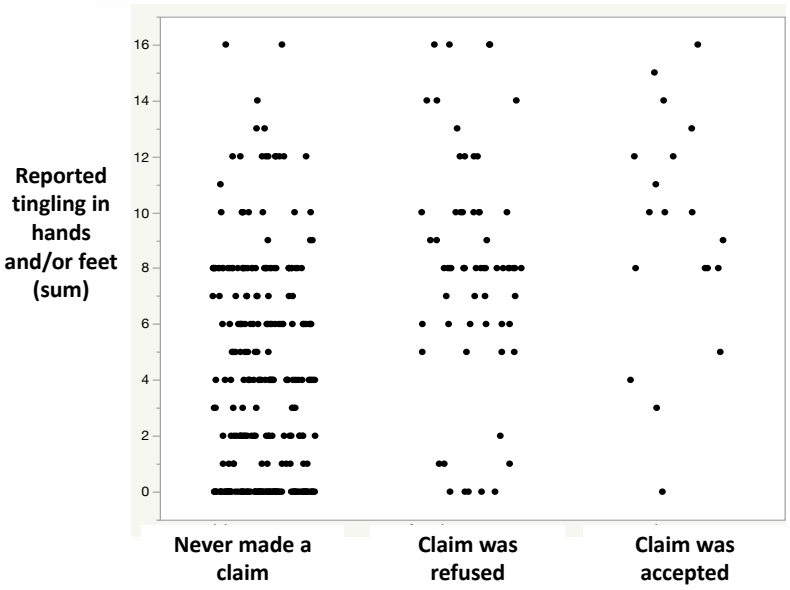
[74] Lax M et al. 2004. Medical Evaluation of Work-related Illness: Evaluations by a Treating Occupational Medicine Specialist and by Independent Medical Examiners Compared, International Journal of Occupational and Environmental Health 10:1-12.
[75] van Rijjsen HJ et al. 2010. Stereotyping of medical disability claimants' communication behaviour by physicians: towards more focused education for social insurance physicians. BMC Public Health 10:666.
[76] Asubpeeschoseewagong Netum Anishinabek Community Health Report. May 2018 . pp.269.

Figure 5. Reported numbness and tingling with respect to claimant status (ANA-CHA data)



- For those who answered all of the above questions, 253 (75.3%) had never made a claim.

- The large majority of persons whose score is zero (i.e. reported never having these symptoms) had never made a claim. Indeed, 93% of those who report never having any of these symptoms have never made a claim.

- 92% of persons who have made claims do report these symptoms.

- The median score for reporting these symptoms is 5 and many people who are at the median or higher (42%) have never made a claim.

- Comparison of the overall score for these symptoms between those who have not made a claim and those who have been accepted or refused are presented in Table 1. The difference between those who have never made a claim and those who have made a claim (refused or accepted) is highly significant ($p<0.0001$). There is no statistically significant difference between those whose claims were refused or accepted.

Table 1. Scores for tingling and/or numbness in hands and/or feet with respect to having made an MDB claim (ANA-CHA data)

	No claim	Refused Claim	Accepted Claim
Average score	4.13	7.92	9.26
Median score	4	8	10

The data from the ANA-CHA shows that generally people who have symptoms of mercury exposure applied, and those who didn't have symptoms didn't apply. Among the people who applied, those with symptoms were not more likely to get benefits than those without symptoms. This provides evidence that the stereotype of community members faking symptoms is false. The false negative stereotype can lead the MDB to reject worthy applicants, and likely has in the past. Doubting the existence and severity of claimants' reported symptoms not only influences the perception of fairness and procedural justice among the claimants in regard to the medical evaluation, but also can lead to a shift in perceptions of the medical assessor with regard to what is considered "normal" and, as a corollary, the normalization of poor health and physical functioning in affected populations.

The findings of the ANA-CHA, presented in Figure 5, likewise show that there is little difference in symptom reporting between those who are refused and those who are accepted, supporting the importance of establishing standardized protocols and validated tools, referred to as anchors, for the clinical examinations (see Chapters 4 and 5).

3.3 The Procedures

The MDB designates authorized physicians, who, in keeping with Section 1 of the Act, *"means a physician entitled to practice medicine in any jurisdiction in Canada or the United States of America and designated as an authorized physician by the Board."* In our interviews with the MDB members, we were informed of the difficulties in recruiting physicians from the region.

For the applicant, the current procedure requires the person to fill out claimant forms that are available in the communities, at the MDB office or on its website. Here, we examine the procedures.

Making a claim

The MDB website is very clear and lays out the steps to make a claim. Despite this, in our visits to the communities, several community members mentioned that they did not understand the procedure or how decisions were made. Not everyone, particularly Elders, has internet access and they need to hear by word of mouth whether they may be eligible and how to make a claim (issue of communication).

There is an expectation that everyone should know: i) that there is the possibility to make a claim to the MDB; ii) what type of signs and symptoms are consistent with mercury poisoning; iii) how to make a claim; iv) the role of an independent medical examiner, and the right to receive notice and appear before the MDB when his or her application or

award is to be considered or reviewed[77]. We were informed by Ms. Wanlin[78], current interim and previous MDB Chairperson, that claimants are now being told to expect an examination of 20 - 30 minutes and that physicians need to record how long the examination takes. While this may serve to reduce expectations and misunderstandings, it does not address all of the issues.

To our knowledge, not all of the health professionals in the area are informed of these communities' rights to disability payments. For example, if a treating physician notes signs and/or symptoms of nervous system dysfunction in a member of one of the communities, will the physician identify this as a possible sign of mercury poisoning and suggest that the person look into making a claim to the MDB? There does not appear to be a formal mechanism in place to inform and seek collaboration of local health authorities.

The examination and scoring procedure

Persons who have filled out the Initial Application Form are examined by a neurologist according to a pre-determined protocol. Over time there has been a change in the procedure that follows the examination. Between 1988 and 2000, the claims were scored by Great-West Life Assurance. According to Cosway[79], only 16% of the 509 claimants were awarded benefits during this period. She noted that a total of 148 were reviewed and 39% were accepted. Late in the year 2000, the MDB re-reviewed all cases that had applied to the MDB and when judged necessary, the MDB invited the applicants for re-assessment. Ms. Wanlin informed us that between 2001 and 2004, the scoring was done by the neurologist. The Board then decided there was a need for more distance between the examination and the scoring (i.e. the examiner and the scorer should not be the same person), and since 2004, the scoring is done by the two MDB physicians, who sit on the Service committee[80,81].

When there are sufficient claims, a neurologist is called in to examine approximately 12 claimants/day for two to four days. The examinations now take place either in Kenora or in the communities.

Informing the claimants

Claimants are informed by a letter from Great West Life Assurance (now Canada Life) as to whether their claim is accepted or refused. When refused, they are not provided either with the score or the reasons for refusal. The legislation indicates in 14 b. : *if the application does not appear to the administrator to qualify in accordance with the plan document or is not accompanied by the material set out in section 10, [the administrator*

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[77] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, Statutes of Ontario, 1986, chap. 23, s.24(2).
[78] Telephone interview with M. Wanlin [August 9, 2019].
[79] Cosway S. 2001. The Grassy Narrows & Islington Band Mercury Disability Board: A Historical Report 1986-2001, p.88.
[80] Telephone interview with M. Wanlin [August 9, 2019].
[81] Mercury Disability Board Adult Assessment Scoring Process Nov 17, 2006 (approved in principle), Mercury Disability Board, January 19m 2011 – addendum (#8).

shall, within 21 days] advise the applicant and the Board in writing of the reason it does not appear to qualify[82].

The reason provided to refused claimants is *"The medical information has been reviewed and it does not support a claim for disability as defined under the above Act."*[83] Community members told us that, to them, this curt response showed a lack of respect. This minimalist response does not appear to meet the legal requirements set out in section 14b of the Act, nor does it appear to comply with the "duty of procedural fairness" that applies to the MDB.

The Supreme Court of Canada judgement in *Baker*[84] describes the duty of procedural fairness in these terms:

"The duty of procedural fairness is flexible and variable and depends on an appreciation of the context of the particular statute and the rights affected. The purpose of the participatory rights contained within it is to ensure that administrative decisions are made using a fair and open procedure, appropriate to the decision being made and its statutory, institutional and social context, with an opportunity for those affected to put forward their views and evidence fully and have them considered by the decision-maker. Several factors are relevant to determining the content of the duty of fairness: (1) the nature of the decision being made and process followed in making it; (2) the nature of the statutory scheme and the terms of the statute pursuant to which the body operates; (3) the importance of the decision to the individual or individuals affected; (4) the legitimate expectations of the person challenging the decision; (5) the choices of procedure made by the agency itself. This list is not exhaustive."

More recently, the Supreme court in Canada (Minister of Citizenship and Immigration) v. Vavilov reaffirmed the criteria first enunciated in Baker and noted: *"Cases in which written reasons tend to be required include those in which the decision-making process gives the parties participatory rights, an adverse decision would have a significant impact on an individual or there is a right of appeal"*[85].

Applied to the MDB process, it is clear that the decisions to be made are of vital importance to the individual claimant, in that they will affect their livelihood. The MDB is a product of remedial legislation, which should be interpreted in favour of the claimant[86]. Claimants have a legitimate expectation to be treated fairly; the legislator has

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[82] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, Statutes of Ontario, 1986, chap. 23, section 14b.

[83] Information obtained from the MDB on June 22, 2020 shows that the MDB recently modified the letter concerning the results of reapplication, Canada Life's (formerly Great West) letters for initial application had not changed.

[84] Baker V. Canada, 1999. 2 S.C.R. 817.

[85] Canada (Minister of Citizenship and Immigration) v. Vavilov, 2019 SCC 65, par. 77.

[86] Lippel K. 2011 *L'interprétation libérale des lois sociales : une pratique révolue?* , In Stéphane Beaulac et Mathieu Devinat (Ed.), *Interpretatio non cessat : mélanges en l'honneur de/Essays in honour of Pierre-André Côté*, Éditions Yvon Blais, Cowansville, p. 201-232.

stipulated the right to be heard in the legislation itself[87], yet the members of the Expert Panel found that some of the statutory provisions had not been complied with in the past and that reasons for decisions were not usually provided, contrary to what would be expected in a context where the duty of fairness should apply.

Importantly, there is no mention in the letter from Great West Life Assurance about the right to review, provided for in Section 16 of the Act : "*An applicant or the Board or any member of the Board may, at any time after a determination by the administrator under clause 14 (a) or (b), by notice in writing to the Board or to the applicant or to the Board and the applicant respectively, require that the decision of the administrator be reviewed"*[88].

Review process

The Act provides further rights to the applicant with regard to the application and review process:

- Section 24 (2): *"Any applicant may appear and be heard at any meeting of the Board at which his or her application or award is to be considered or reviewed and the Board shall provide notice to each applicant accordingly."*

- Section 27: "*The Board shall consider any information, advice, report, evidence or other material or matter which, in its sole discretion, it deems useful for the purpose of deciding any matter including whether it may be appropriate to make or vary any award or awards, and may hear or, subject to subsection 24 (2), not hear any person."*

We learned from the communities that some persons provide further information, including cord blood, hair or blood measurements that were taken during their life, letters from their family physician or from the nurse practitioner or a letter relating their experience. The First Nation and Inuit Health Branch of Indigenous Services, Canada has made available to persons from Grassy Narrows and Wabaseemoong their biomarker data (cord blood, hair, blood) that was sampled and analysed between 1970 and 1997. Claimants should have the right, but not the obligation, to provide the MDB with their data. When making their decision, the MDB should consider these data, without penalizing those that do not have them. The monitoring programs did not cover all Band members and there is much missing data. Moreover, concentrations vary with the time of year, reflecting seasonal fish consumption habits. Persons sampled when fish

[87] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, Statutes of Ontario, 1986, chap. 23, section 24 (2).
[88] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, Statutes of Ontario, 1986, chap. 23, section 16.

consumption was low, may have had much higher values when fish consumption was high or when they were acting as fishing guides (see Chapter 11).

The Panel was informed that, in some cases, decisions had been reviewed and decisions were subsequently modified. However, many persons informed us that they were unaware of their right to review, right to attend MDB meetings when their review is considered and right to provide further information in support of their claim.

In this context, we also think it would be important for the credibility of the system that claimants have access to a funded second medical opinion to be provided by a specialist who is at arms-length from the MDB.

Re-application

We were informed by Ms. Wanlin that the re-application process was introduced in 2008. The reapplication process applies to claimants who consider that their symptoms have worsened over time. Forms for re-application claims are available on the MDB website and in the communities. In the 18/19 fiscal year, there were 61 adult first reapplications.

The person who re-applies is scheduled for an appointment with a designated neurologist, who adopts the same protocol as in the initial application. The MDB physicians then apply the grading system and determine if the person is eligible for benefits or an increase in the amount already awarded.

The letter from the MDB informs the applicant of their score (i.e. number of points determined from the neurological assessment) and includes a statement that he/she could re-apply in 2 years if symptoms change, but does not contain any other information. However, the MDB website specifies that *"In cases where there is medical evidence, the waiting period may be reduced."*[89]

We were told by a re-applicant that the first letter he received indicated a score of 2, the second a score of 5 and the third, a score of zero. Although this may reflect an actual improvement in the person's conditions, it could also reflect non-reproducibility of the examination protocol. For the applicant, it reflected an absence of transparency and consistency.

3.4 Claimants' Right to Receive a Copy of their File

The right to access personal information contained in IME files is confirmed through privacy legislation, and the general rule is that a physician must provide an examinee

[89] Mercury Disbility Board. http://www.mercurydisabilityboard.com/applications (accessed August 18, 2020).

with access to his/her personal information upon request[90]. The MDB adjudication process is based on the factual information contained in the claim file, and as in other compensation systems, claimants should have the right to a copy of their file, including all medical opinions specific to their claim, and the right to authorise their representative to receive a copy of their file[91].

3.5 Summary of Rationale and Recommendations

Given the legal and ethical concerns that may arise from the medical evaluator's role and the need to ensure a trustful and culturally safe climate,

Given the evidence from the Community Health Assessment that contradicts the voiced suspicion on the part of several of the persons involved with the MDB of wide-scale malingering by claimants;

Given the difficulties in recruitment of professionals;

Given that section 1 of the Act defines "authorized physician" *as a physician entitled to practice medicine in any jurisdiction in Canada or the United States of America and designated as an authorized physician by the Board"*,

We recommend that:

- The MDB recruit culturally sensitive, authorized specialists from Canada or the United States of America.

Given the perception of procedural complexity,

We recommend that:

- The Community Support Workers (see Chapter 2 and recommendation 4) inform and assist potential and current claimants through the process, from eligibility to application, to decision-making interpretation, re-application and review, as needed.

Given procedural fairness requirements,

We recommend that:

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[90] The policy of the Workplace Safety and Insurance Board illustrates this principle: https://www.wsib.ca/en/operational-policy-manual/disclosure-claim-file-information-issue-dispute (accessed August 18, 2020).
[91] *ibid*

- Claimants have access to their files including, but not limited to, the evidence provided by the specialists who undertake the evaluation at the behest of MDB.

- Acceptance and denial letters include detailed justifications of the decisions.

Given that the right to be present when one's claim is heard and the right to review are clearly laid out in the Act,

We recommend that:

- All claimants should be invited to attend the meeting when their claim is on the agenda.

- Claimants whose initial applications or reapplications are denied, or who receive, by the decision, a lower level of benefits than they expected, be informed of their right to review.

- All claimants should be informed of the reapplication process when they receive their decision.

- Funding should be provided to allow claimants in review to secure a second opinion and to access counsel for the review hearing by the MDB.

Chapter 4 Adult Clinical Examination

4.1 Background

The clinical examination is carried out within the confines of the Act. For clinicians, not familiar with concepts in administrative law, this considerably differs from differential diagnoses, required for adequate health care, therapeutic measures and follow-up. The examinations, performed within the context of the Act, are not meant to differentiate aetiologies, but to provide information on whether the claimant displays signs and symptoms consistent with mercury poisoning, as laid out in the Plan Document.

In an article, published in 1987, West[92] explains:

> *"…the Objibway Bands really did not have an alternative to settlement. By settling, they are assured of a Fund, established by legislation and guaranteed by the Province of Ontario, to compensate victims of mercury poisoning - a remedy that would not have been available as the result of litigation. Individuals applying for compensation for health problems which are reasonably consistent with mercury poisoning will be relieved from meeting the strict standard of proof required by the courts, but will instead be subject to a less stringent standard (the reasonably-related standard) established by the Mercury Disability Board."*
>
> *West L. 1987 Environmental Law 18: 131-150.*

"Standard of proof", used in Canadian administrative law, is "more probable than not" or the chance of the proposition being true is more than 50%. This is considerably less than 95%, which is the "cut-off" to establish statistical significance in scientific studies. The reasonably-related standard is less than 50%.

In his 1986 affidavit to the Ontario Supreme Court, Justice Emmet Hall wrote[93] *" I verily believe that the following features of the Board contribute to making it a uniquely satisfactory vehicle for ensuring adequate compensation for Plaintiffs in the within action and for all present and future members of the Bands who claim their health has been adversely affected by mercury pollution, including minors:*

- *the level of proof required for an individual to receive an award from the Board is less onerous than the judicial standard of proof."*

Since the early seventies, there have been several studies on the people from Grassy Narrows and/or Wabaassemoong. A team of experts in Minamata Disease, led by Dr Masazumi Harada, carried out clinical research with the two communities in 1975, 2002,

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[92] West L. 1987. Mediated Settlement of Environmental Disputes: Grassy Narrows and White Dog Revisited, Environmental Law 18: 131-150.
[93] Justice Emmett Hall affidavit to the Supreme Court of Ontario, June 18, 1986.

2004 and 2010, using the Japanese diagnostic criteria for Minamata Disease. Following their 2010 examination of 160 persons from Grassy Narrows and Wabaseemoong, they wrote[94]: "*under our diagnostic criteria used in Minamata City, 33.7% of the target group would be diagnosed as Minamata Disease patients; and 25.0% would be suspected Minamata Disease patients with light or changing symptoms. A total of 58.7% was affected by mercury. This reinforces the conclusion that the residents suffer from the effects of Minamata Disease."* They note that, at that time, *"only 15% of those who were tested have been given some compensation."*

In 1989, at the request of Chief Steve Fobister of Grassy Narrows, Dr Brian Postl, at the time, professor and head of the Department of Community Health Sciences of the University of Manitoba, and member of the MDB from 1993 to 2005, reviewed mortality and morbidity records of Grassy Narrows' residents[95]. The research team[96] concluded that *"Mortality and morbidity rates far exceed Ontario figures. Although consistent, by trend at least, with Canadian Native rates, the gap remains large and is unacceptable."*

The clinical examination carried out by the MDB is based on a report and recommendations by Prichard and McIntyre, who analyzed the data from 1976, 1977 and 1979, collected by medical teams appointed by Health and Welfare Canada[97]. A total of 90 persons from Grassy Narrows and Wabaseemoong (Whitedog) were examined, but there is no indication in the report on what basis these persons were selected. They note that "*forty-three people (47.7%) were found to be neurologically abnormal on at least one occasion where the abnormality was not entirely explained by a recognized disease process other than organic mercury poisoning."*

At the time the Act was passed, sequelae of toxic-induced nervous system disorders were mostly diagnosed and treated by neurologists. In 1987, Hartman[98] noted that neuropsychological assessment for naturally or industrially produced nervous system poisons were only just beginning to enter the United States' neuropsychological literature. Today, neuropsychological testing is a recommended practice in the

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[94] Harada, M. et al., 2011. Mercury Pollution in First Nations Groups in Ontario, Canada: 35 years of Canadian Minamata Disease. Journal of Minamata Studies 3: 3-30 (translated from Japanese).
[95] Postl, BD. Community Health Assessment Grassy Narrows Band Final Report. June 1989 (document provided by the parties). pp. 151.
[96] The team from the Department of Community Health of the University of Manitoba included Dr. B.D. Postl, Professor and Head, Dr. M.E.K. Moffatt, Associate Professor & Director; J.A., Hildes Northern Medical Unit; Mr.R.G. Whitmore, Administrator Northern Health Research Unit, Ms. N. Ling, Research Associate, Northern Health Research Unit, Dr. J.P. Dooley, Medical Program Coordinator, J.A. Hildes Northern Medical Unit, Dr. B. Wright, Community Medicine Resident, Dr. J. Kettner, Community Medicine Resident.
[97] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-exposed Indians of the Grassy Narrows and White Dog Reserves: Report and Recommendations pp. 13.
[98] Hartman DE. 1987. Neuropsychological toxicology: Identification and assessment of neurotoxic syndromes. Archives of clinical neuropsychology 2:45-65.

assessment of nervous system disorders resulting from toxic exposures[99]. Nervous system disruption by toxic substances can also have neuropsychiatric manifestations[100] ; although psychosis was one of the conditions mentioned by in the Memorandum of Agreement[101], it was later replaced in the Plan Document.

Since 1986, a very large number of mechanistic and observational studies have greatly increased our understanding of how mercury exposure targets the nervous system, as well as other organs. The MDB clinical examination needs to incorporate these new conditions, as stipulated in Section 22 (2) Act[102]. Within the context of the Act, the Expect Panel considered Known Conditions, the addition of Further Conditions and the inclusion of Other Material, as defined in Section 10 (d) of the Act, which indicates that the application shall be accompanied by *"such other material as the board prescribes"*.

4.2 Delayed Neurotoxicity

It is noteworthy that the authors of the report wrote *"It is our honest belief that delayed effects of mercury ingestion will not appear as late as ten years after cessation of mercury-contaminated fish"*. This, unfortunately, has proved to be untrue.

There is evidence from animal and human studies that delayed neurotoxicity may be a feature of methylmercury poisoning[103,104]. Weiss[105] illustrates delayed onset described in early studies (non-human primate data and Minamata cases, Figure 6). More recent studies of congenital Minamata Disease patients show accelerated functional loss with aging[106]. Delayed neurotoxicity may be due to an accumulation of mercury in the brain over time, or a more pronounced effect of the aging process on brain functions damaged by mercury exposure.

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[99] Bowler RM and Lezak M. 2015. Ch. 3: Neuropsychologic evaluation and exposure to neurotoxicants. In Aminoff, M. J., Boller, F., Swaab, D. F., Bleecker, M. L. (Eds.), *Handbook of Clinical Neurology, Volume 131, 3rd Series* (23-45). Edinburgh: Elsevier.

[100] Yorifuji T et al. 2011. Long-term exposure to methylmercury and psychiatric symptoms in residents of Minamata, Japan. Environment International 37:907-913.

[101] Memorandum of Agreement between Her Majesty the Queen in Right of Canada as represented by the Minister of Indian Affairs and Northern Development, Her Majesty the Queen in right of the province of Ontario, Reed Inc, Great Lakes Forest Products Ltd. The Islington Indian Band and the Grassy Narrows Indian Band, November 1985. p. 25.

[102] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, 1986, Statutes of Ontario, 1986, c.23; 22 (2); p. 277

[103] Rice DC. 1996. Evidence for delayed neurotoxicity produced by methylmercury. Neurotoxicology 17:583-596.

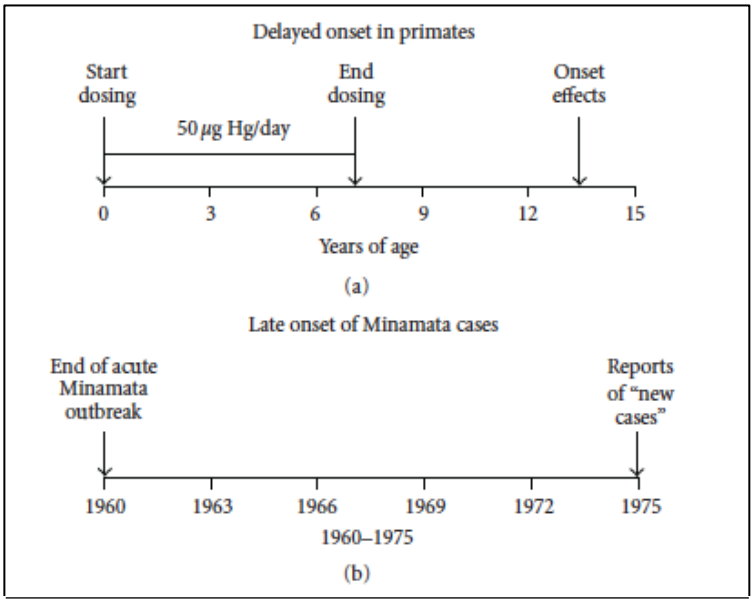
[104] Weiss B et al. 2002. Silent latency periods in methylmercury poisoning and in neurodegenerative disease. Environmental Health Perspectives 110:851-854.

[105] Weiss B. 2011. Lead, manganese, and methylmercury as risk factors for neurobehavioral impairment in advanced age. International journal of Alzheimer's Disease 2011: 607543.

[106] Yorifuji T et al. 2018. Accelerated functional losses in ageing congenital Minamata disease patients. Neurotoxicology and Teratology 69:49-53.

The MDB implicitly recognizes delayed neurotoxicity or worsening of dysfunction with the reapplication process, inviting claimants to re-apply after a two-year interval if their symptoms have worsened.

Figure 6. Delayed neurotoxicity with methylmercury poisoning
(reproduced from Weiss et al. 2002)



4.3 Prenatal and Childhood Exposure to Mercury

At the time of the creation of the MDB, there were few studies on the long-term effects of prenatal and/or early childhood exposure. In an article in the New England Journal of Medicine in 1971, Snyder[107] reported that children with congenital mercury poisoning developed cerebral palsy and mental retardation. These conditions were retained in Appendix III of the Plan Document as 'known conditions' for the children examination. Since that time, many birth cohort studies have shown that, even at very low concentrations of *in utero* exposure to methylmercury, children's neurodevelopment is affected[108,109]. Rationale and recommendations for changes in the children's examination are presented in Chapter 13. Here, we focus on the consequences of *in utero* and early childhood exposure in adulthood.

[107] Snyder R. 1971. Congenital Mercury Poisoning. New England Journal of Medicine 284:1014-1016.
[108] Bose-O'Reilly S et al. 2010. Mercury exposure and children's health. Current Problems in Pediatric and Adolescent Health Care 40:186–215.
[109] Ha et al. 2017. Current progress on understanding the impact of mercury on human health. Environmental Research 152:419-433.

Analysis of the MDB data (Chapter 1.4) shows that 60 % of all adults and all of the children, who are currently receiving compensation, were born since 1960 and may have been exposed *in utero* and/or early childhood to mercury. Figure 8 in Chapter 7 shows the distribution of lesions in adult, infant and prenatal brains of persons with Minamata Disease. Neurodevelopmental deficits in childhood have important consequences on children's learning capacity and behaviour, which can persist into adulthood, affecting social functioning and economic productivity[110]. Decreased economic capacity has been estimated at maternal hair concentrations above 0.58µg/g[111]. The long-term effects of neurodevelopmental disorders are not considered in the current MDB examination.

4.4 Freshwater Fish: Source of Mercury Poisoning

An element to further consider is that the source of mercury in the Wabaseemoong and Grassy Narrows is fresh water fish, while most of the studies on mercury toxicity have been carried out with populations who consume marine fish and/or mammals. Marine fish and mammals have high levels of omega-3 fatty acids and selenium, which are known to have beneficial effects on many of the organs that are affected by mercury. We do not know the full importance of these differences, but feel that it is important to keep an open mind and not necessarily expect that mercury poisoning from freshwater fish consumption will be in all points similar to mercury poisoning from marine fish and mammals. The latter may not be the "gold standard" in this case.

To illustrate how omega-3 fatty acids may counteract the effects of mercury, we refer to the findings of Jacobson et al, 2015[112] who showed a fourfold higher likelihood for borderline intellectual disability in Inuit children, whose umbilical cord blood mercury concentrations were higher than or equal to 7.5µg/g. The authors also measured docosahexaenoic acid (DHA), an omega-3 fatty acid, and showed that it reduced some of the effects of mercury. The authors reported that when omega-3 fatty acids are included into the multiple regression model, the association with prenatal mercury becomes stronger.

> *"The initial adjustment for the other contaminants weakened the association of mercury with IQ (model 1). However, the association with mercury became stronger when cord DHA and selenium were entered in model 2, indicating that the negative association between prenatal mercury and IQ was biased toward the null due to negative confounding. Post hoc analysis showed that the addition of DHA to model 1 significantly increased the β for cord mercury from –0.15 to –0.19, $t(250) = 2.03$, $p < 0.05$, providing support for the hypothesis that the beneficial effect of higher prenatal DHA obscured the adverse effect of prenatal mercury exposure.*

[110] Trasande L et al. 2006. Applying cost analysis to drive policy that protects children: Mercury as a case study. Annals of the New York Academy of Sciences 1076:911-923.
[111] Pichery C et al. 2012. Economic evaluation of health consequences of prenatal methylmercury exposure in France. Environmental Health 11:53.
[112] Jacobson JL et al. 2015. Relation of prenatal methylmercury exposure from environmental sources to childhood IQ. Environ. Health Perspect. 123:827-833.

[Similarly, the entry of cord mercury in a regression of IQ on DHA and the other contaminants significantly increased the β for DHA from 0.17 to 0.20, $t(250) = 1.93$, $p < 0.05$.]"

Jacobson et al. 2015; Environ Health Perspect. 123: 827–833.

The counterbalancing risks and benefits from methylmercury exposure and omega-3 fatty acids have been reported not only for nervous system outcomes, but also for heart conditions, such as myocardial ischaemia[113] and myocardial infarction[114,115]

4.5 Assessment of the Current Clinical Examination Protocol

The Expert Panel members examined the current clinical examination protocol (Great West Life Assurance Company Clinical Adult Neurological Examination Protocol for Grassy Narrows and Islington Bands Mercury Disability Board (Group #51033) and consider that:

- The report made by the neurologist about medical history, nervous system, eye and hearing complaints and personal history (Sections 2 -5) is cursory.
- Based on the current scientific evidence, many documented known nervous system conditions associated with prenatal and postnatal methylmercury exposure, such as neuropsychological deficits and neuropsychiatric symptoms, are lacking.
- There is growing evidence that mercury can contribute to some non-neurologic systemic chronic health conditions.
- In keeping with current best practices, the clinical examination protocol has substantial limitations and requires modification to improve consistency and precision of application.
- Nearly all of the components of the examination lack validated anchor descriptors, making it almost impossible to ensure reproducibility.

The Expert Panel was informed by Ms. Wanlin that the examinations take approximately 20 minutes and that recently the MDB required the neurologist to indicate the duration of

[113] Tajik B et al. 2019. Serum long-chain omega-3 fatty acids, hair mercury and exercise-induced myocardial ischaemia in men. Heart. 105:1395-1401.
[114] Hu XF et al. 2017. Mercury diminishes the cardiovascular protective effect of omega-3 polyunsaturated fatty acids in the modern diet of Inuit in Canada. Environ Res. 152:470-477.
[115] Wennberg M. et al. 2012. Myocardial infarction in relation to mercury and fatty acids from fish: a risk-benefit analysis based on pooled Finnish and Swedish data in men. Am J Clin Nutr. 96:706-713.

the examination for each claimant[116]. During this time period, and prior to the neurological examination, the neurologist is required to take a short medical history, write down the claimant's nervous system, eye and hearing complaints and personal history, including regular medications and perform a brief general examination. This is done rapidly and the both Panel members and the MDB physician interviewed[117] consider that it is insufficient to provide valuable information.

Indeed, one of the major complaints that the Expert Panel heard from claimants is that the MDB appointed neurologist does not take the time to listen to them. Many have suffered over several years and the decision to make a claim to the MDB is a considered one, not made lightly. Once deciding to make a claim, there is an expectation that the neurologist will listen to the story of their symptoms and disabilities. Moreover, like for other neurological disorders, symptoms are not necessarily present all of the time; they may have intermittent moments of inability to swallow, difficulty seeing, joint pain, etc. The symptoms may be worse in times of stress.

The Expert Panel considers that an authorized nurse practitioner would be a more appropriate professional to take information on past medical and personal history and perform the general examination. Medical history should include the history of the claimant's symptoms, not just as presence/absence, but when they began, when they occur, etc. Many of the claimants from ANA and WIN have undergone clinical neurological or psychological examinations by a specialist either through referral or as part of clinical research projects. At the written request of the claimant, the results of these examinations should be included in the medical history. The medical history chart produced by the nurse practitioner would be an integral part of the claimant's application file as per Section 10 (d) of the Act: "such other material as the Board prescribes".

Having a nurse practitioner to gather information on past medical history, personal history and perform the general examination, would provide more time for the neurological examination, as well as a "safe place" for claimants to tell about their symptoms and their history.

As a guide for this aspect of the examination, the items in the Standard Neurologic Checklist for Medical History, presented in Table 2 should be addressed by the nurse practitioner.

In the following chapters, we present the background, current knowledge on the effects of mercury poisoning, with our recommendations for the clinical examinations for Known Conditions and Further Conditions and the professionals required to carry out these examinations. We likewise recommend further relevant information be included as Other

[116] Information received from M. Wanlin [August 9, 2019]
[117] Interview with Dr. A. Jackson [April 11, 2019]

Material[118]. We then propose an updated grading system, which takes into account our current knowledge on signs and symptoms consistent with mercury poisoning.

Table 2. Standard Neurologic Checklist for Medical History

CONSTITUTIONAL

Weight loss	☐ Yes	☐ No
Loss of appetite	☐ Yes	☐ No
Fevers	☐ Yes	☐ No
Chills	☐ Yes	☐ No
Sense of ill feeling	☐ Yes	☐ No
Fatigue / tired	☐ Yes	☐ No

EYES

Blurred vision	☐ Yes	☐ No
Double vision	☐ Yes	☐ No
Changes in vision	☐ Yes	☐ No

EARS / NOSE / THROAT

Hearing loss	☐ Yes	☐ No
Ringing in ears	☐ Yes	☐ No
Nosebleeds	☐ Yes	☐ No
Difficulty swallowing	☐ Yes	☐ No
Pain with swallowing	☐ Yes	☐ No

CARDIOVASCULAR

Chest pain	☐ Yes	☐ No
Chest tightness	☐ Yes	☐ No
Abnormal beats	☐ Yes	☐ No
Lightheadedness	☐ Yes	☐ No
Fluid retention	☐ Yes	☐ No

RESPIRATORY

Shortness of breath	☐ Yes	☐ No
Shortness of breath with exertion	☐ Yes	☐ No
Shortness of breath lying down	☐ Yes	☐ No
Shortness of breath at night	☐ Yes	☐ No

GASTROINTESTINAL

Abdominal pain	☐ Yes	☐ No
Nausea	☐ Yes	☐ No
Vomiting	☐ Yes	☐ No
Vomiting blood	☐ Yes	☐ No
Black / tarry stools	☐ Yes	☐ No
Bright red blood from rectum	☐ Yes	☐ No
Constipation	☐ Yes	☐ No
Diarrhea	☐ Yes	☐ No

ENDOCRINE

Heat or cold intolerance	☐ Yes	☐ No
Unexplained weight gain / loss	☐ Yes	☐ No
Hair loss	☐ Yes	☐ No

MEDICATION ALLERGIES ☐ Yes ☐ No
(please list below and reaction):

_____
_____
_____
_____
_____
_____

GENITOURINARY

Urinary frequency	☐ Yes	☐ No
Burning with urination	☐ Yes	☐ No
Blood in urine	☐ Yes	☐ No
Leaking of urine	☐ Yes	☐ No
Urgency	☐ Yes	☐ No

MUSCULOSKELETAL

Joint pain	☐ Yes	☐ No
Muscle soreness	☐ Yes	☐ No
Swelling in arms / legs	☐ Yes	☐ No
Weakness	☐ Yes	☐ No

SKIN

Suspicious or changing moles	☐ Yes	☐ No
Dryness / itching	☐ Yes	☐ No

NEUROLOGIC

Headache	☐ Yes	☐ No
Numbness	☐ Yes	☐ No
Tingling	☐ Yes	☐ No
Difficulty thinking	☐ Yes	☐ No
Difficulty with walking	☐ Yes	☐ No

PSYCHIATRIC

Depression	☐ Yes	☐ No
Anxiety	☐ Yes	☐ No

HEMATOLOGIC / LYMPHATIC

Lymphadenopathy	☐ Yes	☐ No
Excessive bruising / bleeding	☐ Yes	☐ No
Anemia	☐ Yes	☐ No

ALLERGIC / IMMUNOLOGIC

Environmental allergies	☐ Yes	☐ No
Frequent infections	☐ Yes	☐ No

BREAST (if applicable)

Skin changes	☐ Yes	☐ No
Dimpling	☐ Yes	☐ No
Masses	☐ Yes	☐ No
Pain	☐ Yes	☐ No
Nipple discharge	☐ Yes	☐ No

Last mammogram: _____

CURRENT MEDICATIONS (dose, frequency):

_____
_____
_____
_____
_____
_____
_____
_____

[118] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, Statutes of Ontario, 1986, c23, section 10 (d).

4.5 Summary of Rationale and Recommendations

Given that the adult examination, carried out by the MDB, is based on the Prichard and McIntyre report, using data from examinations conducted between 1976-1979;

Given that the belief, at the time of the Act, that delayed effects of mercury would not appear as late as 10 years after cessation of exposure, has been proven incorrect;

Given that there is scientific evidence that neuropsychological deficits and neuropsychiatric symptoms can result from methylmercury exposure;

Given the extensive literature on the neurodevelopmental toxicity of prenatal exposure to mercury exposure and that almost all claimants, born in 1962 and after, were exposed *in utero*.

Given the growing evidence that methylmercury exposure can contribute to non-neurologic chronic health conditions,

Given that according to Section 10 (d) of the Act, the MDB can prescribe "other material" for the application,

We recommend that:

- The clinical examination for Known Conditions be updated to current best practices.
- The examination be expanded to include documented Further Conditions.
- Relevant elements, not included in Known or Further Conditions be included in Other Material prescribed by the MDB.

Given that the medical history, nervous system complaints, personal history and general examination included in the current Clinical Adult Neurologic Examination Protocol is cursory;

Given that one of the major complaints of claimants is a feeling of being short-shifted and that the story of their symptoms is overlooked;

Given the need for a good medical history that includes symptoms that are consistent with mercury poisoning and sometimes sporadic, as is the case for other neurological conditions;

Given that some claimants may have undergone clinical neurological and/or psychological examinations through referral by their primary clinician or in the context of research projects;

Given the need for a "safe place" where the claimants can relate the history of their health problems in their own words;

Given that according to Section 10 (d) of the Act, the MDB can prescribe "other material" for the application,

We recommend that:

- The general examination be eliminated from the neurologist's examination.

- A medical history, including current symptoms, and general examination be performed by an authorized, specially trained nurse practitioner and the report be included in Other Material to be submitted with the application.

- If the claimant so wishes, information from previous clinical neurological and/or psychological examinations, carried out by referral or as part of a clinical research project, be provided to the nurse practitioner and included in Other Material.

Chapter 5 Neurologic Examination

5.1 Background

In the Memorandum of Agreement (MOA), the list of "known conditions" includes: Ataxia, Tremor, Reflex changes, Sensory changes, Visual fields, Psychosis and Dysarthria. The inclusion of psychosis in the list was caveated in paragraph 2.1.4(b) of the MOA as a "known condition yet to be determined". In Appendix III of the Plan Document (1987), "Incoordination" replaces "Psychosis".

After a 2011 review of the literature on the health effects of mercury exposure, the original neurologic examination protocol was simplified.[119]

5.2 Current Scientific Evidence

There is an extensive literature on neurological sequelae of mercury poisoning. Figure 7 presents a timeline of some of the major events and studies concerning neurological examinations for mercury poisoning. In addition to the major events (in italics), we included some of the relevant studies on freshwater fish eaters (left side) and some of the studies carried out in Grassy Narrows and Wabaseemoong communities (right side).

While most of the "Known Conditions" currently part of the neurologic examination are still relevant, there is an urgent need to update the assessment to include best practice, validated measures that have been shown to be reproducible. The current adult neurological examination protocol has substantial limitations and requires modification to improve consistency and precision of application. There are several unnecessary elements included and nearly all of the components lack anchor descriptors. This makes it nearly impossible to ensure that the examination will be reproducible. The following issues are core to the recommended updates:

- Cranial nerves assessment is not reproducible as structured and components like pupillary responses are not used in the compensation.
- Tremor is common, but the assessment includes body parts that are not affected by tremor typically and there are no anchors for the ratings. A standardized tremor rating scale would provide much more consistency.

[119] Information received from M. Wanlin [August 9, 2019].

- Ataxia is a clinical diagnosis and the components of the exam should reflect standard examination categories. Coordination and gait should be assessed independently and with standardized ratings with reproducible anchors.
- Reflexes are not used in the compensation plan but are reasonable to include. However, reflexes are graded on a 0-4 scale by neurologists.
- Sensory loss is a key finding in mercury poisoning and requires a more systematic approach.
- Visual field constriction is a well-known feature of mercury poisoning, but confrontation visual field examination is unreliable.
- The rating of mild, moderate and severe is recognized as having poor inter-rater reliability.

5.3 Proposed Neurologic Examination

We used the headings in the current neurological examination (Great West Life Assurance Company Clinical Adult Neurological Examination Protocol for Grassy Narrows and Islington Bands Mercury Disability Board (Group #51033) for our proposals for changes: Section 5: Neurologic examination, which includes subsections for Cranial Nerves, Tremor, Speech (dysarthria), Ataxia, Reflexes, Sensation, Incoordination and Alternating movement rate.

Subsections: Cranial nerves, Ataxia, Incoordination, Alternating motor rate and gait
Cranial nerve examination in the present examination concerns visual functions (vision, Visual field (confront), Fundus, Ptosis, Extraocular Movements and Nystagmus and is used to determine whether a claimant should undergo Visual Field assessment by an optometrist. Since we recommend that all claimants undergo appropriate visual field assessment (see Chapter 6), the section on cranial nerves and pupillary reflexes is removed from the neurologic examination. The oculomotor examination is included as one of the items in the Brief Ataxia Rating Scale described below.

To replace the present examination protocol, we recommend the adoption of *The Brief Ataxia Rating Scale (BARS)*, first published in 2009 as a tool for movement disorder specialists and general neurologists[120]. Previous rating scales for ataxia are considered

[120] Schmahmann JD et al. 2009. Development of a Brief Ataxia Rating Scale (BARS) based on a modified form of the ICARS. Movement Disorder 24:1820-1828.

cumbersome and not designed for clinical practice[121]. Several components of the current neurological examination are included in the Brief Ataxia Rating Scale (BARS).

The assessment of each motor domain is necessary because there is topography of motor function in the cerebro-cerebellar system. The BARS focuses on each of the five major motor domains (coordination of gait, arm, leg, speech, and eye movements), and the resulting score provides an estimate of overall cerebellar motor function, a target for methylmercury exposure. Magnetic Resonance Imaging carried out on patients with Minamata Disease, forty years after exposure, show lesions in the cerebellum[122]. This is supported by a large number of animal studies[123].

The BARS, presented in Table 3 has been validated and shows good internal consistency and inter-rater reliability[124,125] .

For Dysarthria, we suggest that the patient read a standard, culturally appropriate paragraph from which the rating would be derived. The text could be selected with the help of the community representatives on the MDB.

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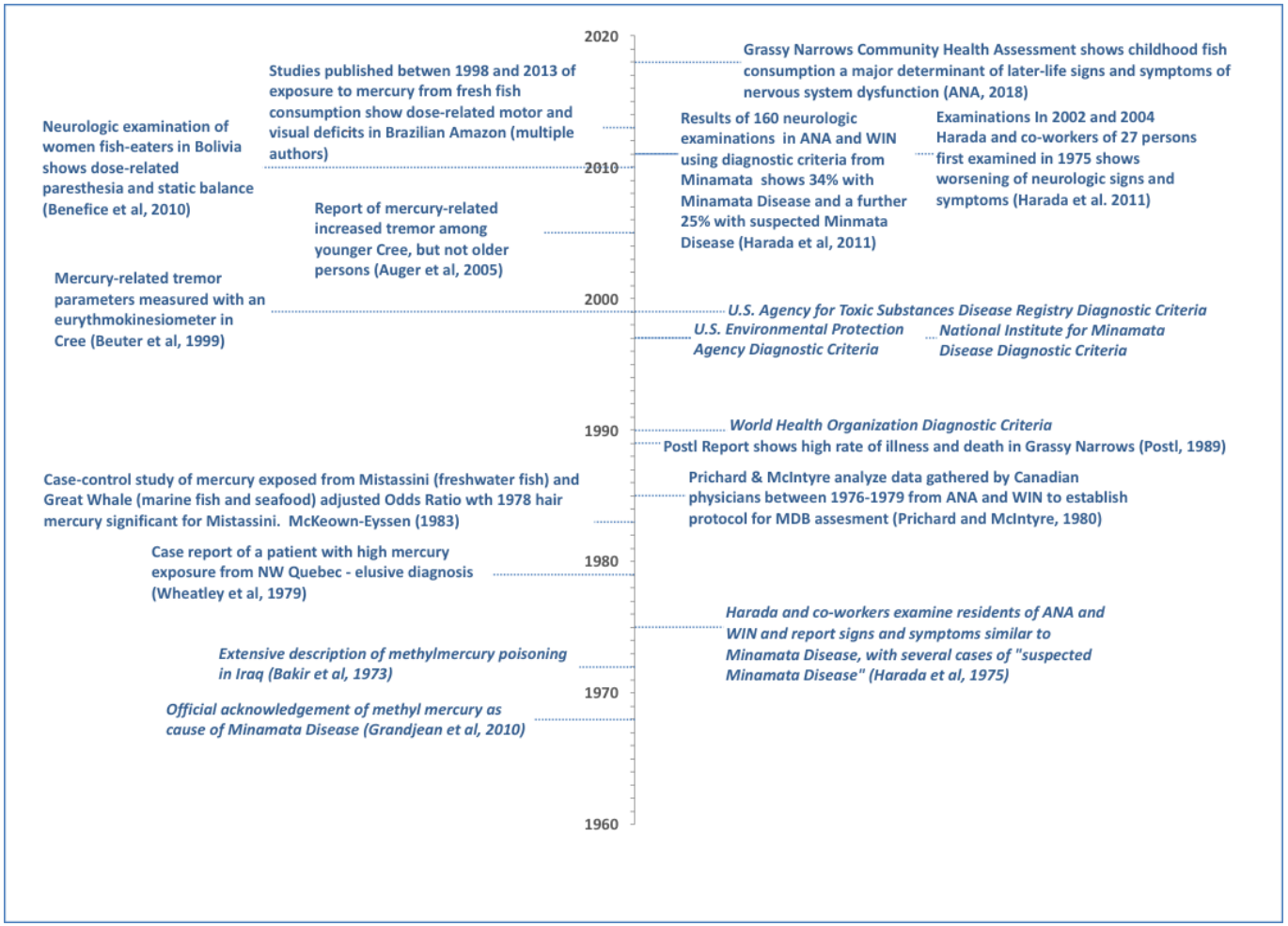
[121] Bürk K and Sival D. 2018. Scales for the clinical evaluation of cerebellar disorders in The Cerebellum: From Embryology to Diagnostic Investigations. The Handbook of Clinical Neurology (3rd version) 154:329-339.
[122] Korogi Y et al. 1998. Findings of Minamata Disease – Organic mercury poisoning. Journal of Magnetic Resonance Imaging 8:308-316.
[123] Dos Santos AA et al. 2016. Methylmercury and brain development. Journal of Trace Elements in Medicine and Biology 38:99-107.
[124] Schmahmann JD et al. 2009. Development of a brief ataxia rating scale (BARS) based on a modified form of the ICARS. Mov Disord. 24:1820-1828.
[125] Carmagos S et al. 2016. Brief Ataxia Rating Scale: A reliable tool to rate ataxia in a short timeframe. Movement Disorders Clinical Practice 3:621-623.

Figure 7. Timeline of major events and studies on adult neurological examinations



See references Appendix 6

Table 3. Brief Ataxia Rating Scale

Supplement 4. Brief Ataxia Rating Scale (BARS) (Schmahmann et al., 2009)

BRIEF ATAXIA RATING SCALE (BARS) ☐☐☐☐

Gait ☐☐☐☐
0: Normal
1: Almost normal naturally, but unable to walk with feet in tandem position
2: Walking without support, but clearly abnormal and irregular
3: Walking without support but with considerable staggering; difficulties in half turn
4: Walking without support not possible; uses support of the wall for 10-meter test.
5: Walking possible only with one cane
6: Walking possible only with two canes or with a stroller
7: Walking possible only with one accompanying person
8: Walking impossible with one accompanying person (2-person assist; wheelchair)

Knee-tibia test (decomposition of movement and intention tremor)
(Left and Right scored)
0: Normal
1: Lowering of heel in continuous axis, but movement is decomposed in several phases, without real jerks, or abnormally slow
2: Lowering jerkily in the axis
3: Lowering jerkily with lateral movements
4: Lowering jerkily with extremely long lateral movements, or test impossible

LEFT ☐☐☐☐
RIGHT ☐☐☐☐

Finger-to-nose test (decomposition and dysmetria of arm and hand)
(Left and Right scored)
0: Normal
1: Oscillating movement of arm and/or hand without decomposition of the movement
2: Segmented movement in 2 phases and / or moderate dysmetria in reaching nose
3: Segmented movement in more than 2 phases and / or considerable dysmetria in reaching nose
4: Dysmetria preventing the patient from reaching nose

LEFT ☐☐☐☐
RIGHT ☐☐☐☐

Dysarthria ☐☐☐☐
0: Normal
1: Mild impairment of rate / rhythm / clarity
2: Moderate impairment of rate / rhythm / clarity
3: Severely slow and dysarthric speech
4: Speech absent or unintelligible

Oculomotor abnormalities ☐☐☐☐
0: Normal
1: Slightly slowed pursuit, saccadic intrusions, hypo/hypermetric saccade, nystagmus
2: Prominently slowed pursuit, saccadic intrusions, hypo/hypermetric saccade, nystagmus

TOTAL (out of 30) ☐☐☐☐

Subsection: Tremor

As early as 1983, a study of Minamata patients, patients with other neurologic diseases, and controls, using quantitative tremor analyses, showed that the tremor of

methylmercury poisoning was different from other pathological tremors[126]. In 2016, Iwata and co-researchers[127] quantitatively assessed tremor parameters among persons with fetal-type Minamata Disease and showed a larger tremor and a lower central frequency compared to a reference group. Tremor is included as a Known Condition, and amplitude, rate, terminal, movement, static and rest tremor are noted for eyelids, face, tongue, and upper and lower extremities on the right and left side.

In 1993, Fahn, Tolosa, and Marin developed a clinical rating scale for tremor, to quantify rest, postural, and action/intention tremors[128]. Today, it is widely used. It assesses tremor severity at rest, with posture holding, and with action and intention maneuvers, for nine parts of the body and orthostatic tremor. Tremors are rated on a 5-point scale where 0 = none; 1 = slight, barely perceivable, may be intermittent; 2 = moderate, amplitude <2 cm, may be intermittent; 3 = marked, amplitude 2 to 4 cm; 4 = severe, amplitude >4 cm.

Stacy and coworkers[129] reported good inter-rater reliability, with neurologists examining videos of patients. Correlations improved when the same examiner performs repeated measures. A task force of the Movement Disorder Society reviewed rating scales for the assessment of tremor[130]. Part A correlated highly between 2 raters. The authors concluded that *"This scale fulfills criteria for a recommended scale in the assessment of tremor severity, because it has been used in multiple studies of tremor and has demonstrated good overall clinimetric properties. However, good inter-rater reliability requires training, and there is a potential ceiling effect for upper extremity tremor."*

We recommend this rating scale (Table 4) to better anchor the neurologic examination for tremor.

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[126] Yamanaga H. 1983. Quantitative analysis of tremor in Minamata disease. Tohoku Journal of Experimental Medicine 141:13-22.
[78] Iwata T et al. 2016. Characteristics of hand tremor and postural sway in patients with fetal-type Minamata disease. Journal of Toxicological Science 41:757-763.
[128] Fahn S, Tolosa E and Marin C. 1993. Clinical Rating Scale for Tremor. *In*: Jankovic J, Tolosa E, editors, Parkinson's Disease and Movement Disorders, 2nd ed. Baltimore: Williams and Wilkins p. 225-234.
[129] Stacy et al. 2007. Assessment of interrater and intra-rater reliability of the Fahn Tolosa-Marin Tremor Rating Scale in Essential Tremor. Movement Disorders 22: 833-838.
[130] Elbe R et al. 2013. Task force report: Scales for screening and evaluating tremor: critique and recommendations. Movement Disorders Nov. 28: 1793-1800.

Table 4. Fahn Tolosa Tremor Rating Scale

Tremor (rate tremor) 1-9

1. At rest (in repose), for head and trunk, when lying down.

2. With posture holding
   UE: arms outstretched, wrists mildly extended, fingers spread apart;
   LE-legs flexed at hips and knees), foot dorsiflexed;
   tongue-when protruded;
   head and trunk when sitting or standing.
3. With action (ACT) and intention (INT):
   UE-finger to nose and other actions;
   LE-toe to finger in a flexed posture).

Definitions for 1 – 9:

0 = None
1 = Slight; barely perceivable. May be intermittent.
2 = Moderate; amplitude <2 cm (extremities). May be intermittent.
3 = Marked; amplitude 2-4 cm (extremities).
4= Severe; amplitude > 4 cm (extremities).

	REST	POSTURAL	ACT/INT	TOTAL
1. Face tremor			XXXXXXXX	
2. Tongue tremor			XXXXXXXX	
3. Voice tremor	XXXX		XXXXXXXX	
4. Head tremor			XXXXXXXX	
5. Right upper extremity tremor				
6. Left upper extremity tremor				
7. Trunk tremor			XXXXXXXX	
8. Right lower extremity tremor				
9. Left lower extremity tremor				

Subsection: Reflexes

Deep tendon reflexes should be elicited by the examining physician as in standard practice and should be graded as per standard clinical practice (Table 5).

Table 5. Reflexes

0- Absent
1+ - Decreased
2+ - Normal
3+ - Increased but no clonus
4+ - Increased with clonus

	Deep Tendon Reflexes (Right)	Deep Tendon Reflexes (Left)
Tendon		
Biceps		
Triceps		
Brachioradialis		
Patella		
Achilles		

The scientific literature on mercury toxicity reports decreased/absent distal reflexes. The etiology of these decreased reflexes is likely due to mercury-induced neuropathy. Peripheral neuropathy of any etiology also results in reduced ankle deep tendon reflexes, but very rarely would this also impact the patellar reflexes. As a result, we consider absent reflexes at the ankles to be « mild » and loss at the ankles and patella to be « moderate/severe ».

Subsection: Sensation

Sensory loss and paresthesia are commonly reported among persons with methylmercury poisoning[131]. Recent studies have shown that the loss is not only due to cortical dysfunction, but may also be due to changes in peripheral nerve pathways. In an animal model, Shinoda et al.[132] showed neurodegenerative changes to Dorsal Root Ganglion sensory neurons. Assessment of sensory abnormalities needs to consider loss due to both central and peripheral dysfunctions.

Takaoka reported quantified sensory loss among persons of Grassy Narrows[133]. The ANA-CHA showed a significant association between childhood fish consumption and symptoms of numbness, tingling and neuropathic pain, taking into account factors such as

[131] Takaoka S et al. 2014. Signs and symptoms of methylmercury contamination in a First Nation community in Northwestern Ontario, Canada. Science of the Total Environment 15:468-469.
[132] Shinoda Y et al. 2019. Methylmercury-induced neural degeneration in rat dorsal root ganglion associated with the accumulation of microglia/macrophages and the proliferation of Schwann cells. The Journal of Toxicological Science 44(3):191-199.
[133] Takaoka et al., 2014 *Ibid.*

age, sex, diabetes and alcohol consumption[134] . These findings have since been confirmed using biomarker data (unpublished data).

There are few good rating scales for peripheral sensory loss. The Modified 5-Item Total Neuropathy Score-Reduced (TNSr)[135] (Table 6) is well validated and performs better for sensory, rather than motor loss[136]. The TNSr scale includes an evaluation of reflexes, which we removed since reflexes are addressed separately (see Table 5). The scale includes measured sensory loss (pin and vibration sensitivity) and a measure of strength. The muscles, toe, ankle, wrist and finger extensors and flexors, quadriceps, hamstrings, biceps and triceps are assessed and the muscle with the worst score is used as the strength score.

Table 6. Scale for Sensory Loss (adapted from the TNSr)

Symptom Extension					
Tingling, numbness, neuropathic pain	None	Limited to fingers or toes	Symptoms extend to ankle or wrist	Symptoms extend to knee or elbow	Symptoms above knee or elblow
	0	1	2	3	4
Pin sensibility					
Upper Extremity	Normal	Reduced in fingers	Reduced up to wrist	Reduced up to elbow	Reduced above elbow
	0	1	2	3	4
Lower Extremity	Normal	Reduced in toes	Reduced up to ankle	Reduced up to knee	Reduced above knee
	0	1	2	3	4
Vibration sensibility					
Upper Extremity	Normal	Reduced in fingers	Reduced up to wrist	Reduced up to elbow	Reduced above elbow
	0	1	2	3	4
Lower Extremity	Normal	Reduced in toes	Reduced up to ankle	Reduced up to knee	Reduced above knee
	0	1	2	3	4
Strength					
Total score					

[134] Asubpeeschoseewagong Netum Anishinabek Community Health Report. May 2018. p.150.
[135] Smith EM et al. 2010. The Reliability and validity of a modified total neuropathy score-reduced and neuropathic pain severity items when used to measure chemotherapy-induced peripheral neuropathy in patients receiving taxanes and platinums. Cancer Nursing 33:173-183.
[136] Park SB et al. 2019. Overview and critical revision of clinical assessment tools in chemotherapy-induced peripheral neuropathy. Journal of the Peripheral Nervous System 24:S13-S25.

The TNSr scoring indicates that the highest score from the strength assessments (see below) be included in the total score.

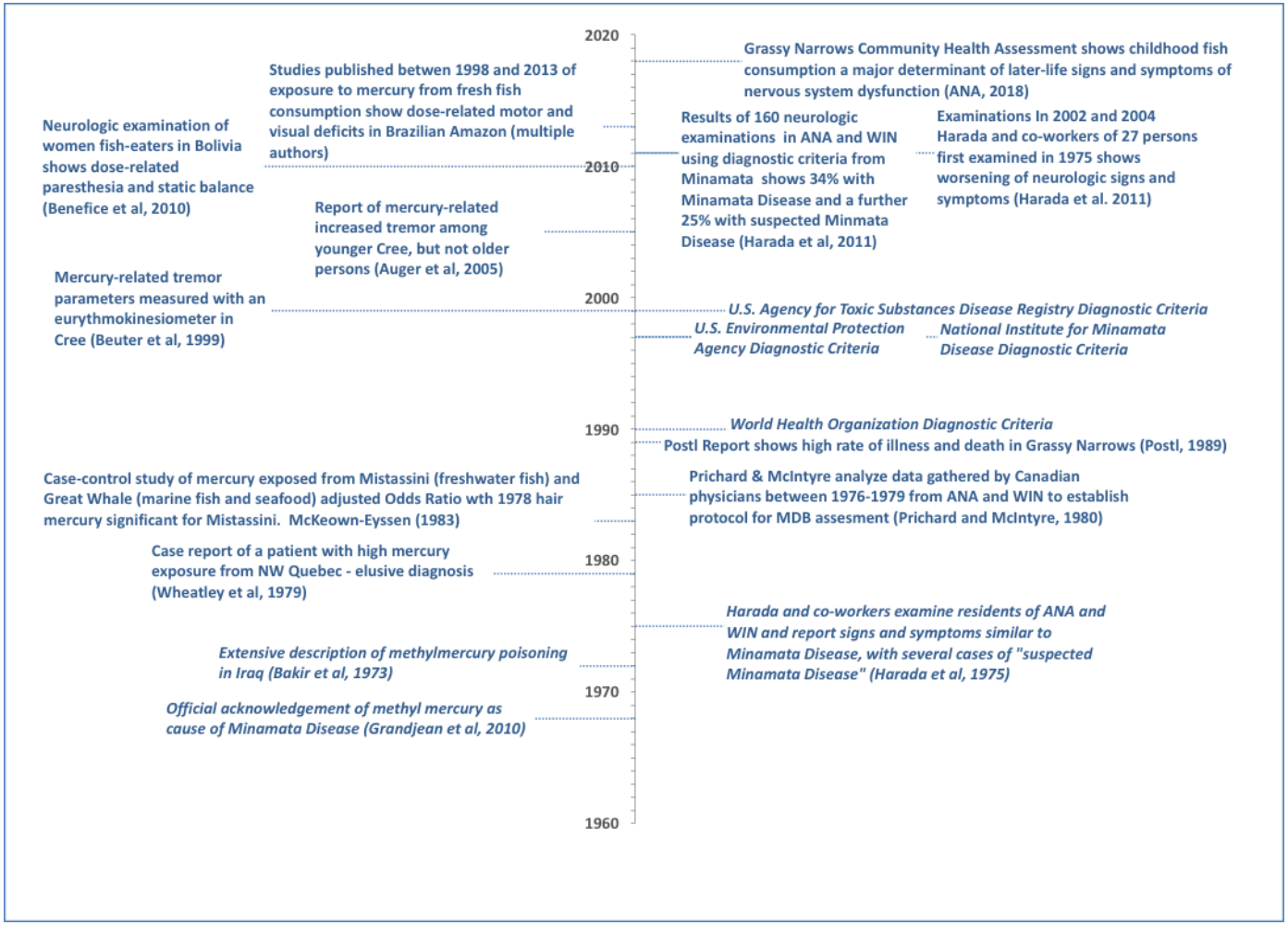
Muscle Group	MRC rating (0-5)
Shoulder abduction	
Elbow Flexion	
Elbow Extension	
Wrist Flexion	
Wrist Extension	
Hand Grip	
Hip Flexion	
Knee Extension	
Knee Flexion	
Plantarflexion	
Dorsiflexion	

The recommended changes cover the 6 of the 7 "Known Conditions" that are listed in the Plan Document. The seventh, visual field constriction, is discussed in the next chapter. Table 7 summaries the proposed changes to the neurologic examination.

Table 7. Recommended Modifications to the Current Neurological Assessment

Section	Current	Revised	Tools
1	Identifying information	Remains as is	
2	Past medical history	Taken by a nurse practitioner	
3	Personal history	Taken by a nurse practitioner	
4	General examination	Performed by a nurse practitioner	
5	**Neurologic examination**		
	Cranial Nerves	Oculomotor Abnormalities	Brief Ataxia Rating Scale (Table 3)
	Speech (dysarthria)	Remove sub-heading: dysarthria	Brief Ataxia Rating Scale (Table 3)
	Ataxia	Remove heading	Brief Ataxia Rating Scale (Table 3)
	Incoordination, alternating motor rate and gait	Merge and retitle	Brief Ataxia Rating Scale (Table 3)
	Tremor	Validated scale	Fahn Tolosa Tremor Rating Scale (Table 4)
	Reflexes	New table	Rating (Table 5)
	Sensation	Validated scoring system	Modified 5 Item TNSr Scoring (Table 6)

Figure 7. Timeline of major events and studies on adult neurological examinations



Seen references Apprendix 5

5.4 Summary of Rationale and Recommendations

Given that the Known Conditions included in the current neurologic examination are still relevant;

Given that current best practices in neurology include validated, anchored protocols, ensuring better consistency, precision of application and reproducibility;

Given that the current examination of visual functions in the neurologic examination serves solely to determine whether the claimant should be referred for visual field examination,

We recommend that:

- Specific rating protocols be adopted for tremor and ataxia (encompassing incoordination and dysarthria) and sensory loss.

- Vision loss be removed from the neurologic examination and assessed by an optometrist.

Chapter 6 Visual Field Examination

6.1 Background

Prichard and McIntyre included visual field perimetry for the temporal fields in the recommended examination[137]. Perimetry was adopted in the Plan Document to test visual field loss. Vision testing in the present MDB neurological examination is in the *Cranial Nerves* section and includes an assessment of vision, visual field (confront), fundus, ptosis, extra-ocular movements and nystagmus. A further section entitled *Pupils* includes size/shape, light, consensual and convergence.

Confrontation visual field tests have low diagnostic accuracy and are insensitive at detecting visual field loss when performed individually; they are considered poor screening tests[138,139]. As early as 1981, a comparison of finger confrontation with Goldman perimetry, revealed that the former identified 11% or fewer optic nerve field defects[140]. Currently, the MDB recognizes the unreliability of confrontation visual field evaluation and notes in the *Neurological Grading Guidelines and Cultural Illustrations of Functional Impairments:*

> *"Neurologist only does visual fields on confrontation – a notoriously unreliable way to measure field loss. To the present (April 2016) we have been sending applicants for whom the Neurologist has a hint or suspicion of field defect, and all applicants who reach a total score of 4 or greater on the other dimensions, for a Perimetry examination by an Optometrist. We try to use the above definitions based on degrees of field loss to judge mild, moderate and severe. As per a number of other dimensions, unilateral vision/field loss has been disregarded as likely being incompatible with effects of mercury."*

In 2018, the MDB commissioned Dr. William Turk and Dr. Ian Clark to carry out a complete ophthalmologic examination of 14 claimants (6 women and 8 men). We received a copy of their summary report from the MDB and Dr. Jeremy Levi provided us with a slide presentation of the findings. The report begins with a very brief list of some of the studies, published between 1968 and 2008, that have described visual deficits associated with exposure to methylmercury or inorganic mercury vapours. All persons underwent formal ophthalmologic examination: visual symptoms, past medical and ocular history, pupil exam, anterior slit lamp exam, best corrected visual acuity, dilated retinal exam and colour vision.

The report notes:

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[137] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-exposed Indians of the Grassy Narrows and White Dog Reserves: Report and Recommendations, p. 13.
[138] Pandit RJ et al. 2001. Effectiveness of testing visual fields by confrontation. Lancet 358:1339-1340.
[139] Kerr NM et al. 2010. Diagnostic accuracy of confrontational visual field tests. Neurology 74:1184 - 1190.
[140] Trobe JD et al. 1981. Confrontation visual field techniques in the detection of anterior visual pathway lesions. Annals of Neurology 10:28-34.

- Clinical examination revealed multiple eye diseases such as cataract, diabetic retinopathy and age-related macular degeneration;
- All patients were normal on the visual confrontation test;
- There was a low reliability in the Standard Automated Perimetry visual fields
- 9 of 14 patients had one or more electro-diagnostic abnormalities;
- 5 patients showed abnormalities in Visual Evoked Potentials, possibly consistent with bilateral optic neuropathy;
- The 3 patients chosen to undergo Goldmann visual field testing showed moderate to severe visual field constriction, as well as abnormal Visual Evoked Potentials.

The ophthalmological examination reports were very informative, however, when assessing *"signs and symptoms consistent with mercury poisoning",* the following elements, based on current scientific literature should be noted:

1. Colour vision was assessed with the Ishihara plates, a commonly used test to assess congenital colour vision deficits, but not blue-yellow defects which are common in acquired color losses that are caused by lenticular, retinal and neuro-eye disease processes. A number of studies have shown that persons exposed to methylmercury may do well on tests using saturated colours like the Ishihara plates, but performance on desaturated tests is dose-related[141,142143], and persistent even following reduction of exposure[144]. It would have been useful in these evaluations to compare results on a desaturated colour vision test and electro-retinography.

2. The authors suggest that the poor performance on the Automated Perimetry Test, reflected in the false negatives was due to patients trying to fool the system in order to receive compensation. An alternative explanation would be that patients with central nervous system deficits have fixation difficulties, cannot focus on the light, and may struggle to maintain their attention because they become fatigued with the test. Fixation losses are usually caused by patients' wandering eyes, but can also indicate dragged disc syndrome, high myopia, or trauma[145].

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[141] Feitosa-Santana C. et al 2018. Color vision impairment with low-level mercury exposure of an Amazonian population – Brazil. Neurotoxicology 66:179-184.
[142] Lebel et al.1996. Evidence of early nervous system dysfunction in Amazonian populations exposed to low-levels of methylmercury. Neurotoxicology 17:157-167.
[143] For review see: Fox D. 2015. Retinal and visual system: occupational and environmental toxicology. Ch. 18 in Handbook of Clinical Neurology Vol. 131:325-340 (3rd series) Occupational Neurology, Eds. Lotti M and Bleecker M. Elsevier, New York.
[144] Fillion M et al. 2013. Toxic risks and nutritional benefits of traditional diet on near visual contrast sensitivity and color vision in the Brazilian Amazon. Neurotoxicology 37:173-181.
[145] Graves D. 2013. Visual field testing: How to avoid fixation losses. Ophthalmic professional 2:26-27.

Cognitive deficits have as well been associated with increased errors in visual field measurements[146,147].

6.2 Current Scientific Evidence

The visual system is a well-known target of methylmercury exposure; visual field abnormalities (constriction and depression) and disturbed ocular movements are considered among the cardinal features of high-dose exposure to methylmercury in adults[148]. Initial studies on mercury-related visual deficits focused primarily on central loss, which would result in bilateral impairment, Indeed, autopsied brains from mercury exposed persons show that mercury concentrates in the that the occipital lobe, notably in the calcarine sulcus[149]. Autopsy data for persons from Grassy Narrows obtained from the Ontario ministry for Health and Long-term Care and the First Nations and Inuit Branch of Indigenous Services Canada shows high levels in the calcarine sulcus and the cerebellum (unpublished data).

Studies of methylmercury exposed populations have further shown dose-response relations between exposure and other visual deficits, including near visual contrast sensitivity[150], near visual acuity[151] and acquired color vision loss[152], which are not necessarily bilateral. Early onset age-related cataracts have also been reported in relation to methylmercury exposure[153]. Evidence from animal studies supports the findings that the effects of methylmercury exposure on vision, are not only due to modifications within the central nervous system, but also the optic nerve and the retina[154]. Mercury-related visual deficits are supported by imaging studies and electrophysiological assessments of

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[146] Honjo M et al. 2017. The association between structure-function relationships and cognitive impairment in elderly glaucoma patients. Nature Scientific Reports 7, 7095.
[147] Diniz-Filho A et al. 2017. Association between neurocognitive decline and visual field variability in Glaucoma. JAMA Ophthalmology 135:734-739.
[148] National Academy of Sciences (USA) 2000. Toxicology of Methylmercury. Toxicological Effects of Methylmercury. Washington, DC: The National Academies Press 364p.
[149] Fox D and Boyse W. 2001. Toxic Responses of the Cornea, Retina and Central Visual System. Ch. 17 in Cassarett, Doyle Klassen (Ed). Cassarett and Doyle's Toxicology, the Basic Science of Poisons, McGraw-Hill Education, New York (5th ed.).
[150] Fillion et al. 2013. Toxic risks and nutritional benefits of traditional diet on near visual contrast sensitivity and color vision in the Brazilian Amazon. Neurotoxicology 37: 173-181.
[151] Fillion et al. 2011 Visual acuity in fisj consumers of the Brazilian Amazon: risks and benefits from local diet. Plublic Health Nutrition 14:2236-2244.
[152]Feitosa-Santana et al. 2018. Color vision impairment with low-level methylmercury exposure of an Amazonian population – Brazil. Neurotoxicology 66:179-184.
[153] Lemire M. et al. 2010. Selenium and mercury in the Brazilian Amazon: opposing influences on age-related cataracts. Environmental Health Perspectives 118:1584-49.

[154] Korbas et al. 2013 Methylmercury target photoreceptor outer segments ACS Chemical Biology 18:2256 -2263.

the brain and retina[155]. Studies by Rice and colleagues[156] suggest that the pattern of spatial and temporal vision defects produced by developmental exposure to methylmercury are different from those produced during adulthood.

Focusing solely on visual field constriction with temporal field constriction to 60, 40 and 20 degrees is inadequate to fully appreciate the extent of visual field loss that would be consistent with methylmercury poisoning. Over the past 25 years, automated threshold static perimetry has been used to quantify peripheral vision sensitivity, using efficient and standardized testing algorithms.

6.3 Recommended Visual Examination

The most appropriate instrument is Humphrey Visual Field (HFA) Analyser with gaze tracking capability, using the 30-2 Swedish Interactive Thresholding Algorithm (SITA). The SITA Standard strategy offers high accuracy and relatively short test times of 3 to 7 minutes per eye.

The criteria for mild, moderate and severe loss are derived from Hirasawa et al (2013)[157]. For a visual field to be considered abnormal, it must meet one of the two following criteria:

1. Pattern deviation plot with 3 contiguous spots <5%, at least one of which being < 1%

   OR

2. Corrected PSD index or PSD index with $p < 0.05$

If one of the criteria is met, the visual field index (VFI) is used:

Stage 1 = mild: abnormal field + VFI ≤ 82%

Stage 2 = moderate: abnormal field + 63% ≤ VFI ≤ 81%

Stage 3 = severe: abnormal field + VFI < 62%

Reliability

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[155] Fox D and Boyse W. 2001. Toxic Responses of the Cornea, Retina and Central Visual System. Ch. 17 in Cassarett, Doyle Klassen (Ed). Cassarett and Doyle's Toxicology, the Basic Science of Poisons, McGraw-Hill Education, New York (5th ed.).

[156] Rice DC and Gilbert SG. 1990. Effects of developmental exposure to methylmercury on spatial and temporal visual functions in monkeys. Toxicol. Applied Pharmacology 102:151-163.

[157] Hirasawa K, Shoji N, Morita T, Shimizu K. 2013. A modified glaucoma staging system based on visual field index. Graefes Arch Clin Exp Ophthalmol. 25:2747-52. 5

To be considered **invalid**, a test must have EITHER:

- False positives above 15%[158]

  OR

- Fixation losses above 20%[159]

False negatives (FN) are not considered as a reliability index. First, the FN index may be high among persons with neurocognitive deficits[160,161.] The FN index is of limited utility for cases of advanced eye disease, since severely affected visual fields may translate into a high FN index. A high FN rate should therefore not be blamed on the patient, but often constitutes a characteristic of the disease, such as in the case of glaucoma[162,163].

All claimants should undergo visual field testing, under the supervision of a qualified optometrist. The optometrist should be familiar with mercury visuo-toxicity and be aware of the difficulties that persons with signs and symptoms consistent with mercury poisoning may have in carrying out the visual field examination.

It would be useful to re-analyse the examination results after 60 persons to ensure that information is not missed.

6.4 Summary of Rationale and Recommendations

Given that the visual system (retinal and cortical) is a well-known target for methylmercury;

Given that visual field loss is included in the Known Conditions for mercury poisoning;

Given that visual field analysers quantify the sensitivity of peripheral vision;

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[158] Heijl V et al. 2012 Effective Perimetry: The Field Analyser Primer 4th Ed. Carl Zeiss Meditiec Inc. p.55
[159] Heijl V et al. 2012. *Ibid*
[160] Honjo M et al. 2017. The association between structure-function relationships and cognitive impairment in elderly glaucoma patients. Nature Scientific Reports 7; 7095.
[161] Diniz-Filho A et al. 2017 Association Between Neurocognitive Decline and Visual Field Variability in Glaucoma. JAMA Ophthamology 135:734-739.
[162] Bengtsson B and Heijl A. 2000. False-negative responses in glaucoma perimetry: indicators of patient performance of test reliability? Investigative Ophthalmology and Visual Science 41:2201-2204.
[163] Heijl V et al. 2012. *Ibid*

Given that persons with mercury-poisoning may have deficits that affect their ability to adequately follow the testing procedure for visual field loss,

We recommend that:

- All claimants undergo a visual field examination.
- The visual field examination be performed using a Humphrey Visual Field (HFA) Analyser with gaze tracking capability, with the 30-2 Swedish Interactive Thresholding Algorithm (SITA).
- The scoring procedure to assess visual field constriction be adapted to possible neurocognitive deficits.

Chapter 7 Neuropsychological Assessment

7.1 Background

The only mention of cognitive dysfunction in the Plan Document is mental retardation as a "Known Condition" for children. In her 2001 review, Cosway notes in her summary and conclusions:

> *"The original developers of the neuro-assessment protocol did not believe that screening for psychosis/dementia was of primary importance at that time since this effect would occur later in time. The current clinical examinations in many cases are actually assessing the long-term effects of methylmercury poisoning, therefore the inclusion of a culturally sensitive mental status screening tool at this time may be worth considering".*[164]

A report on the 1970 International Conference on Environmental Mercury Contamination in the New England Journal of Medicine[165] included the following symptoms of organic mercury poisoning: inability to concentrate, lack of interest at home and at work, apathy and extreme fatigue, and inability to recall basic things, as well as emotional instability, with fits of anger, depression or rage, which are addressed in Chapter 8. In their examinations of persons from WIN and ANA, Harada et al. (2011)[166] also report intellectual disabilities, but did not measure them. Self-reported symptoms of loss of concentration and memory problems are more accurately assessed with validated tests, specifically designed to measure these functions[167].

7.2. Current Scientific Evidence

The major advancements to our knowledge on metal neurotoxicity since 1985 are i) the recognition of neuropsychological deficits associated with exposure, even at very low levels, and ii) the development of neuropsychological test batteries to assess this loss. Neuropsychology is the scientific methodology used to assess brain-behaviour relationships. Initially used to identify the location of brain lesions, it is now extensively used to describe neuropsychological incapacity in research and clinical evaluations of persons with disabilities, including those resulting from exposure to environmental

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[164] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986-2001 p.166.
[165] Eyl TB. 1971. Organic-mercury food poisoning. New England Journal of Medicine 284: 706-709.
[166] Harada M et al. 2011. Mercury Poisoning in First Nations Groups in Ontario, Canada: 35 years of Minamata Disease in Canada. Journal of Minamata Studies p.3-30 (translated from Japanese).
[167] Bowler RM et al. 2017. Validity of self-reported concentration and memory problems: Relationship with neuropsychological assessment and depression. Journal of Clinical and Experimental Neuropsychology 29:1-11.

toxics[168]. The relative sensitivity and precision of neuropsychological measurements make them well suited for following the course of many neurologic diseases and neuropsychiatric conditions. Nervous system disruptions caused by toxic exposures may not be detectable without neuropsychological testing[169,170].

Clinical neuropsychological evaluations are acknowledged to be useful in assigning disability in workers compensation[171]. In Canada, qualified neuropsychologists provide assessment for disability, including compensation for occupational toxic exposures[172].

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the principal authority for psychiatric diagnoses. The most recent version, DSM-5[173], introduced the term neurocognitive disorders (NCD), which cover disorders that do not cause sufficient impairment to qualify for a diagnosis of dementia. NCDs are on a spectrum with the more severe conditions[174]. In the DSM-5, the use of standardized neuropsychological testing is specifically discussed in the context of distinguishing between major and mild NCDs. It is noted that standardized testing is particularly important when evaluating patients with suspected mild NCD and suggested cut-offs are provided: *"For major NCD, performance is typically 2 or more standard deviations below appropriate norms (3rd percentile or below). For mild NCD, performance typically lies in the 1–2 standard deviation range (between the 3rd and 16th percentiles)"* [175]

In his 2014 presentation of the changes in the DSM-5, Simpson states that: *"The conceptualization in DSM-5 of mild neurocognitive disorder, and the elimination of the diagnosis of cognitive disorder, not otherwise specified, may be helpful to the forensic practitioner tasked with examining a person who is in the early stages of a dementing illness, or who has experienced a traumatic brain injury, and may help in the explanation of his condition and impairments to a finder of fact."*

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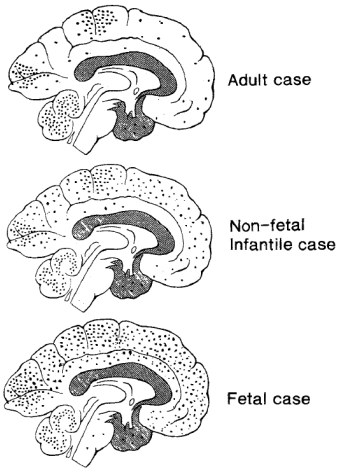
[168] Lezak MD et al. 2012. *Neuropsychological Assessment* 5th Ed. Oxford University Press pp. 1161.
[169] Hartman D. 1995. *Neuropsychological Toxicology: Identification and Assessment of Human Neurotoxic Syndromes* 2nd Edition. Springer-Varlag, New York pp. 525.
[170] Bowler RM and Lezak M. 2015. Ch. 3: Neuropsychologic Evaluation and exposure to neurotoxicants. In Aminoff, M. J., Boller, F., Swaab, D. F., Bleecker, M. L. (Eds.), *Handbook of Clinical Neurology, Volume 131, 3rd Series* (23-45). Edinburgh: Elsevier.
[171] Puente AE and Gillespie JB. 1991. Workers' Compensation and Clinical Neuropsychological Assessment. Ch. 3 in: Dywan J., Kaplan R.D., Pirozzolo F.J. (Eds.) *Neuropsychology and the Law. Springer Series in Neuropsychology.* Springer, New York, NY.
[172] Canadian Academy of Psychologists in Disability Assessment 2016. The joint OPA/CAPDA Guidelines for Best Practices in Psychological Insurer Examinations pp. 59.
[173] American Psychiatric Association 2013. *Diagnostic and statistical manual of mental disorders* (DSM–5). Washington, DC: Publisher, 5th Edition. pp. 947.
[174] Simpson JR. 2014. DMS-5 and Neurocognitive Disorders. Journal of the American Academy of Psychiatry and the Law 42:159-164.
[175] American Psychiatric Association 2013. *Diagnostic and statistical manual of mental disorders* (DSM–5). Washington, DC: Publisher, 5th Edition pp. 607.

There is an extensive literature on prenatal and early childhood methylmercury exposure and children's neurocognitive deficits[176] at cord blood and childhood mercury concentrations well below those reported by the Medical Research Branch of Health Canada for Grassy Narrows and Wabaseemoong[177] (for the distribution of cord blood concentrations for Grassy Narrows between 1970 and 1992, see Chapter 11). There is consensus among scientists and policy makers that prenatal and childhood exposures to methylmercury are particularly toxic[178].

Since 2000, 255 adult claims were accepted; 55 % were born after 1960, and therefore were exposed *in utero* or through breastmilk; 24 (17%) have since died. Of the 141 claims accepted since 2010, 99 (70%) were exposed both *in utero* and postnatally (data provided by the MDB), and this percentage will continue to increase. Figure 8, taken from Korogi et al.[179] shows the distribution of lesions in adult, fetal and infant brains of persons who had suffered from Minamata Disease.

Figure 8. Lesion sites in adult, non-fetal infant and fetal Minamata Disease



Neuropsychological deficits, such as learning difficulties, concentration and memory problems, that affect childhood development, impact adulthood. Using an economic analysis, Trasande and co-authors[180] estimated that the loss of intelligence from methylmercury exposure *"causes diminished economic productivity that persists over the entire lifetime of these children."*

[176] Ha E et al. 2017. Current progress on understanding the impact of mercury on human health. Environmental Research 152:419-433.
[177] Wheatley B and Paradis S. 1995. Exposure of Canadian Aboriginal peoples to methylmercury. Water Air and Soil Pollution 80:3-11.
[178] Health Canada. https://www.canada.ca/en/health-canada/services/healthy-living/your-health/environment/mercury-human-health.html (accessed November 6, 2019)
.[179] Korogi Y et al. 1998. MR findings of Minamata disease--organic mercury poisoning. J Magn Reson Imaging. 8:308-316.
[180] Trasande L et al. 2005. Public health and economic consequences of methyl mercury toxicity to the developing brain. Environmental Health Perspective.113:590-596.

The findings of the ANA-CHA are consistent with these long-term effects of childhood exposure. For persons under 50 years of age, reported childhood fish consumption was a significant determinant of symptoms of nervous system dysfunction, as was having done poorly in school and earning an income of less than $20,000/y[181]. As expected, school success in this community was correlated with further education, income, good health, nutritious diet, sense of belonging to the community, controlling one's destiny, having a good social support network and taking part in the community's cultural events[182]. The above findings have been confirmed by subsequent analyses with biomarker data obtained from the First Nation and Inuit Health Branch (unpublished data).

A further consideration for neuropsychological testing is the recognition of the Cerebellar Cognitive Affective Syndrome, described by Schumahmann and Sherman in 1998[183]. A 2019 systematic review and meta-analysis of studies of adult patients with isolated cerebellar lesions led the authors to confirm that cerebellar patients have significant and relevant deficits in the visuospatial, language and executive function domain[184].

Since the initial descriptions of Minamata Disease, symptoms, noted by successive authors, include not only motor and sensory disturbances, but also mental impairment and unexamined mental, cognitive, emotional and motivational disturbances. As early as 1963, Inoue reported on Minamata patients with impairment of intelligence when they had the following symptoms: lack of initiative, slow movement or speech, memory disturbance, reduced thinking, impaired ability to concentrate, reading disorder and loss of judgment[185]. Citing Inoue's work, Yurifugi et al.[186] note that *"the participants were not examined using psychological batteries."*

Since 1998, several studies have demonstrated significant dose-dependent associations between exposure and neuropsychological deficits in freshwater and marine fish-eaters (Figure 9). In the Baltimore Memory Study, persons 50-70 years of age showed visual memory loss with increasing blood mercury, but not for other functions; median level was 2.1µg/L, ranging from 0 – 16[187], while in a study among freshwater fish-eaters in the Brazilian Amazon, Yokoo et al.[188] reported dose-dependent loss in attention, fine-motor function and verbal memory with hair mercury concentrations ranging from 0.56 to 13.6 µg/g. The authors note that this is similar to what has been reported for children.

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[181] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report (May, 2018) p.34.
[182] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report (May, 2018) p.13.
[183] Schmahmann JD, Sherman JC. The cerebellar cognitive affective syndrome. *Brain*. 1998; 121:561-579.
[184] Ahmadian et al. 2019. The Cerebellar Cognitive Affective Syndrome-a Meta-analysis. Cerebellum. 18:941-950.
[185] Inoue S. 1963 (article in Japanese), cited *in* Yurifugi T et al. 2011.
[186] Yurifugi T et al. 2011. Long-term exposure to methylmercury and psychiatric symptoms in residents of Minamata, Japan. Environ International 37:907-913.
[187] Weil M et al. 2005. Blood mercury levels and neurobehavioural function. JAMA 293:1875-1882.
[188] Yokoo EM et al. 2003. Low level methylmercury exposure affects neuropsychological function in adults. Environ Health 2:8.

Biomarker data obtained for ANA from the First Nation and Inuit Health Branch shows that many persons, who are still alive, greatly surpassed these concentrations during their lifetime (see Chapter 11 Biomarkers of Mercury Exposure).

With respect to prenatal exposure, published estimates of mercury-related IQ loss suggest that maternal hair level of 1µg/g corresponds to an average loss of 0.465 IQ points in children[189]. Learning deficits in childhood translate into poorer academic success, higher school dropout rate and poorer economic achievement. It is noteworthy that in the ANA-CHA, for persons born since 1966, childhood fish consumption, which reflects mercury exposure, is significantly associated with poorer school success and lower income, taking into account other relevant variables[190].

In addition to mercury, other factors likewise contribute to poorer neurodevelopment, including socio-economic conditions and mother's IQ[191]. The impact of mercury exposure may be compounded over generations. For example, a mother's exposure can affect her intellectual capacities and socio-economic conditions; her child's neurodevelopment would not only be impacted by his//her prenatal exposure, but also by the mother's loss of ability to provide her children with a stimulating rearing environment.

7.3. Proposed Neuropsychological Assessment

The Expert Panel considers that neuropsychological deficits constitute 'Further Conditions' of nervous system dysfunction and should be assessed for all claimants. To this end, we examined several neuropsychological tests to determine the most appropriate for the MDB assessment. Among the screening tests commonly used by clinicians are the Mini-Mental State Examination (MMSE)[192], the Montreal Cognitive Assessment (MoCA)[193] and the Toronto Cognitive Assessment (TorCA)[194]. These tests, which can be administered in 5-20 minutes, were developed primarily as tools for detecting signs of cognitive decline, particularly involving memory functions relating to dementia. Although these tests have been found to perform reasonably well in predicting cognitive

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[189] Pichéry et al. 2012. Economic evaluation of health consequences of prenatal methylmercury exposure in France. Environmental Health 11:53.
[190] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report Part 1 (May, 2018) p.35.
[191] Tong et al. 2007. Socioeconomic position, maternal IQ, home environment and cognitive development. J. Pediatrics 151:284-288.
[192] Folstein et al. 1975. "Mini-Mental State » a practical method for grading the cognitive state of patients for the clinician. J. Psychiatry Research 12:189-198.
[193] Nasreddine ZS et al 2005. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. J. Am. Geriatrics Soc. 53: 695-699.
[194] Freedman M et al. 2018. The Toronto Cognitive Assessment (TorCA): normative data and validation to detect amnestic mild cognitive impairment [published correction appears in Alzheimers Res Ther. 2018 Dec 7;10:120]. Alzheimers Res Ther. 10:65.

impairment (i.e., in terms of sensitivity, specificity, positive predictive value, negative predictive value), in our judgment they are not adequate as screens for cognitive impairment, consistent with mercury exposure, due to their brevity and limited breadth of the cognitive functions they assess. The use of screening tests such as the MMSE, MoCA or ToRCA would likely result in false negative classifications, i.e., individuals with mercury-related cognitive impairment, consistent with mercury exposure, being classified as impairment-free.

Another screening battery that the Expert Panel considered is one proposed by Bowler and Lezak[195] as a generic neuropsychological screening battery for toxic exposures. It can be administered by a psychometrician in approximately 30 minutes and provides more detailed assessment of many of the functions assessed by tests such as the MoCA, as well as additional domains that are not assessed by dementia screening tests (e.g., psychomotor efficiency, cognitive flexibility). However, it lacks assessment of some of the domains demonstrated to be associated with mercury neurotoxicity, such as confrontational naming[196].

An appropriate neuropsychological test battery would provide a pattern of neurocognitive dysfunction, where some functions are preserved while others may be affected by past or present mercury exposure. In the situation of MDB claimants, there may be differences between persons who were exposed *in utero* and early childhood and those who were exposed only as adults. The recommended neuropsychological test battery, presented in Table 8 with the time required for each test or subtests, assesses a wide array of functions. The tests and sub-tests have standardized normative data that are used for determining loss.

A qualified person is required to administer the test battery and we recommend that it be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist familiar with neuropsychological testing.

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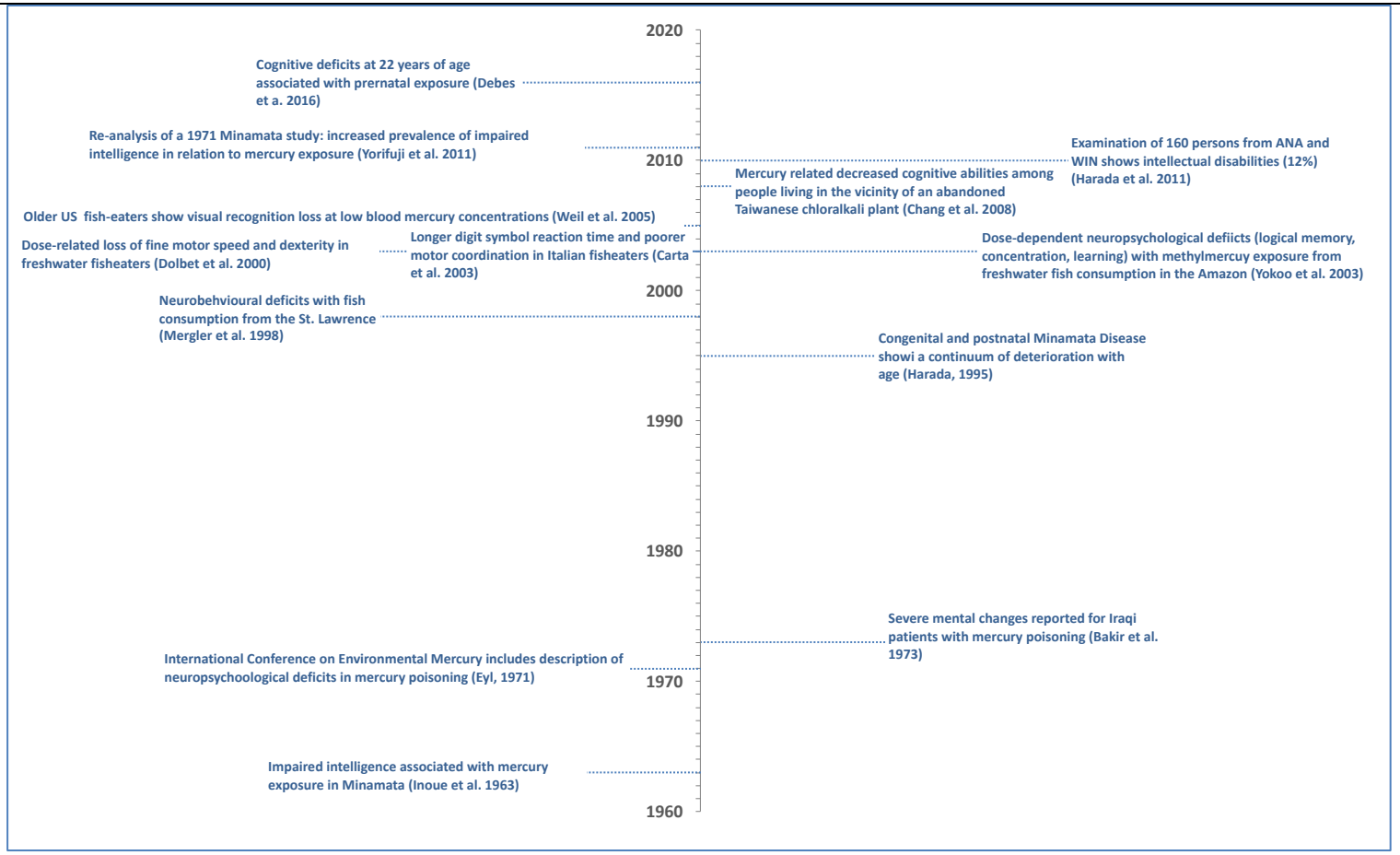
[195] Bowler RM and Lezak MD. 2015. Neuropsychologic evaluation and exposure to neurotoxicants. Handb Clin Neurol. 131:23-45.
[196] Debes F et al. 2016. Cognitive deficits at age 22 years associated with prenatal exposure to methylmercury. Cortex 74:358-369.

Table 8. Recommended Neuropsychological Test Battery

Domain	Test	Sub-domains	Approximate Time (min)
General cognitive ability	WAIS-IV - Core subtests	Verbal comprehension Perceptual reasoning Working memory Processing Speed	65
Memory	California Verbal Learning Test-3	Learning Immediate recall Delayed recall Delayed recognition	35
Executive Functioning	D-KEFS Trail-making Test 5 - trials	Cognitive Flexibility	8
	DKEFS Verbal fluency	Letter and category fluency Category Switching (cognitive flexibility)	10
	D-KEFS Colour-Word Interference (1-3)	Ability to inhibit an over-learned response	8
Visual-Spatial/visual-motor	Rey Osterreith Figure: copy and delay trials	Visuo-spatial recall memory Visuo-spatial recognition Visuo-spatial constructional ability	8
Manual Dexterity	Grooved Pegboard dominant and nondominant hands	Visuo-motor coordination Fine motor control	4
Motor control	Fingertapping test	Upper extremity function	10
Reaction Time	Reaction Time test	Simple reaction time Go/no go simple reaction time Complex reaction time	10
Language	Expressive One-Word Picture Vocabulary Test-4	Confrontational Naming	20
Total time			188

Figure 9. Timeline of selected studies of mercury-related neurocognitive impairment



See references in Appendix 6

7.4 Summary of Rationale and Recommendations

Given that it is well recognized that methylmercury exposure, even at very low levels, is associated with neurocognitive disorders;

Given that the analysis of MDB data shows that a large number of adult claimants and in all probability future claimants were exposed *in utero* and/or in early childhood;

Given that the developing brain is the most sensitive target for methylmercury toxicity;

Given the evidence of neurocognitive deficits associated with cerebellar lesions;

Given the scientific literature showing that neurodevelopmental deficits affect future functional capacities;

Given that neuropsychological test batteries provide a quantified assessment of brain functions;

Given that nervous system disruption caused by toxic exposures may not be detectable without neuropsychological testing,

We recommend that:

- Neuropsychological deficits be included as Further Conditions.

- All claimants undergo an examination of neurocognitive status, using validated neuropsychological tools for the following domains: cognitive ability, memory, executive functioning, visuo-spatial/visual-motor ability, manual dexterity, attention/vigilance and language.

- The neuropsychological test battery be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist trained in the administration and interpretation of neuropsychological tests.

Given that the neuropsychological test battery is lengthy and time-consuming;

Given that we expect a pattern of deficits, with some brain areas more affected compared to others,

We recommend that:

- The results of a first cohort of 60 consenting persons[197] be analyzed to identify domains with the greatest and least deficits, with a view to refining the battery and reducing the time required to administer the tests.

[197] This number was ascertained using power calculations from a Pilot Project with 11 adults from Grassy Narrows.

Chapter 8 Neuropsychiatric Assessment

8.1 Background

The historic documents address the issue of mental illness, consistent with mercury poisoning in the following manner:

- The Memorandum of Agreement (MOA, dated November of l985) includes 'psychosis' as a known condition. However, its inclusion is caveated by paragraph 2.1.4 (b) of the MOU as follows: *"...it is acknowledged further that the inclusion of psychosis as a known condition is yet to be determined."* In Appendix III of the Plan Document (1987), it no longer appears as a 'known condition'; 'psychosis' is replaced by 'incoordination'.

- The Prichard and McIntyre report and recommendations[198] appears to be the source of this change: *"Recommendation 4. The category of psychosis/dementia has not been included in the recommended protocol because it is a late and severe effect of organic mercury intoxication which would appear only in an individual who also had deficits in the other neurologic categories and who would thereby also be eligible for maximum compensation..."*

- In her 2001 report on the MDB, Cosway writes: *"The testing of chronic symptoms of disease (e.g. dementia) was not considered necessary in the l980s, but now that it is almost 40 years since the mercury contamination began, inclusion of a culturally sensitive mental status screening tool would be worthwhile."* [199]

8.2 Current Scientific Evidence

In 1971, the New England Journal of Medicine published the report of the International Conference on Environmental Mercury Contamination[200]. Emotional instability, with fits of anger, depression or rage were included among the symptoms of organic mercury poisoning. In 2007, Ekino[201] reviewed, and published in English, Tatesu's 1968 extensive descriptions on psychiatric disturbances among patients with Minamata

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[198] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-Exposed Indians of the Grassy Narrows and White Dog reserves: Report and Recommendations p.4.
[199] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986-2001, p.166.
[200] Eyl TB. 1971. Organic-mercury food poisoning. New England Journal of Medicine 284: 706-709.
[201] Ekino S et al. 2007. Minamata disease revisited: an update on the acute and chronic manifestations of methyl mercury poisoning. Journal of the Neurological Sciences 262:131-44.

Disease[202], published at the time in Japanese. Forty patients, diagnosed in the 1960's, were followed up over a 2-year period. At both times, symptoms of personality, emotion, or volition were manifest. In 2011, Yurifugi and colleagues[203] published an analysis of 1971 data from 3 regions in Japan. The results show an increasing prevalence of participants with mood and behavioral dysfunction with respect to regional exposure to mercury. There was no difference in the prevalence of dementia with respect to region. A high prevalence of depression was reported among Iraqi patients with mercury poisoning[204]. A 2008 review of the scientific literature on methyl mercury toxicity stated that psychiatric symptoms are common and include loss of volition and apathy, excessive interpersonal sensitivity, perseveration, and loss of inhibition[205].

Results from the 2008 – 2013 Korean Health and Nutrition Examination Survey (KNHANES) reported a significantly increased risk of depression in the highest quintile for blood mercury (range of blood mercury: 5.01 – 168 μg/L) among women but not men[206]. The presence of depression was determined by the question : *"Have you ever been diagnosed with depression, confirmed by a physician?"* These results are consistent with the findings of Philibert and co-authors[207], who observed associations between hair mercury concentrations and mood states for women freshwater fish-eaters in Quebec, at much lower concentrations of exposure. Using a standardized questionnaire, the Brief Symptom Inventory (BSI), the authors reported dose-response relations for the overall severity indices and the following specific scales: obsessive-compulsive, interpersonal sensitivity, depression, anxiety and psychoticism. Median hair and blood mercury concentrations were 0.4 μg/g and 3.59 μg/L, considerably lower than those measured between 1970 and 1997 in Grassy Narrows and Wabaseemoong (see Chapter 11 Biomarkers of Exposure).

In 2010, 160 persons from Grassy Narrows and Wabaseemoong were examined by Harada and coworkers[208], using same examinations that are used for Minamata Disease, observed that *"psychiatric symptoms were more prevalent than prior studies and vivid."*.

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[202] Tatesu S. 1968. Psychiatric symptoms of Minamata disease. In: Study Group of Minamata Disease, editor. Minamata Disease, a Japanese-language edition. Kumamoto: Kumamoto University p.148-177 (Japanese).
[203] Yurifugi T et al. 2011. Long-term exposure to methylmercury and psychiatric symptoms in residents of Minamata, Japan. Environ International 37:907-913.
[204] Maghazaji HI. 1974. Psychiatric aspects of methylmercury poisoning. Journal of Neurology, Neurosurgery, and Psychiatry 37: 954-958.
[205] Taber KH and Hurley RA. 2008. Mercury exposure: effects across the lifespan. Journal of Neuropsychiatry and Clinical Neurosciences 20, IV-389.
[206] Kim et al, 2020. Association of blood mercury level with the risk of depression according to fish Intake level in the general Korean population: Findings from the Korean National Health and Nutrition Examination Survey (KNHANES) 2008–2013. Nutrients 12:189.
[207] Philibert A et al. 2008. Neuropsychiatric symptoms, omega-3, and mercury exposure in freshwater fish-eaters. Archives of Environmental & Occupational Health 63:143-53.
[208] Harada, M. et al. 2011. Mercury Pollution in First Nations Groups in Ontario, Canada: 35 years of Canadian Minamata Disease. Journal of Minamata Studies 3: 3-30 (translated from Japanese).

The authors noted that 20% were thought to have emotional and mental disturbances, based on facial expression, exchanges during screening, and subjective complaints.

A recent study of Inuit adolescents likewise shows a significant association between mercury exposure and anxiety disorders, measured with the Screen for Child Anxiety Related Emotional Disorders (SCARED)[209]. The authors of this study mentioned:

> *"In addition to alterations of brain areas that serve emotion processing, mercury exposure is known to increase oxidative stress and to concomitantly decrease glutathione reductase, which reduces oxidative stress. Recent studies support the notion by which oxidative stress and glutathione reductase dysregulation favor development of anxiety and depression."*
>
> *Lamoureux-Tremblay et al. Neurotoxicology and Teratology 81; 2020.*

While there is not an extensive literature on neuropsychiatric effects of methylmercury exposure, the reports over the past 50 years are consistent. Further considerations about methylmercury neurotoxicity support the inclusion of neuropsychiatric assessment: i) Methylmercury in the brain is demethylated to inorganic mercury[210,211], which is well known for its psychotropic properties[212]; ii) Omega-3 fatty acids, which have a positive effect on mood states and depression[213] may counteract the deleterious effects of mercury, are high in marine fish and considerably lower in fresh-water fish; iii) Methylmercury impacts cerebellar functions (see Figure 8).

In their description of the Cerebellar Cognitive Affective Syndrome, Schumahmann and colleagues included Affective Disorders[214]. The authors indicate that a dysregulation of affect that occurs when lesions involve the 'limbic cerebellum' (vermis and fastigial nucleus). In their study of 77 patients with cerebellar dysfunction and healthy matched controls, Hoche and coworkers[215] report the following:

> *"Neuropsychiatric symptoms measured by a standard assessment of executive behavioural dysfunction (Frontal System Behavior Scale) revealed that patients scored higher than controls on apathy, executive dysfunction and disinhibition*

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[209] Lamoureux-Tremblay et al. 2020. Risk factors associated with developing anxiety in Inuit adolescents from Nunavik. Neurotoxicology and Teratology 81:106903.
[210] Takeuchi T et al. 1989. Mercury level and histochemical distribution in a human brain with Minamata disease following a long-term clinical course of twenty-six years. Neurotoxicology 10:651-657.
[211] Castoldi AF et al. 2003. Neurotoxic and Molecular Effects of Methylmercury in Humans. Review on Environmental Health 18:19-31.
[212] Park JD and Zheng W. 2012. Human Exposure and Health Effects of Inorganic and Elemental Mercury. Journal of Preventing Medicine and Public Health 45:344-352.
[213] Horikawa C et al. 2018. Longitudinal Association between n-3 Long-Chain Polyunsaturated Fatty Acid Intake and Depressive Symptoms: A Population-Based Cohort Study in Japan. Nutrients 10:1655.
[214] Schmahmann JD et al. The neuropsychiatry of the cerebellum - insights from the clinic. Cerebellum. 2007; 6:254-267.
[215] Hoche F et al. 2018.. The cerebellar cognitive affective/Schmahmann syndrome scale. Brain. 141:248-270 (supplementary material 3)

> *(all P < 0.001). Patient self-report was no different than family member ratings. Neuropsychiatric behaviours evaluated with the Cerebellar Neuropsychiatric Rating Scale revealed that family members reported difficulties with emotional control (P < 0.001), autism spectrum symptoms (P < 0.001), psychosis spectrum symptoms (P < 0.001) and deficient social skills (P = 0.002). Patients were also impaired on a questionnaire of social skills and communication (Social and Communication Disorder Checklist)."*
>
> *Hoche et al, Brain 141; 249-270;2018.*

In a 2008 article in the journal, Neurotoxicology, Genuis[216] aptly pointed out that *"Toxic causes of mental illness are overlooked"*. The Expert Panel considers that neuropsychiatric disorders should no longer be overlooked and be included in Further Conditions, consistent with signs and symptoms of mercury poisoning.

While the early studies, mentioned above, relied on clinical descriptions of mental state, the neuropsychiatric disorders, the later studies use scales with stringent psychometric properties and validated clinical cut-off scores. The Expert Panel examined the possible use of several of these scales and selected the SCL-90-Revised[217].

8.3 Proposed Neuropsychiatric Assessment

The SCL-90-R, developed as a clinical tool to measure current psychopathology along nine symptom constructs, has since been applied as a psychiatric case-finding instrument, as a measure of symptom severity, and as a descriptive measure of psychopathology in different patient populations[218]. It is extensively used worldwide, with community respondents, patients (including people with brain injuries), and people experiencing psychiatric inpatient and outpatient services, and its validity and reliability has been ascertained with First Nation communities[219,220].

Gray and her coworkers[221] note that mean scores obtained for the Northern Plain Indian population are similar to published norms, and Cronbach's alpha coefficients (measures of internal reliability and consistency) for all measures were similar to or exceeded

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[216] Genuis SJ, 2008. Toxic causes of mental illness are overlooked. Neurotoxicology 29:1147-1149

[217] Derogatis LR. 1992. SCL-90-R, administration, scoring & procedures manual-II for the revised version and other instruments of the psychopathology rating scale series. Townson, MD: Clinical Psychometric Research. pp. 61.

[218] Derogatis LR and Savitz KL. 2000. The SCL-90-R and the Brief Symptom Inventory (BSI) in Primary Care. In: Maruish, ME, Ed., Handbook of Psychological Assessment in Primary Care Settings, Vol. 236, Lawrence Erlbaum Associates, Mahwah, p. 297-334.

[219] Pearce ME. 2018. The Cedar Project: exploring determinants of psychological distress among young Indigenous people who use drugs in three Canadian cities. Global Mental Health 5:e35; 16p.

[220] Gray JS et al. 2019. Psychometric evaluation of depression measures with Northern Plains Indians. American Journal of Orthopsychiatry 89: 534–541.

[221] Gray JS et al. 2019. Psychometric evaluation of depression measures with Northern Plains Indians. American Journal of Orthopsychiatry 89: 534–541.

published alphas for the general population. Pearce[222], who validated the SCL-90 with First Nation communities in British Columbia (Cedar Project), did a further confirmatory factor analysis that revealed very high scores on internal validity. The SCL-90 has also been used to document mental health of the Aboriginal primary caretakers in Alberta[223].

The SCL-90-R provides three global indices of distress related to the number and intensity of individual symptoms endorsed, as well as a profile of scores based on nine subscales that are related to categories of disorders. The scale has internal checks to account for extreme answers.

Subscales:

- Somatization (SOM)
- Obsessive-Compulsive (OBS)
- Interpersonal Sensitivity (INT)
- Depression (DEP)
- Anxiety (ANX)
- Hostility (HOS)
- Phobic Anxiety (PHOB)
- Paranoid Ideation (PAR)
- Psychoticism (PSY)

Global Measures

- Global Severity Index (GSI)
- Positive Symptom Distress Index (PSDI)
- Positive Symptom Total (PST)

The SCL-90-R consists of 90 items rated on a 5-point scale and can be completed in 12-20 minutes. Test formats for the SCL-90-R include: paper-and-pencil, audiocassette, and computer administration. It is easy to score. The test has been normed on four groups: adult psychiatric outpatients, adult non-patients, adult psychiatric inpatients, and adolescent non-patients. In terms of psychometric properties, the internal consistency reliabilities for the scales of the SCL-90-R range from 0.77 to 0.90. Test-retest reliability with a one-week interval ranges between 0.80 and 0.90[224].

With respect to scoring, the author of the SCL-90-R indicates :

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[222] Pearce ME. 2014. The Cedar Project: Understanding the association between childhood maltreatment and psychological distress, resilience and HIV and HCV vulnerability among your Indigenous people who use drugs in three Canadian cities. PhD thesis, University of British Columbia https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0167644 (accessed August 28, 2020)

[223] Templeton et al. 2012. Social Determinants of Health for the Aboriginal families who participated in the Families First Edmonton study. A Families First Edmonton report for *Alberta Centre for Child, Family and Community Research and Ministry of Human Services*. pp. 27.

[224] Prinz U et al. 2013. Comparative psychometric analyses of the SCL-90-R and its short versions in patients with affective disorders. BMC Psychiatry 13,104.

> "*The GSI represents the most sensitive single quantitative indicator concerning the respondent's overall psychological distress status on the SCL-90-R series of tests. It reflects information on both the number of symptoms of distress the individual is enduring, and the intensity level of his/her distress. By comparison, the PSDI is designed to be more of a "pure" intensity measure, adjusted for numbers of symptoms. The PSDI can also prove useful in communicating about the respondent's distress posture, that is, whether he/she is apt to be an "augmenter," typically exaggerating distress, or a "minimizer," more likely to be stoic and understated."*[225]

He provides an operational definition of "caseness'", the "cut-off" score at or above which the respondent is considered to be a "positive" or a case. He notes that *"The caseness criterion is a probabilistic value, chosen to maximize valid case identification (e.g., sensitivity and specificity), and minimize errors (i.e., false positives and false negatives)".*[226]

8.4 Summary of Rationale and Recommendations

Given that psychiatric symptoms are known to be associated with methylmercury poisoning;

Given that psychiatric symptoms affect functional capacities and quality of life;

Given that there are validated, normed questionnaires to assess neuropsychiatric symptoms;

We recommend that:

- Neuropsychiatric disorders be included as **Further Conditions.**
- All claimants be screened for neuropsychiatric symptoms, using the SCL-90-R, which includes 3 Global Scores and the following dimensions: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticism.

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[225] Derogatis LR. 2017. Symptom Checklist-90-Revised, Brief Symptom Inventory and BSI-18; Chapter 22 in Handbook of Psychological Assessment in Primary Care Settings 2nd Edition (Ed. MR Maruish). Routledge, Francis and Taylor.
[226] Derogatis LR. 2017. *ibid*

- The neuropsychiatric questionnaire be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist.

Chapter 9 Non-neurologic Chronic Health Conditions

9.1 Background

In keeping with the knowledge at that time, the Memorandum of Agreement and the Plan Document only addressed neurological outcomes. The current clinical examination includes a general examination of head and neck, heart, lungs, abdomen, extremities and other, with no indication of the extent of these examinations. Since then, there have been many studies that have examined possible links between methylmercury exposure and non-neurologic chronic health conditions.

9.2 Current Scientific Evidence

Since 1985, a large number of studies have examined the possible contribution of methylmercury exposure to non-neurologic systemic illnesses, including diabetes, hypertension, other cardiovascular conditions and diseases, gastrointestinal disturbances, allergies and autoimmune disorders. We examined the evidence for each of these conditions. For the present report, two chronic health conditions (diabetes and hypertension) were retained. The other conditions should be further investigated in these communities.

Diabetes

The last two First Nation Regional Health Surveys[227,228] report a prevalence for diabetes of 16-17%. Women have been found to have a higher lifetime risk of developing diabetes than First Nations men[229]. Trans fats, high sugar diet, sedentary lifestyle, genetic susceptibility, autoimmune status and toxic/metabolic conditions are commonly recognized as contributing to its development[230].

With respect to mercury exposure, recent systematic reviews of the literature on diabetes and/or metabolic syndrome report that findings are inconsistent[231,232]. The authors of these reviews note the difficulties in establishing a relationship because of the multifactorial nature of the disease. Most studies were cross-sectional and although the

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[227] First Nations Information Governance Centre (FNIGC) 2012. First Nations Regional Health Survey (RHS) 2008/10: National report on adults, youth and children living in First Nations communities. Ottawa: FNIGC pp. 431.

[228] First Nations Information Governance Centre (FNIGC) 2018. National Report of the First Nations Regional Health Survey Phase 3. Ottawa; FNIGC pp. 171.

[229] Turin TC et al. 2016. Lifetime risk of diabetes among First Nations and non–First Nations people. CMAJ 188(16):1147-1153.

[230] Leung L. 2016. Diabetes mellitus and the Aboriginal diabetic initiative in Canada: An update review. Journal of Family Medicine and Primary Care 5:259-265.

[231] Roy C et al. 2017. Is mercury exposure causing diabetes, metabolic syndrome and insulin resistance? A systematic review of the literature. Environmental Research 156:747-760.

[232] Planchart A et al. 2018. Heavy Metal Exposure and Metabolic Syndrome: Evidence from Human and Model System Studies. Current Environmental Health Reports 5:110-124.

authors indicate that there seems to be an association, based on both experimental and observational studies, there is not sufficient evidence to establish a causal relationship[233].

While experimental studies provide evidence of mercury interference with glucose metabolism, observational studies are of populations from many parts of the world with different dietary habits and socio-economic conditions, which may influence positively or negatively the onset of diabetes. Here, we examine the results of studies on the basis of the following criteria: i) First Nation populations; ii) prospective studies; iii) downstream of a chlor-alkali plant;

First Nation populations: Data from the First Nations Food Nutrition and Environment Study[234] shows that the risk for diabetes is 2.5 times higher among First Nation people in Ontario who consume fish at least once a week, compared to those who eat fish less than once a month or do not eat fish (Odds Ratio: 2.50 [95th C.I: 1.38 – 4.58]). The ANA-CHA survey showed a similar elevated risk for adult diabetes in relation to childhood fish consumption: the likelihood of diabetes for those who reported consuming fish at least once a week during childhood was 2.5 times higher compared to those who reported that they ate fish less frequently (Odds Ratio: 2.50 [95th C.I: 1.38 – 4.58]) [235]. It is noteworthy that proportionally more persons in Grassy Narrows report being treated with insulin compared to other First Nations in Canada (36% compared to 21%).[236] Pal and coworkers[237], compared pollutant concentrations between diabetics and non-diabetics in two First Nation communities of Northern Ontario; while diabetics presented higher hair mercury concentrations, the difference was not significant. Diabetes is a chronic disorder and current exposure does not necessarily represent past exposure; in Grassy Narrows and Wabaseemoong, past exposure was considerably higher compared to present day exposure.

***Prospective studies*:** A prospective study in the United States, carried out in 4 cities (CARDIA Trace Element Study)[238], examined incident cases of diabetes over an 18-year follow-up with respect to toenail mercury measurements in young adulthood. Those with highest mercury in young adulthood had a significantly higher incident risk of diabetes and a dose-related lower beta-cell function. These findings are supported by a recent

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[233] Roy C et al. 2017. Is mercury exposure causing diabetes, metabolic syndrome and insulin resistance? A systematic review of the literature. Environmental Research 156:747-760.
[234] Lesya M et al. 2017. Association between fish consumption, dietary omega-3 fatty acids and persistent organic pollutants intake, and type 2 diabetes in 18 First Nations in Ontario, Canada. Environmental Research 156:725-737.
[235] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report Part 1 (May, 2018) p.34.
[236] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report Part 1 (May, 2018) p.130. Note: The ANA CHA survey used the same questions as the First Nation Regional Health Survey (2008/2010) and for comparison purposes, the analysis was limited to ANA Band members living on reserve (ANA CHA).
[237] Pal et al. 2013. The association of type 2 diabetes and insulin resistance/secretion with persistent organic pollutants in two First Nations communities in northern Ontario. Diabetes Metab. 39:497-504.
[238] He et al, 2013. Mercury exposure in young adulthood and incidence of diabetes later in life: the CARDIA Trace Element Study. Diabetes Care 36:1584-1589.

population-based prospective birth cohort study, published after we submitted the draft report, that used data from studies performed in 5 European countries and reported that *"moderate fish intake consistent with current health recommendations during pregnancy was associated with improvements in the metabolic health of children, while high maternal mercury exposure was associated with an unfavorable metabolic profile in children."*[239]

Downstream of a chloralkali plant: A situation similar to the English-Wabigoon River contamination, took place in Taiwan. In southern Taiwan, between 1942 to 1982, a now-deserted chloralkali plant, discharged mercury laden sludge and wastewater into the ecosystem[240]. In 2005, adults living near the chloralkali plant still showed high concentrations of blood mercury (mean17.37 ± 10.9 (1.7–89.2) µg/L) and a study of 1449 non-diabetics living in the region showed a significantly increasing risk of insulin resistance with blood mercury concentration[241].

Diabetic co-morbidity

Complications (co-morbidity) associated with diabetes include: peripheral nerves, vision, the cardiovascular system, kidneys and foot ulcers[242,243]. In the ANA-CHA survey, the questions on diabetic co-morbidity, taken from the First Nations Regional Health Survey 2008/2010[244], allowed for comparison of the responses of Grassy Narrows Band members living on reserve with First Nation communities in Canada and in Ontario[245].

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[239] Stratakis Net al. 2020. Association of Fish Consumption and Mercury Exposure During Pregnancy With Metabolic Health and Inflammatory Biomarkers in Children. JAMA Netw Open. 3:e201007.
[240] Chang JW et al. 2008. Cognitive function and blood methylmercury in adults living near a deserted chloralkali factory. *Environ Res.108:334-339.*
[241] Chang JW et al. 2011. Simultaneous exposure of non-diabetics to high levels of dioxins and mercury increases their risk of insulin resistance. J Hazard Mater. 185:749-755.
[242] Craig R. 2018. Diabetes and care management in Indigenous populations in Canada – Summary report of a pan-Canadian policy roundtable. Institute of Health Economics, Alberta, Canada 31p.
[243] Bruce S and Young TK. 2008. Prevalence and Risk Factors for Neuropathy in a Canadian First Nation Community. Diabetes Care 31(9):1837-1841.
[244] First Nations Regional Health Survey (RHS). 2008/10: National report on adults, youth and children living in First Nations communities. Ottawa: FNIGC. pp. 431.
[245] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report Part 1 (May, 2018) p.130.

Table 9. Comparison of reported diabetic co-morbidity in ANA and other First Nation communities (ANA-CHA)

	ANA on Reserve	FN in Canada	FN in Ontario
Co-morbidity: Has diabetes…			
Affected your kidney function (n =48)	23%	18%	23%
Affected your circulation (n = 50)	44%	29%	a
Affected the feeling in your hands and feet (neuropathy) (n = 51)	61%	34%	a
Affected your lower limbs (n=49)	35%	23%	a
Affected your vision (N = 54)	48%	36%	38%
Resulted in infections (n = 51)	25%	15%	14%

[a]The results for First Nation communities in Ontario were presented separately for men and women. The comparisons are presented in Table 10.

Table 10. Reported diabetic co-morbidity for men and women in ANA and other First Nation communities in Ontario (ANA-CHA)

	ANA on Reserve		FN in Ontario	
	men	women	men	women
Affected your circulation (n = 50)	39%	50%	40%	28%
Affected the feeling in your hands and feet (neuropathy) (n = 51)	57%	65%	43%	29%
Affected your lower limbs (n=49)	30%	41%	34%	20%

While there is no difference in the percentage of diabetics reporting that their kidney function had been affected by diabetes, the prevalence of those who report that diabetes affected their circulation, feeling in hands and feet, lower limbs, vision and infections is higher in ANA compared to the others, with the exception of circulation problems in ANA and First Nation men in Ontario. The largest difference is observed for *'affected the feeling in your hands and feet (neuropathy)'*, a sentinel feature of mercury poisoning. Although the numbers were too small to carry out statistical analyses, this difference may reflect the compounding of diabetes and mercury exposure.

Hypertension

Hu and colleagues have carried out very well documented systematic reviews and meta analyses of mercury exposure and cardiovascular disorders. Their systematic review of 29 studies, published in 2018, identified a positive association between mercury exposure and hypertension[246]. The authors report a nonlinear dose-response relationship with an

[246] Hu XF et al. 2018. Mercury Exposure, Blood Pressure, and Hypertension: A Systematic Review and Dose-response Meta-analysis. Environ Health Perspectives 126:076002.

inflection point at hair mercury concentrations of 3 µg/g. Their estimates of association are based on more than 55,000 participants from 17 countries, including occupational exposures and populations exposed to mercury through diets rich in fish. In the 1970 – 1997 biomarker data provided by Health Canada, 41%, who are now 40 years or over, surpassed this level for, at least one sampling, 33% surpassed 5µg/g and 18% surpassed 10 µg/g.

Of note, for the present report, is a study carried out with Inuit communities in Canada on the interaction between mercury and selenium[247]. The highest prevalence of hypertension was observed for persons with high blood mercury and low blood selenium compared to those with low mercury and high selenium; the cut-off used for high mercury was 7.8 µg/L, the equivalent of 2 µg/g hair mercury. Selenium concentrations are high in Inuit communities due to their diet of marine fish and mammals; selenium concentrations among freshwater fish eaters is much lower and similar to the low blood selenium levels reported in this study.

In a more recent review of systematic and meta-analyses for methyl mercury exposure and fatal/nonfatal ischemic heart disease (IHD), stroke, and all cardiovascular disease, Hu and co-authors[248] concluded that *"chronic exposure to mercury was associated with an increased risk of all-cause mortality and fatal/nonfatal IHD."* The authors propose: *"The cut-off hair Hg concentration of 2 µg/g can be used as a threshold level for establishing guideline values"*. The authors examined subgroup of studies that reported fatal outcomes because hair mercury concentrations were higher than those that reported non-fatal outcomes *(4 – 30 µg/g vs 1 – 5 µg/g); the Odds ratio for* mortality due to all CVD was 1.68 (95% CI: 1.15, 2.45). It is noteworthy that the median concentration of hair mercury in 1975 for 141 persons from Grassy Narrows, who are still alive, was 7 µg/g (25^{th} percentile: 2.9 µg/g; 75^{th} percentile: 13.65 µg/g); 86% had measured hair mercury concentrations greater to or equal to 2 µg/g[249].

The Expert Panel considers that the body of evidence supports the inclusion of diabetes and hypertension in considering compensation by the MDB. A letter from the claimant's physician, with the diagnosis and a description of treatment, verified by the nurse practitioner, should be used to ascertain the existence of these chronic health conditions. Since the evidence is not as strong as for the neurological, neurocognitive and neuropsychiatric deficits, we propose that the information concerning diagnosed diabetes and hypertension be included in the Other Material that a claimant may provide to the MDB in keeping with Section 10 (d) of the Act, and a score be applied to those whose neuro-assessment impairment score reaches the cut-off for compensation.

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[247] Hu XF et al. 2017. High selenium exposure lowers the odds ratios for hypertension, stroke, and myocardial infarction associated with mercury exposure among Inuit in Canada. Environment International 102:200-206.

[248] Hu XF et al. 2021. Mercury exposure, cardiovascular disease, and mortality: a systematic review and dose response meta-analysis. Environ Res. 193:110538.

[249] Calculated from archival hair mercury concentration provided by the First Nations and Inuit Health Branch of Indigenous Services, Canada.

9.3 Summary of Rationale and Recommendation

Given that many studies indicate that mercury may play a role in the etiology and/or course of several multifactorial chronic health conditions;

Given that the strongest evidence points to diabetes, including diabetic co-morbidity (peripheral neuropathy, vision), and hypertension;

Given that the claimant's quality of life can be further affected by these conditions,

We recommend that:

- Diagnosed diabetes and hypertension, verified by the nurse practitioner, be included within Other Material that the claimant can provide to the MDB and included, when appropriate, in the final scoring.

Chapter 10 Quality of Life and Limitations in Activities

"The compensation process in place has not examined potential compensation for individual social and emotional upheaval and the concomitant consequences of the exposure. How, or if, it deals with this issue has yet to be determined."[250]

Postl, 1986.

10.1. Background

The Act defines "*a condition, as an observable medical symptom, sign or condition, or combination of related medical symptoms, signs or conditions which, (a) is a known condition, or (b) has been determined by the Board to constitute a condition, on the basis that it is reasonably consistent with mercury poisoning and capable of significantly impairing the quality of life or limiting the activities of an applicant*…"[251]

The current *Cultural Illustrations of Functional Impairment*[252] used to classify types of impairment have not been updated since the creation of the Plan Document in 1985. As addressed in Chapter 1, within the context of cultural safety and stereotyping, the Expert Panel has the following observations about these "cultural illustrations":

- A large number of "cultural" illustrations refer to fishing activities. It is noteworthy that at the time that these were established, fishing activities had greatly diminished because of the mercury contamination of the River system and there has been less and less hunting due to forestry practices.

- There is a distinct gender bias in the "cultural" illustrations. Most examples refer to male-dominated jobs, with the exception of sewing, beading, threading a needle and craftwork.

- There is no recognition that prior to mercury contamination, these were thriving communities, with little unemployment.

- There is no mention of office work, care for children or care for the elderly. There is no mention of working on a computer, or training for employment or setting up businesses that did not revolve around the commercial fishery.

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[250] Postl, BD. Community Health Assessment Grassy Narrows Band Final Report. June 1989 pp. 151.
[251] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, 1986, Statutes of Ontario, c.23; p. 269
[252] Neurological Grading Guidelines and Cultural Illustrations of Functional Impairments – adult (provided by the MDB).

- The Act is in the singular, i.e. how an applicant's quality of life has been impaired and his/her activities limited, while the current "cultural illustrations" do not address individual impairment.

- A further difficulty is that persons without an illness have a very different outlook on what constitutes loss of quality of life compared to those with an illness[253]. The resulting discrepancies are most likely exacerbated by differing cultural viewpoints on what constitutes health.

The current *Cultural Illustrations of Functional Impairment* are used as a guideline for the MDB physicians who score the protocol forms that are provided by the neurologist. For the most part, the physicians translate the neurologists' assessment of 'mild', 'moderate' and 'severe' into points, which are then added to grade for compensation.

The inadequacy of rating scales, based on clinical observations, to appreciate the consequences of disabilities on an individual's life has been recognized for at least the past 50 years. Indeed, in 1993, Dr. Robert Elgie, neurosurgeon, Progressive Conservative Ontario Minister of Labour from 1978 – 1982 and Chair of the Nova Scotia Worker's Compensation Board (1992 – 1996) noted that *"The clinical rating schedule, more commonly known by its critics as the "meat chart", has been vociferously criticized, particularly over the past two decades, because it has not proven to be a good proxy for the true impact of the impairment on an individual's earnings capacity"*[254]. For example, if a surgeon loses the use of his/her hands in an accident, the award would be hiher than if a lawyer loses the use of his/her hands.

The contrast between the current guidelines and individual situations of loss of functional capacity and quality of life was vividly illustrated during one of the Expert Panel's community visits. Panel members met an artist in his thirties with mild tremor. We were able to admire his earlier work. From early childhood, this man's artistic drawing abilities were praised. He was preparing for a career as an artist. We continued talking and he showed us the work he had done. He told us that over time, he developed a tremor, and could no longer draw a straight line. While we did not perform a neurologic examination, we did witness his tremor which we would have noted as mild. But like the surgeon mentioned above, it was sufficient for him not to be able to continue as an artist. He had tears in his eyes when he told us that he could no longer continue in his field and was working as a manual labourer, a job that did not require fine motor control. Tremor is one of the Known Conditions and this man's tremor significantly impaired his quality of life and limited his activities.

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[253] Ubel PA et al. 2003. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. Quality of Life Research 12:599-607.
[254] Elgie, RG. 1993. Focus on the Individual: A Decade of Workers' Compensation Board reform in Ontario. In Health Care, Ethics and Law/Soins de santé, éthique et droit. (Ed. Bernard Dickens, Monique Ouellette). Proceedings of the 1990 Annual Conference of the Canadian Institute for the Administration of Justice. Éditions Thémis, p. 131 - 135.

The Act stipulates that the condition should be "capable of significantly impairing the quality of life or limiting the activities of an applicant". Unless a claimant requests to be heard by the Board, which we were told is rare, the physicians have no contact with the claimants. There is no place for the claimant to indicate which activities he or she cannot do, nor is there opportunity for claimants to indicate how this impairment affects his or her quality of life. The Expert Panel examined a series of validated questionnaires that could be useful in the assessment of quality of life or limiting the activities of a claimant.

The Expert Panel examined the possibility of including a Quality of Life questionnaire to better assess functional impairment.

10.2 Functional Impairment and Quality of Life

Since 1985, a large number of functional impairment and quality of life questionnaires have been developed to assess how medical and psychiatric conditions impact a person's life. We examined several Quality of Life and Functional Impact questionnaires for possible use in the present situation. We consider that Quality of Life questionnaires exceed functional impairment and encompass elements, such as social and physical environments. We thus focused our attention on functional impairments, and, using the criteria listed below, recommend that the Medical Outcomes SF-36v2 be used, at this time, to assess the impact of claimants' disabilities on their everyday life.

Criteria used in the selection of the SF-36v2:

- Covers several domains of limitations[255]
- Is designed for use in clinical practice[256]
- Has good psychometric properties (validity and reliability)[257]
- Has Canadian population normative data[258,259]

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[255] Ware JE and Sherbourne CD. 1992. THE MOS 36-Item Short Form Health Survey (SF-36) I. Conceptual Framework and Item Selection. Medical Care 30:473-483.
[256] Ware JE and Sherbourne CD. 1992. *Ibid.*
[257] McHorney CA et al. 1993. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Medical Care 31(3):247-263.
[258] Hopman WM et al. 2000. Canadian normative data for the SF-36 health survey. Canadian Multicentre Osteoporosis Study Research Group. Canadian Medical Association Journal 163:265-271.
[259] Hopman WM et al. 2004. Stability of normative data for the SF-36: results of a three-year prospective study in middle-aged Canadians. Can. J. Public Health 95:387-391.

- Has been validated with a First Nation population[260,261]

The SF-36v2 was constructed for self-administration by persons 14 years of age and older, and for administration by a trained interviewer either in-person or by telephone[262]. It is one the most used surveys to determine the impact of medical and psychiatric conditions on quality of life[263]. The SF-36v2 includes one multi-item scale that assesses 8 health concepts. Two major scale scores are derived: one for physical limitations and one for mental limitations.

Health concepts assessed by the SF-36v2:

- Limitations in physical activities because of health problems
- Limitations in social activities because of physical or emotional problems
- Limitations in usual role activities because of physical health problems
- Bodily pain
- General mental health (psychological distress and well-being)
- Limitations in usual role activities because of emotional problems
- Vitality (energy and fatigue)
- General health perceptions

Table 11 describes the meaning of the scores and Figure 10 shows the model for scoring.

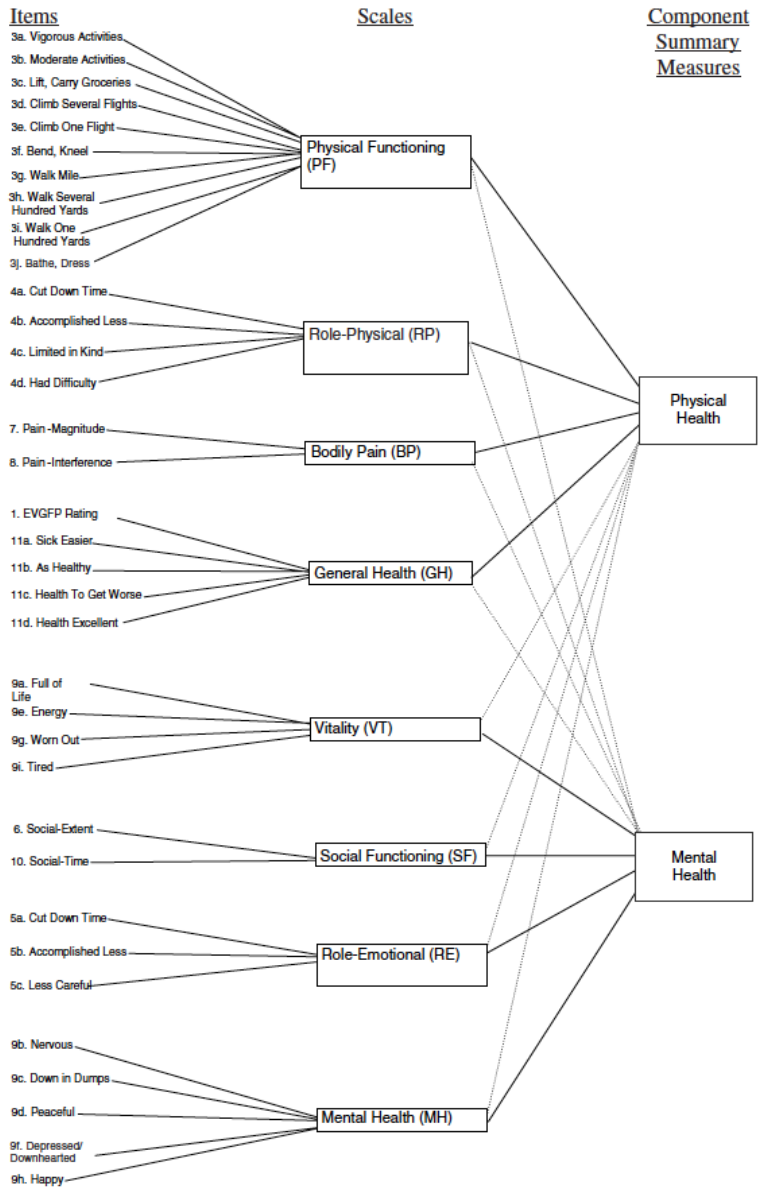
[260] Lix LM et al. 2009. Measurement Equivalence of Osteoporosis-Specific and General Quality-of-Life Instruments in Aboriginal and Non-Aboriginal Women. Quality of Life Research 18:619-627.
[261] Tennehouse LG et al. 2017. Health-related quality of life for First Nations and Caucasian women in the First Nations Bone Health Study. BMC Research Notes 10, 755.
[262] Ware JE and Sherbourne CD. 1992. THE MOS 36-Item Short Form Health Survey (SF-36) I. Conceptual Framework and Item Selection. Medical Care 30:473-483.
[263] Scoggins JF and Patrick DL. 2009. The use of patient-reported outcomes instruments in registered clinical trials: Evidence from ClinicalTrials.gov. Contemporary Clinical Trials 30:289-292.

Table 11. Information About SF-36 Health Status and the Interpretation of Low and High Scores (from Ware et Sherbourne, 1992)

Concepts	No. of Items	No. of Levels	Meaning of Scores: Low	Meaning of Scores: High
Physical functioning	10	21	Limited a lot in performing all physical activities including bathing or dressing	Performs all types of physical activities including the most vigorous without limitations due to health
Role limitations due to physical problems	4	5	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities as a result of physical health, past 4 weeks
Social Functioning	2	9	Extreme and frequent interference with normal social activities due to physical and emotional problems	Performs normal social activities without interference due to physical or emotional problems, past 4 weeks
Bodily pain	2	11	Very severe and extremely limiting pain	No pain or limitations due to pain, past 4 weeks
General mental health	5	26	Feelings of nervousness and depression all of the time	Feels peaceful, happy, and calm all of the time, past 4 weeks
Role limitations due to emotional problems	3	4	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities as a result of emotional problems, past 4 weeks
Vitality	4	21	Feels tired and worn out all of the time	Feels full of pep and energy all of the time, past 4 weeks
General health perceptions	5	21	Believes personal health is poor and likely to get worse	Believes personal health is excellent

The SF-36v2 is a self-administered questionnaire. Persons complete one response from a range of options for each of the 36 questions. A combination of item response(s) is then aggregated to calculate a score for each of the eight dimensions listed. The scores for each dimension range from 0 to 100, with higher scores indicating better health status. Bodily Pain is also scored in this way, with higher scores indicating less pain. The two summary scales (PCS and MCS) are scored differently from the eight-dimension scores. These scales are scored using norm-based methods. A score of 50 reflects an average score with respect to these populations. Scores lower than 50 reflect less than average health and scores greater than 50 reflect better than average health.

Figure 10. An excerpt from the User's Manual for the SF-36v2 Health Survey



Note. All health domain scales contribute to the scoring of both the Physical and Mental Component Summary measures. Scales contributing most to the scoring of the summary measures are indicated by a connecting solid line (—). Scales contributing to the scoring of the summary measures to a lesser degree are indicated by a dotted line (·····).

10.3 Summary of Rationale and Recommendations

Given that significant impairment to the quality of life or limitations in activities are important aspects of the compensation process;

Given that the *Neurological Grading Guidelines and Cultural Illustrations of Functional Impairments* in the Plan Document refers primarily to traditional activities, many of which were halted due to the contamination;

Given that there is no consideration in the current guidelines of the potential impact of mercury poisoning on the physical and mental requirements for today's jobs, training, education and daily activities;

Given that clinical rating schedules for compensation are considered inadequate to assess the impact of an impairment on an individual's earnings capacity;

Given that in Section 1 Act defines a condition as *"capable of significantly impairing the quality of life or limiting the activities of an applicant.";*

Given that since the adoption of the Act, a very large number of questionnaires have been developed and validated to assess quality of life and limitations of activities,

We recommend that:

- A questionnaire with good psychometric properties, Canadian normative data and validated with a First Nation population (Medical Outcomes SF-36v2), serve to assess a claimant's quality of life and limitations of activities.

- The questionnaire be administered by the nurse practitioner and the results be included in Other Material.

Chapter 11 Biomarkers of Mercury Exposure

11.1 Background

Following the discovery of the mercury discharge in the 1960's, several governmental ministries and agencies initiated biomarker programs to monitor exposure in ANA and WIN[264]. One program, initiated in 1970, involved measuring mercury concentrations in cord blood samples from mothers who gave birth at the Lake of the Woods Hospital in Kenora. Another program monitored mercury exposure through blood and hair samples from children and adults for the period 1970 - 1997. Emphasis was placed on persons who were working in occupations with possible high mercury exposure, such as guiding and fisheries, and their families, but all persons were eligible for testing. Usher[265] notes that between 1962 and 1970 nearly all community members were either directly or indirectly affiliated with the fishing industry, as guides or fishers and that fish was the dietary mainstay.

In their 1980's recommendation, Prichard and McIntyre[266] wrote that *"all participants in a compensation assessment be asked to provide a sample of blood and/or hair for mercury analysis at the time of the neurologic examination*". We since know that blood and hair mercury only represent recent exposure; chronic effects result from lifespan exposures, with different periods of sensitivity.

Cosway[267] repeated this suggestion, noting that: "*Even though the Health Canada mercury-monitoring program collects data on mercury levels in the hair and blood of Grassy Narrows and Wabaseemoong Band members, this information is not available to the members of the MDB or the Boards' consultant neurologists."* She recommended that biomarker data be included in the assessment for compensation[268].

While current blood and hair concentrations reflect current fish-eating practices, the scientific literature, summarized in the previous chapters, indicate that prenatal and childhood methylmercury exposure and high exposures in adulthood have a long-lasting impact on health and well-being. This is evidenced, as well, by the results of the ANA-CHA, showing that childhood fish consumption is a major determinant of later-life health

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[264] Wheatley et al. 1997. Exposure patterns and long-term sequelae on adults and children in two Canadian indigenous communities exposed to methylmercury. Water, Air and Soil Pollution 97: 63-73.
[265] Usher et al. 1979. The Economic and Social Impact of Mercury Pollution on the White Dog and Grassy Narrows Indian Reserves, Ontario. A report to the Ant-Mercury Ojibwa Group c/o Grand Council Treaty 3, Kenora Ontario; The Chief, Islington.Band, Whitedog, Ontario; The Chief, Grassy Narrows Band, Grassy Narrows, Ontario. pp.380.
[266] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-Exposed Indians of the Grassy Narrows and White Dog reserves: Report and Recommendations p.6.
[267] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986-2001, p.166.
[268] Cosway S. 2001. *Ibid*, p.4

and well-being[269], and confirmed using the historic biomarker data provided by the First Nations and Inuit Health Branch (FNIHB), (unpublished data).

The Expert Panel examined how historic biomarkers of mercury could be included in the assessment for compensation.

11.2 Cord Blood Measurements Between 1972 and 1992

Between 1972 and 1992, the Medical Research Branch of Health Canada and the Ontario Ministry of Health carried out a cord blood-monitoring program of persons born in the Lake of Woods Hospital in Kenora. Table 12 presents the data obtained from the First Nations and Inuit Health Branch (FNIHB) for ANA. The average age of these persons today is 37 years, ranging from 28 to 48 years of age.

Table 12. ANA Cord blood concentrations (µg/L (ppb)) for ANA (n = 211)

	n	Median µg/L	25th - 75th percentile µg/L	Maximum µg/L
1972-1974	18	38	2.9 - 53	172
1975-1980	57	5.5	2.6 - 13	160
1980-1985	77	6.4	3.4 - 11	73
1985-1992	59	2.1	2.9 - 4.9	13

1µg/L = 1 ppb

Health Canada guidelines for pregnant women considers 8 µg/L as a cut-off for intervention. However, a study among Inuit children shows that children with cord blood mercury greater or equal to 7.5 µg/L are almost four times as likely to have an IQ score less than 80, the clinical cut-off for borderline intellectual disability[270]. It is noteworthy that in the Inuit study, the association with mercury was stronger when omega-3 fatty acids and selenium, known to be beneficial to neurodevelopment were included in the statistical model. As stated before, freshwater fish do not have the high concentrations of these beneficial nutrients, suggesting that the stronger association would apply to freshwater fish eaters. As noted in previous chapters, prenatal and childhood exposure have been associated with poor neurodevelopmental outcomes at much lower concentrations.

Mercury cord blood for ANA (n = 211) from the cord blood-monitoring program varied between 0.2 ppb and 172 ppb. For the 182 for whom information was available, 25

[269] Asubpeeschoseewagong Netum Anishinabek Community Health Report. May 2018; chapter 8 p. 134-154.

[270] Jacobson SW et al. 2015. Relation of Prenatal Methylmercury Exposure from Environmental Sources to Childhood IQ. Environmental Health Perspectives 123:827–833.

(14%) have since died. The median age at death was 14.5 years of age. Table 13 presents the distribution of cord blood for those who are living.

Table 13. Distribution of cord blood mercury concentrations (ppb)

Mercury concentration in cord blood (µg/L)	Percentage of persons
Less than 5	49%
5-9.9	24%
10-19	12%
20-49	9%
50 or more	6%

11.3 Hair and blood concentrations in childhood and adulthood

Blood and hair samples were measured in children and adults between 1970 and 1997. Figure 11 presents the results for ANA hair equivalent concentrations of mercury during this time. The highest equivalent hair mercury measure in ANA was 183 µg/g[271], taken in 1975.

Figure 11. Mean equivalent hair concentrations for men and women from ANA between 1970 and 1995 (unpublished data)

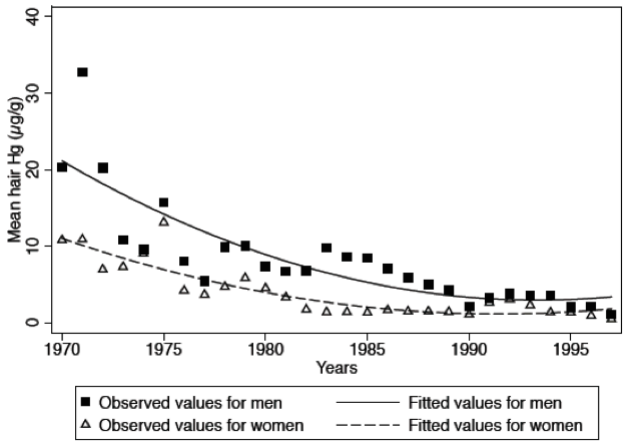


Table 14 shows the distribution of equivalent hair mercury concentrations by age category among the 413 currently living ANA Band members, for whom mercury concentrations were assessed at least once between 1970 and 1997.

[271] 1 µg/g = 1 ppm

Table 14. Equivalent historic hair mercury concentrations for Grassy Narrows Band members currently alive

Hair mercury concentration	Age category		
	70 +	50 - 69	30 - 49
	n = 21	n = 125	n = 251
Greater than 3 µg/g	81%	78%	19%
Greater than 5 µg/g	71%	69%	12%
Greater than 10µg/g	33%	42%	5%
Greater than 15 µg/g	29%	29%	2%
Greater than 20µg/g	19%	16%	1%

While proportionally fewer persons under 50 years of age presented very high equivalent hair mercury concentrations, the majority of them were exposed *in utero* and in early childhood.

11.4 Summary of Rationale and Recommendations

Given that individual's umbilical cord blood, hair and blood biomarker data collected by Canadian and Ontario ministries and agencies are available from the archival data repositories (e.g. historical records of the First Nation and Inuit Health Branch of Indigenous Services), upon the written request of the sampled individual;

Given that Section 10 of the Act states that the MDB may consider any material, it *"deems useful for the purpose of deciding any matter including whether it may be appropriate to make or vary any award or awards…"*[272];

Given that biomarker data represents the situation at the time of sampling; mercury exposure varied throughout the year and with the type of fish recently consumed and the size of the fish,
We recommend that:

- If the claimant so wishes, biomarkers of past mercury exposure be included in the Other Material submitted to the MDB.

- High exposures be presumptive of mercury poisoning, but low values not disqualifying.

[272] English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act, 1986, Statutes of Ontario, 1986, c.23; p. 278.

Chapter 12 Adult Grading System

12.1 Background

The Expert Panel was asked to grade Known and Further Conditions with respect to degree of impairment. The point of departure for all recommended points is the Degree of Impairment in Appendix III of the Plan Document (Table 4), with the entitlement score at 6 and the maximum entitlement score at 16.

Table 15. Known Conditions (Adult) and Degree of Impairment (Appendix III of the Plan Document)

KNOWN CONDITIONS (ADULT)	DEGREE OF IMPAIRMENT			
	None	Mild	Moderate	Severe
1. Tremor	0	1	4	8
2. Ataxia	0	1	4	8
3. Inco-ordination	0	1	4	8
4. Dysarthria	0	-	2	8
5. Absent tendon reflexes	0	-	1	4
6. Sensory abnormality	0	1	4	8
7. Visual field constriction	0	2	4	8

Maximum score:	52
Entitlement score:	6
Maximum entitlement score:	16

Currently, the authorized physician, a neurologist, carries out the examination and classifies impairment as none, mild, moderate and severe, as recommended by Prichard and McIntyre[273] and included in Appendix III of the Plan Document. The neurologist's report is sent to the physicians on the MDB, who attribute scores; these are then approved by the MDB and sent to Great-West Life Assurance (now Canada Life).

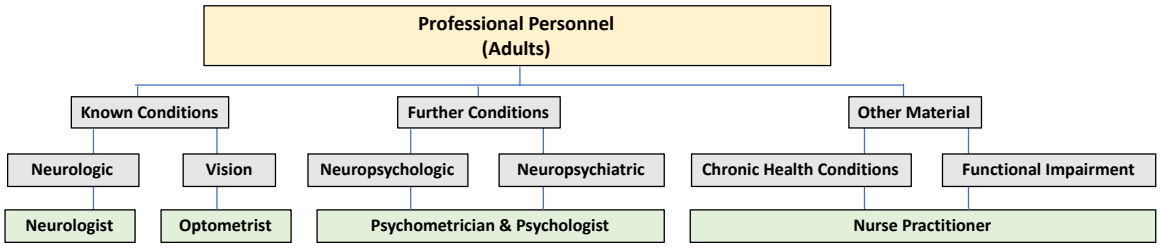
Figure 12 presents the professionals required to implement the updated examinations. With regard to the current situation, this will require, in addition to the neurologist, recruitment of

[273] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-Exposed Indians of the Grassy Narrows and White Dog reserves: Report and Recommendations. p. 10.

a nurse practitioner, an optometrist and a neuropsychologist; the latter two may require technical assistance, i.e. a technician in optometry and a psychometrician to administer the tests. The examinations provided by these authorized clinicians would constitute the basis for scoring as described below.

The procedure for implementation of the present scoring system is the following: Results of the examinations carried out by the Neurologist (neurologic examination), Optometrist (visual field examination), Psychologist (neuropsychological and neuropsychiatric assessment) and the nurse practitioner (symptom checklist, general health, medical history and personal information, verification of diagnoses of diabetes and/or hypertension, results of the medical outcomes questionnaire) and, if the claimant so wishes, biomarker data, are sent to the MDB and graded within the categories of Known Conditions, Further Conditions and Other Material, according to the recommended grading system.

Figure 12. Professional Personnel for Updated Adult Examinations



12.2 Known Conditions

We recommend that Known Conditions 1- 6 in Appendix III of the Plan Document continue to be assessed by a neurologist, using the protocols recommended in the present report. The protocols provide scores that can then be used for grading.

- **Tremor:** For tremor, we recommend using cut-off the following points on the **Fahn Tremor Rating Scale:** mild (1-4), moderate (5-9) and severe (10+), using the same impairment distribution as in Appendix III of the Plan Document:

    - 0 = none, with an impairment score of 0
    - 1 - 4 = mild, with an impairment score of 1
    - 5 - 9 = moderate, with an impairment score of 4
    - 10+ = severe, with an impairment score of 8

- **Ataxia: The Brief Ataxia Rating Scale (BARS)** includes 3 of the Known Conditions that are included in Appendix III of the Plan Document, Ataxia, Incoordination and Dysarthria. Since the scale provides a combined assessment of three "Known Conditions", we attribute points in the following manner:

- 0 - 1 = none, with an impairment score of 0
- 2 - 5 = mild, with an impairment score of 4
- 6 - 9 = moderate, with an impairment score of 10
- 10 + = severe, with an impairment score of 24

- **Absent tendon reflexes:** We have attributed different points to the absence of reflexes in a similar manner to Appendix III: No points are attributed for none or mild loss; absent ankle reflexes = moderate, with a score of 1; absent ankle and patellar reflexes = severe, with a score of 4.

- **Sensory abnormality:**

  TNSr score :

  - 0 - 1 = none, with an impairment score of 0
  - 2 - 4 = mild, with an impairment score of 2
  - 5 – 8 = moderate, with an impairment score of 4
  - 9 + = severe, with an impairment score of 8

Known Condition 7 of Appendix III of the Plan Document is visual field constriction. The examination should be performed under the supervision of an optometrist, using a Humphrey Visual Field (HFA) Analyser with gaze tracking capability, using the 30-2 Swedish Interactive Thresholding Algorithm (SITA) and use the appropriate protocol to examine visual field loss.

- **Visual field loss:**

  - No deficit: impairment score of 0
  - For **abnormal visual fields** the following criteria need to be met:

1. Pattern deviation plot with 3 contiguous spots <5%, at least one of which is < 1% **OR** corrected PSD index or PSD index with $p < 0.05$;
2. False positives below 15% **OR** fixation losses above 20%
3. False negatives should not be considered.

  - Mild visual field deficits: abnormal field + VFI greater than or equal to 82%: impairment score 2 points

  - Moderate visual field deficits: abnormal field + VFI 63% - 81%: impairment score 4 points

  - Severe deficits: abnormal field + VFI less than 62%: impairment score 8 points

12.3 Further Conditions

Neuropsychological status
The examination is performed by a psychometrician under the supervision of a neuropsychologist.

The neuropsychological test battery provides a pattern of neurocognitive dysfunction, where some functions are preserved while others may be affected by past or present mercury exposure. The recommended neuropsychological battery includes tests to measure a wide array of functions. There are standardized normative data for each test or group of tests (subtests). In attributing impairment points, we considered whether the test scores were derived from one test or several tests.

General Cognitive Ability (4 subscales of WAIS-IV):

- All of the subtest scores are equal to or above 90 (25^{th} percentile) = 0 (None)
- One subtest score is between 80 and 90 (9^{th} - 24^{th} percentile) and all of the others are greater or equal to 90 ($\geq 25^{th}$ percentile) = 2 (Mild)
- 2+ subtest scores are between 80 and 90 (9^{th} – 24^{th} percentile) and the others are greater or equal to 90 ($\geq 25^{th}$ percentile) = 4 (Moderate)
- Any subtest score between 70 and 79 (2^{nd} - 8^{th} percentile) = 4 (Moderate)
- 2+ subtest scores between 70 and 79 (2^{nd} – 8^{th} percentile) = 8 (Severe)
- Any of the subtest scores are less than 70 ($<2^{nd}$ percentile = 8 (Severe)

Memory (California Verbal Learning Test-3):

- All of the subtest scores are equal to or above 90 (25^{th} percentile) = 0 (None)
- One subtest score is between 80 and 90 (9^{th} - 24^{th} percentile) and all of the others are greater or equal to 90 ($\geq 25^{th}$ percentile) = 2 (Mild)
- 2+ subtest scores are between 80 and 90 (9^{th} – 24^{th} percentile) and the others are greater or equal to 90 ($\geq 25^{th}$ percentile) = 4 (Moderate)
- Any subtest score between 70 and 79 (2^{nd} - 8^{th} percentile) = 4 (Moderate)
- 2+ subtest scores between 70 and 79 (2^{nd} – 8^{th} percentile) = 8 (Severe)
- Any of the subtest scores are less than 70 ($<2^{nd}$ percentile = 8 (Severe)

Executive Functioning (D-KEFs):

- All of the subtest scores are 7 or more ($\geq 25^{th}$ percentile) = 0 (None)
- One subtest score is 5 or 6 (9^{th} - 24^{th} percentile) and all of the others are 7 or more ($\geq 25^{th}$ percentile) = 2 (Mild)
- 2+ subtest scores are 5 or 6 (9^{th} – 24^{th} percentile) and all of the others are 7 or more ($\geq 25^{th}$ percentile) = 4 (Moderate)
- Any of the tests is 4 (2-8^{th} percentile) = 4 (Moderate)
- 2+ subtest scores is 4 (2 – 8^{th} percentile) = 8 (Severe)
- Any of the subtest scores are 3 or less ($<2^{nd}$ percentile) = 8 (Severe)

Visual-Spatial/visual-motor (Rey Osterreich Figure):

- The score for Copy is 31 or higher and the score for Delay 1 is 19 or higher and the score for Delay 2 is 13 or higher = 0 (None)
- The score for Copy is equal to or greater than 31 and the score for Delay 1 is equal to or greater than 19 and the Score for Delay 2 is 11 or 12 = 2 (Mild)
- The score for Copy is equal to or greater than 31 and the score for Delay 1 is 17-18 and the Score for Delay 2 is equal to or greater than 13 = 2 (Mild)
- The score for Copy = 30 and the score for Delay 1 is equal to or greater that 19 and the Score for Delay 2 is equal to or greater than 13 = 2 (Mild)
- The score for Copy is equal to or greater than 31 and the score for Delay 1 is 17 or 18 and the Score for Delay 2 is 11 or 12 = 4 (Moderate)
- The score for Copy = 30 and the score for Delay 1 is equal to 17 or 18 and the Score for Delay 2 is equal to 11-12 = 4 (Moderate)
- The score for Copy = 30 and the score for Delay 1 is equal to 17 or 18 and the Score for Delay 2 is greater than or equal to 13 = 4 (Moderate)
- The score for Copy is equal to 29 or the score for Delay 1 is equal to 15-16 or the Score for Delay 1 is 9-10 = 4 (Moderate)
- The score for Copy is equal to 29 and the score for Delay 1 is equal to 15-16 = 8 (Severe)
- The score for Delay 1 is 15-16 and the score for Delay 2 = 9 -10 = 8 (Severe)
- The score for Copy is less than 29 or the score for Delay 1 is less than 15 or the score for Delay 2 is less than 9 = 8 (Severe)

Manual Dexterity/Motor Control (Grooved Pegboard and Finger-tapping), using age-adjusted norms:

- Both test scores are $\geq 25^{th}$ percentile = 0
- One test score is in the 9^{th}-24^{th} percentile = 2 (Mild)
- Both test scores are in the 9^{th} – 24^{th} percentile and the other is $\geq 25^{th}$ percentile = 4 (Moderate)
- One test score is in the 2-8^{th} percentile = 4 (Moderate)
- Both test scores are in the 2 – 8^{th} percentile = 8 (Severe)
- Either test score is in the $<2^{nd}$ percentile = 8 (Severe)

Reaction Time (simple Reaction Time, Go/no go, Complex Reaction Time), using age-adjusted norms:

- All of the test scores are $\geq 25^{th}$ percentile = 0
- One test score is in the 9^{th}-24^{th} percentile and all of the others are $\geq 25^{th}$ = 2 (Mild)
- Two test scores are in the 9^{th} – 24^{th} percentile and the others are $\geq 25^{th}$ = 4 (Moderate)
- Any of the test scores is in the 2-8^{th} percentile = 4 (Moderate)

- Two of the test scores are in the 2 – 8th percentile = 8 (severe)
- Any of the subtest scores are in the <2nd percentile = 8 (Severe)

Language (Expressive One-Word Vocabulary):

- Test score is 90 (≥ 25th percentile or more) = 0
- Test score is 80 – 89 (9th-24th percentile) = 1 (Mild)
- Test score is 70 - 79 (2nd – 8th) = 2 (Moderate)
- Test score is <70 (<2nd percentile) = 4 (Severe)

Neuropsychiatric assessment
The assessment could be performed by a psychometrician, under the supervision of a psychologist.

The SCL-90-R and the BSI were designed to be interpreted in terms of three distinct but related classes of information: global scores, dimension scores, and individual test items[274]. Scores on the SCL-90 are transferred onto a profile sheet displaying the 9 symptoms dimensions and three global indices. Each score has a standardized mean of 50 and a standard deviation of 10[275]. We recommend the following impairment scores:

- All scales below 60 = 0 (None)
- 1+ scale score above 60, but all global indices below 60 = 2 (Mild)
- 1 scale score above 60 and 1 Global Index above 63 = 4 (Moderate)
- 2+ scale scores above 60 and 1 Global Index above 63 = 8 (Severe)

12.4 Other Material

In conformity with Section 10 (d) of the Act which indicates that the MDB *"may prescribe any other matter or thing that by this Act is to be or may be prescribed."* and Section 27 of the Act, which states : "*The Board shall consider any information, advice, report, evidence or other material or matter which, in its sole discretion, it deems useful for the purpose of deciding any matter including whether it may be appropriate to make or vary any award or awards*", the Expert Panel propose that the category Other Material groups a certain number of items, some of which to be specifically considered in the grading scheme, others are to inform the decision.

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[274] Derogatis LR and Savitz KL. 2000. The SCL-90-R and the Brief Symptom Inventory (BSI) in Primary Care. In: Maruish, ME, Ed., Handbook of Psychological Assessment in Primary Care Settings, Vol. 236, Lawrence Erlbaum Associates, Mahwah, p. 297-334.
[275] Groth-Marnat G. 2009 Handbook of Psychological Assessment 5th Ed. John Wiley and Sons Inc. pp. 731.

Items considered in the Grading System

The Act does not require proof of mercury exposure, but uses the presence of nervous system dysfunction, consistent with mercury exposure, as the basis for individual compensation. In keeping with the spirit of the Act, the Expert Panel considers that a score of 6 points or more attests to the presence of *"signs and symptoms consistent with mercury poisoning"* and therefore recommends that further points be added to the impairment score for claimants whose score is sufficient to warrant compensation.

- ***Non-neurologic conditions***
  While diabetes and hypertension are multifactorial, there is growing scientific evidence that mercury can contribute to these conditions.

  For those with diagnosed diabetes:
  - the addition of 1 point for persons whose score is between 6 and 9 points
  - the addition of 2 points for persons whose score is 10+

  For those with diagnosed hypertension:
  - the addition of 1 point for persons whose score is between 6 and 9 points
  - the addition of 2 points for persons whose score is 10+

- ***Quality of Life/Limitations of Activities***
  In Chapter 10, the Expert Panel recommends a validated questionnaire to assess an applicant's quality of life and activity limitations, the Medical Outcomes Study Short Form – 36 v2. This questionnaire has eight dimensions, with 2 summary scores: Mental Component Summary (MCS) and Physical Component Summary (PCS). We recommend using the two summary scores to provide an indication of overall loss of the quality of life. The scoring is standardized to a mean of 50, with a standard deviation of 10.

  Mental Component Summary Score:
  - Greater than 40 = 0 (None)
  - 30 - 39 = 2 (Mild)
  - 20 – 29 = 4 (Moderate)
  - Less than 20 = 8 (Severe)

  Physical Component Summary Score:
  - Greater than 40 = 0 (None)
  - 30 - 39 = 2 (Mild)
  - 20 – 29 = 4 (Moderate)
  - Less than 20 = 8 (Severe)

Items that serve to inform the MDB

In the current examination, several items serve to inform the MDB, notably the medical and personal history, a short list of symptoms, medication, and the general examination. In our recommendations for the updated examination, we propose that these not be

performed by the neurologist, but by a nurse practitioner. The short list of symptoms would be replaced by a standard list of symptoms used in neurology, and clinical information from previous neurological or psychological examinations, performed either by specialists or within the context of clinical research project, be included.

12.5 Historic Exposure Data

Cord blood
Since cord blood concentrations provide evidence of *in utero* mercury exposure, the Expert Panel recommends that, if a claimant so wishes, cord blood concentration be considered in the attribution of compensation in the following way:

- Persons whose cord blood level was 20 ppb or more be given full compensation without an examination (which, on average, corresponds to a loss of 10 IQ points or more).

- Persons whose cord blood concentration was between 10 – 19.9 ppb: 8 points added to their score.

- Persons whose cord blood concentration was between 7 – 9.9 ppb: 4 points added to their score.

- Persons whose cord blood concentration was between 5 and 6.9 ppb: 2 points added to their score.

Blood and/or hair data
Hair mercury is considered the most appropriate biomarker for exposure since each centimeter provides a measure of approximately 1 month's exposure. Wheatley and colleagues at the Medical Research Branch of Health Canada presented the measurements in equivalent blood mercury[276] and when there were several measures from a hair strand, they chose the highest. Philibert and coworkers[277] present the measurements in equivalent hair mercury and reports the corresponding month of sampling. In both cases, same blood to hair ratio, reported by Legrand was used[278].

When considering mercury exposure among claimants, it is important to remember that in these communities, mercury values are most often representative of chronic exposure, rather than exposure at one moment in time. Exposure varied over time with values

[276] Wheatley B and Paradis S. 1995. Exposure of Canadian aboriginal peoples to methylmercury. Water, Air & Soil Pollution 80:3–11.
[277] Philibert et al, 2020. Mercury exposure and premature mortality in the Grassy Narrows First Nation community: a retrospective longitudinal study. Lancet Planetary Health 4: 141-148.
[278] Legrand M et al. 2010. Methylmercury blood mercury guidelines for Canada. Canadian Journal of Public Health 101:28-31.

during seasons with high fish consumption almost 4 times higher than those with low or almost no fish consumption. The Expert Panel proposes that the highest measure of either blood or hair be used for scoring purposes. If a claimant has both umbilical cord blood and blood or hair; prenatal (umbilical cord blood) and the highest of blood or hair should be included.

Table 16. Recommended scoring for blood/hair exposure

Highest measure		Score
Hair	or Blood	
≥ 25 ppm	≥ 100 ppb	Full compensation without examination
20 – 24 ppm	80 – 99 ppb	4 points added to score
10 - 19 ppm	40 – 79 ppb	3 points added to score
5 - 9 ppm	20 – 39 ppb	2 points added to score

It should be noted that persons born between 1962 and 1972, during the discharge of mercury and before the cord blood program, prenatal and childhood exposures may have had important long-term health impacts. These persons are now between 58 and 68 years of age.

A flow chart of the Adult Grading System is provided in Figure 13 and Table 17 contains the distribution of points for the Adult Grading System.

Figure 13. Flow Chart for the Adult Grading System

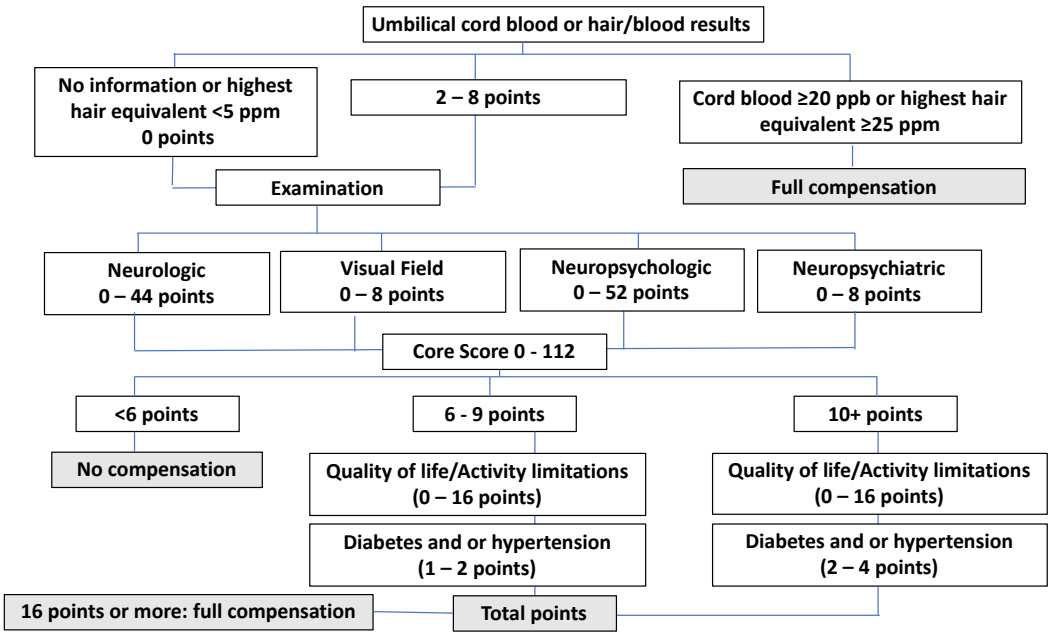

Table 17. Adult Grading – Distribution of Points

Grading for Known Conditions: Neurologic

	Test/ Rating Scale	None		Mild		Moderate		Severe	
		Rating	Points	Rating	Points	Rating	Points	Rating	Points
Tremor	Fahn Tremor Rating Scale	0	0	1-4	1	5-9	4	10+	8
Ataxia, Incoordination Dysarthria	Brief Ataxia Rating Scale	0-1	0	2-5	4	6-9	10	10+	24
Absent tendon reflexes	Observation	No loss	0	Mild loss	0	Absent ankle reflexes	1	Absent ankle & patellar reflexes	4
Sensory abnormality	TNSr (Scale for sensory loss neuropathy)	0-2	0	3-5	2	6-9	4	10+	8

Grading for Known Conditions: Visual Field Loss

	Test/ Rating Scale	None		Mild		Moderate		Severe	
Visual field constriction	Humphrey Visual Field (HFA) using 30-2 SITA gaze tracking capability	No deficit	0	Abnormal field + VFI ≥ 82%	2	Abnormal field + VFI 63%-81%	4	Abnormal field + VFI less than 62%	8

Grading for Further Conditions: Neuropsychological

	Test/ Rating Scale	None		Mild		Moderate		Severe	
		Score	Points	Score	Points	Score	Points	Score	Points
General Cognitive Ability	WAIS-IV Verbal Comprehension WAIS-IV Perceptual reasoning WAIS-IV Working memory WAIS-IV Processing Speed	All of the subtest scores = 90 or more (≥ 25th percentile)	0	One subtest score is between 80-90 (9th-24th percentile) and all of the others are ≥ 25th	2	2+ subtest scores are between 80 and 90 (9th – 24th percentile and all of the others are ≥ 25th or Any of the subtest scores are between 70 and 79 (2-8th percentile)	4	2+ subtest scores are between than 70 and 79 (2 – 8th percentile) or If any of the subtest scores are less than 70 (<2nd) percentile)	8
Memory	California Verbal Learning Test - 3 Learning	All of the subtest scores = 90 or more (≥ 25th percentile)	0	One subtest score is between 80-90 (9th-24th percentile) and all of the others are ≥ 25th	2	2+ subtest scores are between 80 and 90 (9th – 24th percentile) and all of the others are ≥ 25th or Any of the subtest scores are between 70 and 79 (2-8th percentile)	4	2+ subtest scores are between 70 and 79 (2 – 8th percentile) or If any of the subtest scores are less than 70 (<2nd) percentile)	8
Executive Functioning	D-KEFs Trail-making Test 5 Trials D-KEFS Verbal Fluency D-KEFS Colour-Word Interference (1-3)	All of the subtest scores = 7 or more	0	One subtest score = 5 or 6 and all of the others 7 or more	2	2+ subtest scores = 5 or 6 and the others are 7 or more or Any of the subtest scores is 4 (2-8th percentile)	4	2+ subtest scores = 4 (2 – 8th percentile) or Any of the subtest scores are 3 or less (<2nd) percentile)	8

	Test/ Rating Scale	**None**		**Mild**		**Moderate**		**Severe**	
		Score	Points	Score	Points	Score	Points	Score	Points
Visual-Spatial/visual-motor	Rey Osterreith Figure: Copy	Copy ≥ 31 Delay 1 ≥ 19 Delay 2 ≥ 13	0	Copy ≥ 31 Delay 1 ≥ 19 Delay 2 = 11-12 or Copy ≥ 31 Delay 1 = 17-18 Delay 2 ≥ 13 or Copy = 30 Delay 1 ≥ 19 Delay 2 ≥ 13	2	Copy ≥ 31 Delay 1 = 17 - 18 Delay 2 = 11 – 12 or Copy = 30 Delay 1 = 17 - 18 Delay 2 ≥ 13 or Copy = 30 Delay 1 ≥ 19 Delay 2 = 11-12 or Copy = 29 or Delay 1 = 15-16 or Delay 2 = 9 -10	4	Copy = 29 and Delay 1 = 15-16 or Delay 1 = 15 – 16 and Delay 2 = 9 – 10 or Copy <29 or Delay 1 <15 or Delay 2 <9 or	8
	Rey Osterreith Figure: Delay 1								
	Rey Osterreith Figure: Delay 2								
Motor Dexterity and Motor Control (age dependent percentile scores)[1]	Grooved Pegboard	Both are in the ≥25th percentile	0	One test score is between in the 9th-24th percentile and of the other is ≥ 25th	2	Both test scores are between the 9th – 24th percentile and all of the others are ≥ 25th or One of the scores is between the 2-8th percentile	4	Both test scores are between the 2 – 8th percentile or One of the scores is less than 70 (<2nd) percentile)	8
	Fingertapping								

	Test/ Rating Scale	None		Mild		Moderate		Severe	
		Score	Points	Score	Points	Score	Points	Score	Points
Reaction Time[279]	Simple Reaction Times Go/no go Complex reaction time	All of the subtest scores are ≥ 25th percentile	0	One test score is between the 9th-24th percentile and the others are ≥ 25th	2	2 test scores are between the 9th – 24th percentile and the other is ≥ 25th or Any of the test scores are between the 2-8th percentile	4	2 test scores are between the 2 – 8th percentile or If any of the subtest scores are less than the 2nd) percentile	8
Language	Expressive One-Word Picture Vocab'y	90+	0	80 - 89	1	70 – 79	2	<70	4

Grading for Further Conditions: Neuropsychiatric

Test	Rating Scale	None		Mild		Moderate		Severe	
		Score	Points	Score	Points	Score	Points	Score	Points
SCL-90-R	9 scale scores and 3 global indices)	All scales below 60	0	1+ scale score ≥60 Global Indices <60	2	1 scale score ≥60 1 Global Index >63	4	2+ scale scores ≥60 1 Global Index >63	8

[279] The manual contains age and sex normative data for the Reaction Time Test that is used.

Grading for Other Material: claimants whose score is equal to or greater than 6

Test	Rating Scale	None		Mild		Moderate		Severe	
		Score	Points	Score	Points	Score	Points	Score	Points
Medical Outcomes Short Form – 36 v2	Mental Component Summary Score	≥ 40	0	30 – 39	2	20 – 29	4	<20	8
	Physical Component Summary Score	≥ 40	0	30 – 39	2	20 – 29	4	<20	8
Diagnosed Conditions	Diabetes	Grading 6 – 9 points	1	Grading 10+ points	2				
	Hypertension	Grading 6 – 9 points	1	Grading 10+ points	2				

Grading for Biomarkers of Exposure

	Measure	Value	Points	Value	Points	Value	Points	Value	Points	Value	Points
Cord Blood	µg/L or ppb	<5	0	5 – 6.9	2	7 – 9.9	4	10-19.9	8	20+	16[a]
Hair or Blood	µg/g or ppm	<5-9	0	5 – 9	2	10 – 19	3	20 – 24	4	≥25	16[a]
	µg/L or ppb	<20	0	20 - 39	2	40 - 79	3	80 – 99	4	≥ 100	16[a]

a. Full compensation without examination

12.7 Summary of rationale and recommendations

Given our mandate to assign appropriate points to the Further Conditions, in conformity with the distribution of points in effect for the Known Conditions,

We recommend that:

- A core grading schedule include both the original Known Conditions and Further Conditions for neuropsychological and neuropsychiatric dysfunction, with points based on recommended validated protocols.

- For persons whose score is equal to or greater than 6 (the minimum number of points for compensation), further points be attributed if they have been diagnosed with diabetes and/or hypertension.

- For persons whose score is equal to or greater than 6 (the minimum points for compensation), further points be attributed for severity of impairment to the quality of life and limitations of activities.

- A sliding scale for point attribution for historic biomarker data that recognizes potential damage caused by moderate, high and very high exposure to mercury.

- The Known Conditions, Further Conditions and Other Material be considered in accordance with the Recommended Grading Scale for Adult.

Chapter 13 Pediatric Examination

13.1 Background

Appendix III of the Plan Document[280] only included two Known Conditions for children: mental retardation and cerebral palsy. For cerebral palsy the document provided grading guidelines for mild, moderate and severe[281]. For mental retardation, the *Neurologic Grading Guidelines for Children* referred to scores on the Stanford-Binet Intelligence Scale (1985) and the Leiter International Performance Scale with cut-off points for IQ. This appears to have been based on the Prichard and McIntyre report[282], which provided the medical rationale for the clinical examinations and recommended that children's intelligence be assessed, using these specific scales. The authors of the report indicated that *"The test battery should be administered by a trained psychologist" and that the higher IQ score would be used for scoring in the grading protocol."*

In 1999, the pediatric protocol was revised[283] to include assessment of seven Known Conditions:

- Orientation
- Cranial nerves/visual fields
- Dysarthria, strength
- Coordination
- Sensation
- Reflexes
- Mental retardation

According to Cosway[284], this new pediatric neuro-assessment protocol was adapted from the form in use at that time at the Neurology Clinic at the Winnipeg Children's Hospital. For mental retardation, the following items, assessed by the pediatric neurologist, were included:

- Developmental status (up to 6 years of age)
- Orientation to time, place and person (age 6 and up)
- Recent and remote memory (age 6 and up)
- Language (naming, repetition, spontaneous speech, reading) (age 6 and up)
- Knowledge (address, OB, phone number, current events) (age 6 and up)

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[280] Appendix III Plan Document: Known Conditions and Benefits Payable, 1986.
[281] Appendix III Plan Document: Neurological Grading Guidelines (Child), 1986.
[282] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-Exposed Indians of the Grassy Narrows and White Dog reserves: Report and Recommendations p.8.
[283] Cosway S. 2001 The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986-2001. p. 76.
[284] Cosway S. 2001. *Ibid.*

Cosway analyzed the prevalence of mental retardation among the 26 child claimants between 1986 and 2001[285]. She reported that two were diagnosed with mild mental retardation, two with moderate and four with severe mental retardation. Since three had missing information, the percentage of accepted child claimants with mild to severe mental retardation was 35%; 17% were severe. She noted that "*the most susceptible group of humans is the developing fetus and children. The degrees of the effect are dependent on the amount of the exposure and the timing of the exposure in utero"*[286] and cited the Agency for Toxic Substances & Disease Registry (1999): *"small dose exposures may result in subtle or small decreases in intelligence and may only be determined by neuropsychological testing,* and noted that *other developmental effects include behaviour, problem solving, and the ability to think and learn".*

The ANA-CHA Child and Youth Report[287] further supports the relation between prenatal mercury exposure and children's health conditions that impact school performance and children's behaviour, taking into other conditions that are known to affect these outcomes, such as alcohol consumption during pregnancy and difficulties during childbirth. The report likewise addresses the issue of intergenerational harm. For children of Grassy Narrows, having a grandfather who was a fishing guide is a determinant of having been in care of Child and Family Services, again taking into account conditions such as poverty, maternal heavy drinking and grandmother having been in a residential school. While there is growing evidence of the intergenerational trauma of residential schools on children's physical and mental health[288], the psychological consequences of the documented social disruption that occurred in these communities, following the contamination of the River System, has not been sufficiently addressed[289].

The Expert Panel met with teachers and special education counselors at the schools in the two communities. In both communities, the teachers described the difficulties that many of the children displayed: Impulsivity/executive function, high levels of learning disabilities, difficulties in attention and concentration. Neuropsychological testing, performed at the request of the schools, showed attention deficits, language disorders, phonemic difficulties, poor working memory and inability to summarize paragraphs. Teachers also mentioned that some children perform academically well and do very well on literacy tests, but manifest behavioural problems. The teachers likewise mentioned that a high proportion of children consider suicide and many have attempted suicide.

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[285] Cosway S. (2001) The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986-2001, p. 91.
[286] Cosway S, *Ibid*, p.100.
[287] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report Part 2: Children and Youth Report (December 2018).
[288] Hackett C et al. 2016. Canada's residential school system: measuring the intergenerational impact of familial attendance on health and mental health outcomes. Journal of Epidemiology and Community Health 70:1096-1105.
[289] Wheatley B and Wheatley M. 2000. Methylmercury and the health of indigenous peoples: a risk management challenge for physical and social sciences and for public health policy. Science of the Total Environment 259(1-3):23-29.

These observations are consistent with the findings of the ANA-CHA Child and Youth Report showing that proportionally more children in Grassy Narrows have diagnosed conditions that can impact school performance compared to other First Nation communities in Canada and a much higher prevalence of attempted suicide among the youth[290]. The teachers explained that one's concept of "normality" changes and told us that the children could be divided into 3 categories: severely and moderately learning disabled and 'normal'. When the "normal" children from the community go elsewhere, they qualify for the Ontario Individual Education Plan.

13.2 Current Scientific Evidence

Mercury has a lifelong impact on brain function. Neuropsychological deficits, such as learning difficulties, concentration and memory problems affect childhood development and thus impact adulthood. According to Trasande et al.[291], the loss of intelligence from methylmercury exposure in early childhood *"causes diminished economic productivity that persists over the entire lifetime."*

The developing brain is particularly vulnerable to toxic chemicals, like methyl mercury[292,293] . The rapid growth of the brain during the second trimester of fetal development is followed by neuronal migration, differentiation, proliferation, and pruning throughout early childhood[294] . Growing cells are more vulnerable to toxic chemicals[295]. The brain is composed of many different types of neurons, each type having a distinct growth phase and potentially a different toxicity profile. Methyl mercury affects proliferation and migration of neurons, as well as synaptogenesis[296]. Moreover, mercury concentrations in the developing fetus are higher than those found in the mother[297] . Mercury also disrupts dopamine in the prefrontal cortex[298]. This disruption is consistent

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[290] Asubpeeschoseewagong Netum Anishinabek Community Health Assessment Report Part 2: Children and Youth Report (December 2018).
[291] Trasande L et al. 2005. Public health and economic consequences of methyl mercury toxicity to the developing brain. Environmental Health Perspective.113:590-596.
[292] Karagas MR et al. 2012. Evidence on the human health effects of low-level methyl mercury exposure. Environmental Health Perspectives 120:799-806.
[293] Boucher O et al. 2012. Prenatal methylmercury, postnatal lead exposure and evidence of attention deficit/hyperactivity disorder among Inuit children in Arctic Quebec. Environmental Health Perspectives 120:456-1461.
[294] Rodier PM. 1995. Developing brain as a target of toxicity. Environmental Health Perspectives 103(Suppl. 6):73-76.
[295] Rice D and Barone S Jr. 2000. Critical periods of vulnerability for the developing nervous system: evidence from humans and animals. Environmental Health Perspectives 108(Suppl. 3):511-33.
[296] Rice D. et al. 2000. *Ibid.*
[297] Ramirez GB et al. 2000. The Tagum Study I: analysis and clinical correlates of mercury in maternal and cord blood, breast milk and meconium and infants' hair. Pediatrics 106:774-781.
[298] Jones DC and Miller GW. 2008. The effects of environmental neurotoxicants on the dopaminergic system: a possible role in drug addiction. Biochemical Pharmacology 76:569-81.

with the hypothesis that Attention Deficit Hyperactivity Disorder (ADHD) is due to a deficiency or imbalance of dopamine in the prefrontal cortex[299,300].

There is an extensive literature on prenatal and early childhood methylmercury exposure and children's cognitive deficits[301]. In a 2012 review, Karagas and her coworkers report consistent evidence of adverse effects of prenatal mercury exposure on cognitive abilities in preschool children[302]. The effects of prenatal exposure were less apparent for younger children – that is, the adverse impact was not yet quantifiable in children younger than three years – than older children. Studies carried out with respect to prenatal exposure among Inuit children in Canada have found decreased IQ[303], motor difficulties[304] and an increased risk of ADHD symptoms[305]. A recent study of Inuit adolescents likewise shows a significant association between mercury exposure and anxiety disorders[306].

Despite the extensive scientific literature on **neuropsychological deficits** associated with pre- and post-natal exposure to mercury, and the difficulties reported by school authorities, neuropsychological testing was never included in the children's assessment.

13.3 Recommended Assessment of Children

Consistent with the recent scientific evidence regarding the effects of mercury exposure on children's neurodevelopment, the recommended revision of the battery of measures expands beyond traditional neurologic indices to include a broad range of neuropsychological abilities.

The proposed neuropsychological battery (Table 18), which will involve approximately 2 hours of testing with a child, is composed of tests that are widely used in both clinical

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[299] Swanson JM et al. 2007. Etiologic subtypes of attention-deficit/hyperactivity disorder: brain imaging, molecular genetic and environmental factors and the dopamine hypothesis. Neuropsychology Review 17:39-59.
[300] Sagiv SK et al. 2012. Prenatal exposure to mercury and fish consumption during pregnancy and attention-deficit/hyperactivity disorder-related behavior in children. Archives of Pediatric and Adolescence Medicine 166:1123-1231.
[301] Castoldi AF et al. 2008. Human developmental neurotoxicity of methylmercury: Impact of variables and risk modifiers. Regulatory Toxicology and Pharmacology 51:201-214.
[302] Karagas MR et al. 2012. Evidence on the human health effects of low-level methyl mercury exposure. Environmental Health Perspectives 120:799-806.
[303] Jacobson JL et al. 2015. Relation of Prenatal Methylmercury Exposure from Environmental Sources to Childhood IQ. Environmental Health Perspectives. 123:827-833.
[304] Boucher O et al. 2016. Altered fine motor function at school age in Inuit children exposed to PCBs, methylmercury, and lead. Environment International 95:144-151.
[305] Boucher O et al. 2012. Prenatal methylmercury, postnatal lead exposure and evidence of attention deficit/hyperactivity disorder among Inuit children in Arctic Quebec. Environmental Health Perspectives 120:456-1461.
[306] Lamoureux-Tremblay et al. 2020. Risk factors associated with developing anxiety in Inuit adolescents from Nunavik. Neurotoxicology and Teratology 81:106903.

work and research because of their demonstrated validity and reliability. It includes an age-appropriate test of general cognitive ability, which yields an overall score, the Full-Scale IQ. It also includes tests that assess specific domains of neuropsychological functioning. The domains assessed include memory, executive function, visual-spatial/visual-motor skills, manual dexterity and language. All tests in the battery yield standard scores that are based on sound normative data for children, permitting the identification of children performing below the expected level.

Table 18. Recommended neuropsychological test battery for children

Domain	Test	Sub-domains	Time (min)
General cognitive ability	Wechsler Preschool and Primary Scale of Intelligence-4th edition (WPPSI-4) (ages 2.5-7 years) or Wechsler Intelligence Scale for Children-5th Edition (WISC-V) (ages 7-16 years)	core subtests	65
Memory	Wide Range Assessment of Memory and Learning-2nd edition (WRAML-2)	Story, Design, Verbal Learning and Picture Memory	25
Visual-Spatial/visual-motor	Beery-Buktenica Developmental Test of Visual-Motor Integration-6th edition		15
Manual Dexterity	Grooved Pegboard	dominant and nondominant hands	5
Language	Expressive One-Word Picture Vocabulary Test-4th edition	Naming of full-colour pictures	15
Total time			110

For behavioural assessment we recommend two validated questionnaires that a parent or a teacher (when appropriate) fills out.

- **Behavior Assessment for Children-3rd edition (BASC-3):** For children and youth 2-18 years of age, this test assesses behaviour using a comprehensive questionnaire that a parent and a teacher completes. This instrument yields standard scores on 9 behaviour problem subscales (Hyperactivity, Aggression, Conduct Problems, Anxiety, Depression, Somatization, Atypicality, Withdrawal, Attention Problems) and 3 composite scales (Externalizing Problems, Internalizing Problems, Behavioral Symptom Index). It also includes 6 subscales that assess adaptive functioning (Adaptability, Social Skills, Leadership, Activities of Daily Living and Functional Communication) that yield a composite score (Adaptive). For the behaviour problem subscales, a higher score indicates greater problems. For the adaptive subscales, a lower score indicates greater problems.

- **Behavior Inventory Rating of Executive Functioning-2nd edition (BRIEF-2):** For children 2.5 years to 18 years of age, this questionnaire, completed by a parent and a teacher assesses executive functioning. It has 9 subscales (Inhibit, Self-Monitor, Shift, Emotional Control, Initiate, Working Memory, Plan/Organize, Task Monitor, Organization of Materials) and 4 composite scales (Behavioral Regulation Index, Emotion Regulation Index, Cognitive Regulation Index, General Executive Composite). For all subscales and composite scales, a higher score indicates greater problems.

Finally, in the current pediatric examination, the medical history and past medical history are currently carried out by the pediatric neurologist. Depending upon the examining neurologist, this can be anywhere from cursory to in depth. A nurse practitioner practitioner would be able to take more time to listen to the parents and/or child about pregnancy, children's medical, neurodevelopmental and behavioural history and symptoms, and to carry out the general examination.

13.4 Summary of Rationale and Recommendations

Given that the neurologic pediatric protocol was modified in 1999 to improve and better quantify the examination;

Given the absence of neuropsychological and behavioral assessment in the current examination, despite the wealth of knowledge on the harmful effects of prenatal and early childhood mercury exposure on children's neurodevelopment and behaviour;

Given the importance of allotting adequate time for the medical history of pregnancy and childhood, the general examination, the parent or care-givers and child's impressions of development and behaviour,

We recommend that:

- The current revised pediatric neurologic examination be maintained for the examination of cranial nerves, strength, tone, involuntary movements, reflexes, motor coordination and sensation.

- The current assessment of developmental status, orientation to time, recent and remote memory, language and knowledge be replaced by a neuropsychological test battery composed of tests widely used in both clinical and research settings.

- Neuropsychological deficits, including the following domains: General Cognitive Ability, Memory, Visual-Spatial/Visual-Motor functions, Manual Dexterity and Language, be included as Further Conditions.

- Behaviours be included as Further Conditions and assessed using validated rating scales for behavioural problems, adaptive functioning and executive functioning.

- The neuropsychological and behavioural tests be administered and interpreted by a pediatric neuropsychologist.

- The general examination, developmental and behavioural history, currently part of the prescribed examination, be performed by a pediatric nurse practitioner.

Chapter 14 Grading for Pediatric Examination

14.1 Background

The current neurological examination provides a grading scale for abnormalities: mild (1), moderate (2), and severe (3) for all components, including those referring to neurodevelopment (developmental status, orientation to time, place and person, recent and remote memory, language and knowledge). Appendix III of the Plan Document includes the administration of a neuropsychological test battery for the assessment of mental retardation, however, this was never carried out in the MDB child examinations. Since that time, the field of pediatric neuropsychology has greatly evolved and there is an extensive scientific literature on neurodevelopmental effects of *in utero* and early childhood exposure to methylmercury.

14.2 Known and Further Conditions

The current pediatric neurologic examination includes a rating scale that should be maintained. The use of 4 as non-applicable in the assessment may be confusing and we suggest that it be replaced by N/A. The current grading should be used for cranial nerves, strength, tone, involuntary movements, contractures, reflexes, fine and gross coordination, Romberg, walking and running gait and sensation.

In addition, the results of the neuropsychological and behavioural test batteries should replace “developmental status”, “orientation”, “memory”, “language” and “knowledge”, currently part of the neurological examination. The recommended battery includes tests to measure a wide array of functions. There are standardized normative data for each test or group of tests (subtests). The degree of impairment is calculated based on the percentile of a child’s score with respect to an instrument’s normative data. In attributing impairment points, we considered whether the test scores were derived from one test or several tests:

- For combined test scores with a standardized norm of 100 and a standard deviation of 15 (the 4 WISC-V composite scores, the Beery-Buktenica Developmental Test of Visual-Motor Integration, and the Expressive One Word Picture Vocabulary Test):
    - 90+ is considered normal, with an impairment score of 0 (≥25th percentile)
    - 80-89 is considered mild, with an impairment score of 1 (9th-24th percentile)
    - 70-79 is considered moderate, with an impairment score of 2 (2nd to 8th percentile

  - 70 is considered severe, with an impairment score of 4 (<2nd percentile)

- The standard scores from the 4 subtests of the WRAML-2 should be averaged and points assigned as follows:

  - 7+ is considered normal, with an impairment score of 0
  - 5-6 is considered mild, with an impairment score of 1
  - 4 is considered moderate, with an impairment score of 2
  - 3 or less is considered severe, with an impairment score of 4

- For the Grooved Pegboard, age-norms should be used to classify children's time to complete as follows:
  - Time to complete >25th percentile, an impairment score of 0
  - Time to complete 9th-24th percentile, an impairment score of 1
  - Time to complete 2nd-8th percentile, an impairment score of 2
  - Time to complete <2nd percentile, an impairment score of 4

- For the behaviour problem subscales and composite scales of the BASC-3, scores of 60-70 are considered "at risk," and scores greater than 70 are considered "clinically significant"; points should be assigned as follows:
  - All scale scores less than 60: none=0
  - 1 or more subscale scores greater than 60 but all composite scales less than 60: mild=2
  - 1 or more subscale scores greater than 60 and 1 composite score greater than 60: moderate=4
  - 2 or more subscale scores greater than 60 and 2 or more composite scores greater than 60: severe=8

- For the adaptive functioning subscales and composite scales of the BASC-3, scores less than 40 are considered "at risk" and scores less than 30 are considered "clinically significant"; points should be assigned as follows:

  - All scale scores greater than 40: none=0
  - 1 or more subscale scores less than 40 but the composite scale score is greater than 40: mild=2
  - 1 or more subscale scores less than 40 the composite scale is less than 40: moderate=4
  - 2 or more subscale scores less than 40 and the composite scale score is less than 60: severe=8

- For all subscales and composite scales of the BRIEF2, scores of 65 or greater are considered to be "clinically elevated"; points should be assigned as follows:

  - All scale scores less than 65: none=0

- 1 or more subscale scores greater than 65 but all composite scales less than 65: mild=2
- 1 or more subscale scores greater than 65 and 1 composite score greater than 65: moderate=4
- 2 or more subscale scores greater than 65 and 2 or more composite scores greater than 65: severe=8

Figure 14 shows the flow chart for pediatric grading and Table 19 includes the distribution of points for the grading.

Figure 14. Flow Chart for the Pediatric Grading System

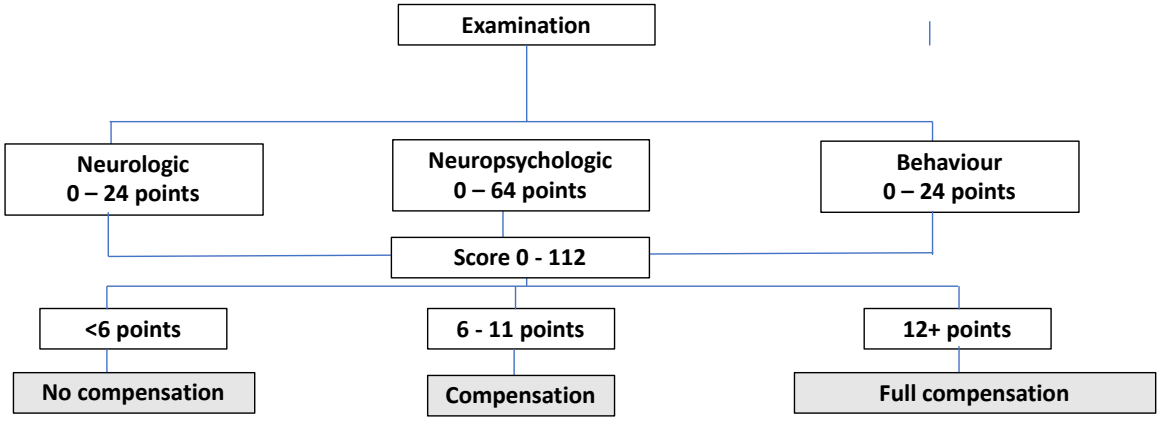


Table 19. Pediatric Grading – Distribution of Points

Grading for Pediatric Neurologic Examination

	None		Mild		Moderate		Severe	
	Rating	Points	Rating	Points	Rating	Points	Rating	Points
Cranial Nerves/Visual Field	0	0	1	1	2	2	4	4
Dysarthria (Speech)	0	0	1	1	2	2	4	4
Strength	0	0	1	1	2	2	4	4
Coordination	0	0	1	1	2	2	4	4
Sensation	0	0	1	1	2	2	4	4
Reflexes	0	0	1	1	2	2	4	4

Grading for Pediatric Neuropsychological Examination

			Score	Points	Score	Points	Score	Points	Score	Points
		Percentile	≥25th		9th – 24th		2nd – 8th		<2nd	
Domain	Test	Subtest								
General cognitive ability	Wechsler Preschool and Primary Scale of Intelligence-4th edition (WPPSI-4) (ages 2.5-7 years)	Verbal comprehension	90+	0	80 - 89	1	70 - 79	2	<70	4
		Visual Spatial	90+	0	80 - 89	1	70 - 79	2	<70	4
		Working Memory	90+	0	80 - 89	1	70 - 79	2	<70	4
	Wechsler Intelligence Scale for Children-5th Edition (WISC-V) (ages 7-16 years)	Verbal Comprehension	90+	0	80 - 89	1	70 - 79	2	<70	4
		Visual Spatial	90+	0	80 - 89	1	70 - 79	2	<70	4
		Fluid Reasoning	90+	0	80 - 89	1	70 - 79	2	<70	4
		Working Memory	90+	0	80 - 89	1	70 - 79	2	<70	4
		Processing Speed	90+	0	80 - 89	1	70 - 79	2	<70	4
Visual-Spatial/visual-motor	Beery-Buktenica Developmental Test of Visual-Motor Integration-6th edition		90+	0	80 - 89	1	70 - 79	2	<70	4
Language	Expressive One-Word Picture Vocabulary Test-4th edition		90+	0	80 - 89	1	70 - 79	2	<70	4
Manual Dexterity	Grooved Pegboard		90+	0	80 - 89	1	70 - 79	2	<70	4
			90+	0	80 - 89	1	70 - 79	2	<70	4
Memory	Wide Range Assessment of Memory and Learning-2nd edition (WRAML-2)	Story	+7	0	5 - 6	1	4	2	≤ 3	4
		Design	+7	0	5 - 6	1	4	2	≤ 3	4
		Verbal Learning	+7	0	5 - 6	1	4	2	≤ 3	4
		Picture Memory	+7	0	5 - 6	1	4	2	≤ 3	4

Grading for Behaviour Functions

			Score	Points	Score	Points	Score	Points	Score	Points
Behaviour	BASC-3	Behaviour Problems	All scales < 60	0	1 or more subscale scores > 60 but all composite scales < 60	2	1 or more subscale scores > 60 and 1 composite score > 60	4	2 or more subscale scores > 60 and 2 or more composite scores > 60	8
		Adaptive Functioning	All scales < 40	0	1 or more subscale scores < 40 but all composite scales < 40	2	1 or more subscale scores < 40 and 1 composite score > 40	4	2 or more subscale scores < 40 and 2 or more composite scores > 40	8
Executive Functioning	BRIEF-2		All scales < 65	0	1 or more subscale scores > 65 but all composite scales < 65	2	1 or more subscale scores > 65 and 1 composite score > 65	4	2 or more subscale scores > 65 and 2 or more composite scores > 65	8

14.3 Summary of rationale and recommendations

Given that the pediatric neurologic examination was revised in 1999 and contains a grading protocol for its components;

Given that the assessment of neurodevelopment and behaviour does not use validated, standardized test batteries,

We recommend that

- The current grading system for Cranial nerves/Visual Fields, Dysarthria, Strength, Coordination, Sensation and Reflexes, be maintained.

- Points be attributed with respect to the scores obtained on the pediatric neuropsychological test battery with respect to severity of impairment.

- Points be attributed in relation to the scores obtained on the validated behaviour questionnaires.

- The physicians on the MDB consider all of the above, as well as the qualitative report from the nurse practitioner.

Conclusions, Action-Targets and Overarching Considerations

In the time since the MDB was established, scientific understanding about the human health impacts of mercury exposure has grown considerably. In the past thirty years, and particularly so in Canada's Post Truth and Reconciliation Commission era, Canada has committed to a reconciliatory relationship with Indigenous people and communities. The mandate of the Expert Panel was to update the examinations and processes of the MDB within the context of current knowledge and best practices.

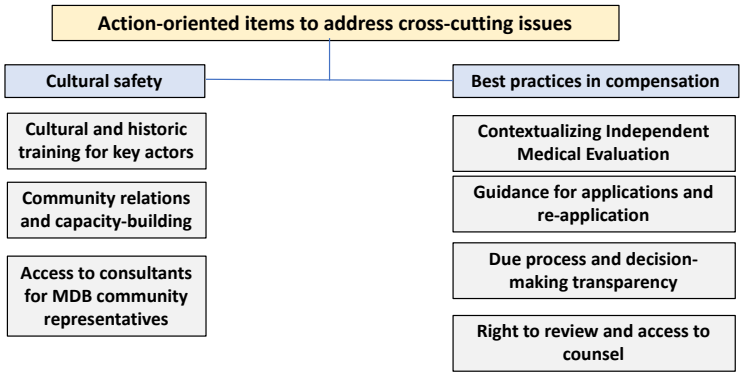
What has been overwhelmingly clear to the Expert Panel, from evidence drawn from all sources, including persons we consulted, is that changes to the MDB examination and processes are long overdue. As such, our recommendations seek to provide the communities with a culturally safe and juridically sound environment in which to make claims to the MDB. The role and responsibilities of the Independent Medical Evaluators should be understood by all, be they claimants, evaluators or Board members. Each professional recruited by the MDB should be aware of the history and culture of these communities, as well as the possible consequences of mercury poisoning.

Scientific evidence has grown exponentially over the last 35 years. Especially in the context of these communities, wherein the health, social and cultural impacts of mercury contamination have been so broadly felt, it appears insufficient for clinical examinations to be limited to a brief neurologic assessment. In addition to a neurologist, the updated examination requires a nurse practitioner to provide the claimants with a safe space to recount their medical history, perform the general examination and administer the questionnaire on the claimant's individual functional impairment functional Adequate assessment of damage to the nervous system requires a neuropsychologist and/or a psychologist to supervise test administration and interpret the results. The visual examinations require an optometrist, familiar with the possible effects of neurocognitive deficits on visual testing.

The updated examination will require more work on the part of the MDB physicians, who will receive input from all of the examining professionals for the decision-tree grading system.

Each chapter of the present report focused on one element of the Expert Panel's update of the MDB's processes presented in the multi-tiered framework. The following expanded framework summarizes the action targets for each of the components of the framework, beginning with the cross-cutting issues of cultural safety and best practices in compensation.

Figure 15. Cross-cutting Items



In the charts below, the different components of the adult and child clinical examination are presented along with the professionals required for the examinations and/or supervision. All of the information derived from these examinations is assessed by the MDB physicians using a decision-tree grading system.

Figure 16. Synthesis of the Recommendations for Adult Examination and Grading

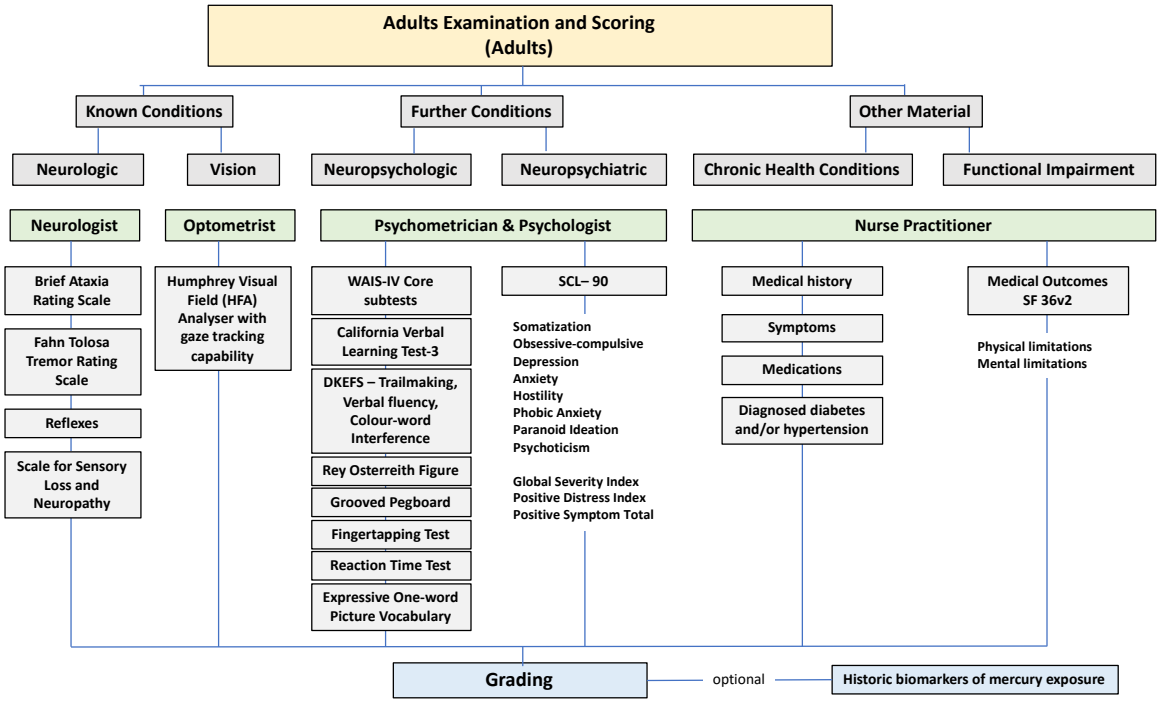
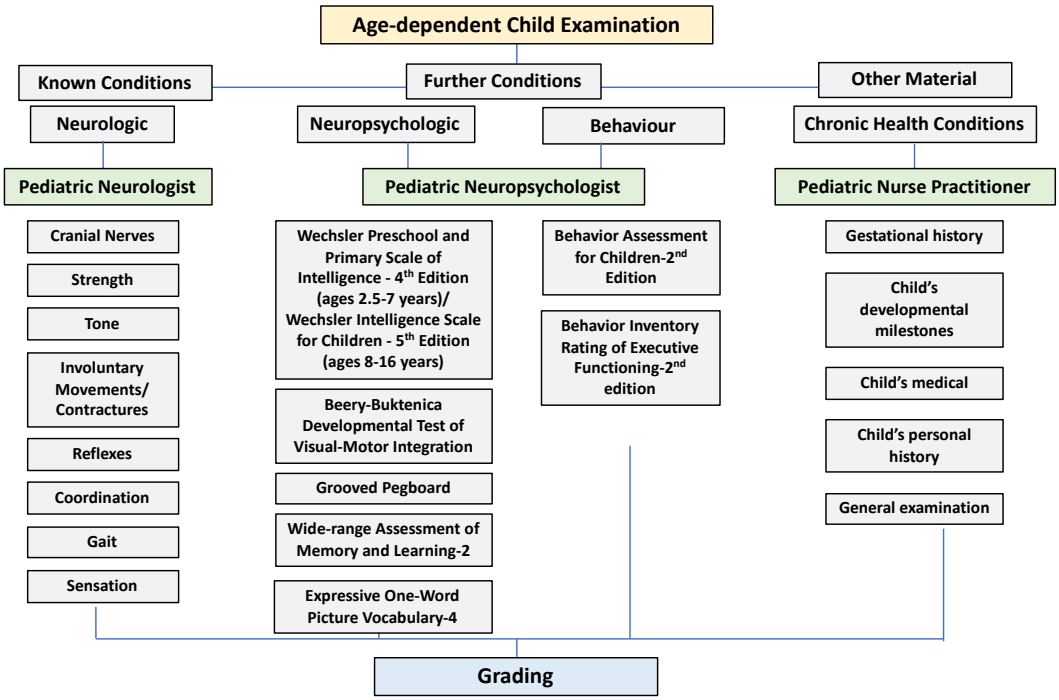


Figure 17. Synthesis of the Recommendations for Child Examination and Grading



Overarching considerations

During the review, the Expert Panel was faced with some of the short-comings of the MDB processes and examinations, that were formulated over a 1986 settlement between several parties, including those responsible for the disaster. This was not an accidental spill, but a continuous release of mercury over a period of 13 years into the English-Wabigoon River System, which provided not only employment and nourishment for Grassy Narrows and Wabaseemoong, but constituted a central aspect of their culture and traditions. Many of initial premises about health and remediation have been shown to be false, with the most important, for the MDB, being the *"honest belief that delayed effects of organic mercury ingestion will not appear as late as ten years after cessation of mercury-contaminated fish ingestion"* [307] and that natural recovery would suffice to remove the mercury from the River System since remediation was too costly[308]. The 2017 report of the Environmental Commissioner of Ontario[309] states:

> *"For almost 60 years, mercury contamination has severely damaged the Wabigoon-English River ecosystem. This contamination has stripped the people of Wabaseemoong and Grassy Narrows of important facets of their cultural*

[307] Prichard JS and McIntyre LL. 1980. Neurologic Findings in Mercury-exposed Indians of the Grassy Narrows and White Dog Reserves: Report and Recommendations, p.5
[308] Saxe D. 2017. Good Choices, Bad Choices. Environmental Rights and Environmental Protection in Ontario. Environmental Protection Report, Ontario. pp. 289.
[309] Saxe D. 2017. *ibid*

> *practices, livelihoods and health. The company that profited from the pollution sold the property, settled legal claims, and moved on 30 years ago. The government long ago abandoned the communities to bear the consequences, and has only very recently begun to take the first steps towards remediating the river system, as well as the government's relationship with the affected communities."*

From the perspective of the communities' health and wellbeing and right to compensation, The Expert Panel puts forward the need to regularly evaluate the examination process. A growing number of scientific studies, show the importance of *in utero* exposure on later-life development and health, even at very low concentrations, and most of the claimants today and over the next years were exposed in utero, as infants or as young as children.

Keeping in mind that scientific knowledge and awareness of the short and long-term effects of *in utero*, child and adult exposure to mercury is constantly and rapidly evolving,

- We urge the parties to establish a regular review and revision schedule of the MDB process and further conditions if and when new scientific data is available, with a maximum of every 5 years.

- We deem appropriate that current claimants be informed of the modification and update in the examination process and that they be invited to re-apply, if they so wish.

The Expert Panel acknowledges the magnitude of the work carried out by the late Sylvia Cosway[310], which provided crucial background on the MDB. The Expert Panel strongly supports Cosway's suggestion to carry out statistical analysis of data from the MDB examinations[311], which could provide, at the same time, valuable information on the understanding of the health of people in these communities, and serve to optimize the examination strategy and possibly reduce time and cost.

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[310] Cosway S. 2001. The Grassy Narrows and Islington Band Mercury Disability Board: A Historical Report 1986 – 2001 (3 volumes) prepared for the Grassy Narrows and Islington Band Mercury Disability Board, October. pp. 249.
[311] Cosway S. 2001. *Ibid* p. 167.

- We urge the parties to regularly conduct a scientifically sound analysis of the results of the examinations.

In the spirit of the report Royal Commission on Health Services, tabled by Justice Emmett Hall in 1964[312], and in keeping with Health Canada's current commitment to ensures access to high-quality health services,

And, considering that the information, collected during the examination process, can be useful for further treatment, referrals and follow-up,

- We believe that the examination results should be transferred to the primary care provider, subject to the written consent of the claimant, compensated or not.

The analysis of accepted claims with respect to premature mortality, presented in Chapter 3, coupled to the recent evidence of premature mortality associated with long-term exposure to mercury in Grassy Narrows First Nation[313], raises the issue of survivor benefits. Many of the recipients have families that depend on their income. Workers' compensation systems throughout Canada provide for survivor benefits when a worker dies because of an occupational disease or when death is attributable to a workplace accident[314]. The same is true for no-fault compensation for automobile accidents which exists in several Canadian provinces[315]. Beyond survivor benefits, some regimes such as the Québec workers' compensation, also ensure that if a compensated injured worker dies of causes unrelated to the work injury, a worker's dependent continues to receive the worker's income replacement for a period of three months to allow them to adapt to the loss of income from the worker's pension[316]. By analogy, survivors of an MDB pension recipient should have access to interim support equal to the recipient's pension, and then to survivors benefits that could be modelled on workers' compensation legislation. It is unclear why survivors of MDB pension recipients should have no rights as compared to survivors of workers injured or made ill at work, given that these regimes already provided for survivors benefits back in 1986, date of the enactment of the English and Wabigoon River Systems Mercury Contamination Settlement Agreement Act.

- We encourage the parties to consider including a provision for compensation to families of claimants who were receiving benefits at the time of their death.

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[312] Ford AB. 1964 Royal Commission on Health Services, Vol I. JAMA. *190*:1138.
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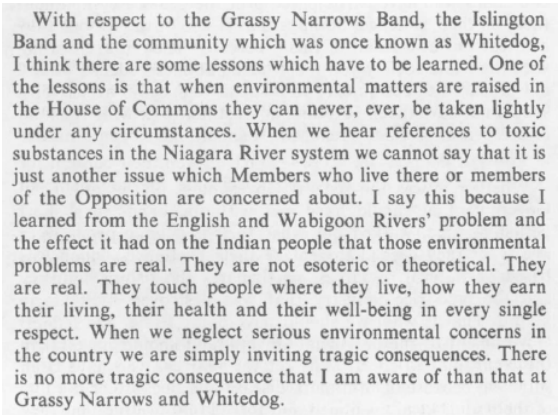
While we often associate health and wellbeing solely with the health system, there are many consequences of *'signs and symptoms consistent with mercury poisoning'* on other facets of life, notably the school and welfare systems. During the Expert Panel's visits to the communities, we learned of the difficulties faced by the schools.

- We urge the parties to ensure that 'benefits' go beyond the financial aspects and to adopt holistic approach that includes adequate schooling approaches and therapeutic measures.

Finally, the Expert Panel recognizes that implementing our recommendations will entail human and financial resources;

- We advise the parties to ensure adequate funding for MDB staffing, recruitement and hiring of the appropriate professionals required to carry out the updated examination, as well the work of the MDB physicians in reviewing and scoring the examination results.

It is the sincere hope of the members of the Expert Panel that these recommendations will be implemented with minimal delay.



With respect to the Grassy Narrows Band, the Islington Band and the community which was once known as Whitedog, I think there are some lessons which have to be learned. One of the lessons is that when environmental matters are raised in the House of Commons they can never, ever, be taken lightly under any circumstances. When we hear references to toxic substances in the Niagara River system we cannot say that it is just another issue which Members who live there or members of the Opposition are concerned about. I say this because I learned from the English and Wabigoon Rivers' problem and the effect it had on the Indian people that those environmental problems are real. They are not esoteric or theoretical. They are real. They touch people where they live, how they earn their living, their health and their well-being in every single respect. When we neglect serious environmental concerns in the country we are simply inviting tragic consequences. There is no more tragic consequence that I am aware of than that at Grassy Narrows and Whitedog.

Keith Penner, Liberal MP from Cochrane-Superior, House of Commons May 21, 1986.

"It's been very slow, it's been 50 years, and we keep protesting, and we keep asking and to try to improve things but it just doesn't really get anywhere,"

Grassy Narrows Chief Rudy Turtle in an interview with APTN, April 3, 2019

Appendices

Appendix 1 Panel members

Donna Mergler PhD, Panel Chair

Professor Emerita, *Centre de recherche interdisciplinaire sur le bien-être, la santé, la société et l'environnement, Université du Québec à Montréal*

Expertise: Research on neurotoxic effects of occupational and environmental pollutants (methylmercury exposure) and scientific consultant on the Grassy Narrows Community Health Assessment

David Bellinger PhD, Panel Member

Professor, Department of Neurology and Psychology Harvard Medical School, with a secondary appoint in the Department of Environmental Health at the Harvard School of Public Health

Expertise: Research and clinical practice on the impacts of chemical (methylmercury) and metabolic insults in children and adults.

Jane Hightower MD, Panel Member

Physician Internist in private practice in San Francisco, California

Expertise: Clinical practice includes patients with mercury poisoning and author of the book, *Diagnosis: Mercury*: *money politics and poison. Island Press 2009*

Bruce Lanphear MD, MPH, Panel Member

Professor, Faculty of Health Sciences, Simon Fraser University

Expertise: Research on fetal and early childhood exposures to prevalent environmental neurotoxins including mercury

Katherine Lippel LLM, Panel Member

Professor and Canada Research Chair Occupational Health and Safety Law, University of Ottawa

Expertise: Legal issues relating to occupational health and safety and workers' compensation

Brad Racette MD, Panel Member

Neurologist and Professor and Vice Chairman of Neurology, Robert Allan Finke Professor of Neurology, Washington University School of Medicine in St, Louis, Missouri

Expertise: Research and clinical practice on adult neurologic disorders associated with exposure to toxic substances.

Chantelle Richmond PhD, Panel Member

Anishinabe scholar and Canada Research Chair in Indigenous Health and the Environment. Professor at the University of Western Ontario, with cross-appointments in the department of Geography, First Nations Studies and the Department of Family Medicine

Expertise: Community-based health research with Indigenous communities

Appendix 2 List of Recommendations

Number	Recommendation
Cultural Safety	
1	Every individual involved in any capacity with the MDB and/or mandated to interact with the actual or potential claimants, receive specific training on ANA and WIN culture, history and experiences with mercury.
2	The professionals, recruited by the MDB to carry out the examinations, be required to complete a program on Indigenous Cultural Safety.
3	The MDB enhance their outreach strategies, including appropriate communication tools, website architecture and content, integration of cultural rituals in opening and closing of meetings, and co-learning through face-to-face activities.
4	The hiring of a Community Support Worker for each community, with a contractual relation with the MDB, to ensure that claimants meaningfully participate in, and benefit from, the mandate of the MDB.
5	Community members on the MDB be provided with the financial support to hire consultants when they consider it necessary.
Best Practices in Compensation	
6	The MDB recruit culturally sensitive, authorized specialists from any jurisdiction in Canada or the United States of America.
7	The Community Support Workers (see recommendation 4) inform and assist potential and current claimants through the process, from eligibility to application, to decision-making interpretation, re-application and review, as needed.
8	Acceptance and denial letters include detailed justifications of the decisions.
9	Claimants have access to their files including, but not limited to, the evidence provided by the specialists who undertake the evaluation at the behest of MDB.
10	All claimants should be invited to attend the meeting when their claim is on the agenda.
11	Claimants whose initial applications or reapplications are denied, or who receive, by the decision, a lower level of benefits than they expected, be informed of their right to review.
12	All claimants should be informed of the reapplication process when they receive their decision.
13	When requested, financial support should be provided to cover fees of counsel and/or access to a second medical opinion, for claimants seeking review.
Adult Clinical Examination	
14	The clinical examination for Known Conditions be updated to current best practices.
15	The examination be expanded to include documented Further Conditions.
16	Relevant elements, not included in Known or Further Conditions, be included in Other Material prescribed by the MDB.

Number	Recommendation
17	The general examination be eliminated from the neurologist's examination.
18	A medical history, including current symptoms, and a general examination be performed by an authorized, specially trained nurse practitioner, and the report be included in Other Material to be submitted with the application.
19	If the claimant so wishes, information from previous clinical neurological and/or psychological examinations, carried out by referral to specialists or as part of a clinical research project, be provided to the nurse practitioner and included in Other Material.
Neurologic Examination	
20	Specific rating protocols be adopted for tremor and ataxia (encompassing incoordination and dysarthria) and sensory loss.
21	Vision loss be removed from the neurologic examination and assessed by an optometrist, within the context of the visual field examination.
22	All claimants undergo a visual field examination.
23	The visual field examination be performed using a Humphrey Visual Field Analyser (HFA) with gaze tracking capability, with the 30-2 Swedish Interactive Thresholding Algorithm (SITA).
24	The scoring procedure to assess visual field constriction be adapted to possible neurocognitive deficits.
Neuropsychological Assessment	
25	Neuropsychological deficits be included as Further Conditions.
26	All claimants undergo an examination of neurocognitive status, using validated neuropsychological tools for the following domains: Cognitive ability, memory, Executive functioning, Visuo-spatial/Visual-motor ability, Manual dexterity, Attention/Vigilance and Language.
27	The neuropsychological test battery be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist trained in the administration and interpretation of neuropsychological tests.
28	The results of a first cohort of 60 consenting persons, be analyzed to identify domains with the greatest and least deficits, with a view to refining the battery and reducing the time required to administer the tests.
Neuropsychiatric Assessment	
29	Neuropsychiatric disorders be included as Further Conditions.
30	All claimants be screened for neuropsychiatric symptoms, using the SCL-90-R, which includes 3 Global Scores and the following dimensions: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticism.
31	The neuropsychiatric questionnaire be administered by a psychometrician and reviewed by a neuropsychologist or a psychologist.

Number	Recommendation
Non-neurologic Chronic Health Conditions	
32	Diagnosed diabetes and hypertension, verified by the nurse practitioner, be included within Other Material that the claimant can provide to the MDB and included, when appropriate, in the final scoring.
Quality of life/Activity Limitations	
33	A questionnaire with good psychometric properties, Canadian normative data and validated with a First Nation population (Medical Outcomes SF-36v2), serve to assess a claimant's quality of life and limitations of activities.
34	The questionnaire be administered by the nurse practitioner and the results be included in Other Material.
Biomarkers of Exposure	
35	If the claimant so wishes, biomarkers of past mercury exposure be included in the Other Material submitted to the MDB.
36	High exposures be presumptive of mercury poisoning, but low values not be disqualifying.
Adult Grading System	
37	A core grading schedule include both the original Known Conditions and Further Conditions for neuropsychological and neuropsychiatric dysfunction, with points based on recommended validated protocols.
38	For persons whose score is equal to or greater than 6 (the minimum number of points for compensation), further points be attributed if they have been diagnosed with diabetes and/or hypertension.
39	For persons whose score is equal to or greater than 6 (the minimum points for compensation), further points be attributed for severity of impairment to the quality of life and limitations of activities.
40	A sliding scale be used for point attribution for historic biomarker data that recognizes potential damage caused by moderate, high and very high exposure to mercury.
41	The Known Conditions, Further Conditions and Other Material be considered in accordance with the Recommended Grading Scale for Adults.
Pediatric Examination	
42	The current revised pediatric neurologic examination be maintained for the examination of cranial nerves, strength, tone, involuntary movements, reflexes, motor coordination and sensation.
43	The current assessment of developmental status, orientation to time, recent and remote memory, language and knowledge be replaced by a neuropsychological test battery composed of tests widely used in both clinical and research settings.

Number	Recommendation
44	Neuropsychological deficits, including the following domains: General Cognitive Ability, Memory, Visual-Spatial/Visual-Motor functions, Manual Dexterity and Language, be included as Further Conditions.
45	Behaviours be included as Further Conditions and assessed using validated rating scales for behavioural problems, adaptive functioning and executive functioning.
46	The neuropsychological and behavioural test be administered and interpreted by a pediatric neuropsychologist.
47	A pediatric nurse practitioner perform the general examination and record medical, developmental and behavioural history.
Pediatric Grading System	
48	The current grading system for Cranial nerves/Visual Fields, Dysarthria, Strength, Coordination, Sensation and Reflexes, be maintained.
49	Points be attributed to the scores obtained on the pediatric neuropsychological test battery with respect to severity of impairment
50	Points be attributed in relation to the scores obtained on the validated behaviour questions.
51	The physicians on the MDB consider all of the above, as well as the qualitative report from the nurse practitioner.
Overarching considerations	
	We urge the parties to establish a regular revision schedule of the MDB process and Further Conditions if and when new scientific data is available, with a maximum of every 5 years.
	We deem appropriate that current claimants be informed of the modification and update in the examination process and that they be invited to re-apply if they so wish.
	We urge the parties to regularly conduct a scientifically sound analysis of the results of the examinations.
	We believe that the examination results should be transferred to the primary care provider or a specialist designated by the claimant, subject to his/her written permission, compensated or not.
	We encourage the parties to consider including a provision for compensation to families of claimants who were receiving benefits at the time of their death.
	We urge the parties to ensure that 'benefits' go beyond the financial aspects and adopt a more holistic approach that includes adequate support for schooling and therapeutic measures.
	We advise the parties to ensure that the MDB staffing, funding and project allocation be adequate to this purpose.

Appendix 3 Meeting notes from community visits

1. **Community visits concerning adults (April 10-12, 2019)**

2. **Community visits concerning children (May 1-2, 2019)**

Purpose
To learn about the reality of the claims process from the point of view of the community members.

Meeting with communities
In both communities, we heard dissatisfaction and lack of confidence with the process and the medical examination. The participants were knowledgeable and asked very good questions.

Pre-meeting planning
ANA and WIN representatives, Lara Koerner-Yeo and Nick Hobbs, for logistics and community contacts.

Chantelle Richmond was the panel member responsible for the organization. She provided instructions to panel members, including a day-to day breakdown and a reminder on interacting with indigenous people. Hand-outs presenting the panel members were sent to the organizers.

The information supplied to the communities prior to the meeting included a list of the panel members and the objectives of the meetings:

- The panel members seek to ensure that the recommendations that they make are relevant to the communities and address the communities' issues and experiences with the MDB.

- To support the Panel members in providing recommendations for an updated MDB process, we will visit Wabaseemoong Grassy Narrows to hear directly from those in the community.

- We greatly appreciate your direction in making this visit the most productive it can be.

Key people the Panel would like to meet during the day:

- Adults who have been accepted for MDB disability payments and their families;

- Adults who have not been accepted for MDB disability payments and their families;
- Health Care providers;
- Others who want to be heard

1. Community visits concerning adults

Date: April 10-11, 2019
Place: Wabaseemoong and Grassy Narrows
Type: Participation in community-organized events
Panel participants: Donna Mergler, Chantelle Richmond, David Bellinger, Brad Racette, Jane Hightower

Day 1: WIN: community organizers: Georgina McDonald and Gloria Paishk

The meeting was opened and closed by an elder and drummers. The format was a general meeting in the morning, with small focus groups around different issues in the afternoon.

The general meeting began with a description of the panel's mandate and then was open for discussion. The major points brought by community members were:

- Hopelessness with the process and explaining;
- Delays associated with claim submission and decision;
- Many doctors in Kenora do not believe that mercury is affecting their health;
- The rating system is erratic;
- Lack of support for the process;
- The entire lifestyle and health of the community is disturbed by the history of mercury exposure; everyone should be compensated;
- Non-compensated health conditions that community members felt may be related to mercury: severe eczema, heart condition, auto-immune hepatitis, hypothyroidism;
- A large number of children with developmental and learning difficulties; inadequate help for school children;
- Problems of transparency; the "turn down" letter should be detailed, including the point system, right to review and when to re-apply;

- We are sick by the time we reach 38-40 years old;
- Difficulty in recruiting teachers;
- Favoritism by the MDB;
- Feels human rights denied;
- Too wide a range of compensation and too low.

Focus group tables were organized with panel members.

Day 2: ANA: community organizers: Judy Da Silva, Michael Fobister and Bridgette Fobister

The meeting was opened by a drum ceremony. The format was a general meeting in the morning, with private individual encounters with the panel members in the afternoon.

The general meeting began with a description of the panel's mandate and then was open for discussion. Several members told of their personal experiences, others discussed the overall process. The major points brought by community members were:

- Lack of community information and awareness;
- Recommend a formal community health committee to support claimants and be a voice to the MDB;
- Delays in the appointment schedule;
- Testimony of mental health problems, headaches, anxiety, depression, grief in adolescents;
- Questions about premature aging and non-compensated health conditions that community members felt may be related to mercury: eczema, allergies, gastrointestinal, hypertension and heart related diseases, diabetes;
- Teachers uninformed about the effects of mercury on learning and behaviour;
- Neurological examination feels expedited;
- Negative bias in the context of compensation (money-driven);
- Lack of cultural sensitivity and training;
- History of racists remarks;
- Why is the evaluation different from those of the Japanese doctors?
- Random scoring which do not follow a pattern (ex. 2 on the first examination, 5 on the second and 0 on the third);
- The point system should be changed;
- The patient should have right to full disclosure.

Individual meetings:

Several individual meetings were organized with different panel members. Dr. Racette performed cursory examinations of some claimants who had been compensated and some who were not. The neurologic findings were not fundamentally different between these groups. Postural tremor and sensory complaints were frequent. He also remarked on the cognitive impairment in participants. He met with a case of frontotemporal dementia and was told that there were other Band members with the same constellation of symptoms. Dr. Bellinger met with a young person with learning disabilities. Dr. Hightower and Dr. Richmond met with a number of individuals in the community to discuss their general health and the health of the community.

Selected quotes from the two communities:

"The point system should not be a game; where does it come from?"

"Do we have to die to show the MDB that we are suffering?"

"Sadly, we are all sick."

"Everyone should be compensated. We have all been affected."

"People are dying before being compensated."

2. Community visits concerning children

Date: May 1 and 2, 2019
Place: Wabaseemoong and Grassy Narrows
Type: Participation in community-organized events
Panel participants: Donna Mergler, Bruce Lanphear

Pre-meeting planning

ANA and WIN representatives, Lara Koerner-Yeo and Nick Hobbs, for logistics and community contacts.

Purpose

To learn about the reality of the children's situation.

Meeting with communities

Day 1: ANA: community organizers: Judy Da Silva, Michael Fobister and Bridgette Fobister; Pat Stoddart, Director of Education and Principal for the Sakatcheway Anishinabe School

In the morning we meet with mothers who had made claims accepted and non-accepted for their children.

In the afternoon, school visit, where we attended a school event (Global Food), spoke informally with some of the teachers and met formally with the science teacher (Sasha Sadrudin) and the psychology counselor who had recently been hired.

Issues raised included:

- Impulsivity/executive function;
- High levels of learning disabilities;
- Difficulties in attention and concentration;
- Some perform academically well and do very well on literacy tests;
- Repeated school absences, which at times reaches 40%;
- Immediate need for additional human resources and one on one support for children with learning disabilities and attention deficits;
- Problems of substance use and abuse;
- Mental health issues, including suicidal ideation;
- Lack of assessments for access to Ontario IEP (Individual Education Plan);
- The science teacher's initiatives to counteract impulsivity and short attention span have been quite successful, but require further professional support to extend to the entire school.

Day 2: WIN: community organizers: Georgina McDonald and Gloria Paishk.

Mothers/grandmothers recounted their efforts to obtain compensation for their children with neurological problems.

- Difficulties in transportation and taking time from their other duties;
- Complexity and lack of transparency of the process; unable to meet the deadlines;
- An onerous task to continually have to reapply as the child's disabilities worsen;
- Noted the good work that the representative on the Mercury Disability Board, Charles McDonald, had done; unfortunately, he is ill and unable to pursue this task;
- In one case, the MDB pediatrician had indicated that her daughter should get compensated, but she was denied; her brother was accepted;

- One mother spoke she used the Firefly program[317] for her child with neurological problems, unfortunately the service stops when the child reaches 18 years of age.

A meeting with teachers and the special education counselor (Barbara Mach) was organized at the Mizhakiiwetung Memorial School. Similar issues to those raised in the Grassy Narrows community. In addition, the group discussed:

- Systematic use of the Jordan principle[318] to get help for the children;
- One teacher mentioned using and documenting similar techniques to those reported by the science teacher in Grassy Narrows;
- Special education measured outcomes: Attention deficits, language disorders, phonemic difficulties, working memory, inability to summarize paragraphs;
- High level of special education cases. The Special Education counselor noted that one's concept of 'normality' shifts: She mentioned that the children could be divided into 3 categories: severely and moderately learning disabled and 'normal'. When the "normal" children from the community go elsewhere, they qualify for IEP.

[317] The Firefly program is a multi-service agency, whose mandate is to strengthen the health and well-being of children, youth and families, and communities across Northwestern Ontario. Services focus on responding to the diverse and often critical needs of families and communities by utilizing a wide range of physical, emotional, developmental and community services (http://www.fireflynw.ca/).

[318] The Jordan Principle states that "all First Nations children can access the products, services and supports they need, when they need them. It can help with a wide range of health, social and educational needs." (https://www.canada.ca/en/indigenous-services-canada/services/jordans-principle.html).

Appendix 4 List of consultations with physicians presently or formerly involved with the MDB and experts on methylmercury poisoning

Activity	Date	Panel members	External consultations	Main agenda
In person meeting	19-02-21	Mergler	Dr. Hanada, Dr. Takaoka, Dr. Tsuruta (Minamata, Japan)	Criteria used for Minamata Disease
Formal meeting	19.03.26	Lippel, Mergler	Mercury Disability Board meeting	Opinion of current Board physician
Telephone call	19.04.01	Mergler	Dr. Postl	Background on the medical aspects of the MDB
In person meeting, Kenora	19.04.09	Bellinger, Mergler,	Dr. Lawrence Hunt	Portrait of his consultations with persons from WIN and ANA
In person meeting	19.04.11	Bellinger, Hightower, Mergler, Racette	Dr. Alan Jackson	Review of neurological procedures
In person meeting, Winnipeg	19.04.30	Lanphear, Mergler	Dr. Michael Moffatt; Dr. Frances Booth	Informal discussion of MDB history and pediatric examination
Telephone meeting	19.11.14	Mergler	Dr. Donald Fox	Discussion of Vision Examination

Appendix 5 Log of Expert Panel Meetings

Activity	Date	Panel members							Main agenda
		DM	KL	BL	BR	JH	DB	CR	
Formal teleconference	18.11.28	X	X	X	X	X		X	Introduction and discussion of the mandate
Formal teleconference	18.12.04	X		X	X	X	?	X	Further discussion of the mandate and responsibilities
Skype meeting	19.01.10	X						X	Community visit planning
Skype meeting	19.01.10	X						X	Community visit planning
Skype meeting	19.01.25	X						X	Community visit planning
Skype meeting	19.01.31	X		X			X		Discussion of background and specific responsibilities
Skype meeting	19.02.05	X	X						Discussion of background specific and responsibilities
Skype meeting	19.02.05	X				X			Discussion of background specific and responsibilities
Teleconference	19.02.07	X						X	Community visit planning
Skype meeting	19.02.15	X	X						Meeting planning for MDB
Teleconference	19.03.01	X		X	X	X	X		Update of the work done to date
Teleconference	19.03.05	X						X	Preparation of community visit
In person meeting	19.03.08	X	X						Analysis of relevant documents
In person meeting	19.03.27	X	X						Debriefing of meeting with MDB
In person meeting	19.03.28	X						X	Discussion of organization of the community visits
In person meeting	19.04.10	X			X	X	X	X	Debriefing of meeting with WIN
In person meeting	19.04.11	X			X	X	X	X	Debriefing of meeting with ANA
In person meeting	19.05.01	X		X					Debriefing of meeting with ANA
In person meeting	19.05.02	X		X					Debriefing of meeting with WIN
Skype meeting	19.06.26	X					X		Discussion of neuropsychol. & neuropsychiat. assessment
Skype meeting	19.06.26	X			X				Discussion of neurolologic assessment
Skype meeting	19.07.02	X		X		X			Discussion of children's examination
Skype meeting	19.07.09	X	X						Discussion of policy & procedure
Skype meeting	19.07.21	X					X		Discussion of neuropsychol. & neuropsychiat. assessment
Skype meeting	19.08.07	X						X	Discussion of Quality of Life Measures

Activity	Date	Panel members							Main agenda
		DM	KL	BL	BR	JH	DB	CR	
Skype meeting	19.08.09	X	X					X	Preparation of meeting with M. Wanlin
Skype meeting	19.09.13	X			X	X	X	X	Panel meeting to update work
Skype meeting	19.09.18	X			X				Discussion of children's examination
Skype meeting	19.10.07	X			X	X	X		Panel meeting to update work and discuss scoring
Skype meeting	19.10.14	X					X		Discussion of neuropsychol. & neuropsychiat. scoring
Skype meeting	19.10.21	X		X					Discussion of children's examination and scoring
Skype meeting	20.01.16	X					X		Discussion of neuropsychol. & neuropsychiat. scoring
Skype meeting	20.02.05	X	X			X	X		Discussion of the final draft report for submission
Skype meeting	20.02.06	X		X	X		X	X	Discussion of the final draft report for submission
Skype meeting	20.06.29	X	X					X	Discussion of comments received from the parties (Ch 2 & 3)
Skype meeting	20.07.06	X					X		Discussion of comments received from the parties (Ch 5 & 6)
Skype meeting	20.07.19	X	X						Discussion of comments received from the parties (Ch 3)
Skype meeting	20.07.28	X			X				Discussion of comments received from the parties (Ch 5 & 6)
Skype meeting	20.08.19	X	X						Discussion of comments received from the parties (Ch 3)
Skype meeting	20.09.12	X			X				Discussion of comments received from the parties (Ch 5 & 12)
Skype meeting	20.09.14	X					X		Discussion of comments received from the parties (Ch 12, 13 & 14)
Zoom meeting	20.09.29	X						X	Recording of the presentation to the communities
Zoom meeting	20.10.11	X						X	Second recording of the presentation to the communities

Appendix 6 References for time line graphs

Figure 7; p. 74

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Figure 9; p. 95

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Appendix 7 References by Chapter

Message from the Expert Panel

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