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Deconstructing Multiple Chemical Sensitivity (MCS)

Bruce M. Small

M.Ed. Program in Counselling Psychology Ontario Institute for Studies in Education, University of Toronto

Author Note

Bruce M. Small, Department of Applied Psychology and Human Development, Ontario Institute for Studies in Education (OISE), University of Toronto.

This paper and its companion website *http://www.envirodesic.com/DeconstructingMCS* were completed in fulfillment of the Fall 2012 product requirement of an OISE graduate course (AECP1408H) entitled Working with Survivors of Trauma, taught by Dr. Bonnie Burstow.

Correspondence concerning this product should be addressed to Bruce M. Small, Small & Rubin Ltd., 21 Carlton St., Unit 3407, Toronto ON M5B 1L3. E-mail: bruce@envirodesic.com.

Decosntructing Multiple Chemical Sensitivity (MCS)

The product I have created is a website accessible from the following URL:

http://www.envirodesic.com/DeconstructingMCS

Upon entering this URL in your browser and pressing ENTER, the following screen will appear. If you would like to review the site, email me at bruce@envirodesic.com and I will send you a password that will allow you access. Fill in the blanks with your email address and password below, then press ENTER:

WELCOME

to a website under development (tentatively called "Deconstructing MCS")

(for authorized private access only)

E-mail address:			
F	assword:		
	(ENTER	

Once accessed, the website can be navigated by means of the menu bar in the heading of

each web page, without further sign-in. The following pages discuss what you will see, who it

addresses, why I have produced it, and what happens to it next.

Bruce M. Small, M.Ed. (Counselling Psychology), OISE, Yr. 1

Specific Traumatized Population

This product is designed to be helpful to those individuals who have become particularly responsive to environmental factors such as: air and water pollution; indoor pollutants from building materials, furnishings and household products; pesticides other food contaminants; perfumes; electromagnetic fields; emissions from clothings and fabrics; indoor and outdoor moulds and bacteria; and both processed and whole foods. This population is hard to gather in one physical location because many have difficulty travelling and may be physically uncomfortable in certain indoor environments. Although some of this population have difficulty using computers, many have found ways of adapting to computer screens for at least short periods of time. I have therefore chosen a website as a product that may have a higher chance than many others of reaching them. Although theoretically this website could be open to English-speaking individuals throughout the world, much of my material so far relates to potential audiences in Canada and the United States. The format is adaptable enough, however, to allow future expansion to accommodate other languages and cultures.

Nature of the Trauma

I have spent much of the last thirty-five years dealing with people in this population, and for up to the first two decades of that time I included myself in the population. It is clear from my experience in the field that people who are particularly environmentally responsive are a traumatized population. For those with a single precipitating event, their experience of environmental intrusion can be traumatic in itself, since any sudden assault on the body resulting in negative health effects can bring on typical signs of trauma, including a generalizing distrust of the surrounding environment that affects daily functioning and peace of mind. Once the body begins to become reactive to a wide variety of environmental factors, there is not only a

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continued feeling of vigilance and wariness, but ongoing experience of insidious emotional trauma from encounters with others in one's family, in the workplace, or among the health professions who believe that the condition is psychosomatic and who blame the individual for his or her plight. Even in Ontario the condition is not well covered under the Provincial insurance plan, nor well handled within many medical institutions. Individuals seeking help often exhaust their financial resources before achieving any success in addressing their condition.

Psychological Needs of the Traumatized Population

The psychological needs of the environmentally responsive population have in general not been well addressed. The situation is complicated by the fact that some of the psychological byproducts of trauma appear to exacerbate physical symptoms for some individuals. For example, it is well-known that asthma attacks may be more frequent under stress even if they are environmentally triggered. In their concern to educate the rest of the medical profession about the effects of *physical* environmental factors, physicians working with environmentally sensitive clients have tended to ignore and downplay *psychological* effects, and as a result there is not a well-developed professional community providing good psychological support to this population. Also many affected individuals have been further traumatized by their encounters with mental health professionals who have disbelieved their situation and labelled them with psychological dimensions or consequences of their environmental responsivity. The website is therefore designed to spur a discussion about the psychological dimensions of multiple chemical sensitivity and the psychosocial support needs of their traumatized population.

The Deconstructing MCS Website

It became abundantly clear as I began this project that producing a website alone and

opening it up suddenly to an unsuspecting environmentally sensitive community would be from my point of view like walking through a minefield and from their point of view as if it were a grenade thrown in their front window. I know many many people in this community, including health providers, individuals, and product manufacturers and suppliers. Each has their own unique concerns about how the field is perceived by others, and how the ways that it is talked about will affect both their own circumstance and that of others. That said, I also have no doubt that many would agree that the psychological dimensions of environmental responsivity need to be discussed and addressed more than they have been in the past. But I know they will have strong opinions about *how* that should be done in order to minimize potential damage.

I have proceeded with designing and creating a website that addresses the ideas I personally think need to be addressed, in a way that is tempered by my experience as an environmental adviser and as a psychotherapist. But I have deliberately put a temporary "lock" on the site so that I may proceed slowly and carefully through a review and consultation process before the website is fully released to the public. The website is also deliberately "bald" (for example, devoid of graphics and pictures) at this stage so that others may contribute to its beautification at the same time as they comment on and contribute to the text content and primary messages contained within the site. I have also deliberately refrained from creating a special domain name for the site, pending feedback from others. In the interim it will be known to reviewers simple as the *Deconstructing MCS Website*.

The website itself is built around a common menu bar that leads the reader through various groups of web pages that develop each topic. The main topics covered so far are Deconstruction, Trauma, Psychology, and Empowerment. Each contains a number of specific webpages linked back and forth to each other, that develop the theme in a way designed to be supportive and interesting, though at the same time challenging of basic concepts.

The website also contains a network database that is designed to be expanded automatically by select readers who may wish to be visible on the site for a number of reasons, including offering products and services, medical and other health support, psychotherapeutic support. Affected individuals can also list themselves if they wish to be accessible for private conversations with other readers. There is also a news data base and a blog section wherein readers can post articles and other items of current interest, and also post their own views on any relevant topic related to the theme of the site, which his defined in an open letter to readers on the home page. While there are only representative entries in each of these databases at the moment, they are fully functional and capable of automatic expansion at the will of the readers.

In addition to addressing in a positive way the trauma experienced by environmentally responsive individuals, and reassuring the target population that *someone* understands what it feels like to go through such experiences, the website also challenges both the health professions and the people affected to examine hegemony, patriarchy and oppression wherever it is tied into environmental sensitivity. In the course of doing so, I believe that some affected individuals will find the site helpful in terms of providing ideas and text that can be reused to advantage in dealing with their local medical profession, government officials, teachers and school boards, as well as renovation contractors, family and friends. I also hope that the very existence of this kind of website will help to confront a society that first pollutes its inhabitants and then denies the damage that has been caused.

What Happens Next

Upon review and feedback of this draft website, I will decide whether to proceed towards a public launch and when to start the consultation process. Currently it is my intention to have private conversations or meetings with a number of individuals to discuss the project and my intent, and to engage their assistance in reviewing and "tweaking" the site to make it useful to the community.

The Strengths and the Weaknesses of the Product

At the moment I can see that my set of writings in the website's pages represent something different than this field and this particular population are used to seeing. I think that affected individuals in particular will find it refreshingly honest. I think that the writing flows well and the logic in each section comes through relatively clearly.

However, I am also clear that the project took on a magnitude that was extremely daunting in the time available. Rather than cut it back, I continued to produce the minimum that I thought was necessary to make this site substantial enough to have an impact and to be helpful to the affected population. I know that each and every page that I wrote would be different if I had taken the many months that such a project would normally take to complete. To me some of the writing still sounds a bit glib, overly general, and somewhat preachy.

There are likewise advantages and drawbacks to sharing an uncompleted website with my contact list. On the negative side, a site with nothing but words is so far from what is ultimately needed that I fear those reading it at its present stage will not be able to imagine it fully developed and enhanced by pictures, graphics, videos and audio clips. On the positive side, presenting an unfinished site is an open invitation for collaboration and inclusion of others in the remaining work, which I think will be very necessary in order to make this a site *owned by* the community, rather than *aimed at* the community.

The site itself, even when finally ready for public presentation, is also designed to grow, expand and be influenced by its audience, and therefore will never be complete. It may be

important to recognize that starting *anywhere* is good, and that over time, co-operative work with others in the affected community will ultimately focus future efforts in the right directions.

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Following is a bibliography of references that informed this project. I have included citations within the web pages where text would be immediately available to readers via the internet.

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