

# Pain in the Rear

**“voices of people with disabilities  
about complementary and alternative  
medicine”**  
by **scott allan white**

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**Research Topic: (questionnaire development)**

**Complementary and alternative medicine is used in conjunction with conventional medicine for health and wellness. How are the lives and experiences of people with intellectual disabilities shaped by complementary and alternative medicine?**

**Independent Research Report April 2008**

**Researcher: Scott Allan White**

**Title:** "Pain in the Rear"

**Research Topic:** CAM use in the disability community.

**Objective:** Using an emancipatory approach, develop a questionnaire on the use of complementary and alternative medicine (CAM) in the disability community. People with disabilities are historically the objects of research, rather than the curators of research. The inequities reflected in asymmetrical power relationships between social researchers and the people with disabilities as the objects of research become evident when we consider how research is linked to political and social action to serve the disability community. This research project intends to include people from the disability community in forming the questions that are relevant to them in regard to CAM. This research establishes the groundwork for further research on the topic, and forms a basis for employment

of a formal survey across the disability community. The strength of the research lies in the relevance of the questions that are formed, as they are distinctly the questions asked by that community, and not the query of non-disabled persons.

The academic community, government and other international agencies provide support and funding for research on the topic of disability that emerges from a social construction theory. This theoretical framework is important because it recognizes that the absence of impairment is not itself a prerequisite for health for persons with a disability, and that a socially constructed reality forms the basis of inaccessibility for persons with disabilities. The medical model of disability as a former theoretical research model, has not included people with disabilities in the grassroots development of research, and more importantly it has seen impairment through the lens of a diagnosis. The diagnostic system of medicine sees the disabled person as broken, and provides treatment that is intended to fix or rehabilitate them as a means of empowerment. Through this former model, the person with a disability is less than whole, and strives for wholeness through rehabilitation. The social construction model sees the person as a whole person, who is limited by the way we create structures and social ideas, and is therefore compelled to change society rather than the disabled person. Homeopathy, as an example of a non-diagnostic system of medicine, places little emphasis on a medical diagnosis or label.

Non-diagnostic systems of medicine perceive disease and disability within a framework of changes from a state of functional ability or health that is unique

to each patient. This non-diagnostic emphasis fits within the social construction ideology, because it envisions a state of health that includes disability. The traditional medical model of disability has created many labels through diagnosis that stigmatize people with disabilities, in some cases where the social stigma of a diagnostic label is arguably a greater barrier to participation in society than the impairment itself. It is the objective of my project to develop an understanding of how and why people with disabilities access alternative healthcare, but not as a fundamental basis of a research question. This project will simply introduce the topic of CAM use through discussions and individual interviews within the disability community to interpret the interest and important questions of this consumer group.

In introducing the idea of medicine in general, I expect there to be questions and query about the nature of CAM itself and confusion about the differences between diagnosticians and holistic practitioners who do not work within the conventional paradigm. Above all, an ecological framework of understanding consumer interest in CAM is stressed in this research project, and therefore; there is a co-evolution in preparing ourselves systematically and from a research perspective in asking the disability community about CAM use to fully understand their own understanding, their own questions and assertions related to treatment using CAM modalities.

**Research Question:** Complementary and alternative medicine (CAM) is used for health and wellness in conjunction with conventional medicine. How are the lives and experiences of people with disabilities shaped by complementary

and alternative medicine? What questions are raised by disability groups in regard to CAM use?

**Importance:** People with disabilities are more affected by healthcare reform than any other group, and they are most likely to have access to a single modality of treatment (*Canadian Community Health Survey*). The *Participation and Activity Limitation Survey (PALS)* conducted by Statistics Canada indicates pain related disability affects the income and participation of people with disabilities. The report on which it is based, titled *A profile of disability in Canada in 2001*, contains findings on the number of persons with disabilities, type and severity of disability by age and gender. It is available free of charge on Statistics Canada's website ([www.statcan.ca](http://www.statcan.ca)). Some people with disabilities use alternative therapies and complementary medicine to treat disease and optimize health in conjunction with conventional therapies. For instance, homeopathy is an alternative or complementary system of medicine used to treat disease, albeit limited in Canada due to public awareness and education about homeopathy. This can be said of many CAM approaches to care, and include Traditional Chinese Medicine (TCM), Naturopathy, Acupuncture, Chiropractic Medicine etc.

Similar studies on the use of CAM in the European Union indicate poverty, limited access, public awareness and education are factors that affect the choices and ultimately the use of alternative and complementary therapies. Information about people with disabilities and their management of health using therapies like homeopathy is constrained by the limited funding to research

alternative medicine in Canada and abroad. The Holistic Health Research Foundation of Canada notes, *“that despite the popularity of complementary and alternative health care in Canada, research funding in this area is extremely sparse”*. Currently, only a tiny fraction of health research funding by government or disease-specific charitable organizations is spent on examining the effectiveness of complementary and alternative therapies.

Newly regulated health professions in the Province of Ontario include Homeopathy, Traditional Chinese Medicine, Psychotherapy, Kinesiology, Naturopathy and Acupuncture (ie. Ontario Ministry of Health, Bill 171 Health Systems Improvement Act). These recognized systems of medicine offer a new approach to the management of health. A research project to investigate the general awareness and use of these modalities among those most affected by disability and other conditions is necessary to further educate, understand and explore options in healthcare management within the disability community.

# Literature Review

*While community participation is espoused widely as a positive process and goal for adults with an intellectual disability, there is surprisingly little research evidence presenting their own experiences of “the community”. Given the long history of isolation and rejection from “the community”, this lack of direct “voice” is disturbing.*

Walker P. 1999. From community presence to sense of place: Community experiences of adults with developmental disabilities. *The Journal of the Association for Persons with Severe Handicap* 24(1): 138-50.

The literature that is referenced for this study is comprised of a variety of health related research papers published by professional social work journals, conventional medical journals, journals on complementary and alternative medicine, disability related journals, studies conducted by hospitals and in community care. The materials are selected from a variety of sources that include Canadian research organizations like the Frasier Institute and foreign research organizations and journals such as the British Medical Journal. Women’s health, the aged, individuals with HIV, cancer and those with mobility issues are some of the topics that relate to disability. I have selected a cross section of studies that relate to primarily qualitative aspects of patient care and satisfaction, and that analyze barriers, limitations, merits and shortcomings of the current trends in offering complementary and alternative medicine to the public. Studies published in various countries demonstrate the breadth of current research on the topic worldwide.

There is a growing trend to understand different modalities of care and this is supported by recent legislation around the regulation of several holistic systems of medicine in the Province of Ontario. Of the 29 studies I cite as related to CAM use, only a few of these studies speak to a social construction of disability. None actually cite “social construction theory”, however; I have attempted in my annotated bibliography to speak directly to the indirect connections between the social construction of disability and the holistic (non-diagnostic system) of medicine. In relationship to diseases there are inherent relationships between conditions like HIV, cancer, fatiguing illnesses and serious impairments from accidents that impose what is termed a disability, but authors often cite specific disease names and do not impart a sense of the relationship to quote the term “disability”. Evidently the term disability is implied, vague, non-specific or perhaps unnecessary when speaking about the efficacy of treatment and a patient with a specific set of symptoms related to a diagnostic label. Again, the label takes precedent within the literature. The diagnostic stratification is about the lexicons and vernacular of allopathic medicine, and from the perspective of writers and researchers on the topic, this language creates a lens through which medicine is understood. There is a recurrent theme within the context of having to name a disease by a certain label that further entrenches the conventional paradigm within the studies of alternative medicine. This is a key problem in addressing the shortcomings of research on CAM. The lexicons of the conventional paradigm are piggy backed onto the topic of disease and disability before the analysis of understanding the efficacy of a treatment. A recent publication from the Journal on Traditional Chinese Medicine in Ontario

cites this as a major factor in understanding the benefits of treatment using alternative therapies.

I have provided information about paradigm theory that relates to this very difficult dilemma. Thomas Kuhn (*see Appendix*), a scientist and theorist in the area of paradigms, argues that rival paradigms are incommensurable – that is, it is not possible to understand one paradigm through the conceptual framework and terminology of another rival paradigm. Most of the research performed, and likewise papers published on the topic of complementary and alternative medicine are in fact attempting to commensurate varying paradigms and more specifically, most research begins with the lexicons and analytical framework of the conventional scientific framework to begin the investigation. Regardless of the problems created through incommensurable paradigms, there are still measures of success accomplished in these studies, and some studies refer to general symptoms like pain or are investigating trends in usage, general practices of better diet or prayer. Other studies focus on the concepts of relationship building and empathy demonstrated more fully by CAM healthcare providers (ie. doctor-patient relationships).

The research question I raise is a general question about complementary and alternative medicine and the disability community, and my selected bibliographical topics are a cross section of general themes about the experiences of people using CAM, about conventional healthcare practitioners perceptions of their patients use of CAM, trends and attitudes in Canada, the

efficacy of some treatments based on a qualitative-interpretive analysis and a few specific diagnosed illnesses where disability and disease intersect. To be more specific, *“Complementary and Alternative Medicine in Canada: Trends in Use and Public Attitudes”*, published by the Fraser Institute investigates the factors influencing CAM use and explores different conditions and therapies predominant in Canadian society. The concept of “disability related illness” and the imposition of poverty influencing CAM use is first noted in this literature. Other articles related to a qualitative analysis of CAM use include, *“Disabilities, Moving to a Holistic Model of Health Among Persons with Mobility Disabilities”* explores the contrasts between the medical model and the holistic paradigm, noting how disability is portrayed in different terms through CAM. This is a central objective of my study. The medical model of disability is a paradigm that has dramatically influenced the lives of people with disabilities. Seeing an individual as diseased or broken and applying disease labels is a fundamental basis of prejudice. One aspect of the sociological framework of disability study is to understand disability and the social phenomenon created by the way we develop systems, language, institutions and law related to people with disabilities in relationship to these labels. Holistic medicine sees disease in a way that creates a different perspective, a different paradigm in understanding disability. This is reinforced by the notations I have made in regard to several of the research articles in my annotated bibliography. The non-diagnostic system of treatment provided in CAM modalities like homeopathy provide a different perspective on disability.

A theme of qualitative analysis is apparent in the articles and research papers I have chosen to use as bibliographical references. This stems from the incongruity of understanding CAM strictly through a rigid set of Newtonian principles that support only the conventional paradigm, and to more fully realize health and wellness through the patient's own experiences using CAM. The concept of citizenship arises when we consider the "choices" each person makes in regard to their own healthcare. From this we can then examine the limitations of poverty, advocacy and education arise in healthcare choices. Issues confronting consumers with intellectual disabilities is not referred to in any sources I have cited, but it is obvious that poverty and a lack of education about CAM in the general public includes this consumer group. In the article, *"Academic Doctors views of complementary medicine and its role in the National Health Service"*, published by BioMedCentral, a combination of support and skepticism exists for CAM in the United Kingdom, noting that conventional doctors have little training in CAM, and therefore lack the knowledge to adequately advise patients on these matters.

A few articles synthesize a relationship of disability or a medical diagnosis and the use of complementary and alternative medicine. They are foremost articles that convey a limitation arising from pain that equates to disability, and are therefore relevant. The initial research direction was in relationship to pain management, disability and CAM use, but evolved to become more focused on people with intellectual disabilities using a variety of CAM practices to manage health.

In the article *“Efficacy of Homeopathy Arnica: A systematic review of placebo-controlled clinical trials”* by Ernst E, Pittler, pain can be differentiated from disability, however; people with disabilities often seek palliative treatments for acute pain management. Arnica is a common homeopathic remedy for the treatment of pain. Homeopathic doctrine does not indicate remedy prescription on the basis of a single symptom, yet certain polycrest remedies are well suited to conditions of pain, in that proving symptoms from the substance in overdose create similar symptom pictures of inflammation, bruising and consequently pain. Plant remedies and other natural substances are common in many CAM treatments and often the origins of conventional treatments stem from earlier use in Botanical Medicine, German Folk Medicine or Herbalism.

The trademark approach to marketing conventional medicine fits within a social construct that separates the person from nature, hence building upon the ideology that the human organism is collateral to nature, rather than sharing a synergistic relationship with the natural order of the world. Conversely, disease in holistic medicine is seen as an imbalance with a natural state, and remedies are seen as inciting a state of attunement unique to the individual. This theory is relevant to the social model of disability, as no person is in a state of imbalance in relationship to another individual. The state of balance refers to a relationship with the world that is harmonized by factors outside a conventional ideology of pathology, and factors such as mental emotional states, spiritual states and body-mind, energetic or ecological states are important to the healing

mechanisms of the body, in addition to pathology. In an ecological context any individual organism, a single-species or population of organisms exists not in isolation, somehow separable from the complexity of interactions around it, but as an integrated component within a complex ecological 'whole' - one part only of an intricate mechanism of interdependent, individually moving parts. The differentiation with conventional health ideology lies at a root philosophical level, where the origins of disability construction are a part of a principle where the patient is compared to a common group within the community, and then grouped within the stratification of a diagnostic system that dictates certain invasive or medical protocols. The highly individualized holistic approach sees each person as unique and identifies philosophically with an ecological theme of connectedness.

Another theme within the literature I have selected involves the topic of "integrative medicine" and is cited in, *"Integrative approaches to pain management: how to get the best of both worlds"*, Brian M Berman, British Medical Journal. The idea of a panacea in medicine needs to be dismissed. No one therapy or system of medicine is curative in every way or in all circumstances, and many studies indicate favorable outcomes using both conventional and CAM approaches.

The concept that co-existence and merging medical practices in a single treatment plan are possible is explored through all cited publications. In the Statistics Canada, *Canadian Community Health Survey (appendix)*, it is noted

that “persons with disabilities are about one and a half more likely to consult an alternative health care provider than are persons without disabilities”, and are also more likely than the average Canadian to have both a regular medical doctor and an alternative healthcare practitioner. As my research topic evolved and focused on people with intellectual disabilities through Community Living Toronto and the Self Advocate Council, it became apparent that there were important issues unique to this community, and that within this domain integrative medicine raises important questions about safety, quality of care, informed decision making and advocacy. Support agencies and this consumer group share decision making and can make informed choices through education. Merging healthcare practices include the collision of two ultimately different spheres of treatment philosophically and sometimes physiologically. Peoples assumptions that CAM is ultimately good, and the applied and practiced use of CAM in conjunction with conventional medicine poses risks that are seen and unforeseen. This is also true of reliance only on conventional treatment. There are best practices within both conventional and CAM paradigms.

The concept of the conventional paradigm as a panacea stands in contrast to the many successful treatment options available through CAM approaches. There is not a silver bullet to approaching treatment options, and in building a constituency within the disability community for the purposes of this project I discovered that the literature on the topic was relevant and as diverse as the community itself. Agencies need support to understand the benefits of supporting consumers with CAM options, and consumers need literature and

education on the topic to make informed decisions. Under the *Regulated Health Professions Act (RHPA see appendix)*, all healthcare practitioners are responsible to refer to outside practitioners when they haven't adequate knowledge or training to treat the patient. In terms of concerns about "best practice" the implication or legality of taking someone with an intellectual disability to a CAM healthcare practitioner is similar to the referral practice exercised when requesting a primary healthcare practitioner to provide a referral to a dietician, or any other healthcare provider in the Province of Ontario who is defined in legislation and under regulation as a "healthcare practitioner".

Describing the social model of disability is a complex undertaking when approaching a group unfamiliar with the term or concept, and further hampered in a group who have intellectual disabilities. The term paradigm or shifting paradigms and incommensurable paradigms, and the sheer magnitude of literature that can be compiled to support the notion that integrative medicine is beneficial, isn't as significant as the simple comparison that can be made in stating the differences between the choices we exercise in our own healthcare as people without an intellectual disability and compare the choices of people with intellectual disabilities. Community living has many advantages to the institutions of the past. People integrated into community settings have more choices in everyday life. With the growing trends in healthcare and the growing interest in complementary and alternative medicine, it would be wise to begin early in securing a place at the table for people with intellectual disabilities. The Ontario Disability Support Program may offer additional supports to people with

intellectual disabilities if referred by a medical doctor. In many ways, CAM introduces a new fee-for-service tier in healthcare that can be expensive and out of reach for people with disabilities. Options in healthcare are significantly more important to people with disabilities, as they tend to have more health concerns than the average Canadian.

My literature review on the topic Complementary and Alternative Medicine and disability attempts to address a plethora of issues that include efficacy of treatment, physician training, diagnostic vs. non-diagnostic systems of medicine and a myriad of topics around patient satisfaction and qualitative aspects of healthcare. I have provided an annotation of each bibliographic citation to describe the context of the article in relationship to the topic of CAM use in the disability community. More importantly, I have emphasized the importance in recognizing that the diagnostic system of treatment or “diagnosis” socially constructs labels that stigmatize people with disabilities. I have done this to impress upon the reader how disability is socially constructed and not simply about physical or mental impairment. The medical diagnosis is not necessary in all systems of medicine.

## ABSTRACT

*Qualitative Social Work* 2006; 5; 470

Kyung Mee Kim and Michael H. Fox

Moving to a Holistic Model of Health among Persons with Mobility Disability

*“Researchers have defined health as being associated with a sense of personal well-being, merging such multidimensional aspects as physical, mental, social, and spiritual wellness (Zajicek-Farber, 1998). **The World Health Organization (WHO) in 1947 proposed a definition of health that emphasized its positive quality: ‘health is a state of complete physical, mental, and social well-being and not merely the absence of disease’ (Tempkin, 1953: 21).** Pender (1987) suggests that the concepts of health and illness are qualitatively different. He defines health as the actualization of inherent and acquired human potential through goal-directed behaviors, competent self-care, and satisfying relationships with others, while making adjustments to maintain structural integrity and harmony with the environment. This definition of health warrants close attention, for the absence of illness or impairment is not by itself a prerequisite of health for people with disabilities (Stuifbergen et al., 1990).”*

As a minority group in Canada, the interests of people with disabilities are placed “in the rear” so to speak, not unlike alternative medicine which can be unsupported by conventional science. This research project has set out to examine CAM in a disability community. It illustrates quite simply, ideas from personal discussions within the disability community.

The social model of disability is often resonant of a previously popular “medical model”, where the tendency to diagnose and treat illness is ever present throughout the history of conventional medical practice. New social thinking and research recognizes that people with disabilities have been affected socially, culturally and what is more, they have been affected personally by the experience of being labeled or treated exclusively by a diagnosis. Alternative and more aptly, holistic approaches to understanding health tend to steer away from a diagnosis and see each person as unique.

The unique nature of each individual in response to a disease process, injury or a disability is a determinant in developing treatment options that are highly individualized. CAM crosses many borders in regard to conditions, diseases, injuries or what is termed disability. I hope to better understand how people with disabilities in Canada use CAM in conjunction with conventional medicine.

The *Canadian Community Health Survey* conducted through Health Canada in conjunction with Statistics Canada asked: “In the past 12 months, have you seen or talked to an alternative health care provider such as an acupuncturist, homeopath or massage therapist about your physical, emotional or mental health?” Those who answered “yes” were asked what type of practitioner had been consulted or visited. Chiropractors were not listed among the alternative health care providers. Information about them was sought in another question: “In the past 12 months, how many times have you seen or talked on the telephone, about your physical, emotional, or mental health with a chiropractor?” In 2003 more than one quarter of Canadians diagnosed with a chronic condition sought out the advice of an alternative healthcare provider.

Medicine is a social response to what it considers disease, injury and disability. The perspective on a particular disease or disability varies depending on the modality of medicine and the understanding of pathological processes. The oppression of people with disabilities is understood as a social construct,

where in certain circumstances medical approaches to ameliorate impairment can create additional barriers to full participation in society. In further researching the topic of disability and health management, it is unlikely to fully expand upon the whole ideological philosophy behind modalities such as, Homeopathy, Naturopathy or Traditional Chinese Medicine, however; it is intended to comprise the expressions of people with a disabilities who utilize CAM for health management and therefore, explain to some extent why they choose alternative medicine in conjunction with conventional care. Some individuals may choose a certain modality or approach to complementary care for personal, religious or philosophical reasons. Different countries and governments worldwide are recognizing the individual right to make choices about healthcare, and self-determination around treatment options that may not be supported by conventional medical science. Conventional medical treatment is seen as one possible approach to disease and disability, and many people choose not to utilize certain conventional therapies, and opt for CAM or use conventional medicine in concert with complementary and alternative medicine. According to Michael Bach, Acting Vice-President & Director of Research at the Roeher Institute, Canada's national institute for the study of public policy, disability, and human rights, self-determination is about citizenship.

Self-determination ultimately provides choices, and choices shape the landscape and terrain of the institutions and organizations we manage in Canada. Individual rights and citizenship, mean the right to make decisions and not be limited by government or the special interests of others in regard to

fundamental choices. Choices involving where you live, your occupation, religion etc. are considered fundamental. Universal healthcare does not mean that ultimately every Canadian will have every treatment option available to them, however; future endeavours to include other modalities of care into mainstream conventional treatment is indicative of the cultural diversity of Canadians, and is likely to provide greater self-determination in healthcare. People with disabilities in Canada can benefit from the inclusion of CAM treatment options, as affordable choices to managing their health.

## **Community Partners**

I expect to be involved with the Toronto School of Homeopathic Medicine, Ryerson School of Disability Studies, Community Living Toronto and other members of the public interested in CAM use in the disability community.

## **Ethics review protocol: (attached)**

### **Participants:**

One or more focus groups 3-5 individuals or a larger group comprised of 8-10 individuals from the disability community who are willing to participate voluntarily and share information in regards to the development of a questionnaire that is pertinent to an interest in complementary and alternative medicine (CAM). All participants would be volunteers and be willing to share ideas and personal insights in regard to CAM use in their everyday lives.

A disclosure of information and the objectives of the study will be provided to all participants. No personal information in regard to the identity of the individual will be necessary to participate; however, participants may provide consent to share information in regard to the study.

## **Direction of Research:**

This research project differs from most research on the topic of CAM use in Canada, as most research is conducted to determine the extent of use in the general population. CAM use was the topic of a recent study with the Multiple Sclerosis Society of Canada. The objective of that study was to understand the extent of use and what therapies were being utilized in that particular community. Modalities of care in CAM tend to be less researched, or quite difficult to test using standard empirical scientific methods, and as a result, there is less support amongst conventional western medical primary healthcare providers in referring patients to CAM healthcare practitioners.

The majority of medical research worldwide is conducted by pharmaceutical companies who historically have not had an interest in CAM use, efficacy, trends or the modalities of medicine outside of a conventional mainstream model. My research project is intended to explore the issue from a social model of disability perspective. I will use a qualitative and interpretive approach to the research topic. Disability is often understood through the conventional medical diagnosis or what is termed the “medical model of disability”, and some element of the project will draw on that theme. Participant feedback may reveal some insight about a medical diagnosis and treatment using conventional therapies in concert with CAM.

The research project is not intended to compare systems of medicine or types of therapies, however; it is intended to understand the extent of CAM use

for health management and why people choose alternative or complementary medicine in conjunction with conventional care or apart from it. Identifying a particular disability is not a focus of the research, so it will not pertain to any one particular type of disability, but rather, include people with varying degrees of disability and perhaps different types of disability labels. Participants will not need to disclose any information about their disability, but may decide to speak about this at their own discretion. The social construction of disability will be addressed in the approach to the research question of CAM use in conjunction with conventional primary healthcare. CAM in Canada is only beginning to emerge as a modality of medicine for primary care. The recent government regulation of Naturopathy, Homeopathy, TCM, Acupuncture, Kinesiology and Psychotherapy in Ontario are evidence of a trend toward supporting diversity in treatment options.

Traditional Chinese Medicine, Naturopathy, Chiropractic and Homeopathy represent some treatment options that do not fit within the everyday social construct of a medical diagnosis that can define disability through a diagnostic label. Complementary and Alternative Medicine can represent a challenge to the status quo of a diagnosis that tends to define disability, as it proposes each person is unique, that healthcare be highly individualized and more importantly, that a perception of a patient through the lens of a diagnosis steers treatment in directions that are focused on the label alone, and often away from the very individual nature of the patient. Highly individualized care can lead to effective treatment plans, when patients have exhausted all other conventional healthcare

strategies. This is cited in many studies as the primary reason for choosing CAM. Self-determination around healthcare treatment plans is a critical element of citizenship affecting the lives of people with disabilities. This is particularly true of people with intellectual disabilities who rely on guardians or family members to make choices about treatment plans. No particular therapy or treatment should be considered superior or subordinate to another, but ultimately a right of the individual to choose medical interventions or treatments. Choices around healthcare can be very personal. Ultimately, the use of CAM affords people options that are outside of mainstream medicine or complement conventional treatment.

Homeopathy, Traditional Chinese Medicine, and Chiropractic medicine are systems of medicine that understand disability in different terms (ie. holistic paradigm), therefore, creating the possibility of alternative realities under a socially constructed ideological framework of disability.

## **The Final Product:**

Focus group participants received feedback and information about the project.

Focus group feedback helped form a common theme or “narrative” as it relates to their ideas about alternative medicine (see attached). This report also includes actual narratives of participants however; names have been changed for purposes of confidentiality or are removed to ensure confidentiality. This report attempts to establish a bottom line or limits of the findings and how findings may indicate further investigation. This may be important to the community agency/partner in further investigation on the topic of CAM. Other possible research questions will be raised as a result of the findings of this project. The final report will be a starting point for further investigation on the topic of “voices of people with disabilities about Complementary and Alternative Medicine”.

Information about CAM in the Province of Ontario will be put into a format for delivery to present or introduce CAM to social service agencies. I.e. overhead projector slides.

## **Focus Group:**

### **Community Living Toronto - Self-Advocates Council**

**The Self Advocates Council (SAC)** is a group of Community Living Toronto members who have an intellectual disability. We assist Community Living Toronto by voicing points of view on issues that affect our lives. We assist in breaking down barriers for people with intellectual disabilities. We connect with self advocates in Community Living Toronto programs, in the community and across the province.

To learn more about the Self Advocates Council please contact the Coordinator of Self Advocates Council, John Balatka, at [jbalatka@cltoronto.ca](mailto:jbalatka@cltoronto.ca) or call the SAC office at (416) 968-0650 ext 2249.

**Self Advocates Council Participants: 12**

**Feedback from meetings with this group formed the basis of a consumer survey. These are the questions that this disability group is asking, and an interpretive analysis of their feedback provided insight to developing a narrative, that can serve as one possible strategy for change.**

# Consumer Questionnaire

[What Focus Group Participants and agencies want to ask practitioners about CAM](#)

What is complementary and alternative medicine? What is western medicine?  
What is eastern medicine?

What is the difference between quote “normal” medicine and complementary and alternative medicine?

Can CAM treatments be toxic or have toxic effects?

What is a normal doctor?

Does regulation of CAM mean there are strict rules established?

What does “Holism” mean?

Conventional medicine trials medicines on people to see if they work and if they don't they just give you another medicine. Comment: “Doctor's guess what medicine they should give and sometimes they are wrong”. Is this something to consider in CAM treatment?

People can be harmed by conventional medicine. Are there circumstances where CAM could be harmful to a patient?

Conventional Doctors don't really know you as a patient and see you very briefly. How does CAM improve upon the Doctor-Patient relationship?

Some conditions cannot be treated with conventional medicine with good results. Are there conditions that cannot be treated effectively with CAM?

Doctors see you different as a person with a disability, less caring, less powerful. Comment: If you are in a group home you are not competent. How would this be different for someone with a disability seeing a CAM healthcare provider?

Foods we eat are tainted and not healthy (ie. tainted). Doctors don't talk to patients about foods too often. Do CAM healthcare providers talk about diet and nutrition, supplements and other things besides the medicines they prescribe?

Conventional doctors don't think about using alternative medicine ie. herbs, botanicals, homeopathy etc. They just treat you with standard conventional medicine or nothing at all. What can be done to improve the status of relations between the two systems to ensure patients receive the best possible supports?

Are there less side effects to CAM?

People discussed the following alternative therapies with successes: Shiatsu, Massage, TCM, Homeopathy, Botanicals, dietary changes, Supplements, Accupressure, Reflexology, Colloidal Silver. Are there other CAM therapies?

There are issues of informed decision making in choosing alternatives to conventional medicine, but there are also the same informed decision making issues with conventional medicine choices in the disability community. How does CAM accommodate for the special communication needs or supported decision making of people with disabilities?

Why don't Eastern and Western medicine agree?

Basic language issues prevail with decisions around all kinds of medicine and the disability community. Not all people with intellectual disabilities have choices about their own healthcare. How can CAM healthcare providers improve on the language barriers and plain language issues of people with intellectual disabilities?

In the past people didn't take as many pills and they were healthy. Is health management possible without a prescription and how do CAM healthcare providers intend on promoting prevention rather than cure in community healthcare?

Costs for alternative medicine pose a significant barrier to accessibility ie. Poverty issues. Is there a way that leaders in the CAM community can accommodate for those living in poverty? Could there be changes to ODSP that could provide special funding for CAM use in the future?

An example of informed decision making was raised in regard to flu shots. The right to choose or decline flu vaccination. Do all CAM healthcare providers agree on vaccination?

Choices in group homes are largely dependent upon the counselor or supervisors knowledge. Can community awareness campaigns be organized that reach social service agencies, personal support workers and management teams of major organizations?

Agencies that support people with disabilities need evidence that best practices exist in regard to CAM use. How is the safe and effective use of CAM communicated to community agencies that support people with disabilities?

Group home staff need training in regard to supplements, herbs and other natural remedies. How do community support agencies educate themselves about CAM and the use of supplements?

The issue of “best practice” was raised in relationship with the employment of medicine in agencies, namely, that conventional medicine is a best practice approach. How does CAM interpret best practice?

The public makes choices around the use and practice of CAM in their lives, and people with disabilities are largely removed from that decision making process. Will literature be disseminated to community health and social service agencies about CAM options in healthcare?

Plain Language is the most important issue when asking questions in the developmental service sector. Can CAM literature be put in plain language to accommodate for people with intellectual disabilities?

# Developing a narrative

- about a survey on complementary and alternative medicine use in the disability community.

**“A survey about complementary and alternative medicine use in the disability community should use plain language, be facilitated and include a cross section of different people from the community”.**

## Key Themes (barriers)

- **The barrier of poverty (alternative healthcare is expensive)**
- **The barrier of choices (ie. plain language, advocacy, bureaucracy, having the same choices as those without an intellectual disability)**
- **The barrier of education (exposure to reliable easily understood information about CAM, promoting CAM as an agency vision)**

## **Possible solutions and/or outcomes:**

1. Develop a survey using “plain language” to further understand how people envision the opportunity to access CAM professionals in their community.
2. Develop literature using “plain language” to further educate people with intellectual disabilities.
3. Provide feedback to agency about all findings and offer support to network with other non-profits who face similar obstacles. (ie. many non-profits have consultants ie. Homeopaths, Chiropractors, Traditional Chinese Doctors who work with an agency for free, as a tax deductible donation or with reduced costs. Building a network in the community to accomplish this may be a foreseeable goal ie. Ryerson TCM program, the Naturopathic College, Toronto School of Homeopathic Medicine, Chiropractic College) Networking to develop a list for CLT could be another research goal and provide options for management councils to consider policy change. This may also respond to the high costs being significantly reduced, a noted barrier by the consumer group ie. SAC. A formal linkage to training institutions might provide the opportunity for staff development opportunities and advice on special issues on an as-needed basis.
4. Develop a thorough report to agencies about legislation and developments on CAM in Ontario, HPRAC and New Directions for Healthcare in Ontario Bill 171 (appendix).
5. Taking into consideration the roles that agencies play in supporting people with intellectual disabilities, liaise with such agencies to develop a long-term goal that envisions “choices” that are reasonable, affordable and safe. Under the RHPA members of the College of Physicians and Surgeons have a responsibility to refer to other regulated health professions, and these include those regulated “health professions” set out by the Ministry of Health. In this respect, the issues relating to “best practice” as defined by the CPSO alleviate agencies of any responsibility. Furthermore, some areas of CAM pose no significant risk in administration ie. most forms of energy medicine, therapeutic touch, nutritional counselling, reflexology and accupressure, or pose very minimal risk ie. acupuncture, supplementation, chiropractic care, herbalists/botanical medicine etc. Envisioning the possibilities of CAM could be a long term management team goal and a specialized research opportunity could alleviate the burden to an agency in gathering relevant information on the topic.

## **Conclusion - The Bottom Line!**

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***Education is key to informing people with intellectual disabilities about CAM and how it is included in today's healthcare system ie. community health.***

*People are shaped by the environment, its structure, social rules, norms and obligations. They are placed in a role and work within structures to enact change that shapes the world around them. In some way they are both adapting themselves to a system that is evolving in a very complex inter-relationship with many other social groups, and through this the structure itself changes. We are shaped by the world, and we shape the world. The actors in this role for the purposes of my investigation were people with intellectual disabilities. They arrive with self-interests ie. health and desire the right to choose. They require that the language and format of information related to CAM change to include them. A broader Inclusion by this group in terms of CAM use is likely to shape the contours and complexity, perhaps the legality and safe-use of CAM. Stepping further into the future with this study, would mean developing some of the educational materials to allow people with intellectual disabilities, care-givers, families and agencies adequate information to understand more of how CAM is included in community health, and how it will impact them in the future.*

***My research objective was to better understand the disability community around the issue of CAM use.***

This objective was met, but by a much smaller and well defined group of individuals from the intellectual disability community. The Self Advocates Council of CLT forms a network of people who represent individuals with intellectual disabilities, and accordingly, they raise questions in regard to the barriers confronting that group on a number of issues related to service delivery. Unique to this group is the partnership they have with a formal agency in creating change. I believe this formal linkage between the Self Advocates Council and the Management Council of Community Living Toronto represents an important and powerful partnership to support positive change. The agency has a positive mission and vision committed to the consumer group, and the consumer group has a positive role in the partnership of change.

The consumer group raises very important issues in respect to CAM. It would be very achievable for them to formalize this and provide feedback to the Management Council of CLT. My perception is that the group is interested in having a voice on the matter and my intention is to provide them with a summary report to deliver to the Management Council. *This report may serve as an example of literature on the topic for future reference, and be the subject of further research to broaden the agencies vision of CAM use in the disability community.* Ultimately, that is an auspicious end to this research work. To explore the topic, to educate and to inform.

***The lives of people with intellectual disabilities is shaped by the use of complementary and alternative medicine.***

Disability Studies is based on the premise that the disadvantage typically experienced by those who are disabled reflects primarily the way society defines and responds to certain types of 'difference'. Complementary and Alternative Medicine is simply 'medicine' seen through a different perspective of understanding health and wellness. It is traditionally non-invasive,

holistic, individualized and non-diagnostic. CAM frames disability within a structure to treat without diagnosis. A tenet of social construction theory is a medical model of diagnosis, however; CAM offers the possibility of an alternate socially constructed reality. Social construction theory can be complicated and difficult to grasp, and in addition to this, CAM offers another complicated paradigm shift. It is through social construction theory that we identify the medical model, and through this we can compare how people are stigmatized by different systems of medicine. If the experience of disability is partly or in whole a phenomenology, and there are implications related to disease labels, it is of some importance to recognize that only some systems of medicine utilize disease labels. A manner in which to communicate this in simpler terms is provided to illuminate this, and described in the conclusion of the final research report.

***Development of a survey or list of questions as suggested by the SAC in “plain language” was developed.***

Although it is not to be employed, it serves as a starting point in understanding the issues confronting a researcher in this area of study.

***This research report does provide special insight to understand how advocacy and change work logistically within the consumer movement of community living chapters across Canada.***

***This research report provided insight and education about CAM to a Toronto Social Service Agency and to a group of consumers with an interest in CAM. These stakeholders will be provided with a copy of this report as a resource for further discussions on the matter of CAM use in the disability community.***

# Annotated Bibliography

**Esmail, Nadeem, “Complementary and Alternative Medicine in Canada: Trends in Use and Public Attitudes”. Public Policy Sources, Fraser Institute, May (2007); 1-53.**

The social model of disability is implicated in the study, but not referred to specifically. The study implicates that health affects all Canadians and that factors influencing this include the wealth of the individual, a need for special therapies or diets and/or specialized care. These are factors that shape the culture of living with a disability in Canada, and are therefore relevant to understanding how medicine in particular influences the quality of life of the individual. The study is focused on complementary and alternative medicine (CAM) use in Canada. A questionnaire/survey was used by the Fraser institute in gathering relevant data on the trends, usage and attitudes toward CAM.

This recent study (2007) has quantitative data on the use of complementary medicine in Canada among the general population, citing demographics that include disability. It is also intended to understand the qualitative aspects of choices people make in regard to complementary and alternative medicine.

Disability is mentioned in regard to demographic information about employment status. Pain is mentioned in regard to back pain, chest pain, chronic pain, burn pain and general pain. Conditions such as cancer, diabetes, high blood pressure, fatigue, prostate problems, headaches, allergies, irritable bowel syndrome, pains/strains, edema, inflammation, arthritis, rheumatism, and dental problems are cited, as well as, stroke, Parkinson’s, neuropathies and liver or bladder problems. A multitude of factors influence the average Canadian seeking out CAM, and one aspect of this is disability related illness.

Alternative therapies or modalities/systems of medicine include Chiropractic, Naturopathy, Homeopathy, Prayer, Relaxation Techniques, Acupuncture, Aromatherapy, Folk Remedies, Osteopathy, Hypnosis, Chelation, Biofeedback, Spiritual or Religious Healing, Energy Medicine, Yoga, Herbal Remedies and Vitamin Supplements. This study is a good recent baseline study of the general population in regard to CAM use in Canada.

**Kyung Mee Kim and Michael H. Fox, “Disabilities, Moving to a Holistic Model of Health among Persons with Mobility”. Qualitative Social Work (2006); 5; 470**

The model of disability is referred to in the article and explains it in the context of health and wellness. This article is pertinent to my research, as it reflects the holistic paradigm as a model that portrays disability in different terms. The contrast between the medical model and the alternative medical model of

perceiving health is approached from a very similar stance as my interests in this project.

Disability is referred to in the article as well as health and wellness. This research is related to alternative medicine and health and is therefore relevant to the project I am undertaking. Research related to a holistic healthcare paradigm that is also about individuals in the disability community is limited. This is one of the few articles I could find on the topic.

**Guthlin C, Lange O, Walach H. “Measuring the effects of acupuncture and homoeopathy in general practice: an uncontrolled prospective documentation approach”. BMC Public Health. (2004);4:6.**

The social model of disability is implicated in the study, but not referred to specifically. The research was funded by a German health insurer to understand the use and effectiveness of acupuncture and homeopathy. This was achieved through the distribution of ‘quality of life’ questionnaires to 5000 acupuncture patients and 900 homeopathy patients in 2003. Work absenteeism and the cost associated with both homeopathy and acupuncture were key aspects of the research.

People with back pain tended to take more time off work than subjects of the German study who experienced other types of pain. Pain and pain management has economic influences, as it relates to the patients ability to be employed or remain employed.

Acupuncture and homeopathy were the focus of the study. Pain management is a factor in seeking out acupuncture and homeopathy. The use of homeopathy and acupuncture for the management of pain is cited in the article. Key factors instigating the research include a very limited understanding of the usefulness of such therapies, and also, costs associated with this type of care, absenteeism from the workplace or unemployment. People with disabilities are not specifically mentioned in the study, however; long term unemployment is a factor facing people with disabilities, including those who utilize CAM.

**J. Tsao, A. Dobalian, C. Myers, L. Zeltzer. “Pain and Use of Complementary and Alternative Medicine in a National Sample of Persons Living with HIV”. Journal of Pain and Symptom Management, Volume 30, Issue 5, (2005); Pages 418-432**

The condition arising from HIV – AIDS is considered a disability in Canada. Further to this, the social imposition of stereotypes related to a diagnosis of HIV is relevant to the social construction of disability. This qualitative and quantitative study.

This article refers to disability and pain, and was published in a professional journal on pain management. This research is related to alternative medicine and patients with HIV. It intends to understand CAM use in this community, as complementary or apart from conventional methods of treatment.

**Maha N, Shaw, A. “Academic doctors' views of complementary and alternative medicine (CAM) and its role within the NHS: an exploratory qualitative study”. BMC Complement Altern Med. (2007); 7: 17.**

The social model of disability is implicated in the study, but not referred to specifically.

This exploratory study used qualitative methods to explore academic doctors' views of CAM and the rationales they provided for their views. Several like minded studies in the USA have provided varied feedback from doctors about CAM and the factors influencing the use of CAM by patients. This is a small study that makes reference to the supportive care ie. Doctor-Patient relationship that is more entrenched in holistic healthcare training and practices with patients. A lack of judgement around making an informed decision in regard to CAM was cited by doctors, as they are not formally trained in such therapies. This relates to the social model of disability, as disability is a social construct or condition stemming from a diagnosis that further impairs the individual beyond the symptoms alone. The perspective that all people experience health and wellness, as well as, illness or disease, and that each person is unique in response to their condition or health status is a universal tenet of many complementary and alternative forms of medicine, including homeopathy.

A combination of skepticism and support exist for CAM in the UK, similar to other countries. Doctors trained in allopathic medicine have little training in CAM. General practitioners are aware that their patients seek out CAM for conditions that are ineffectively treated by conventional therapies. This is a small study that examines attitudes toward CAM by General Practitioners in the UK. It cites doctors opinions on the use of CAM, and the limited knowledge they have of the use of other modalities and the reason for patient use of CAM. This is relevant to my research topic, as it relates to the attitudes of physicians toward CAM, and when they might refer a patient with a disability to an alternative medical practice. Awareness of CAM is further limited in Canada by the single modality of treatment available under national funding.

**MacNevin , Audrey, “Remaining Audible to the Self:Women and Holistic Health”. Atlantis 27.2, (2003); 1:2.**

The social model of disability is not referred to specifically. The paper is based on holistic health perspectives and is a qualitative piece of research about how women perceive their personal health. Themes consistent with the contrast of holistic health paradigms and western medical paradigms about the perception of one's personal health is congruent to my research interests.

Disability is not specifically referred to in this article. This research article is related to alternative medicine in the reference to growing trends in holistic health perspectives.

**Mercer SW, Reilly D, Watt GCM. The importance of empathy in the enablement of patients attending the Glasgow Homoeopathic Hospital. Br J Gen Pract. (2002); 901–905.**

The social model of disability is implicated in the study, but not referred to specifically. This study was undertaken as an exploratory questionnaire to understand the qualitative aspects of the doctor-patient relationship. The importance of empathy was focussed upon and included aspects of the consultation length with patients. Patient enablement in general practice is known to be limited by consultation length. The objective of the study was to investigate patient enablement in a setting where time is less of a constraint than in primary care. CAM, and in this particular case homeopathic case-taking is explored as a therapeutic aspect of treatment that enables the patient. People with disabilities are not mentioned in the research, however; patient care, empathy and time factors are seen as intrinsically important in patient care, and particularly relevant to people with disabilities who may require facilitation to communicate to healthcare providers, or present with significantly more complex healthcare needs.

Disability is not specifically mentioned in the research study. Alternative medicine is a focus of the study. Pain management is not mentioned in this research, however; conditions that concern chronic pain management tend to also involve diseases, injuries and disability. In this respect, enablement of the patient through more thoroughly understanding the patient's lifestyle, condition and sense of wellness is seen as relevant my intended research question and topic.

Disability crosses the threshold of many conditions. Disability is a complex and often very individual experience, and consequently in regard to disability, the patient may require longer consultation with a physician than someone with acute types of injuries or conditions.

**Gerry E. Hendershot, PhD. “Mobility Limitations and Complementary and Alternative Medicine: Are People with Disabilities More Likely to Pray”? American Journal of Public. (2003); 1079–1080.**

The social model of disability is not referred to specifically but is implied in the context of the research. The relevant question raised in this research study is related to the practice of prayer, a non-conventional and alternative approach to managing personal health. Prayer is an alternative choice in relationship to healthcare treatment options, and is therefore a basis to establish the argument that CAM approaches to health represent practical choices outside of mainstream conventional medicine, and that these approaches are important for

reasons beyond the scope of empirical evidence to support the practice. Self-determination of CAM practices relevant to the individual matter regardless of scientific evidence to support them.

Conditions where pain is a factor in choosing prayer are referred to and disability is inherent within the context of a medical diagnosis of the conditions mentioned in the research. The article is about non-conventional approaches to managing health conditions.

**Massimo Giannelli, Marina Cuttini, Monica Da Frè, and Eva Buiatti, “General practitioners' knowledge and practice of complementary/alternative medicine and its relationship with life-styles: a population-based survey in Italy”. *BMC Family Practice*, (2007); 1471-2296/8-30.**

The social model of disability is implicated in the study, but not referred to specifically. A cross sectional study disseminated to 1798 physicians in the Italy to determine the use of CAM by patients, and the physicians understanding of type of CAM. A response rate of 82% was achieved with the most commonly practiced modality used by patients being homeopathy. The general interest of the survey was to understand quantitative aspects of CAM use and physician knowledge of different types of alternative medicine. The outcome of the survey indicated that although CAM usage is quite common, physicians lack an understanding and training around CAM. This has relevance to the social model of disability, as the social construct of disability in medical terms is largely based upon a diagnosis and relevant prescribed types of care. Labels and the social construction of negative images of those affected by a disability are in part related to a system of medicine that sees the individual as part of a certain group because of presenting symptom pictures. Patients with similar symptom pictures are labelled according to a stratification or typology (a classification of things according to their characteristics), where medical treatment is less concerned with the individual per se, and more concerned with what medical classification they fit into according to a prescribed set of standards. The resulting medical care a patient receives is dependent upon what category of disability they fall into, and thus, this creates a regiment of treatment that works toward resolving that individuality that is unique and considered sick or broken. Holistic medicine sees each person as unique and groups symptoms together for treatment without the need for medical diagnosis, and while similar symptom pictures arise among individuals, holistically, this is of less importance as the persons own unique responses to the process predominate treatment plans. Social construction of disability begins with the medical diagnosis, and terms and conditions of care hinge upon a patient accepting only one singular modality of care and often a very limited scope of understanding disease, illness, disability or treatment options. This study of Italian physicians indicates again, that there is a disparity between the publics use of CAM and physician knowledge about alternative medicine.

Disability is not specifically referred to in the study. Pain is referred to in regard to chronic pain, acute pain and some limitations in western medical practices to

resolve or assist in pain management. The list of CAM in this study included the following eleven types which were investigated: acupuncture, phytotherapy (also referred to as herbal medicine), homeopathy, manipulative therapies (including chiropractic and osteopathy), moxibustion, Bach's flower therapy, Shiatsu, plantar reflexology, Ayurveda, mesotherapy (technique where medication is injected into the mesoderm) using unconventional medications, and pranotherapy (energy healing based on the laying-on of hands). Pain management was one factor in patients seeking out CAM.

Alternative therapies need to be further explored to understand why some patients cope or resolve health issues through the use of CAM. Public awareness around the management CAM is of significance to my research topic. People with disabilities rely on healthcare practitioners for sound advice to cope with a myriad of different symptoms. All systems of medicine are relevant if patients seek them out and find that they are effective, regardless of empirical scientific studies to understand why they are effective. The empirical scientific approach to evidence based medicine creates limits that tend to support only western medical theories to disease and treatment, and institutions that only fund particular types of medical research and accordingly that only ask specific questions about patient care. The disability community in Canada is more affected by limited scopes of practice, as they more often seek out medical care than the average Canadian.

**Park, Jungwee, "Use of alternative health care". Alternative health care: Statistics Canada, Catalogue (March 2005;) Health Reports, Vol. 16, No. 2, 82-003.**

The social model of disability is not referred to specifically. The research is published by Statistics Canada and refers to the demographics related to CAM use in Canada. This information is relative to my research topic. Disability and pain are not referred to in this article, however; certain specific health conditions are referred to in reference to CAM use.

This statistical information is about alternative medicine use and refers to conditions for which pain management is a common concern.

**Heather S Boon, Folashade Olatunde, and Suzanna M Zick. "Trends in complementary/alternative medicine use by breast cancer survivors: Comparing survey data from 1998 and 2005". BMC Womens Health. (2007); 7: 4.**

The social model of disability is implicated in the study, but not referred to specifically. This study is in reference to the use of CAM in women diagnosed with breast cancer. It finds that most women diagnosed with breast cancer use both traditional and non-traditional approaches to care, and suggest that further research be carried out in regard to the safety and efficacy of CAM. Cancer is seen as a disability for the purposes of my research topic. Cancer treatment is largely limited to the scope of understanding disease through an allopathic

doctrine and while usage of CAM appears to be quite high it is not reflected in physician knowledge or understanding of CAM. This particular community is very affected by the limited research and knowledge of CAM. This joint study by the University of Toronto and University of Michigan clearly indicates a public demand for alternative medicine.

Pain is cited as one factor in seeking out CAM in cancer care. Cancer is seen as a disability. Pain itself can be disabling, however; from the social construction perspective pain is seen as a symptom and further to this, how the medical community responds to pain becomes the disability. Different approaches to pain management are required to lessen the resulting disability.

Cancer and many other diseases or conditions cannot be fully explained or understood by science, and therefore treatment options are limited to only a few scientifically supported therapies. People with cancer seek out and use other forms of medicine. When a patient uses many approaches to treatment, the efficacy of a single treatment cannot be understood or measured. Some forms of cancer treatment can be very toxic to the patient, and are therefore not seen as beneficial in some patient care. A person diagnosed with cancer should have many treatment options, based upon different perspectives of a disease process. Pain is a significant factor facing breast cancer patients, especially those in more advanced stages.

**Herman CJ, Allen P, Hunt WC, Prasad A, Brady TJ. "Use of complementary therapies among primary care clinic patients with arthritis". Prev Chronic Dis. (2004); 1-4.**

The social model of disability is not referred to specifically in this article. The condition of arthritis is referred to in the article. Arthritis is a common condition where disability is present. CAM is often used by patients with arthritis and rheumatism, as a primary treatment option or in conjunction with conventional medical approaches. Arthritis is considered a chronic disease process. The research is both quantitative and qualitative in nature.

Arthritic complaints and disability are commonly associated with a symptom of pain. People experiencing pain are limited from full participation in society, and as a result are affected by the stereotypes and issues of poverty through exclusion similarly to other disability groups. Arthritis a complex and widespread condition in people of various ages, however; many older people are affected. Age is a factor in the social construction of disability.

**Max Haidvogel, David S Riley, Marianne Heger, Sara Brien, Miek Jong, Michael Fischer, George T Lewith, Gerard Jansen, and André E Thurneysen: "Homeopathic and conventional treatment for acute respiratory and ear complaints: A comparative study on outcome in the primary care setting". BMC Complement Altern Med. (2007); 7: 7.**

The social model of disability is implicated in the study, but not referred to specifically. This 2007 study of 1,500 patients was a comparative analysis of allopathy and homeopathy for acute illnesses in a primary care setting. The study indicates acute pain management is effective using homeopathic medicine. Acute care or crisis is not seen as a disability, however; the allopathic approach to acute pain management has been successful, and emergency medicine is largely an allopathic enterprise. One distinction between allopathy and homeopathy is the urgency to act in a manner which is suppressive i.e. anti-pyretics for fever. This is a common approach in allopathic care, and often thought of as a last resort in holistic medicine. The transference of this practice of suppression outside of emergency medicine and into a wider range of treatments such as mild acute illness or in chronic care is seen as unhealthy, and can complicate the disease state of an individual. For the purposes of my research, this literature is relevant because it raises important questions about paradigms in medicine and how we understand and treat disease. It is not relevant because one practice is better or as good as another, but only to support the idea that different ideologies about disease processes are relevant.

Pain is mentioned in the article, but references to disability are absent. The condition of the patients in the study are of an acute nature. Pain management and the use of CAM is a theme of the article. Merging or even conflicting paradigms in medicine create different approaches to care. Different approaches to care are relevant, because individuals respond differently to alternative and complementary treatment regimes. People with disabilities use CAM, sometimes in conjunction with other treatments.

**McEachrane-Gross FP, Liebschutz JM, Berlowitz D. “Use of selected complementary and alternative medicine (CAM) treatments in veterans with cancer or chronic pain: a cross-sectional survey”. BMC Complement Altern Med. (2006);6:34.**

The social construction of disability is not referred to specifically. Since the medical diagnosis of cancer is one which is inherently life threatening, the patient is often faced with concerns and treatment in relationship to conventional medical approaches to care. The medical diagnosis is a social construct or typology that compels patients to make choices about treatment plans, and these treatment plans can create disability through the secondary side effects of therapies. The social construction of disability then, has the ability to transcend potential limits of positive effect and result in harm to the patient. This contrasts many CAM approaches to care that are safe, reliable and arguably effective. Treatment options that pose no impending threat to the individual become attractive, without assuredness of positive results from conventional treatment. Conventional so-called “evidence based” treatment is often ineffective and also a theoretically based approach. The term “evidence based” used in conventional healthcare terminology only refers to treatment that is tested within the parameters and scope of a currently evolving understanding of science, and by these limits is also a theoretical framework from which to understand healing arts and sciences.

The research article is in regard to cancer care and recognized as a medical condition for which limitations exist that limit an individual's full participation in society. Age is also a factor in the use of CAM. Age is a factor in developing disability within the social construction theory.

Disability and conditions for which pain is a factor in choosing CAM is referred to in the research article. This article is about alternative medicine and treatment. Pain is a factor in cancer care.

**Caul Ong CK, Peterson S, Bodeker GC, Stewart-Brown S. "Health status of people using complementary and alternative medical practitioner services in 4 English counties". American Journal of Public Health. (2002); 1653–6.**

The social model of disability is not specifically referred to in this research paper, however; health status implies conditions for which disability is inherent and obvious. This article was published in the American Journal on Public Health. Within the context of healthcare in Canada the term health status can refer to disability. The inference of non-health or unhealthy patients dependent upon a medical diagnosis is one manner in which language or terminology subjects the individual to the imposition of a negative status within the population of those considered healthy. A medical diagnosis confers disability depending on the type of condition, severity of impairment or injury and/or progression of a disease process. The health status of an individual limits and delimits participation, and depending on the condition or diagnosis, it can result in prejudice and personal harm. Health status is a term related to the social construction of disability.

Disability is referred to in the article. This research article is about CAM and various conditions for which CAM is chosen.

**Field T, Debow S. "A systematic review of how homeopathy is represented in conventional and CAM peer reviewed journals". BMC Complement Altern Med. (2005); 5:12.**

The social model of disability is implicated in the study, but not referred to specifically.

This study was conducted to compare any publication biases in respect to CAM. The study involved 251 research experiments between 1994 and 2004 and found that (46 peer reviewed articles in some 23 medical journals), of those in conventional journals 69% (18/26) reported negative findings compared with only 30% (6/20) of CAM journals reporting negative findings. Of those with negative findings, the language used to condemn homeopathy was more critical and harsh in the conventional journals. This comparative analysis of studies on homeopathic medicine cannot wholly speak to the multitude of other studies

published in other languages, however; there is a suggestion that some type of publication bias may exist in the publishing of articles on homeopathic medicine.

Disability not mentioned in the above article. The social construction of a bias toward a group or even toward an academic discipline can be the result of special interests or a multitude of other factors. Economics is usually a major factor in discrediting one theory over another. The adopted theoretical approach is often difficult to refute as it becomes the status quo or standard accepted truth, regardless of evidence that might suggest anything contrary. Western medicine is largely deemed an evidence based medicine, although theoretical frameworks abound the entire practice of allopathy. Medicines based upon other tenets or principles outside of the empirical quantitative scientific paradigm tend to be compared to that paradigm for approval, even if they are not based on the same principles. When we compare things like this, they just don't make sense, and so literature and studies tend to reflect negative findings when those doing the research have a single paradigm in use.

The social construction of disability is partially if not wholly the result of an oppressive medical model. The social construction of disability is connected to a medical diagnosis. Our consciousness has been shaped to see human beings as collateral to nature, and therefore a great deal of subjectivity prevails in the many attitudes we have adopted over time. There is a new milieu in medicine, science and in social research that demonstrates a greater connectivity between us all, between ourselves as human beings and also between ourselves and the planet. Our sense of disconnection has contributed to the creation of large systems, primarily destructive to human kind. Of course, it has yet to be fully realized, but some attitudes and influences are changing that, and may shape a new status quo.

**Witt CM, Ludtke R, Baur R, Willich SN. "Homeopathic medical practice: long-term results of a cohort study with 3981 patients". BMC Public Health. (2005); 5:115.**

The social model of disability is implicated in the study, but not referred to specifically.

A 2005 German and Swiss study of 4000 patients who seek homeopathic care. German studies show there is a growing public interest in naturopathic and homeopathic therapeutic models. This particular study surveyed both patients and physicians around illness and quality of life, finding pronounced benefit from these models of primary care. One of the findings of the study revealed that there was a predominance of patients seeking out homeopathic care we experiencing long term chronic disease. The study gathered qualitative and quantitative data on participant health and choices for healthcare.

**Ernst E, Pittler M. "Efficacy of Homeopathy Arnica: A systematic review of placebo-controlled clinical trials". Arch Surg. (1998); 133:1187–1190.**

The social model of disability is not referred to in this research paper. It is a quantitative study of the use of a homeopathic remedy to understand the effectiveness of a CAM approach to treatment.

The research article is related to pain management using CAM. Pain is a symptom of conditions for which CAM is sought out by members of the public. My research topic refers to CAM use for pain management and individuals experiencing pain. Pain can be differentiated from disability, however; people with disabilities often seek palliative treatments for acute pain management. Arnica is a common homeopathic remedy for the treatment of pain. Homeopathic doctrine does not indicate remedy prescription on the basis of a single symptom, yet certain polycryst remedies are well suited to conditions of pain, in that proving symptoms from the substance in overdose create similar symptom pictures of inflammation, bruising and consequently pain. Homeopathy is based on the law of similars, and as such, the remedy fits within the symptom picture where pain is exhibited. Several species, such as Arnica montana and Arnica chamissonis contain helenalin, a sesquiterpene lactone that is a major ingredient in anti-inflammatory preparations (mostly against bruises). The remedy is used in both concentrated applications such as ointments and in highly diluted homeopathic remedies. I am citing this in my research as an example of a commonly used remedy for the treatment of pain and inflammation as an alternative medicine that overlaps with herbal medicine and conventional medicine. Plant remedies and other natural substances are common in many CAM treatments and often the origins of conventional treatments stem from earlier use in folk medicines or native medicines. The trademark approach to marketing conventional medicine fits within a social construct that separates the person from nature, hence building upon the ideology that the human organism is collateral to nature, rather than sharing a synergy with the world around us. Disease in holistic medicine is seen as an imbalance with a natural state, and remedies are seen as inciting a state of attunement unique to the individual. This theory is relevant to the social model of disability, as no person is in a state of imbalance in relationship to another individual. The state of balance refers to a relationship with the world that is harmonized by factors outside a conventional ideology of pathology, and factors such as mental emotional states, spiritual states and body-mind, energetic or ecological states are important to the healing mechanisms of the body, in addition to pathology. "In an ecological context any individual organism or single-species population of organisms exists not in isolation, somehow separable from the complexity of interactions around it, but as an integrated component within a complex ecological 'whole' - one part only of an intricate mechanism of interdependent, individually moving parts" (Putman, 1994). The differentiation with conventional health ideology lies at a root philosophical level, where the origins of disability construction are a part of a principle where the patient is compared to a common group within the community, and then grouped within the stratification of a diagnostic system that dictates certain invasive or medical protocols. The highly individualized holistic approach sees each person as unique and identifies philosophically with an ecological sense of belonging.

**Vallerand AH, Foulabakhsh JM, Templin T. “The use of complementary/alternative medicine therapies for the self-treatment of pain among residents of urban, suburban, and rural communities”. American Journal of Public Health. (2003); 93:923–925.**

The social model of disability is not referred to in this article. The article pertains to comparisons in CAM use in urban and rural communities. Geography plays a part in our experiences as members of society. Our knowledge of healthcare is affected by where we live. Having options in healthcare is ultimately empowering, and conversely disempowerment evolves from a lack of choices in treatment. This is reflected in the social model of disability, where status and membership, segregation, integration and citizenship are concerned. The theme of oppression or disempowerment by limited choices evolves from a theme of isolation. Interconnectedness versus disenfranchisement is apparent in a model of the social construction of disability. Pain management is a focus of this research. CAM use for the treatment and management of pain is the primary objective of the research. An array of different strategies qualify as CAM and are cited in the article.

**Tyler C Smith, Margaret AK Ryan, Besa Smith, Robert J Reed, James R Riddle, Gia R Gumbs, and Gregory C Gray. “Complementary and alternative medicine use among US Navy and Marine Corps personnel”. BMC Complement Altern Med. 2007; 7: 16.**

The social model of disability is not referred to in this article. The focus of the research is to understand the use of CAM in the US Navy and Marine Corps. The social model of disability is entrenched in social construction, whereby certain groups are adversely affected by treatment, and more specifically within a medical context a label or diagnosis. We expect certain people to require special treatments or therapies depending on the label or diagnosis they have. Pain transcends a particular disease, disorder or disability. Pain is a symptom. Pain is a human condition that we have all experienced, and can expect to experience in the future. The focus on CAM use within the US Navy and Marine Corps indicates the very diversity of application and interests in CAM in the United States. The social construction of disability is contrasted by the social construction of ability. The US Navy and Marine Corps represent an enclave of individuals who are typically perceived as very healthy. We socially construct concepts of health and wellness by perceiving some groups as more or less healthy in comparison to other members of society. Certain individuals are perceived to be more entitled to care than others.

Disability is not noted in regard to a particular disability. Themes of disability and pain can overlap, where a person discusses pain that may be interfering with activities of daily living but that person may not identify or associate that with a disability. Self-identification is a factor in the social model of disability.

**Shen J, Andersen R, Albert PS, Wenger N, Glaspy J, Cole M, Shekelle P. “Use of complementary/alternative therapies by women with advanced stage breast cancer”. BMC Complementary and Alternative Medicine. (2002); 2:8.**

This research article pertains to the use of CAM by women with advanced stage breast cancer. Reasons for using CAM and as a complementary therapy are discussed. The research is qualitative and quantitative in nature.

Cancer is a condition for which pain is a factor in seeking out CAM. The diagnosis of cancer has social implications beyond the scope of a label or disease process. Quality of life issues around treatment plans and the option to utilize complementary medicine can be seen as empowering. This article is written about CAM for advanced stages of breast cancer and patients cite pain as a symptom of the condition.

**M Haetzman, AM Elliott, BH Smith, P Hannaford and WA Chambers, “Chronic pain and the use of conventional and alternative therapy”. Oxford Press: Family Practice Vol. 20, No. 2, (2003); 147-154.**

The social model of disability is not referred to in this article. This research paper pertains to general aspects of pain and the use of both conventional and non-conventional approaches to pain management. Is one treatment better than another? Should medical ideologies be a merger of different practices or should a single modality in medicine be predominant in a culture. The growing interest in CAM use demonstrates an interest in diversifying our healthcare portfolio to address complicated healthcare needs. This is just one study looking at the practice of non-conventional and CAM approaches to health.

Pain is a major focus of this paper. Chronic pain is often the result of a condition or diagnosis, where symptoms have persisted for more than a few weeks. Many conditions considered to be chronic health conditions limit participation in society. Chronic conditions are often thought of as a disability. Chronic pain regardless of a diagnosis is a condition is disabling, however; playing within the context of social construction, it is imperative within the conventional medical system to assign a diagnosis in order to develop a treatment plan. The necessity to label in order to treat effectively is not an aspect of CAM. Both CAM and conventional medicine are looked at to explore the management of pain, especially chronic pain.

**Brian M Berman, “Integrative approaches to pain management: how to get the best of both worlds”. British Medical Journal. (2003); 1320–1321.**

The social model of disability is not referred to in this article. Integrative medicine is a method through which treatment is coordinated, usually between a

conventional medical doctor and a CAM doctor or practitioner. Complementary usually refers to a patients use of an alternative health care practice that might not be advised or supported by a conventional medical doctor. Often patients do not discuss the use of CAM with their medical doctor. Alternative medicine can mean using systems of medicine or therapies that are non-conventional, sometimes apart from conventional treatments. These terms overlap and are sometimes synonymous. The concept of utilizing combined treatment strategies is a relatively new concept.

Disability is a focus of the research. Alternative Medicine for health management is a focus of this research paper. The term “integrative” is key to understanding some treatment plans that involve coordinated use of both CAM and conventional medicine. The concept that co-existence and merging medical practices in a single treatment plan are possible. Issues raised but not discussed in the article that pertain to further exploration on the topic of merging healthcare practices include the collision of two ultimately different spheres of treatment philosophically and sometimes physiologically. Peoples assumptions that CAM is ultimately good, and the applied and practiced use of CAM in conjunction with conventional medicine poses risks that are seen and unforeseen. Excessive use of CAM or over-use of any particular treatment ie. megadose of vitamins is potentially harmful, as is the expeditious and extremist practice of any therapy without a thorough knowledge of healthcare implications. Being unaware of options in healthcare can be disempowering. Being aware of treatment options can be empowering. Improper application of therapies or treatments that are at the immediate disposal to the layperson because of financial means or simply perceiving CAM as ultimately beneficial without weighing need, risk or even benefit is another aspect of a growing application of CAM in modern culture. Simultaneous use of many therapies may be less useful, and dependent upon the proper application. Education about CAM is needed to inform the public about the benefits and risks. The goal of integrating therapies should be carefully considered to ensure the systems complement each other in ways the ultimately improve the health and vitality of the individual.

**Amir Shmueli and Judith Shuval, “Are Users of Complementary and Alternative Medicine Sicker than Non-Users”? Evidence Based Complementary and Alternative Medicine (2007); 251–255.**

The social model of disability is not specifically referred to in this article. The term sick is raised as a term applied to people those experiencing illness. Sick is also a term sometimes improperly applied to individuals with disabilities. Having a disability does not imply being sick, however; in conventional medicine there is an implication of being sick if a medical diagnosis is applied to the patient.

Alternative medicine and disability related illness are a focus of this research study. The study finds that individuals who use CAM are less likely to experience illness. The concept of prophylactic use of CAM is implied, something inherent in prevention rather than treatment. CAM doctors tend to look at the etiological beginning of disease processes and focus on maintaining or re-establishing

balance or homeostasis. The preventative aspects of CAM can be more fully realized in the absence of disease, however; outcomes are often not measurable. The focus on healthcare as a practice of treatment for a disease processes rather than on prevention is a social construct dictated by a scientific methodology that demands measurable outcomes. We can more accurately measure the number of people who have been treated and survive an illness, than those who we treat preventatively who never become sick. This aspect of conventional care is predominant in our culture and arguably created many forms of complicated illnesses.

**James F Jones, Elizabeth M Maloney, Roumiana S Boneva, Ann-Britt Jones and William C Reeves, “Complementary and alternative medical therapy utilization by people with chronic fatiguing illnesses in the United States”. BMC Complement Altern Med. (2007); 7: 12.**

The social model of disability is not referred to in this article. Chronic fatigue illnesses are the focus of the study. The term chronic fatigue is a purely descriptive term and the underlying disease processes are not fully known. The term chronic fatigue syndrome has evolved and is a more recent type of diagnosis in conventional medicine. CAM approaches to fatigue vary greatly from conventional care. People diagnosed with chronic fatigue syndrome often seek out CAM therapies in the absence of effective and clear treatment options in conventional medicine. The concept that CAM is an alternative treatment option when patients have exhausted all conventional attempts to cure, raises questions about the need for education around prevention rather than treatment. The “easter egg hunt” for treatments can complicate medical treatment. CAM is sometimes thought of only as a last resort.

Chronic fatigue syndrome is classified as a condition that interferes with full participation in activities of daily living. It is categorically a disabling condition, and has social implications because of the question of real illness. Again, the lack of a label outside of a purely descriptive title indicates it is not well understood. This can be interpreted by co-workers or family as malingering. The need for a clear medical diagnosis given a range of symptoms has become a mainstream expectation, and at times, in its absence the individual experience of illness is not validated, supported or treated effectively. This is a socially constructed reality that is the result of a societal expectation that all illness must have a name or label. This concept has been shaped by conventional medical science and contrasts the CAM approach to care.

**Marja J Verhoef, Laura C Vanderheyden, Trish Dryden, Devon Mallory, and Mark A Ware, “Evaluating complementary and alternative medicine interventions: in search of appropriate patient-centered outcome measures”. BMC Complement Altern Med. (2006); 6:38.**

The social model of disability is not referred to in this research paper, however; it is implicated in patient-centred outcomes. Patient-centred models exist in contrast to other models of care where the self-determination of the patient is not recognized. CAM approaches tend to be patient-centred and holistic practices in general carry a theme of connectedness that can be absent in conventional medical approaches to care. The diagnosis and label alone stand to interfere with personal practices of recognizing the individual, and it stands to reason that impersonal treatment follows. Patient centred outcome measures are difficult to identify, as the unique aspect of care varies according to the unique aspects of each patient. This study attempts to understand how CAM practitioners interact with patients to achieve successful treatment plans.

**L Carney, L Jones, F Braddon, AM Pullyblank, and AR Dixon. A Colorectal Cancer Patient Focus Group Develops an Information Package". Department of Colorectal Surgery, Frenchay Hospital, North Bristol NHS Trust, Bristol, UK, Annals of The Royal College of Surgeons of England. (2006) September 447-449.**

The social model of disability is not referred to in this research paper. This research paper refers to the developments of a focus group among 22 colorectal cancer patients. The intention of the research paper is to explore how improved communication and improve the patients decision making around his/her own care. It is relevant to my research project in regard to its emphasis on improving decision making around personal health care practices. Successful treatment plans include an awareness of all facets medical treatment.

**Helen Lester, Jonathan Q Tritter, and Helen Sorohan. "Patients' and health professionals' views on primary care for people with serious mental illness: focus group study". Department of Primary Care and General Practice, Medical School, University of Birmingham, Birmingham, UK. British Medical Journal. 2005;330:1122–1136.**

The social model of disability is not referred to in this article, however; the group providing feedback about primary care are a group of consumer survivors. The framework of the feedback by both care-givers and by consumer survivors is layed out in an organized manner and provides an example of how participant feedback can be integrated into a final research report.

# **Presentation Slides**

# **Importance:**

- **Relevance?**

**How is complementary and alternative medicine relevant to the disability community?**

- **What is CAM?**

**What do we mean by complementary and alternative medicine?**

- **Disability?**

**Is disability and CAM related? How are the lives of people with intellectual disabilities shaped by the use of complementary and alternative medicine?**

# Statistics Canada

The Canadian Community Health Survey (Disability Information Sheet (*appendix*) provides statistics on persons with disabilities and their contacts with medical professionals and alternative healthcare providers.

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The Participation and Activity Limitation Survey (PALS) outlines statistical materials on disability and societal participation.

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The report on which it is based, titled *A profile of disability in Canada in 2001*, contains findings on:

- **number of persons with disabilities**
- **type and severity of disability**
- **Age age and sex.**

[www.statcan.ca](http://www.statcan.ca)

# Complementary and Alternative Medicine

## Ministry of Health and Long-term Care Health Care Professions : Regulation

Ontario has 23 self-regulated health professions that are governed by bodies called colleges that set the standards for skills, knowledge and behavior for their members.

Eg.

The College of Audiologists and Speech Language Pathologists

The College of Physicians and Surgeons

The Royal College of Dental Surgeons

More recently regulated health professions that fall within the scope of complementary and alternative medicine include:

The College of Chiropractors

The College of Massage Therapists

The College of Midwives

The College of Acupuncturists

The College of Psychotherapists

The College of Homeopaths

The College of Naturopaths

The College of Traditional Chinese Medicine

The College of Kinesiologists

Ref. Health Systems Improvement Act

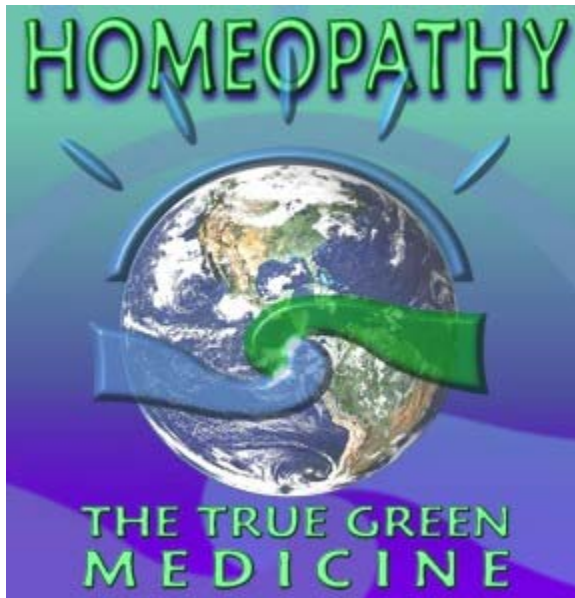
# Unregulated Health Professions:

Aromatherapy, Music Therapy, Reflexology,  
Herbalists, Yoga, Aryurveda, Reiki, Shiatsu,  
Osteopathy, Therapeutic Touch, Cranial Sacral  
Therapy, Iridology etc.

# Definitions and Distinctions: **Traditional Western Medicine**



# Complementary and Alternative Medicine



## **Differentiating systems of medicine vs. therapies:**

A system of medicine differs from a therapy. Systems of medicine refer to modalities of care. A modality is an approach to practice, a conceptual framework of understanding human illness that employs methods of treatment. A therapy is simply one type of treatment within a modality or entire system of medicine.

## **Traditional Western Medicine**

**Allopathic Medicine** – a single system of medicine

broken down into specialized practices. Eg.

Orthopedics, Psychiatry, Oncology etc.

## **Complementary and Alternative Medicine**

**Homeopathic, Naturopathic, TCM, Ayurveda,**

**Botanical, Chiropractic** – multiple systems of

medicine that are “holistic”. Each system has its

own philosophies, methods and treatments, and

is holistic in nature.

# Reductionist paradigm

- In conventional medicine or what we like to call western medicine there is a great emphasis in the duty of searching out disease, diagnosing it, and treating it.
- Most often, this means a doctor prescribing a pharmaceutical drug or a surgical procedure to remedy a chief complaint.
- There is a distinction between the disease and the person and disease labels are applied to the patient.
- The disease is treated as a separate entity from the body.
- Treatment regimes hinge upon the assignment of a diagnosis or label.

Footnote: The medical model of disability refers to this understanding of medicine, and labels are seen as a part of the social construction of disability.

# Holistic Paradigm

- Holistic health care practitioners see a symptom as a healing mechanism of the body.
- Holistic medicine does not employ disease labels or a diagnosis, and symptoms are seen as a unique characteristic of an individual's response to disease.
- Holistic health involves the “whole person” not just a physiological state of disease or disability.
- Holistic paradigms in medicine offer a different perspective on health and therefore provide a different context to understand disability.

**Opponents of reductionism**, also point out that this philosophy is based on the false premise that the sum of all the separate parts is equal to the whole. Increasing interest in holism and systems theory however, reveals that various systemic qualities are not revealed by examining the individual components. When it comes to the human body, ***“the whole will always be greater than the sum of the separate parts”***. Most importantly, in regard to the social construction of disability; this means that impairment per se is not a disability but in fact a normal state and that understanding health and wellness is not defined by a diagnostic strata, but by a state of vitality defined by each person. This highly individualized system of understanding health does not require a disease label to treat illness. All holistic systems of medicine see the whole state or holistic state as a sense of well being or harmony in a person. The so called “state of health” as defined in diagnostic strata to understand the parts that are broken or non-operational or even absent, do not explain the whole experience of health, disease or disability. If we treat by diagnostics alone, we place the experience of wholeness or holistic health in subordination to a system of labels that at once defines us, defines our experience, our abilities and in a very real way our future. Newtonian concepts in science see all things as parts that together form a whole. Pseudoscience, theoretical physics and relativity inform us of systems beyond a Newtonian concept, and what we call evidence based medicine is extrapolated from laws of science that themselves have limitations. What we can prove and what works is very much in controversy between the reductionist and holistic paradigms.

In most circumstances, holistic medicine can be included in evidence based treatment, so long as the outcomes of treatment are successful, however; many evidence based studies relate to understanding the actions of medicines, and disregard if they work and not as treatments. “Best practice” as it is termed in evidence based medicine, becomes limited by the constraints of the reductionist paradigm. “Best practices” need to be identified within each system of medicine to understand the range of treatment options and when they can be employed.

***Finally, there is no panacea when it comes to medical paradigms, and both the reductionist and holistic paradigm are relevant and postured toward health and well-being.***

## Holistic versus Reductionist **2+2=5?**

This is a major shift in perspective. Taking a holistic perspective means that you cannot understand a single problem with a single part of the human body without looking at the whole person. We use the short-hand "*mind, body, spirit*" to refer to the whole person.

Even those three parts of the person are treated by separate people in Western society. The body is the domain of the medical doctor. The mind is the domain of the psychiatrist. Spirit is left to the priest, rabbi or pastor. There is no overlap in roles, except for referrals from one to the other. In our bodies, of course, there is tremendous overlap and our mental emotional states have tremendous influences on physical health. Holistic medicine attempts to address the synergistic state of mind, body and spirit, and to accomplish this the healthcare practitioner must take time to understand the patient, his/her lifestyle and mental/emotional aspects of the world.

Holistic medicine has three main themes that set it apart from what we consider conventional western medicine in Canada. It is often seen as non-suppressive ie. it sees symptoms as a healing process of the body; it integrates physical, mental/emotional and spritual aspects of the human experience to fully understand the condition of a patient and lastly, it employs medicines or therapies that are natural, less toxic and less invasive than many conventional treatments.

## **Nature of this study/investigation:**

The medical model of disability is a paradigm that has dramatically influenced the lives of people with disabilities. Seeing an individual as diseased or broken, applying disease labels etc. is a fundamental basis of prejudice, and the sociological framework of disability study is to understand disability as a social phenomenon created by the way we develop systems, language, institutions and law related to people with disabilities. Holistic medicine sees disease in a way that creates a different perspective, a different paradigm in understanding disability.

# **What do we mean by disability:**

**The Charter of Rights and Freedoms 1985** does not define disability but prohibits discrimination related to mental or physical disability.

How does the **CPP** legislation define "disability"?

The CPP defines "disability" as a condition, physical and/or mental, that is "severe and prolonged". "Severe" means that you have a mental or physical disability that regularly stops you from doing any type of work (full-time, part-time or seasonal). "Prolonged" means your disability is likely to be long term, or is likely to result in your death.

## **Ryerson School of Disability Studies:**

Disability Studies is based on the premise that the disadvantage typically experienced by those who are disabled reflects primarily the way society defines and responds to certain types of 'difference'.

## **Medical System Definitions:**

### **Medicine Act, 1991 defines,**

The practice of medicine is the assessment of the physical or mental condition of an individual and the diagnosis, treatment and prevention of any disease, disorder or dysfunction.

### **Traditional Chinese Medicine Act 2006,**

Traditional Chinese Medicine means the promotion, maintenance and restoration of health and prevention of a disorder, imbalance or disease based on traditional Chinese medicine theory.

### **Naturopathy Act 2007 defines,**

Naturopathy as the assessment of diseases, disorders and dysfunctions and the naturopathic diagnosis and treatment of diseases, disorders and dysfunctions using naturopathic techniques to promote, maintain or restore health.

### **Homeopathy Act 2007 defines,**

The practice of homeopathy is the assessment of body system disorders and treatment using homeopathic techniques to promote, maintain or restore health.

## **Complementary and Alternative Medicine**

CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.

## Appendix B (- a rationale -)

"In the sky, there is no distinction of east and west; people create distinctions out of their own minds and then believe them to be true."

Siddhattha Gotama (Buddha)

The purpose of the research project "Pain in the Rear" was to emphasize an emancipatory approach to understanding questions arising in the disability community about complementary and alternative medicine. A theme of "vision, passion and action" arose from this survey development in the disability community, revealing an important connection between social construction theory, a dominant approach within the field of disability studies research and the homeopathic paradigm. The theory of social construction within disability studies opposes former oppressive medical model views of disability, where disability is seen as an impairment and the person with the disability needs rehabilitation to evolve into normal activities of daily living, employment and health. The social construction theory perceives the person with a disability as healthy, and sees the way society is built physically and socially as the real barrier to full participation. The holistic perspective of homeopathy aligns itself with this tenet, and is similarly opposed to the medical diagnosis. The medical diagnosis is a socially constructed ideology, that creates labels to treat disease, and in doing so creates social stigma associated with those labels. In some cases of disease or impairment, the stigma of the medical diagnosis or label is seen as a greater barrier to participation than the disease or impairment itself. The diagnostic system of medicine has a history of oppression within the disability community.

Homeopathy as a non-diagnostic system of medicine treats impairment or changes from a healthy state to a diseased state through the lens of symptoms to establish a gestalt or portrait of disease. From a Hahnemannian or classical homeopathic approach, disease labels are not a constructive manner in which to understand or treat disease. Through this lens, a different social reality exists for persons with a disability. It is through this, that I have developed a conference paper entitled no-name (non-diagnostic systems of medicine and the social construction of disability). In no way can social construction theory or the homeopathic paradigm be fully understood through this paper. Separate reading on both social construction theory and homeopathy is suggested to fully appreciate the connection between the two and the common ground they share in medicine that works without the need to diagnose or label people, and therefore a state of health that includes a person with a disability.

Ryerson School of Disability Studies scholarships committee provided an award and monies to deliver the paper at an international disability studies conference at Lancaster University in the United Kingdom in September 2008. The Bill and Lucille Owen Award in Public Policy helped provide the opportunity to travel overseas and network with other researchers and present this social policy paper. The Center for Disability Studies Research (CeDR) provided a forum to deliver a message about medicine that sees disability in a different social framework than the conventional medical model, and offers an opportunity to envision a more inclusive society.

## **Appendix C ( - research - )**

**Topics related to this project were presented at the following academic forums:**

### **Center for Disability Studies Research (CeDR) 2008 Lancaster University United Kingdom – Disability Studies Conference**

CeDR is the hub of a network of teaching and research staff across a range of disciplines in the social sciences and humanities, science and technology, management, and health and medicine. CeDR also has close links with a range of local, national and international organisations and groups.

### **HomeoNet Forum – Breaking New Ground 2008 Toronto, Ontario**

A poster presentation of the theoretical relationship between social construction theory and non-diagnostic systems of medicine will be on display at the fifth IN-CAM symposium and the 1st annual HomeoNet Forum - Breaking New Ground: A Drive for Understanding in Homeopathic Research ([www.homeonetresearch.ca](http://www.homeonetresearch.ca)). at the Leslie Dan Faculty of Pharmacy, University of Toronto, from November 7th - 9th, 2008. The objectives of the IN-CAM symposium are to:

- Disseminate CAM research results and present emerging ideas related to CAM research
- Highlight specific areas of research (i.e. CAM education, CAM and Cancer)
- Foster new collaborations, and strengthen existing partnerships, within the Canadian and international CAM communities, as well as with partners outside of these communities
- Support the development of a viable Canadian CAM research program

### **Congress of the Humanities and Social Sciences 2009 Ottawa, Ontario**

A paper presentation on this project will be delivered at the Congress of the Humanities in Ottawa in May, 2009. *The Congress of the Humanities and Social Sciences is the largest multidisciplinary academic gathering in Canada, attracting delegates from every corner of Canada and around the world. Steeped in over 75 years of tradition, Congress is a gathering of researchers, scholars and students in the humanities and social sciences, leading public intellectuals, authors, artists and many more.*

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