**Learning/Memory Disorder Review and Advocacy Plan**

**Assignment Description**

This assignment is worth 25% of your final grade.

Disorder Topic and Interview Plan: Due xx,202x

Disorder Review and Advocacy Plan: Due xx, 202x

Peer Review: Due xx, 202x

**Rationale:**

The purpose of this assignment is to present students with the opportunity to understand the personal and situational challenges and experiences of individuals living with learning and memory disorders. The assignment requires students to study the clinical characteristics of the disorder, treatment options, and community support program available to support the integration of these individuals into society. There will be two streams by which to achieve this: 1) a more advocacy focused approach involving interviewing a patient with the disorder (or their caregiver) and writing an individual advocacy report, or 2) an approach more focused on a scholarly review of the disorder and a review of treatment and community resources available to patients with that disorder in general. The overall goal of this assignment is to help students develop the necessary skills needed to maintain a career in the healthcare sector, specifically professionalism and how to adequately collaborative with patients and their families in order to advocate for their needs.

Upon completing this assignment, the student will have a deeper understanding of a single disorder that affects learning or memory. The student will have exercised their ability to use scholarly research to review the scientific understanding of this disorder, and have developed their capacity for empathy and advocacy after learning and considering the lived experience of individuals with the disorder. The student will also practice writing with different audiences in mind – their disorder review will be geared towards peers or academics, while the advocacy component should be geared to a lay person in the community. Finally, all students will provide a short critical review of another students report on a different disorder. This will give them an opportunity to learn about another disorder and practice their peer review skills.

Overall, the student will gain an appreciation for how impairments of learning/memory emerge, and how they impact a person’s quality of life and integration within society.

**What you need to do:**

Given COVID-19 restrictions, for 2020/2021 there will be two streams possible for this assignment.

**Stream 1**. Disorder review (short), remote interview of an individual with that disorder or their caregiver, and written advocacy report for that individual.

**Stream 2**. Disorder review (detailed scholarly review), general advocacy report for individuals with that disorder.

**If you choose Stream 1 (Interview/Advocacy focused report):**

**Identification of Interviewee**

You are required to identify a person with a neurological disorder that affects learning or memory. The person you identify may be a relative, a friend, a neighbor, someone accessing a local community service, or otherwise. This project will be completed through the course, so that you have as much time as possible to plan who you will invite to participate. Examples of a neurological disorder that might affect memory include, but are not limited to, amnestic disorders (due to stroke or other damage), Alzheimer’s disease or other dementias, concussion syndrome, post-traumatic stress disorder, neurodevelopmental disorders, severe learning disabilities, etc.

**Interview Plan**

After you have selected the individual you will submit an Interview Plan to the instructor for approval. This plan should begin with a short description of the potential interviewee and how you plan to contact them, followed by a list of proposed interview questions. The interview questions should be structured such that the interview will last between 20 and 30 minutes. Interviewers should be sensitive to the lived-experiences of the interviewer and abide by ethical guidelines for collecting data from vulnerable persons where appropriate. Do not include real names; initials are fine.

**Description:** In your description, include information on the person’s diagnosis, how long they have been living with the disorder, and whether they are independent or require care. If this information is not yet available to you, you must at least include their disorder and any other details you are aware of.

Method of Contact: When making contact, you should be professional and respectful to the person identified and others that live with neurological disorders. Given COVID-19, your interview must be conducted remotely, either over the phone or video conference, unless this individual is a family member or roommate, etc. that is within your social bubble. You may interview their caregiver if it is inappropriate to interview the individual.

**Proposed Interview Questions:** Questions that are developed should be designed to understand how this person’s life is impacted by the identified neurological disorder, the care or services they/the person they care for requires, and their effective integration into society. You should also aim to learn about your interviewee’s experiences with and perspectives on existing systems and services, as you will be required to identify potential gaps in resources for this population in your Advocacy Plan.

In order to proceed with the Interview, you are required to receive approval from the course instructor. Your Interview Plan can be submitted ahead of the interview plan submission deadline if you wish to do the interview earlier in the course; every attempt will be made to provide feedback on your Plan within 48 hours.

Important: Principles of informed consent and respect for confidentiality must be adhered to and a note about how you achieved this must be included. Further resources can be found here:

**Informed consent:** http://www.pre.ethics.gc.ca/eng/tcps2-eptc2\_2018\_chapter3-chapitre3.html Just section A is relevant.

**Confidentiality:** http://www.pre.ethics.gc.ca/eng/tcps2-eptc2\_2018\_chapter5-chapitre5.html. Only sections A and B are relevant.

Before starting your interview, you also must gain consent from your interviewee at the very least through the provided Letter of Information and Informed Consent Form.

**Disorder Review**

Using recent (last 10 years) scholarly review articles you will write a brief review of all relevant information surrounding the etiology, diagnostic criteria, and a description of possible treatment options on the disorder affecting the individual you will be interviewing. Your review should also describe the main molecular underpinnings and/or physiological mechanisms of the disorder. It should be written at a level that would be understood by a peer.

Note: Although you may not have completed writing your Review before interviewing your chosen individual, it is recommended to have a basic understanding of the disorder when drafting your Interview and when conducting the interview.

**Interview Summary**

Although you have likely discussed this assignment with your potential interviewee to gauge interest, once you have received approval from the course instructor, you may contact your interviewee to gain their consent and confirmation, by providing them with information on why you wish to interview them. You are required to at least provide your interviewee with the provided Letter of Information and Informed Consent Form. It is recommended that you schedule your interview as soon as possible to allow time for potential schedule changes.

During the interview, take careful notes in a professional manner or record interviewee responses in a manner that is approved on the Consent Form. Write a summary of what you have learned from this interview (recall, only use initials as identifying information). The contents of this summary should describe the lived experiences of your interviewee, the challenges they face and/or have overcome in society, and their experiences with stigma and their perceptions of existing available services they have utilized. This summary should clearly inform the next part of this assignment, the Advocacy Plan.

**Advocacy Plan**

The next step is to develop an Advocacy Plan to describe how you believe you could advocate for the person living with the learning/memory disorder that you interviewed. Using your gained understanding of the neurological disorder, develop an Advocacy Plan to meet some of the gaps you identified in your interview.

This may include:

* A brief description of the interviewees main symptoms and challenges
* A plan to advocate for reducing gaps in existing systems and services that would benefit a person’s treatment, care, and integration into society.
* A description of and a plan to disseminate the existing resources that have resulted in the most positive outcomes for the interviewee. This can include resources available in your community or otherwise.
* The goal with the Advocacy Plan is to come up with potential next steps to improve the quality of life for the interviewee and other individuals with similar disorders. If difficult to develop this plan, outline the process you used and identify these gaps in resources for individuals with this disorder and where it became difficult to proceed further in this plan.

Language used for this Advocacy Plan should be for the general public – accessible at a high school level. Keep the Advocacy Plan straightforward and to the point, using only publicly available resources.

**If you choose Stream 2 (Disorder review focused report):**

**Identification of Disorder to be Studied (0%, but mandatory!)**

You are required to choose a neurological disorder that affects learning or memory upon which to base your review. Examples of a neurological disorder that might affect memory include, but are not limited to, amnestic disorders (due to stroke or other damage), Alzheimer’s disease or other dementias, concussion syndrome, post-traumatic stress disorder, neurodevelopmental disorders, severe learning disabilities, etc. You will submit the disorder for approval 1 month before the due date. If you choose a predominantly motor disorder (e.g., ALS or Parkinson’s) be sure that you also describe the cognitive deficits that are present.

**Disorder Review**

You will complete scholarly research on a disorder of your choice that affects learning and memory, using a variety of recent scholarly journal articles and reviews as your primary source material. Your review should describe in scholarly detail the main molecular underpinnings and/or physiological mechanisms of the disorder. Contrast different theories of disorder causation, development and progression if appropriate. This disorder review should also include a brief history of the disorder and its main symptoms, review of the etiology, diagnostic criteria, and a description of current and promising treatment options. The expectation is that this be written at a level for reading by a professor.

**Advocacy Component**

Conduct research online through websites by organizations advocating for such patients in order to learn about the key issues this patient population faces in terms of access to treatment and support services that help them integrate meaningfully into society. Recommend steps that might close some of the gaps you identified in this research.

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**Required for Both Streams:**

Peer Review

You will review the Disorder Review and Advocacy Plan of one other student who chose a disorder different than yours. Provide constructive feedback that highlights the positive aspects of the report, any areas that could benefit from improvement, and any additional ideas regarding the advocacy component that came to you while reading your peer’s report.

**Stream 1 Specifications:**

**Interview Plan specifications:**

* This is to be submitted at least 1 month before the final report is due
* A description of the potential interviewee, their disorder, and how you plan to contact them and conduct the interview adhering to COVID-19 guidelines. Include a list of your proposed interview questions, keeping in mind the intended interview length is 20 to 30 minutes, and you should account for the fact that their answer might stimulate follow-up questions.
* This should be a maximum of 2 pages, double-spaced
* Times New Roman, size 12 font, 1 inch margins, standard 8.5” by 11” paper
* Submit as a .doc or .docx (.pages will not be accepted) to the ‘Stream 1 – Learning/Memory Disorder Interview Plan and Final Report Submission’ assignment submission folder

**Final Report Submission**

* There are three components, but they should be uploaded as a single file with clear subheadings for each component.
* You must also separately upload a photo or scan of your completed and signed Letter of Information and Informed Consent Form.

**1. Disorder Review component specifications:**

* The length of this review should be a maximum of 4 pages, double-spaced
* At least 4 references from the scientific peer-reviewed literature (review articles are fine) from the last 10 years. These should follow the format employed by the Journal of Neuroscience. Note that you will need to include in-text citations.
* Reference formatting: see references section of <https://www.jneurosci.org/content/information-authors#preparing_a_manuscript>

**2. Advocacy Plan component specifications:**

* Maximum length is 6 pages, double spaced

**3. Interview Summary component specifications:**

* The Interview Summary is a separate component and should be included as an Appendix.
* Provide a summary of your interview; transcribed word-for-word responses should not be included
* Interviewee may be quoted where appropriate if they provide consent to do so
* No identifying features, such as name, should be present in the interview summary; initials of the interview (e.g. HM) can be included
* Maximum length is 5 pages, double spaced

**General specifications for all three components of the report**

* Note that the page counts for the components does NOT include references, which can be additional pages.
* Times New Roman, size 12 font
* 1 inch margins, standard 8.5” by 11” paper
* Submitted file should be .doc or .docx (.pages will not be accepted) and be uploaded to the ‘Stream 1 – Learning/Memory Disorder Interview Plan and Final Report Submission’ assignment submission folder,
* You may submit a draft of your report to the assignment submission folder to the ‘Stream 1 – Learning/Memory Disorder Interview Plan and Final Report Submission’ in order to check it against Turnitin. Once ready, you can resubmit a final version -- the most recent version uploaded to the assignment submission folder will be graded
* Additional resource regarding patient advocacy: https://www.cbc.ca/radio/whitecoat/blog/when-patient-advocates-are-better-than-doctors-1.3428867

**Stream 2 Specifications:**

**Identification of Disorder to be Studied, and Basic Outline (if you want feedback)**

* This is to be submitted 1 month before the final report is due
* Identify the disorder you have chosen, you may also choose to propose an outline of your report and your strategy for sourcing information if you wish to obtain feedback on this from the instructor or TA.

**Final Report Submission**

There are two components, but they should be uploaded together as a single file with separate subtitles.

**1. Disorder Review specifications:**

* The length of this review should be a maximum of 14 pages, double-spaced, not including references
* At least 15 references from the scientific peer-reviewed literature (maximum of 3 review articles) should be cited, with a focus on articles published in the last 10-15 years. Older articles that are classics in the field are fine to include. These should follow the format employed by the Journal of Neuroscience. Note that you will need to include in-text citations.
* Reference formatting: see references section of <https://www.jneurosci.org/content/information-authors#preparing_a_manuscript>

**2. Advocacy Plan specifications:**

Maximum length is 4 pages, double spaced

**General specifications for both components of the final report**

* Times New Roman, size 12 font
* 1 inch margins, standard 8.5” by 11” paper
* Submit your file as .doc or .docx (.pages will not be accepted) to the ‘Stream 2 - Learning/Memory Disorder Topic, Disorder Review and Advocacy Plan’ assignment submission folder for grading.
* You may submit a draft of your final paper to the assignment submission folder to the Stream 2 - Learning/Memory Disorder Topic, Disorder Review and Advocacy Plan’ in order to check it against Turnitin. Once ready, you can resubmit a final version -- the most recent version uploaded to the assignment submission folder will be graded

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**Required for Both Streams:**

**Peer Review specifications:**

* Provide constructive feedback regarding their Disorder Review and Advocacy Plan; maximum of 250 words.
* Feedback should be specific, organized and clear.
* Indicate in your document which student’s work you selected to peer review.
* Submit your peer review as a .doc or .docx (.pages will not be accepted) to the ‘Peer Review of a Learning/Memory Disorder Review and Advocacy Plan’ assignment submission folder.

**Support:**  NSCI483 Letter of Information & Consent Form

**Additional Resources:** The Writing Centre for Distance Students