The Polyvocal Fugue:
Frame and Counter-Frame in the Management of an Environmental Health Conflict

by

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Abstract

It began with the loss of the use of her forearm, then the use of her other arm, and then her legs. Headaches became severe migraines; seizures occurred. Her body wasted away and she became needle-thin. A neurologist, a psychiatrist, her family physician could not determine what was wrong. A local specialist, however, recognized the symptoms as those he had seen in others over several years. Concerned that the symptoms might be related to environmental toxins, he alerted the local health authorities. His concerns and those of his patients were not taken seriously, not, that is, until he and his patients coined a name for the symptoms: Somatic Chemically Induced Dysfunction Syndrome, or SCIDS. What was expected to be simply a name for a set of symptoms suddenly became contested. A social problem was defined, and experts from Agriculture, Health, and the Environment Ministries entered the fray.

Unrelated at first, degradation of the local aquifer, death of wildlife, and a noticeable decrease in small mammals in the area had been noted. Questions were raised about the links between the two; between the environment and health. Somatic Chemically Induced Dysfunction Syndrome (SCIDS) suggested a causal link with chemicals, moreover with chemicals in the environment. This raised doubts in people's minds about the responsibility and accountability of government, and the authority of experts and the role of science was thrown into question. A private trouble became a public issue. The ensuing conflict revolved around naming and owning a social problem. Both experts and persons with SCIDS invoked science to make their case. Sides were drawn and the conflict was played out to the wider public through the media.

It has been commented that research about illnesses of the environment have a bias towards the stories of the sufferers. This dissertation focuses mainly, though not exclusively, on the stories of the various experts involved. Set within the wider frame of social constructionism, I address the ways in which private troubles become public issues and are defined as a social problem. The frames used in this contest to wrest both ownership and thus management of the problem are investigated. The impact of this on a local social movement is examined.
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As you begin you are alone, making notes, placing a line here, a piece of dialogue there. And then perhaps when you have a moment of doubt, because for instance the scene you have described is not quite right or strikes a false note, you shudder as you become aware of the others. A sea, an obdurate mass, a jeering crowd, disappointed with your feeble efforts. But you keep your nerve. You adjust the language. Shift the focus. Add complexity to the order of events. Until slowly, by almost imperceptible degrees, the gaze of the others no longer troubles you. Not because you are pleased with your efforts—you are still erasing, adding, altering—but because you have joined the audience yourself. Curious and attentive, you too are watching, eager to see how the plot proceeds.

CHAPTER ONE: COMPOSING THE SCORE

Risk. It has become a lurking presence on the Canadian and the world news-cape, thrust into our minds against our will. In Britain, Creutzfeldt-Jacob disease. In Canada, the Walkerton, Ontario, groundwater tragedy. These brought illness and death that we would have thought unlikely in this modern age. Now, the safety of our basic needs for living, food and water, are suspect, no longer to be trusted. How can we tell these necessities to our lives are safe? We no longer know when we are at risk. Risk now has an unseen presence.

Risk used to have a different connotation. It was associated with losses and gains, with the calculation of probabilities, as in gambling or undertaking some endeavour. Today however, risk has taken on a negative connotation, that of hazard or danger, with a negative outcome. Risk is the likelihood that a set of circumstances will cause harmful consequences. Risk consists of the magnitude of harm and the probability of its occurrence.¹

Gone are the days when risk was forewarned and we could choose to avoid it. Now we even question the trust placed in our elected representatives and their departments to protect us against risk, or to warn us that such risk exists. Even the experts in whom we placed the confidence that should accompany authority appear to have let us down. Certainly risk-taking and risk-avoidance were considered the responsibility of the individual. How do we take responsibility now, not knowing what risks we are facing? How do we deal with this anxiety-ridden, stress-inducing uncertainty that the air we breathe, the food we eat and the water we drink contain risks that are unheard, unfelt, unseen? Have we returned to the miasmic horror of the eighteenth century? Or is this a millennial angst that is as contagious as any epidemic?

Such anxiety is a side-effect of a risk society, suggests Beck. Together with the progress that was lauded with industrial production was the systematic production of risk. At first, as the latent effects of production processes, risk appeared manageable, able to be phased out with the elimination of one product and its substitution with another. However, the production of risk now

¹ Rogers and Bates, 3; British Medical Association, 13; Fox, "Risks, 'Hazards' and Life Choices," 665.
escapes the institutions responsible for monitoring and protection, unable to be contained within the standards developed within industrial society. The threats of the risk society begin to predominate. Risks now are no longer discernible, not even to the imagination, and increasingly cannot be determined by science.²

In early 2000 in Walkerton, Ontario, Canada, contaminated groundwater was found to be the source of illness and death among the town’s residents. Residents became ill, and science determined that the groundwater was the source. An agri-business of intensified beef farming in the district, with leaching from manure into the groundwater, resulted in a devastating outcome for the community. Human error, and outdated technology were at fault. How could a glass of clear liquid, water, contain the elements of illness and death? A hazard, its existence unknown, became a risk, its existence still unknown. How did this glass of water, a commodity we expect to be able to take for granted as safe, become the grim reaper?

Contrast Walkerton, Ontario, with another Canadian community, in the Fraser Valley in British Columbia, in which intensified farming of poultry, beef, and berries are the primary industries, where the residues of animal manure and pesticides leach into the groundwater, and where an increasing number of residents suffered a variety of neuromuscular symptoms. Whereas the effects of groundwater contamination in the Walkerton case occurred rapidly, were severe and life threatening and took on epidemic proportions, in the Fraser Valley, symptoms were progressive over a much longer period of time, were not immediately life threatening, and fewer people were affected. In Walkerton, contaminated groundwater was identified as the source of illness, and boil orders as well as an alternate water supply were relatively quickly put in place. In the Fraser Valley, the source of illness was contested, as was the illness itself. In Walkerton, residents suffered from a readily identifiable illness, with an etiology that is accepted by biomedicine. In the Fraser Valley, residents claimed they were suffering from an illness, but one not recognized by biomedicine. An environmental illness, they maintained.

² Beck, Reinvention of politics; idem, Risk Society; Beck, Giddens and Lash, Reflexive Modernization.
Introducing SCIDS

In the early 1990's, newspaper headlines warned of contaminated groundwater in a small farming community in British Columbia.

**Abbotsford water contaminated, scientists claims**

Chicken manure has contaminated Abbotsford’s drinking water, an Environment Canada scientist says. Nitrates from manure stockpiling, excessive fertilizing and septic tanks are leaching into the natural underground reservoir that provides the district with water, he told the B.C. Institute of Agrologists. 

[...] He said 60 per cent of the test wells drilled by the federal department last year near Abbotsford airport exceeded the allowable level of nitrates in drinking water in Canada—10 parts per million. Another 20 per cent exceeded 20 parts per million or double the allowable limit. 3

A year or so later, headlines also told of an environmental disease linked to environmental toxins, possibly including those in the groundwater.

**Enviro-disease**

An environmental toxin may be the cause of a mysterious illness afflicting a number of people in the Fraser Valley. The disease with no name, and no known cause, stymies the brain’s messages along the spinal cord, affecting normal joints and muscles. 4

“Dubbed” cybernetic paresis by the local orthopaedic surgeon, he hypothesised that an exterior agent in the air or drinking water was damaging the central nervous system. In 1991, enviro-disease and cybernetic paresis were re-named SCIDS (Somatic Chemically Induced Dysfunction Syndrome), and in August that year, a group of concerned residents, those suffering the symptoms of the enviro-disease, formed a SCIDS support group. Members of the group suffered a wide variety of symptoms, any two people not necessarily having the same complaints. Symptoms consisted of, in the teenaged, “knee pain and apparent muscle ‘weakness’; lack of flexibility in the back; a particular pattern of muscle ‘weakness’ in upper and lower arms and

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legs; poor posture with head forward and shoulders stooping; excessive curvature in the lower back; hyper-sensitivity to pin pricks in the lower back; skin a doughy consistency and tender around the lower spinal region.” In the ‘middle-aged’, symptoms presented were “constant aches in joints and bones; massive headaches; chronic fatigue; blurred vision; pins and needles in the arms, legs and back; spasm in most muscle groups; changes in digestive capabilities; irritable bowel conditions; constant thirst; and short-term memory lapses.” Females were more often affected than males, as well as being affected at lower levels of exposure to chemicals than males. The local specialist observed a ratio of 4 females to 1 male in the population diagnosed at his clinic. A number of diagnoses had been considered, but they did not fit the pattern for chronic fatigue, or fibromyalgia, or multiple sclerosis, although they did share some of the symptoms of each of those disease clusters. Having an unrecognized diagnosis, none of the group were eligible for compensation from the Workers Compensation Board. In fact, most people had been to more than one physician looking for answers, and it had been implied that for some of them their illness was all in their head. A few people from the support group, SCIDS, became politically active and vocalized their concerns about the state of the environment and their symptoms, linking the two. Government at provincial and federal levels entered the fray, and debate about both the illness and the environment eventuated.

The Social Context

The ensuing conflict was centred in a river valley rich with alluvial soil just a few minutes north of the United States border. The Fraser Valley extends in triangular formation from the shores of the Pacific in British Columbia to the apex of the north and south mountains at approximately the town of Hope to the east. Abbotsford is at the centre of the river valley, set between the Fraser River to the north, and the United States border to the south. Previously two districts, Abbotsford and Matsqui merged, politically in 1995, but commercially much earlier as the expansion of both resulted in the convergence of the two central business districts in the early

Settlement patterns have matched resources in the area. Some five thousand years ago the Sto:lo nation were established in the region, sustained by the extraordinary abundance of salmon in the river and the wealth of game and plant life in the forests. It was not until relatively recently, the early nineteenth century, that the fur trade brought Europeans to the district. The river, a telegraph trail, a gold trail from the United States into British Columbia, and the construction of the Canadian Pacific Rail link furthered settlement. The British government, concerned at the increasing American presence in the area, especially following the gold rushes, sent a corps of engineers in the late nineteenth century who were responsible for surveying the lower mainland and many of whom settled in what was to become Abbotsford. The landscape of the area at the time was described by one of the engineers as a sweeping prairie, with many marshes and towering stands of forest, abundant with fowl and wild game. Logging was the main industry in the early 1900s, attracting Sikhs as well as Europeans to settle. Other groups had previously settled in the Abbotsford region, however a paucity of information about their settlement exists. It is the negative references to some groups that indicate their presence; for example, the Chinese were settled there, evident from the anti-Oriental sentiment expressed at the time about the “Chinese drug problem.” The town’s newspaper, The News, published statistics portraying the Chinese as the main traffickers of opium and morphine, the use of which was reported to be rising rapidly in the district. By the 1930s, newspapers and even Maclean’s magazine were carrying fearful stories of Japanese settlement and ‘takeover’ allegedly at the instigation of the Japanese government.

Prosperity from the lumber industry encouraged a small business district to develop by the early 1900s, providing both necessities, such as a grocery store, banks and dentists, as well as recreational facilities which included a movie theatre and restaurants. The Abbotsford and

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7 Abbotsford: A City in the Country. 1996/97, 5
8 Peters, 3.
9 Farrow, 5.
District Chamber of Commerce was established in 1913, and Abbotsford was incorporated in 1924. This was much later than neighbouring Matsqui and Sumas municipalities, both of which had been incorporated in 1892.11

With the Depression of the late 1920s and 1930s and the lumber industry failure, economic dependence shifted to agriculture. The fertile soil had already attracted farmers to the district. A dyke system had been built in the late 1800s to re-channel the Vedder river, the source of many a flood, defeating farming efforts. This infrastructure together with logging operations which had helped pave the way for further farming by clearing the land of trees, reduced the extent of the catastrophe that the collapse of the logging industry might have had.12 In 1932, the Abbotsford Chamber of Commerce brochure was titled Abbotsford: The Land of the Cow, signifying the shift from logging to farming at that time.13

Early farmers were predominantly horticulturalists, growing an assortment of crops which included hops, tobacco, beets, fruit and vegetables. At the turn of the century, dairy farming increased and operated alongside horticultural farming. Berry farming was introduced in the early 1900s. Strawberries and raspberries flourished in the hot, wet, short summers where peaches and apricots did not. In the 1920's the local berry farmers formed the Abbotsford District Fruit Growers & Co-operative Association.14

With the change in economy came an influx of new settlers.15 The Mennonites had migrated from the Prairies in the early twentieth century and became established in berry and dairy farming. Dutch immigrants who arrived after World War Two were predominantly concentrated in dairy farming and Hungarians who settled to the east of the Valley harvested hops and tobacco. Further Sikh immigrants arrived in the 1960s; and in the 1970s and 80s, Cambodian, Vietnamese, and Laotian refugees arrived.16 Currently, prosperity continues to be

11 Peters, 4-27.
12 Ibid.
13 Farrow, 1 & 10.
14 Farrow, 7-17.
15 Ibid.
16 Peters, 29; Farrow, 10 & 11.
based on agricultural produce.\textsuperscript{17}

Population in Abbotsford in 1991, at the time of the escalating conflict around SCIDS, was 86,930. Twenty-one percent of the population were of British descent, 13 percent of German descent, and 38 percent of multi-ethnic origin. While some of the Matsqui-Abbotsford population (20\%) list no religious affiliation on their 1991 Census return, of those declaring their religion, 13 percent were Mennonite, 11 percent Roman Catholic, 10 percent United Church, and 6 percent Anglican with another 6 percent Sikh. As part of what has been referred to as the “bible belt,” the district has many places to worship (77 in 1994), some of them capable of holding large congregations. For example, two churches have auditoria that will seat 2000 people at a time. The average congregation size is 500, with the largest church having a congregation of 4000.\textsuperscript{18}

The majority of families in the district in 1991 were two-parent families (90\%). Eighteen percent of families in the Central Fraser Valley Regional District, which is primarily comprised of Matsqui and Abbotsford, earned $70,000 and over, while 45 percent of families earned between $20,000 and $49,999.\textsuperscript{19} Prior to 1991, education levels were low. In 1981, less than 26 percent of the population had greater than a grade 9 education in Abbotsford. This was even lower in neighbouring Matsqui. This has changed somewhat since 1991, with more students graduating, and more with post-secondary, college-level education. Economic diversification has contributed to an increase in work outside the agricultural sector, traditionally a sector that has not required high education levels.\textsuperscript{20}

Today, the city of Abbotsford is the organizational centre for the rural surrounds. There is a growing commercial sector based on manufacturing, processing, transportation, construction, and trades and services industries. The continuing importance of agriculture to the region is not just economic, but symbolic. It is at the core of a carefully constituted collective identity. This can be seen in the portrayal of community identity in publicity brochures and in the public events

\textsuperscript{17} City of Abbotsford Economic Profile 1996.
\textsuperscript{18} Simpson and Elliott, 129.
\textsuperscript{19} City of Abbotsford Economic Profile, 1996.
\textsuperscript{20} Simpson and Elliott, 129 & 130.
to which the outside world is invited. The annual publication of the Abbotsford Chamber of Commerce, *Abbotsford: City in the Country*, heavily emphasizes the rural farming community together with the regional prosperity from the legacy of agricultural production.

ABBOTSFORD-MATSQUI: The Best of Both Worlds

Absorbed in the beauty and tranquility of the countryside, it is often difficult to imagine Abbotsford-Matsqui as one of the fastest growing communities in North America. But it's very true according to the Abbotsford-Matsqui Chamber of Commerce, noting that this community is quickly becoming a leading business centre in the Lower Mainland. The Chamber prides the community on its ability to capture and preserve the splendor of its beautiful prairies, rolling hills and meandering rivers/streams, while offering the conveniences of the big city with luxurious residential development, large commercial complexes and lucrative industrial enterprises just a stones throw away.21

Brochure photographs of the tranquil outdoors of this lake or that mountain reveal the region’s beauty. Farm visits, hiking and walking trails and many outdoor activities are the focus.22

Abbotsford’s public events predominantly continue the rural emphasis. Three events in particular, the Berry Festival and the Agrifair highlighting the rural, and the Abbotsford International Airshow profiling the urban side of the region, are provided the most publicity in the Chamber of Commerce publications.

The Abbotsford Berry Festival is an event upon which the city prides itself. A regular street festival for the past fifteen years, it is advertised as a family event. Offerings of free entertainment which include parades, shows, and sales as well as “berry-indulgent” food items set this festival apart from others. Abbotsford is known as the Raspberry Capital of Canada, and is the second largest raspberry producer in North America. The Lower Fraser Valley supplies ninety percent of all raspberries used in Canada.23

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The Abbotsford Agrifair is advertised as the Best Little Country Fair. It is a regular agricultural show, parading the best in agricultural products the region has to offer. Animals, food and entertainment, and both riding events and amusement rides constitute this family fair.\(^{24}\)

Contrasted with the two major agricultural shows is the Abbotsford International Airshow. It too is a major visitor attraction, advertised as a world-renowned experience. It has been reported as the fifth largest airshow in the world. Aerobatic feats, aircraft displays and various airshow performers are advertised each year. An annual event, it is augmented in the week prior by another airshow festival called “The Flight Begins” in which local businesses take part in the aeronautical theme with a variety of displays and competitions. Each second year another festival occurs in conjunction with these two, Airshow Canada, a tradeshow and symposium of aeronautical giants from around the world. “Kids ‘young and old’” are encouraged to participate.\(^{25}\) This event, whilst obviously requiring the airspace the countryside provides, promotes the prosperous and flourishing “cityside” identity of Abbotsford business and trade.

The overall image is one of a modern, urbanized community enveloped in and surrounded by nature. Implicit in this image is one of health. Couple that with the wealth that eminates from a city with an economy based on diversified agricultural products, and a collective image of health and wealth is presented--the city in the country. The suggestion that there might be illness induced by the same industries upon which the region’s prosperity rested was shocking. And yet it was not entirely unpredicted.

Concern with the degradation of the environment generally had been steadily increasing through the 1980s and 1990s. Air pollution, funneled from Greater Vancouver and Whatcom County (US), was becoming a major problem. The Fraser Valley was reported as having one of the three worst concentrations of ground level ozone in Canada.\(^{26}\) Groundwater pollution was


also a problem. The Environment Committee of the Association of Professional Engineers and Geoscientists of British Columbia had, in the 1980s, sent several missives to the provincial government outlining the problematic practices of local farmers and consequent groundwater contamination.\textsuperscript{27} Between 1984 and 1990, Environment Canada, the National Research Institute, and Agriculture Canada scientists had found the Abbotsford aquifer contaminated with nitrates and low levels of pesticides.\textsuperscript{28}

Farmers and farm workers in the region surveyed in 1982 reported suffering the immediate effects of mild to moderate pesticide poisoning.\textsuperscript{29} A report from the Canadian Farmworkers’ Union, May 1990, \textit{Pesticide Use and Handling in the Fraser Valley Berry Industry},\textsuperscript{30} pointed out that the processes in place to ensure safety at the farm level were flawed. Reliance was heavily concentrated on labeling of pesticides, which were in English language. Many farmworkers as well as farmers were illiterate in English. Levels of pesticide application training and certification were found to be low, standardized record keeping was non-existent, and regulatory presence on farms was lacking.

At a more general level, degradation of the environment was noted. While the local orthopaedic surgeon had noted in 1991 in his address to the newly formed SCIDS group that wildlife was disappearing, this theme was the subject of newspaper articles in 1992. A member of the Association of Reptile Keepers stated that whereas 30 years ago she could immediately find a garter snake in her backyard, for the past 15 years this had not been so. The disappearance or rapid decline of species of frogs, salamanders and snakes in the region were noted by spokespersons for the Zoology Museum at the University of British Columbia and the Conservation Data Centre of the Ministry of Environment.\textsuperscript{31} Decline in hummingbirds, increasing

\begin{thebibliography}{10}
\bibitem{28} Trudy Beyak, "No tests for cheaper pesticide," \textit{Abbotsford/Matsqui News}. September 02, 1992, sec. A. p.2.
\bibitem{30} Report prepared by Juri Oja, David Riehm, and Aleck Ostry with the assistance of Robert Milen, Gurwinder Uppal and Gurmail Brar.
\end{thebibliography}
numbers of deaths in bald eagles and other species of eagles, hawks, and falcons were reported by a Canadian Wildlife Service scientist and a Chilliwack field naturalist who had kept records on Fraser Valley birds since 1977. Cause of these deaths and declines is posited as increased use of pesticides.

Wildlife service logs 20 years of birds falling prey to pesticides

The Canadian Wildlife Service has a two-decade history of confirmed pesticide poisonings of birds in the lower Fraser Valley.

For example, in December 1979, a pesticide killed 120 ducks; in August 1989, another pesticide poisoned 40 Canada geese.

During the 1980s, the largest bird kill in the valley from a single pesticide poisoning was the previously unpublished death of an estimated 1,000 sparrows in August 1986. [...] Government records show instances of large numbers of pesticide-killed ducks and other water fowl in a single farm field, but birds of prey die alone.32

This underbelly of the bucolic environment is hidden as much as possible from wider public view by those advertising the region and hoping to attract new business, industry and residents. The city in the country is not about contamination, pollution, pesticides and poisoning. A group exposing this underbelly would be challenged locally and regionally by those with vested interests. Their claims would be resisted and denied by powerful elements in the community--elements that were invested in the image of Abbotsford as a safe, prosperous place. Others, including residents, just did not want to know.

In an investigation in the Valley as to why, in the face of concern for the environment, so few people behave in ways that would protect the environment, Simpson concluded that although most people were concerned about their local environment and support environmental issues, this concern was not sufficient to motivate environmental activism, lifestyle change or a shift in attitude/belief from economic to environmental sustainability.33 Earlier research by Blake et al had similarly found British Columbians concerned about the environment. They also found

33 Simpson, 291-294.
residents of British Columbia (B.C.) to be active participants in simple energy saving and recycling programs as well as passive actors who contributed monetarily, signed petitions or boycotted products in relation to environmental concerns. Women were more concerned about the environment than men, as were the middle-aged in B.C. At the local level, the objective condition of the environment, especially related to its visibility, was the determinant of concern. Air pollution, especially from cars, was more likely to raise concern than the less visible or geographically remote conditions such as ozone depletion. However, even though directly affected by pollution and ranking pollution as a significant problem, a later survey found that individuals do not necessarily support solutions that are a more serious attempt to solve these problems. Residents of Abbotsford, an oversample in a representative survey of 1,652 randomly selected respondents in B.C. ranked motor vehicle exhaust pollution and air quality as their major environmental concerns (numbers one and two respectively) yet were less likely than respondents from B.C. generally to support individualized penalty measures to combat it. Abbotsford is the major recipient of motor vehicle exhaust pollution from the Lower Mainland. Other research however has found that although individuals feel they have some personal control over their health and over some environmental activities such as household recycling, they do not feel that they have a lot of individual control over the environment. In fact, it is believed that to change the condition of the environment, group action is necessary. However, apparently even where health is seen as linked to a deteriorating environment, individual responsibility for group membership and activism may be lacking. At environmental group meetings attended by Department of Sociology faculty and graduate students in 1993 as part of an Eco-Research Project being conducted by the University of British Columbia, community apathy was a common theme.

Toward the end of the meeting Brian [Elliott] asked about the community apathy members had been referring to. He asked if they thought this community is different in this respect than other communities. In the wide-ranging discussion that followed it seemed that people thought there was more apathy

34 Blake, Guppy and Urmetzer, 41-61.
35 Urmetzer, Blake and Guppy, 345-359.
than in other communities (such as those on the Island where some members
had lived), and disagreed on what the explanation of the apathy was. One
member thought it was because people are so busy these days with two incomes
needed by a family; another thought that was not an explanation because many
of the people who are involved are very busy too; another member said that
there are three groups in the community: the ethnic group, the non-religious, and
the religious. The religious people in the community are scared because their
influence is reduced from what it used to be (he may have been implying that no
group has taken the place of the religious groups' informal influence and
activity, but he did not in fact say this).36

In an earlier interview (October 08, 1993) with The Abbotsford News reporter for the
environment, researchers’ had heard the same concerns about community involvement with
environmental issues. The reporter commented “that there was much apathy” and that “it was
really dead in terms of public response to problems.”37 In a comparison of community
environmental activism in four Lower Mainland municipalities, Burnaby, Richmond, Langley,
and Abbotsford, McKinnon found the Abbotsford groups to be smaller and less influential than
those of the other municipalities, nor had they developed an independent and self-reliant
‘environmental public sphere’. An environmental public sphere consists of a network of groups,
considered necessary for the maintenance and continuation of environmental activism. It
provides a platform from which groups can “take-off.”38

Despite the fact that this was a community which prided itself on its natural, rural
resources, with an image of a clean, green, healthy environment from which stemmed its wealth,
in which individuals were less likely to be environmentally active and with a weak
environmental public sphere, environmental illness surfaced here and group activism emerged.

37 Alldritt, Fieldnotes, October 08, 1993. Brian Elliott also present.
38 McKinnon, 81-109.
Problematic Diagnostics: Environmental Illness

Neither a case definition nor methods acceptable to the biomedical community exist for verifying the entity of environmentally caused illness. Discourses and counter discourses have been waged about environmental illness in the scientific and medical literature, in the media, in professional association position statements, and in the courts for at least the past decade.

Environmental illness (EI) is an umbrella term for a collection of syndromes which include Gulf War syndrome, multiple chemical sensitivity syndrome, chronic fatigue syndrome, 20th century disease, enviro-disease, total allergy syndrome and many others. Although each of these syndromic names is used interchangeably in the literature, I am going to focus in this brief section on the discussion around multiple chemical sensitivity as it is the term closest to SCIDS, the subject of this dissertation.

The underlying concepts of multiple chemical sensitivity were developed by allergist Theron G. Randolph, M.D. in the 1940s. He suggested that exposure to substances at doses far lower than levels normally considered safe caused fatigue, irritability, behaviour problems, depression, confusion and nervous tension in some people. This new form of sensitivity represented a failure of humans to adapt to modern day synthetic chemicals, he suggested.  

Multiple chemical sensitivity is diagnosed and treated predominantly by a group of clinicians who are clinical ecologists. Clinical ecology is not a recognised medical speciality, and lies outside the biomedical model. In 1965, a group of clinicians from various specialities banded together to form a medical society, the American Academy of Environmental Medicine (AAEM). Considered a strategically comprehensive, proactive and preventive approach to medical care according to the AAEM, environmental medicine focusses on evaluating, managing, and preventing the adverse effects resulting from environmentally triggered illnesses. The AAEM’s position is that the human body is constantly coping with the dynamic environment in which it is situated through inherited, complexly interacting and reversible

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39 Randolph practiced in Chicago and was also on the staff at Northwestern University Medical School and two affiliated hospitals. Following his suggestion that chemical sensitivity was an inability of humans to adapt to the modern age, he lost his medical school and affiliated hospital positions, being declared “a pernicious influence on medical students” (Barrett and Gots, 5 & 6).
biologic mechanisms and systems. Substances in the diet or environment are potential stressors capable of destabilizing "homeodynamic functions" and thereby causing disease. Homeodynamic functioning refers to an active (rather than passive) process of health and function maintenance.40

Located outside the biomedical mainstream, diagnosis and treatment by clinical ecologists is the subject of much criticism. Multiple chemical sensitivity is not a diagnosis listed in medical text books, nor is it classified as a medical condition in the standard manual, *International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM)*. According to critics of clinical ecology, there is no clear definition of multiple chemical sensitivity. There is a lack of elucidation of potentially contributing pathophysiologic and psychologic mechanisms, no substantiated diagnostic tests, and no scientific validation for any single case. Multiple chemical sensitivity is considered a label, rather than a diagnosis, by those within the biomedical tradition. Further, critics claim that interpretation of published research on multiple chemical sensitivity is limited by methodological problems. These include over-reliance on survey method, on self-reported symptoms, selection bias, blinding issues, inconsistent laboratory quality assurance, and lack of validation of outcome measures. The American College of Occupational and Environmental Medicine (ACOEM) in their position statement on multiple chemical sensitivities recommends that "idiopathic environmental intolerance" (IEI) more accurately reflects the current state of knowledge and eliminates the inference of immunologic dysfunction and chemical exposure that is *sine qua non* in the term "multiple chemical sensitivity."41

"Multiple chemical sensitivity," was coined by Michael Cullen, M.D., professor of occupational medicine at Yale University. He does not identify as a clinical ecologist. Acknowledging the difficulty in defining the syndrome, and mindful of the need to do so, various

40 American Academy of Environmental Medicine Home Page (AAEM) &lt;http://www.aаем.com/who_we_are.htm&gt; accessed April 07, 2001; Barrett and Gots, 7.
committees and consensus groups have attempted to develop an encompassing definition. Characteristics of these definitions can be found in Table 1.

Biological markers for diagnostic purposes have also been the subject of research. Heuser, Wojdani and Heuser (1992) evaluated 135 patients effected by small concentrations of multiple chemicals after a previous event of chemical exposure and suggested that abnormality in four of seven systems tested (central nervous system, peripheral nervous system, nose and sinuses, pulmonary function, T-cell subsets, chemical antibodies and auto-immunity) be indicative of a diagnosis of MCS.

Cumulative data from an increasing number of studies provide support for the importance of three groups of symptoms: those predominating in the central nervous system and consisting of, for example, fatigue, headache, dizziness, loss of memory, sleeplessness; those categorized as irritational symptoms, including nasal congestion, asthma, eczema, skin rashes, itching eyes; and those that are gastrointestinal symptoms such as nausea, diarrhoea, constipation, bloating and cramps.  

Symptoms are chronic and recurrent, with progressively smaller amounts of a widening array of incitants provoking symptoms. Cosmetic fragrances, body care products, cleaning products, air fresheners, fresh paint, adhesives, new construction materials and carpeting, office machinery, automobile exhaust, tobacco smoke, food additives, moulds, and pesticides are the most common incitants. Varying degrees of morbidity are experienced by individuals. For some, total disability in relation to carrying on the normal activities of contemporary, urbanized, everyday life is the result. Voluntary restrictions to lifestyle in order to limit contact with suspected substances are extremely disruptive and constraining to the individual's social and economic life. Despite the self-imposed restrictions, some studies have shown that none of the participants associated the restrictions with feeling better.

The low levels of chemical exposure that are reported as triggering symptoms raise

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42 Kilburn, 4 & 5.
43 Lipson, 103-116; Szarek, Bell, and Schwartz, 345; Nethercott et al, 19 & 20; G. Heuser, A. Wojdani, and S. Heuser, 117-138.
44 Lax and Henneberger, 429.
Table 1: Characteristics of Definitions of Multiple Chemical Sensitivity.

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<td>symptoms improve/resolve with removal from exposure</td>
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45 Barrett and Gots, 8.
46 Ibid.
47 Barrett and Gots, 7 & 8.
49 Barrett and Gots, 8 & 9.
50 "Multiple Chemical Sensitivity: A 1999 Consensus," 147-149.
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<td>symptoms involve central nervous system</td>
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<td>individual susceptibility</td>
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<td>varying degrees of morbidity, from mild discomfort to total disability</td>
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<td>symptoms recur/abate to predictable stimuli</td>
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<td>no accepted test of physiological function</td>
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<td>length of time of exposure</td>
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<td>chemical and pharmacological nature of toxin</td>
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<td>amount and variety of other body stressors (total load) and synergism at time of reaction</td>
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<td>derangement of metabolism from initial insults</td>
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<td>frequency/severity of symptoms worse with subsequent exposure</td>
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scepticism about the causal relationship between exposure and symptoms. Multiple chemical sensitivity has been somewhat acrimoniously described as perhaps “the only ailment in which the patient defines both the cause and the manifestations of his (sic!) own condition.”

ACOEM, critical of both clinical ecology and “polemic and social activism of groups representing the spectrum of opinion about multiple chemical sensitivity,” in its position statement of June 08, 1999, concedes “that data have now accumulated that supports some tentative conclusions about multiple chemical sensitivity.” These include strong support against an immunological basis; and overlap between multiple chemical sensitivity, chronic fatigue syndrome, fibromyalgia, and other non-specific conditions. There is support for an excess of premorbid somatic complaints in some multiple chemical sensitivity patients and an etiologic role for conditioned response. Prevalence of pre-existing and concurrent psychiatric disease remains highly controversial.

**Collective Hysteria**

Environmental illness has been described as a “peculiar manifestation of our technophobic and chemophobic society.” This popular appeal is said to be rooted in widespread fear of chemicals, distrust of science, medicine, technology and government, worry about the environment, and a mindset of victimization. It is manifested as hysteria, some have suggested. Mass hysteria is said to exist today in the shape of syndromes such as multiple chemical sensitivity, chronic fatigue syndrome and Gulf War syndrome. The angst that accompanies millennial change has been condensed into specific bodily conditions. Whilst the causes of such conditions are cultural, symptoms are experienced as psychological pain and discomfort with no clinical explanation. Dispersal mechanisms are the mass media, telecommunications, and electronic mail. Requisite conditions for the emergence of an hysterical

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52 Barrett and Gots, 111.
54 Barrett and Gots, 111.
55 Showalter, *Hystories*, quoted in Hatty and Hatty, 239 & 240.
response include

- a medical practitioner or other authorized knower, who defines, names and publicizes a disorder; a vulnerable individual reporting vague symptoms, who learns of the disorder and begins to believe she is suffering from it; and a cultural environment, complete with self-help books, confessional television shows, and the Internet, to spread information about the new disorder and that feed the cycle of its growth.  

An apparent hysterical response that met these criteria occurred in the Fraser Valley in British Columbia, and was described by Leiss and Chociolko. They begin with the following description:

> In late 1991 public hysteria about allegations of toxic substances (pesticides) contaminating water supplies spread through some Fraser Valley communities in British Columbia.

The origin of this public fear, they continue, was a diagnosis by a local physician of pesticide residues originating in contaminated groundwater. The residues were described as lodging in people’s bodies and affecting the central nervous system. Commonly referred to as “cluster disease” by the diagnosing physician because a number of patients with symptoms resided in contiguous areas, he gave it the medical definition of cybernetic paresis. Fear of this disease spread through the community, fanned further by the activities of a local group of residents. The Ministries of Health and Environment actively responded to these concerns. Although a team of University of British Columbia epidemiologists investigated the syndrome, local residents brought in their own “expert” from Florida. The “alarming statements” made by the residents’ expert following his analysis of water samples, undertaken in an “astonishingly short time,” could not be corroborated with independent proof of the toxins claimed to be present in the environment, Leiss and Chociolko write. Both the physician’s diagnosis and the Florida expert’s allegations were “entirely unfounded.” The hysteria dissipated over time.

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56 Ibid.
57 Leiss and Chociolko, 267.
The dissertation

This dissertation challenges Leiss’ and Chociolko’s version of what became known as the SCIDS case. Their facts of the case, as well as their arguments, differ considerably from those presented in the dissertation. Certainly the position of the local group to which they refer might be called risk-averse as they suggest. The risk-averse insist on zero risk and will not negotiate over acceptable risk and possible trade-offs. However, they continue, the onus should be on local groups to also take responsibility and educate the public about unreasonable fears that can be engendered by an extreme risk-averse stance. Taking a risk-averse stand, the group and the local physician inflamed unreasonable and unfounded fears in the community about groundwater contamination and its health effects, they maintain. And yet to characterize the conflict as a hysterical position rooted in unfounded fear on the part of some residents is far too simple. The SCIDS conflict is about perceptions of risk as well as about controversies of science, divisions between experts, uses of the media and a contest for ownership of a social problem. It is about collective behaviour on the part of the lay public as well as experts. It is a story of claims and counter-claims. It is an example of a not-oft-told tale: the demoralizing of a local movement, the defusing of collective behaviour, the discrediting and delegitimizing effects of authorities confronted with a grass-roots challenge. It is a complex and multi-faceted story, in which many voices vied with each other to have their version of the story heard, and accepted. The voices are those of the press; the experts who examined the patients, tested the groundwater, and/or were involved on behalf of a government organization; the founder of the SCIDS group; and the written reports on groundwater testing, an epidemiology study, and the management of the ensuing conflict. It is a polyvocal fugue.

Subject/counter-subject, frame/counter-frame

A fugue is a polyphonic musical composition with its theme taken up successively by different voices. It begins with a single voice or instrument stating the theme or subject of the
piece. A second voice then takes up the theme whilst the first voice continues with a separate melody, called the “countersubject.” When a third voice takes up the theme, the first and second voices go their own independent way. The effect, when all the fugue’s voices are going at once, is of a conversation between different melodies, each echoing or commenting on what the other is saying while retaining their own individual characters.59

This dissertation is about the different voices which successively take up the theme of the social problem of SCIDS. These voices frame the problem, albeit in different ways. Distinct frames compete as interpretive schemes in defining environmental illness and the state of the environment. Frames are the “schemata of interpretation” whereby individuals render the meaningless meaningful. The individual locates, perceives, identifies and labels occurrences and experiences within an organized framework.60 The process of framing inevitably includes an explanatory component. Frames are analogous to a picture frame which organizes the experience of understanding what is within it, confining the “vision” to inside the frame and obliterating that which is outside from consideration.61 In this sense, the world is inevitably seen, framed, from that vantage point.

Counter-frames are the antithesis of the established dominant frames. A counter-frame is one that resists or confronts the frame that has dominance at that point in time. It co-exists at the same time as it opposes the dominant frame, limiting the latter by eliminating the questions, attempting to abolish the scaffolding of the dominant frame and erecting its own in its place. The counter-frame establishes its own boundaries while limiting others. The legitimacy and status of a dominant frame may well be toppled, losing its legitimating arguments, and the counter-frame may become dominant.

The frames and counter-frames of this dissertation are often told as narratives. Narratives

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60 Goffman, 21.
are organized units of discourse that have as their central function the telling of a story. They have some degree of organization, temporality, and thematic coherence. We construct ourselves in and through narratives. They are "texts of experience." In a sense, the drama of the body provides the model for all narrative. As far as I can surmise, the mysterious need for narration is seated in the body. What else is a small cry of pain or pleasure but a small story?

Stories or accounts of significant life events, changes and loss for example, are routinely narrated in an effort to infuse these with coherence and meaning.

"We live in and through stories," the construction of the self an effect of the narrative, rather than its cause. We take our subject positions in the telling of the story simultaneously as it is assembled to meet situated interpretive demands. Memory, experience, time and biography are constituted through the conventional acts of narrating. The relationship between a life and its life history is far from simple, however. Narratives as situated practices are often framed as embodiments of shared beliefs and understandings. Story telling creates social life, framing narratives in such a way as to lend legitimacy to the narrative. Where beliefs, ideas, and values are contested, narratives constitute the crucial means of generating, mediating, sustaining and representing conflict at all organizational levels.

While the trend in the social sciences has been towards the use of narrative (the narrative turn), perhaps in an effort to bring the subject back in, in medicine there has never been any doubt about the role of narrative. Medical narratives have existed from at least the eighteenth century. The narratives of the sick were to be converted into a physician’s diagnostic, nosological account after filtering through the lens of observation. The narrative form however, was to be retained. Today, exchanges of narratives in academic rounds, grand rounds, patient reviews and other occasions, wherein the telling of medical work is enacted, function as "circuits of

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62 Hoshmand, 180.
63 Gubrium and Holstein, 166.
64 Griffin, 14.
65 Frank, "Illness and Autobiography," 137.
66 Gubrium and Holstein, 164.
67 Briggs, 3-20.
68 Julia Epstein, 27-55.
Narratives however, are not transparent. Personal, private aspects of experience cannot be rendered visible through dialogue. Narratives cannot convey experience in pristine and authentic form. The concern with the authenticity of the narrative reflects at least two anxieties: first, the anxiety of the researcher that the narrative data they have collected is more than mere anecdote; and second, a larger anxiety by both individuals as well as society generally about the credibility of experience and identity. Authenticity originates in the private or personal sphere and can be conferred by the authority of the public domain, either from within the group in which the experience or identity is deemed authentic, or from outside the group. Both Frank and Griffin state that a key purpose of their illness narratives is to provide the conditions or create the space where such narratives can be credited. However, Frank insists that the authenticity of the narrative cannot be judged, and therefore not credited from outside the narrative. Authenticity is relational. It is in the dialogical process of relating to each other that authentic experiences and identities are created.

Authenticity contains notions of certainty, timelessness and stasis. This means that to be genuine we should be able to return to the experience/identity and recreate it since it would be stable, static and there for the finding. Authenticity however, is as much about what will be or what should be, as about what is. Illness narratives in particular are about disruption, discontinuity, and becoming. Authenticity then may be about resisting what one has been made to be (the diagnosis conferred with authority perhaps), or accommodating it. Authenticity and narrative involve the imaginary in the form of both the past and the future. Experiences and selves are crafted in the telling and the telling of the story involves uncertainty, destabilization and imagination as much as it draws upon certainty and stability.

There is a further danger with narrative however, related to authenticity, and that is the

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69 Atkinson, 325-344.
70 Ibid.
71 Gubrium and Holstein, 164.
72 Paine, 79-81.
73 Frank, “Illness and Autobiography,” 152-154; Griffin, 222.
74 Paine, 79-81.
loss of the social. Narratives may accord privileged, private space to an isolated individual. Stripped of social context and social consequences, the narrative is understood as an individualized view of the self. Illness accounts for example may reify the individual to compensate for what is seen in comparison as the authoritative stance of the medical account. Instead of privileging autobiographical accounts, narratives should be placed in socio-historical context, considered one mode of presentation among many, one form of social action amidst others.75

This dissertation is about the individual experience of illness as well as about medical narratives, and the narratives of other experts. The narratives take place within the discursive practices of institutions such as science and the media which become part of both lay and expert stories. These narrative stories are the stuff of the dissertation, beginning first as taped and then transcribed interviews, the quotes of which are used throughout the dissertation. At times, the stories are re-constructed to protect the identity of individual participants in the research. Although the story of SCIDS was told in the media, the process of interviewing, or even of requesting interviews, solicits/invites a side of the story that up until that moment had remained untold, at least publicly.

Everyone feels the need to describe experience. Of this there is no doubt. But why the need exists is still unexplained. There is, of course, the fact that when knowledge is kept silent, it loses potency, fades, or even moves backward, erasing itself.76

There is, in this dissertation, some testimony which must remain silent, given by phone at the time of withdrawal of consent to interview or cancellation of the interview appointment. While it has enriched my understanding of the dissertation topic, of the politics of diagnosis, disease, discovery and deceit, it cannot be woven into the understanding here except in the hyphens, the gaps, the silences. That which becomes the public discourse is often not whole, not complete, for there may be parts of the story that must stay private, and perhaps be erased. This is how a history is constructed and how the present may be framed.

75 Atkinson, 325-344.
76 Griffin, 276.
And there is this too. In the process of telling a story, you will come to understand events on a far deeper level. This is as true of public discourse as it is in a private life. Every society repeats stories about itself, fashioning a history that will frame the present.77

In addition, conflict entails many emotions, some negative, many misunderstandings, and feelings of ill-will between some of the individuals involved. Things said, sentiments expressed, cannot always be quoted as the affront caused may lead to disrepair of working relationships, legal action, or loss of livelihood. Re-constructed narratives in which one voice may speak for a number of participants have been used in this dissertation as a technique to protect participant confidentiality, and at times, anonymity. These re-constructed narratives were used to introduce chapters and/or provide the background, the frame, against which the analysis is set. They were based on the interviews and have attempted to keep close to what was said there.

**Becoming the composer**

In retrospect, research can be seen as the juncture of many paths which have led to this point. For myself, the paths are those of health and the environment, community activism and politics, the intersections of which I only now recognise as I write this section.

My entry into the health field began with nursing training when I left school. This was followed by a stint of raising children and being at home for a number of years. Settled in a pulp and paper mill town at this time, I became politically active at the community level, petitioning the borough council over a decision they had made and with which the majority of the community did not agree. As those before me who have questioned the decisions of others who are ultimately accountable to the public have found, I, and my family were confronted and threatened, and referred to with malice by borough councillors.

In a town constructed and controlled by the pulp and paper mill company, it was impossible to avoid considering matters of the environment. Forests planted specifically for harvest by the mill company, of Douglas Fir and Radiata Pine which were fast growing and harvestable within 25 years, were generally taken for granted. The forests, two of them, one in

77 Ibid.
the Tokoroa area in the central North Island and the other in Kawerau on the east coast of New Zealand, had been founded in the depression of the 1930s, as work fare for increasing numbers of unemployed men. The time spent in the forests, with its undergrowth of ferns, and the orchids and supplejack that nested and laced through the trees, together with the songs of the New Zealand wood pigeon, tuis and bellbirds seems now, in retrospect, somewhat idyllic. However it was the dissonance and disjunctions when the same area of trees was felled, and the birds were displaced, the undergrowth wrenched out of earth and discarded that began thoughts about the relationship of the economy, the environment, nature, and culture. However, in those years it was not something spoken of publicly. The town, and everyone’s livelihood, was dependent upon the pulp and paper company, and dissidents were quashed.

A paid job however eventually seemed a necessity, and I found myself soon working as a policy advisor in the Ministry (then Department) of Health in New Zealand. While seen as a “traitorous” move by some in the community, it was here that I was to learn how expertise was brought to bear and presented to the public through government statements, policy, codes of practice, and through the voice of government ministers.

A Masters degree later, which examined the construction of women’s identity in the pulp and paper mill town I had just left; a summer school course at La Trobe University, Melbourne, Australia, on Women and the Environment; and eventually as full-time faculty on a Bachelor of Nursing degree in, ironically, the Department of Environment and Health Sciences at Wellington Polytechnic (now Massey University), I began to weave the strands of health and the environment together.

During this time, the New Right took over New Zealand through the Left door. Creeping into the minds of the people and the structure of the society like a scourge, unseen and unquestioned, it demolished all that workers before had fought for and won. Entry to the doctoral program at the University of British Columbia in Vancouver, Canada, made escape possible. Here, in time, I took research work on the Fraser Basin Ecosystem Study, a Tri-Council funded, interdisciplinary Eco-Research Project. Involving a retrospective investigation of a group of people with health symptoms which they had very vocally linked to the environment, it was to become my dissertation.
Another job, this time in Halifax, working on clinical drug trials in Alzheimer’s disease while simultaneously writing the thesis. Here, a microcosm par excellence (for my purposes), of experts. While not part of my thesis matter, nonetheless it provided me with the opportunity to watch and wonder and mull over what was emerging from my research data. The results presented here as the dissertation are the point to which, retrospectively, these various paths seem to have led.

**Conducting the Fugue**

Assembling the voices takes place not haphazardly but methodically with an eye to the requirements of research methods. Research results in the compilation of data for viewing simultaneously in ways that would never have occurred otherwise.

> Scattered through time and space, these leaves would never have met without her redistributing their traits into new combinations.78

Compilation of data, methods and results are the response to the questions of the research. At a very basic level, and to decipher among the multiple voices, the fugue, I found myself asking, “what is going on here?” This led to other questions. It appeared a conflict about the environment and its effect on health was in part what was going on. There was a contest over the definition of an illness, which was eventually named SCIDS. How was SCIDS constructed and legitimated by the experts involved, by people with SCIDS, and by the media. The link with the environment implied that risk was involved. How then was risk defined and legitimated? And management by government seemed to be occurring, but of what? Was it the illness, the SCIDS group, risk or the conflict that was being managed? Or all of those? Were they all one and the same thing? These questions and my answers to them provided the framework for the thesis.

In Chapter Two, I outline the method for collection and analysis of data in the dissertation. Mindful of the fact that I am critiquing research methods used in the construction of what became the public issue of SCIDS, I question my own research methods and their potential to do the same.

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Chapter Three establishes the parameters within which the dissertation is set. The literature review, it provides an overview of the thinking, including preliminary thoughts and theories, about the thesis, and the theories within and across which the dissertation lies.

The next chapter, Chapter Four, provides the lone voice of the founder of the SCIDS group, and her experience as a person with SCIDS. She illustrates her cooption of expert discourse to understand the embodiment of risk.

Chapter Five examines the media perspective provided to the public in the newspapers and news magazines, local and regional. Here, the voices of the various experts are introduced in conjunction with the voices of those with SCIDS. The frames and counter-frames begin to take shape as the lay public and experts situate themselves.

The voices of experts are the focus of Chapter Six. The role of science and technical frames in contesting ownership of the problem is established and examined. By no means an homogeneous group, the perceived authenticity of the experts drawn into the conflict plays a large part in the eventual ownership of the social problem.

Chapter Seven outlines the management strategies put in place by the provincial Ministries of Health, Agriculture and Environment to conclude the conflict and restore community trust. Civility lost must be won back, and the opportunity for an environmental conflict such as SCIDS to rear its head again, put to bed.

The final chapter, Chapter Eight concludes the dissertation by setting the conflict in a wider theoretical framework.
CHAPTER TWO: ARRANGING THE COMPOSITION: RESEARCH METHODS

During the years 1994-1996 I worked as a research assistant on the Eco-Research Project, *Prospects for Sustainability*, a multi-disciplinary project at the University of British Columbia (UBC), Vancouver, B.C. Involving twenty-three faculty and more than forty graduate students across twenty different departments and institutes at UBC, the final report in 1997 indicated that present human activity in the lower Fraser Basin was not sustainable. A considerable variety of projects were undertaken as part of this research, and a broad range of human impacts investigated.\(^7^9\)

My involvement in the Eco-Research Project was a preliminary investigation into the environmental conflict I shall refer to as SCIDS, using data from newspaper articles predominantly. I was able to benefit from the work of other Sociology graduate students\(^8^0\) who had been in the field, and who together with faculty had interviewed individuals involved in various environmental groups or organizations dealing with environmental concerns. A background in health care and health policy, together with an academic interest in body/identity and social movements paved the way for a more intense interest in the interactions of all the players in the SCIDS conflict. Contact with some of the key people in this doctoral research was made at that time through my work on the Eco-Research Project.

This chapter begins with a history of the early research process, then outlines the data collection, preparation of data and analysis methods. I have drawn upon the structure of the fugue as an organizing framework. The structure of qualitative data, its management and analysis share something of the rhythmic regularity and irregularity of the fugue. The entry of voices (the data) one by one as is characteristic of the fugue, the statement and restatement, fragmentation, imitation and repetition of themes, as well as themes which begin and do not

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\(^7^9\) Healey to Eco-Research Study participants; Michael C. Healey, *Final Report*; idem, *The Lower Fraser Basin Eco-Research Project*.

\(^8^0\) Especially Barbara Alldritt and Andrea Kastner.
Finding the Theme(s)

My major theoretical and research interest upon beginning this doctoral research was that of self, body and identity. My involvement in the eco-research project, and especially my assignment to look at the SCIDS group piqued this interest. My initial and emergent curiosity from the research of newspaper articles about SCIDS was the major discernible discourses and their effect on both individual and collective identities. I had identified three main discourses, those of health/illness, the environment, and gender. There were three main groups of knowledge/information in which these discourses circulated. They were the SCIDS group, the newspapers and a group of experts. These I had anticipated would become the three data groups in the dissertation. My research question was “how do the discourses of the environment, health and gender become part of individual and collective identity?” This question was further divided into “what are the discourses of health, gender and environment espoused in relation to the SCIDS conflict? Are these discourses the same among the three groups: the experts, the newspapers, and the SCIDS group, or are there important differences? What is the self that these discourses establish, and how does that discourse construct an individual identity? What are the processes by which the discourses become part of collective identity, particularly the collective identity of a social movement? What are the interactive processes between individual and collective identity?”

My primary focus was the SCIDS group itself, with the experts and newspapers secondary. The conversations with SCIDS group members would, I hoped, provide insight into the processes of identity formation, both individual and collective. Further, I was interested in the effect of these discourses on the formation of identity. Experts were to be interviewed to elicit contrapuntal character to the research.

Contrapunctal is defined as “of, or relating to, counterpoint.” Counterpoint comes from the Medieval Latin (circa 15th Century) contrapunctus (contra: counter; punctus: musical note, melody). Counterpoint is defined as “1. one or more independent melodies above or below a given melody; 2a. a complementary or contradictory claim; 2b. use of contrast or interplay of elements in a work of art.” (Merriam-Webster Online http://www.m-w.com/cgi-bin/netdict?contrapuntal)
their understanding of the three discourses in relation to SCIDS, and the transmittal of these discourses to the public gleaned from the newspaper articles. My main interest, however, was with the influence of the media interpretation and expert discourses on identity, self, and conceptions of the body of SCIDS group members. Eager to interview members of the SCIDS group, I was surprised and frustrated to discover how inaccessible they were (the group was defunct for some 3 or so years by the time I entered the field). The founder and spokesperson of the group was contacted and granted me an interview. However, no introduction or provision of names of previous members of the group was forthcoming. Meanwhile interviews with the experts involved in the SCIDS conflict were completed.

My deployment to another city on the farthest coast from Vancouver meant that it was impossible to do the kind of ‘detective’ work necessary to trace the former members of the SCIDS group. The dissertation research took on a new persona as my interviews were now with the experts predominantly, with one interview only with a SCIDS group member. No longer able to focus on identity, self and body as I had originally planned, the discourses of the expert group now took predominance. While speaking of health, the environment and very little of gender, there was another frame that overshadowed the three discourses in which I had initially been interested. The frame was that of science, and was an ‘echoing’ frame in each of the discourses. As in the fugue, the frame of science was the central theme that was stated by each of the voices, repetitious and fragmented, recurring in episodes leading to new statements of the theme. The frame of science dominated the experts’ thinking about and approach to SCIDS, and was an accepted frame by the SCIDS group founder herself. Like an echo, it resounded unexpectedly throughout the data.

SCIDS was an environmental conflict. At a surface level, some of the experts, the health experts, appeared to be attempting to unravel the mysteries of environmental disease. Yet it seemed as I dug deeper, and as potential research participants began to hesitate or refuse invitations for interviews, that something a little more than unravelling the mystery of disease had occurred. My research question became, “What is going on here?” I now needed to immerse myself in the data and listen, letting “what was going on” emerge from the data itself.

Government had responded to the conflict with various research studies and regulations
which, while they were a concerted effort across ministries to respond, had something of an ad
hoc ring to them. The concerns of a portion of the community with regards to the degradation of
the environment and the perceived links between the environment and the symptoms they
suffered were not seriously considered. The experts it seemed were involved in managing the
conflict much more than they were in attempting to identify the constituent symptoms of the
syndrome SCIDS and to locate its causes. Based on this observation, my research question
became “what was the role of the experts in the SCIDS environmental conflict?” Risk was
implicated in this conflict. The experts involved were the allocators of risk, basing their decisions
on whether the toxicology or epidemiology study results fell within safe limits, allocating on the
basis of scientific evidence. “Were the experts then managing risk or managing conflict, and
were those two necessarily exclusive of one another? And what was the role of science in this?”
This was where I began in analysing the data. However, first I need to return to the data
collection itself and to provide a more detailed outline of the data and the processes of collection
and preparation of data for analysis.

Assembling the Voices: Data Collection
The voices of the fugue announce and answer the main theme or subject. Data (voices) are not so
much collected as generated in an interactive process with the sources of that data. This study
included several types of data: newspaper/magazine articles, in-depth interviews, documents and
video.

The news articles
I began the research with newspaper and news magazine articles, which provided a
background to the initial concerns about the possibility of some outbreak of illness that might be
linked to environmental factors. This provided the impetus to further research in the field. The
newspapers and news magazines in which articles were located were:
• The Abbotsford News
• Abbotsford Times
• The Chilliwack Progress
Sixty-two articles from the years 1986 to 1994, covering both groundwater contamination and what was soon to be known as the SCIDS phenomenon were analyzed. Searches were made of newspapers and news magazines from local communities in the Fraser Valley, as well as Vancouver and the wider British Columbia region, with a preponderance from Abbotsford where SCIDS was centred. Articles about SCIDS were the initial focus for searches until it became evident that a link was being made between groundwater pollution by nitrates and pesticides and the health concerns expressed in the Valley. Articles on groundwater contamination concerns ranged throughout the years 1986 to 1994 whilst SCIDS was more specifically covered in the news between May 1990 to July 1993.

In-depth interviews

Interviews are dynamic social interactions characterized by multiple dialogues between multiple selves. Not simply a source of data or the repositories of "objective facts," interviews are mutually constructed social events. Interviews were conducted with the main experts involved in the SCIDS conflict, as well as the founder of the SCIDS group. The interview participants were:

- The Director of Project Enviro-Health
- A Fraser Valley Medical Officer of Health
- A B.C. Ministry of Agriculture agrologist
- A Fraser Valley orthopaedic surgeon
- Two University of British Columbia (UBC) epidemiologists
- A hydrogeologist (private company)
- The founder of the SCIDS group

Multiple interviews were conducted with some of these participants. An additional

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82 Collins, 1
hydrogeologist and an environmental toxicologist refused to be interviewed. The hydrogeologist was asked twice for an interview, with several months interval between requests. He remained fearful of losing his job if he discussed the SCIDS case. The environmental toxicologist involved with water testing during the SCIDS case agreed to an interview and declined at the time of interview appointment. Two further key participants did not respond to requests for interview or to follow-up messages left for them. One of the two epidemiologists who conducted the epidemiology research was located in Ottawa and was not interviewed. Out of a total of 12 key people involved in the SCIDS conflict, I was able to interview seven. This set of interviews was complemented by access to a further 106 taped interviews with community leaders in Abbotsford in which perceptions of environmental issues were explored.

A letter was sent to each individual to be interviewed, explaining the study and the rationale for their inclusion, requesting their participation. This was followed by a telephone call to arrange a date, time and place for interview. Before beginning the interview, a consent form which included a clause ensuring confidentiality was signed by both the participant and myself. Interviews were from one to three hours in length.

Interviews were unstructured but guided by themes and topics I was interested in covering. These were the state of the environment in the Lower Fraser Valley, health issues in the Valley, the SCIDS group, the role of environmental groups in the community, involvement of environmental groups in the SCIDS conflict, experts’ roles in the SCIDS conflict, farming practices, and conflict management practices. The interviews were taped, later transcribed verbatim, and formatted for use in qualitative data analysis software programs. The decision to interview rather than mail out a more structured and impersonal questionnaire was made for several reasons. The judgement that this was a fraught, political issue was vindicated by the nervous responses and occasional refusal. In addition, interviews enabled the gathering of in-depth information through face-to-face interaction in which probing, directing, interpreting, clarifying, questioning, and summarizing of responses by all interview participants, interviewer(s) and subject(s), could be undertaken.
Documents

Various reports were published by government departments on the quality of the groundwater and the status of SCIDS, many instigated by the publicity around SCIDS. In addition, some documents which were of importance to the undertaking of government contracted research in relation to SCIDS were provided by research participants. These became a third set of data. Documents included in the analysis were:

- the epidemiological report and associated documents:

- Project Enviro-Health Quarterly and Annual Reports, 1993-1996

- Ground water research reports:

Video data

The video *Project Enviro-Health: Ensuring a Healthy Environment in the Fraser Valley through Community Action* was produced as both a public relations exercise and an education tool by the project. It provided further insight into the perspective from which the project
addressed what it referred to as the SCIDS problem.

**Triangulation of data**

Multiple data collection techniques measuring a single concept or construct is referred to in qualitative research as triangulation. Triangulation is a method used in surveying, mapping, navigation and military practices. Three known points or objects are used to draw sighting lines towards an unknown point or object, the lines generally intersecting to form a triangle called the triangle of error. Assuming the lines are equal in error, the centre of the triangle is the best estimate of the true location of the new point or object. This concept has been transferred to other types of research where several data sources are used to verify through replication a conclusion, or rule out other conclusions. Where different sources are inconsistent or conflicting, triangulation can push towards a more complex, context-respecting set of explanations. Findings can be elaborated or a new line of thinking initiated. The data collected for this current study are triangulated in that there are multiple data samples: documents, interviews, video, and newspaper articles.

**Preparation of data**

Interviews were transcribed verbatim from audio tape in preparation for coding in the qualitative software. Transcription was completed by both myself and a paid transcriber. Transcription conventions were incorporated to denote pauses (.....), emphasis (CAPS), non-verbal language {laughter}, and recollections and observations for myself ([S is showing me newspaper articles about the case]). Difficulties with hearing and understanding a spoken word on tape were denoted with the possible word between forward-slash symbols (/aquifer/) or as a question mark between forward-slash symbols (/?/).

Transcripts were edited after transcribing was completed. This involved listening to the tape with the transcript on screen, and corrections made and observations added. Each transcript was provided a ‘.ed’ suffix to indicate that it had been edited.

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83 Berg, 4-6; Miles and Huberman, 266 & 267.
At the time of transcription, the document was also formatted for use in the software. Decisions were made as to the amount of text that would initially be selected for coding as well to how far the coding could expand beyond that for context. The software QSR NUD*IST, revision 4, requires a choice between one line of text and one paragraph of text for initial coding. Since people don’t often speak in paragraphs, I opted for one line of text, which also allows for finer coding. From one line of text, coding could be expanded to a section (denoted by the character ‘*’ at the beginning of a section) or to the whole document. The speech of the interviewer and the respondent in one turn was designated as a section in this research. Coding by dragging the cursor to highlight the amount of speech to be coded also allowed chunks of text larger than a section to be coded. Following transcription, editing and formatting, interviews were ready for use in the various software.

A number of key documents in hard copy were summarized, formatted and read into the software. The documents were *The Abbotsford Pattern of Muscle Weakness: A Summary*, undated; An Investigation into a Cluster of Muscle Weakness in the Fraser Valley, British Columbia. February 26, 1992; An Investigation of Muscle Weakness in the Fraser Valley, British Columbia." *BC Health and Disease Surveillance* 1992:1:8:64-70. Other documents and the newspaper articles were used as hard copy. The video was digitized to CD-Rom for coding in the software.

**Giving Voice to the Themes: Data analysis**

Giving voice to the themes required recognizing the themes in the data. Two qualitative software packages, QSR NUD*IST and ATLAS/ti, were used to manage the data as well as assist in thematic and grounded analysis. In a fugue, once all the voices have stated the theme the challenge to the composer is to develop the material, the theme, in the most inventive and clever way possible. A similar process was undertaken using the software with the data. The themes or frames were explored and developed, fragmented and restated, ensuring their grounding in the

data (the voices). Although I had intended to use all the data in each of the software (to the extent that the software would take each type of data), in the end I used each program for its strengths in relation to the other program. ATLAS/ti was used for analysing the video, the only software at the time that could do so easily, while coding of the interview data, the newspaper articles and documents took place in QSR NUD*IST 4. A brief description of the two selected software programs can be found in Appendix 2. The process and details of analysis can be found in Appendix 3.

The benefits of qualitative data analysis (QDA) software

Analysis of data requires a set of mechanical operations. Tedious, time-consuming and mundane when traditionally performed by hand, the computer will do anything that can and has been done on paper in qualitative research, more efficiently and easily.85

Data in written form can be speedily recorded, and rapidly retrieved. Similarities, differences and relations between text passages can be identified and mechanically coded and retrieved. Coding schemes can be easily and quickly changed at whim. Ideas can be inserted as they occur, and new coding and new codes done at will. The raw data remains close by, at hand, immediately available for investigation. And less paper makes the analytical process significantly less cumbersome, and less tedious.86

Further, an enhanced ability is provided to sort, sift and think through the patterns to be found in the data.87 Not only are the clerical-type tasks rapidly dealt with, but the quality of data analysis is enriched. The computer's ability to handle data easily and efficiently means that data are less likely to be disregarded, or worse, lost. The small but significant pieces of information buried within the larger mass of material are more easily located; the deviant case more easily found. And there is encouragement to "play" with the data, to have "fun" in the analytic stages,

85 Lee and Fielding, “Computing for Qualitative Research,” 3; Richards and Richards, “Transforming Qualitative Method,” 38; Drass, 334-346.
86 Lee and Fielding, “Computing for Qualitative Research,” 3; Richards and Richards, “Transforming Qualitative Method,” 38; Tesch, “Introduction,” 150; Drass, 340
rather than approaching this process as one that is mundane and boring.\textsuperscript{88}

The research routine too is altered. The savings in time also amount to savings in energy. Intellectual energy can now be directed towards the analysis rather than tiringly spent on the mechanical tasks of the research process.\textsuperscript{89} Coding can begin as soon as the first data are collected, providing the opportunity for a more thorough reflection of the data collection process with consequent redirection or amendment if necessary. Coding becomes a process that goes the length of the project, rather than merely being one stage of the research. It becomes much easier to multi-task, entering data, coding, testing assumptions for example almost simultaneously, rather than pursuing these in linear fashion as traditional qualitative methods encourage.\textsuperscript{90}

With acceptance and use of computerized QDA comes destigmatization and legitimation of qualitative research. Qualitative research has tended to be defined in relation to quantitative research. That is, the "'non-quantitative' handling of 'unstructured' data."\textsuperscript{91} Negatively defined, of low status, and with a reputation for untrustworthy results supported by anecdotes, qualitative research has been legitimized by computerized QDA by providing the rigour and transparency that qualitative method purportedly lacked.\textsuperscript{92}

\textit{The Disadvantages of QDA software}

The speed and efficiency with which clerical tasks can be undertaken by computer, and the flexibility for coding schemes provide not only benefits but some further implications as well. A revered, if not reified, aspect of qualitative research is "closeness to data." Many qualitative researchers value close involvement with and interaction with their data, and fear its loss with computerized QDA. The tactile, handling of data has been extolled by many, often linked to research insights and creativity. In contrast, quantitative researchers have been

\textsuperscript{88} Lee and Fielding, "Computing for Qualitative Research," 4; Richards and Richards, "Transforming Qualitative Method," 46-51; Tesch, "Computer Software," 150.
\textsuperscript{89} Tesch, "Computer Software," 143.
\textsuperscript{90} Richards and Richards, "Transforming Qualitative Method," 46-51; Tesch, "Computer Software," 144
\textsuperscript{91} Richards and Richards, "The NUD*IST System," 39.
\textsuperscript{92} Richards and Richards, "Transforming Qualitative Method," 39; Tesch, "Computer Software," 148.
perceived by qualitative researchers as being distanced from their data, engaged with computerized analysis of huge data sets.\(^{93}\)

Qualitative research traditionally has tended to value smaller data sets, trading breadth for depth, the latter one of the prized characteristics of qualitative research. The inherent difficulty, however, in dealing in-depth with huge quantities of data has constrained traditional qualitative data analysis. At the same time there has been the criticism by the quantitative research community that no basis exists, namely quantity, for staking qualitative research claims. The results of qualitative research have been, quite simply, labeled untrustworthy.\(^ {94} \)

The ability to now efficiently and speedily search, retrieve and analyze by computer every bit of data, no matter how large the data set is enticing. The concern lies where a large data set is selected merely because the availability of the technology makes it more feasible to do so. In addition, volume of data may well drive the analysis, with important and interesting things being missed. Instead of analyzing identified phenomena for example, analysis may be reduced to counting occurrences of phenomena. Attention and energy may well be spread out over large numbers of instances with little analytical effort put into any one instance. The ease with which computer technology allows the researcher to use voluminous data may well lead to a trade-off of resolution for scope.\(^ {95} \)

Commodification of qualitative research may occur. The speed and efficiency of computerized QDA can all too easily result in a lack of knowledge and understanding as to how the final results were achieved. Seduced by the convenience and credibility of the program's rendering of sense, attention is diverted from the logic and research design issues that actually govern the adequacy of analyses.\(^ {96} \) An added outcome is "quick and dirty" research characterized, in addition, by preemptive data reduction and quasi-quantitative analysis posing as qualitative.\(^ {97} \)

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\(^ {93} \) Seidel, 115; Ragin and Becker, 51; Tesch, "Computer Software," 151.
\(^ {94} \) Tesch, "Computer Software," 151.
\(^ {95} \) Seidel, 115.
\(^ {96} \) Lee and Fielding, "Computing for Qualitative Research," 6-9
\(^ {97} \) Richards and Richards, "Transition Work!" 20.
Often ignored is the fact that computerized QDA is embedded in a culture of technology. Technology is not merely a "thing" of material culture, but is a "socially and culturally constituted system of knowledge and social relationships."\(^9\) An implemented technology carries with it a vision of the society in which it is to be used, which includes a set of symbolic and social circumstances which oblige people to direct their affairs in certain ways. Taking the view of neither the technological somnambulist nor the technological determinist, both of whom consider technology to be an object external to social behaviour, or a "thing," I want to argue that technology is social behaviour, and as such loaded with pre-understandings, not least of which is the built-in denial that it is a form of social behaviour.\(^9\)

While the cybernetic model [implicit in computing] may be a useful paradigm for knowledge, it is markedly different from that of qualitative research which emphasizes diagnosis, not control, and interpretation, not explanation. On learning to use the computer the fieldworker is consuming a culture of control, not just a tool.\(^1\)

What we want to do is changed by what we can do. Technology does not merely do what it is told, but influences our ideas of what is possible and desirable.\(^1\) Previous research on the introduction of computers into offices has found that work functions change to accommodate the computer, for example. Tasks become increasingly fragmented, repetitive and meaningless; knowledge, previously the possession of the worker, becomes encoded into the computer database; menu-driven software places control of communication with the computer; and the loss of skills and introduction of new skills required to operate sophisticated systems requires the individual to evolve to accommodate the machine.\(^2\)

Perceived by many researchers as merely a tool,\(^3\) QDA software may come to define

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\(^9\) Pfaffenberger, 15.
\(^9\) Pfaffenberger, 15.
\(^1\) Lyman, 86-87.
\(^1\) Crang, Hudson, Reimer, and Hinchliffe, 771-787.
\(^2\) Damarin, 16-20.
\(^3\) Smith & Hesse-Biber's research with 12 qualitative researchers (faculty and graduate students) about their experience with QDA software indicates that the computer is seen as a tool that allows them to be more efficient and organized (Smith and Hesse-Biber, 425).
method. The unstructured abyss that often follows data collection, the sense of not knowing what to do next, and the desire for an ordered process may lead to the grasping of a software program that then becomes the method. The problem, it is suggested, is that the use of software presupposes a way of seeing the problem and the situation.

Further, the structure of individual software programs may influence research results. Where software defines method, the goals of the study may be completely missed. In addition, studies comparing software programs using the same data have found a qualitative difference in results for each program. This points to the importance of knowing the developer’s assumptions about research that are built into the program, as well as the implications of using one program only for analysis of research data.

A further criticism, and one linked to the developer’s assumptions about qualitative research, has been an increasing tendency towards homogeneity in what has been a methodologically diverse field. Most QDA software programs require text in ASCII format, expect the data to be easily divided into single files, and drive the research process towards code-and-retrieve at the expense of any other sort of approach. Rather than a creative approach to analysis, researchers are led methodically to code every chunk of text. Rather than thinking about the ideas emerging from the data, this creativity is submerged in a process in which coding remains a task to be done, and a way of controlling messy data.

Linked here is the central role of grounded theory as a premise of many of the QDA programs. The choice of techniques available, for example coding, may also prescribe choice of method (grounded theory). Homogeneity in the software can coerce qualitative research in

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104 Agar, 181-193.
105 Crang, Hudson, Reimer, and Hinchliffe, 775.
106 Again, a situation is described where The ETHNOGRAPH's code and retrieve approach completely missed the goals of a study (Agar, 181-193). However, although The ETHNOGRAPH has been described by Agar, this is not a situation specific to The ETHNOGRAPH software in any way. The point is that it can and does happen when QDA software is used blindly without an awareness of how the software structures the researcher's view of the data.
107 For example Walker, 91-111, found in a comparison of three QDA programs with the same data, that Martin yielded "thick description" whilst The ETHNOGRAPH and Gator were more geared towards the discovery of regularities and patterns in the data.
restricted directions.\textsuperscript{109}

Not only is there a tendency towards homogeneity among qualitative research methods, but as well, a closing of the qualitative-quantitative dichotomy. There has been renewed insistence in the past decade or so that techniques for sorting and analyzing qualitative data be rigorous. The introduction of computers has coincided with an increased call in qualitative research for developing and justifying rigorous methods of data processing. Absurd as is the notion of the absence of rigour in qualitative research, since qualitative researchers seldom if ever proceed in an "impressionistic, haphazard or non-sequential fashion," but rather in a thorough and orderly manner,\textsuperscript{110} nonetheless this supposed lack has burdened the paradigm with low status and a reputation for untrustworthy results. Rigour in qualitative research has pushed towards quantification and scale. Coincidentally, QDA software is ideally placed to serve just this goal, and can be expected to reinforce any trend towards dealing with "soft data" rigorously.\textsuperscript{111}

Since the time of the General Inquirer,\textsuperscript{112} computer techniques have provided the opportunity to quantify a wide range of characteristics of text. And the trend in qualitative research in the past decade has been towards "harder" analysis of "soft" data. The computer offers a "Trojan horse for the infiltration of the narrowest goals of quantitative sociology."\textsuperscript{113} And those goals include the positivist dream of converting raw phenomena into data that can be treated scientifically; that is, objective data, susceptible to measurement and quantification, able to be generalized beyond the sample analyzed.\textsuperscript{114}

Qualitative software itself, not merely its use, is instrumental in bridging the gap between

\textsuperscript{109} Hinchliffe, Crang, Reimer and Hudson, 1118 & 1119; Lonkila, 49 & 50; Richards and Richards, "Using Computers," 460; Ragin and Becker, 53.
\textsuperscript{110} Tesch, "Computer Software," 150.
\textsuperscript{111} Richards and Richards, "Transforming Qualitative Method," 39 & 40.
\textsuperscript{112} The General Inquirer was the first software for use in the qualitative field. Developed over thirty years ago for content analysis, it was unique as the first program designed to analyze text (Tesch, "Introduction," 225).
\textsuperscript{113} Richards and Richards, "Transforming Qualitative Method," 40.
\textsuperscript{114} Ibid.
quantitative and qualitative methods. Some of the QDA programs include quasi-statistics, and many provide the facility to export data to a statistical package such as SPSS. Certainly there is a "blurring" between the two methods, with the microcomputer providing "...a common technical ground for the meeting of qualitative and quantitative researchers."

Possibilities

Are the disadvantages noted above enough to deter researchers from using QDA software? Is there good reason for qualitative researchers to be deterred from qualitative computing? I maintain that too much is made of the disadvantages, that these so-called constraints can actually work to enlarge a researcher's thinking about his or her project.

Firstly, replacing the "tactile" with the "digital" may not be quite the loss envisioned by some qualitative researchers. The creativity that potentially comes with "feeling" the data as we shuffle through mounds of paper may itself be mythical, or at the very least, prevent other forms of creativity. The necessity to feel the data on the paper need not be denied by importing the data to the computer. There is always the possibility for hard copy, and many qualitative computer users work in both media, with data both on screen and on paper. Perhaps the digitalization of data will lead us to "see" in other ways, encouraging further creativity.

Whilst many software programs invite coding and retrieval as a first step in analysis, code and retrieve programs are not all the same. Many diverge in analysis functions after this first step. For example, the software NUD*IST allows coding to be connected in hierarchical...
categories, enabling the researcher to explore relations between codes and categories (see Appendix 3). NUD*IST also has links with two other qualitative software packages—Decision Explorer and Inspiration, both concept mapping programs, allowing the researcher to export her/his coding system to another format for further consideration and inspiration. Another software, ATLAS/ti, enables non-hierarchical networks to be developed, and hyperlinks between text segments to be established. And HyperRESEARCH enables the identification of coincidences and associations between codes with the use of hypothesis testing. Still other software employ other strategies, all encouraging visioning the data anew, in ways difficult to achieve in the traditional, manual method of doing qualitative research.  

Grounded theory certainly has been the prevailing approach embedded in some of the QDA software. Early articles written by the developers indicate that this has been the case. This does not apply by any means to all QDA software developers, however. This is a large and growing field, and the important point is to understand the assumptions embedded into the software. This means knowing something of the developer’s ideas about qualitative research, regardless of whether these are based in grounded theory or another qualitative method. For example, phenomenological and ethnographical research approaches are embedded in The ETHNOGRAPH. MAX and WinMAX were developed using Max Weber’s concept of ideal types and a Popperian methodological approach is integrated into AQUAD.  

For my purposes, however, grounded theory was a useful approach. With grounded theory, the central process is coding, in which data are broken down, fragmented, conceptualized and reformulated in new ways. This coding process is used to provide the grounding, density, sensitivity and integration necessary to build explanatory theory that closely approximates the reality it represents.  

While grounded theory has been criticized as no more than a common sense view of the

120 Kelle, 2-9.
121 For example, Richards and Richards, "The NUD*IST System," 307-324; Muhr, "ATLAS/ti—A Prototype," 349-371. Lonkila has also suggested that the influence of grounded theory can be found in HyperRESEARCH and in Kwalitan, in addition to other qualitative software (p.46).
122 Kelle, 15.
123 Strauss and Corbin, 96-142.
data, detached from context and thus producing trivial knowledge, a detailed and grounded analysis allows the researcher to be immersed and fully engaged with the data rather than distanced from it. Theory is bracketed out and the data understood from the participant’s point of view. And comparison of the research results with appropriate substantive and theoretical literature takes the method beyond a mere affirmation of the researcher’s own biases.

It has been suggested that a gap between quantitative and qualitative research has no foundation. Some researchers, both quantitative and qualitative, welcome the convergence, perceiving the possibility for quantitative researchers to attend more to diversity in their analyses, and for qualitative researchers to compare and contrast more thoroughly across cases. Computational techniques could lead qualitative research away from its traditional base towards the stereotypically quantitative. On the other hand, qualitative computing "may push qualitative research towards far more subtle, varied, powerful, and rigorous ways of doing what the method has always attempted to do."

On a final note: it has been suggested that the real danger with qualitative computing is applying techniques structured in the software without considering the necessary methodological prerequisites. As an example, computing invites qualitative researchers to engage in theory construction and hence hypothesis testing. Inductive hypothesis testing is seldom achieved in qualitative research, but interactive hypothesis testing is more likely. Hypothetico-deductive hypothesis testing requires coding into mutually exclusive categories. Qualitative research, by the very nature of its data, is seldom able to achieve mutually exclusive coding. Nor does it so desire. The difference rests on the idea of hypotheses as propositions which will be verified or falsified by the data, versus hypotheses as vague and general assumptions about possible relations between and across categories which may be explored, clarified or modified through a thorough analysis of the text. Unless these two very different approaches are understood by the analyst, “one can easily produce artifacts.”

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125 Kuckartz, 158-167; Ragin and Becker, 54.
126 Richards and Richards, “Transforming Qualitative Method,” 53.
127 Kelle, 12.
What seems evident in the discussion of the benefits and limitations of computer use in qualitative research is the need for an awareness, a reflexivity on the part of the researcher of the capabilities of the software program, and what that means for the analysis of his/her research project. Researchers need not be ensnared by the software program. The researcher can have control over their use of the software, abandoning it if it does not meet their requirements. Of course, not all researchers are going to be aware of the way their research analysis is being structured by the software program they are employing. Even within the traditional techniques of manually coding and analyzing qualitative data there were always some researchers who were interested only in a “quick and dirty” approach. So too, they are there within the qualitative computing research community.

Now, however, researchers can design projects that would have been unthinkable without QDA software. The code-and-retrieve model embedded in most QDA programs was the cut-and-paste of traditional qualitative research, a method that even then had serious problems. I found that the software allows for the "constant interrogation" of themes, both emerging and developing, enhancing theory construction and theory testing. And the "confidence and thoroughness" with which claims can be made and validated far exceeds that of traditional qualitative research. The advantages of no longer losing data, of being able to retain and manipulate ideas instead of being limited by the capacity of the human brain, and of being able to take advantage of new visual approaches to the whole research project, allowing innovative and creative ways to think about the data far outweigh the disadvantages of computer use for qualitative data analysis.

The following chapters are the result of analysis using qualitative data analysis software. Coding of data within the software contributed to the emergence of the narratives of the media, the experts, the SCIDS founder, and the management of the conflict. These narratives are the content of Chapters Four to Seven. But first the theoretical framing for the research must be established and described. That is the content of Chapter Three.

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CHAPTER THREE: SITUATING SCIDS

Chemicals have been used to control pests, usually insects, for thousands of years. Ashes, ground roots, road dust and sulphur have been regularly employed since the ancient Greeks. However, it was the industrial revolution and its aftermath of industrialization that bequeathed environmental pollution to the societies that followed in its path. Yet it wasn’t until this century that industrial pollution as toxic exposure became a major problem to be faced by communities. It was the air pollution disasters of smog in Donora, Pennysylvania in 1948, London in 1952, and New York city in 1953,1963, and 1966 that brought toxic, industrial pollution, or the risk of the same, to attention as a social problem.

It is not that risk has not been ever-present. Personal risk has always existed, accompanied by the notion of bravery and adventure. However, it is the nature of risk that has changed dramatically as society has progressed. The assault to the senses, the nose and eyes in particular, characterized risk in by-gone centuries. Risks then were localized and temporal. Today however, risks escape sense perception and remain largely invisible, unheard, without smell or feel. Rather than localized and temporal, risks now are global, and will outlast generations.

Risks are a feature of reflexive modernity. Techno-scientific development has been proffered as the key to concealed sources of wealth and the escape from poverty and dependence. The key has turned out to be that to Pandora’s box however, Beck claims, as the sources of wealth are accompanied by hidden hazards. “In advanced modernity, the social production of wealth is systematically accompanied by the social production of risks.” We live today in a risk society.

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130 Hodgson et al, 4.
131 Edelstein, 2.
132 Beck, Risk Society, 3, 8 & 9
133 Beck, Risk Society, 1.
Toxic Communities

Many communities in Canada have experienced toxic risks, and many continue to do so. Among one of the first recognized industrial contaminations in Canada was the pollution of the Great Lakes. Its shores are highly populated and industrialized, with both domestic and industrial activities resulting in eutrophication of the Lakes. The St Lawrence River has also not escaped pollution. Its banks, like the shores of the Great Lakes, are similarly populated and industrialized.\(^{134}\)

In Marathon, Ontario, historic milling operations have produced high concentrations of mercury, expelled in the mill effluent into Lake Superior. Pressure from government in the 1980's encouraged the kraft pulp mill owners to make apparent remedy by “installing a high-pressure diffusion pump and a retaining pond.” This however was nothing more than a technological quick-fix, with no reduction of chemical level in the effluent released into the lake.\(^{135}\)

Hamilton Harbour has the distinction of being the worst in-place pollution site on the Great Lakes. The shores of the harbour are lined with huge industrial facilities, their smoke stacks contributing to air pollution and high levels of chemical effluent contaminating the lake waters, the vegetation and aquatic life to be found there. Opposite the heavily industrialized harbour area, dust and particulate matter, as well as water pollution from industrial wastes, particularly from the steel and chemical plants, contaminate the residential Beach Strip.\(^{136}\)

Dumping of radioactive waste from uranium milling operations, begun in 1932, is the major source of pollution in the Port Hope, Ontario region. Deposited in vacant lots and ravines

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\(^{134}\) Guay, 282-284; Gould, 159.

\(^{135}\) Gould, 161-162.

\(^{136}\) Gould, 169 & 170.
throughout the area, it wasn’t until 1975 that high gamma levels in and around a local school led to the “accidental discovery” of the contamination.\(^{137}\)

One hundred and twenty-five kilometers northwest of Toronto, Ontario, is the small town of Elmira. Nestled within the town is the company, Uniroyal Chemical Ltd, a resident there for over five decades. Producing a number of chemicals together with their by-products: “noxious air emissions, toxic run-off, buried chemical drums and contaminated waste water effluent,” Uniroyal Chemical Ltd was charged with destroying the town’s water supply. In 1989, the local aquifer was found to be contaminated with the carcinogenic chemical, DMNA.\(^{138}\)

In 1985, in southwestern Ontario, fifty percent of 351 wells were found to be polluted by atrazine and other chemicals.\(^{139}\) The problems continue today for Ontario, with 120 communities reported to have contaminated water supplies.\(^{140}\)

Since the 1950's, acid deposits on trees and in lakes in Canada had been noted. Studies showed that close to a large nickel smelter in Sudbury, Ontario, trees and fish were dying or were developmentally impeded. In Quebec, maple syrup producers observed the yellowing, rapid aging and slow growth of their trees. Metal smelters in both Canada and across the border in the United States together with Ontario Hydro were named as the main problem, producing the acid

\(^{137}\)Ibid.  
\(^{138}\)Cameron, 297 & 298.  
DMNA is a trade name for N-Nitrosodimethylamine ((CH\(_3\))\(_2\)N\(_2\)O), a combustible liquid considered to be a potential carcinogenic (“NIOSH Pocket Guide to Chemical Hazards” http://www.cdc.gov/niosh/npg/npgd0461.html accessed 17 August, 2001)  
\(^{139}\)Greenprint for Canada, 10.  
Atrazine is a herbicide used for pre- and post-emergence weed control in crops such as corn and for total vegetation control in non-cropland and industrial areas. The chemical persists in soils in temperate climates for a full season or longer under average field conditions. In Canada it is ranked highest of 83 pesticides as a potential groundwater contaminant, and most daily intake is from contaminated water. Evidence is inadequate with regards exposure to atrazine and increased risk of ovarian cancer or lymphomas. It is classified as possibly carcinogenic to humans. (Guidelines for Canadian Drinking Water Quality—Supporting Documents. Health Canada. July 03, 2001).  
rain that resulted in this contamination.\textsuperscript{141}

Further afield, Regina, Saskatchewan, has a reputation as the “bad drinking water capital” of Canada. In 1982, trace amounts of DDT, 2,4D, PCBs, trihalomethanes, bacteria, and arsenic reportedly added to, or perhaps caused, the offensive odour, taste and colour of the drinking water.\textsuperscript{142} An aquifer provided approximately one-third of Regina’s water supply, and tests to wells drawing upon the underground water supply were found to have high levels of arsenic, with the highest levels found in a well near the Interprovincial Steel Pipe Corporation (IPSCO) plant. Whilst the source of the arsenic contamination is unknown, IPSCO, whose operations produce about 16 tonnes of dust per day containing arsenic and other contaminants, was

\textsuperscript{141} Guay, 284 & 285.

\textsuperscript{142} DDT is an insecticide, and was used for controlling insects on agricultural crops and disease-carrying insects. It was banned in the US in 1973, and is still in use in some parts of the world. The chemical is classified as a probable carcinogen (“DDT.” Public Health Statement, Agency for Toxic Substances and Disease Registry, Division of Toxicology, Atlanta, Georgia http://www.atsdr.cdc.gov/ToxProfiles/phs8908.html) 2,4-D (2,4-Dichlorophenoxyacetic Acid) was the first successful selective herbicide developed and became the most widely used and the most thoroughly researched herbicide in the world following its introduction in 1946. A member of the phenoxy family of herbicides, it is used in agriculture on wheat, small grains, corn, rice, sugar cane, rangeland and pasture as well as on roadsides, rights-of-way, forestry, lawns and aquatic weeds. Toxicity in humans and animals is considered low; no scientifically documented health risks exist. Net economic benefit to Canada alone is estimated at a third of a billion dollars, and 2,4-D is considered a major tool in the continuing fight to reduce world hunger (“Industry Task Force II on 2,4-D Research Data.” http://www.24d.org/ accessed 17 August, 2001). PCBs (Polychlorinated Biphenyls) are synthetic organic chemicals with the same basic chemical structure and similar physical properties. Used extensively in industrial and commercial applications, production ceased in 1977 in the United States due to concern over their toxicity and persistence in the environment (“PCB Background.” PCB Home Page at EPA. Http://www.epa.gov/opptintr/pcb/ accessed 17 August, 2001). Acute and chronic toxic effects include cancer, neurotoxicity, reproductive and developmental toxicity, immune system suppression, liver damage, skin irritation and endocrine disruption (U.S. Environmental Protection Agency, vi).

Trihalomethanes are a group of chemicals formed in water when chlorine reacts with natural organic matter. They are a by-product of chlorinated water that contains natural organics. Some studies have linked trihalomethanes to cancer and to reproductive problems.

suspected as the culprit.\textsuperscript{143}

In Manitoba, Winnipeg's mosquito spraying programme was found to cause various symptoms and illnesses among residents. Irene Paparo-Stein, affected by the mosquito spraying, discovered others similarly afflicted when she made her symptoms public. Litigation against the city however, though prolonged, was unsuccessful.\textsuperscript{144}

Also in Manitoba, in Pukatawagan, polluted drinking water causing a range of symptoms and illnesses, from skin rashes to hepatitis, in the majority of the reserve's population, was the subject of community action. A 650 kilometre protest march to Ottawa was undertaken by Pukatawagan residents. Not confined only to Pukatawagan however, native leaders expressed their concern at the state of drinking water in northern Canada communities. In Pukatawagan itself, the water treatment plant is located nearby a sewage treatment lagoon.\textsuperscript{145}

In 1988 and 1989, in Newcastle, New Brunswick, soil and groundwater were found to be contaminated by the chemical benzo (a) pyrene, one of a family of polyaromatic hydrocarbons (PAHs), suspected of causing cancer in humans.\textsuperscript{146} Discovered in wells close by the Domtar Inc. wood treating plant which had closed down in 1986, Domtar Inc. was suspected as the cause of the contamination. The provincial government was not able to determine the source of the pollution. Newcastle residents were provided with a new water source, at tax payers' expense, and Domtar undertook to clean up the contaminated soil and ground water at its old site.\textsuperscript{147}

\textsuperscript{143} Clare Powell, "What's WRONG with Regina's water?" citizens' bulletin, June 6, 1982, 12 & 13.
\textsuperscript{144} Paparo-Stein.
\textsuperscript{145} The Vancouver Sun, 1994, sec.A. p.5.
\textsuperscript{146} Polycyclic Aromatic Hydrocarbons (PAHs) are a group of chemicals, including benzo(a)pyrene, that form during the incomplete burning of coal, oil, gas, wood, garbage or other organic substances such as tobacco and charbroiled meat. PAHs may also be manufactured for use in medicines, dyes, pesticides, asphalt, for example. They are carcinogenic ("Public Health Statement for Polycyclic Aromatic Hydrocarbons (PAHs)." Agency for Toxic Substances and Disease Registry (ATSDR). August, 1995. \url{http://www.atsdr.cdc.gov/ToxProfiles/phs8805.html} accessed 17 August, 2001).
\textsuperscript{147} Maclean's, January 12, 1990, 41.
In New Minas, Annapolis Valley, Nova Scotia, the water supply was contaminated by drycleaning fluid, 1981.\textsuperscript{148} In Sydney, Cape Breton Island, a steel plant (SYSCO) and its coke ovens have left behind the legacy of years of steelmaking, seeping toxic ooze into the backyards of Frederick Street residents. Suffering from a variety of symptoms, including birth defects, asthma, migraines, and ear infections, no compensation for residents and little clean up has been undertaken to date.\textsuperscript{149} Also in Nova Scotia, thirteen communities were reported to have water supplies contaminated by trihalomethane (THM), a byproduct of the combination of chlorine, used to treat water, and organic materials such as leaves. Water treatment facilities in these thirteen communities reportedly do not have adequate filtering systems to screen out leaves and other organic material.\textsuperscript{150}

Response to toxic contamination has occurred as community and nationally-based environmental organizations and self-help groups have developed at local and/or national levels. A number of theories attempt to provide some understanding of the risk associated with toxic contamination, as well as the response (or non-response) of citizens to these threats, hazards and risks.

\textbf{A Theoretical Beginning}

In 1957, Herbert Blumer pointed out that little had been added to the field of collective behaviour since Park and Burgess introduced it in 1924.\textsuperscript{151} Blumer saw the increasing importance of collective behaviour to explain changes in an increasingly complex and highly organized

\begin{itemize}
  \item \textsuperscript{148} Jones, 932
  \item \textsuperscript{149} Maude Barlow and Elizabeth May, "The shame of Frederick Street," \textit{The Coast}, May 25, 2000, 10-13.
  \item \textsuperscript{150} Cathy Nicoll, "Unlucky 13 suffer from tainted water," \textit{The Daily News}, August 04, 2000, 4.
  \item \textsuperscript{151} Gustave Le Bon had written about crowd behaviour in 1897 (\textit{The Crowd: A Study of the Popular Mind}) and is credited with being the first theorist to consider collective behaviour (See Blumer, 1955).
\end{itemize}
society.\textsuperscript{152} Early theories of collective behaviour focused upon the frustrations and grievances of collectivities of actors\textsuperscript{153} and how these became organized in new forms of group and institutional conduct.\textsuperscript{154}

Collective behaviour was defined as occurring in undefined and unstructured situations which were outside cultural prescription. As “the behaviour of two or more individuals who are acting together, or collectively,”\textsuperscript{155} collective behaviour refers to interactions between individuals where those individuals have influence over each other. This behaviour occurs in large groups with which the individual participates and/or identifies. Group relationships tend to be impersonal, indirect and hierarchical, reflecting bureaucratic organization and directed towards authority and control.\textsuperscript{156}

By no means homogeneous, theoretical explanations drew upon a variety of interpretations that in one way or another centred around individuals’ frustrations and grievances.\textsuperscript{157} “Circular reaction” was the key mechanism, understood as an “interstimulation” or reflection of individuals’ states of feeling.\textsuperscript{158} Circular reaction was thought to occur in conditions of unrest and disturbance in life’s routines. Beginning spontaneously and individually, and experienced as discomfort, frustration, and alienation expressed through random, restless and unco-ordinated activity, social contagion was the catalyst for the organization of this behaviour as new forms of group behaviour.\textsuperscript{159} Collective behaviour theory linked individual’s

\textsuperscript{152} Blumer, “Collective Behaviour,” 127 & 131.
\textsuperscript{154} Blumer, “Collective Behaviour: Part Four,” 177.
\textsuperscript{155} Blumer, “Collective Behaviour,” 128.
\textsuperscript{156} Blumer, “Collective Behaviour,” 127-130.
\textsuperscript{157} McAdam, McCarthy, and Zald, 696 & 696.
\textsuperscript{158} One individual’s response reproduces the stimulation from another individual which in reflection back reinforces the stimulation from that individual (Blumer, “Collective Behaviour: Part Four,” 170).
\textsuperscript{159} Blumer, “Collective Behaviour: Part Four,” 170-177.
psychological states with individual behaviours that in the right conditions became organized collective action.

**Social movements**

Collective behaviour theory concentrated on the behaviour of crowds, the masses, and the public as precursors, though primitive, to new forms of social order. Social movements were a more advanced form of collective behaviour directed towards similar goals as the more primitive forms.\(^{160}\) Distinguishing between general, specific, expressive, and revival and nationalistic movements, Blumer describes social movements as "groping and uncoordinated" in their efforts at first. Unorganized, with no established leadership, membership, and little guidance and control, these early movements were the mere aggregate of individuals making individual decisions and taking individual actions.\(^{161}\) Dissatisfaction, hope and desire awakened by the social movement and leading to a dissatisfaction with life and a disjuncture between new conceptions and old actualities of the self may eventually crystallize and provide a specific focus for the social movement. Objectives and goals are developed, leadership emerges, together with a cohesive and "we-identifying" membership. Traditions, philosophy, values, rules, allegiances and loyalties emerge. Behaviour as well as organization solidify. Agitation by the leader arouses people's interest and participation in the movement. A sense of belonging, an "esprit de corps" develops. A "them" and "us" mentality arises and a sense of fellowship, encouraged by participation in demonstrations, rallies and so on. Group will and collective endurance are demonstrated with the conviction that the movement can make a difference and will be successful in reaching its goals.\(^{162}\) However, by the 1970s, collective behaviour theories were

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\(^{161}\) Blumer considered the labour movement, the youth movement, the women's movement and the peace movement to be examples of these early or general social movements (Blumer, "Collective Behaviour: Part Four," 199).

unable adequately to explain the movements that had arisen in the 1960s, leading to a critical rethinking of these theories.\textsuperscript{163}

\textit{Resource Mobilization}

In the United States, resource mobilization theory emerged in the 1970's in response to the needs of both theory and practice. Protest was burgeoning, and many sociologists belonged to activist groups or were empathetic with the variety of causes. There was however, an impotence of theoretical explanation. Deliberately eschewing issues of consciousness and ideology and focusing on micro-structural accounts of movements, resource mobilization theory was principally concerned with resources (money and labour) provided by supporters; with strategy and tactics, ranging from mobilizing supporters to transforming the masses into a sympathetic public to negotiating and mediating with authorities; and the social structure within which social movement industries are situated and upon which they draw.\textsuperscript{164}

Focusing on questions of recruitment, motivation and participation, resource mobilization theory introduced the rational actor model to social movement theory. According to this model, individuals weigh the costs and benefits of participation in movement activity, opting to participate when the potential benefits outweigh the anticipated costs. However, free-riding becomes a problem when movement goals are public goods which cannot be denied to non-participants. In these cases, selective incentives which are not available to non-participants may be offered to movement participants.\textsuperscript{165}

Although resource mobilization theory was able to divest social movement theory of its early emphasis on pathology, it has been variously criticized. Some have suggested that the

\textsuperscript{163} Ingalsbee, 139-155; McAdam, McCarthy and Zald, 697 & 698; Klandermans, 583; McCarthy and Zald, 1212-1239.

\textsuperscript{164} Klandermans and Tarrow, 2 & 3; Klandermans, 583; McCarthy and Zald, 1212-1239.

\textsuperscript{165} Buechler, 218; Klandermans and Tarrow, 4; Klandermans, 583.
emphasis on a social movement's need to control resources has led to a failure in resource mobilization theory to recognize, other than superficially, the need to mobilize individuals. Grievances are considered a necessary, but not sufficient condition for social movement mobilization by resource mobilization theory. Ideology is dismissed as mere background information, and the emphasis on bureaucratic organizational structures is limiting. As a meso-level theory, the resource mobilization perspective has been unable to address, at the micro-level, the necessity of some social movements to offer selective incentives for recruitment, and other's ability to recruit without such incentives. The rational actor model of this perspective is problematic, based as it is on the male actor, who rationally weighs the costs and benefits of participation, underestimating the role of grievances and ideology. Collective identity as a concept has been of little interest to resource mobilization theory, and the role of culture in the construction of meaning in collective mobilization has been ignored.

**New Social Movements**

Meanwhile, across the Atlantic, in Europe, new social movement (NSM) theory emerged amid a different set of social and historical circumstances. Social movements were conceptualized as being brought to life only through actors' mobilizing actions. In contrast to resource mobilization theory, NSM theory viewed actors not as resources but as sources of collective action. New social movements struggle as much over cultural meanings as they do for material resources or political rewards. Individual and collective identity, autonomy and

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166 Ingalsbee, 139 & 140; Klandermans and Tarrow, 4; Ferree and Miller, 38-61.
167 Johnston, Larana and Gusfield, 5-10; Buechler, 221; Klandermans and Tarrow, 4.
168 Buechler, 222; Ferree and Miller, 41 & 42.
169 Buechler, 225-228.
170 Brown and Ferguson, 164; Buechler, 227; Klandermans and Tarrow, 9; Klandermans, 584.
171 Buechler, 222-231.
172 Ingalsbee, 142-146; Melucci, “A Strange Kind of Newness,” 342.
solidarity, as well as ideology are a central focus for NSM theory.\textsuperscript{173}

New social movements break with the traditional values of capitalist society, and establish new values related to work, consumption, and the body. Self-actualization and participation appear to have replaced material needs, the traditional work ethic is eroding, and attitudes towards work and career changing. In addition, loss of identity, of traditional ties and loyalties are considered the outcome of increasing industrialization and bureaucratization. The result is vulnerability/receptivity to visions of new utopias and new commitments.\textsuperscript{174}

NSM action tends to be unconventional, and decentralized, antihierarchical democratic organization is favoured. The constituency of NSMs are the non-stratified, marginalized, and those, middle class and well-educated, who are paying the price of sensitivity to the problems of modernization.\textsuperscript{175}

Critiqued for moving too hastily towards “cultural” explanations, some theorists have admonished NSM theory for abandoning concepts of political economy and power relations too readily.\textsuperscript{176} The idea of contemporary social movements as “new” is argued,\textsuperscript{177} and as a representation of middle class interests, debated.\textsuperscript{178} In addition, NSM theory it is claimed, provides little in the way of strategies for social movement activists.\textsuperscript{179} Further, identity formation as a focus and politics for NSMs has led to an anti-politics of navel-gazing, a substitution for engagement with the structures of power, it has been suggested.\textsuperscript{180}

\begin{itemize}
\item \textsuperscript{173} Brown and Ferguson, 165; Ingalsbee, 142-146; Scott, 13-35; Klandermans and Tarrow, 7.
\item \textsuperscript{174} Klandermans and Tarrow, 8.
\item \textsuperscript{175} Klandermans and Tarrow, 7.
\item \textsuperscript{176} Adam, 316-336; Klandermans and Tarrow, 9.
\item \textsuperscript{177} Weir, 73-102; Bagguley, 27-48; Cohen and Arato, 510-52; Melucci, “A Strange Kind of Newness,” 104-109.
\item \textsuperscript{178} Bagguley, 27-48.
\item \textsuperscript{179} Barbara Epstein, 35-65.
\item \textsuperscript{180} Kauffman, 67-80.
\end{itemize}
The Toxic Waste Movement

Some theorists have pointed to the inability of either resource mobilization or new social movement theories, or their hybrids, to be able to explain and provide understanding of some social movements. There are some social movements that do not fit either model, it is maintained. The predominant two social movement theories have been developed to explain a finite number of social movements that also happen to coincide with the major movements in contemporary collective behaviour—movements such as the environmental, women’s, and peace movements for example. The toxic waste movement is one social movement for which resource mobilization and new social movement theories are questionabley applicable.181 Whilst the toxic waste movement may be considered part of the environmental movement, in fact it differs in many ways from the latter.

The toxic waste movement is a proliferation of groups dedicated to the prevention and/or remediation of localized and immediate threat of toxic waste. With no national organization, the movement is highly decentralized, and focuses on local causes, impacts and solutions. Not organized by professional organizers, groups spring up spontaneously, often starting with rage or personal loss, and without the likelihood of specific rewards. Although considered part of the environmental movement, the toxic waste movement differs in terms of its local focus in contrast to the wider environmental movement’s concern with destruction on a global scale.182

Citizen’s groups against toxic waste represent a powerful grassroots movement which has grown exponentially since the Love Canal incident in 1978. In 1981, Freudenberg identified two hundred and forty-two community organizations in a survey to identify the parameters of the movement. The Citizen’s Clearinghouse for Hazardous Waste, formed after Love Canal, had had contact with six hundred organizations by late 1984, and by 1990, with five thousand active

182 Brown and Ferguson, 145-172; Brown and Masterton-Allen, 269-287.
citizens. The toxic waste movement has also been instrumental in numerous local and national victories, such as the SuperFund legislation in the United States.183

Toxic waste organizing is predominantly led and undertaken by women. Typically working or lower middle class, often mothers with young children, women in the toxic waste movement have not previously been politically active.184 An enormous amount of their time is spent organizing around the debilitating effects of disease. Situated in their traditional role as mothers, it is women who make the link between toxic-related hazards and their children's ill-health. The extended networks, the “more-extended family”185 that working class women draw upon as resources of survival for themselves and their families, become the same networks and resources that allow them, in discussion with others, to discover patterns in illness, the beginnings of a popular or lay epidemiology if you will. For example, at a Tupperware party in a local Detroit community, women discovered a particular pattern of health problems.186 These early beginnings of an epidemiology often lead to a more serious engagement, by toxic waste activists, with lay science or “popular epidemiology,” challenging professional and scientific knowledge.187

Community-based grass-roots environmental groups represent a new trend in the larger environmental movement suggest Cable and Benson.188 Their focus is specifically local environmental problems, and their pursuit, environmental justice rather than environmental reform. They are citizen-initiated responses to what is seen as the failure of the state to protect community well-being. Local residents notice local conditions which are a part of their everyday lives—quality of air and water for example. Corporate production processes which result in

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183 Masterton-Allen and Brown, 485-500.
185 Krauss, 252.
186 Krauss, 254.
188 Cable and Benson, 464-477.
pollution over time provoke a sense of injustice in community members who perceive regulatory controls and processes as ineffective. The state, responsible for both public welfare and facilitating corporate economic objectives, may be seen as siding with industry. Confronted with this perceived failure of formal systems to protect the ordinary citizen, grass-roots organizations develop and mobilize to challenge the effectiveness, integrity and motives of authorities.  

**Environmental and Social Justice**

Environmental justice refers to the greater risk of environmental contamination experienced by some populations, particularly minority groups. In addition, these populations suffer more from environmental nuisance (for example, having waste management facilities located in their neighbourhood), and do not have the access to policy-making and decision-making processes that dominant groups enjoy.

The environmental justice movement is the convergence of the civil and environmental rights movements. Its beginnings are in the United States in the 1980s, embedded in the right of people to a safe environment, to the continued existence of wilderness, and to the equitable distribution of both benefits and effects of environmental protection and degradation. Government was charged with ensuring these. In addition, the advent of the right-to-know legislation in the 1980s in the United States meant that neither government nor industry could exclude citizen access to information and decision-making processes.

A key factor in environmental justice is the recognition of race and income in environmental injustice. In 1987, the United Church of Christ’s report emphasized race over income. Almost 80 percent of Blacks and 65 percent of Hispanics compared to 55 percent of whites live in areas in the US that do not comply with the Clean Air Act standards at least part of

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189 Ibid.
190 Clarke and Short Jr., 375-399; Sarokin and Schulkin, 121-129.
191 Ibid.
the year, for example.\textsuperscript{192}

Other work in environmental justice has found class, race and ethnicity to be important. Krauss's interviews with working class white, African American and Native American women in the toxic waste movement showed that the analyses of these activists were mediated by issues of class, race and ethnicity. For white working class women, disenchantment with government and the injustice of a system that will not protect their families from environmental contamination are reflected in a deep sense of loss, betrayal and hurt. Previously not politically active, these women were transformed into self-confident, assertive political activists in their experience in challenging the system. For these working class women, the definition of environmental justice that developed was rooted in class issues.\textsuperscript{193}

African American working class women already view government with mistrust, having experienced racist policies previously. Toxic waste issues are immediately framed as environmental justice issues and linked to social justice issues such as jobs, housing, crime. Environmental justice is a civil rights issue, requiring the resolution of the broad social inequities of race.\textsuperscript{194}

A genocidal analysis, rooted in colonialism, cultural identification, and the ever-present inherent threat to their culture are aspects of Native American women's analyses of environmental justice. As with African American women, Native American working class women have no illusions of a charitable, protective state. For both African American and Native American women, definitions of environmental justice are rooted in race rather than class issues.\textsuperscript{195}

\textsuperscript{192} Sarokin and Schulkin, 121-129; Wernette and Nieves, 16-17.
\textsuperscript{193} Krauss, 247-262.
\textsuperscript{194} Krauss, 247-262.
\textsuperscript{195} Ibid.
The experts

Attaining goals for both environmental justice and toxic waste groups may involve a citizen-expert alliance, serving two purposes: firstly scientific legitimacy of the group's claims, and secondly as a means of self-education. Experts associated with a social movement may be establishment intellectuals, outside the social movement, but important in the creation of social space for the movement to emerge.\textsuperscript{196} Challenges to the authority of government and the motives of corporations, exposing failure to prioritize public safety over profits, and denial and inaction in response to community concerns, are part of both environmental justice and toxic waste movements' repertoire.\textsuperscript{197}

At the same time however, government and industry may also parade experts before the local community to legitimize decisions. Scientific knowledge and the authority that accompanies it are powerful resources that may be marshaled by each side.\textsuperscript{198} There may well be a number of different lay perspectives as well as a number of expert viewpoints.

Experts are defined as those individuals, who by virtue of their technical training within an academic discipline, have expertise legitimated by the authority or prestige of science.\textsuperscript{199} This expertise is used in the making of public policy; science moves from the laboratory to decision making, from the world of scientific practice to the daily practice of political life.\textsuperscript{200}

Most often, experts brought into the fray in relation to the toxic waste and environmental justice movements are concerned with the allocation of risk. Couto suggests that these experts are part of a community of calculation, consisting of a community of consequence calculation, those officials, public and private who allocate resources related to environmental health risks including pollutants and toxicants, and a community of probability calculation, which includes

\textsuperscript{196} Eyerman and Jamison, 94-119.
\textsuperscript{197} Albrecht, 67-72; Masterton-Allen and Brown, 485-500.
\textsuperscript{198} Albrecht, 67-72.
\textsuperscript{199} Chociolko, 3
\textsuperscript{200} Salter, 55.
epidemiologists.  

Experts have, by virtue of the status and authority endowed from the pursuit of truth as a scientific endeavour, been conventionally considered neutral arbiters of the issues under consideration, reflecting an unbiased view. The changing relationship between experts and the public, the loss of trust in expert systems, and the collapse of the “grand narrative” within which the legitimacy of science resides, has made the authority of the expert much less automatic. 

Studies investigating the role of the expert in policy and decision making related to risk reveals that experts are as much prone to unstated assumptions and mindsets, or heuristic bias, as are the lay public. Experts may be influenced by the framing of a problem prior to their involvement, for example a problem that has public prominence. Experts may have a stake in the outcome of the analysis or decision. They may overestimate easily recalled events and underestimate less dramatic and less vivid events; may fail to adjust original estimates in light of new information, or be more certain about probability estimates than their knowledge can justify.  

Clarke has referred to these biases as a disqualification heuristic that leads experts and decision makers to neglect information that contradicts a conviction, for example that a sociotechnical system is safe. It is heuristic in diminishing uncertainty and permitting a sense of control over sociotechnical systems. It disqualifies disconfirming information, critical data and viewpoints, while highlighting confirming information. 

The disqualification heuristic channels information about risks so that decision makers are protected, in a sense, from seriously considering the likelihood of catastrophe. It is a source of organizational naivety, narrowing the range of alternatives available for consideration so that

201 Couto, 56 & 57.  
202 Salter, 64.  
204 Clarke, 304-307.  
205 Clarke, 289-311.
particularly troublesome ones are relegated to secondary, even trivial status.\textsuperscript{206}

Whilst Hannigan suggests that technical experts set an agenda for risk which includes the lay public only as an afterthought, or late in the decision making process, others suggest it is the outrage and/or activism of the lay public that brings experts into play.\textsuperscript{207}

\textbf{Calculating risk}

The expert's role in environment and health, whether as a scientist working within their discipline, or as an expert involved in policy and decision making, is in relation to the calculation of risk. Risk itself is defined according to both the discipline and the theoretical frame within which it is studied.

The field of risk studies began as a fact gathering exercise.\textsuperscript{208} Technical risk analyses objectively observe or measure the physical harm to humans or ecosystems by appropriate scientific methods. Actuarial analysis, toxicology and epidemiology, and probabilistic risk assessments anticipate actual harm to human beings or ecosystems, average such events over time and space, and employ statistical frequencies to specify probabilities.\textsuperscript{209} Risk then is a multiplication of probability of events and consequences.\textsuperscript{210} A normative approach, these technical risk analyses are instrumentally used to reveal, avoid or modify the causes that lead to unwanted effects, and are employed in decisions about risk sharing and risk reduction.\textsuperscript{211}

Technical risk analyses however have been criticized for excluding social context and meaning.\textsuperscript{212} Values and preferences influence what people perceive as an undesirable effect.

\begin{footnotes}
\textsuperscript{206} Ibid.
\textsuperscript{207} Hannigan, 92-108; Brown, “Popular Epidemiology,” 267-281.
\textsuperscript{208} Krimsky, 4-6.
\textsuperscript{209} Renn, 53-79.
\textsuperscript{210} Rayner, 85; Paul Slovic, 118-121.
\textsuperscript{211} Renn, 53-79.
\textsuperscript{212} Irwin, “Technical Expertise and Risk Conflict,” 339-364; Renn, 67-79; Wynne, “Unruly Technology,” 147-167.
\end{footnotes}
Interactions between human activities and consequences are more complex than the single dimension of technical risk analyses. In addition, experts work on the basis that mitigation or reduction of risk should be in proportion to the expected harm to human beings, whereas lay people incorporate objectives such as fairness, equity, flexibility and/or resilience to the goal of risk minimization. Risks may also be increased by organizational failures and deficits in the management and control of risk. Consideration of organizational failures and deficits is excluded from technical risk analyses.\textsuperscript{213}

Given that technical risk analyses neglect the social processing of risk, a number of social theories of risk have developed in the past two decades.\textsuperscript{214} Since lay people did not always base their decisions on mere fact alone, social scientists have asked why it is that people fail to follow the advice of experts in responding to the risks of contemporary society.\textsuperscript{215}

The economic concept of risk transforms undesirable effects into subjective utilities. Focusing on degree of satisfaction or dissatisfaction associated with potential consequences, this cost-benefit analysis however has been criticized as a naive version of the rational actor paradigm. People provided with full information about risks do not always act in accordance with that information. People smoke, drink alcohol, and engage in activities that do not provide any utility for them. As well, the reliance on utilitarian ethics in economic theory is considered problematic in relation to risk allocation. In utilitarian ethics resources are allocated so as to maximize their utility for society, so that for example a poor community would accept the siting of a hazardous waste facility in their community in order to increase employment potential for its members, accepting a risk in exchange for money, whilst the wealthy community would not be

\textsuperscript{213}Jennifer Brown, 13-15; Renn, 58-61.

\textsuperscript{214} Funtowicz and Ravetz, 253; Irwin, “Technical Expertise and Risk Conflict,” 339-364; Krimsy, 4-6; Macgill, 48-50; Renn, 53-79; Slovic, 118 & 119; Wynne, “Unruly Technology,” 147-167; Idem, “Frameworks of Rationality,” 42-47.

\textsuperscript{215} Krimsy, 5; Renn et al., 137-160.
exposed to the risk.  

Perceiving risk

Psychological theories of risk focus on how people perceive risk, and why they make the decisions they do in relation to risk. Public perceptions of risk are of far more import than the technocratic view recognizes and require more serious exploration. Risk in perception theory is a subjective concept, not existing "out there," but constructed by individuals to cope with the dangers as well as uncertainties of life. People are risk averse if the potential losses are high, and risk prone if the potential gains are high. In addition, many people pursue a risk taking strategy that balances a satisfactory pay off against the avoidance of a major disaster. Biases in the intuitive processing of uncertainty favour the most readily recalled information about events, and contextual variables, such as beliefs associated with the cause of risk, shape individual risk estimations and evaluations.

The psychological perspective on risk provides an understanding of individual responses to risk, however it is difficult to aggregate individual responses and to find a common denominator for comparing individual risk perceptions. Further, the perceiver of risk is a passive, not an active, agent. The individual is perceived as receiving information about risk and in no way involved in developing a shared meaning of risk with other individuals, institutions, and communities. Lacking also is the effect of societal structure and organization on individual perceptions and decisions about risk.

216 Renn, 61-64.
217 Jennifer Brown, 1-18; Renn, 64-67.
218 Macgill, 48-53.
219 Renn, 64-67; Slovic, 120.
220 Renn, 64-67.
221 Rayner, 85 & 86.
222 Douglas and Wildavsky, "How Can We Know The Risks We Face?" 49-51; Renn, 67-72; Slovic, 146-152.
Cultural bias and/or particular way of life are implicated in what and how individuals select to fear, Douglas and Wildavsky suggest. The risks selected for worry and concern are functional to society by strengthening one particular lifestyle and weakening another. Whatever objective risks may exist, social organizations will emphasize those that reinforce the moral, political and religious order that holds the group or society together.  

Cultural risk analysis is informed by group/grid analysis, first developed by Mary Douglas in 1970, and further elaborated by Michael Thompson in conjunction with risk preferences in West Germany around the nuclear energy debate. *Group* refers to the degree (weak or strong) to which the individual is socially incorporated into a social unit, whilst *grid* refers to the constraining nature of the social interactions within the group, including hierarchy, gender, race, age and so on. Very different ways of seeing risks is implied in the conjuncture of group and grid.

Cultural theory of risk however has been criticized as cultural relativism and solipsism. According to this criticism, the cultural theory of risk suggests that the knowledge created in one social circumstance is entirely self-validating and incommunicable to members of any other group or society. In addition, one person’s theory of the world is claimed to be as valid (as a scientific truth) as another’s. Funtowicz and Ravetz suggest that this cultural relativism and solipsism may lead to social irresponsibility in facing threats to life and limb arising from technology and the environment. Rayner however retorts that public knowledge must always be evaluated as part of the social system, the workshop, the laboratory, the community that creates and sustains it. This is not to deny the role of natural phenomena that constrain experience and knowledge and that feedback into the knowledge process. However, although some of these

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223 Douglas and Wildavsky, *Risk and Culture*.
224 Thompson, “Aesthetics of Risk: Culture or Context?” quoted in Rayner, 84.
225 Rayner, 87-93.
226 Rayner, 98-102.
227 Funtowicz and Ravetz, 258-263.
phenomena may exist independently of the culturally-created concepts of them, they may be knowable only through one or another cultural version of them.  

The cultural theory of risk has also been criticized as stereotyping people as part of the system of social classification and management of risk. In addition, the theory is considered culturally deterministic or imperialistic. Culture is seen as locking people into a certain worldview. And further, cultural theory is seen as inherently conservative, possibly allowing industry to bypass liability claims on the basis that the claim is only the opinion of the claimant and no others, or that environmental fears are irrational. A lack of empirical evidence in support of its validity, too, continues to plague cultural theory.

Development of risk studies as a series of disjointed, unintegrated theories, most of which are in disagreement, has caused some theorists concern at the direction of the field. In 1988, a new framework called “the social amplification of risk” was unveiled. This framework maintains that the interaction of events pertaining to hazard with psychological, social, institutional and cultural processes can increase or decrease perception of risk and shape risk behaviour. Behaviour in turn generates secondary social and economic consequences that extend far beyond direct harm to human health or the environment. For example, liability, insurance costs, and loss of confidence in institutions often trigger demands for additional institutional response and protective action.

Attempting to include the gaps criticized as being evident in other theories, risk in amplification theory is seen as both an objective threat of harm to people and a product of culture and social experience. The experience of risk is both an experience of physical harm and of

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228 Rayner, 98 & 99.
229 Renn, 76; Kasperson, 154-157; Nelkin, 95-113.
230 Rayner, 111-113.
231 Renn, 76.
232 Kasperson, 153-176; Renn et al., 137-160.
233 Kasperson, 153-176.
cultural and social processes whereby individuals and groups create, acquire or interpret meanings of risk and hazard. Risk amplification is the process of communication and interpretation that occurs following an environmental or technological event or report. An analogy is drawn with the rippling effect from dropping a stone into a pond.

It has been suggested that human and social processes may lead not only to amplification, but to attenuation of risk as well. The electronic analogy inherent in the diagram of the amplification process too, has been criticized as too passive to account for human behaviour in its complexity. As well, the focus on how responses to risk events are amplified or attenuated, takes as given, the risk object. Further, the theory's usefulness for generating hypotheses and directing empirical research has been questioned.

**Constructing risk**

Turning the risk object itself on its head, that is not taking it as a given as most of the above theories do, is social constructionism. This perspective focuses attention on those who, through definitional activities, create and use boundaries to demarcate risk. Attention is on who does the constructing. Following Latour and Woolgar's work on the construction of science in the laboratory, Wynne for example, looks at the processes involved in the construction of technology and the discourse of experts in relation to that technology. Discussing the technical-social constitution of technologies, Wynne points to the public, rationalist discourse of professionals that leaves invisible the ad hoc decisions, the private negotiation of rules, regulations and practices that occur with use of technology, and that contribute to knowledge
about the technology. The result when accidents occur is for blame to be laid at the feet of an individual (or team of) expert(s), rather than recognizing that the fault may stem from the process of producing scientific, technical, medical, or engineering knowledge and artifacts.\textsuperscript{240}

Palmlund\textsuperscript{241} points out that the societal evaluation of risk is a contest where the participants offer differing, and competing, views of reality. Thus the environmental movement and scientists for example debate their differing definitions of reality. Environmental health groups such as the toxic waste movement will draw upon science in the form of a lay or popular epidemiology to develop their own definition of the situation and the problem, in contrast to that of the scientists and experts.\textsuperscript{242}

Medicalization of social problems has expanded the field of social construction theory, but until recently, little attention had been given to the scientization of social problems.\textsuperscript{243} Science is a claims-making activity, a negotiated order resulting from the processes of social interaction.\textsuperscript{244} This is an important aspect of the construction of risk which generally draws upon science in one way or another, often with contested views between differing science specialties as they vie for ownership of the problem. Ownership of the problem confers authority to manage or solve the problem, to influence public opinion, and to have ideas and information about the problem receive a high amount of visibility and legitimacy.\textsuperscript{245}

It is not enough to merely define risk as a scientific understanding and not understand how individuals living in the world actually experience that risk, suggests Williams.\textsuperscript{246} Drawing upon Schutz, Williams presents a modified social construction approach. In order to define or

\textsuperscript{241} Palmlund, 179-195.
\textsuperscript{242} Brown and Masterton-Allen, 269-287; Williams and Popay, (1994); Krauss, 247-262.
\textsuperscript{243} For example, Gusfield’s work on the social construction of alcoholism as both a medical and welfare state services problem (“On the side,” 31-49; “Ownership of Social Problems,” 431-441) and Brown’s work on diagnoses as constructing social problems as medical (“Naming and Framing,” 34-52).
\textsuperscript{244} Aronson, 1-29.
\textsuperscript{245} Gusfield, 431-441.
\textsuperscript{246} Williams, 476-497.
frame an environmental or social problem, attention must first be turned towards it, and second, an attempt made to make sense of it. In order to undertake the latter, we draw upon an already constituted stock of knowledge, which is then reconstituted from our experience and understanding of the current problem. Claims-making among groups, and claims for attention between social problems, may mean constituted stocks of knowledge are subtly shaped by powerful interests into a latent ideology, in turn impacting individuals' experience of the problem or risk.  

A constructive addition to the social construction approach to risk might be that of social dramaturgy, which suggests that in addition to consciously turning attention to the problem of risk, and making sense of it, participants also position themselves to an audience. Responses and decisions are always made in reference to one or more audiences, who might consist of the groups that are threatened, the people who speak and act politically on their behalf, the group that produces and uses the technology, and/or the mostly complacent citizenry at large.

Conclusion

Positions and theories on risk take for granted that the risks we confront are known. They do not recognize that we live in a risk society where we know not what risks abound. Hazard and risk are calculated quantitatively, based on probability estimates, limited to technical manageability. Risks which are not yet technically manageable, not yet scientifically calculable, do not exist. In addition, risks today generally are not knowable from experience. Not only do we not know the risks, but we have no say in matters of risk that affect us, such as acceptable levels or length of exposure. These are determined by the community of calculation who allocate risk. They determine each person's potential affliction. How much is safe, how long the

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247 Williams, 476-497; Hannigan, 76-91.
248 Palmlund, Couto, 55 & 56.
exposure permitted, the symptoms, all these are the cognitive property and practice of experts. Knowledge of risk is dependent on the knowledge of experts.\textsuperscript{250}

The following four chapters examine the point of view of both the community of risk calculation and risk allocation, and that of an individual exposed to risk, as well as the media story of the environmental conflict that ensued between the two groups. I begin with the story of an individual involved in the controversy.

\textsuperscript{250} Beck, Reinvention of politics, 12.
CHAPTER FOUR: BODY OF KNOWLEDGE: A SCIDS NARRATIVE

The SCIDS group founder's symptoms began seemingly with a taken-for-grANTED everyday experience. What ensued she at first considered as particular to herself. Private lives operate at a purely personal level. Within the myopia of the private life, the individual experiences problems, what C. Wright Mills refers to as troubles, as personal and private. Troubles have to do with the self, and with the immediate circumstance in which the individual experiences them. Their resolution appear to the individual to lie with themselves and within the immediate social milieu. It wasn't until a visit to the local orthopaedic specialist that the SCIDS group founder became aware that there were others with similar experiences.

The milieu of private troubles exist within a historical time. Private troubles are part of a biography that is lived out in a historical sequence. Individuals are “minute points of the intersections of biography and history within society,” suggests C. Wright Mills. This chapter focuses largely on a private trouble, that of the SCIDS group founder. It begins with a narrative which reconstitutes the sequence of events that unfolded at this particular interjection of biography, history and society.

The SCIDS story

A taken-for-grANTED, everyday movement of her arm resulted in the loss of the use of the forearm and right side of her hand. Neither her family doctor nor a specialist could determine why. A comment from one of the physicians about sick building syndrome led her to throw away anything in her home that might cause an allergic reaction. Headaches were beginning now, steadily increasing until they became severe migraines. At this point they stabilized, not getting any worse, if that were possible. Seizuring had also begun and had progressed to four or five times

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251 Wright Mills, 3-13.
252 As this chapter draws upon one interview only with the founder of the SCIDS group, some repetition can be expected between the narrative which follows and quotes from the interview. The narrative, however, provides an overview of the whole case, the later quotes interspersed throughout the discussion address specifics and detail.
A week. And nobody knew why.

A trace of her medical history unearthed, buried in her mind, that she had been sprayed with Malathion back in '85. She remembered that her second child had delivered a number of weeks early, just after the spraying incident. She recalled that the family doctor had said it was the Malathion. Now, four years later, her two children were unable to go outside because her immobility and seizing imprisoned not only her, but them too.

Progressively she lost the use of both her arms, one from injury, the other from overuse, compensating for the other's lack. And then it started into her legs, and she progressed to canes, and then when they could no longer hold her, to a wheelchair. Her body wasted away and she became needle thin.

Specialist after specialist, test after test, a visit or two to a neurologist, a psychologist, an orthopaedic surgeon, and still nothing conclusive was found. The symptoms were similar to chronic fatigue syndrome, to multiple sclerosis, and yet did not match exactly the cluster of symptoms required for diagnosis to either of these.

A local orthopaedic surgeon noted that she was one of many similar cases he had seen in the past half decade. He began delving into these patients' medical histories, searching for a pattern that might suggest cause. Chemical spray was the only pattern he found at this time. Some of his patients wanted to know if others also suffered from the same symptoms. He put them in touch with each other.

She received a phone call from someone suffering similar symptoms to hers. Then the calls began to increase. She and a couple of others called a public meeting and formed a group, to provide support and to find information, something, anything that would tell them they hadn't gone crazy. A core group of three initially, expanding to seven later, were in constant contact by phone with the Ministries of Health, Agriculture, and the Environment, asking questions, seeking information that might better help them to understand their symptoms and themselves. Meetings of the group were held monthly with around sixty to seventy people attending. Membership of the group gradually increased to five hundred over a three year period. Together they helped each other, sometimes driving others to doctor's appointments, sharing wheelchairs and mobility aids, locating and distributing articles about similar illnesses or symptoms, and becoming a "sounding board" for those who could not find answers from the medical profession. They networked with other environmental and health groups in the province and across the country.

They needed to know what was wrong, "to get to the other side of it." Coining a name, Somatic Chemically Induced Dysfunction Syndrome, SCIDS for short, helped. The name gave a point of reference from which the illness could be discussed, a point with which to identify, a point from which to think about self. The name said something about not just the illness, but
also the diseased body. And government departments at both federal and provincial levels now seemed able to recognize the group. Surprising what a name will do. Although there was no authoritative book on the subject, or a literature about SCIDS to turn to as others with medically recognized illnesses do, there was relief in naming. The nausea, fatigue, muscle weakness, seizures, and atrophying muscles, suddenly made sense.

GreenPeace contacted the group. Aghast, they sat down and discussed the involvement of such a radical group in their small fight. Forget it, they said. Being labeled as fanatics won’t do their cause any good, they reasoned. They wanted to work with government, not against them. They believed that science would win out and government would see the truth, acknowledging their problem and taking responsibility for it.

Her hopes soared when it was announced that a University of British Columbia epidemiologist would conduct a study into the syndrome. They flagged with the first introduction to him when she realized his opinion was already formed, that he knew what he wanted from the test results. She wasn’t surprised, disappointed perhaps but not surprised, when he declared that the results showed that SCIDS did not exist. Just another set back in a long line of dashed hopes. It seemed to her that everything was against them.

She had been excited when the Florida toxicologist had come to town to investigate the pollution that might be causing her’s and other’s symptoms. It was wonderful to be able to talk to someone who understood the problem from her point of view; someone she didn’t have to convince. Yes, he was brilliant, but sadly, his presentation of findings was not. His crying and tears when he publicly reported back to the community was lambasted by other scientists and officials. It became apparent to her that anyone who could legitimize this illness and its symptoms was to be discredited or was cast as biased. The playing field was not level. Her suspicions magnified, her mistrust of government intensified.

She became dejected. Her symptoms continued to worsen. She realized her family needed her as a healthy human being, not this barely functioning but fighting individual. She had wanted answers. Her search had been thorough she thought, and there had been some successes on the way, but her energy was sapped. It was time to leave the group and concentrate on herself now. A couple of months after the toxicology and epidemiology reports she stepped down as spokesperson of the group.

The SCIDS group continued for a while, but foundered eventually, before the year was out. It bothered her to see it exist no more, but she was not in a position to take it on again. She thought about their achievements: distilled water containers installed in public places; public speaking about the illness she continues to suffer; recognition on the street that satisfied her that awareness of the illness has been raised. So perhaps it wasn’t for naught, she sighed, as she returned to her everyday
routine of working her muscles, concentrating on staying out of the wheelchair and off canes. For just a moment the thought lingered that she might get involved in the health board restructuring. Soon perhaps, soon.\textsuperscript{253}

**The diseased body**

In biomedicine, disease is located in the body as a physical object or physiological state. One of the central tenets of biomedicine is that objective knowledge of the human body and of disease are possible apart from subjective experience. Historically, until the eighteenth century, bodies were seen as receptors as well as generators of social meaning. Bodies were understood as open to the “interpretive demands of culture.” In the eighteenth and nineteenth centuries, the progress of science shifted the perspective of the body as a manifestation of self-identity and difference to the very basis of identity and social divisions. With the Enlightenment came the questioning of man’s natural domination of the social order. Bodies were redefined by medicine to explain social inequalities. For example, women’s bodies in particular were subject to re-definition as being unable to withstand the rigours of physical and mental exertion.\textsuperscript{254}

The Enlightenment concern with rationality also contributed to the separation of the mind and body. The purely conceptual or mental was privileged over the corporeal. The body became an object of investigation that existed independently of any knowledge of it, presumed a “reality” resistant to misinterpretation and misrepresentation. The object was/is posited as external to and autonomous from subjects.\textsuperscript{255}

Associated with the changed view of the body was the belief in objective knowledge of disease. In the nineteenth century, disease was located internally, in the body. However, until the late nineteenth century, an exogenous theory of disease was accepted. Foul air working in a slow and insidious fashion was believed to cause disease. This disease-causing atmosphere was called “miasma.” The theory was overturned however by Pasteur and Koch in 1880 who successfully

\textsuperscript{253} Third person narrative constructed by the researcher from the interview with the founder of the SCIDS group.
\textsuperscript{254} Good, 116-118; Shilling, 41-69; Laqueur, 63-113.
\textsuperscript{255} Grosz, 26-31.
postulated the role of germs in illness causation, locating disease inside the body.\textsuperscript{256}

Medical knowledge is the objective representation of the diseased body. The diseased body is the physical object of medical knowledge. Medical knowledge rests upon the concept of disease; the experience of illness is the basis of lay knowledge. As medicine became more scientistic, the patient's view was excluded, marginalised. Perceived as subjective, it was thought to compromise the objectivity that had become the basis of medical knowledge.\textsuperscript{257}

\textbf{The body: from object to subject to object}

People live in a "common sense" reality rather than a scientific reality. Here objects are taken-for-granted rather than submitted to critical review. One such object is the body. The body is experienced as the author of its activities, as the agent of on-going actions, and thus as an "undivided total self." Both body and mind are complex aspects of an indivisible being. We act in the world through our bodies; our bodies are the vehicle through which we experience, comprehend and act upon the world. We do so in a mode of near self forgetfulness about our body, what Sartre called "passed over in silence." It is not that we are unaware of our bodies but that we need to forget our body as we go about our everyday activities. The body constitutes both "subject" and "object." However, physical body and lived body are experienced as one and the same until the relation between the two is broken.\textsuperscript{258}

For the person who is sick, disease is experienced as present in the body. The body is not merely a physiological state or a physical object, but an essential part of the self. As the location of experience and subjectivity, the body is a conscious body, indistinguishable from the conscious mind, but also a disordered agent of experience. Changes can be determined in the body as physiological state, but illness is present and experienced in the lived body. Positing disease as internalized and objectively knowable ignores the subjective experience of the

\textsuperscript{256} Kroll-Smith and Ladd, 7 & 8.
\textsuperscript{257} Disease is defined through physiology; illness is subjective and experiential; sickness is the social response which surrounds disease and illness (Fox, \textit{Postmodernism, Sociology and Health}, 4).
\textsuperscript{258} van Manen, 15 & 16; Melucci, \textit{The Playing Self}; 71-82; Good, 124.
individual. As the “undivided total self,” the body is we ourselves, subject. When the body however no longer functions as it used to, when it is racked with chronic pain of unknown cause, and when it experiences symptoms that do not correspond to any known medical diagnosis, the body becomes an object, distinct from the experiencing and acting self. The relationship between the body, self and the surrounding world is altered. A person’s ongoing life is disrupted. The body has become a problem, and can no longer be taken for granted. The individual can no longer live in a self-forgetful, passed-over relation to the body and to the world. The body “is no longer the subject of unconscious assumption, but the object of conscious thought.” It becomes an encumbrance, confronts, stands before the person as object.

Pain as well as symptoms of unknown cause and entity deconstruct, dissolve and deobjectify the known lifeworld, unsettling the sense of the known. Individuals experience a disintegrative existence. They can no longer forget their bodies in order to be attentive to the everyday aspects of the world. In response, individuals attempt to reconstitute the world by objectifying the deobjectified, forcing meaning onto symptoms. The founder of the SCIDS group discusses her illness as an object separate from herself, embodied, but which must be contained and controlled. Here, she is contrasting her illness to that of another person with SCIDS:

So, I mean hers worked into her upper body eventually, mine worked into my lower body eventually......[...]...and um, hers is progressive, okay, mine was progressive and now its gone into remission and I mean it’s a fight to keep it there, but its worth it, um....

Chronic pain and symptoms of unknown cause have agency, flooding out into the world and shaping not only the experience of self but the experienced world. The sense of being an ‘undivided total self” who authors activities is undermined as the body dominates consciousness.

...severe pain, um, when you have the signals goofing up your central nervous system, then you’re going to have totally unexplainable uncontrollable pain, and

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259 Good, 116.
260 van Manen, 12; Hyden, 51; Kelly and Field, 248; Good, 116 & 124; Giddens, 35-42.
261 van Manen, 23; Good, 128.
what are you supposed to do if you can’t stand on that leg because it’s so
painful, you can’t just climb into bed, its not, you know if you can’t even stand
a sheet on it....
Absorbed by pain and uncertainty, the world is under threat of being “unmade.”\textsuperscript{262}

Pain resists both localization and the objectification of standard medical testing. Neither
visible nor real according to clinical medical practices, the reality of the condition is questioned
and the sufferer and their suffering disaffirmed. Pain remains internal, ambiguous and
unverifiable to others yet of absolute certainty to the sufferer.\textsuperscript{263}

One of the most fundamental assumptions of everyday life is that we live in, inhabit,
experience a world shared by others. This “form of sociality” is called into question by sufferers
of chronic pain and illness. Pain and symptoms of unknown cause subvert everyday life goals.
Suffering and medicine take precedence, replacing the prior social world. The world shared by
others is no longer experienced; others no longer fully understand. Chronic illness changes the
very foundation of a person’s life: new and qualitatively different life conditions are created by
illness. The future is perceived and anticipated from a totally different angle, and the past
acquires new meaning as a part of a life lived.\textsuperscript{264}

However, whilst the interaction of the body and the world are “unmade” by the
vulnerability of the body, it is also “remade” by the institutions of medicine in an effort to find
relief and efficacious treatment. Interactions with the medical system play a crucial role in the
shaping of experience. For many, not only the health care system but also the bureaucracy of
insurance and welfare agencies come to occupy much of their time and activity. The constant
disaffirmation encountered in the struggle for legitimacy leaves its effect on both pain and self-
worth.\textsuperscript{265}

\textsuperscript{262} Good, 124.
\textsuperscript{263} Good, 125.
\textsuperscript{264} Hyden ,52; Kelly and Field, 248; Good, 126.
\textsuperscript{265} Good, 127.
The Politics of Definition

Many of the activities of the medical world are directed towards providing meaning. Diagnosis, therapeutic activities as well as narratives of suffering and illness are examples. Naming the symptoms and experiences, and in so doing providing both a symbol and an image around which a narrative can be shaped is a crucial step in remaking the world and authoring an integrated self.\(^{266}\)

The founder of the SCIDS group found her world being undone, unsettled. She asks in response to her injury in the supermarket and subsequent progressive dis-use of her arm "..what the hell is going on here...." Lack of control over her body is experienced, contrasted with the ability to control other parts of her life:

"..we had some control over our water, by that point I mean, um, I basically lost the use of both arms...the left one from overuse and the right one...cause it didn’t heal...and then it started into my legs...and into the rest of me, um,..."

Naming the condition provides control, personal and emotional, by way of knowing what is wrong.\(^{267}\) It has been suggested by others with associated environmental illness that without a name, a word, that the symptoms may perhaps not even be fully specified.

They come in clusters and, grouped together, form a kind of coherence that can be sensed. The cluster of symptoms, for instance, that you feel when you are coming down with a flu. As one sensation is added to another--headache, fever, fatigue--you begin to grasp the nature of your affliction. Though if you did not know the name for it, you would not be able to diagnose yourself as having the flu. This is where a doctor's knowledge is crucial. In the realm of healing, perception is achieved through collaboration. It is a democratic process of a kind. A doctor may ask you to describe what you feel, for instance, but if you have learned no words for the symptoms you are experiencing, you may not even have delineated them.\(^{268}\)

Naming is experienced as an alleviation of anxiety and fear, as reassurance.\(^{269}\)

\(^{266}\) van Manen, 12 & 13; Hyden, 51; Good, 128 & 129.
\(^{267}\) Brown, "Naming and Framing," 39.
\(^{268}\) Griffin, 284.
\(^{269}\) van Manen, 12 & 13.
It’s a relief. I mean if you get headaches, you don’t know why, its scary, my God, have I got a brain tumour, you know, have I got an aneurism? You’ve still got the headaches, but its less stressful.

The acronym SCIDS contains within it an idea of what is being experienced, of what is wrong. The illness is chemically induced, it results in dysfunction in the body, and it is a set of symptoms that together form a syndrome. In addition, coined by the group itself, a name was seen as necessary, in part for the understanding that came with it:

..you know, SCIDS, probably was a real stupid move on our part,, but it was one that everybody agreed on, we had to have a name...

When asked what happens when you have a name, she replied, “you get recognition.” Recognition from a now more knowledgeable other influences what the sick themselves can say.

What you are able to say or even know about your own experience depends in some mysterious manner on the attitude of the listener. Truth comes into being by call and response. The curiosity of the listener is like a magnet, pulling testimony from an inarticulate obscurity. And as with any tale, when the listener has heard the story, the process of telling will be healing in itself.270

Diagnosis

Naming a set of symptoms is part of the social construction of diagnosis. Whereas invoking a name may have meant giving voice to the lifeworld for the SCIDS group members, it also gave voice to medicine. Diagnosis is the semiotic act of transforming a patient’s complaints into the signs of disease. One symbol system is translated into another. Diagnosis determines the existence and legitimacy of a condition. It begins the process of the social construction of disease. It legitimizes the suffering as well as the sufferers themselves.271

Illness is a negotiated state. The patient’s subjective manifestations of illness, the symptoms, are narratively accounted to the physician. These subjective manifestations are corroborated or confounded in discernible physical signs discovered by the physician upon examination of the patient’s body. These objective, readable signs of the body’s malfunction

270 Griffin, 285.
point toward what may have produced the symptoms and/or what the symptoms mean. Additional diagnostic tests may yield suggestive, sometimes conclusive, results.\textsuperscript{272}

The patient’s complaint and symptoms, the clinical signs, and the test results are part of the diagnostic circle in which these pieces are fitted into a whole and tested against a knowledge of their context. Now with a grasp of the whole, the physician reasons back to the details, questions missing pieces of information that may rule out other possibilities, and confirms the strongest, more likely hypothesis. The patient’s narrative of subjective symptoms becomes the medical narrative of the physician which is then returned to the patient as a diagnosis. This transformed account of illness must be reinterpreted and reintegrated by the patient to explain her ongoing life story. The diagnosis as legitimization of sickness by a physician may constitute and/or confirm a new identity.\textsuperscript{273}

Labeling in the form of diagnosis is often enough for the provision of health services, welfare and unemployment benefits, workers compensation claims and legal testimony.\textsuperscript{274} The SCIDS founder notes that the Workers Compensation Board, whilst not prepared to provide compensation, does at least recognize the illness.

...I mean the fact that WCB, now recognizes it, it won’t do anything, but it’ll acknowledge it...

However to be provided with compensation, as well as exemption from social responsibility, the diagnosis must be accepted by the medical community, not declared as non-existent. It must be detached from its original location so as to establish its autonomy scientifically. Naming and formulating a diagnosis is not enough. Diagnosis consists of both process and category. The definition of a category occurs through a process or set of interactions. Category is the nosological\textsuperscript{275} location in medical knowledge, the often reified definitions of disease, where diagnosis resides.

Brown outlines a typology of diagnostic conditions and definitions.\textsuperscript{276} He points out that

\textsuperscript{272} Hunter, 9-15.
\textsuperscript{273} Hunter, 9-15; Kelly and Field, 248.
\textsuperscript{274} Brown, “Naming and Framing,” 39.
\textsuperscript{275} Nosology is the classification of disease.
\textsuperscript{276} Brown, “Naming and Framing,” 40.
the social construction of diagnosis involves a condition and a biomedical definition. In each of four types (see Figure 1),\textsuperscript{277} the condition (disease, set of symptoms, or physical state for example) may or may not be accepted as a biomedical entity. As well, the biomedical definition (the presence or absence of a specific identification of the condition by medical science) may or may not be applied.

In the vast majority of cases, the conditions (for example, infectious diseases, chronic disease, injuries) are accepted and biomedical definitions applied (cell 1). Sometimes however, conditions may not be accepted but a medicalized definition applied (for example, chronic fatigue syndrome, chronic pain syndrome: cell 2). A medicalized definition may be a form of labeling, and may be applied for a number of reasons, such as expansion of a field on the part of professionals,\textsuperscript{278} or to legitimate their condition on the part of individuals. In other cases, medical conditions may not yet be accepted, and a medical definition not yet applied, but they may be potential medicalization possibilities such as genetic predisposition to diseases (cell 4). Lastly, some conditions are generally accepted, but no medical definition is widely applied. Environmental illness believed to be caused by a local contamination is an example (cell 3). Neither medical nor government authorities are willing to recognize these conditions as attributable to contamination. These latter definitions are contested.\textsuperscript{279} In the case of SCIDS not only the medical definition but also the condition was contested.

The process of medicalization of a condition may begin with labeling, with the definition of the problem debated extensively. A period of claims making by both medical and non-medical parties to further delineate the problem as medical follows, and eventually, legitimacy and institutionalization of a firmly rooted medical definition. Brown, however, argues that this sequential model applies to medicalized definitions, but offers little towards understanding the process of contested definitions. He suggests that lay people experience conditions that may not be recognized by the medical establishment, and bring these to public attention. Whilst many lay-initiated discoveries of disease are conflict ridden because of contradiction of biomedical

\textsuperscript{277} Taken from Brown, "Naming and Framing."
\textsuperscript{278} Gusfield, "Constructing Ownership."
\textsuperscript{279} Brown, "Naming and Framing," 40-42.
knowledge and/or authority, some non-conflictual lay discoveries are also made. These latter are

**Figure 1. Typology of conditions and definitions**

<table>
<thead>
<tr>
<th>Biomedical definition applied</th>
<th>Condition generally accepted</th>
<th>Condition not generally accepted or is questioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Routine defined conditions (infectious disease, chronic disease, injuries)</td>
<td>2 Medicalized definitions (late luteal phase dysphoric disorder, chronic fatigue syndrome)</td>
<td></td>
</tr>
<tr>
<td>3 Contested definitions (occupational diseases, environmentally induced diseases)</td>
<td>4 Potentially medicalized definitions (genetic predisposition to disease)</td>
<td></td>
</tr>
</tbody>
</table>

not the subject of dispute since both lay people and professionals agree that the medical condition exists.

**Self-Help Groups**

Whilst naming and diagnosis are a way of remaking the world for illness sufferers, self-help groups are another. Self-help groups among the chronically ill are a feature of a pluralistic, liberal society in which it is recognized that professional discourses can be augmented by those of sufferers. The goal is to supplement or provide support that is not available within the formal medical institutions.280 The development of groups of like-minded others who share similar world experiences is a feature of the late twentieth century. The SCIDS group was one such

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280 Fox, *Postmodernism, Sociology and Health*, 34 & 35.
group: a support group, a self-help group.

...the group was basically there as a help group, a sounding board for other people, it was basically two reasons, the main one in my mind was, a sounding board for people who had all these things that doctor didn’t know what it was, to say, to hear how other people were dealing with it, how other people are coping with it, cause I mean it got you through the next day and you, you had to have that...um, and the other was, public awareness

Self-help groups consist of people who feel they have a common problem, typically a medical, social or behavioural one, and have joined together to try to do something about it. The need for self-reliance, the ability to retain independence, and reciprocity characterize self-help groups and the individuals in them.²⁸¹

Self-help groups however do not spring up spontaneously. They do so because someone wants them to come into being and puts a great deal of effort into their cause.²⁸²

*SCIDS founder*:...I told [local orthopaedic specialist] if anybody wants to talk, like we’ve got to help each other and um, that sort of started the flow

*Interviewer*: That was the start of the group thing was it?

*SCIDS founder*: Yeah, yeah, and there was the three of us that got it going um, [local orthopaedic specialist] basically what he did is, um, he said look, anybody else, give them our names so then the phone calls started and um, we met some..

Most self-help groups begin at the local level with no immediate ambitions of moving beyond that, although they may encourage the formation of similar groups in other areas as enquiries and interest are received from outside the area. Launching a group satisfactorily is a challenging activity. The founder is often already burdened by his or her own problems and now has to deal with the problems of a whole new set of people plus those of running the organization. Administrative and public relations skills as well as time and energy are needed.²⁸³

...at one point we had 60 to 70 people coming to meetings...but at the same time
I would venture to say that wasn’t even ten percent of the phone calls we had..ah, it was unreal, I mean the phone rang continually, and it still does, you

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²⁸¹ Richardson and Goodman, 2-4.
²⁸² Richardson and Goodman, 33.
²⁸³ Richardson and Goodman, 34.
know, at least once or twice a month there'll be somebody um, um that, they're not getting it from a doctor, they're getting it from newspapers, past articles, things like that, so I mean, its by no means stopped...you know I would venture to say at one point I enlisted 500 people in the valley, I have a list of people who contacted me who were sick, so, and I know it went a lot further than that

Life, especially that of immediate family, may be considerably disrupted.\textsuperscript{284}

...I mean I was right down to a wheelchair, they were going to put me on oxygen and I went okay, I can’t do this anymore I’ve got a family

and

I finally had to say, okay, um, which is more important, my, doing this for everybody else or focusing on myself and getting myself better...and that’s what I finally had to do

Self-help groups don’t necessarily benefit everyone who is a member. Whilst many people benefit enormously, some people put time and energy into helping with little recognition. In addition, the assistance groups are able to provide is not necessarily immediate or free in terms of time, energy and commitment.\textsuperscript{285} These were very real problems for the SCIDS group. The SCIDS group founder recognized that

what works for one person isn’t necessarily going to work for someone else but, you have a lot more, ah, reference...you can call on a lot more information when you’re able to talk to somebody else about it

Being able to share information with each other was considered a strength of the group.

I was able to send other people to that [people who had experienced those symptoms], okay, but because the symptoms are so wide ranged, what’s going on with you today, I might have gone through a month from now, or I may not go through till next month, but because I’m in contact with you and I know, or if a new test comes up...we’ll sort of call it amongst each other...I mean I had migraines, and I’ve had migraines for years, I mean I was living, it seemed like for about three years, a total migraine, they brought out a new treatment, I haven’t had a migraine in four and a half months...and that came through the group

\textsuperscript{284} Ibid.
\textsuperscript{285} Richardson and Goodman, 4.
Most self-help groups do not wish to be thought of as lobbyists or as pressuring government agencies and the like. Nonetheless, they do undertake to get their views known and listened to by the relevant authorities. The SCIDS group certainly distanced itself from any groups it considered radical

...one of the groups that we did have contact us, wanting to get in with us, was GreenPeace. We didn’t need radicals, okay, and the minute you talk GreenPeace, people think fanatics

but saw themselves as having a “fight” with government

...the daily fight really wore me down, you know fighting with the government continually, um I can remember phoning Elizabeth Cull [Minister of Health], I mean, I used to phone her directly (chuckle) “I don’t want to talk to you” and I used to literally say to the secretaries, I am really mad and you don’t want me to take it out on you so just put me through to her, and they would (laugh) and I’d (big growl) I would just chew her up and spit her out and um...

For core group members of SCIDS, contact with government, predominantly the Ministries of Health and Environment and at both provincial and local levels, usually as phone calls, was a daily occurrence. In addition, there were constant calls from other SCIDS members as well as the general public requesting information. Monthly meetings also became part of the routine.

Actively redefining the self

Whilst the self-help group took a big part of her life, medical activities also came to dominate. Medical activities refer to those processes in which the sick participate, such as medical tests and rehabilitation therapies. They come to replace normal interactions, increasingly shaping the lives of chronic illness sufferers to the world of clinics, therapies, tests and medications, increasingly alienating them from the social relations and projects that have been critical to their lives. The SCIDS founder searched for answers to her symptoms from

\[286\] Richardson and Goodman, 46.
\[287\] Interview with SCIDS group founder, June 1998.
\[288\] Good, 124.
many different avenues, taking part in research studies, seeing specialists (including a neurologist and a psychologist), having surgery to remedy atrophied muscles, seeking alternative therapies. Halting a progressive decline of her muscles also meant working at it daily:

It took a lot to get me where I am today. I always worked out almost daily in the hot tub out back, I've backed off on it a bit since we've been here cause, I'm able to stay active in other ways, but it was the only way to keep the muscles from any atrophying more

Eventually she had to retire from the SCIDS group itself in order to get herself well. Getting well took time.

**Narrating the self: Practical Epistemologies**

Naming, diagnosis, self help groups and the activities associated with recovering health remake the unmade world for the ill. These become enfolded into narrative. Ontological narratives are the stories we tell to make sense of our lives, to know who we are. This is a precursor for knowing what to do. “Doing” produces further narratives which produces further action. Narrative and ontology are a mutually constitutive process. “Both are conditions of the other; neither are a priori.”

It is upon an individual’s understanding of themselves in any number of narratives that their actions are based. We understand our lives in narrative form. Further, this understanding and the narrative itself is social and interpersonal. Constructed through social and structural interactions over time, narratives such as naming, diagnosis, those developed in self help groups and in medical activities of recovering health become a tailored and transformed part of our ontological narratives.

Objective medical knowledge and subjective experience are connected in that people deal with their own and other’s illnesses in accordance with the dominant discourse of medical knowledge. That of course is well and good if the illness is recognized by the dominant medical paradigm. However, objective medical knowledge is unable to recognize environmental illnesses such as SCIDS: “the symbols of medical technology are silent on the issue of EI (environmental

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289 Somers and Gibson, 61.
290 Somers and Gibson, 61; Taylor, 51& 52.
It is the narratives and stories of individuals with SCIDS that are the primary source of knowledge about this disorder. The integration of illness experience into medical knowledge remains a constant challenge. Nonetheless, the technical language of medical discourse is used by SCIDS' sufferers to narrate their experience: a narrative of biography understood in scientific, medical terms. Consider the narrative of the founder of the SCIDS group:

I hurt myself at work in what appeared to be just a simple movement. I wound up losing full use of my forearm on my right side. I went to see [local orthopaedic surgeon]. He thought it was really strange that simply by reaching into a shopping cart and grabbing a sausage would... The doctors were doing tests. My family doctor couldn't find out why. I started getting really severe migraines. By August I was seizing four and five times a week, full grand mal. I wasn't able to walk down two stairs.

We [local orthopaedic surgeon and SCIDS founder] started tracing medical backgrounds. Doing my own, my family doctor said, Well [name], when you were expecting [son's name] you got sprayed with Malathion. We went back and looked at that. That probably was what triggered it, because I mean, it brought on my son six and a half weeks early. That was in '85 and my injury was in '89. Some things get stored in your body and don't become active until there's a trauma or stress or something.

I was seizing continually. I had two little ones. We finally said, okay, lets try and get out of here. We sold our house and brought some property where the environment was a little bit cleaner, where we could have some control over our water.

With the family doctor not knowing [what was wrong] I was going to the health unit, getting information and looking at different things, and jeez what could it be, you know. There was an article on TV about Lyme Disease. Hey, I lived in the Laurentians right, I mean what the heck. They determined that no, it wasn't Lyme Disease. We looked at chronic fatigue. I took part in a study with a specialist on Salt Spring Island. The symptoms we had were almost exactly the same as chronic fatigue syndrome. You have the fatigue, you have the nausea, you have muscle weakness and so on. I went and saw a

Kroll-Smith and Floyd, 18; Brown, "Popular Epidemiology,"37.
Good, 117.
specialist at St. Paul's, and a neurologist. When I was getting ready to leave he
said, point blank, I think you've been sprayed with chemicals. I wound up
going back three more times to see him. The very last time he said, there's
nothing wrong with you. I think he couldn't come up with anything. He said he
couldn't find anything conclusive.

She has a clear picture of cause and chronology of her illness. There is a temporal
connotation to illness. Her narrative indicates the beginning of her illness, and a linear
progression of symptom emergence. She also has a theory of disease etiology as well as
pathophysiology. Malathion was the source of her illness. After having an initial effect (the
eyearly delivery of her son), the disease remained dormant for some years, stored in her body
awaiting release. She continued searching for information as to what her illness might be, since
it remained unnamed for a period of time.

She knew from experience that exposure to low levels of chemicals could trigger her to
seizure. Muscles were atrophying; her body was progressively becoming immobile. Around
these experienced facts, changes were made in her life: a move to a healthier environment, and
one over which she felt she might have some control; a daily treatment regime.

Her story of illness experience incorporates technical language into the narration.
Medical language describing her body changes, her experience of illness provide her with an
understanding as well as a means of explaining with authority her symptoms and experience.
This is part of her repossession of her story of illness. Having narrated her symptomatic account
to the physician, a narrative which was then medicalized to identify and treat a disease, she now
reconciles the objective medical account back to her own subjective experience.

This persuasive claim to the truth, both to herself and to others, is part of what Kroll-
Smith and Floyd suggest is a "practical epistemology." Expert knowledge is separated from its
institutional anchoring and applied to the world of personal and biographical history and
experience. This move from one world to another re-shapes expert knowledge. It becomes "a

293 Hyden, 52 & 53; Melucci, The playing self, 75.
294 Hunter, 9-15.
295 Geertz leaves this term vague; Kroll-Smith and Floyd develop a definition for its use in their
technical, rational way of knowing that is responsive to the immediate personal and communal needs of non-experts." It also renders noisy and audible all that has been silenced by the medical paradigm.

Corporeal risk

The acronym SCIDS locates risk in the environment. SCIDS is a chemically induced dysfunction. Her search for causes, the Malathion spraying, testing for Lyme disease are among factors that indicate that she too looks to the environment for possible causative risks. However, risk, external to the body, is silenced by the medical paradigm in the SCIDS conflict.

The concept of risk in health includes two different notions: environmental risk and lifestyle risk. The latter has been the focus of health promotion and health education. The individual is expected to take responsibility for their own health and manage their own risks through self-governance, self-examination, self-care and self-improvement. Minimizing burden on society by maximizing health is a "project of the self."  

Environmental risk on the other hand includes pollution, toxic chemicals and nuclear waste for example. Environmental risk is externally imposed, with corporations or governments generally thought to be responsible. Further, environmental risk is thought to pose a hazard only to the physical self. Unlike lifestyle risk, environmental risk does not threaten the individual’s moral integrity because the risk is not a consequence of something the individual does. Responsibility for their own or other’s exposure is not assigned to any individual in environmental risk. They are the “sinned against” whereas those who are deemed to be at risk from lifestyle become “sinners.”

A third form of risk that is largely implicit in medical discourse is embodied or corporeal risk. Here, the risk of disease is located in the body, for example, people with particular corporeal characteristics such as hypertension might be more likely to develop specific diseases. Threat is imposed from within, and implies only limited possibilities for dealing with the hazard,

296 Kroll-Smith and Floyd, 38; Williams and Popay, 122; Hunter, 14.
297 Kavanagh and Broom, 437 & 438.
298 Lupton, 90; Kavanagh and Broom, 438.
unlike lifestyle risk where the individual has some possibility of managing their risk. 299

The overlap of these categories of risk can be clearly seen in the narrative of the SCIDS founder. She locates the cause of her disease as environmental, with being sprayed with Malathion the precipitating event. Lifestyle is implicated in that she takes responsibility to move to an area where the environment was considered cleaner. The risk however, previously external, was now internal to her body, awaiting release, triggered by other external elements. Referring to the Malathion incident, she says

some things get stored in your body and don’t become active until there’s a trauma or stress or something

which is easily activated, without warning.

Friday night, I mean I haven’t had a major seizure in over a year. Friday night I was dispatching for Citizen’s Patrol, I walked in, the janitor was there and I never gave it a thought. Two hours later I’m in full seizure and they’re whipping me down to the hospital because I can’t breathe. It happens that quick.

Whilst some (external) aspects of her life can be managed, the threat from within remains an uncertainty, to be activated at what seems to be the whim of the body.

An effect of this uncertainty related to embodied risk is conceptualization of the self as separate from and threatened by the body. With lifestyle risk the person is defined by what they do or do not do; with environmental risk, the individual is defined by what is done to them. Corporeal risk defines who a person is: an individual both has and is a body. The threat from within in corporeal risk results in an ambivalent body-self relationship.300 In discussing the trajectory of her illness, the SCIDS group founder disassociates herself from her body. Her body is discussed as some ‘thing’, other, that is being invaded. The invasion however is caused by external pollution. The integrity of the person is not impugned. The name of the disease, Somatic Chemically Induced Dysfunction Syndrome (SCIDS), contains within it causation that places responsibility outside the person. At the same time however, managing the uncertainty of

299 Kavanagh and Broom, 438.
300 Kavanagh and Broom, 440.
corporeal risk requires surveillance of the body and taking the appropriate action.

I’ve got the clubbed feet again, my hands are clawed...and its day after day of
just stretching muscles again to get them responding.

Diagnostics: The inscribed body/the becoming self

Surveillance of the body is part of the inscription of the self as “patient.” The medical
gaze is applied to the body by the body’s self. This is part of a process in which the power of the
physician, which is wielded through the gaze, is de-individualized and taken over by the
observed themselves as they create a subjectivity of patient. Surveillance of the self has become part of the life of the founder of the SCIDS group. She applied the gaze of the physician to herself.

Not only does she talk about the physical effort required to keep herself functioning, but also the gaze, hers, that surveys her body daily and requires her to work at keeping herself functioning. Both she and her condition become the object of surveillance. She is inscribed as a patient. Stating “I am ill,” her knowledgeability of disease inscribes her as a SCIDS sufferer.

The SCIDS self-help group also extended surveillance. The bodies of the SCIDS members are inscribed through their practices as part of the group, and their interaction with the knowledgeability which the group constitutes in its themes of science and self-help. Not only in the self-help group do we see the physical bodies of those with SCIDS but also their embodiment within a subjectivity of what it is to be a sufferer of SCIDS. Taking on the objective language of medicine to understand their own subjective experiences, SCIDS members/sufferers disciplined both physical body and self.

Taking over the surveillance of medical authority, the relations of observer-observed that constitute the gaze begin, in this case, with the diagnosis. The gaze allows the composition of knowledgeability about disease through observable signs and symptoms. In the patient-physician relationship, the gaze provides knowledge and expertise to the physician as the patient relates symptoms that are translated into the signs of disease. What is important is not what the

301 Fox, Postmodernism, Sociology and Health, 28
302 Fox, Postmodernism, Sociology and Health, 34 & 35.
patient thinks, but what the patient says. The body can be “read” only by the expert, the physician.  However, as we have seen, the knowledgeability of the expert is taken over by those with environmental illness. The body in turn is ‘read’ by the sufferers themselves, inscribing both visually and in practice, contributing to the self, to subjectivity. Discourse forms, defines and reproduces subjects at the same time as it seeks to control, regulate, limit or prohibit those subjects.  A discursive field is created, a diagnostic, depriving the person of continuities, dissolving the comfort of temporal identity, establishing difference. She is in the process of becoming something other, what she does not yet know.  She uses technical language for her symptoms (seizure, migraines, grand mal, atrophying muscles), she has knowledge of other, similar illnesses and their clusters of symptoms (multiple sclerosis, chronic fatigue, fibromyalgia), can talk knowledgeably and technically about pesticides, safe levels and synergistic effects, and about alternative treatments. These medical and technical discourses inscribe the body. There is no inner identity; only the subjectivity of the person so inscribed. The body becomes a text, a system of decipherable, read and read-into signs. Her body, coded with and as signs, speaks without necessarily talking. She is the grand mal seizure, the migraine, the atrophying muscles. She is SCIDS.

Inscribing the body is not hers alone to do however. Public and expert narratives also comprise inscriptive practices. Media play a key role in the framing of narrative and are the subject of the next chapter. I return to where the research began and trace a private trouble that becomes a public issue, and how it is played out in the public and expert narratives.

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304 Butler, viii, 2 & 140.
305 Rajchman, 47-49.
306 Grosz, 35.
CHAPTER FIVE: PUBLICIZING THE FRAME OR FRAMING THE PUBLIC? THE MEDIA STORY

It began as an individualized problem. Symptoms seemingly did not fit any specific diagnosis. People were sick, but individually so. However, the numbers of individually sick increased. A doctor noticed a pattern. A group was established, the media informed. The "personal troubles of milieu" became the "public issues of social structure."³⁰⁷

From Private Troubles to Public Issue

C. Wright Mills³⁰⁸ points out that troubles begin with the self, with the character of the individual, and within the immediate relationships and environment within which that individual lives his or her everyday life. Similarly, Strauss wrote that individuals must be understood "embedded in historical context" and "a temporal matrix."³⁰⁹ Biographical processes refer to the responses of the individual throughout the life course. Strauss uses the example of chronic illness as a significant event that resonates in the individual's life as he or she contextualises it, comes to terms with it, reconstitutes his or her identity vis a vis it and recasts their biography in a new direction despite the illness. When many people encounter the same events, share the same experiences and talk about them together then these same biographical processes are collective rather than individual. They are in other words, private troubles become public issues. Historical and structural conditions, and biographical processes together constitute identity for Strauss, and are the conjuncture within which private troubles and public issues are to be found for C. Wright Mills. A trouble is private, and is lived out within the biography of the person. It concerns values the individual holds dear. However, when a number of people share the same troubled milieu, albeit unknown to each other, that private trouble becomes a public issue located within social structures and historical life. As C. Wright Mills explains, we all live our biographies within an

³⁰⁷ C. Wright Mills, 5.
³⁰⁸ Ibid.
³⁰⁹ Strauss, Mirrors and Masks, 164; idem, “Identity, biography, history,” 4.
historical period and the constraints of a social structure.

The following narrative from newspaper articles transforms the private troubles of individuals with symptoms that they believe constitute an environmental illness to the level of public issues. As public issues, contestation over naming, defining and owning the social problem ensue.

**The Media Narrative**

From the mid-1980s, the Abbotsford orthopaedic specialist noticed mainly adolescent girls, 13 to 15 years of age, and women in the 20 to 40 year age group presenting with a number of common characteristics which defied any given medical diagnosis. Most common presenting symptoms were anterior knee pain and recurrent ankle sprain. In addition, individuals are found to exhibit any or all of the following: prominent lumbar lordosis; pain on palpitation of one or more lumbo-vertebral segments; restriction of posterior rotation of the pelvis to one or both sides; trophedema of the lower back; increasing sensitivity to pinprick and pinching when progressing from the lower thoracic to lumbar region of the back; increased sensitivity to pinprick below the knee bilaterally in a distribution not following sensory dermatomes; inability to squat without lifting heels; and difficulty balancing on one foot. As well, some women in their 30's exhibit night blindness and loss of peripheral vision fields. Employing a specific muscle exam, the specialist found all cases commonly exhibit a pattern of muscle weakness of which the individuals are generally unaware. The specialist noted that other doctors in the region were seeing the same symptoms. The majority of individuals were referred to the specialist’s clinic by other physicians who were unable to provide a diagnosis or relieve symptoms.\(^{310}\)

In 1989, the specialist informed the Central Fraser Valley medical officer of health of his concerns about the recurring illness. Two years later, with five of his patients, the specialist shared the story with the Abbotsford Alderman, a Dewdney Allouette Regional District representative, the Upper Fraser Valley medical officer of health, and some community members.

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By this time, the SCIDS group had been founded. A local toxicologist and scientist who attended a meeting of the group stated his concern that SCIDS sufferers may be showing symptoms of chronic toxic poisoning. The Central Fraser Valley Union Board of Health medical health officer confirmed that no funds had been allocated for research to investigate what might be causing the symptoms. This perceived failure on the part of politicians and government officials to take seriously the specialist’s and his patients’ concerns led the group, and in particular its spokesperson and founder, to become more vocal and active.

Unable to secure funding from the Ministry of Health to research the syndrome, in mid-1991, the Abbotsford orthopaedic specialist completed his own study. Together with two Vancouver independent medical examiners he conducted a five month single blind study of eighteen adolescent patients suffering unexplainable knee pain. His report indicated a strong significant correlation among the severe cases. The research data and findings were passed on to a UBC epidemiologist who recommended that another study take place to thoroughly investigate the syndrome.

A link between the environment and the SCIDS member’s symptoms was made by the orthopaedic specialist, and conveyed to the SCIDS group at one of their meetings towards the end of 1991. He pointed to the deluge of pesticides and herbicides in the environment, encouraged by a multi-billion dollar chemical industry and increasing industrial farming in the region, as a causal factor in both the disappearance of frogs, snakes and birds in the region, and the serious health effects experienced by the members of the group. Drawing a parallel with the AIDS movement, he encouraged the group to become politicized in order to gain recognition, as well as research funding, for their illness.

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Since at least the early 1980s, groundwater contamination in Abbotsford had been a concern. The Environment Committee of the Association of Professional Engineers and Geoscientists of British Columbia were aware of the potential for high nitrate and pesticide contaminations in the Lower Fraser Valley groundwater since 1981, and had sent several warnings to government.316 Briefs in 1981 and 1985 were submitted to the then British Columbia Ministers of the Environment, outlining the problems associated with the ongoing agricultural practices of local farmers and groundwater contamination.317 Very few of the brief’s recommendations were implemented.318

From 1984, Environment Canada, the National Research Institute, and Agriculture Canada had been testing for and finding pesticides in the Abbotsford aquifer. The pesticides Dinoseb, Simazine, Alachlor, Atrazine, Dimethoate, Chlordane, Endosulfan and DDT had been found in the groundwater in lower than maximum acceptable concentrations for the years 1984 to 1990.319,320


320 Dinoseb is a herbicide and dessicant used in the control of broadleaf weeds and for pre-emergence control of annual weeds in crop cultivation as well as control of runners in strawberries and raspberries. Dinoseb is classified as very toxic to humans with a variety of symptoms which include personality change. The chemical’s carcinogenic potential has not been adequately investigated, it has potential as a cataract-inducing agent, and has teratogenic (causing malformation of a foetus or embryo) and foetotoxic effects. Simazine is a soil sterilant and a herbicide used to control broadleaf and grassy weeds in the cultivation of a variety of crops and as an aquatic weed control. Simazine is considered to be only slightly toxic to humans. Atrazine is used for weed control in crops and has persistence in soil in temperate climates. See n.198. Dimethoate is an organophosphorous insecticide and acaricide used to control houseflies, insects and mites on fruit, vegetable, field and forestry crops. It is subject to considerable leaching through the soil. It is a cholinesterase inhibitor. There is inadequate evidence available to classify dimethoate as a carcinogen, mutagen or teratogen. (Guidelines for Canadian Drinking Water Quality—Supporting Documents. Health Canada. July 03, 2001). Alachlor is a herbicide used to control annual grasses and broadleaf weeds in field crops such as corn. It is classified as slightly toxic and the chemical’s carcinogenic effects are uncertain given the inadequacy studies to date <http://www.ace.ace.orst.edu/info/extoxnet/pips/alachlor.htm> Chlordane is an insecticide used to control termites and other wood-destroying insects in the cultivation of crops such as corn. It was
In 1986, a railway derailment east of Fort Langley resulted in a spill of an estimated 250,000 litres of ethylene dichloride (EDC), later revised to 336,000 litres, some of which reached the lower aquifer. Ethylene dichloride is an insecticidal fumigant, used in liquid form on stored crops and soil. It has been demonstrated as a carcinogenic in rats and mice, and is thought to be linked to potentially serious health effects involving the nervous, respiratory, hepatic, renal and cardiovascular systems. In 1992, the EDC contaminated groundwater was still being pumped from the aquifer.

An Environment Canada hydrogeologist, speaking to the B.C. Institute of Agrologists in 1990, stated that sixty percent of the wells sampled near the Abbotsford airport by Environment Canada in the past year exceeded the safe standard for nitrates in drinking water. The standard for nitrates in drinking water is 10mg/L. Another twenty percent were at levels more than twice the safe standard for nitrates. High levels of nitrate contamination can cause methemoglobinanaemia (blue baby syndrome) in which nitrates prevent the exchange of oxygen and carbon dioxide in the lung in infants under six months, creating a build-up of carbon dioxide, banned from all use in the US in 1988. It persists in the soil for up to 20 years, and does not dissolve easily in water. It is classified as highly toxic. There is uncertainty as to its carcinogenic effects in humans ("Chlordane Chemical Fact Sheet 12/86." Cornell University website <http://pmep.cce.cornell.edu/profiles/insect-mite/cadusafos-cyromazine/chlordane/insect-prof-chlordane.html>; "Chlordane." Agency for Toxic Substances and Disease Registry FAQ <http://www.atsdr.cdc.gov/tfacts31.html>). Endosulfan is an insecticide and acaricide for the control of insects and mites on fruit, vegetable and grain crops. It is classified as a highly toxic pesticide, and may cause reproductive and mutagenic effects in humans ("Endosulfan." Extension Toxicology Network, Pesticide Information Profiles, Oregon University. 1996. <http://ace.orst.edu/info/extoxnet/pips/ endosulf.htm>). DDT is an insecticide, banned in the US in 1973. It is classified as a probable carcinogen ("DDT." Public Health Statement, Agency for Toxic Substances and Disease Registry, Division of Toxicology, Atlanta, Georgia <http://www.atsdr.cdc.gov/ToxProfiles/phs8908. html>).

321 Larry McCallum, "Abbotsford water contaminated, scientist claims," The Vancouver Sun, May 4, 1990, sec.B. p.1; Glenn Bohn, "Recovering the Blob," The Vancouver Sun, August 15, 1986, sec. B. p.1 & 3. Ethylene dichloride is a manufactured chemical not found naturally in the environment. It is commonly used to produce vinyl chloride, and to dissolve grease, glue and dirt. While it evaporates very quickly, it can stay for years in groundwater. EDC causes damage to the heart, central nervous system, liver, kidneys, and lungs. <http://www.baggettmccall.com.edc.htm>


turning the infant blue. High nitrate levels may also be implicated in higher cancer rates in the general population. Manure stockpiling, excessive fertilizing, septic tanks, and the poultry and raspberry industries were identified by the Environment Canada hydrogeologist as the primary problem and source of nitrate contamination. A B.C. agriculture ministry agrologist stated that a voluntary code of good practice for farmers, rather than stringent legislation governing manure application would be put in place. He noted that action that would jeopardize the economically important poultry, swine and raspberry industries should not be implemented.\textsuperscript{324} The District of Abbotsford assured the public that the municipal drinking water was safe and that the contaminated water was to be found in private wells along a strip of land near the Canadian-US border where nitrates were leaching into the aquifer.\textsuperscript{325} Nitrates and pesticides continued to plague the aquifer of the Lower Fraser throughout the 1990s.

Late in 1991, the orthopaedic surgeon stated that he had sixty to seventy patients with the mysterious enviro-disease, and that the provincial government was “scrambling to check his claims.” A spokesperson for the health ministry said that the following steps were being taken in light of the orthopaedic surgeon’s reports: the ministries of health, environment and agriculture had established a committee of assistant deputy ministers; the health ministry was negotiating a contract with specialists at the University of British Columbia to get a second opinion on the diagnosed patients; and the health ministry was seeking proposals from an engineering or consulting firm for an overall picture of the Upper Fraser Valley groundwater system. The orthopaedic surgeon said that he too was attempting to validate the disease, to make sure it was not “pie-in-the-sky.” He stated that he suspected pesticides as the cause because the symptoms involved the central nervous system and the immune system, and he maintained only a chemical would be likely to do that.\textsuperscript{326}

A problem noted by a UBC epidemiologist was that the orthopaedic surgeon was the only


\textsuperscript{325} “Water okay, Abbotsford says,” \textit{The Vancouver Sun}, May 05, 1990, sec. A. p.5.

person observing the condition. He pointed to the fact that illnesses are not usually located at only one geographical point. The orthopaedic surgeon stated that there were others around the world seeing a similar illness. The spokesperson for the SCIDS group pointed out that family doctors were referring patients to the orthopaedic surgeon.327

Concern was expressed in Ottawa about the illness, and the federal government pledged to investigate. It was reported that the federal government, together with local and provincial health officials had been investigating the reports of SCIDS since the early 1990s, and so far had concluded there was no increase in muscle weakness in the Fraser Valley.328

October 1991, a consulting hydrogeologist was reported as stating that although the Abbotsford aquifer water was clear, it was not pure. Unacceptably high concentrations of DCP (1, 2 and 1, 3 dichloropropanes), toxic compounds commonly used in the area,329 contaminated the aquifer.330 A month later, it was reported that an Environment Canada study found traces of 1,2 dichloropropane, a pesticide, in groundwater testing in the Abbotsford area. 1,2 dichloropropane was registered for use in Canada from 1947 to 1985, and could be applied legally until 1990. It was discontinued from use because it is extremely leachable and lasts a long time in the environment. 1,3 dichloropropane is the second most used pesticide in the Fraser valley by raspberry farmers as a fumigant and is injected into the soil to kill nematodes. Both 1,2 and 1,3 dichloropropane are defined as “probable” carcinogens.331 There was a call for


329 1,2 dichloropropane was used as a soil fumigant (and could be found in some paint strippers, varnishes and furniture finish removers). The breakdown of the chemical in the groundwater is slow, with a half-life of between 6 months to 2 years. Health effects from long-term exposure are unknown (“Toxicological Profile for 1,2-Dichloropropane,” Agency for Toxic Substances and Disease Registry, United states Public Health Service. December 1989.). 1,3-Dichloropropane is a soil fumigant. It is of low acute toxicity. No short-term, long-term, reproductive, or developmental toxicity data pertinent to exposure via drinking-water could be located in the literature. The available data were considered insufficient to permit recommendation of a guideline value (Guidelines for Drinking Water Quality, 82.).


provincial legislation to protect groundwater by the director of the B.C. Public Health Association. It was noted that the British Columbia Royal Commission on Health Care and Costs had drawn attention to the lack of legislation to ensure high quality drinking water. In addition, the same report noted no single ministry was given overall responsibility for the state of groundwater. The spokesperson for the raspberry industry offered to immediately stop using the chemical if requested by environmental and health agencies. The medical toxicologist with the B.C. health ministry stated however that there was no evidence of a link between pesticides and the public health problems in the Valley. A consultant hydrogeologist also stated that, despite the increasing numbers of patients with the symptoms thought to be linked to the environment, there is no concrete evidence that water contamination is the cause. He did however point out that groundwater was deteriorating in agricultural areas such as the Fraser Valley, and that if not dealt with soon, extensive areas would be left without a safe drinking water supply.

The regional hydrologist with the federal environment department had been instructed not to discuss the findings of his study, stating that it had been classified as a sensitive document by Jean Charest, the environment minister, and that the results and the risk assessment would be made public early in the new year. The environmental toxicologist in the provincial health ministry stated that for the two chemicals tested, 1,2 dichloropropene and 1,2 dichloropropane, no traces were found of the former, and the test results for the latter were at 1984 levels and did not indicate any health threat.

Concerned with the media reports on pesticides in the water, and the lack of information from Environment Canada, the Abbotsford district advanced its 1991 annual water testing. The district’s water supply was declared safe, with wells east of those pinpointed by Environment Canada as being contaminated, in the clear. Those wells sampled near the airport however did contain traces of DCPs, and it was not clear, because of a lack of information on water flow in

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the aquifer, whether the water there might contaminate the municipal wells.\textsuperscript{336}

In the meantime, the SCIDS group spokesperson had been warned by the Upper Fraser Valley medical officer of health to “cool her contacts with the media,” to “quit pointing fingers,” and that she wasn’t “making any friends in government circles by telling the public about her unidentifiable illness.” He maintained his concern was the possible contamination of future research from such publicity. In addition, the environmental link was reportedly problematic to government, environmental, and agricultural agencies.\textsuperscript{337}

Water samples from the groundwater supply of a number of SCIDS members were taken towards the end of 1991. Up until this time little action had been taken by the public health authorities other than advising the Abbotsford specialist on how to proceed with his own research on the syndrome. However, the Upper Fraser Valley medical officer was reluctant to make publicly available the results of pesticides tests taken the year before in Norrish Creek, the Abbotsford and Clearbrook public water supply, claiming that the Health Ministry’s interpretation of the data should be sufficient. He maintained that there was no indication of contamination in the public water supply, but groundwater could be a different problem, he said. He had been meeting with federal and provincial officials since May 1991 about the contamination of the Abbotsford aquifer by nitrates and pesticides. Results of the groundwater tests of the SCIDS members were never made public.\textsuperscript{338}

In December 1991, it was reported that a U.S. Geological survey was finding similar data to those being found by Environment Canada in the Abbotsford-Sumas aquifer.\textsuperscript{339} 1,2 dichloropropane and 1,3 dichloropropene were found in the groundwater in levels exceeding the U.S. Environmental Protection Agency standards. The U.S. Geological survey had also found ethylene dibromide (EDB) in the aquifer north west of Lynden. This soil fumigant was used frequently by U.S. raspberry farmers and is now banned because of its health effects.\textsuperscript{340}

\textsuperscript{336} Vic Blas, “Water passes the tests,” \textit{Abbotsford Times}, November 27, 1991, p.3.
\textsuperscript{337} Trudy Beyak, “Victim told to cool it: On speaking out about possible enviro-disease cause,” \textit{Abbotsford News}, October 23, 1991.
\textsuperscript{339} The aquifer is called the Abbotsford aquifer in Canada, and the Sumas aquifer when it crosses the border into the United States.
With the encouragement of the orthopaedic specialist, and in the face of the perceived inertia by government, the SCIDS group decided to fund-raise to hire an American toxicologist, whom it was hoped could identify the toxins hypothesized to be causing the syndrome. The U.S. toxicologist is reported in the newspaper as being “a former University of Florida professor and former research and development manager with a chemical company in the U.S. mid-west and the south.” He had worked in environmental toxicology for approximately twenty-five years, and testified in many lawsuits against chemical manufacturers in the U.S. He had worked with the Environment Protection Agency, U.S. Drug and Alcohol, and the U.S. State Department worldwide, and with thirty American chemical companies and public action groups.

Coincidentally, the provincial Ministry of Health contracted a UBC epidemiologist to study the cluster of symptoms hypothesized to constitute SCIDS. He is described by the Upper Fraser Valley medical officer of health as “knowledgeable, capable and a straight-shooter.” The $30,000 study was expected to take until the end of April 1992. The contracted UBC epidemiologist stated that speed was of the essence for the study, since people labeled as ill will become ill.

Both research projects were conducted over very nearly the same time periods. As part of the epidemiology study, a community advisory committee was established, chaired by the Abbotsford Alderman and Chairman of the Upper Fraser Valley Board of Health, and which

346 Rebecca Wigod, “Mystery illness to be probed by UBC doctors,”The Vancouver Sun, December 19, 1991, sec. A. p.3.
included the founder and spokesperson of the SCIDS group.\textsuperscript{347}

There were efforts made by various community players to keep the two studies, toxicology and epidemiology, very separate. The Upper Fraser Valley medical officer of health and the chair of the epidemiological study community advisory committee pointed out that the link between SCIDS and environmental toxins such as pesticides was mere assumption at this stage;\textsuperscript{348} that the United States toxicologist’s investigation had nothing to do with the epidemiological study; and that people had made the link between the environment and the illness before it was determined whether the syndrome called SCIDS even existed. She implored the media to keep an open mind on the topic. An effort was made to replace the term SCIDS with the Fraser Valley Symptom Complex, removing the link with chemicals from the name.\textsuperscript{349}

The toxicologist was the first to report back to the community. Following the testing of soil, water and air samples which included inspecting poultry, hog and other farms, as well as wells and ditches in the Abbotsford area over a five day period in early 1992, he concluded that local farming practices, including the “sloppy” use of pesticides, were impacting the quality of life in the Fraser Valley.\textsuperscript{350} Tearfully, he told Valley residents that they had been poisoned.\textsuperscript{351} He singled out raspberry farmers, and the use of Captan as “the most misused and overused pesticide” in the Valley.\textsuperscript{352} He also claimed that farmers were using a pesticide banned in Canada since 1986: ethylene dibromide (EDB).\textsuperscript{353} In addition, high nitrate levels, traces of 1,2


\textsuperscript{353} Glenn Bohn and Al Sheehan, “Consultant claims banned pesticide used,” \textit{The Vancouver Sun}, February 13, 1992.
dichloropropane (DCPs), and five and a half times the United States safe drinking water standard of DCPs per litre, were found in some domestic wells.\textsuperscript{354}

The provincial Ministry of Health toxicologist agreed with the toxicology report findings in relation to nitrates and traces of DCPs, however he strongly disagreed with the other findings, stating they were not supported by evidence.\textsuperscript{355} Accusing the Florida toxicologist of causing unwarranted fears in the community, which in itself, it was claimed, might cause illness, the SCIDS group’s choice of an American rather than a local or regional toxicologist was questioned.\textsuperscript{356} The Raspberry Growers Association joined the fray, claiming that their members were well versed in pesticide use. The B.C. Ministry of Environment’s pesticide division called for proof of the toxicology study’s findings;\textsuperscript{357} the epidemiologist in charge of that investigation accused the toxicologist of misinforming the community;\textsuperscript{358} the B.C. Ministry of Health was reportedly checking the American’s credentials;\textsuperscript{359} and the regional hydrologist who had also been testing the aquifer samples was silenced.\textsuperscript{360}

Even more efforts were made by politicians and bureaucrats to distance the toxicology investigation from the epidemiology study. The SCIDS spokesperson agreed that the two studies had nothing to do with each other: the epidemiologists were investigating whether the syndrome existed; the toxicology study investigated the cause and possible treatment of SCIDS.\textsuperscript{361}

The epidemiological report followed on the heels of the toxicology report. Using a diagnostic test devised by the Abbotsford orthopaedic specialist to classify individuals with and

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\textsuperscript{357} Glenn Bohn and Al Sheehan, “Consultant claims banned pesticide used,” \textit{The Vancouver Sun}, February 13, 1992.

\textsuperscript{358} Petra Kossman, “We’re poisoning ourselves,” \textit{Abbotsford Times}, February 15, 1992, 3.

\textsuperscript{359} Glenn Bohn and Al Sheehan, “Consultant claims banned pesticide used,” \textit{The Vancouver Sun}, February 13, 1992.


\textsuperscript{361} Petra Kossman, “Toxicologist tests air, soil,” \textit{Abbotsford Times}, February 12, 1992, 3.
\end{flushright}
without the syndrome, the study concluded that SCIDS did not exist.\footnote{Coldfield, "SCIDS-what SCIDS?" \textit{Abbotsford-Clearbrook Times}, Saturday, February 22, 1992.} The test chosen as an indicator of the syndrome, that used by the orthopaedic surgeon to diagnose the syndrome in his patients, was not reliable, unable to distinguish SCIDS patients from the rest of the population. The test required patients to rotate their wrist whilst a counter-force was applied. Often a sudden weakness was displayed and their wrists turned quickly. This test was reportedly the common denominator in those presenting with the symptoms that became known as SCIDS. The double blind epidemiology study of seventy-nine people consisting of those already diagnosed, those with similar symptoms to the diagnosed, and another group with no problems, found the characteristic weakness in 75 percent of all tested. Acknowledging that members of the SCIDS group were suffering a variety of different symptoms, those symptoms, the report concluded, did not constitute a syndrome.\footnote{"Illness probe hits the SCIDS," \textit{The Province}, February 20, 1992, sec. A. p.6; Glenn Bohn, "Valley mystery sickness debunked," \textit{The Vancouver Sun}, February 20, 1992, sec. B. p.1; Trudy Beyak, "Syndrome is still a mystery,"\textit{Abbotsford/Matsqui & Mission News}, Saturday, February 22, 1992, sec. A. p.2.}

Later in the week, a newspaper article reported that the findings of one of the medical examiners was downplayed during the press conference. The report of one of the medical examiners stated that the muscle weakness was the common factor among the five worst cases, noted as an unusual finding for which he had no explanation. His recommendation that another physiotherapist examine the patients was not accepted by the UBC epidemiologists.\footnote{"Epidemiologists didn't examine patients," \textit{Abbotsford/Matsqui News}, February 26, 1992, sec. A. 9.}

B.C. Minister of Health, Elizabeth Cull, announced that there was no evidence of pesticide-induced illness in the Fraser Valley, and that there would have to be further investigation of the reported neuro-muscular symptoms.\footnote{Glenn Bohn, "Cull cautious over valley health risk," \textit{The Vancouver Sun}, February 21, 1992, sec. B. p.3.} The founder of the SCIDS group, who had been a member of the epidemiology study community advisory committee, said that she was satisfied the study purpose had been accomplished, and was pleased that although not recognized as a syndrome, it had been acknowledged that she and others were sick and that the assistance...
they needed would be forthcoming. Later, when that assistance was not forthcoming, she criticized the study for its lack of depth, and for its culmination before its contracted date. Originally to be a three or four month study (January to April 1992), it was completed in six weeks (January to mid-February 1992).

A complaint against the Abbotsford orthopaedic specialist was laid with the B.C. College of Physicians and Surgeons by an agrologist with the provincial Ministry of Agriculture. Also the chairman of the ethics and practices committee of the B.C. Institute of Agrologists, he stated he was concerned that links made between health and the environment would effect the agriculture industry in the Valley, and questioned the professional ethics involved in making such a causal link.

In his defense, the specialist maintained that he had never singled out pesticides alone, but had suggested that environmental toxins in food, air, and water may be associated with the syndrome, and therefore required further research. He maintained that much of the controversy had arisen because of inaccuracies and misquotation by the media, for which he was not responsible. Satisfied, the College took no further action.

Prior to the reports of both the toxicologist and the epidemiologists, in January 1992, a consultant with a geo-technical and hydrogeological firm stated that a provincial report released six years previously had shown unacceptable amounts of nitrate in private wells drawing from the Abbotsford aquifer. He stressed that unless there was an effort to deal with the problem the aquifer water quality would deteriorate and it would be almost impossible to clean up. Whilst the city had been at pains to ensure that residents knew that the municipal wells were clean, the director of public works for Abbotsford said that employees dilute the water from one well, currently with nitrate levels of 8.68mg/L, with that of another less contaminated well to ensure that residents do not ingest high concentrates of nitrates in the drinking water. He also noted that cleansing the wells of nitrates would be far too costly. The highest concentrations of nitrates

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368 Glenn Bohn, "Physicians withdraw from toxic controversy," The Vancouver Sun, March 09, 1992, sec. B. p.3.
369 Ibid.
were below levels that would affect infants.370

Early in 1992, it was announced that Agriculture Canada, Environment Canada and the National Research Council were to investigate the impact of agricultural practices in the Fraser Valley on health. The Abbotsford aquifer contamination by pesticides and nitrates was to be the focus of this $1.4 million study. The Abbotsford director of public works pointed out the difficulty in estimating the number of pesticides used in the Valley, and speculated that some may be smuggled across the American-Canadian border without permits or regulation.371

Speaking at a Growers Short Course, the director of the soils and engineering branch of the B.C. Ministry of Agriculture, and another speaker from the B.C. Ministry of the Environment drew attention to the build up of nitrates in the groundwater over the past fifteen years, and the role of poultry manure in those excess nitrates. A new Code of Agricultural Practice for Waste Management will require manure to be stored on an impervious surface and to be protected from the rain, they said.372 A few months later, the chairman of the B.C. Agricultural Environment Protection Council (AEPC) contacted raspberry producers and the poultry associations about complaints by residents concerning unsatisfactory storage of manure. His own observations following a tour of the area confirmed these complaints.373

In April 1992, the B.C. Ministry of Health announced that it had conducted tests on both private wells and Abbotsford’s municipal wells in the Abbotsford aquifer. The Upper Fraser Valley Health Unit medical officer of health stated that the results from the six municipal wells indicated the water met the Canadian drinking water guidelines. The private wells identified by members of the SCIDS group for testing had some sewage pollution. Both private and municipal wells were found to have nitrate contamination, but at levels less than those reported in previous years. The SCIDS group spokesperson suggested the wells should have been tested during the growing season, when manure and fertilizer are applied, not in November.374

Also in April 1992, a letter to the newspaper was received from one of the SCIDS

patients who had moved away, having eliminated everything else possible that might be causing her symptoms. She told the town that she was now as well as she’s felt in a long time, after six years of increasingly debilitating headaches, nausea, fatigue and seizures. She stated that she sees wildlife in her new neighbourhood in Alberta, something she rarely observed in Abbotsford. Her message to her fellow SCIDS sufferers was to follow her path and move away, or be prepared to fight for both their lives and the environment.\textsuperscript{375} Her departure followed that of another SCIDS sufferer who found that getting away from the Valley pollution was the only way to fight it.\textsuperscript{376}

In mid-1992, the release of the Gartner Lee Report indicated that nitrate levels above the safe drinking water standards,\textsuperscript{377} and traces of pesticides had been found in the Abbotsford aquifer. SCIDS patients maintained that the report supported their own findings.\textsuperscript{378} A month or so later, the media believed they had been duped when they discovered that what had been provided to them as the official Gartner Lee Report was in fact an edited version of it in which the contamination had been downplayed by providing only average levels. A second report, not given to the media, provided the actual data with detailed area maps and range of concentrations. The medical officer of health of the Upper Fraser Valley Health Unit explained that the full report was not provided to the media for reasons of economy, and that it was not an intent to hide anything. He did concede that not providing all the facts was not very informative. Both a Whatcom County (US) Environmental Health Specialist, and a local toxicologist stated that providing averages was a very deceptive manoeuver.\textsuperscript{379} Whilst the edited media version of the report showed an average DCP level of 4 parts per billion (ppb) in 1987, tapering down to .37 ppb in 1990, the full report indicated there were 11 wells out of 25 with DCP contamination, the highest showing 5.5 ppb in 1987. Significant data gaps were also obvious in the report. Environment Canada stated that it had found DCP average levels higher than those reported in

\footnotesize{\textsuperscript{375}“Letter to editor,”\textit{Abbotsford/Matsqui News} April 01, 1992.  \\
\textsuperscript{377}Gartner Lee sought voluntary information from organizations that had sampled groundwater in the Fraser Valley. Organizations were not required to hand over results from groundwater sampling.  \\
\textsuperscript{378}Trudy Beyak, “Neurotoxins causing sickness?” \textit{Abbotsford/Matsqui & Mission News}, May 30, 1992.  \\
\textsuperscript{379}Trudy Beyak, “Key report is double trouble,” \textit{The News}, June 24, 1992.}
The average nitrate level in the Gartner Lee Report was 17 parts per million (ppm), however a number of wells had exceedences double and triple the recommended safe level of 10 ppm.

In July, the provincial government announced it was accepting some of the Gartner Lee Report recommendations. These included the initiation of an inter-agency co-ordinated database to be managed by the Ministry of Environment with input from the Ministries of Health and Agriculture; a comprehensive groundwater monitoring program; sampling of all municipal and community water supply systems with a groundwater component four times a year for nitrates, once a year for pesticides, and twice a year in areas of intensive pesticide use; and seventy-five private wells to be sampled four times a year for nitrates and once a year for pesticides.

Changes were to be made to the time of year water samples were taken for testing and to the list of pesticides for which testing was to be done, the chief environmental officer of the Upper Fraser Valley Health Unit announced. Stating that one should never assume that certain things are done when it comes to water testing, he pointed out that samples were not taken after prime spraying times, and that some of the most heavily used pesticides, for example Captan, were not on the sampling list. This was about to change however, as approximately thirty pesticides were to be added to the sampling list, with sampling to be conducted soon after prime spraying periods, in May, June, late summer and early fall. He also stated that the health unit would be looking at the sum of concentrations of trace pesticides for exceedence of the Canadian Drinking Water Guidelines. However, the pesticide replacing 1,2 and 1,3 dichloropropene was not put on the sampling list. Vapam was increasingly being used by farmers in the Fraser Valley to kill nematodes.

The Florida toxicologist applauded the B.C. Government’s implementation of a

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groundwater protection program. His final report to the SCIDS group was released the month previous, in June, identifying a number of environmental problems in the Valley. These included misuse of neurotoxic pesticides, illegal dumping of nitrogen-rich manure, pesticide drift and aerial spraying of toxic chemicals, and the Fort Langley train spill of ethylene dichloride. His recommendations were implementation of severe penalties and on-site monitoring of pesticide misuse, and spreading of manure at appropriate times and dehydration of excess for use as fertilizer. The B.C. provincial government promised $500,000 to monitor groundwater in the Valley each year.

A little later in the year, an Environment Canada report indicated nitrate and pesticide contamination of the south flowing Abbotsford aquifer. Excessive nitrates had been found in the aquifer for years. An environmental health specialist with the provincial Ministry of Health commented that given the long-term data, action should have been taken years ago. Nitrate contamination was also common in the Brookswood and Hopington aquifers west of Abbotsford.

A certain “ho hum”ness was evident with the release of the Environment Canada report. It confirmed much of what everyone knew already—that the well water from the Abbotsford aquifer was contaminated. This fact raised concerns from the co-chair of the Central Fraser Valley Health Group about the lack of progress in the fight for clean water, and the preoccupation of agencies and organizations with research and talk, but no action.

A biologist with Canada Health and Welfare, Bureau of Chemical Hazards, Monitoring and Criteria Division stated that, whilst there was still much debate over the topic, nitrates are carcinogenic. The pesticides 1,2 dichloropropane and 1,3 dichloropropane are considered “possible” carcinogens by Canada and “probable” carcinogens by the United States. The United

387 Geordie Wilson, “B.C. pollution of aquifer travels to U.S.,” The Abbotsford Times, September 08, 1992; Margaret Munro, “Manure the hot topic down on the farm,” The Vancouver Sun, October 14, 1992; “Margaret Munro, “Drinking water at risk,” The Vancouver Sun, October 14, 1992, sec. B. p.11.
States has a safe level of 3.0 parts per billion (ppb) of both pesticides in drinking water, whilst the proposed guideline for Canada is 20-30 ppb, although a decision was still to be made. The United States claimed that their regulation was more stringent than that of Canada because of their greater concern for drinking water quality.\textsuperscript{389}

Pesticides found in the aquifer in the Environment Canada study included Carbofuran, Atrazine, Endosulfan, and Diazinon. 1,2 dichloropropane, not used in the Valley since 1987, was found at high levels. Whatcom County health officials expressed some concern that of the twelve pesticides found, whilst none were above Canadian drinking water standards, three did exceed United States drinking water standards. These findings were on the Canadian side of the aquifer.\textsuperscript{390}

The need for water for growing communities in the United States has resulted in a U.S. Geological Survey of wells in the Abbotsford-Sumas aquifer, 625 in total, with a sampling of 72 wells in Canada. This together with the Environment Canada report has resulted in a “flurry of activity both sides of the border.” In Canada, the provincial health department promised $1 million for a two-year monitoring program of 270 wells in the Fraser Valley; there are thoughts about legislation to protect the aquifer; the Upper Fraser Valley Health Unit is to establish a citizen’s environmental health committee; farmers are starting to clean up their manure piles by covering them or giving them away. United States health officials have noted that if the pollution does not stop flowing across the border, the United States could ask for compensation.\textsuperscript{391}

September, 1992, the Ministry of Health announced it was negotiating to establish a clinic at the University of British Columbia to investigate illnesses such as multiple chemical sensitivity, Fraser Valley Complex (also known as SCIDS) and chronic fatigue syndrome.\textsuperscript{392}

Individuals with SCIDS continued to increase. Five hundred people had been diagnosed with the syndrome by the end of 1992, double the numbers diagnosed the previous year. The

\textsuperscript{389} Trudy Beyak, “Cancer risks debated,” \textit{Abbotsford/Matsqui News}, September 02, 1992.
\textsuperscript{390} Geordie Wilson, “B.C. pollution of aquifer travels to U.S.,” \textit{The Abbotsford Times}, September 08, 1992; Margaret Munro, “Manure the hot topic down on the farm,” \textit{The Vancouver Sun}, October 14, 1992; “Margaret Munro, “Drinking water at risk,” \textit{The Vancouver Sun}, October 14, 1992, sec. B. p.11.
\textsuperscript{391} Margaret Munro, “Manure the hot topic down on the farm,” \textit{The Vancouver Sun}, October 14, 1992; “Margaret Munro, “Drinking water at risk,” \textit{The Vancouver Sun}, October 14, 1992, sec. B. p.11.
lack of concern and action that continued on the part of the Ministry of Health was angrily pointed to by the founder and spokesperson of the SCIDS group, who relinquished her position in the face of debilitating symptoms that now confined her to a wheelchair.\(^{393}\)

Traces of a by-product of 1,2 dichloropropane and 1,3 dichloropropane were found in the Abbotsford aquifer in early 1993. Identified as 1,2,2 trichloropropane, the contaminant was found in the aquifer test wells and some domestic wells, but not in the municipal wells. 1,2 dichloropropane and 1,3 dichloropropane were banned for use in 1985 when it was discovered that they persist in the environment for a very long time. The co-chair for the Central Fraser Valley Environmental Health Group called for improved control and monitoring of pesticides in the Valley. The director of the Agassiz located Agriculture Canada research station reiterated the persistence of the two chemicals used by raspberry farmers, and stated that there was no reason to believe that farmers may have continued to use the banned pesticide after 1985.\(^{394}\)

By mid-1993, the SCIDS group was changing. Now renamed the Multiple Chemical Sensitivity (MCS) Society, the new goal was to establish a clinic in the area for MCS patients.\(^{395}\) The focus of the group too had changed, to educating and helping their members cope with chemical sensitivity, pain and symptoms through to mental and acupressure techniques. Attendance at meetings was dwindling.\(^{396}\)

An Abbotsford naturopathic physician was reported mid-1993 as seeing increasing numbers of individuals with MCS-related symptoms. In practice locally for twenty years, he stated that he believed the increase in MCS patients could be related to environmental toxins.\(^{397}\)

**Private troubles to public issue**

The media were instrumental in transforming “private troubles” into “public issues.” In the conjuncture of biography, history, and social structure individual problems of initially

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Figure 2: Private trouble to public issue

**individualized problem**
symptoms of unknown diagnosis
specialist defines pattern in symptoms
specialist and patients meet with government officials
SCIDS group established
media picks up story
**public issue**

undiagnosed symptoms were transformed to the status of issues of public importance, locally, regionally and eventually nationally.

The story however is not only about health matters. Two stories became entwined to become one story. One is a story about health problems, specifically the syndrome SCIDS, in which the environment generally is implicated. The second is a story about the environment, specifically contaminated groundwater, in which health, particularly related to nitrates and pesticides, is implicated. The two narratives over time begin to be related to each other in the newspaper as cause and effect. Eventually they are wrought apart and separated again. It is not only private, individualized troubles that must be examined, but also troubles of the environment.

**Environmental situations/political issues**

Solesbury\(^{398}\) posits a model somewhat akin to C. Wright Mills sociological imagination to explain the way matters of the environment become part of a political agenda. He suggests that environmental problems are part of a web of historical, social, and political structures that together determine what and how environmental problems become social issues. He suggests that continuing change in the agenda of environmental issues occurs partly through changes in the state of the environment (an objective view) and partly through changing views of the environment (a subjective view). Whilst he is most concerned with how environmental matters become part of a government agenda, nonetheless his explanatory schema fits quite well with the

\(^{398}\) Solesbury, 380 & 381.
way personal troubles become public issues and social problems.

Solesbury suggests that environmental problems are best understood as situations. Situations refer to the constantly changing condition of the environment. Changing situations can result in conditions about which the community is concerned, considers unsatisfactory and ought to be remedied. The situation then becomes an issue (a public issue), which by definition calls for a response from government. Water quality is a situation and water pollution is an issue.\textsuperscript{399}

In the case of the SCIDS conflict, C Wright Mills and Solesbury’s schemas can fruitfully be brought together to understand how health and the environment played themselves out in the media. Biography, history, social structure and the environment coincided to become the SCIDS conflict (Figure 3).

Newspaper articles about groundwater and the SCIDS conflict were structured and proximally located in ways that reflected their (non)association. Whilst health problems were at first related to generalized environmental situations such as the disappearance of frogs, birds and snakes from the region, and a more general concern with environmental toxins per se,

**Figure 3: Private troubles and the environment constitute the SCIDS Conflict**

<table>
<thead>
<tr>
<th>Private Troubles</th>
<th>Environmental Situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>individualized symptoms</td>
<td>contaminated groundwater</td>
</tr>
</tbody>
</table>

Public Issue
SCIDS conflict

groundwater and SCIDS remained separate articles in the newspaper. Neither was discussed in

\textsuperscript{399} Ibid.
the same article until October and November of 1991. At this point, a time when government at
local, provincial and federal levels was coming under scrutiny with regards many of the issues
raised by the conflict (adequacy of water sampling and testing, storage of stockpiled manure for
example) contaminated groundwater began to be discussed in the newspapers as possibly causing
SCIDS. At first, the contamination of groundwater by pesticides, especially those used as soil
fumigants in berry farming, and what is often referred to as the mysterious illness (SCIDS), are
discussed in neighbouring paragraphs.400 Or an article about SCIDS may completely surround a
smaller article about groundwater testing, making the link physically and aesthetically, if not
cognitively within the same article.401 Whilst it appeared care had been taken up until this time
to avoid directly linking groundwater contamination as in any way causal in terms of SCIDS, in
one article, amidst claims by various experts that the pesticides cannot be blamed for people’s
health problems, “a spokesman for the $35-million-a-year raspberry industry immediately
offered to stop using the pesticide if requested by environmental and health agencies.”402 It was
at this point, for but a brief moment, that the specific health symptoms and specific
environmental contamination were causally linked, and responsibility accepted by the raspberry
industry, to be later withdrawn.

Competing social problems

Solesbury’s model of environmental situations follows a natural history staging in the
career of social problems. The trouble with this approach however is that social problems
seldom follow a linear path from one stage to another. Many problems exist simultaneously in
several stages, and patterns of progression remain questionable, as does the idea of a career of
social problems. On the contrary, social problems play out their life history in competition with
other social problems in spaces Hilgartner and Bosk term “arenas.” The media is one such arena.
The focus on an arena allows for analysis between problems, rather than focusing on a single

400 Rebecca Wigod, “Government checks claims of mystery ailment in valley,” The Vancouver
401 Trudy Beyak, “On speaking out about possible enviro-disease cause,” Abbotsford News,
402 Glenn Bohn, “Health risk of pesticides in Abbotsford reservoirs unclear,” The Vancouver
Sun, November 14, 1991.
social or environmental problem. In addition, of the myriad social problems that exist, only some come to public attention. Within and between arenas, social problems compete for the scarce resource of public attention.\textsuperscript{403}

Hilgartner and Bosk point out that there is a large stratified population of social problems, of which a small percentage grows to dominate political and social discourse. The vast majority of social problems remain on the margins or outside public consciousness. It is not their correspondence with the real, objective world that brings social problems to the forefront of discursive circles, but a number of other factors they suggest. Arenas, which are wide and varied,\textsuperscript{404} have carrying capacities limiting the number of social problems present at any one time. Limited public space for addressing social problems increases competition and is crucial in the definition of problems. At an individual level, those promoting a particular problem have limited resources of time and money to devote to such issues. The constraints of carrying capacity at both institutional and individual levels mean that as one problem ascends, another must decline.\textsuperscript{405} Tracking the density of articles about SCIDS and groundwater in the newspapers illustrates this.

\textit{The rise and fall of SCIDS}

In 1990, two articles only were written about the quality of water from the Abbotsford aquifer, and none were written about the health problems noted by this time by the Abbotsford orthopaedic specialist. In 1991, seventeen articles in total were presented about either SCIDS or the groundwater contamination. Of the seventeen, eleven were about SCIDS itself, or the group, and six were about contaminated aquifers. By 1992, the topic had become a top news story, and a total of thirty-eight articles were to be found on both SCIDS and the pollution of the Abbotsford aquifer. The balance had changed however. Rather than SCIDS being the focus, it was now on the groundwater. Twenty-five of the articles were on groundwater contamination, whilst thirteen articles were on SCIDS. 1992 saw the implementation of investigations of

\textsuperscript{403} Hilgartner & Bosk, 54 & 55.
\textsuperscript{404} For example, various branches of government, books dealing with social issues, political campaign organizations, the news media, televised movies, the courts, social action groups, the research community, religious organizations and so on (Hilgartner and Bosk, 58 & 59).
\textsuperscript{405} Hilgartner and Bosk, 58-61.
groundwater in Abbotsford, the development of new guidelines for farmers with regards the use of animal waste, and comments and concerns by the Americans across the border, the recipients of polluted groundwater from an aquifer that straddles the border and that flows south. 1992 also saw the demise of SCIDS as an entity, as an epidemiological investigation declared it not to exist, and with the discrediting of professionals associated with the SCIDS group. Only four articles were written in total from January until July 1993. These predominantly followed the further demise of the SCIDS group, as it reformulated itself, and then expired completely. By this time Project Enviro-Health had also come into existence, its mandate to methodically research environmental and health concerns of Fraser Valley communities and to provide accurate information back to residents.

*Competing definitions*

Whilst as Hilgartner and Bosk state, social problems may be presented and defined by a wide variety of “operatives”\(^{406}\) often in competition with each other, the production process of making news may intervene and short-circuit the competitive process of problem definition. The production of news is a collaboration between the journalist and the news source, constrained by the organization of the newsroom itself which imposes order and predictability on seemingly chaotic and unrelated events and issues. Constraints of time (production period) and lack of specialized knowledge may mean that collaboration goes no further than a news source, often someone in an official role, providing a pre-packaged interpretation of an event or a concern that is readily adopted by the journalist.\(^{407}\) Since claims about social problems call attention to more than a condition, that is they also frame problems in particular ways,\(^{408}\) the news source is generally of prime importance.

To become and remain as part of the public and political agenda, social problems must have elements of persuasion, drama, as well as simplicity. If a number of similar social problems exist, decline of the problem will be caused by over-saturation of the arena. Historical and social

\(^{406}\) Hilgartner and Bosk use the concept “operative” rather than “activists” as not all presenters of social problems can be defined this way. Operative “designate[s] the groups and individuals who publicly present social problems” (p57) and includes activists.

\(^{407}\) Hannigan, 59 & 60.

\(^{408}\) Hilgartner and Bosk, 57.
structural factors also influence a social problem's emergence into or decline from public and political attention. In addition, the problem should be framed in a novel way. 409

Media frames and news angles are the organizing devices that make sense and provide meaning to an issue or concern for both the journalist and the public. Over a period of time, frames become story lines. Frames are the means by which an issue becomes contested, as the different players compete to have their frame portrayed by the media. At the same time, the public are not passive receivers of media frames, but actively decode them according to various preferred frames of meaning and interpretation. 410

**Framing**

"Frames refer to stable ways of experiencing and perceiving events in the world which structure social reality." 411 Frames are used to order and sort the world, allowing us to negotiate our way within that world more easily. They provide a means of compartmentalizing the world; they are like empty drawers that can be filled with a variety of meanings. 412 They allow us to manage the continuous stream of events that confront us by providing a schema for selecting and sorting. Frames provide an objective meaning to these selective events. Subjective differences and individual idiosyncrasies are disregarded. 413

Framing devices, the means for constructing frames, are organized by symbolic forms into communicable frames. Frames cannot be understood outside the specific symbolic package that gives them consistency, coherence and validity. Collective actors not only communicate frames but generate alternative frames and compete for control of frames in a given discursive field. Frames function as 'capital', and in similar fashion, accumulation of frame capital is necessary to control the use of frames in public discourse. Master frames result from competition over control of frames and are the emerging discourse which reflects the collective validity of frames of reality. 414

409 Hilgartner and Bosk, 61-66.
410 Hannigan, 59 & 60
411 Eder, 166
412 Eder, 201
413 Eder, 166.
414 Eder, 167-171
Competition over control of frames occurs in a number of different ways. Frame bridging links ideologically congruent but structurally unconnected frames. With frame transformation, old ideas and meanings are supplanted by the seeding and nurturing of new ideas and values. This may involve the correction of erroneous beliefs and the re-framing of misframings. Frames may also be amplified to clarify and invigorate a particular frame, or extended to incorporate the values of and appeal to a group of potential adherents. In most of these framing processes, the frame producers dare not wander too far from existing values and predispositions of the group towards which frames are to be targeted, or frames will not be accepted. Successful frames thus consist of a synthesis of new meanings and old, since resonance with existing popular understandings is crucial. Opponents have a more difficult time delegitimating frames that resonate with existing understandings. Frames that propose a totally new framework of interpretation are much more easily overthrown.

Collective action frames perform a focusing and punctuating function as well as being modes of attribution and articulation. Social movements may single out an existing social condition or aspect of life as unjust, intolerable or immoral. This however is insufficient in itself to direct collective action. Causality or blame must be attributed as well as responsibility for correcting the problem. Collective action frames must also therefore make diagnostic and prognostic attributions. Diagnostically, frames incorporate identification of culpable agents responsible for causing some condition. Prognostically, frames suggest remedial action for problem resolution. In addition, collective action frames align events and experiences in a unified fashion that provides meaning for the interpretation of subsequent events and experiences. As signalling and decoding devices, frames package inconceivable and incongruous events and experiences to be meaningfully interconnected.

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415 Snow et al, 467-473; Tarrow, 188.
416 Tarrow, 189 & 190.
417 Snow, and Benford, 136-138.
Headlining the event

Tessier\textsuperscript{418} hypothesizes that news headlines are not neutral and in fact provide a particular frame of the facts described in the accompanying article. He suggests that the view taken in the headline corresponds with the values of the particular newspaper, so for instance with regards the SCIDS event, if the newspaper valued community and the rights of individuals in that community, it might support the SCIDS group’s view, but if it valued authority and expertise, it would support the views of the scientists and physicians in the conflict.

Sixty-two headlines were analyzed from seven newspapers. A local newspaper was the most supportive of the SCIDS group. \textit{The Abbotsford News} which published the most articles covering the conflict very quickly took the side of the SCIDS sufferers with headlines such as “Toxin disease victims form group”\textsuperscript{419} and “Victim told to cool it.”\textsuperscript{420} The portrayal was that of someone experiencing illness from circumstances beyond their control. Those with regulated or contractual responsibility and decision making authority with regards groundwater and/or health were reproached in headlines such as “Public health tests slow?”\textsuperscript{421} and “Epidemiologists didn’t examine patients,” whilst others perceived as possible perpetrators of the problem were met with metaphors of violence (“Berry farmers under fire”). The main view presented in the headlines however was about the safety of the groundwater and the health and quality of life of residents. Headlines such as “Victims of chemicals,” “Neurotoxins causing sickness?” and “Cancer risks debated” drew attention to the alleged link between contaminated groundwater, pesticides and disease. It also suggested, again, that disease might be caused by something “out there” in the environment, over which the individual had no control.

Other headlines focused on the deteriorating groundwater quality, stating that “Pesticides are in groundwater” and “Banned US toxin found in aquifer,” that this was not an unknown problem (“Pesticides noted since ‘84; What’s in our aquifer”; “Nitrates building for years”) but that it now needed action (“Nitrates need addressing”). Changes were made by those responsible

\textsuperscript{418} Tessier, 391-404.
\textsuperscript{421} Trudy Beyak, “Public health tests slow?” \textit{Abbotsford News}, October 23, 1991
for water testing ("Water tests toughen") and positive feedback provided ("Doctor praises water testing"). Increasing numbers however were being diagnosed with SCIDS or joining the group ("SCIDS stats getting scary"), and the view was that it was not solved, even though by this time the epidemiology report had declared SCIDS did not exist. One of the last articles printed on the conflict by the Abbotsford News was when the SCIDS group became the Multiple Chemical Sensitivity group ("SCIDS no longer"), signaling not the end of SCIDS but its subsummation under another category. To be sure there was no doubt of the fact that the problem still existed, the final headline and accompanying article "Chemical Exposure" turned the conflict full circle with detail about the enviro-disease, the portrait of a family suffering its ravages, and the words of a naturopathic physician who, in practice locally for twenty years, was seeing in patients what he took to be the effects of toxins in the environment.

The metropolitan newspaper, The Vancouver Sun, took the view of experts and authorities responsible for the various investigations throughout the conflict, or for stewardship of the health of the community, such a government agencies. Headlines in The Vancouver Sun, unlike those in the Abbotsford News often used the words "scientist" or "expert" or "physician." The point of view provided was very much that of authority: "Federal government pledges to probe mystery muscle illness plaguing valley"; "Government checks claims of mystery ailment in valley"; "Cull [provincial minister of health] cautious over valley health risk"; "Physicians withdraw from toxic controversy." Where it was the voice of a professional supportive of or contracted by the SCIDS group, the headline used language that conveyed lack of certainty about what was being stated, for example, "Abbotsford water contaminated, scientist claims" and "Consultant claims banned pesticide used." Very quickly, the point of view supported was enlisted to dispose of "claims": "Valley pesticide poisoning bogus, says expert" was the headline in response to "Consultant claims banned pesticide used." That the health concerns of residents and the link with environmental toxins was all pretty much a sham was conveyed in headlines such as "Valley mystery sickness debunked" and "Doctors withdraw from pesticide fracas." There was denial that there was anything wrong with the water in the Valley, conveyed with headlines such as "Water okay, Abbotsford says" and "Valley wells given clean bill of health." Eventually however, The Vancouver Sun did admit that Abbotsford ground water was not as safe as it had wanted to believe with headlines such as "Drinking water at risk" and "Traces of
another chemical contaminant discovered in Abbotsford aquifer."

It has been suggested that the importance to the public of an environmental problem is linked to the amount of coverage given the problem in the media. The public determine how much of a priority the problem should be for the government by the length and frequency of news coverage. The media in this view does not tell people what to think, but what to think about. Headlines work in this way, by bringing attention to certain issues. At a wider level however, media content can influence the social regulation of the problem in question. Project Enviro-Health, established in part to correct erroneous information provided by a newspaper with a mind of its own, became the social regulator of the after effects of the SCIDS environmental conflict. The local newspaper had taken a pro-SCIDS approach, rather than that of government or the experts, and was itself then eventually subject to regulation by having articles and columns written by the Project Co-ordinator, to ensure that “correct” information was passed on to the public. However, analysis of the content of the news articles indicates that it was not that incorrect information was printed, since the experts were able to provide scientific and technical information about the disease, the groundwater, and the contamination; it was that the “wrong” point of view had been published. As Tessier points out, media content is a political and economic tool for the players in a conflict.

Variation obviously exists between public interest and media content however. Some issues that receive a lot of media attention do not catch the public’s interest. People are sensitive to issues that concern them personally, at an individual level. The media in turn identify issues that society as a whole believes important. It has been suggested that parallel to people’s personal interests are the interests and values of society that are shared collectively. Awareness of these collective interests and values it is suggested, may be “pre-set” by the media by bringing issues to the attention of targeted populations before they become an actual agenda in the larger society. People come to appreciate, influenced by the media, the problems requiring solution on the basis of the common good. That is, the common good is put ahead of their own individual good. Headlines are one of the means of “pre-setting” the agenda of interests/values/issues for society. They may dramatize a situation in a certain way by suggesting danger, or loss. They

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422 Tessier, 394 & 395.
423 Tessier, 395.
may imply certain values in the formulation of the headline.\textsuperscript{424} The headline "Quality of life threatened" suggests the value for society, or the community, of a particular lifestyle, of a particular quality to our lives that we as humans in this lifetime have come to expect, and its loss if precautions are not taken in the use of animal waste and pesticides and their leaching into the Abbotsford aquifer. Also implied in the headlines overall is that good quality drinking water is a societal value, as is good health.

Tessier\textsuperscript{425} has suggested that the formulation of headlines is part of a concrete mechanism by the press to express content that is not merely of individual or local interest, but is of societal interest. Whilst the headlines in all the newspapers analyzed do denote wider societal values, in the end, the content of the articles accompanying the headlines indicated that the issue applied only to a certain sub-sample of the society: as far as the water issue was concerned, it was private wells into a very specific part of the Abbotsford aquifer, a strip between the airport and the US-Canadian border, that had contaminated drinking water; as far as the health concerns were concerned, it was mainly women at risk from the environment, if in fact the allegations were found or believed to be "true." The headlines did not convince the wider community of any danger to themselves, and "pre-setting" of the agenda was not accomplished. People could continue to prioritize on the basis of issues that were important to them personally. Vaughan and Seifert point out that the way the issue is framed may lead to non-identification with the group at risk, influencing people’s beliefs about personal susceptibility.\textsuperscript{426} Groundwater, nitrates and pesticides, agricultural practices and ill health were important to only a very small sample of the population in the Fraser Valley.

Environmental problems are often framed within an event orientation. Whilst this has the advantage of raising public awareness of otherwise ignored environmental problems and concerns, at the same time it has been suggested that this allows the frame to be controlled by the news source, journalists to ignore the big picture, and gives the public the impression that corporations or individuals rather than institutional politics and social developments are

\textsuperscript{424} Tessier, 396.
\textsuperscript{425} Tessier, 397.
\textsuperscript{426} Vaughan and Seifert, 127.
responsible for the events. The *Abbotsford News* was supportive of the SCIDS group, and noticeable in the paper’s reporting was that it was this, rather than the news source, that controlled the frame, contrary to Hannigan’s suggestion. At times, the news source was an expert or bureaucratic authority, and although the article quoted the source and cited information from them, the headline often countered the expert/authority point of view by providing a frame that refocused the message of the article. For example, an article printed at the time the epidemiologists declared the SCIDS syndrome did not exist contained one small paragraph stating that the muscle weakness was found in the majority of the population. The same article also stated that the epidemiologists did not examine anyone, and that one independent medical examiner’s findings had been downplayed. The news source for the article appears to have been the epidemiologists. The headline for the article was “Epidemiologists didn’t examine patients.”

Noticeably, headlines for experts and government authorities drew attention to what was not done. In another *Abbotsford/Matsqui News* article the chief environmental health officer for the Upper Fraser Valley Health Unit provided information about a new water testing regime of four times a year, at appropriate times, using an updated list of pesticides. The headline is “Water tests toughen” with a sub-title of “Some common chemicals weren’t on past list.”

On the other hand, the other local newspapers (*Abbotsford Times*, *The Chilliwack Progress*), the metropolitan (*The Vancouver Sun*, *The Province*) and the news magazine (*The Western Producer*, *British Columbia Reports*) headlines reflected the article contents. In *The Vancouver Sun* for example, the headline for an article in which the news source was the epidemiologist in charge of the investigation into the SCIDS syndrome and included as well the SCIDS founder and member of the epidemiology study community advisory council stated “Valley mystery sickness debunked.” The article set out the results of the study and comments from the SCIDS founder in response to those findings. The *Abbotsford Times* announced the

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427 Hannigan, 64 & 65.
428 Ibid.
results of water testing with the headline “Water passes the tests,” and The Western Producer stated “B.C. water checked for contamination” as headline to an article discussing the contaminated water, health concerns of the community, and the disappearance of birds, snakes, and frogs from the environment in Abbotsford. These headlines are non-dramatic, as opposed to those of the Abbotsford/Matsqui News, and provide a more neutral frame to the article. News sources are generally varied, often providing different sides of the story within this neutral frame.

Did journalists ignore the big picture as Hannigan suggests?\footnote{Hannigan, 64 & 65.} It depends upon how the big picture is understood. If it means, was this local environmental health concern framed as a wider national or global concern, then the answer is no. If by “big picture” is meant putting the discrete components of the environmental and health concerns together, then the answer is yes. Minimally, this happened nearly always when SCIDS was discussed, since the link with environmental toxins was readily made by either those who considered it a causal link, or by those who sought to refute it. Groundwater contamination on the other hand was seldom linked to health, except by The Vancouver Sun, who discussed either the health effects of the actual contaminants, or discussed the SCIDS syndrome in the same article as the groundwater contaminants.

Dramatics: Metaphorically speaking

Metaphors are a useful device for both framing and drama. Dramatic presentations of social problems often leave a lasting impression, increasing the social problem’s attention in the public and political eye. An element of novelty is introduced, and individualization of the metaphor to the particular social problem means the problem of saturation is kept at bay momentarily.\footnote{Cameron and Low, 29-47.} Table 2 provides a description of various metaphors from the newspaper articles.

Metaphors allow the individual “understanding and experiencing [of] one kind of thing in terms of another.”\footnote{Lakoff and Johnson,:5. Bateson (p 56) states “A metaphor compares things without spelling out the comparison. It takes what is true of one group of things and applies it to another. When we say a nation “decays”, we are using a metaphor, suggesting that some changes in a nation are like changes} Some newspaper articles, including their headlines, referred to SCIDS
and/or the alleged relationship between pesticides or groundwater and the health of some residents as a "mystery" and those investigating it as detectives. The epidemiologist became a Sherlock Holmes-type, seeking to unravel the riddle. Interestingly, there has been a long connection between medicine and crime, physicians and detectives. The scientific medical case history and the detective story both emerged in the 1830s. The detective story is the genre that most resembles the medical case history. Like the physician, the detective seeks to identify, unravel and eliminate the apparently random evil in the world. "The semiotics of detection are precisely those of medicine."434 Like the physician, Sherlock Homes listens to the stories of those who need his help, observes and examines the physical evidence carefully, asks pertinent questions, and sets about solving the mystery. Both narrators, Holmes and the physician, tell "who done it" and how they solved the puzzle.435

Medical procedures, processes and images were also used in the newspapers to vivid effect. The enviro-disease was, for example, to be probed in much the same way that a wound is explored with an instrument, exposing layers to visual inspection and getting closer to the "truth." Medical metaphors were also applied to the conflict. After it had been shown that the syndrome itself did not exist (although the disease remained a mystery, even at this time) and a complaint had been laid against the local specialist for allegedly over-stepping the boundaries of his profession, the conflict is described as a deadly or fatal dispute ("toxic controversy") from which some people sought to remove themselves ("physicians withdraw"). Like a malignant growth that sought to subsume everything in its path, the environmental conflict was something to be excised. The epidemiologists (the "physicians") were like cells in its path, and they took themselves out of the way.

Fights, war and violence arouse people to a state of fear. However, some of the metaphors of violence imply "right" on the side of "might." Berry farmers, thought to be responsible for the groundwater contamination, come "under fire" in one newspaper article headline, and the farming industry is "slammed" for its indiscriminate and thoughtless use of animal manure and pesticides. The epidemiologists are described as "withdrawing" (retreating which bacteria produce in fruit. But we don’t stop to mention the fruit or the bacteria."

434 Hunter, 169.
435 Hunter, 168-170.
perhaps?) from a neighbourhood fight, the implication being that they are beaten, or at least know that they cannot win. The founder and spokesperson of the SCIDS group is described as a "victim" and as such told to "cool it," implying an unnecessary and threatening silencing.

Perhaps the metaphors of violence are a response to the frame of fear and suspense that is used to describe the groundwater. Contaminated groundwater is referred to as a supernatural "blob" that disappears. The location of this invisible, shapeless body is described as a "nightmare." These metaphors evoke the emotions associated with horror and suspense. There is a sense of invasion and threat from something identified as alien, and experienced as the very worst bad dream.

The groundwater is given agency, personified. The water is a clever agent, able to pass tests, or to give up or produce (yield) pesticides. Stigmatized as tainted further adds to the personification.

Conflicting Frames

Competition among social problems for public and political attention occurs not merely within one arena, but across arenas, with key operatives seeking to control the definition, and hence ownership, of the problem. Feedback between and among arenas often is played out in the media. Social problems will be framed in different ways according to the news source and the particular arena. Attempts will be made to influence the point of view of another arena with regards the problem.⁴³⁶

Dietz et al suggest three ideal types of definitions of environmental problems, each of which legitimizes major types of resources, as well as influencing the kinds of arguments considered appropriate.⁴³⁷ These are set out below in Table 3.

The SCIDS conflict was played out in terms of two frames—the scientific/technical and the economic frames. The economic frame was a mere whisper compared to the growing roar of the science frame. The economic frame reverberated, but relatively quietly, in the response of the agriculture industry, especially the raspberry growers, to what they took to be accusations against them. Although momentarily taking responsibility for pesticide contamination of the

⁴³⁶ Hilgartner and Bosk, 66 & 67.
⁴³⁷ Dietz et al, 61-63.
Table 2: Metaphorical description in newspapers

<table>
<thead>
<tr>
<th>Topic</th>
<th>Metaphor</th>
<th>Newspaper headline or quote from article</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enviro-disease</td>
<td>Detective/mystery</td>
<td>Valley mystery sickness debunked <em>(The Vancouver Sun February 20 1992)</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>But Dr Rick Mathias, a University of B.C. epidemiologist, is a white-cloaked sleuth who uncovers medical mystery clues <em>(Abbotsford/Matsqui &amp; Mission News November 23 1991: A3)</em>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>He has been named as the researcher who will look into a baffling medical condition striking about 120 people.... <em>(Abbotsford/Matsqui &amp; Mission News November 23 1991: A3)</em>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Syndrome is still a mystery <em>(Abbotsford/Matsqui &amp; Mission News February 22 1992: A2)</em>.</td>
</tr>
<tr>
<td>Surgical</td>
<td>Procedures</td>
<td>Disease probe begins <em>(Abbotsford/Matsqui &amp; Mission News November 23 1991:A3)</em>.</td>
</tr>
<tr>
<td>Deadly</td>
<td></td>
<td>Physicians withdraw from toxic controversy <em>(Abbotsford/Matsqui &amp; Mission News February 15 1992: A6)</em>.</td>
</tr>
<tr>
<td>Suspense</td>
<td></td>
<td>SCIDS stats getting scary <em>(Abbotsford/Matsqui &amp; Mission News December 09 1992: A1)</em></td>
</tr>
<tr>
<td>Groundwater</td>
<td></td>
<td>Recovering the BLOB <em>(The Vancouver Sun August 15 1986)</em>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Valley a “nightmare”? <em>(Abbotsford/Matsqui &amp; Mission News February 15 1992: A2)</em></td>
</tr>
<tr>
<td>War/Violence</td>
<td></td>
<td>Berry farmers under fire <em>(Abbotsford/Matsqui &amp; Mission News March 14 1992)</em>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Doctors withdraw from pesticide fracas <em>(The Vancouver Sun March 09 1992:CB3)</em>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Victim told to “cool it” <em>(Abbotsford/Matsqui &amp; Mission News October 23 1991)</em>.</td>
</tr>
<tr>
<td>Harvest/Production</td>
<td></td>
<td>Aldergrove wells yield pesticides <em>(Abbotsford/Matsqui &amp; Mission News March 11 1992)</em>.</td>
</tr>
<tr>
<td>Personification</td>
<td></td>
<td>Water passes the tests <em>(Abbotsford Times November 27 1991:3)</em>.</td>
</tr>
</tbody>
</table>
Table 3: Types of conflict, the resources and arguments legitimized by each.

<table>
<thead>
<tr>
<th>Ideal type of conflict</th>
<th>Type of resource</th>
<th>Appropriate argument</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scientific or technical</td>
<td>Expert authority</td>
<td>Objective truth</td>
</tr>
<tr>
<td>Political</td>
<td>Public opinion</td>
<td>Justice, morality, equity</td>
</tr>
<tr>
<td>Economic</td>
<td>Material resources &amp; money</td>
<td>Economic efficiency or profit</td>
</tr>
</tbody>
</table>

aquifer and the possible link to SCIDS, this was quickly withdrawn and the industry aligned itself with those who were to scientifically refute the existence of SCIDS. Even though the farming industry could be pin-pointed as the source of groundwater nitrate and pesticide contamination by both federal and provincial agencies/experts, the Ministry of Health was able to declare that a link between the contamination and health could not be determined, and the Ministry of Agriculture was loathe to ruffle the sensitivities of an industry upon which the community's wealth and prosperity depended. Further, the economic frame did not require serious deployment as the practices of the agriculture industry could be determined scientifically. The scientific/technical frame took a dominant position in the conflict.

The scientific/technical frame was used by the experts in their role as news sources for the media. The results of scientific testing of groundwater, especially when contamination was found, were reported back to the community. Concern with the validity of research was behind the communication by a medical officer of health to the spokesperson of the SCIDS group with respect to the latter possibly contaminating research by speaking out about the postulated environmental toxin link. The SCIDS group itself also considered the use of science appropriate and contracted a toxicologist to do tests in the Fraser Valley. The local orthopaedic specialist pursued tests on patients in an attempt to determine the scope of the disease and develop a diagnostic test.

The authority that accompanies the scientific frame presents the expert as understanding the risk well, with the added implication that they are in a better position than most people to
judge or decide how safe is safe enough. Interestingly however, factions existed among the experts. Although science remained the frame in which experts disagreed with one another, often another frame came into play as well—that of vested interests. Whilst science produced objective results, experts interpreted them differently. At this point their alignment with their workplace and employer entered into the construction.\footnote{498}

A contracted hydrogeologist and an Environment Canada hydrogeologist were instrumental in demonstrating scientifically and technically the presence of nitrates and pesticides in the Abbotsford aquifer. Public health experts however maintained that whilst that may be so, there is no evidence of harm to human health from the groundwater contamination. Neither the literature about such contamination, or local health data would lead them to conclude that Fraser Valley residents were at risk. Levels of contamination were below the Canadian Safe Drinking Water Standards. Public health officials did however agree that the contamination of the aquifer showed a need for provincial law to ensure that drinking water was protected. The Royal Commission on Health Care and Costs Report stated that not only was there no protective legislation, neither was there a single ministry with overall responsibility for addressing the issue.

Refuting each others points of view often occurred within the same discipline, especially that of medicine and health, and corresponded to the allegiances of the expert. The local orthopaedic surgeon’s story was repeatedly told in the newspapers: the mysterious symptoms, the pattern of muscle weakness that emerged over time among his patients, the apparent link to environmental chemicals, and his search for assistance to research the syndrome that had been named SCIDS. The link between health and the environment was refuted however by medical officers of health and health toxicologists who maintained that scientific studies needed to be undertaken before such a causal link could be made. Even within the scope of the epidemiology study conflict was noted in the newspaper. The principal investigator disagreed with the results of one of the independent examiners and did not accept his recommendation that the five worst cases be seen by another examiner. In most of these cases, interpretation of science was the basis of the disagreement.

\footnote{498} Ibid.
Experts showed a vested interest in keeping responsibility about the conflict away from their profession, workplace or employer. Both consultant and Environment Canada hydrogeologists were “whistle blowers” with regards groundwater contamination. Both spoke without hesitation to the newspapers and to various groups throughout the Fraser Valley, drawing attention also to the problem of stockpiling manure. Others were more moderate in their comments however. And the science frames were used to best advantage to explain the situation. For example, at the end of 1991 after a year of publicity about SCIDS and groundwater contamination, the Abbotsford district’s director of public works could declare the aquifer water to be safe. None of the pesticides previously shown to be culprits of contamination were found in any of the samples taken, which were to the east of the polluted wells sampled by Environment Canada. Obscured towards the end of the article was a comment about whether wells to the east of previously contaminated wells would show pollution. It apparently depended upon the direction of water flow (most of the aquifer flows south). The district had shown responsibility by advancing its tests by a month and undertaking additional tests.\footnote{Vic Blas, “Water passes the tests,” \textit{Abbotsford Times}, November 27, 1991, 3.} The district was also careful to stress that it was not the municipal drinking water system that was contaminated.\footnote{“Water okay, Abbotsford says.” \textit{The Vancouver Sun}, May 05, 1990, sec. A. p.5.} A year later however, high nitrate levels were found in municipal wells which were part of the municipal drinking water system. Total cleansing of the wells to eliminate the nitrates was too costly, however, contaminated well water is diluted with water from another less polluted well to keep nitrate levels down before the water reached local taps.\footnote{“Nitrates need addressing,” \textit{Abbotsford News}, January 29, 1992, sec. A.3p.}

The health units in the Fraser Valley were also careful to explain that elevated nitrate levels occurred only in a narrow strip of aquifer near the Abbotsford airport, and that there were no health problems in the Valley attributable to higher nitrate levels.\footnote{“Water okay, Abbotsford says,” \textit{The Vancouver Sun}, May 05, 1990, sec. A. p.5.} Pesticide levels were explained similarly.

The provincial Ministry of Agriculture stated that they were aware of the groundwater problems and were taking steps to implement a voluntary code of good practice. The economic importance of the poultry, dairy and swine industries to the region meant that stringent
regulations governing manure application and storage should not be implemented as these might jeopardize such industry.\textsuperscript{503} Later, the agrologist from the Ministry of Agriculture, in his role as chairman of the ethics and practices committee of the B. C. Institute of Agrologists, laid a complaint with the B.C. College of Physicians and Surgeons against the orthopaedic specialist, stating that the specialist’s link of health symptoms with the environment was detrimental to the farming industry. “Farmers are following generally accepted practices using legal materials...” the agrologist pointed out, making it clear that neither agri-business nor the agricultural professional associations nor the Ministry of Agriculture accepted any culpability that might result in fiscal responsibility for the state of the environment or the health of citizens in the Fraser Valley.

The local orthopaedic specialist’s frame was that of medical science, particularly the socio-demographic characteristics and the neuromuscular symptoms of his patients with SCIDS. He made the plea for research, emphasizing his frustration at this request being ignored and his inability to access any research funds. The life stories of some of his patients at times accompanied early articles in which he was the news source.\textsuperscript{504}

The SCIDS group, through the voice of its spokesperson, also used the science or technical frame to put its own point of view. Numbers of SCIDS sufferers as well as symptoms were provided in newspaper articles.\textsuperscript{505} The SCIDS founder was accused of having a vested interest in the outcome of future research when she was told to stop contacting people and telling them about the syndrome and its causes.\textsuperscript{506}

That the scientific frame was accepted by the SCIDS group was shown with their contract of a Florida toxicologist to undertake some research on their behalf. The presentation of his scientific findings and ultimately the findings themselves were not accepted by other experts/scientists.\textsuperscript{507} The questioning as to why a United States expert and not a home-grown

\textsuperscript{506} Trudy Beyak, “Victim told to cool it: On speaking out about possible enviro-disease cause,” \textit{Abbotsford News}, October 23, 1991.
Canadian had been hired, together with his discrediting as a scientist of irreputable ilk had the effect of increasing the view that the SCIDS group had a vested interest in the outcome of the research. Other experts were able to make good use of this to show that in contrast they themselves practiced reputable, neutral, objective science, holding that with the same knowledge, the lay public would be able to recognize this, thus making invisible experts own vested interests.

Mistrust of experts was at times a common frame in the newspapers. Reports of groundwater testing continued to show deterioration of the Abbotsford aquifer. Exasperation was expressed by the co-chairman of the Central Fraser Valley Health Group that whilst the same results were continually being presented, nobody was taking any action to rectify the situation.  

A consulting hydrogeologist continued to sound the alarm about the groundwater, indicating that each year the Association of Professional Engineers and Geoscientists of B.C. send letters to the Minister of Environment, and each year they are ignored. He also warned people who use Abbotsford aquifer well water “to beware of health officials who say the domestic wells are safe.” The same wells had not been sampled and analyzed.

Sampling and analysis for contaminants was also a problem. Chemicals used in farming were constantly changing, and researchers were not always asked to test for the latest pesticides for example. An Environment Canada hydrogeologist stated that he was concerned about the latest product used on nematodes, but he has not been asked to sample and analyze for it.

Providing the press with a version of a report on groundwater quality in the Fraser Valley that differed from official versions also served to increase the mistrust in experts and government expressed in the news. Although the Upper Fraser Valley Health Unit medical officer of health assured the press that it was a cost-cutting measure and not an attempt to hide anything, other experts stated that providing averages instead of pesticide and nitrate hits was deceptive.

The science, vested interest and mistrust in experts frames interact with each other to


amplify or dampen the problem. The science and vested interest frames for example was used to dampen the SCIDS problem by the health officials, whilst the science and mistrust in experts frames was used by the SCIDS group and some independent and hydrogeologist experts to amplify the SCIDS conflict. These frames were used to influence events in other arenas besides that of the media. The media became the arena through which operatives could communicate with and influence other arenas.

Experts’ definitions of the SCIDS conflict were not homogeneous. Conflict occurred between experts as much as between experts and the lay public. In the next chapter, the experts speak in their own voice (taped and transcribed interviews) and through their own work (research reports). The scientific/technical frame is elaborated further. The relationship of both technical and social, objective and subjective aspects in the contest to define and own the social problem will be examined.
CHAPTER SIX: CONTESTED OWNERSHIP OF SCIDS: THE EXPERT STORY

The expert knows his stuff. Society needs him, and must have him more and more as man’s technical knowledge becomes more and more extensive. But history shows us that the common man is a better judge of his own needs in the long run than any cult of experts.

Luther Gulick 1937.

Who are the experts? We take the term “expert” for granted at both a common sense as well as at an academic level it would seem. Often used in the academic literature, it is seldom defined. The expert is “a person with special skills or training in any art or science.”\(^{513}\) Experts are “individuals who by virtue of their being trained within an academic discipline, have ‘technical expertise’”\(^{514}\) and whose specialized knowledge distinguishes them from the layperson.\(^{515}\) Expert knowledge is used in judgements that go beyond statements of fact, data, or the conventions of a discipline.\(^{516}\) The users of this knowledge, those responsible for compiling official information and safety regulations, the managers and policy makers who draw upon the skills and information of those with technical expertise have also been defined as experts.\(^{517}\) However, whilst officials may be defined as experts in the wider sense, expertise is a more pervasive phenomenon. Experts, it is suggested, are the mediator between abstract knowledge and the lay public.\(^{518}\)

More specifically, in relation to environmental health, the experts are those who allocate health risk and who form a community of calculation.\(^{519}\) This community is further divided into that of consequence calculation, the public and private officials who allocate resources related to environmental health risks, including pollutants and toxicants; and that of probability calculation,

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\(^{513}\) The Webster’s English Dictionary  
\(^{514}\) Clarke, 289.  
\(^{515}\) Giddens, “Post-traditional Society,” 84  
\(^{516}\) Otway and von Winterfeldt, 84 & 85.  
\(^{517}\) Grinyer, 31-35.  
\(^{518}\) Kroll-Smith and Floyd, 58; Giddens, “Post-traditional Society,” 84  
\(^{519}\) Couto, 55 & 56.
experts such as epidemiologists who conduct analyses of the hazards associated with technology.

A hazard is “a set of circumstances which may cause harmful consequences” and risk is “the likelihood of it doing so.” Hazards are considered real and material, with the potential to cause harm. The manifestation of the hazard in an unpleasant outcome is termed “risk.” This perspective of risk is embedded in the formal process of the scientific analysis of risks.  

Formal risk analysis is a relatively recent activity, with engineers, epidemiologists, actuaries and industrial hygienists for example conducting analyses since early in the twentieth century. However, it was only in the latter part of the century that formal risk assessment became part of the regulatory process, bringing with it the professionalization of risk analysis and a burgeoning of jobs to go with it.

This chapter tells the story of the SCIDS conflict from the voices of experts, experts who are part of the community of calculation. The experts in the SCIDS conflict come from government at local and provincial levels, the university, and from the private sector. They have been trained in, and/or work with, specialized knowledge. That specialized knowledge is used in the interpretation of data and facts as well as judgements that go beyond the discipline’s conventions, data or fact.

Six experts narrate their understanding of the SCIDS conflict. Each was involved in the conflict at some level. The hydrogeologist, who works for a private company, conducts a broad range of research including sampling of groundwater wells for government as well as for other organizations. The agrologist works for the Ministry of Agriculture in policy, and is also the Chair of the Ethics and Practices Committee of the British Columbia Institute of Agrologists. The local orthopaedic specialist diagnosed the symptoms of what became known as SCIDS, developed a diagnostic test and actively researched the illness. Two epidemiologists were involved at different stages of the conflict. One at a Friday morning open house for medical researchers who sought advice on how to pursue their research interests and which the local specialist attended; the other in heading the epidemiology study of SCIDS that was commissioned by the provincial government. The medical officer of health was one of several

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521 Golding, 25; Gabe, 2; Fox, “Risks, Hazards and Life Choices,” 665 & 666.
522 Kroll-Smith and Floyd, 6, 7 & 58; Grinyer, (1995); Otway and von Winterfeldt, 84 & 85.
involved in the conflict. One of his residents\textsuperscript{523} at the time of the environmental health conflict has a presence in a more passive sense. Whilst not interviewed, her critique of the proposed research of the local orthopaedic specialist and her Master of Health Sciences thesis became part of the data set.

Together with the resident's Master of Health Sciences thesis are reports from various studies that impacted the SCIDS case, either directly or indirectly. A report from the epidemiologists and three groundwater reports also give (counter)voice in the construction and ownership of the social problem of SCIDS.

Following is a description of the experts' perspectives from their involvement and experience in the SCIDS conflict. The description is my own interpretation, combining quotes from the interviews and incorporating the tenor of experts' voices. The description is a montage of "original" voices, their inscription as transcribed text, and my interpretation. Voices are denoted in different fonts and single spaced text, juxtaposed in sections to tell the descriptive story. I follow this description with a discussion of the social construction of the problem. It is interspersed with quotes from the interviews\textsuperscript{524}

The experts' story

1.1.
About eight or nine years ago when we started here, we were seeing groups of people who had the same physical complaints, but we couldn't find any structural abnormality to account for them. With one group, early to mid-teenage girls, we tossed around various diagnoses until we were full circle back at anterior knee pain. Of course the girls were told they were lazy, didn't want to do P. E. and so on, but these were girls that were good at sports and suddenly within a six-month period they can't run around the track anymore. I don't buy that it's a totally psychogenic problem. So we started to look a little more closely and found several things they had in common, like an inability to squat on their heels, a recurring ankle weakness, weak front hip muscles, weak forearms, hypersensitive skin on the legs and lower back

\textsuperscript{523} She is described as a resident by the medical officer of health.

\textsuperscript{524} The local orthopaedic specialist's story is in Courier font; the voices of a number of other experts, including the epidemiologists, the agrologist, and the medical officer of health, are narrated through the voice of a composite expert, and is in Charter Bold font; the voice of one of the hydrogeologists is in Arial. The choice of groupings of experts is not arbitrary. They are grouped according to their agreement and sympathy with each other and are a reflection of the conflicts expressed between them. I intend the various experts to have a conversation with each other and thus have not denoted the speaker at the foot of each section as this interrupted the flow of conversation.
and problems with posture. Well, this is a bit odd you know, I can't see that they're all putting this on.

And then I saw some patients that we knew had direct contact with organophosphate pesticides. One woman had had her house sprayed three times in eighteen months, another lived next to a pea patch that was sprayed. They had the same pattern of muscle weakness.

I found a guy in Prague who described something similar, which he called pseudo paresis. But it isn’t pseudo, it isn’t a false weakness, as far as I’m concerned it is very real. Other people do seem to describe it, but nobody has ever pursued it to find out what the hell it is.

So from what we were seeing, there were three possibilities. They were all crazy in the head like most of the government health authorities like to think. I find it just fascinating that they can all fake the same weakness, the same physiologic findings as everybody else. Any rate, psychogenic is a possibility. The only other thing that gives you generalized alteration in function is virus. Over the last ten or twelve years we’ve seen a whole bunch of those come out of the woodwork. But it’s a little bit strange that a virus causes a pattern like this. So it just doesn’t seem to fit for that. We’ve seen it in people who have been in contact with chemicals. I didn’t know anything more about it at the time, and I thought, well, if it is chemical, then there’s something wrong here. I went to the Health Department. They said, look if it doesn’t have a name, how can we research it? I said, well shit, I know it doesn’t have a name or research, that’s why I’m bringing it to you. Well, give it a name they said. So I give it a name and get shot down for it.

I tried to encompass all the things I saw in it. It was Somatic, meaning the general body, Chemically Induced because we’ve seen chemicals doing it. We weren’t sure which ones, but the organophosphates seemed the most likely. Dysfunction, I mean everything wasn’t working right; and a Syndrome because it seemed to fit into a pattern.

SCIDS had been around for a while before any of us got involved. Two people were the main instigators. She founded the group and was central to the SCIDS issue. He diagnosed the illness.\(^525\) He brought it to the Ministry of Health’s attention. It had been investigated at least twice previously before my involvement, and the general conclusion had been that there wasn’t anything there. Health had basically written a report and walked away. They thought that was the end of the matter. This never satisfied her however, and he continued to push it. Strangely, he was the only physician diagnosing it.

Now, don’t get me wrong, he’s a bright surgeon who attempted to find a diagnostic test for what he was finding. Patients were presenting with a range of subjective symptoms such as headaches, weakness, and fatigue, and he was trying to find a more objective measure to classify people, including those who did not yet have the symptoms but who would ultimately manifest problems. He determined that there was a particular reflex constellation, a fast breakaway that the people he was seeing had that others did not. It may not be present on the first attempt, but it would be present at some point. He considered they had a

\(^{525}\) Reference to “she” and “her” and to “he” and “him” in the composite expert voice is to the founder of the SCIDS group and the local orthopaedic specialist respectively.
neuromuscular deficit. He sent a number of these patients for all kinds of neuromuscular testing and they were all normal. However he felt that this group was distinctly different and that he could define people on the basis of the fast breakaway. Now, I think that what he found is something that’s normal.

He contacted several of us about what he was finding and asked for advice on how to pursue it. We talked to him about basic epidemiology. Problem was he was contaminating the process. We took him aside and said “there’s two issues here. One, if you’re going to follow this through, you’ve got to be careful about what you say to people when you examine them. Second, you have to stop making people feel bad about being near to exposure. Everybody can find some instance of exposure, you know like walking through a field that’s been sprayed. You can’t continue to instill these thoughts in people’s minds. Ethically, you’re making people unhealthy.” Unfortunately he and I parted a bit after that. I’d had to say “look, you can study this, but you have to do it the proper way.”

He came to one of our Friday consultation clinics for advice on researching the issue. I recall trying to explain first principles, that first you need a case definition, and once you have that you need to do a proper study. I remember asking him, if this is real, why are others not talking about it? We have surveillance systems all across North America. Why am I not hearing about this from the CDC in Atlanta? Why aren’t people popping up with this all over the world? His answer was that he was the only person out there looking for it. I remember thinking that it doesn’t usually work like that. Even some very local phenomenon that would give rise to this is pretty unlikely. So I told him that there’s issues about the reliability of this, that he didn’t have a case definition, and that the evidence he had was not enough in and of itself. I think he was ready to go open a clinic. He didn’t think he needed any more evidence. He was already convinced as to what it was and its cause.

He wasn’t the only one looking for information. She was also very actively searching for information. At about this time, water issues started to crop up. Residual fungicides had been found in some wells by the federal hydrogeologist. These residues began to be linked by some people to their symptoms. It was “Oh my God, we’re being poisoned. Don’t drink the water.” And then it was “Come one, come all. He will diagnose you with this illness!”

She got together with a few people with well water problems, and he was getting tired of the lack of attention to his problem. He wanted action. She and the others formed a group. They found a reporter interested in fighting environmental issues. We got two days notice that there was going to be a big media spread on enviro-disease. They maintained that we’d been sitting on our haunches, doing nothing. For her, nothing was ever enough.

We’d known about the nitrates in the aquifer long before this issue erupted. But when he linked the quality of the groundwater to SCIDS, an agrologist was brought in. We’d already been active, undertaking a large aquifer study reviewing all the water testing done to date. Environment, Health and Agriculture were involved. Agriculture established an assistant deputy minister level committee that oversaw a further two year study of aquifers in the Valley. Since we already knew about the nitrate contamination of the groundwater we also looked for other contaminants.

The study verified the nitrate contamination in three significant aquifers: the Abbotsford aquifer, an aquifer in the Hopington area and another in the Brookwood area, both in Langley. No other significant nitrate contamination was found, and no pesticide
contamination. There were some detects of chemicals that may have been from pesticides, but none came close to drinking water standards. In addition, if I recall, most of the detects were from chemicals no longer used, and therefore artifacts of a time when more persistent chemicals were allowed. For example, you can still find DDT in water and soil and it hasn’t been used for 25 years. Some of these chemicals have an extraordinary persistence.

1.3.
The problem is the soil over the aquifer is very, very thin, mostly sands and gravels with little organic matter to absorb surface materials. Industrial turkey and beef farms with their thousands of animals produce more waste than can be utilized. Animal and especially poultry manure is used by berry farmers as fertilizer for their crops, and may be applied to the soil at more than the recommended rate in the belief that this will build up the soil profile. But then along comes the rain and leaches the manure away. We have to remember that groundwater eventually flows into surface water and impacts life there.

You know, when I began in this business, the technology wasn’t there to measure to the levels we can today. The sophistication of the modern laboratory means we can detect more minute levels of chemicals. But even if we’d had the instruments then, we wouldn’t have had the ecological information to determine safe levels. And then, communication of those levels is fraught with difficulty. When people hear that a detect has been made, they hear instead “contaminated water," “poisoned water," “health at risk," whereas the levels detected may be very minute and at far less than the safe drinking water standards. The public don’t understand that they’re likely to be more exposed to pesticides in the local nursery, or from everyday packaging than they are from drinking groundwater.

1.4
The SCIDS issue grumbled along until the Ministry decided they had to do something about it. It was probably the most important issue in government for a while. Caucus discussed it regularly. We had a number of meetings about it, and hashed out a plan in conference calls with Ottawa. The Centre for Disease Control came up with a protocol for evaluating these kinds of cluster events. One of the things they talked about was the need to involve the community right from the start. No matter how well you do science, people want solutions and so you involve them early on. Agree on what the hypothesis is, and on how the study will take place, and then no matter what the outcome, everybody’s agreed ahead of time so they can’t come back afterwards. I agreed to do the study with two preconditions. One, it had to be reasonably funded, and two, it had to be done under conditions which included the SCIDS group.

We formed a community advisory committee of politicians and community members. She was involved too. One of our group was banned from involvement however. She stated that he was opposed to anything to do with the illness, that he was interfering. Anyone who didn’t salute got tarred. She couldn’t get the answer from him she wanted. She wanted him to say, yes, this is SCIDS, and not that there’s lots of questions yet to ask. We also formed a scientific advisory group which included the local specialist. He agreed that if his diagnostic test could not identify a cluster of people with SCIDS then it didn’t exist as a syndrome.

Prior to the diagnostic study we sent a group of five people with SCIDS to a muscular-skeletal expert who stated that what these people had was not a syndrome. Each person had different symptoms, but they certainly all were ill. One had progressive paralysis, and there
certainly was something going on there, but it wasn’t evident what it was.

When we got the community advisory group together we said that firstly, we have to be able to say who has the syndrome and who doesn’t. Since the local specialist had the objective findings, we used his definition. We were really concerned about this definition because it defined the SCIDS group founder and a group of adult women in their thirties and forties mostly, and a second group of teenage girls who also had this breakaway and it was believed would manifest the symptoms later. From a public health perspective we were really nervous about his approach to this second group. What we did was set up this fairly standard diagnostic test assessment. We didn’t have a gold standard in the usual sense, so we set it up in as blinded a fashion as we could. We used his group of patients, plus an enriched group of people referred to him but not yet tested, and a general group from the community. We covered each person with a sheet so that all he could see was their arm. But, there’s no question, he could identify people from just a hand, although not with 100% accuracy.

We used him as the gold standard, together with two physiotherapists whom he trained in technique. He agreed that at the end of training they knew what to do. We documented all this. When we started testing people and he saw how things were going, he wanted to retrain them, but we said, no, we have your agreement right here, you can’t change your mind mid-study. We did blinded re-tests. The results were that he had no predictive value. He couldn’t agree with himself particularly well; one of the physiotherapists had no reliability and we took her out of the analysis. And basically the diagnostic test couldn’t classify anybody. You would expect the prevalence in the three groups to differ, but it didn’t. We put this to the community advisory committee who agreed that from their perception, SCIDS did not exist; that at least as defined by him this syndrome did not exist. She also signed off on it.

We were bothered by the labelling of the high school girls with this syndrome and what that meant in the future for them. If we had any agenda, it was that if the label was not appropriate then we get that label off. We spent quite a bit of time with the girls to ensure they understood that the syndrome did not exist, that they did not have it, and that they would not get it in the future.

1.5.

I couldn’t believe they’d actually screw up an investigation for yah. So what we did to prove this weakness, I wasn’t allowed to take part in any of the sample selection at all. They had my secretary pull out a dozen of these people, marked off another list, and got some people off the street by advertising. They got two physiotherapists from Chilliwack to come down and I had to try to teach them how I wanted them to examine. That was a bit dicey as you’ve got to examine the right way. And what they did was set up a screen so I couldn’t see the people. We did the exams and basically people were being sorted into who was weak and who wasn’t. It turned out that there was the same percentage of weakness in the control group as in the other two groups. They wouldn’t let me see the raw results. That was all privileged information so they said. So I badgered and badgered them and they eventually gave me a list of the ones I missed on. And that was really interesting. One person had been out of the country for 6 weeks on a cruise ship and her strength had already returned at the time of the study. Now, six or eight weeks later and its gone, and
she's back here. Another was a mentally disabled girl, who probably had thyroid or something and shouldn't have been selected. The other one, I called her up and she said, "What are you talking about, I wasn’t normal. I was so sore and weak after the two therapists examined me, that the study organizers asked me if I wanted to continue or to quit." Some of the others who were pronounced normal I've since seen here as patients.

1.6.
She brought this fellow up from Florida who had this remarkable psychic power, like walking into the fields and seeing what was wrong environmentally. There was a fine performance. He was weeping, literally weeping. He has no credibility. The nice review of the water we'd done counted for nothing. In the meantime, the whole Fraser Valley is being tarred. The farmers are being painted the bad guys. I think the real estate agents were probably the most upset.

Now the U.S. toxicologist, he actually screwed the whole thing up. That stupid bugger put on that performance. He used a kind of act that he uses in the courts in America I mean it's just the kind of thing they lay up there. But it goes over here like a lead balloon. Its an act that's better for the public press or whatever. I mean, it really shot down the credibility of this. On the other hand he really dug out all kinds of data. Like this was the time they told us there was nothing in the groundwater, period. Someone phoned him and told him about the railcar spill of ethylene dichloride in Langley that travelled into the aquifer. I went there with a newspaper reporter. She was ill for three days afterwards, from the vapours escaping. Its still being pumped out, and this is years later.

1.7.
One of us sent in a complaint to the B. C. College of Physicians and Surgeons because in my view and that of others at the Institute, he was making comments for which he had no qualifications. He had no expertise in pesticides, and some of his statements were beyond his own area of expertise, and at times in the area of agrology. We felt the College should tell him to stick with his own expertise.

Instigation for our complaint was the Florida toxicologist's report. How someone could fly in from thousands of miles away, from an area that probably uses more pesticides in agriculture than the whole of Canada, and with no knowledge of the issues could tell citizens that they were being poisoned was beyond us. However, its one thing when someone who makes their living from doing this sort of thing does it, but another when a fellow professional from another licensing body in this province fans the flames. We expected some scientific basis to support what is being said; a certain level of objectivity and scientific rigour. It was time for science to reign.

1.8.
You don't get any support. I mean, it almost cost me my practice back then. So I'm definitely not going to stick my neck out too much until we get this definitely proven. My colleagues are studying it now, but back then, it was bend over backwards not to refer anyone to me. They
told people there was nothing wrong with them, they didn’t need to go see anybody. A physician, what does he know about it? Well, you’re probably aware that chronic fatigue syndrome, or fibromyalgia, by no means gets one hundred percent agreement in the medical profession that it even exists.

The SCIDS group are virtually defunct now. The enthusiasm’s not there. That’s what most government departments rely on I guess, that given long enough most people just lose enthusiasm and peter out because they just get nowhere, they don’t get any funding, they don’t get any help, they don’t get any money. And you know, to try and do any clinic in this country is just impossible finance-wise to set up. The provincial government was looking at doing something like that at one stage, then it got downgraded to an investigation, then to a resource centre, and now its downgraded to nothing.

You know, someone in federal government knew about the chemicals in groundwater. But they said, if he talked, he walked. The background to that was an enormous international incident. It started off in the town of Lynden, across the U.S. border. They wanted to get more water for their growing populus. So they thought they would tap into the wells at Sumas. And Sumas I guess wanted too much bucks for setting it up, so Lynden thought they would dig their own wells. They dug just north of the town, and found loads of nitrates. They tried farther away from the town, closer to the border, and the nitrate levels increased. It became bloody obvious where they were coming from. Anyway, they started testing for other chemicals, found they matched the ones being found up here. Then it became federal, and tests were done along the border.

I get fairly paranoid about this sort of stuff. Like we’ve been sending all this stuff down to the States which is fairly expensive. I had one of the local labs doing tests but they sent me a note saying they couldn’t keep doing them. You know, is it just happening, or has somebody bounced on them? I’m concerned about what’s happening.

The SCIDS group itself was an illness-based group looking for a cause, rather than a group looking at environmental contamination in a more ecological sense. The people diagnosed with SCIDS did have an illness, but what they were showing was a physiologic response to stress. Their attribution was external, but I don’t think that their cause was external at all. Their causation was stress, which although probably external to a certain extent, is internalized in their handling of it. There is no evidence of more people in Abbotsford with this syndrome than elsewhere. Some people with SCIDS moved away from the area and attributed cure to the move. They moved from the area of stress to a completely different life situation, and one would expect things to change. However, at the same time, these people with SCIDS are not clustered geographically. They come from as far away as Tsawwassen, the North Shore, as well as Abbotsford. What the SCIDS group did was attract a group of people who have a syndrome, causally unknown. The people are there because of the support group. They’re not there because the area has the causative factor. It’s the self-help group that has drawn them.

Stress does some amazing things to the immune system. But when people get an illness of unknown cause, in order for them to get legitimacy they have to have attribution. They can’t attribute it to stress because that doesn’t give them legitimacy at all. They can’t go to
government and say, I’m stressed, because that will make it a personal problem and they’ll be
told to hit the road. There are powerful external forces on people with this problem to have
to attribute it. In addition, the support from having a group is very therapeutic.

He believed that what he had found had an environmental cause, and of course this
fitted nicely with the group’s external causation. He became convinced that what was going
on was an environmental issue. He, of course, didn’t like what we’d found. Physicians are not
trained to make population-based linkages. He’s extremely well-trained to make one-on-one
patient decisions. Basically our mechanistic approach to this is evidence-based where we go
out and try to get evidence to support one way or the other. What we’re dealing with are
people who have a belief-based, not an evidence-based, system. I can understand the Ministry
of Agriculture’s frustration at having to deal with someone who should be evidence-based in
his perception but is not. Hence the complaint to the B.C. College of Physicians and
Surgeons. We all make causal inferences on how the world works. He’s seeing this syndrome
and asking how can I fit it into MY universal perceptions. Once you’ve made that association,
there’s virtually no evidence that will shake it. When once it becomes a belief issue its no
longer a scientific issue, and you might as well forget it.

There exists a “we’re being poisoned” movement, by our carpets, our modern life, our
buildings. The modern world is poisoning us. I don’t entirely disagree. All of us recognize
that there is some basis for this, some basis for some of the SCIDS. They were ill, but
suddenly it’s the farmers using pesticides that’s the cause. Where did that come from? They
had an agenda. And emotional attachment on the part of scientists involved is to be avoided.
There were fears that this had happened to the federal hydrogeologist. Other highly respected
scientists took his data and could not come to the same conclusions he had reached. It was
questioned as to whether he was interpreting the data in a way that furthers an agenda, rather
than being the dispassionate, objective scientist.

Show me that Abbotsford has some higher outcome than people who are not exposed
to pesticides. Can’t do it. We don’t have any data that is independently collected to support
that right now. None. And yet it’s a very common perception that its occurring all the time.
Well, I count dead bodies for a living, and until you can show me the dead bodies, and we
agree that those bodies are dead, and that they died from..... you know, I don’t got a problem.
And yet they’re coming at it another way. They’re saying we have an exposure, therefore we
must have dead bodies. Sorry, it doesn’t work that way.

The (dis)interested expert

Following the successes of the second World War, scientists were placed on a pedestal,
not by their own doing, but by others who sought to idealize, and even idolize, them. Post-
World War II was a period of unquestioned faith in technological progress. Many discoveries
aimed to assist the war effort made life following the war more comfortable, safer and healthier.
The hegemony of progress was confirmed with the victory of science as the symbol of the

526 Merton, 112.
victory of war. Experts, as the producers of technological progress, were portrayed as creatively godlike whilst at the same time as necessarily passionately, attitudinally and socially deprived.

The characterization of science as a dispassionate activity has its roots in the 16th century. In an effort to dissociate scientific activity from theologically-based distortion, Frances Bacon sought to found knowledge accumulation on observation of reality rather than on imagination. Knowledge accumulation was to be a neutral process with respect to religion or politics. Scientific work was outside the social and political bickering of individuals and groups. Values did not enter science. Science was undertaken as a neutral, value-free exercise, and the disassociation of the expert with the products of science was considered at the heart of the success of scientific and technical progress. Science had replaced tradition, and experts were the authoritative source of knowledge, the “modest witness,” defrocked of opinion and embodied bias, the “legitimate and authorized ventriloquist” for science, for the object world, endowed with the power to establish the facts.  

Today, while experts retain some of the respect and authority imbued by science, they are also subjected to questioning and doubt. While their judgement determines the worthiness of a problem, its dimensions and solution(s) as well as the data, the research methods, the models of interpretation, and the analysis, this authority is less secure. The homogeneity of experts as a group and their cohesive rhetoric have vanished today. No sooner has the expert declared something as safe than new research shows it is not. Concepts and terminologies change as theories are revised or abandoned. Alternatives abound (for example, alternative therapies in medicine) calling into question the dominant discourse. Disagreements exist among experts. Disagreement exists about the long term consequences of many technologies. Monitoring technologies no longer seem adequate. Risk may be taken for granted and human error allowed to creep in. Certainty is posited in a world of uncertainty. Scientific information may not be available at all. And adequate scientific information exists for only a small proportion of potential health hazards. Organizations responsible can neither identify nor keep abreast of the testing of the many chemicals, drugs and contaminants in use. Death and disease, drawn-out and painful, the indirect result of the decisions of experts based on science, fill the newspapers.

Problems, their causes, their health effects, and appropriate remedial action are all subject to diverse interpretation. Experts engage one another and the public in conflicts and disputes. Subjectivity, values, displace the objectivity the public has come to expect. Their emotional neutrality in their own research results is questioned. Experts increasingly find themselves under interrogation, their interests viewed with suspicion, their motives questioned.528,529

Experts, it is suggested, construct their definition of the problem through the lens of their specialized knowledge area. Most specialized fields of study have a somewhat narrowly defined span of knowledge. This allows the development of in-depth knowledge, or expertise. This allows experts to tap into a larger fraction of relevant information within their field, however it also provides a mono- rather than inter-disciplinary orientation.530

Disciplinary specialisation is a positioned perspective: “What we observe depends upon where we are.” Experts produce positioned knowledge. Categories and concepts from a disciplinary specialization construct experience by formulating the lens through which the world is seen, felt and interpreted.531

The expert knowledge of disciplinary specialisation constitutes an interpretive, formative practice in which objects are constructed.532 The toxicologist, the epidemiologist, agrologist, medical officer of health, hydrogeologist, and orthopaedic specialist each have a disciplinary specialization with formative practices appropriate to that discipline. The basis of each of their disciplines, and embedded in their interpretive practices, is science.

The Reign of Science: Claims and Counterclaims

The experts’ narratives express a concern with scientific authority and integrity, as well as the need to manage the conflict. The expert’s construction of the problem is framed by their

528 Freudenburg and Youn, (p.4) suggest the term recreancy to describe this. Recreancy comes from the Latin re- (back) and credere (to entrust), and is defined as “a retrogression or failure to follow through on a duty or trust.....” and “fails to fulfill the obligations or merit the trust.”

529 Frodeman, 341-352; Haraway “Modest Witness”; idem, Simians, Cyborgs and Women; Williams and Popay, (1994); Freudenburg and Youn, (1993); Giddens, 121-123; Jasanoff, (1990); Jennifer Brown, (1989); Nelkin, 97.

530 Spangler, 104.

531 Kleinman, Writing at the Margin, 72; Clarke, 305.

532 Good, 65-87.
attachment to science as a way of "being" at the professional level. The concern with science, the expert viewpoint, is opposed to the SCIDS group’s concerns as perceived by the experts.

The SCIDS group was seen as having an agenda. That agenda was to locate a cause for their illness. As the agrologist put it

..these people were obviously ill with something, there’s that, and then, well, it’s
the farmers using pesticides, you know... hold on here a minute, where is that
coming from?

An agenda implies a determined, organized and explicit plan to be pursued. “Looking for a cause” suggested that a determining factor was to be found and assigned, attributed, to their illness. Further, this cause was suggested as external to the sick individuals.

Attribution is a process wherein social perception leads to causal judgement and social inference, resulting in behavioural consequences. It provides a framework within which bits and pieces can be fitted together in order to draw inferences. Behaviour that happens to a person, that is that a person suffers, is explained by both actors and observers with causes. An effect is attributed to a cause. Causes are conditions and events that produce effects, and effects are conditions and events produced by causes. Attributing a cause to an effect provides a degree of certainty in the face of uncertainty. The SCIDS group was seen as having overestimated the influence of the environment and underestimated the impact of personal dispositional factors. However, the “correct” path to causal inference is the continual process of elimination using appropriate research design. Practical steps must be taken to ascertain the absence or control of confounding. Causal inference must be judged on the basis of criteria. In the absence of this research process, causation should not be judged or inferred or attributed except as a personal disposition. If SCIDS was a syndrome or a disease, its causation was internal. Disease is located in the body.

I think their causation is stress...now the stress itself is probably external to a
certain extent, but their handling of that stress is internalised and its coming out
in this particular way.

Opposed to the perception of the group as pursuing a misguided plan based on misunderstanding of the disease is that of science as the authority, as able to determine the truth.

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533 Kaufman and Poole, 102; Hilton, 65; Crittenden, 426 & 427; Buss, 1311.
of the matter. The expert becomes synonymous with science and objective truth.

As experts, our only job is to tell the truth, you know, and if we don’t, if, if
that’s not our job, then we’re next to useless, if we are not objective, and that’s
really, I’ve said many times, that’s really all we’ve got to sell, is objectivity.

The division established with the use of a science rhetoric was that of a counter-claim to
the claims of the SCIDS group. It was however, only some scientists, some experts, who were
synonymous with science and objective truth. It was not only the group itself, but scientists,
experts who were associated with the SCIDS group who were considered not scientific or
objective. At the very least, those factors were questioned. Controversy among experts ensued.

Experts whose research produced findings not consistent with the general knowledge
base about the region were also called into question. Where a study’s findings might add fuel to
the fire of perceived subjectivity and non-science, the scientist as well as the findings became
tainted.

There was some concern on a number of our parts that [federal hydrologist] got
himself into a sort of a, almost a personal, almost an emotional attachment to
this groundwater issue and ah, that ah, I know other scientists have taken his
data from some of his projects and not been able to arrive at the conclusions
he’s arrived at, so there starts to question, you know, are you interpreting your
data in a way that, ah furthers an agenda, rather than simply being the
dispassionate, objective scientist.

The importance of others within a broad discipline replicating research findings is also
illustrated with regards to the local orthopaedic specialist who is doubted further on the basis that
his preliminary findings were not replicable in the epidemiology study. The implication of
course is that scientific rigour and objectivity are absent.

I’m not sure on what basis he determined there was even a disease, because
subsequently, subsequent as I understand it ah, medical studies have determined
there was no such thing as SCIDS, there wasn’t a discrete kind of pathology or
whatever. How he concluded that that, he had something here in terms of a
discrete kind of ah pathology, and then he, ah, looking for the cause of this
thing, how it, how he started to determine or how he came to believe that it, or
understand that it was of environmental cause, I don’t know. Certainly the other
medical experts that I’m aware of couldn’t make that link.

The phrase “how he came to believe that” is important. Scientists in any discipline are
not supposed to “believe.” On the contrary they should, “know” via objective facts and truth. This point is taken up by another expert, one of the epidemiologists, who is also discussing the local orthopaedic specialist’s approach to the SCIDS issue.

You know I don’t think that in medicine we have any more people who...who develop belief systems. Belief systems by definition are testable. Okay, he’s got a belief system. We think of physicians as being evidence based....we go out and try to get the evidence to support one way or the other. The people we’re dealing with belong to a belief based system, and so we’re basically trying to attack with reason...just as tough to do as with religion....this is almost an equivalent sort of attack, and....yet he by being a physician is seen as being part of one system when in fact he’s part of another.

Seen as having a belief system, the local specialist is very quickly associated with the SCIDS group who are also posited to have beliefs, rather than facts, upon which their conclusions are purportedly based. Attribution of their illness to environmental toxins, at odds with the biomedical model of internalised disease causation, must after all be mired in beliefs rather than anchored in fact. Beliefs are considered the product of ignorance and irrationality. That the local specialist’s diagnostic test failed to define a population with SCIDS further reinforced claims of a non-scientific approach on his part. Further, a number of experts noted that the local specialist had contacted them for advice about proceeding with research, again indicating that he did not have the requisite knowledge and skills to proceed. These factors, which might in other circumstances have combined to reduce his credibility as a scientist, do not do so. In fact, he is considered a credible person, good at what he does.

As far as I can understand talking to other people he is a very competent orthopaedic surgeon.

and...

He has a basic credibility. I think he is a hell of an observer.

His mistake, it appears, was to extend himself, firstly, outside of the role for which he has been

534 The local specialist does have close links with the SCIDS group. However his connection with the group is not generally put in terms of his having a belief system as do they. He is expected to be separate from the group, at least cognitively. He is not expected to share their lay perceptions and beliefs.

535 Williams and Popay, 133.
trained

He's a LOUSY epidemiologist. He doesn't really understand the issues and that's part of the problem....

and secondly, outside the bounds of his discipline of medical science

...in my view and certainly in the view of ah, others at the Institute, he was making comments he wasn't qualified to make, about ah, pesticides and about certain ah, ah statements that we felt were beyond his area of expertise, he was in fact in the area of agrology in some of his statements....

Boundary work is noted by Jasanoff as inclusion/exclusion of relevant peer groups and networks of authority. This is one of the most frequent strategies scientists use to enhance and define their authority. Scientists construct a social boundary to distinguish some intellectual activities as science and others as non-science by attributing selected characteristics such as its practitioners, models, knowledge, values and work organization to science. Science’s authority can only be protected by insulating its specific expertise from lay knowledgeability. Drawing the line between science and other disciplines or knowledge denudes them of any cognitive authority as well as resources.

Boundary work occurs not only between science and competing non-science intellectual activities, but also to monopolize authority and resources in favour of some scientists by excluding others as pseudo-scientists. To have their findings taken seriously, the expert must engage in successful boundary work to secure their legitimacy and repel efforts to portray them as having overstepped their proper authority. The local orthopaedic specialist was considered out of his depth in relation to related disciplines within science. He simply wasn’t trained to be an epidemiologist.

He is not in fact trained to be an epidemiologist in public health, we don’t train physicians to do that. We take some entire training to do that.

Defining the local orthopaedic specialist as an “amateur” at epidemiology retained the epidemiologist as the authority. However, the local orthopaedic specialist is exempted from

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536 Jasonoff, 14.
537 Gieryn, 782.
538 Frodeman, 342; Giddens, “Post-traditional Society,” 185.
539 Gieryn, 789.
540 Hilgartner, 10.
responsibility for the consequences of his work (the test did not identify SCIDS) and blame was placed outside the group. The U.S toxicologist, however, was excluded from any claims to science. He was variably described as an impostor

The guy’s a quack, an absolute and utter quack. I mean this is how he makes his living, is he goes to environmentally damaged areas and comes up with all this crap...and I mean that’s all it is. And the guy knew exactly what he was going to say before he ever got here. Some of his claims to expertise were not well supported. He certainly was at university, but his degrees, we were not able to confirm some of them.

and as a performer

He was in tears at a public meeting about how the community was being poisoned...he was crying and saying how he felt so bad that people were sick all because of this water, you know, amazing...

Emotions do not befit the scientist. He was disqualified from the claim of scientist, stripped of any cognitive authority, and subject to enquiry as to his credentials, which were found wanting.

A key aspect of science is not that scientists discover facts in a passive relationship between the scientist and nature, but that scientists interpret findings in a negotiated order with the scientific community. It is, as Aronson maintains, a claims-making activity. Scientists make “cognitive claims” about their findings which must be accredited by the scientific research community, specifically by the research community of the scientist’s specialization, in order for those findings to become scientific fact. This is a process in which, akin to the transformation of private troubles to public issues, scientists turn their observations into publicly accredited factual knowledge. An assiduous attachment to their ideas is required in order for this transformation to take place. This of course flies in the face of the Mertonian view of the scientist disinterested in their own ideas. At this stage however, the claims-making remains internal to the scientific discipline. At the point at which observations are accredited publicly, human agency in the discovery is obliterated. Scientific facts, divorced from individuals or circumstances that led to their discovery become objective facts, observable in the world.\textsuperscript{541} This “a-social” character of science is the goal, variably achieved, of the social process of producing science. This

\textsuperscript{541} Aronson, 5-19.
“purification” of scientific practice successfully separates the technical from the social.\textsuperscript{542} Anyone who wanted to find scientific facts in the natural world could do so, in a similar manner to the way in which social problems are fully observable within the social world.

Claims within the scientific community pertain to the construction of scientific knowledge. Scientific claims-making however is not confined solely within the scientific community. It moves outside the research community and contributes to the construction of social problems through “interpretive claims” in which scientific facts are explained to both the lay public, and scientists of other specialities. In both the social and the scientific arenas, expert documentation, commanding the attention of the audience, and defending against opposing views through access to resources are involved. Interpretive claims rest on the authority science asserts in persuading the audience that science is relevant to this particular case, and essentially useful to society. The construction of social problems as being of a scientific or technical nature and the claims making activities of science work in tandem, each strengthening the claims of the other.\textsuperscript{543}

It is what Salter refers to as \textit{mandated science}, wherein the interpretive claims of science in the social arena are made. For Salter, mandated science refers to science that is used in the making of public policy. It is distinct from the science that is undertaken in the laboratory for the sake of “pure” science as an academic enterprise. The distinction is that it is science that is commissioned for the purposes of supporting policy regulations, and generally involves advice from experts to government. Public concern about issues that become controversial is a key arena in which mandated science serves. It is mandated in the sense that pressure is placed on scientists and science as a useful tool in governmental decision making.\textsuperscript{544} The experts, the scientists providing such policy advice are what Jasanoff refers to as the “fifth branch.”\textsuperscript{545} The policy advice they provide, suggests Aronson, is technical interpretive claims.

Technical interpretive claims however need not be restricted solely to the policy arena. They may become part of the public realm as social problem interpretive claims. At the same time, social problem interpretive claims by scientists are not restricted solely to technical aspects.

\textsuperscript{542} Latour, \textit{Science in Action}, 64-70.
\textsuperscript{543} Aronson, 11.
\textsuperscript{544} Salter, \textit{Mandated Science}.
\textsuperscript{545} Jasonoff, \textit{The Fifth Branch}. 
Aronson suggests that there are three conditions under which scientists are likely to make a social problem type of interpretive claim: first is to obtain material and political support for a new discipline; second is if government, who controls access to public funding, questions the value of science; and third is when science and research is questioned by the public, through a social movement for example. These three conditions however, portray scientists as reactionary. That is, the condition occurs, and scientists then step in to argue for science.

Science and experts however may actively define the conditions that become the social problem. In the SCIDS case, the local specialist was confronted with symptoms of which to make sense, did so, and defined the problem by bringing it to government authorities. He describes the complaints, his investigation of a number of diagnoses that the symptoms might constitute, the pattern in his patients’ histories indicating some had been sprayed with chemicals, and then states

but it just didn’t seem to fit for those [other possible diagnoses], so from positive reasoning we’ve seen it in people that have been poisoned, from negative reason there is nothing else there, and think well this really can only be chemical. And then I didn’t know anything more about it at the time, so thought well if it is chemical there is something wrong here. I then went to the Health Department. They said, well look, it doesn’t have a name, it doesn’t have anything, how can we research it? I said well, shit, I know it doesn’t have a name or research, that’s why I’m bringing it to you. Well give it a name. So I give it a name and I get shot down at that......

The local orthopaedic specialist appears to have followed a process that would be expected of a physician; one that is responsible, scientific and objective.\(^{546}\) Science is medicine’s foundation; knowledge of scientific principles is applied to the understanding of disease in patients. Medicine is the science of individuals. Science is used in the care of the ill, however it is the individual case that bridges the gap between principles and application. Clinical casuistry is the comparative analysis of a case and its circumstances with received principles. Scepticism

\(^{546}\) Lewinsohn (1261-1270) points out that prior to the increasing importance of science to medical practice that the patient was not only medicine’s main concern, but also the source of all information. Science did not encroach upon medical practice. Since the coming of medical science, the physician has had available masses of information that has multiplied her/his powers as medical scientist but not his/her powers as healer.
is employed in the process of reasoning from the parts (the symptoms, signs, tests) to the whole and back to the detail to determine the diagnosis. This diagnostic circle of interpretive reasoning allows the ruling out of alternative possibilities and confirmation of the strongest, most likely hypothesis. Taking this to the authorities however was met with a hesitancy on their part to investigate without further information. They required a name for the condition. The local specialist realises that follow-up will be left to him. He acknowledges that he does not have the expertise or the time to undertake this research, but wonders who else will.

I have to list off all these patients and get some sort of flow sheet and computerize it and find out the incidence of symptoms compared to a control group. Its very difficult to get a control group. And get all that on computer. Well fine, but I got to earn a living! So it is very difficult. I mean I can always ask these questions and they are quite valid but to start giving direct answers with proof and statistical verification it’s a huge undertaking. And my background obviously isn’t in statistics either, or in public health or whatever. But I also say, who the hell else is going to do it?

He understands the role of objectivity and the need to have objective results to credibly demonstrate that the syndrome exists.

In addition, the local specialist saw the benefits of extending his learning outside the narrow confines of his specialty, especially in relation to the presenting symptoms of his patients. Surgery was not the only answer he was prepared to offer.

I’m basically an orthopaedic surgeon. You’re trained to cut people not really look for anything else. Most of the people you’re seeing don’t require surgery, so you see them, out the door, you see them, out the door, or you refer them to a chiropractor. Then after a few years at this I thought, what else have we got to offer? There was a physician in England who started orthopaedic medicine. He provided a good basis for doing a series or a specified way of examining every bone and joint and muscle. Then I went on a course for osteopaths and chiropractors. Parallel with this we’ve got all these other things coming in, chronic fatigue syndrome, fibromyalgia, anterior knee pain, a whole bunch of things to say nothing of unresolving whiplash injuries from car accidents, and back pains from WCB.

\[547\] Hunter, 10.
This additional knowledge outside his narrowly defined speciality of orthopaedic surgeon may have resulted in the orthopaedic specialist casting his net wider for information than would be expected. This imaginative unconventional approach was then to be disciplined. Creativity and innovation in science are expected to come from within the bounds of a discipline.

Traditionally, the context of knowledge generation has been disciplinary, primarily cognitive, and is identical with what is meant by science. However, emergent is a second, distinct set of cognitive and social practices which differ from those of traditional knowledge production. This second set of knowledge practices is transdisciplinary, characterised by heterogeneity, and organizationally is more heterarchical than hierarchical. It is more socially accountable and reflexive than the traditional mode, and includes a wider, more temporary and heterogeneous set of practitioners. In contrast, traditional knowledge generation is discipline-bound, characterized by homogeneity, and hierarchically organized. The transdisciplinary mode is more akin to the local specialist’s mode of knowledge production. Here, knowledge results from a broader range of considerations, and is intended to be useful for someone, an imperative present from the beginning. The traditional disciplinary mode corresponds with that used by experts from the university in particular, where this mode is found in its most intensive form.

The problem for the local specialist was not his lack of scientific expertise. His theory of causation, that environmental toxins were somehow implicated in the pattern of symptoms he was seeing in patients, is based on his observation of effects when an individual removed themselves from the environment for a period of time. As would be expected of any scientist, this raised questions in his mind. These he pursued in the only way available to him at that time in the absence of any funding for research—developing his own theories and discussing these publicly.

We’ve seen a number of people improve when they remove, physically remove themselves from here. One thing that fascinates me about people is that some of them will get better when they go away from here, but will still live here. I find that incredible, that somehow their job, and their money and their house are more important than their health. One of the first people I saw with this, she was about nineteen or twenty, either in a wheelchair or on crutches, couldn’t

548 Gibbons et al, 1-3.
work in the mall anymore because the fumes would knock her to her knees. She started having seizures, couldn’t concentrate, couldn’t walk more than thirty or forty yards. She went and stayed with an aunt in Alberta, and within six or eight weeks, she’s walking without crutches, she had a job, she could concentrate and read a book again, she was off her seizure medication, and she hasn’t looked back since.

Again, the individual case is the basis for the specialist’s reasoning. The narrative act of case presentation is at the centre of medical communication. It conveys the physician’s observations, thought process and conclusions about the illness presented by the patient. It is the basis of medical training. The expectation however was that this narrative interpretation be supported by rigorous scientific research before conclusions were espoused. The specialist did not follow the process of claims-making within the sciences. The local orthopaedic specialist quite simply did not follow the rules. This point was taken up early in the conflict, in 1990, by the resident working with the medical officer of health.

Contesting Claims

The resident’s critique of the specialist’s research proposal and process for diagnosing the disease illustrates quite clearly how early on in the development of ideas that the claims-making process starts. She asserts that public perception, results of medical research, and disease and mortality surveillance are the usual methods in which the medical community is alerted to potential hazards. That the alert was raised by the local specialist she points out as an anomaly.

Quite clearly there are rules to be adhered to in medical science. Being aware of and eliminating bias is but one. Referring to SCIDS as the Abbotsford Pattern of Muscle Weakness (APMW), the resident further states that a number of biases were operating that led the specialist to believe there was an excess of APMW. These biases included patterns of referral akin to a membership bias; awareness on the part of the examiner of prior pesticide exposure;

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549 Hunter, 51-68.
550 Bell, 2.
551 The symptoms originally named SCIDS went through a number of other guises, usually in an effort to disentangle the chemical association from the symptoms. It became the Fraser Symptom Complex, the Abbotsford Pattern of Muscle Weakness, enviro-disease.
awareness of the patient’s APMW after physical examination, intensifying the search for pesticide exposure; and informing patients of APMW findings, increasing the likelihood of recall of possible pesticide exposure.552

Further, she suggests that the local specialist is incorrect about what he interprets as the “failure” or weakness of the patient’s muscle group as determined by the diagnostic physical examination. Assessment of muscle strength in a physical examination is subjective, the resident points out. The physical examination the local specialist used was a technique akin to arm wrestling.

...the examiner, while stabilizing the proximal joint, provides resistance to the maximal isometric contraction of a particular muscle group. While encouraging the patient to maintain maximum effort he suddenly increases his force, and there is sudden release or “failure” of the patient’s muscle group. The degree to which this occurs is compared between the two limbs and with the opposing muscle group of the same limb.553

The resident suggests that the abrupt failure of muscle contraction may reflect simply that no further contraction can occur since with maximal sustained effort all myofibrils are contracted. Rather than an occurrence of weakness as the local specialist posits, it is an occurrence of fatigue, she suggests. It is not that the patient is suddenly giving in, but that the examiner is overcoming the patient. Her recommendation was that the subjective test be replaced with an objective measure using electrodiagnostic tools such as the dynamometer or electromyography (EMG).

Research design is an important component in determining reliable and valid results, the resident points out. A staged cluster investigation as detailed by the Centre for Disease Control must be followed before conclusions can be drawn about the presence of muscle weakness in a group of patients. Progression of research hypotheses will lead toward demonstrating causality of APMW by pesticides. To claim that such a causal association exists before the above research progression has been undertaken is both premature and irresponsible suggests the resident. Cause is postulated by the local specialist to be toxicologic factors, such as community wide exposure to pesticides through inhalation, skin absorption, ingestion, or contaminated drinking

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552 Bell, 13 & 14.
553 Bell, 3.
water supply. She suggests he has not considered infections, nutritional, autoimmune, congenital or idiopathic causes of APMW. She points out that establishing the biologic plausability of pesticide causation is difficult, confounded by hidden issues of magnitude, timing and duration of the exposure. In addition, it is inappropriate to blame community levels of exposure to pesticides in general. Rather, specific pesticides used locally over the past decade and quantification of community-wide exposure will have to be determined.

Should the results of the specialist’s proposed study design not demonstrate muscle weakness and its relation to pesticide exposure, two aspects of major public health significance will require resolution, the resident states. The first is the “negative social and functional implication of healthy young individuals being labelled chronically ‘weak’” when their weakness may be temporary and minimal. Individuals labelled with a condition may alter their behaviour to conform to the diagnosis, she suggests. Second is “the alarm within the community that this so-called health problem is related to environmental levels of pesticide exposure.” She states it is premature to make this claim. Further, the link between APMW and pesticide exposure has enormous economic, social and political implications in a community where agriculture is the primary industry. Sound epidemiologic data should influence pesticide regulation, not unfounded health concerns or simply economic or productivity information. The impact of both labelling and community alarm “may require correction through a local public health education initiative.”

The resident’s critique largely set the terms for the later epidemiology study. The latter took place approximately twelve months after the resident’s critique.

Consolidating the Counter-claim: The epidemiological study

The objectives of the epidemiological study, as stated in the published report, were to obtain epidemiological information that would describe the characteristics of the group of people suffering from the pattern of muscle weakness; obtain an independent medical opinion on a

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554 Bell, 27.
555 Ibid.
556 Bell, 28.
557 The results of the B. C. Ministry of Health funded study were published in B.C. Health and Disease Surveillance, July 1992.
number of typical cases; and establish a case definition and test it for intra- and inter-observer reliability. To satisfy the first objective, self-administered questionnaires were provided to fifty individuals (20 adolescents and 30 adults) diagnosed as having Fraser Symptom Complex\textsuperscript{558} (previously referred to as SCIDS). A further fifty questionnaires were provided to individuals who were waiting to be diagnosed and had similar presenting symptoms to those already diagnosed. Distribution to the second group was the same as to the first.

Twenty questionnaires were returned, six from adolescents and fourteen from adults. Whether these were from the diagnosed or yet-to-be diagnosed group is not reported. The results as discussed in the report infer that they were returns from the diagnosed group.

The adolescent group ranged in age from 14 to 18 years. All but one had lived in the Fraser Valley longer than nine years. Five of the adolescents presented with knee pain, the sixth with leg weakness. All had been to other physicians before coming to the Abbotsford orthopaedic specialist, five to one other physician, and four to two other physicians. One of the group had asthma and took a steroid inhaler, four had difficulty walking up stairs, five had spent four days or less in the previous month in bed, whilst one had spent fifteen days out of the month in bed. The epidemiology report stated that the adolescent group was healthy.

The adult group ranged in age from 28 to 58 years. All but one had lived in the Fraser Valley for more than five years. For the adult group, the presenting symptom for seven individuals was pain, primarily in the shoulders, arms or several different locations. The remaining adults had presented with generalized weakness, joint swelling, and stiffness in arms and legs. These symptoms had been present in eleven of the fourteen adults for at least five years. All adults had seen other physicians seeking a diagnosis. Four adults had seen one other physician, one had seen two, and nine had seen three or more physicians, before coming to the Abbotsford orthopaedic specialist. Thirteen adults were on medications, mostly analgesics or anti-inflammatory agents. All but six individuals were unable to take part in any vigorous exercise, and six adults had spent more than five days in bed in the previous month.

Three adults and two adolescents who represented typical cases of Fraser Symptom

\textsuperscript{558} This term was substituted for SCIDS, to eliminate the causation aspect of the SCIDS acronym (Fraser Symptom Complex Community Advisory Committee Minutes. Abbotsford Health Unit. File: 159-7-1. January 6, 1992.)
Complex and selected by the Abbotsford orthopaedic surgeon were examined by a specialist in Rehabilitation Medicine. The purpose was to obtain a second opinion with regards these cases. A full medical history, and musculoskeletal physical examination was conducted. The specialist's opinion was that a variety of diagnoses were needed to explain the various signs and symptoms of these five individuals. Suggested diagnoses included carpal tunnel syndrome, patello-femoral syndrome, biomechanical disorders such as pelvic obliquity and length discrepancy, a supination pattern of weight bearing, and perhaps also a demyelinating disorder.

The case definition, as defined by the orthopaedic surgeon, was based on a demonstration of a characteristic muscle weakness in his patients. The demonstration or test was similar to arm wrestling, with a characteristic "giving away" on increasing applied force to the forearm. An individual with this characteristic weakness in one or both arms meets the case definition.

This test was selected for the epidemiology study. Two female physiotherapists in addition to the orthopaedic surgeon performed the test on 79 female subjects (21 from the surgeon's list of known cases; 16 from his waiting list of individuals concerned that they had the Fraser Symptom Complex; 42 from the community, matched approximately by age, and not having seen, nor intending to see the orthopaedic surgeon.) All examinations were double blinded, with subjects covered by a sheet with only their forearm exposed, identified only by number. The subjects were instructed to hold an arm, flexed at the elbow, with forearm in vertical position relative to the table surface, then to rotate their forearm in pronation and supination whilst the examiner challenged the maximal force to detect sudden "giving away." Each subject was examined by each examiner for inter-examiner reliability, with a number of people being examined twice for intra-examiner reliability.

Intra-examiner reliability was fair, inter-examiner reliability was low. The epidemiology report concluded that this latter precluded the usefulness of the test for examining this condition in the community. Further, the prevalence of the muscle weakness was virtually the same for all groups. Overall, 81% (17:21 cases) of the diagnosed group, 75% (12 out of 16 cases) in the waiting list group, and 76% (32 out of 42 cases) of the community group were found to fit the case definition. This strongly suggested that the muscle weakness is not related to the symptomatology exhibited by the group of patients the epidemiology report stated. The conclusion was that without a reliable case definition it is not possible to define a cluster, nor
was there any basis on which to establish further studies to determine prevalence or etiology. Fraser Symptom Complex (or SCIDS) did not exist.

Blinded by facts

Epidemiology is defined as the study of groups of people in which the observation unit is the individual person. Further, it is the “study of the distribution and determinants of diseases and injuries in human populations.” Epidemiology was used in the SCIDS case as a diagnostic device. The test, that used by the diagnosing physician, was considered a diagnostic marker test. That is, it was expected to demarcate a specific disease entity, SCIDS, from other entities contained in the spectrum of human diseases. A diagnostic test may be definitive, and produce conclusive evidence for a diagnosis. On the other hand, a test may be contributory, producing not definitive evidence but results which, when combined with other results, may lead to a diagnostic decision. The diagnostic test in this latter instance is not used alone for the decision.

The epidemiologists appear to have approached the diagnostic test as definitive, and when the results from the test did not demarcate those cases with SCIDS from those without (nosological sensitivity and nosological specificity), the disease was considered a non-entity. The diagnosing physician however considered the diagnostic test one of several indicators of SCIDS. The test produces contributory, not definitive diagnostic evidence.

[Epidemiologist] met on only one occasion with myself to discuss the procedure of examining for this specific muscle weakness. I suggested to him at that time that all the SCIDS patients I had examined had this forearm weakness, but I also emphatically told him that at least one-third or more of the population in the area had the same latent weakness, and I suggested that we needed to test more than one muscle group. This was suggested on the basis that SCIDS patients always have a number of groups in a particular pattern, whereas the forearm weakness is a latent finding much more commonly in females than males, and I believe is somewhat of a too sensitive indicator of the degree of involvement of virtually the entire population. However, the patients we are seeing are the “canaries” who are the most sensitive and have the least effective detoxifying mechanisms and thus become symptomatic. [Epidemiologist] would

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559 Feinstein, 1.
560 Blumenthal, 13.
not accept the suggestion that at least two separate muscle groups would have to be tested to confirm the degree of involvement in the potential SCIDS patient versus a latent condition in the general population.\textsuperscript{561}

Clearly, the social problem, and its solution, is considered able to be determined by the “facts” expressed in scientific form. Particular forms of expertise, in this case epidemiology, are thought to be uniquely placed to assess questions of safety and toxicity.\textsuperscript{562} The construction of expert knowledge however is not the neutral, value free stance often claimed, but is equally subject to the influence of values and beliefs, to information overload, and factors other than strict technical information. That is, experts, as much as lay people, are subject to heuristic bias.\textsuperscript{563} These biases come from the very nature of their specialized training. Experts acquire worldviews from shared experiences, databases and their discipline’s common conventional wisdom.\textsuperscript{564} Worldviews serve experts well most of the time, but implicit is the diversion of the professional gaze away from opinions and facts that may be relevant to risk reduction. The normative frameworks of scientific and technical communities about what constitutes “truth” also contribute to worldviews.\textsuperscript{565}

Together these factors constitute ideological blinders which lead to a range of biases. Structural bias for example, occurs when the expert(s) is influenced by the prior presentation of a problem.\textsuperscript{566} The SCIDS conflict was well publicized by the media. The causal attribution for SCIDS was a well known “fact” by the time most of the experts entered the fray. By this time, a resident had conducted a critique of the local specialist’s proposed research design; the specialist had met with a local medical officer of health, had sought resources from the ministry of health, and had sought advice from UBC’s Department of Epidemiology. The problem was not unknown in the networked circles of medicine.

\textsuperscript{561} “Section 4. The Recent U.B.C. Study” is part of a brief concerning the governments’ lack of concern about patients diagnosed with SCIDS. Proposals are presented for pursuing the problem together with the response to the epidemiology study. The brief is written on the local orthopaedic specialist’s professional letter head. A covering letter presumably accompanied the brief, however this was not made available, hence the reader for whom the brief was written is unknown. The brief was provided to the researcher at time of interview with the local orthopaedic specialist.

\textsuperscript{562} Funtowicz and Ravetz, 253-258; Irwin, “Deciding about Risk,” 19.

\textsuperscript{563} Clarke, 305-306; Wynne, “Frameworks of Rationality,” 33-36; Macgill, 48 & 49.

\textsuperscript{564} Otway and von Winterfeldt, 91.

\textsuperscript{565} Clarke, 305-306.

\textsuperscript{566} Otway and von Winterfeldt, 91.
In addition, debate has ensued in the literature with regards the legitimacy of environmental illness. SCIDS falls into a group of labels that includes multiple chemical sensitivity syndrome, environmental illness, chronic fatigue syndrome, sick building syndrome, and indoor air syndrome, among others. The medical profession remains divided as to whether these labels constitute psychological, biological or somatic problems.

Structural bias then led to motivational bias for some experts, since retaining the integrity of science became the stake of highest interest. Motivational biases occur if the experts have an interest in the outcome of the analyses.

Biases may also be of a cognitive nature and manifest in a variety of ways. Experts may be more certain about probability estimates than their knowledge can justify. In addition to overconfidence, an expert may fail to adjust his or her estimate sufficiently as disconfirming or new evidence accumulates, holding on to or anchoring the original estimate. Availability of information also influences approaches to and judgements of the problem. Events that are easily recalled or imagined are likely to be overestimated in frequency, whilst events that are common but less dramatic and less vivid will be underestimated. Clarke refers to these biases as a disqualification heuristic. That is, experts may neglect information that contradicts a widely held conviction, for example that a socio-technical system is safe. In permitting a sense of control over socio-technical systems, uncertainty is diminished. Disconfirming information, critical data and viewpoints are disqualified while confirming information, data and viewpoints are highlighted.

The disqualification heuristic is a source of organizational naivete. Organizations develop risk perceptions through a process that involves experts, and experts' heuristics become important in this sense. The disqualification heuristic may contribute to narrowing the range of alternatives available for consideration so that particularly troublesome ones are relegated to secondary, even

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567 Clearly this debate would not be known to all experts in this sample, for example, the agrologist.
568 Jones, 933; Kilburn, 4 & 5; Lax & Henneberger, 425; Miller & Mitzel, 120; Nethercott et al, 19 & 20; Richter, 366.
569 Clarke , 305-306.
570 Ibid.
trivial status. This can occur simply in choice of research design to assess safety, disease and/or risk, or in interpretation of research results. The epidemiology study, although appearing to draw upon the resident’s critique of the local specialist’s proposed research, decided against the recommendations for an alternative test to that used by the physician. While it was acknowledged that an objective test such as an EMG was desirable, it was noted that such an approach would take additional time and effort, and would be very expensive. In addition, the diagnostic test was taken as definitive rather than as contributory, ignoring the advice of the local specialist.

Organisations are formally constituted systems in which information is processed, technology utilised, and roles and practices structured. These processes convert ambiguous and uncertain messages into organizationally workable procedures. It is the context in which this process occurs that will govern how information will be interpreted. Although supposedly the “facts” speak for themselves in science, the technical decision over when risk becomes a problem seems very much dependent upon institutional judgement as to what constitutes “sufficient proof.”

The Groundwater Research: Disqualifying bias

Three major groundwater studies were undertaken in the early 1990s in the Fraser Valley, in response to community health concerns, namely SCIDS. Two of the studies covered the wider area of the Fraser Valley just east of Vancouver whilst the Environment Canada study focused on the Abbotsford aquifer only. The former research studies were part of an extended groundwater testing program initiated by the provincial Ministry of Health. The first part of the study in this duo analyzed results collected between 1970 and 1990 by a variety of different local, provincial and federal government departments. Additional objectives included identifying potential risk areas with highest contamination potential, a prioritized list of pesticides for future

571 Clarke, 301.
573 Grinyer, 33.
574 Irwin, “Deciding about Risk,” 25.
575 Gartner Lee Limited, 5; Carmichael, Wei and Ringham, 1.
576 Discussed in Gartner Lee Limited and Carmichael, Wei and Ringham, respectively.
577 Discussed in Liebscher, Hii and McNaughton.
monitoring, and a compiled data base that could be easily updated.

The second part of the study was the result of recommendations made in the Final Report: Fraser Valley Ground Water/Drinking Water Study (1992) and saw the collaboration of the provincial Ministries of Health; Environment, Lands, and Parks; and Agriculture, Fisheries and Food. In a two-phase two year monitoring study, selected community and private wells were sampled for organic and inorganic constituents (1992 and summer 1993), and later for organic constituents only (winter 1993). In addition, site assessments for all study wells were conducted to locate possible sources of contamination as well as to identify areas with possible water quality concerns; preliminary capture zones for all community wells in the study were mapped out; and preliminary well protection plans developed. The Environment Canada study set out to review nitrate and selected pesticide concentrations detected in groundwater in south Matsqui and Abbotsford, using data collected between 1950 and 1990. Comparison of the results of the 3 studies can be found in Table 4.

Since 1978, sampling of groundwater in the Fraser Valley east of Vancouver has shown nitrate contamination. The Canadian Drinking Water Guideline for nitrate is 10mg/L, expressed as nitrogen (Nitrate-N). Each of the groundwater studies found nitrate contamination of the aquifers, with some concentrations above the Canadian Drinking Water Guidelines. Nitrate levels exceeding 10mg/L were found in areas where risk to groundwater was potentially highest. This included the Abbotsford aquifer south of Abbotsford. The Environment Canada study showed a trend towards “progressively higher groundwater nitrate contaminations over time,” supported by the results of the 1993 evaluation of groundwater by the Ministries of Health; Environment, Lands, and Parks; and Agriculture, Fisheries and Food.

Whilst monitoring and testing for nitrates had become routine over the past few decades,

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578 Gartner Lee Limited, 3.
579 High risk was identified as an unconfined aquifer used for municipal supply or extensive domestic use; surficial coarse-grained, highly permeable soils such as sand and gravel; high animal concentration; and a history of nitrate contamination above 5mg/L or pesticide concentration above drinking water criteria (Gartner Lee Limited, 14 & 26).
580 Other areas of high risk were south of Aldergrove, east of Langley around the Salmon River (Hopington), and southwest of Langley near Brookwood (Gartner Lee Limited, 29).
Table 4: Comparing findings from the three reports.

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<tbody>
<tr>
<td>Nitrates as nitrogen exceeding 1.0 mg/L</td>
<td>28% of wells tested</td>
<td>67% (49:73) (1989)</td>
<td>25% exceeded 3 mg/L</td>
</tr>
<tr>
<td>Nitrates as nitrogen exceeding 10 mg/L</td>
<td>2% of wells tested</td>
<td>6% of community wells tested</td>
<td></td>
</tr>
<tr>
<td>Pesticides</td>
<td>12 detected</td>
<td>12 detected between 1984 &amp; 1990</td>
<td>6 detected (6:75)</td>
</tr>
</tbody>
</table>

1. Analysis of data collected between 1970 and 1990 from wells in the Fraser Valley
2. Data collected between 1955 and 1990 from wells and piezometers in the Abbotsford/Sumas aquifer
3. Two year monitoring program of selected community and private wells, 1992 and 1993, with emphasis on 1993.

Sampling for pesticides is relatively recent. The Final Report: Fraser Valley Ground Water/Drinking Water Study (1992) indicated that twelve pesticides had been found in the data samples, none exceeding the maximum acceptable concentrations of the Canadian Drinking Water Guidelines. Positive pesticide detections can be found in Table 5. A few months later in the same year, Environment Canada reported pesticide contamination continued to occur in the Abbotsford aquifer south of the airport. 1,2 dichloropropane and 1,3 dichloropropane both exceeded the Washington State ground water quality standards (there are no standards for these pesticides for the Canadian Drinking Water Guidelines). The remaining ten pesticides (dinoseb, simazine,
## Table 5. Study wells in Phase 1 and 2 with positive pesticide detections

<table>
<thead>
<tr>
<th>Well No.</th>
<th>Phase of Study</th>
<th>Pesticide detected</th>
<th>Aquifer</th>
<th>Amount detected (mg/L)</th>
<th>Guideline/Standard (mg/L)</th>
<th>Nitrate-N Phase 2</th>
<th>Depth of Well Sampled (m)</th>
</tr>
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<tr>
<td>208</td>
<td>2</td>
<td>1,2-DCP</td>
<td>Hopington</td>
<td>0.5</td>
<td>20 (WHO)/5 (EPA)</td>
<td>14</td>
<td>42.7</td>
</tr>
<tr>
<td>209</td>
<td>½</td>
<td>1,2-DCP</td>
<td>Hopington</td>
<td>1.1/0.9</td>
<td>20 (WHO)/5 (EPA)</td>
<td>19.6</td>
<td>21.6</td>
</tr>
<tr>
<td>234</td>
<td>½</td>
<td>1,2-DCP</td>
<td>Abbotsford/Sumas</td>
<td>0.5/0.4</td>
<td>20 (WHO)/5 (EPA)</td>
<td>13.5</td>
<td>13.1</td>
</tr>
<tr>
<td>236</td>
<td>1</td>
<td>oxamyl</td>
<td>Abbotsford/Sumas</td>
<td>1.7</td>
<td>200 (EPA)</td>
<td>14.4 (Phase 1)</td>
<td>6</td>
</tr>
<tr>
<td>237</td>
<td>½</td>
<td>1,2-DCP</td>
<td>Abbotsford/Sumas</td>
<td>0.6/0.5</td>
<td>20 (WHO)/5 (EPA)</td>
<td>21.1</td>
<td>21.1</td>
</tr>
<tr>
<td>237</td>
<td>1</td>
<td>oxamyl</td>
<td>Abbotsford/Sumas</td>
<td>1.3</td>
<td>200 (EPA)</td>
<td>21.1</td>
<td>21.1</td>
</tr>
<tr>
<td>238</td>
<td>2</td>
<td>bromacil</td>
<td>Abbotsford/Sumas</td>
<td>1.4</td>
<td>none set</td>
<td>11.7</td>
<td>31.1</td>
</tr>
</tbody>
</table>

WHO = World Health Organization  
EPA = U.S. Environmental Protection Agency  
Phase 2 = Phase 2-Summer.

alachlor, atrazine, dimethoate, diazinon, chlordane, endosulfan, DDT, and carbofuran) were found in concentrations below the maximum acceptable concentrations of the Canadian Drinking Water Guidelines.⁵⁸³

The following year, 1993, pesticides were found in a total of six wells in the testing undertaken as part of the Phase 2 evaluation of groundwater quality in 75 selected wells in the Fraser Valley. All six wells were private wells, relatively shallow, located in agricultural areas in the Abbotsford/Sumas and Hopington aquifers. All six wells also had nitrate concentrations

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⁵⁸² From Carmichael, Wei and Ringham, Table 4.3, page 64.  
⁵⁸³ Liebscher, Hii and McNaughton, 45-65.
exceeding 10mg/L. Pesticide detections were below any Guideline maximum levels or standards.

The Fraser Valley Groundwater Monitoring Program: Final Report concluded that the overall water quality in the Fraser Valley was good. At the same time, the Report acknowledged that exceedences were present for nitrates, arsenic, fluoride, lead, total dissolved solids, chloride, sodium, pH, iron, manganese, copper and zinc. Nitrate was the main contaminant of concern. Pesticides and Volatile Organic Compounds were also detected but not at levels of any health concern.

The Environment Canada report, Nitrates and Pesticides in the Abbotsford Aquifer Southwestern Canada, suggested higher contaminant concentrations in the western and central sections of the aquifer with a trend of nitrate concentrations in the south Matsqui groundwaters gradually increasing with time. The persistence of the pesticide 1,2 dichloropropane at levels that exceed the Washington State ground water quality, despite it being withdrawn from use over a decade ago, was also signaled in the report.

Filtered Facts

The groundwater studies are indicative of an “objective” approach which is based on measuring individual chemical levels. The “safe” levels of individual chemicals in groundwater, presented as a-social, have been estimated in the social process of scientific practice. In addition, chemicals that have contaminated a water supply do not sit in discrete individualized areas within the aquifer, but combine. The synergistic effects of the chemicals are not considered, as the local specialist has pointed out. It was taken-for-granted that the “facts” would speak for themselves. Hence the groundwater, it could be concluded, was of good quality since only a small percentage of wells tested had nitrate levels exceeding the drinking water guidelines, and pesticides did not exceed any drinking water standard. The fact that many of the pesticides do not have drinking water standards is filtered out by the report and by the organizations making decisions based on

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584 Carmichael, Wei and Ringham, 33-40.
585 Liebscher, Hii and McNaughton, 63 & 64.
586 Carmichael, Wei and Ringham, 1.
587 Liebscher, Hii and McNaughton, i.
the reports.

Other factors not taken into account in the groundwater studies include the constraint of ninety days for reporting back in the Fraser Valley Ground Water/Drinking Water Study undertaken by Gartner Lee Limited. This limited the data able to be obtained from ministries and agencies. The data sample in this study consisted of the results of monitoring programs and other well samples undertaken by the various ministries, agencies and organizations involved in groundwater quality. Submission of data to Gartner Lee Limited, who were undertaking the study, was voluntary. Further, the data of the different organizations and monitoring programs had been collected at different times of the year, for different purposes and using different analytical methods. Data were collated in a variety of different, and usually incompatible, database programs. Some data had not been entered into the computer and required review of paper files. It is unlikely that all data available for study were included, and there was no indication as to whether the data that were included constituted a representative sample of all data available.

The Environment Canada study had narrowed its study sample since 1955, as the focus became the higher nitrate concentration areas in south Matsqui. Since 1984 groundwater sampling specifically for nitrates had been concentrated on the most severely impacted area of the Abbotsford aquifer. This poses problems in terms of comparison of results over time, and as an indicator of water quality in the wider aquifer.

The Fraser Valley Groundwater Monitoring Program, 1993, was also not without its problems. The community wells sampled were predominantly in low risk areas (60% of community wells sampled) whilst the private wells were located in predominantly high risk areas (51% of private wells sampled). These facts are filtered out of decisions about health, safety and risk. Filtering begins at the start of the research process and extends throughout it.

Methodological Claims-making

Numerical estimates based on the scientific practice of risk assessment have tremendous claims-making power. Methodology, the source of numerical estimates, therefore is a key aspect

588 Gartner Lee Limited.
589 Liebscher, Hii and McNaughton, i.
590 Carmichael, Wei and Ringham, 93-95.
of claims-making. Risk assessment methodology differed for the two claims making groups in this environmental controversy (see Table 6). Those experts with a pro-economic approach, that is the agrologist, the epidemiologists, the medical officer of health and the resident defended perspectives of health and economics.

The strongest...the strongest association that we can find for health, and I mean health in its human sense, my sense of health, is socio-economic determinants. So we go out there and we wipe out spraying and we get small berry disease out there, and we wipe out all these growers, those kids and those people are going to get sick. I know that. And I will be able to tell you what percentage...and stated by another expert.....

...speculating that farming is causing children in the community to be sick is a little reckless in our view, you need to have a bit more substance than what you've got to be damaging the reputation of the support industry in the community.

What had surfaced as a mere whisper in the media, the economic frame here becomes a much louder voice as this group of experts tie economy to health, measure it using the tools of science and in so doing, support the local agricultural industry and its practices. The assessment method used by this pro-economic group was epidemiology with the groundwater research as secondary. The epidemiology study was diagnostic, its intention to discern and record a cluster of symptoms, and to verify the diagnosis of SCIDS. The groundwater research was a response to the effect of the SCIDS group concerns on the local economy.

The focus of the pro-environment group, consisting of the SCIDS group, the local orthopaedic specialist, the toxicologist, and two hydrogeologists, was the environment and its impact on health. Methodology of choice was toxicology and groundwater research. The

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591 These are artificially defined groups, since no formal or official alignment or coalition existed between them. The local orthopaedic surgeon was connected to the SCIDS group by referring patients to them. The SCIDS group did contract the Florida toxicologist. One of the hydrogeologists had spoken with the local orthopaedic specialist about groundwater concerns. Together with the silenced hydrogeologist, they have been grouped for the purposes of this next section into the pro-environment group. Other experts, constituting what I have called the pro-economic group, supported each other in their statements in the media and in their interviews. Strongly valuing science and its ability to solve the conflict, they are also well networked with some of the experts from the pro-environment group, such as the local orthopaedic surgeon, and the silenced hydrogeologist.
Table 6: Summary of claims-making of the different groups

<table>
<thead>
<tr>
<th>Claims-making Attribute</th>
<th>pro-environment group</th>
<th>pro-economic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Claim</td>
<td>The syndrome SCIDS is caused by environmental toxins.</td>
<td>It is premature to link the environment to health symptoms when it has not been determined that SCIDS exists.</td>
</tr>
<tr>
<td>Risk Assessment Method</td>
<td>toxicology (chemicals)</td>
<td>epidemiology (health)</td>
</tr>
<tr>
<td>World View</td>
<td>egalitarian</td>
<td>hierarchical</td>
</tr>
</tbody>
</table>
| Risk Management Strategy| • reduction/elimination of contamination  
• precautionary principle | • education  
• communication |
| Claims making Style     | • emotive             | • authoritative     |
| Conclusion              | the contamination of the environment by low levels of chemicals has health effects | SCIDS does not exist, just different symptoms for different people |

hydrogeologists expressed concern about the declining quality of the aquifer. The toxicologist contracted by the SCIDS group was also concerned about environmental contaminants and their effect on the health of a sub-population. As stated in the newspaper, he told the community that they were being poisoned.

Whilst regulation and education of the agriculture industry was to be applauded, one of the experts with pro-environment sentiments proposed precautionary measures.

Set some precautionary measures......we don’t have absolute proof that this is a carcinogen or a mutagen but some work being done suggests it might be......why
not have people take some precautions and make sure this stuff doesn’t get in there...be cautious, take a precautionary principle until further research is available.

The precautionary principle “demands that the environment must not be left to show harm before action is taken.” This principle is a response to the uncertainty of science; science’s inability to determine with finality what is safe. It suggests that in the face of such uncertainty the better approach is to take precaution until it can be shown with certainty that not only is there proof of safety but also proof of lack of harm.

With regards the precautionary principle, one of the pro-economic experts has this to say:

But if by not eating those things you result in significant nutritional problems to the groups of people that you are now banning from doing that, then you may be creating far more illness and disease than you are preventing. And you have to show that in balance...cause we’re involved with some of the native bands who live on natural foods, and if...if you remove those then you really are damaging those people, and so you’ve got to be careful of your attribution here, and your “what if” philosophy. I mean we get into this all the time...is can you prove something can’t happen at some time in the future, and the answer is well I certainly can not, and I think its unlikely and you think its likely, but both of us however are prognosticating in the entrails of whatever is we examine for entrails, and its no different than prophesy.

The precautionary principle is the subject of much debate. It is also considered non-science. To take action before causal links are established by clear scientific evidence is not science. Science requires a null hypothesis, that events have a chance link rather than a causal one, within a chosen measure of probability.

The precautionary principle is considered an administrative and legal matter, with nothing to do with science, and in fact appears to have been proposed by civil servants in Germany in

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592 Wynne and Mayer, 34.
593 Of note is the 1854 case when a London, UK, physician, John Snow, noted that individuals who developed cholera obtained their drinking water from the Broad Street pump. Medical folklore tells that by ordering the removal of the pump handle, he halted an epidemic. It was not until thirty years later that Koch discovered the bacterium responsible for cholera. Knowing the mechanism of a disease is not necessary in order to prevent it (Ashford and Miller, 51). An early example of the precautionary principle perhaps?
594 Milne, 36.
1965 as the "foresight principle." It remains a source of debate, considered bad science or non-science by some, and ineffectual at the legal level because, it is said, there can be no absolute proof of safety or harmlessness.\textsuperscript{595}

Whilst the suggestion of the precautionary principle further illustrates the divisions between experts, other factors however, besides science, also come into play. Non-scientific, non-technical, social factors are also part of the construction of scientific and social problems, but are generally downplayed or made invisible altogether.

The (dis)passionate expert

Whilst the claims-making in relation to defining, naming and owning the problem was framed in terms of scientific/technical terms, in fact a number of other things were occurring that were obscured by the science frame. Experts were not dispassionate, but were very emotionally involved as they made their claims.

Discrediting of those associated with the SCIDS group is embedded in the language of the experts. Rhetoric can be extensively employed as a means of undermining the alternative viewpoint.\textsuperscript{596} As seen above, the toxicologist from the U.S. is referred to as a "quack," and his results as "crap."\textsuperscript{597} The local specialist is described as "lousy" at epidemiology.\textsuperscript{598} The founder of the SCIDS group is termed a "ringleader,"\textsuperscript{599} a negatively charged term implying someone who deliberately foments or provokes trouble. Another of the scientists negatively stated that she "was an interesting person to look at as an individual," and questioned her decision to stay in an environment where she was becoming progressively debilitated. She had been advised several times to leave, but had not.\textsuperscript{600} The implication is that she chose to stay and be a troublemaker. Further, her voice is mimicked at several points by one of the experts in an interview with him. This response by the experts is emotionally charged and conveys their sense of the SCIDS

\textsuperscript{595} Ibid.
\textsuperscript{596} Irwin, "Deciding about Risk," 23.
\textsuperscript{597} Interview with epidemiologist, November 1994.
\textsuperscript{598} Ibid.
\textsuperscript{599} Interview with medical officer of health, March 11 1999.
\textsuperscript{600} Interview with epidemiologist, November 1994.
founder as dishonest, a failure, and irrational: “an irritating reflection of scientific illiteracy.”

A sense of lack of respect for each of these individuals on the part of the experts is conveyed, as well as a discounting of their experience and knowledge.

Silencing

An effect of discrediting, or the threat to do so, is to silence the individual. This happened in differing ways to two of the experts in the SCIDS conflict. For the local orthopaedic specialist, the agrologist’s complaint to the specialist’s professional association quietened him publicly. He has this to say:

Well, here you don’t get any support. I mean it almost cost me my practice back then. So I’m not going to stick my neck out too much until we get this stuff definitely proven....

He remains convinced that there is something to be researched scientifically, and continues to work with Simon Fraser University to develop an objective technical test of the muscle weakness. He will not however speak publicly about his research.

Another expert was silenced for a period of time in relation to his analysis of groundwater samples from the Abbotsford aquifer. Other experts recognized this silencing. When asked whether the hydrogeologist was silenced, one expert had this to say:

he was sort of silenced....you know I’ve known him personally for a long time and I have a lot of respect for him and ahh....I got...when I prepared my paper, I said, can I quote you? No I’m sorry you can’t. But can I quote what the federal government has done? Yes you can I think that’s okay. So I could ahh....but he had actually had a draft paper that was out for a long time and he was very frustrated he couldn’t get it released. And so.

The draft paper referred to is the groundwater research report, *Nitrates and Pesticides in the Abbotsford Aquifer Southwestern British Columbia*. The agrologist also knew of this silencing.

We put together a six agency co-ordinating committee consisting of provincial and federal Ministries of Health, Environment and Agriculture to share and let each other know kind of what, what they were up to, because I think that was one

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601 Williams and Popay, 134.
of the problems with the federal hydrolgeologist's report was that ah, it was sort of, ah, ah, putting other government agencies possibly in a difficult position, ah, and sort of notion, look lets not blindside each other. Lets at least share with each other what we're up to and what we're about to publish so that we can have some input or some comment or at least have a heads up. And so that was where, I think ah, it wasn't so much in any way trying to muzzle or silence or scuttle what the federal hydrogeologist was up to, it was just that his report as was written I think, would have ah, was going to fan some of the concerns and ah, lets make sure we have it so it comes out in a way that, not to be, undersell the situation or hide anything but in a way that doesn't necessarily cause disturbance or panic, well, panic is probably too strong a word, but concern.

This silencing had far reaching effects however, since it extended to the federal hydrogeologist's non-availability for interview. When asked to be part of the dissertation study sample, he agreed on two occasions but later withdrew each time. He had this to say at the time of withdrawal:

I am unable to be interviewed at this time. It's too politically dangerous. There is a lot of coverup, with ongoing degradation of the Abbotsford aquifer. I've been employed with the Federal government for 24 years, and have witnessed the degradation happening. I want to shoot my mouth off, but need my job. I can confirm that a gag order was applied to me during the SCIDS case.

The local specialist too commented on the hydrogeologist's silencing.

He was saying that yes, there are these pesticides and nitrates in the water and that the government agencies that were testing were saying no, no, no......Not only that, he knew about that two years before hand. But they said that if he talked he walked. So he wasn't allowed to say anything.

Mistrust of experts

For the local orthopaedic specialist, notifying the health department of the SCIDS issue, his quest for research funding and research advice, his involvement in the epidemiology study and the complaint to the B.C. College of Physicians and Surgeons resulted in a mistrust of government and other experts and their knowledge. After discussing the problems that he saw in the epidemiology study, and countering them with his own insights, he has this to say:

So, you know, white lies, black lies and damn statistics fit right in there, you
make them believe what you want. So I... I have gross distrust in these people now.

This distrust further surfaces as he talks about the epidemiologist and health department officials. The local specialist claims that the epidemiologist was hand in glove with a chemical company, that his research was biased by this involvement (he gives several examples of what he sees as the misconduct of the epidemiologist in this regard), and that he came to the epidemiology study already decided that the SCIDS patients were “liars,” and therefore had decided the results before the research took place. His comments stand as a mirror image of the negative perceptions of himself and the SCIDS group held by the health officials.

Evident in the local specialist’s talk is a sense of betrayal that accompanies mistrust. He expected that those with the task of protecting public health would do so. He expected a responsibility on their part similar to the responsibility that he felt he had shown in bringing the issue to the health officials and experts. This mistrust of government and other experts increases his silencing, now self-imposed as he chooses not to divulge anything of what he is doing with regards to researching SCIDS. Collusion with their patients against the medical profession is unusual, and as we have seen, has consequences.

Returning the Diagnosis to the Patient: Public issues back to private troubles

Contesting social problems is a process that takes place both internally within the scientific discipline and externally in public as the scientific frame is brought to bear on those whose views are to be overturned. The scientific frame however is manifested in a context of emotion, personal attack and silencing. The authority of the scientific frame filters out these aspects and they may remain invisible to the public.

In the course of “talking past each other,” any opportunity for dialogue between experts on behalf of both the risk creators and the risk bearers is lost. The social meaning of environmental threats and attendant risks is not taken into account. Unilateral decisions are made by experts on the basis of objective facts to the exclusion of those possessing other relevant information.

Kroll-Smith and Floyd note that in their sample of one hundred and twenty one people, only nine reported supportive physicians who respected their accounts of environmental illness. They also note that their sample was not random and that a self-selection bias may be present, especially by those who wished to express anger at the medical profession (p.96, fn2).
To name the problem is to suggest a structure to deal with it. SCIDS was named by the local specialist in response to the demand of the Ministry of Health when informed of the problem. The structure for resolution as denoted by the acronym SCIDS however was not accepted by the authorities. To “own” a social problem is to possess the authority to name it a “problem” and to suggest what might be done about it. To name the problem infers the power to marshall resources to help solve the problem. To own the problem implies speaking for the interests of the public (“society”) and for those one is acting towards.

In naming and owning the problem, the local specialist pointed to the potential failure of public institutions to fulfill their obligations to the public, specifically the obligation to protect the environment and the health of present and future generations. The social trust usually enjoyed by institutional actors, experts, was under question; the experience for the lay public was the difficulty in knowing whether or not they were indeed safe. Alternate and highly conflictual responses were inflamed. Trust in authority had to be wrested back. What was expected to be an uncontested meaning was transformed into a political contest.

Science was the frame within which the contest took place. However, although the frontispiece was science, the contest was fought emotionally with name calling, attacks on the person and serious efforts to discredit individuals. It was science however that had the final say. The finding that SCIDS did not exist on the basis of an epidemiology study returned the social problem to the individuals who suffered its symptoms.

As a private trouble rather than a public issue, the problem now resided within the character of the person. Those suffering a pattern of symptoms named SCIDS were now each individually ill but not with the same complaint. Somatic Chemically Induced Dysfunction Syndrome, a public issue, a social problem, no longer existed. The trouble and its resolution were returned to the individual as a biographical entity. It was now located in the individual’s immediate milieu, not in the wider public arena. Each individual’s symptoms were now a private matter, and a matter of personal experience.

It is difficult to describe the effect of being told you are not really ill when you

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603 Gusfield, “Constructing Ownership,” 432.
are. The disjuncture between private experience and public image is so severe, you can easily become obsessed with establishing the truth. The degree of discomfort felt so intensely in body and soul at such a fracture could itself be a subject for psychosomatic medicine. As certainly as a kind of epiphany is achieved with naming, a shock of recognition that can be physically felt, so also an equally intense and negative shock is experienced with misnaming. It is a sinking feeling, something like missing a train for a journey that is not at all casual. You are left hanging. Disoriented. Strangely lonely. Though this will not be a peaceful solitude. You will be followed into your privacy by the phantoms of rejection and even ridicule for what your body continues to know. The sound of these phantoms may be inaudible, but it will be distracting enough to erase your own voice, to quell any attempt to articulate even for yourself what it is you experience. And this is a serious loss because it is this voice, the intelligent and observing companion to feeling, that dignifies even the worst misery.606

Returned to the individual, the public issue is depoliticized, drawing attention away from the institutional and structural aspects that had previously been implied in the acronym and in the framing and counter-framing of the problem. It was the sick individual who was deficient; not the expert or the institutions assigned the stewardship of public health and the environment.

However, returning the trouble back to the person was only the first step. Trust had still to be regained; and the lay public to be educated to remove erroneous perceptions. Project EnviroHealth was birthed to do just this, and is the subject of the next chapter.
CHAPTER SEVEN: MANAGING SCIDS: EMBEDDING AND SECURING THE SCIENTIFIC/TECHNICAL FRAME

Government is confronted today with the heightened concerns of individuals and groups in relation to the potential dangers in the environment. These concerns are precipitated by the advances and complexities of technology. Government in particular is assigned stewardship responsibilities, expected to ensure that the health and well-being of the population is not harmed. Increasingly decision-makers find themselves involved in managing environmental controversies and conflicts.607

Controversies, conflicts, outbreaks of concern are disruptive of community. Absence of trust and commitment, and loss of civility may be the result. Civility is a necessary component of a functioning community. Civil behaviour is described as respectful, deferential and gracious, of extending the self towards others. Repetitions of respectful, extending behaviour express and reaffirm the safety of public places. However, environmental issues, especially that involve perceived threats to human health, often lead to a loss of civility as the sense of safety and of community is called into question. Just as Sartre suggested that we need to forget our bodies in order to go about the world (passed-over-in-silence), so too is it necessary to have the same taken-for-granted “passed-overness” with regards the environment in order to undertake meaningful social interaction that is respectful and self-extending, that confirms physical space as safe.608

Civility consists of reaching out and establishing secondary ties, of emotively controlled public encounters, and a willingness to apprehend the past and the future of others, their biography, in social interactions. Boundaries between safe and dangerous environments are matters of personal and public concern. As the environment is perceived as dangerous, social interactions become emotively charged. People voice their fears of contamination, of pollution, of loss of property values for example. There is also the realization that the community is no longer a source of nurturance. The contraction rather than extension of the self in social

607 Cole, Tarasuk, Frank, and Eyles, 352; Jennifer Brown, 2.
608 Sennett, 136-148; Kroll-Smith, 377-396.
interactions and an unwillingness to recognize the biography of others reinforce not only the erosion of civil life but also are instrumental in returning the public issue to the person, obliterating it from the collective consciousness and refusing recognition of its incorporation into the biography of self.

In order to reconstitute the community as safe, to allay the fears that accompany loss of civility, and to restore civility itself, a number of management strategies, culminating with Project Enviro-Health, were put in place by the provincial Ministries of Health, Agriculture and Environment, ostensibly to manage a specific environmental conflict, that of SCIDS.

The chapter begins with an overview of the early management strategies, strategies that were important in embedding the science frame. Central to this is a document that appears to be key to the two main Health strategies. “Guidelines for Investigating Clusters of Health Events” disseminated in the *Morbidity and Mortality Weekly Report*, July 27, 1990, informed both the epidemiology investigation of SCIDS and shaped some components of Project Enviro-Health.

The second section of the chapter is devoted to Project Enviro-Health. The section begins with the Project co-ordinator’s narrative description of the Project and the rationale for its creation. Project Enviro-Health, more than any other strategy, hammered the final nail in the coffin of SCIDS. For although it was the epidemiology report which tolled the death knell for SCIDS as an entity, it was Project Enviro-Health that ensured it would not be resurrected. Whereas the early management strategies asserted the primacy of the science frame, it was Project Enviro-Health that secured it.

I

**Embedding the Science Frame**

The social construction of SCIDS as a social problem involved the deliberate juxtaposition of, on the one hand, emotional, subjective belief systems and on the other hand, dispassionate, objective systems of fact and truth. This dichotomy played itself out in the management of SCIDS. As with entry into the SCIDS conflict, management of it was cued by the specific focus of a particular government ministry, although some strategies were co-ordinated across government ministries. Groundwater research, sustainable farming practices, an epidemiology report, and finally, Project Enviro-Health were measures enlisted to manage the
environmental conflict.

Three major groundwater studies were undertaken in response to community health concerns in the Fraser Valley. The *Fraser Valley Groundwater Monitoring Program: Final Report*, 1995, Executive Summary states

In response to public concerns over impacts of land use activities above groundwater supply sources (aquifers), a 2-phase evaluation of the groundwater quality in 192 community wells and 75 selected private wells in the Fraser Valley was completed between 1992 and 1993.

The Introduction section in the same document elaborates further on this topic.

In the Fraser Valley, public concerns over degradation of groundwater quality have been raised due to apprehensions about quality of drinking water and land use activities over aquifers and around wells.

and

Public health concerns, international cross-boundary contamination issues with the Abbotsford/Sumas aquifer and detections of nitrate concentrations exceeding the Guidelines for Canadian Drinking Water Quality (GCDWQ) led the B.C. Ministry of Health in 1991 to initiate a preliminary study.

The contamination of the aquifer by nitrates had been known for some time, and was reported in one of the groundwater reports.

Evidence of nitrate contamination from agricultural manure stockpiles or improper manure application has been detected in ground water monitoring carried out since 1978.\(^{609}\)

That this was a well known fact was also confirmed verbally by one of the government experts

I mean, we certainly were aware of, ah, nitrates in the groundwater, certainly in this aquifer and other aquifers long before this issue came up so it wasn’t news to anyone.

With the concerns expressed by some residents however, government began to close ranks and ministries cooperated in an attempt to resolve the discontent. The link between groundwater and SCIDS brought a response from the Ministry of Agriculture. The agrologist states

the [local specialist] as I recall had identified some kind of illness that was affecting, I’m not sure if the entire population or mostly young girls, I think, and ah...he pointed towards environmental causes, air and water, and...ah...ah...I

\(^{609}\) Gartner Lee Limited, 3
think started to make a link between SCIDS and the quality of water in the ground water, that’s I think when I got called in, our Ministry did...ah...and ah...there’s a response, there was an assistant deputy minister level committee of, consisting of the Deputy Ministers of Environment, Health and Agriculture...ah...at that time, my Assistant Deputy Minister of Agriculture was run by a man named [...] who, who’s retired and he was at that time my boss and I was sort of the, I guess the technical support to him...ah...on this, on this issue.

With an in-depth investigation of the presence of nitrates and pesticides in the aquifer over two or three years, government could indicate that they were responsive to citizen’s concerns as well as putting fears about contaminated groundwater to rest, regaining faith in the government’s role as stewards of the environment.

The research confirmed what was already known about the quality of the groundwater.

I think the conclusion of the studies was that there are three aquifers that we already know about as having nitrate, three sort of significant aquifers [Abbotsford, Hopington and Brookwood], those were well-known and were verified. I don’t believe any other significant nitrate contamination was found...ah...and certainly no pesticide contamination was found, although there were some some detects of certain chemicals that...ah...probably came from pesticides, they certainly were not anywhere close to drinking water standards......based on that...ah...it was, you know, sort of our approach to ah...ensuring and trying to ensure that farmers used sustainable farming practices with, sustained as the correct approach and ah...that’s the approach we’re using to this day.

The Ministry of Agriculture’s response then was an education program to implement sustainable farming practices. Not all farming groups were responsive to this initiative, however. The poultry farmers, fingered in official reports as well as newspaper articles as major contributors to the nitrate contamination, were credited by the agrologist with doing a “tremendous job” to turn around their farming practices, especially in relation to the storage and stockpiling of manure.

One that was targeted in this area was called, is called The Sustainable Poultry Farming Group, and a credit to the poultry farmers in operation to this day...ah...it employs...ah..the key person running the show is our key advisor and administrator by the name of [...] he’s done a tremendous job in, in co-operation with, certainly with the poultry producers, they collectively I think have done a
real good job at coming to terms with the issues, and the concentration of the
animal waste over this vulnerable aquifer, the need to deal with excess manure
and ah...so he’s, he’s got quite an ambitious program of transporting manure
from there to be used at cropping systems elsewhere.

But, another key farming group with regards groundwater contamination hadn’t come to the
party.

Now we haven’t been as successful in ah....working with the raspberry growers,
unfortunately they’ve kind of sorted some of their internal politics out and have
reformed ah....revitalized a a ah...a raspberry growers organization, now
collecting funds through a compulsory check-off, having the processors level
contribute, to go back to a pot of money to go back to whatever they, market
and promotion etc and hopefully they’ll contribute some money towards an
environmental program. So that’s the other producer area that hasn’t been as
active or as progressive as the poultry farmers have been.

Concern about the voluntary nature of the program however, is expressed by the
agrologist. Yet while acknowledging that the vulnerability of the aquifer requires extensive
protection as far as farming practices is concerned, he notes at the same time that the agriculture
industry will not tolerate government interference.

More needs to be done, now whether or not, in the end, these kinds of voluntary
educational approaches will actually get to the, you know, absolutely get to
where we need to get to or or if there is some more constraining kinds of
regulatory approaches need to be brought in I don’t know, obviously the
industry is, the agriculture industry is going to say no no we can get to where we
need to without government stepping in and being heavy-handed with all we
farm, whether that’s true or not, I, I don’t know. You can make a powerful
argument both ways....where you’ve got highly vulnerable... whether its this or
fisheries, some fisheries resource, or whatever...highly vulnerable
environmental resource, you know it begs the question whether you can afford
the luxury of a completely voluntary approach to, now I wouldn’t like to say
that its completely voluntary, there is a code, there is a regulation that these
farmers have to abide by, its called the Code of Practice and in our view if
farmers comply with the code we’ll clean the aquifer up, so in the enviro-view,
and in the industry too, is we’ve got the laws, all the laws that are necessary to
clean it up, its one of getting the information out there and maybe in some cases,
increase, increasing enforcement if that’s what necessary.

Education is considered by the agrologist as a more beneficial route than enforcement. The private hydrogeologist doesn’t share this view. Whilst he too acknowledges the importance of education, he also believes there is a need for enforcement measures. Here he has previously discussed the cost to gas stations of cleaning up contaminated soil, and the imperative of economic incentives

...whether there is a huge economic incentive, but you got to turn this around, what about the farmers? You’ve gotta ask, can that same analogy there.....is there a big consequence? Unfortunately there is not. There is this, well you might have contaminated a neighbour’s well, or you may have had a small amount but it is such a nebulous thing. There is no monitoring done to say it definitely came from your property and you have mismanaged it on your property.

He also suggests that it is necessary to have someone looking over the farmer’s shoulder so-to-speak, since economic incentives can work both ways

...but gee if someone’s not watching why don’t we just double the rate [of manure application] and get rid of it a heck of a lot more quickly and I can make a heck of a lot more money...and the farmer probably doesn’t care, initially anyway because he’s thinking well, the organics system, its good for the top soil

In the end though it is evidence that will indicate whether an incentive is working, whether that be an education or economic incentive

...the Ministry of Agriculture people work very closely with the farmers and farmer groups and they try to educate them but....from a professional point of view I would really like to see...if they’re saying they are doing a good job well give me some water quality data that shows they’re doing a good job.

Environmental management emerged as the new conventional wisdom following the revelation in the 1960's that economic activity was damaging to the earth, and in turn damaging human health and economic activities themselves. Sustainable development, which suggested that with proper management of renewable resources and control of pollution it would be possible to sustain economic growth, was the preferred solution to this problem.

It was the United Nation’s 1987 Brundtland Commission report, *Our Common Future*, which presented the sustainable development formula. Improved management of the
environment would increase the renewable resources from the land and sea; and improved
efficiency in the use and re-use of energy and materials, and reduction of pollution would be
assisted with technological innovation. Indefinite economic expansion was possible if
government, business and the public played their parts.\textsuperscript{610}

The wise and moderate use of natural resources was not new to Canada. In 1915, the
Canadian Commission of Conservation, created in 1909, suggested that while each generation
had the right to capitalize on the interest from nature's capital, that this capital had to be
maintained as it was for future generations to enjoy and use similarly.\textsuperscript{611} However, tension exists
about both what sustainable development means and how to implement in practice such a
concept. The Canadian Commission of Conservation 1915 statement is an example of strong
sustainability. Here, natural capital stocks would be held constant independently of
manufactured capital. Others however, advocate the substitution of manufactured capital for
natural capital. With this latter, weak sustainability position for example, the destruction of a
forest would be given the go-ahead as long as the resulting income is put into factories thus
continuing to ensure jobs.\textsuperscript{612}

Sustainable farming practices put in place by the Ministry of Agriculture gave the
economy and industry dominance over ecosystem and human well-being. Market forces rather
than government's regulatory role is the controlling factor.\textsuperscript{613} Farming is made sustainable with
the introduction of measures to ensure less leaching of nitrates into the aquifer. It is a program of
education that is voluntary, not enforced nor regulated except as a code of practice, devised with
a view to not ruffling the sensitivities of agri-business. Not all farming groups could be made to
comply, and the farming group that was described as the worst offender for contamination of the
aquifer had not yet complied with the voluntary code several years after the SCIDS conflict. A
code of sustainable farming practice was a technological quick-fix to a system (groundwater) that
was monitored, subject to surveillance, its ongoing degradation known, yet not the subject of
concern until a community group brought it to public attention. However, this green patina of

\textsuperscript{610} Clow, 85.
\textsuperscript{611} Vaillancourt, 222.
\textsuperscript{612} Wackernagel and Rees, 31-60.
\textsuperscript{613} Gibbs, 187.
sustainable practice was intended to satisfy both those coming from an environmental position and those individuals and groups concerned about the economy. Government was able to show it had taken a responsible stance with regards its stewardship responsibility and accountability.

The contamination of the aquifer is but a side-effect of necessary economic growth for community prosperity. Reducing the side-effect will, in this view, sustain both the aquifer and the economy. While science was a necessary instrument to measure contamination of the aquifer, it had shown there was nothing to be very worried about, hence no need for more than a voluntary code of practice to satisfy the public concern and to provide a show of faith and responsibility by government. It was an initial step at regaining the trust and confidence of the public and making the community a safe place again. Loss of civility was beginning to be addressed.

Working with farmers to reduce contamination of the aquifer, and undertaking groundwater research to examine the extent of aquifer pollution tackled only the groundwater aspect of the problem. In so doing, the external causation by the SCIDS group and supportive experts is legitimated, albeit in “silence.” The reactive measures of government to municipal and business level concerns about the portrayal of the community and possible detrimental economic effects were never publicly acknowledged as a response to the concerns expressed by the SCIDS group.

Beyond the groundwater, a group of people who were responsible for the negative portrayal of the community required managing. An early management strategy was the epidemiology study.

Interviewer: The solution in terms of the SCIDS case was Project Enviro Health was it not?

Medical Officer of Health: Well, partly, the solution really was the epidemiology study.

A document published by the well-respected U.S. Center for Disease Control, “Guidelines for Investigating Clusters of Health Events” disseminated in the Morbidity and Mortality Weekly Report, July 27, 1990, was part of the tool kit used by the epidemiologists and
medical officers of health involved in investigating SCIDS.\textsuperscript{614} One of the epidemiologists stated that

\textit{...we used the basic outline of the Center for Disease Control cluster investigation which is published in the MMWR among other places.}

This is reiterated in the report to the Director of the Environmental Health Protection branch of the B.C. Ministry of Health.

\textit{The approach to the investigation of this cluster was patterned after the outline described by the Centres for Disease Control in Atlanta, USA.}\textsuperscript{615}

It is essentially a set of practices for managing communities in which clusters of health events are perceived. The Guidelines point out the difficulties of cluster investigations.

The unofficial consensus among workers in public health is that most reports of clusters do not lead to meaningful outcome. Often a "case" is not clearly defined, and the "cluster" is, in fact, a mixture of different syndromes. Frequently, no exposure or potential cause is obvious, and--to make the investigation even more difficult--there are many possible causes.

Even so, community relations must be maintained through management approaches which include a sensitivity to the psychology of the situation, an understanding of the principles of risk-perception, a recognition of the functions of public media, and an awareness of potential legal ramifications of the investigation.

That the public is difficult to deal with is noted.

From a public health perspective, the perception of a cluster in a community may be as important as, or more important than, an actual cluster. In dealing with cluster reports, the general public is not likely to be satisfied with complex epidemiological or statistical arguments that deny the existence or importance of a cluster. Achieving rapport with a concerned community is critical to a satisfactory outcome, and this rapport often depends on a mutual understanding.

\textsuperscript{614} "Guidelines for Investigating Clusters of Health Events" were developed by a working group following a two-day conference (1989) on the clustering of health events, sponsored by the Center for Disease Control, the Association of State and Territorial Health Officials, and the Agency for Toxic Substances and Disease Registry, and reviewed by an expert panel and the conference cosponsors. Those involved in the working group and as reviewers of the Guidelines are listed in footnotes to the preface of the Guidelines. Authorship is not assigned to the Guidelines as published in \textit{Morbidity and Mortality Weekly Report}, July 27, 1990.

\textsuperscript{615} "An Investigation into a Cluster of Muscle Weakness in the Fraser Valley," British Columbia. February 26, 1992.
of the limitations and strengths of available methods.

Rapport with the community is to be gained by understanding the individual and community psyche.

Investigators of clusters should understand the various ways in which individuals respond to stressful situations and react to uncertainties. Investigators also should be able to recognize the source of inevitable community suspicions (e.g., of deliberate delay and cover-ups) and demands (e.g., for the unrealistic allocation of resources and schedules). Investigators should respond to these suspicions and demands without hostility and should be able to diffuse them. Finally, investigators must be aware of and responsive to the fact that a perceived problem must be resolved responsibly and sympathetically, even if no underlying community health problem or cluster of disease truly exists.

A key management strategy is to incorporate “concerned groups and individuals” in the health response.

The health agency should consider the establishment of an advisory committee (or similar group) to oversee the decision-making process for evaluating clusters. Such a committee might include representatives from the health agency, other government agencies, private and voluntary sectors, concerned citizens’ groups, and the media, as well as selected individuals. This committee should provide oversight, guidance and advice to the Program Director. The duties should be carefully specified a priori and agreed to by the committee members. Since the committee is likely to consist of persons with diverse backgrounds, the main focus should be on overseeing the process rather than on making technical decisions.

Further, collusion of concerned groups and individuals as part of the advisory group is to be enhanced before the investigation begins by agreement of the appropriate and acceptable levels of excess. This, the Guidelines state, “will facilitate acceptance of the results.”

The Guidelines are positioned on the dichotomy between the perceived and the real. The public perceive, the expert has access to the real. Therefore, the public require a management process that overturns their poorly-informed perceptions and illuminates the real. At the very least, they must be convinced that scientific fact is more real than their own unscientific understanding.
People’s faulty perceptions of risk are considered the result of ignorant, misinformed minds, prey to deception and fear by irresponsible and unrepresentative political activists and the media.\textsuperscript{616} Perceptions, however, are people’s positions on risk or about some event. It is through an individual’s own reflective practices, accumulated and assimilated over a lifetime of experiences, together with their wider interaction and communication within a social milieu that perceptions are produced, re-produced and revised. The use of personal experience, individual awareness and interpretation, and available information lead to a rationally developed position about any event, risk or hazard. Yet experts believe the lay public to be misinformed, irrational and to misperceive risk, which leads them to shape strategies to redirect a misguided public and reveal the real facts of the situation.\textsuperscript{617} The use of a community advisory committee for the epidemiology study would do just that. If members of the lay public were part of an overseeing process which included an understanding of the science of epidemiology and risk and an agreed-upon level of excess, then the wider public’s fears could be somewhat allayed.

At the first community advisory committee meeting the members were introduced to the two epidemiologists who were to conduct the investigation. Committee members consisted of the Chairman of the Upper Fraser Valley Union Board of Health, a representative each from the Central Fraser Valley Union Board of Health, Healthy Communities, and the SCIDS group, the Director of the Abbotsford Mental Health Centre, the Medical Officer of Health from the Upper Fraser Valley Health Unit, and a teen representative with SCIDS. Including in the community advisory committee the individual who had been most vocal in the media about SCIDS and its causal connection with the environment was a coup d'état so-to-speak. Her acceptance of the epidemiology study results based on her written agreement of level of excess would effectively silence her. One of the epidemiologists clarified why they had formed a community advisory group and the group’s role.

Because he and [the other epidemiologist] have no community roots, he explained why they need the community group to represent the community and provide input and support. He indicated that the committee will be involved in the primary evaluation of the results and will be asked to provide a judgement

\textsuperscript{616} Macgill, 48  
\textsuperscript{617} Lupton, 432
The steps voted on and accepted by the community advisory committee in their meeting approximate those in the Guidelines. They were first, to establish a case definition for Fraser Symptom Complex and test it for reliability; second, to have an independent musculoskeletal expert examine several classic cases; third, implement a questionnaire to collect descriptive information from cases; and four, to include a review of data from [local specialist's] previous research. One of the epidemiologists suggested to the committee that an objective test such as an EMG was preferred but not possible because of the time and expense required to do so. The plan was to complete the basic work of the investigation by the end of February before one of the epidemiologists left the country.

At the completion of the epidemiology study, the community advisory committee provided its recommendations to the provincial Minister of Health, the Honourable Elizabeth Cull. The recommendations reiterated the epidemiology results, that the case definition based on the local specialist's test was not reliable and did not warrant further investigation, but that there was a group of people with significant illness and a variety of diagnoses that required support and treatment. Appropriate resources were called for.

The letter to the Director of the Environmental Health Protection branch of the B.C. Ministry of Health which accompanied the epidemiologists' report stated how useful it was to have worked with the community advisory group, and recommended this as a strategy for future such investigations.

I wish to thank you and the officials of the Ministry for your support. Working with a community advisory group was a useful experience and contributed to our ability to approach this as a community problem. Without the community support, we would not have been able to complete the study as planned. Utilizing a community advisory group is an approach that we would recommend

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618 Fraser Symptom Complex Community Advisory Committee Minutes, January 6, 1992: 3.30pm, Abbotsford Health Unit.
619 Recommendations from the Fraser Symptom Complex Community Advisory Committee to the Minister of Health. Attachment to Agenda for Meeting Honourable Elizabeth Cull, Minister of Health with Upper Fraser valley Mayors, Thursday March 12, 1992, 4.30pm Red Baron Restaurant.
for further studies of this type.\textsuperscript{620}

A number of issues continued to be of concern even though SCIDS as an entity no longer existed. A meeting between community leaders and the Minister of Health in March 1992 attempted to address these. They involved the credentials of the Florida toxicologist who had been contracted by the SCIDS group and who, at a public meeting in February 1992 had strongly alleged that toxic substances found in commercial chemicals in use in the Fraser Valley were linked to human illness.\textsuperscript{621}

Concern was raised that he had provided false information about the wide use of prohibited chemicals in the Valley and that “the public had a right to the facts.” Earlier concerns about the toxicologist’s credentials had been raised after his report back to the community.

The Florida toxicologist’s business webpage <http://www.richardlipsey.com/> advertises his services as an “expert witness for plaintiff and defense; onsite inspections/sampling of laboratories, offices, factories and homes; research of personal injury from chemicals, drugs or alcohol; training for professionals and government representatives; analysis of chemical labels, warnings and MSDS sheets; and review of federal and state regulations.” He has “worked closely with Fortune 500 corporations, government agencies, nonprofit organizations” as well as individuals. From both his webpage and other documents\textsuperscript{622} can be gleaned that he has a PhD in Toxicology from the Department of Entomology at the University of Illinois, was a Professor of Toxicology at the University of Florida, and a resident expert in poisoning at the Environmental Protection Agency (EPA), and is currently Professor of Toxicology and Entomology at the University of North Florida. A number of endorsements from judges, deputy attorney generals, attorneys and clients, both on his webpage, and a legal chatboard <http://www.counsel.net/chatboards/torts/>, speak of him as “a credible and believable” expert in his field, a thorough and rigorous scientist, “impartial,” “simply follows the science no matter who it favours (defense or plaintiff)” and a “very good” witness. He is listed in the Expert

\textsuperscript{620} Correspondence accompanying the epidemiology report to Mr. A. Hazlewood, Director, Environmental Health Protection, B. C. Ministry of Health.

\textsuperscript{621} Fraser Valley Update. B.C. Ministry of Health, Communications & Education. March 16, 1992.

In addition to concerns about the Florida toxicologist, it was agreed by those present at the meeting with the Minister of Health that there was a need to sever the "suspected or alleged" link between human illness and the environment until there was scientific evidence to verify or discount it. To pursue the search for an environmental cause for a group of people with a variety of undefined/undiagnosed illnesses would be costly and unproductive. At the same time, there was a call for less fragmented collection of environmental data by government and for increased environmental monitoring and reporting of results. It was reported by a Whatcom County mayor that

a region west of Lynden is currently having to have water trucked in because
their water supply is unfit to drink due to contamination from chemicals used by
raspberry farmers in southern B.C.

Air pollution, and the collection of better population health data were issues also raised. A communication/education program by provincial government was recommended and the Upper Fraser Valley Union Board of Health given the mandate to develop a plan and budget for an environmental health community action plan.

This official narrative from the minutes of the meeting between community leaders and the Minister of Health was portrayed differently by one of the experts, however. Community concern about the environment and health had provided the opportunity for the Health Unit to garner funding to investigate issues which were also of concern at a wider level than the local and implicated in Canada-United States relations.

At the end of the study [epidemiology] though, there was the opportunity to fund a project to look at some of this stuff. That became Project Enviro-Health. We kept getting asked questions, they didn’t go away. We have the international committee with regards the Abbotsford aquifer, we have the pollution from cars coming up the Valley. Getting some money up front allowed us to look at and respond to some of these things in detail. The Project consisted of experts and bureaucrats working with the public, and seemed a good model.

Project Enviro-Health was also considered a political solution to inter-departmental concerns the

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Health Unit faced.

...and [medical officer of health] he just thought its an opportunity to get some money to bully the environmental health department 'cause they kept getting asked questions about lots of things right, so, this isn't going to go away, we've got this international committee with water and our people are down there, there's not going to be an end to it, to look at this and then we'll respond to all those questions, so that helped.

The additional work that the SCIDS case had brought about could be funded through a project focussed on this topic. Not everyone was happy with this decision. One of the epidemiologists complained that the Project was funded far in excess of what was provided for the epidemiology study.

well, the Ministry went on and set up the support group. Not to be unduly cynical, they kicked in about four times more than it cost to do the study...which was difficult...we were pulling teeth to try to get that done...for a year...and put full-time people on....you know...etc etc....okay...next time, next time we come through this we're going to be talking a different order of magnitude here....but yeh, that's essentially what they did, and that was their response and that was basically [medical officer of health].

Others, in this case the agrologist, recognised that the mistrust of experts and government had to be reversed.

The government response to SCIDS was Project Enviro-Health. It cast SCIDS and the health-environment thing into a broader context of environmental quality, taking a citizen-based approach to give guidance to government about what should be done with air, water, and so on. At the time, the government expert was viewed with suspicion by the public, seen as putting a particular spin on information to make government look good. Even if we were telling the absolute truth, we weren't believed because of this mistrust of government experts. Project Enviro-Health seemed a good model to counter this: a publicly-based group to which experts could present information in a way that could be examined, questioned, queried, filtered so that the public could have faith in both the information and the expert seemed to us a reasonably decent model. As experts, our only job is to tell the truth; really all we have to sell is objective truth.

Providing the opportunity for the public to critically evaluate both information and experts is
presented as the route to regaining the community’s confidence and trust.

II

Project Enviro-Health: Securing the Science Frame

Residents of the communities in the Fraser Valley have expressed concern about the degradation of the environment and its effects on their health. Environmental and health groups have been very active and have received considerable attention from the media. At times the information provided by representatives of these groups and their advocates has been incorrect or misleading, causing unwarranted fear and distress.

To address these concerns, the Upper Fraser Valley Union Board of Health has contracted with the B. C. Ministry of Health through its Health Services Society to establish a project to investigate environmental health issues using a community development process and with the support of a Health Assessment Unit. This project is called “Project Enviro-Health” with a motto of “Ensuring a Healthy Environment through Community Action.”

The Director of Project Enviro-Health describes the experience of creating and maintaining a project to contain an unruly group of residents and to provide the community the lens through which to see and understand environmental and health problems. He has a degree in biochemistry from the University of British Columbia, Vancouver, B.C., and was at the time of interview completing a Masters in Public Administration through the University of Victoria, Vancouver Island. Following his description is an overview of the Project as described in its quarterly and annual reports.

A few years ago the SCIDS issue came up...the toxicologist from the States, the local orthopaedic surgeon from here. Had a lot of people asking a lot of questions, and the municipality and the province, not having a lot of answers available to them....readily available, they may have been stored in some data somewhere, but it wasn’t available, they couldn’t answer some of the questions, so they decided to do a few things...one is the [Health Services] Society decided to set up this project...to look at it not only just to investigate, but also to get out some of the correct information because the toxicologist, the toxicologist from the States, came up and cried on TV and was telling quite a few erroneous statements...literally said everyone is poisoned in the Fraser Valley so people employed by the Society wanted to get correct information out. So this project arose basically out of those problems that existed at that time.

That was only one component of it, the SCIDS issue, that was

just one component....'cause the statement was made, these people are ill, there's no question of that...what it was they didn't know...what was causing it, but they made a great leap into it being in the environment, whether it was water, air, pesticides, whatever, they said that was the cause and just believed it...because a physician said so...so that was...was providing a lot of grief in the area 'cause...people would phone and they'd say well I want to know this and I want to know that, and you'd just have to tell them that this just did not exist, this particular disease as it was defined, Somatic Chemically Induced Dysfunction Syndrome (SCIDS).

It was named by the people in the group. You see, there's five pages of symptoms on this SCIDS thing, and people are diagnosing other people over the phone....and there are lots of things going on, so....the project stems from 'let's get the right information out there', and the other part of that, 'let's just see in the Valley what the problems are from people's point of view'. First, lets have them identify issues...of environmental health, so what are the issues, let the people identify them, lets have a group of people that will investigate those issues to first of all determine if they are...that's just the public's perception or if it is a real issue. If it's a real issue, lets set a priority list and we'll investigate as directed by people in the Valley, so the Society established a committee structure throughout the Valley. We set up five local committees to get local input about local concerns.

The committees depend upon the people involved. The Chilliwack group for instance is a little eccentric, a little too far one way and not the other. There are also divisions within groups, for example, some people left the Central Fraser Valley group because they didn't agree with what was happening.

One of our objectives is to set up a database of environmental factors that impact human health. That we haven't really got to yet. Do literature searches, use scientific journals...we're doing phase one of a groundwater monitoring program....air quality trends....with database...use studies that are being done by people at UBC...try to use studies and break it down and interpret it for people and what it means for them.

As Project employees we don't make any decisions, the community does. The Project does the investigation, research, takes the results back to the respective committees and asks them what they want to do about it. Then when it goes forward to the different levels of government, we can say it already has community support, rather than selling it from the top down.

Public awareness is essential. And by public awareness I mean generally and specifically making people aware of the problem, aware of what they can do, and provide them with alternatives. It's in providing the alternatives that we sometimes fall short. I used to enjoy guest hosting a talk show on radio, and would bring in federal and provincial people on air quality, groundwater, that sort of thing. My philosophy is to provide the most correct and most recent information possible. The radio show was one way to do this. I also wrote a column for the local newspaper, because again, you get the story out there first, and you get it right, then people have a tendency to read that rather than the stories that follow.

Why do you have an information campaign? Its because you want to make some sort of impact. What impact do you want to have? You want to change the way people contaminate groundwater say. You want to have behavioural change. I work backwards in developing this. I
look at the outcomes that are needed to make the impact, I look at the
target audiences, and then I develop different strategies for the
different groups based on where, what level they’re at. The outcome
is the goal, and it goes one step further than public awareness. I
mean, I wouldn’t be able to claim that the aquifer is all cleaned up
because of what we did, but if we all work on it together and not
worry about who gets the credit, then we should be able to get it
done.

We didn’t get to address health issues because we didn’t have the
expertise to do so. Health was part of our hyphenated name, Project
Enviro-Health. We’d have people phone us about spillage of oil or gas
in a well, for example, or about a bee population mysteriously dying,
but we couldn’t ever go to actual diagnosis, treatment or questions on
health itself because it was out of my area of expertise. The extent
that health was addressed was when a medical expert who worked with us
for a few months looked at nitrates and found they had a different
effect on aboriginals. Pesticides we didn’t pursue because there
weren’t any exceeding the health standards. Now, you’re correct in
pointing out that for most there are no standards. You can look at the
US guidelines, those of the World Health Organization, those of
different countries. They’re all different. Which do you choose? If
I was a resident I’d choose the lowest level. But what does that
number mean? That’s questionable. We can probably drink nitrates for
example at much higher levels than the 10mg/L health standard. We
also don’t know the synergistic effect of having several pesticides in
your water.

The Project’s process was a stumbling one at the beginning.
There was supposed to be a team in place, but it didn’t materialize
until one month before the Project was supposed to end. It never
really got off the ground. I have an equation—expectation minus
satisfaction equals dissatisfaction, and that’s what we had at times
in the beginning. We didn’t have the expertise, and when we did, they
worked on just one among a myriad of problems. We could have set up a
medical panel I guess, but our approach was not to deal with the SCIDS
problem. Basically, I wasn’t there to deal with the SCIDS problem, I
was there to determine what people were concerned about as far as
environmental health issues were concerned. What did people want to
do about those issues? What suggestions did they have? As we began to
address these local concerns, we became a service, with people phoning
us, so we went beyond our mandate. We had one stop shopping. We
didn’t have all the answers, but we’d find them.

In response to the frustration, anger and fears of residents regarding the effects of the
environment on health, Project Enviro-Health was established in December, 1992 by the Union
Board of Health and the Health Services Society of the Upper Fraser Valley. The concern of
local residents with groundwater quality, especially the presence of nitrates and pesticides in the
Abbotsford aquifer; the “unwarranted public alarm” from “many unsubstantiated allegations” by
the Somatic Chemically Induced Dysfunction Syndrome (SCIDS) group, transmitted through the

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media and at public meetings; and the possible cross-boundary contamination of the south flowing aquifer and the impact of this on the international agreement between the province of British Columbia and the state of Washington, were the principal reasons that ushered in Project Enviro-Health. The Final Report (1995/96) describes the events that brought Project Enviro-Health into existence.

A local orthopaedic surgeon was diagnosing in some of his patients what he termed Somatic Chemically Induced Dysfunction Syndrome (SCIDS). This syndrome, he maintained, was attributed to a breakdown of the central nervous system, specifically interference of messages from the brain to the nerves. The symptoms exhibited by these patients were similar to those of influenza, allergies and Lyme disease.

A support group, the Somatic Chemically Induced Dysfunction Syndrome (SCIDS) Society was formed by a number of patients diagnosed with the syndrome in August 1991. The local orthopaedic specialist was at the time also actively seeking funding to pursue research of the syndrome. Both his and the SCIDS society’s concerns received considerable press coverage.

In 1992, a study of the syndrome by two University of British Columbia epidemiologists concluded that although a case definition for SCIDS could not be made, people exhibiting these symptoms were ill. It was suggested that a variety of diagnoses might explain the symptoms. Also in 1992, a Florida toxicologist, contracted by the SCIDS society, announced in a public meeting that people had been poisoned with toxic cancer-causing chemicals in the air, water and food. A press conference with health providers shortly thereafter did not stem the increasing numbers of people joining the SCIDS society, nor allay their concerns. Patients stated that they had not been provided with any alternative explanation for their symptoms. Their fears seemed supported with the groundwater report in June 1992 that nitrates above safe drinking water standards and traces of pesticides were found in the Abbotsford aquifer.

Later in 1992, as a result of the University of British Columbia (UBC) study, the Ministry of Health was negotiating to establish an environmental health SWAT team at UBC, which would investigate controversial problems and trends in the Fraser Valley. Some

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627 In the 1993/94 Annual Report, reference to international concerns regarding the contaminated aquifer is omitted. The raison d'etre in 1993/94 for Project Enviro-Health is the anger and concern of residents, and the irresponsibility of the media in providing incorrect and unsubstantiated information. This latter aspect, an irresponsible media, remains a common theme in the three Annual Reports and the Final Report of Project Enviro-Health. It is however addressed as being remedied through the Project’s elaborate communication strategy, and written out as one of the reasons for the Project’s existence by the Final Report.

Purpose and Objectives

Improving environmental health in the Valley through community action was the Project’s primary purpose. Residents were to be empowered by the Project. As a mechanism for residents to voice their concerns about the environment and its impact on their health, residents would “take ownership” of issues as informed players in the community decision-making process. A community survey to ascertain environmental health issues, the implementation of a community-determined communication strategy, community committee structures to identify and investigate local environmental health, and a database of key environmental factors impacting human health were to be put in place.\(^{629}\)

Structure of Project Enviro-Health

A hierarchical committee structure was designed. The Project was overseen by the Upper Fraser Valley Union Board of Health and Health Services Society, and was given direction by the Environmental Health Steering Committee. Several committees advised the Project: a Community Environmental Health Advisory Committee, local Environmental Health Action Committees, and Environmental Health Technical Advisory Committees.\(^{630}\)

The Health Services Society was conceived in 1990 by the Upper Fraser Valley Union Board of Health as a mechanism to access additional resources for public health programs for the region. The same board existed for both the Upper Fraser Valley Union Board of Health and the Health Society, and comprised six councillors from six municipalities, five trustees from five school boards and a director from the Fraser Valley Regional District. This group created Project Enviro-Health and negotiated funding with the Ministry of Health.\(^{631}\)

The Environmental Health Steering Committee consisted of the six municipal councillors from the Upper Fraser Valley Union Board of Health and Health Services Society, a Medical  

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\(^{630}\) Project Enviro-Health: 1995/96 Final Report to the Ministry of Health. Appendix C.

Officer of Health, and the Program Manager of Environmental Health. This group designed the committee structure of the Project. Referred to as the “hub and spoke” model in the Final Report, two levels of committee were devised. To oversee local communities a Community Environmental Health Advisory Committee was to consist of the Steering Committee members plus three representatives from the agricultural community, one representative from the Chamber of Commerce, two representatives from the general public living in Abbotsford, one representative from the Central Fraser Valley Union Board of Health, and attendance and representation as appropriate from Langley municipality and the mayors of Sumas and Lynden, Washington, U.S. This committee was charged with providing the focal point for community participation, ownership and ultimately resolution of environmental health issues in the Fraser Valley. It was to provide direction and support for the Project, and act as the hub, with which other committees would interact. The local committees were to provide submissions and proposals of environmental health issues brought to them by citizens and organizations; the technical advisory committees would provide recommendations for action on environmental health issues as requested by the Community Environmental Health Advisory Committee. Dissemination of information as well as gathering of concerns was to be conducted through a communication plan that was to include public forums, and the local committees.632

The Local Environmental Health Action Committees were to be established by the standing municipal councillor on the Upper Fraser Valley Union Board of Health in each community: Matsqui, Abbotsford, Chilliwack, Agassiz, Harrison, and Hope. Four local committees were formed, with some communities combining on one committee: Abbotsford-Matsqui; Agassiz-Harrison; Hope; and Chilliwack. Membership was to consist of major stakeholders in agriculture, industry, business, environment, health, local government and community, and was to be volunteer. The local committees were to hold public forums to gather environmental health concerns presented by community groups and individuals, to disseminate information about environmental health, and to make recommendations through the chair of the committee (the municipal councillor) to the Community Environmental Health Advisory

632 Project Enviro-Health: 1995/96 Final Report to the Ministry of Health. iii, 4-6 & Appendices C & D; Project Enviro-Health: 1993/94 Annual Report to the Ministry of Health. Appendix C.
Committee.\textsuperscript{633}

In operation, the Local Environmental Health Advisory Committees often did not include all the identified major stakeholders (see Table 7). For example, the 1993/94 Annual Report listing of the Abbotsford-Matsqui local committee indicates that a First Nations and a school district member were yet to be assigned, and no general public/community representative was

\textbf{Table 7. Membership of Local Environmental Health Action Committees (LEHAC) 1993/94 \& 1995/96.}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|c|c|c|c|}
\hline
\textbf{Membership\textsuperscript{634}} & \textbf{Abbotsford-Matsqui} & \textbf{Agassiz-Harrison} & \textbf{Chilliwack} & \textbf{Hope} \\
\hline
Councillor(s) & 2 & 3 & 2 & 4 & 1 & 1 & 1 & 2 \\
Environment & 2 & 2 & 2 & 2 & 1 & 2 & 0 & 0 \\
Agriculture & 1 & 2 & 1 & 1 & 1 & 1 & 0 & 0 \\
Industry & 2 & 2 & 0 & 0 & 1 & 2 & 1 & 1 \\
Medical/Health & 2 & 2 & 1 & 1 & 1 & 1 & 0 & 1 \\
School District & 0 & 0 & 1 & 1 & 1 & 1 & 1 & 1 \\
First Nations & 0 & 0 & 1 & 1 & 1 & 0 & 1 & 1 \\
Business & 0 & 1 & 1 & 2 & 1 & 1 & 1 & 1 \\
Local Government & 2 & 3 & 1 & 4 & 1 & 2 & 1 & 2 \\
Community & 0 & 0 & 1 & 3 & 0 & 0 & 4 & 5 \\
Project Enviro-Health Coordinator & 1 & 1 & 1 & 1 & 1 & 1 & 1 & 1 \\
Science & & & & & & & & \\
\hline
\textbf{Total Membership} & 12 & 16 & 12 & 21 & 10 & 12 & 11 & 15 \\
\hline
\end{tabular}
\end{table}

\textsuperscript{633} Project Enviro-Health: 1993/94 Annual Report to the Ministry of Health. Appendix D; Project Enviro-Health: 1995/96 Final Report to the Ministry of Health. 5 \& Appendix E.

\textsuperscript{634} Some memberships are counted more than once, since it is possible some people will represent more than one category. For example, a councillor may also represent local government.
included. The 1995/96 Final Report indicates that representatives for these categories had never been appointed and remained unrepresented on the committee. For this same committee, Abbotsford-Matsqui, poultry farmers were the sole agricultural representatives; development and construction constituted the stakeholders for industry, and a physician represented the medical sector. A representative of the Healthy Communities Committee and the Deputy Chief Environmental Health Officer of the Abbotsford Health Unit were constant members throughout the Project’s existence. In 1995/96, a realtor is an additional member, presumably for the business sector which was not represented until that time, and the Dean of Arts and Sciences of the University College of the Fraser Valley also joined the committee. The Abbotsford-Matsqui Committee membership increased in number from 12 to 16 between 1993/94 and 1995/96.635

Increase in membership occurred in all four local committees. The three other committees also included more of the identified stakeholders who were absent on the Abbotsford-Matsqui committee. Chilliwack, Hope and Agassiz-Harrison included First Nations as well as School District members, and Hope and Agassiz-Harrison committees had more than one member representing the local community. Membership in all the committees averaged at 16 members in 1995/96, up from an average of 11.25 members in 1993/94.

Technical Advisory Committees were also established to provide advice to any of the other committees as requested. These committees consisted of the Program Manager of Environmental Health, representatives from the Ministries of Health, Environment, and Agriculture, a representative from each of Environment Canada and Whatcom County Planning (Washington, U.S.), and others as required.636

A project coordinator and a four member assessment unit staffed the activities of Project Enviro-Health. However, until nearly the end of its second year of existence, Project Enviro-Health consisted of the coordinator only, with some accounting support. The Project was fully staffed for a short period of four months of its existence, in 1994. That staff consisted of a physiologist, an environmental biologist, a chemist and an office assistant.637

Environmental Health Issues Identified

Regional as well as local environmental health issues were identified through the local environmental health action committees. Committees met regularly through the year, and held an occasional public forum.

The first Annual Report, 1993, produced after just a few months of Project Enviro-Health's existence, identified a number of concerns at both the local and regional level which continued to be issues of concern throughout Project Enviro-Health's existence. Table 8 provides an overview of these issues and their continuity over time. Groundwater contamination with pesticides, degradation of outdoor ambient air quality, and animal waste and fertilizers were the major regional concerns and groundwater contamination from mining operations; pesticide use; housing developments and a proposed feldspar mine on Sumas Mountain were the predominant local concerns.

Major recurring issues were identified in the Final Report, 1995/96. These are presented in Table 9. Outdoor air quality was the major concern of residents. Emissions from vehicles, especially private and heavy duty (diesel) vehicles, from industry, anthropogenic activities and natural sources are identified as the key sources of outdoor air degradation. Outdoor air quality problems in the Fraser valley airshed are exacerbated by weather patterns. In the summer, residents face increased ozone and particulate matter blown up the Valley from the Greater Vancouver Regional District. Obscured mountain ranges, and air advisory warnings make this a grim reality. In winter, air quality is impacted as high winds blow sand and dust from river beds, and smoke is emitted from household wood fires and outdoor burning to clear

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638 Vehicles produce approximately 85% of the five major pollutants in the Fraser Valley airshed (Project Enviro-Health Final Report to the Ministry of Health 1995/96, 10).
639 The private automobile is responsible for 73% of the five major pollutants (Project Enviro-Health Final Report to the Ministry of Health 1995/96, 10).
640 Emissions from heavy duty (diesel) vehicles account for 20% of particulate matter air pollution in the Fraser Valley (Project Enviro-Health Final Report to the Ministry of Health 1995/96, 10).
641 Up to 40% of particulate matter under 2.5 microns in size is produced by bulk shipping, wood products, cement works, and other products (Project Enviro-Health Final Report to the Ministry of Health 1995/96, 10).
642 This refers to human activities such as burning, landfills, and space heaters for example (Project Enviro-Health Final Report to the Ministry of Health 1995/96, 10).
643 Growing and decaying vegetation, forest fires, and volcanic activity emit hydrocarbons, nitrous oxide (NOx) and sulphurous oxide (SOx).
Table 8. Environmental Health Issues reported and investigated by Project Enviro-Health for the years 1993-1995/96.

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<tbody>
<tr>
<td>Groundwater contamination</td>
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<td>Outdoor air quality</td>
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<td>Pesticide use</td>
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<td>Mining proposals</td>
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<td>Housing developments</td>
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<td>Household hazardous wastes</td>
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<td>Biomedical waste disposal</td>
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<td>Treatment of drinking water</td>
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<td>Indoor air quality</td>
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<td>Septic systems</td>
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<td>Underground storage tanks</td>
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<td>Public awareness &amp; education</td>
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<td>Impact of agriculture</td>
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<td>Sulphur pile</td>
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<td>Gas station soil contamination</td>
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<td>Sawdust/Road dust</td>
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<td>Odours</td>
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<td>Overhead transmission lines</td>
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</table>

**Key**

- Issues investigated by year

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644 Annual Report of Project Enviro-Health to the Ministry of Health by the Upper Fraser Valley Health Services Society, March 31, 1993, 1.


Table 9: Major environmental health concerns raised by Local Environmental Health Action Committees over Project Enviro-Health’s term.\(^{648}\)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Abbotsford-Matsqui</th>
<th>Chilliwack</th>
<th>Agassiz-Harrison</th>
<th>Hope</th>
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<tbody>
<tr>
<td>outdoor air quality</td>
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<td>groundwater quality</td>
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<td>indoor air quality</td>
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<td>pesticides</td>
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<td>solid waste</td>
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<td>public awareness &amp; education</td>
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<td>liquid waste &amp; septic systems</td>
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<tr>
<td>impact of Ryder Lake proposal</td>
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</tbody>
</table>

Key

\(\text{\blacksquare} = \text{concerns raised}\)

land, agricultural and yard waste.\(^ {649}\) Groundwater is the only source of drinking water for many Fraser Valley residents.\(^ {650}\) Not surprisingly it ranked as one of the main environmental health

\(^{648}\) *Project Enviro-Health: 1995/96 Final Report to the Ministry of Health*, 24-26

\(^{649}\) *Project Enviro-Health Final Report to the Ministry of Health 1995/96*, 11.

\(^{650}\) Clearbrook Water District, the former District of Abbotsford, and residents of the city of Abbotsford living south of Highway 1 draw water directly from the Abbotsford-Sumas aquifer. Wells in the same aquifer serve as back-up when the second water source for the urban areas of the former District of Matsqui, Norrish Creek, requires maintenance or has problems. Other Districts in the Fraser Valley draw drinking water from other major aquifers (*Project Enviro-Health Final Report to the*
concerns. Nitrates, pesticides and volatile organic compounds from surface activities had been found, in several studies, to have contaminated the Abbotsford-Sumas aquifer. Other aquifers in the Fraser Valley were either at the time the subject of testing or had never been tested for contaminants. Both home and workplace were identified by residents as the source of concerns about indoor air quality. Noise, smells, moisture, particulate matter, and unknown biological organisms in indoor living and work environments together with symptoms of fatigue, headaches, general muscular aches, respiratory and/or gastro-intestinal problems were the subject of complaint to Project Enviro-Health.

The use of pesticides, especially in agriculture, their migration to groundwater as well as the drift from aerial spraying, and the uncertainty and lack of answers regarding SCIDS had created a highly suspicious public. Significant media coverage of the SCIDS issue was reported to have contributed to this public distrust. Related to pesticide use and groundwater contamination were concerns about agricultural practices. Poultry, swine and dairy are the major forms of animal farming, and animal waste products, used in raspberry, blueberry and strawberry farming, were considered the source of most aquifer nitrate contamination. The Sustainable Poultry Farming Group had implemented a program to send poultry manure for use on crops to sites outside the aquifer area. The province had introduced two bills, the Code of Agricultural Practice for Waste Management, April 1, 1992, and The Farm Practices Protection (Right to Farm) Act which addressed using, storing and managing agricultural waste and the education of farmers on these practices. A monitoring process was also incorporated in which farmers were to inspect other farmer’s situations. This latter aspect has been duly criticized as inadequate, as has the lack of BC Environment officers to monitor compliance with the Act. Further, the presence of the pesticide 1,2 dichloropropane in the groundwater had been linked to an expanding raspberry farming business. In addition to animal waste, hazardous household,

\[\text{Ministry of Health 1995/96,12).}\]

\[\text{These studies have been undertaken by Agriculture Canada, Environment Canada, B.C.}\]

\[\text{Ministries of Health, Agriculture, Fisheries and Food, and Environment, Lands and Parks (Project Enviro-Health Final Report to the Ministry of Health 1995/96,12). The Reports from these studies are discussed in more detail in later chapters.}\]

\[\text{Project Enviro-Health Final Report to the Ministry of Health 1995/96, 12 & 13.}\]

\[\text{Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, 13.}\]

\[\text{Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, 15 & 16.}\]
construction and demolition, and biomedical solid wastes were identified by residents as being of concern.\textsuperscript{655}

Research undertaken by Project Enviro-Health

Some of the concerns raised in local committee meetings and public forums were pursued by the Assessment Unit of Project Enviro-Health. The quality of groundwater, specifically of nitrates, was investigated through monitoring programs, as well as indoor air quality and contaminated sites.\textsuperscript{656}

Investigation of an aquifer in the Agassiz area showed nitrate contamination in rural areas from land use activities. Benzene was also detected at sixty times the concentration of the health standard in another Agassiz well following complaints of a gasoline smell from her well by a resident. A nearby gasoline station was the suspected source. Other nearby wells sampled had benzene concentrations at lower than the health standard. The well owner was provided with a new well. The results from one well (twenty-two were sampled) in another aquifer in the Columbia Valley indicated nitrate concentrations approaching the health standard.\textsuperscript{657}

Staff and students at an elementary school in Abbotsford complained of being ill eight months after the school opened. Tests conducted by the University of British Columbia Epidemiology Department resulted in advice about changes to the ventilation system and its operation. Later changes were made as other problems arose.\textsuperscript{658}

Parents of students feared the impact of poor air quality on their children and requested a study be undertaken. The Risk Assessment and Toxicology Section, Health Protection and Safety Division of the Ministry of Health, and the University of British Columbia Epidemiology Department stated that there would be little conclusive evidence from such a study. On the advice of the British Columbia’s Premier’s office no study was undertaken. Additional air quality problems were investigated at an Abbotsford Mall, and at MSA Manor.\textsuperscript{659}

Site evaluations and water tests were conducted to investigate potential cyanide and

\textsuperscript{655} Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, 14.
\textsuperscript{656} Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, 18.
\textsuperscript{657} Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, 18 & 19.
\textsuperscript{659} Ibid.
arsenic contamination from a local gold mine, and wells were tested for sulphur contamination from a pile of sulphur that had been stock-piled in temporary storage for seventeen years. No contamination was found in each of these instances. The acquisition of sewage sludge and its application on cottonwood plantations on Carey Island in the Fraser River was investigated at the request of concerned residents. Project Enviro-Health worked with B.C. Environment, local governments and companies remediating contaminated gasoline sites.\textsuperscript{660}

Communication Strategies

As one of the key objectives of the Project, a communication plan was developed and implemented. The purpose of the plan was to raise awareness of Fraser Valley environmental health issues among identified stakeholders through a two-way exchange of information and provide "the most recent, relevant, correct information on issues of concern" for residents. Referred to as risk communication, Project Enviro-Health engaged in two strategies: calming people and exciting or scaring them. At times, according to the Report, it was necessary to calm people down, for example following the discovery of radon gas in some homes, while at other times, people needed to be scared or excited about serious health threatening issues, such as elevated nitrates in the groundwater, or smoke from outdoor fires.\textsuperscript{661}

Groups of stakeholders in the two-way exchange of information identified were the general public; the agriculture industry; advocacy groups; pesticide, fertilizer and chemical manufacturers; various businesses, especially those using chemicals (dry cleaners, printers), or involved in waste disposal, or potential soil contamination; the construction, petroleum, and transportation industries; developers and planners; airports; the various levels of government; schools; and the media. The exchange of information seemed less than two-way, and more directed to dispersion of information from the Project to, and amongst, stakeholder groups, except for the general public. For this latter group, both identifying and communicating environmental concerns as well as receiving and understanding information about them does fulfill an interactive exchange between themselves and Project Enviro-Health. This however was not expected of other stakeholders. They were implored to employ practices which reduced

\textsuperscript{661} Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, 22.
environmental problems, whether this be agricultural methods to prevent contamination of soil, groundwater and air, or sell products that cause the least contamination, or make use of the best “environmentally friendly” products. Behaviour modification was the goal in the interests of protecting the environment; as well as support, promotion, information and education with regards attitudes, approaches, environmental practices and preventative measures.\textsuperscript{662}

The Local Environmental Health Action Committees (LACs) and public forums were a key part of the communications plan. The LACs met between eight and eleven times over the term of the Project, and public forums were held once in both Hope and Chilliwack, twice in Agassiz, and three were held in Abbotsford.

The media played an important part in the overall plan. Previously castigated by Project Enviro-Health for erroneous reporting of issues based on information from the general public\textsuperscript{663}, the media become a major means of disseminating “recent, relevant and correct” information. Newspaper articles were written by the Project Co-ordinator, newspaper advertisements publicized Project sponsored events, press conferences were held to release and explain groundwater monitoring studies in the Valley, radio talk shows were hosted by the Project Co-ordinator, and the Project was promoted on local cable television programs.\textsuperscript{664}

Information about Project Enviro-Health was further disseminated through the presence of a staffed display booth and with a variety of brochures and display material garnered from sources such as government departments, environmental groups, businesses and industry at many public and community events, such as agricultural fairs. The display booth was aimed not only at providing information, but also to receive information about environmental issues from the public. The idea of the display booth at community events was stated as based on a philosophy of “going where the people are.”\textsuperscript{665}

A twenty minute video about Project Enviro-Health and the main environmental health issues was created and used at public displays as well as being distributed to various

\textsuperscript{662} Project Enviro-Health: 1993/94 Annual Report to the Ministry of Health, Appendix H, 1-3.
\textsuperscript{663} Annual Report of Project Enviro-Health to the Ministry of Health by the Upper Fraser Valley Health Services Society, March 31, 1993, 3.
\textsuperscript{664} Project Enviro-Health: 1993/94 Annual Report to the Ministry of Health, 15.
organizations. The Project Enviro-Health office was also available for calls, providing information and investigation of issues brought directly to their attention.\footnote{Project Enviro-Health: 1993/94 Annual Report to the Ministry of Health, 15 & 16.} Presentations to organizations and the general public, lectures at Simon Fraser University, seminars at the University of British Columbia, and participation in local and regional committees and workshops as well as liaison with special interest groups, representatives of government at all levels in both Canada and the United States, private industry, community and agricultural associations were undertaken by the Project Co-ordinator.

The 1993/94 Annual Report and 1994/95 First Quarter Report informed that the Project had been using a variety of sources of information for researching issues of concern. Computer databases and printed information were available to other Ministry of Health departments. Coordination was proposed to avoid duplication of materials. The Final Report 1995/1996 makes no mention of a database, but does state that Project Enviro-Health primarily focused on the first two objectives. Establishing a database was the third objective.

Recommendations

Recommendations to the Ministry of Health by Project Enviro-Health fell mainly into the key areas identified as having been of concern for residents: outdoor air quality, groundwater, indoor air quality, pesticides, agriculture, solid waste, contaminated sites, and public awareness and education. Additional recommendations were made about land use planning, disease prevention, jurisdiction, indeterminate fatigue-related syndrome and about Project Enviro-Health itself.

Recommendations focused largely on the environment, rather than health per se, although links with potential health consequences were made. Monitoring in most key areas of concern was recommended, and responsibility for doing so placed with government at the appropriate level. Environmentally detrimental practices were discouraged, and the need for alternatives voiced. The need for information to be readily available to the public about the quality of either products or natural resources was recognized. Education programs and public awareness campaigns were recommended. Industry was called upon to undertake research to eliminate
environmentally unfriendly products and practices and their replacement with “green-friendly” alternatives. It was recognized that legislation was needed for the protection of some resources, such as groundwater. The provincial government was urged to establish a resource centre to diagnose and study “indeterminate fatigue-related syndrome,” and to retain Project Enviro-Health or a similar organization.  

**Re-defining the problem**

Project Enviro-Health was established to manage the excesses of an environmental conflict. The conflict itself had, by this time, been managed with a variety of methods, however the residues of public mistrust and an out-of-control media required taking in hand. To do so, the problem had to be re-defined, and the solutions outlined.

The problem that brought Project Enviro-Health into being was the SCIDS group, a self-help and support group for people and their families suffering, or potentially suffering, from Somatic Chemically Induced Dysfunction Syndrome. The vocality of the leaders of this group, and the media’s interest in them, so we are told in Project Enviro-Health’s annual and final reports, led to misinformation to the general public and subsequent “unwarranted public alarm.” Membership of the SCIDS group continued to increase, even after the UBC epidemiology study declared the syndrome did not exist.

Managing this problem required a mechanism to counter the “unsubstantiated allegations” and the “misinformation” that was coming from the SCIDS group via the media. An elaborate system of citizen-based committees and an integrated communications package located in an organization with science and expert based authority was put in place. Retaining the grass-roots aspect was important. As the 1993/94 Executive Summary of the Annual Report states, residents were to “take ownership of environmental health issues” through the local community committees, the public forums, and via phone calls to Project Enviro-Health’s office. Project

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668 Annual Report of Project Enviro-Health to the Ministry of Health by the Upper Fraser Valley Health Services Society, March 31, 1993, 3.
670 Annual Report of Project Enviro-Health to the Ministry of Health by the Upper Fraser Valley Health Services Society, March 31, 1993, 3.
Enviro-Health provided “one-stop shopping” for residents’ environmental and health concerns.\textsuperscript{671}

Despite the intention of a grass-roots base, committees however did not consist of the general public and lay person, but experts and authorities in prescribed areas. Whilst the membership of some committees did include up to three community members, these members were outnumbered by the preponderance of members representing (and generally specialist in) a substantive area, such as industry, agriculture, and business. These members were charged with identifying concerns from their areas, and thus were spokespersons for that area, rather than for the general community itself. This was a more paternalistic and top-down approach for the committees, contradicting the aim of the Project to empower residents to take ownership of their environmental concerns. Further, these committees were originally to be short-lived, but to be reconvened as necessary as further environmental issues arose. Implicit here is that environmental issues were not to be defined by the community through the committees, since the committees would not be continuously accessible for doing so.

The public forums and direct contact by phone with Project Enviro-Health’s offices may have provided an easier route for the community to voice their concerns. Public forums however were not well attended, and were occasional. Anywhere from approximately fourteen to approximately fifty people attended these occasionally held public forums.\textsuperscript{672} Direct calls to the Project office are not discussed as a separate item in the Annual Reports so no indication of number of calls and concerns from the general public is provided.

The perceived problem with the media was overcome by implementing a process in which the Project Co-ordinator wrote newspaper articles, penned a newspaper column, held press conferences and hosted a radio talkback show. Information about environmental concerns was now controlled by government and channeled through Project Enviro-Health.

Although the SCIDS group and the media were originally defined as the problem for which Project Enviro-Health was established to manage, throughout the existence of the Project, and interactively with the community committees and residents, the problem was redefined to become that of the environment. Whereas the SCIDS group, including the physician diagnosing the syndrome, had linked their symptoms to the environment, essentially a health problem with

\textsuperscript{671} Project Enviro-Health: 1993/94 Annual Report to the Ministry of Health, 4.

\textsuperscript{672} Project Enviro-Health: 1995/96 Final Report to the Ministry of Health, Appendix H.
environmental causes, by turning this on its head and focusing on environmental concerns for which investigations and remedial action could be undertaken, and information and education of the public be provided, the fear for personal safety and of environmentally-caused embodied risk could be defused.

This was however a top-down approach to the perceived problem, as it was a quasi-government organization that was responsible for addressing environmental issues. Although considered by Project Enviro-Health itself as a grass-roots or participatory approach, and had the elements of such an approach such as education and local responsibility for the local environment, this management strategy was vested in a particular issue, SCIDS, and the prevention of future such groups/issues/conflicts arising. It was a band-aid approach to fix a problem. It rested on the idea that the cause of the problem was lack of scientific knowledge. To be a grass-roots approach, the whole community would be involved, the concern of a group of citizens about the state of the environment acknowledged, and shared responsibility between the community, industry, organizations and government for problem-solving around issues about the state of the environment accepted.

Defining Problems, Constructing Conflicts

The early management strategies of sustainable farming practices, groundwater research and the epidemiology study as well as Project Enviro-Health shaped and constructed the problem. Social problems, Gusfield (1989) suggests, are perceived as experienced by “troubled persons,” are of a deplorable nature, and able to be relieved by state agencies. The “troubled persons” industry was spawned with the welfare state to define and bestow benevolence upon problem populations. These benevolent professionals are the experts who convey that a situation exists, or not, whether or not we are aware of it. The discovery, diagnosis, and treatment of the said detrimental social problem is discerned from some specialized knowledge of it which is superior to popular belief. Science and/or objective research is generally the authoritative knowledge upon which social problems are defined as real. In part accepted because they are espoused with the authority of science, these definitions may also resonate with our existing knowledge because

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these same actors, the experts, are in part responsible for the construction, maintenance, and manipulation of knowledge. And we experience social problems in terms of what we already know.⁶⁷⁴

Naming a problem carries with it the structure or mechanism to deal with the problem, and the social responsibility to do so.⁶⁷⁵ The manner in which a problem is defined embodies ideas about who or what is the cause of the problem, who or what must change to solve the problem, and who has the power to make decisions about the problem(s) of concern. Defining a problem legitimates the resources, including the actors, that may be called upon.⁶⁷⁶ Further, it implies that a social consensus exists with regards the defined problem, in effect limiting or ignoring adversarial elements, and framing the problem in such a way that alternatives are unthinkable.⁶⁷⁷

Early management strategies eliminated the SCIDS counter-frame as an adverserial element over time. Government implemented sustainable farming practices thereby showing its responsibility for the environment. Monitoring of groundwater had been responsibly undertaken for years. Additional studies showed nothing to worry about. Levels of nitrate and pesticide contamination were at acceptable levels. The epidemiology study researched Fraser Symptom Complex, not SCIDS, thereby beginning to remove the chemical causative link between health and the environment. Only when SCIDS could be shown not to exist do we find Somatic Chemically Induced Dysfunction Syndrome used again. Any panic and fear in the community was dissipated as the arguments and hypotheses of the SCIDS group and the diagnosing specialist were struck out one by one. Management strategies such as incorporating the most vocal person in the SCIDS group onto a committee to oversee and agree upon acceptable results in the epidemiology study, discrediting of the SCIDS group’s contracted expert, the American toxicologist, and the complaint to his professional body against the local orthopaedic specialist further delegitimized their claims. These management strategies came under the rubric of science, of what constituted good science and how it should be done. It was Project Enviro-Health, however, that put in place the science model, thereby framing thinking about the environment and

⁶⁷⁴ Williams, 483 & 484.
⁶⁷⁶ Dietz, Stern, and Rycroft, 47-70.
its impact on health.

Project Enviro-Health secured the science frame by using two other frames to make the point. These were the frames of differential knowledge and mistrust of experts. Each is embedded in Project Enviro-Health’s rationale and objectives. If there was any doubt with the declared non-existence of SCIDS, the social problem was now firmly returned to the individual as a private trouble. It was in the character of the individuals that the problem resided.

Mistrust of experts

According to this frame, conflict occurs because people have learned to mistrust expert knowledge. Industry’s scientists are considered to almost always support their employers’ positions, as do environmental groups’ scientists. The mistrust extends even to the scientific findings of public agencies as possibly distorted by economic or political influence. In this view, the credibility of the scientific establishment is threatened. Even knowledge developed by purportedly disinterested parties is not immune, since it is believed that interests affect knowledge as well as opinion.678

Project Enviro-Health was established as a response to mistrust on the part of a group of the community, a mistrust it was feared may have become more pervasive through the entire community with the actions of the SCIDS group. The 1993/94 Annual Report notes that residents became frustrated and angry at the lack of answers to their concerns, and stated that they did not trust information from government.679 The government’s remedial strategy was to regain trust through a public relations communication program. What was needed was a change of attitude on the part of the public. This was to be brought about by providing “correct,” that is, scientific information about issues of concern in the community. This latter suggests that the community was not only misinformed, but did not have the information required to come to the “right” conclusion about issues.

678 Dietz, Stern and Rycroft, 50 & 61.
Differential knowledge

The differential knowledge perspective of the environmental conflict emphasizes the complexity, the uncertainty, and the difficulty in understanding the issues at hand. Assessment of risk requires detailed and quantitative analysis. These methods, the theoretical bases of risk analysis, and the technologies that generate, control or monitor the environment are little understood by lay persons. The majority of the public are ignorant at best, and prone to unreasonable fear and expectation at worst. An irrational, uninformed public is the root cause of conflict. If the public were better informed they would make the same judgements as the experts. Experts understand the risks and have realistic expectations. Further, they are in a better position to make a judgement about how safe is “safe enough.” By using a public decision-making model of committees and public forums in which expertise and information could be made available to all parties more or less, Project Enviro-Health could facilitate the emergence of “truth” in a discourse in which all sides, informed by expertise, actively participated.

(Mis)perceptions

The differential knowledge frame rests on the idea that the lay public misperceives risk. Scientific findings are all too often found to diverge from popular perceptions of risk. Research into people’s perception of risk since the mid-1970s has found that experts tend to estimate risk in terms of mortality whilst the lay public consider a variety of other factors in addition. How well the risk is understood, how feared the hazard, how many people are exposed, and how exposure to risk can be controlled are all factors taken into account by the lay public. In addition, whether an activity is voluntary, certain, and familiar or the opposite (unfamiliar, uncertain and involuntary) affect the acceptance of risk. Common events tend to be overestimated, and rare events underestimated, research suggests.

Research investigating the public’s perceptions has traditionally been undertaken in the laboratory, and/or employing gaming scenarios and survey techniques, all of which utilize quantitative determinations of risk acceptance. These situations are artificial, and present risk

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681 Somers, 681; Nelkin, 101.
scenarios in a vacuum with no lived context. The public on the other hand draw upon a lifetime of experiences and knowledge as well as interaction and communication in formal and informal networks to reflect upon and understand any risk, hazard or event that occurs. Risks occur in a lived situation not in the artificiality of the laboratory or on the survey page. Drawing upon their lifetime of experience and knowledge, the information available, and their discussions and interactions with others in their social milieu, individuals rationally develop a position (perception) about risk. To misconstrue this as irrationality or misperception clearly misunderstands how everyone, including we ourselves, deals with conflicting realities.682

Lay public perception frames take for granted that there is an objective world of concrete facts that will be revealed with systematic inquiry. Implicit is the notion of a rational knower sorting and assessing the facts. In situations of potential danger individuals seek to identify the source of the threat, assess its specific harmfulness, the types of damage likely to be caused, and establish avoidance strategies. However, identifying toxins in the environment, as well as identifying the pathways they are likely to follow, their potential harm, as well as solutions for managing or avoiding their discharge, is fraught with difficulty for scientists, let alone the lay public. Yet people behave as though they do know with certainty in situations where the presence of toxins and the degree of danger remain uncertain. In the absence of objective “facts” it is more likely that people will construct subjective “facts” to define the extent of risk and outline for themselves an appropriate course of action.683

Furthering understanding of the lay public’s cognitive processes in relation to notions of health and environment, James and Eyles’ exploratory study found participants considered poor environmental conditions to be the source of many health problems, ranging from respiratory conditions such as colds and allergies to cancer to mental ill-health. Although not able to be fully elaborated by the lay public, the environment was considered one of the most important influences on health. Over-population and heavily populated areas, traffic volume and cars, pollution and dirt, and the social relations characteristic of urban areas were considered detrimental to health.684

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682 Lupton, 425-435.
683 Kroll-Smith and Couch, 56.
684 James and Eyles, 86-104.
While people felt they had considerable control over their own health, however, predominantly through lifestyle choices, they did not feel the same way about the wider environment. Although respondents referred to choices to live and act in environmentally responsible ways through recycling and purchase of safe, “green” products, most felt they had little personal control over the larger quality of the environment and had little responsibility for its protection and remediation. Individual action was felt to be inconsequential. Group effort was considered necessary to any change in the environmental situation. Fault and responsibility for the state of the environment was placed predominantly with industry and government, and other powerful players referred to as “they.” Lay views of health and environment were shaped by a belief in personal responsibility for healthy and wise choices in lifestyle options and ambivalence towards an environment outside of personal control.

The lay public’s constructions of danger and risk are more than mere perception. More than the senses are involved in constructions of risk and hazard. The definition and magnitude of what is considered as risk is dependent upon an individual’s social location (the organizations and groups with whom they identify) and the negative events, accidents and disasters that occur in the society. To have symptoms of illness, as in the SCIDS case, and to posit causality to environmental toxins is not a matter of perception but of belief. Beliefs confer certainty on uncertain situations. A belief is committed to with conviction, is a publicly ratified view of some aspect of the world, is internalized, tenacious, and not easily modified.

In addition, protests, fears, criticism, and resistance by the public may not be a pure problem of information or education, but instead a rejection of the naive assumptions about an ideal social and material world which are embedded in experts’ models of risk taking. The critique of science and technology arises not from the irrationality of the lay public, but from the failure of science and technology in the face of growing threats and risks to society. This failure is not just the past, but also present and future. Although the failure of science and technology are

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685 "To perceive is to become aware of something directly through the senses" (Kroll-Smith and Couch, 58).
686 Kroll-Smith and Couch, 58.
687 Kroll-Smith and Couch, 58.
688 Wynne describes this as ‘naive sociology’. (Wynne, “Frameworks of Rationality,” 35; Grinyer, 32)
often individualised to the expert and/or the scientist, it is not the individual, not even the
discipline, but is systematically grounded in science's methodological and institutional approach
to risks. Science is unable to react adequately to risk. Science itself is prominently involved in
the origin and growth of the very same risks. Science is the “legitimating patron” of risk.689

Defining conflict as the disagreement between the informed and the uninformed increases
the value of technical expertise as a resource. The problem becomes a scientific/technical
problem, in which only certain kinds of arguments, those of objective truth, are considered
appropriate and relevant. Public opinion and knowledge is devalued by implying that there is a
correct answer to be provided by scientists, suggesting that those who oppose this response are
misinformed. In addition, defining the problem as technical characterizes the SCIDS group
pejoratively, suggesting that they are working in pursuit of their own special interests, rather than
the common good. Defining the group thus, shuts them out of legitimate participation.690

Management of the perceived problem by a technical rather than social services agency
underestimated the full extent of the personal, social and economic loss incurred by the group
defined as the problem. Restricting debate to technical analysis excludes underlying social issues
and concerns from discussion. The quantification of technological applications ignores the non-
quantifiable fragility of disrupted social relationships and emotional distress that are associated
with risk, and the development of attitudes toward authority that may foster mistrust. Considered
as a public relations and information problem, the actual concerns of the SCIDS group were never
addressed. Management is focused on preventing panic, subduing frightened attitudes, rather than
taking seriously, other than in its scientific/technical frame, the possibility that environmental
toxins were/are hazardous to health. A plurality of scientific accounts which may arise from
technical disagreements are neglected; institutional processes which contributed to the conflict are
removed from discussion.691 Project Enviro-Health, in securing the scientific frame, dissipated the
conflict.

689 Beck, Risk Society, 59.
690 Dietz, Stern and Rycroft, 50 & 61.
691 Kroll-Smith and Couch, 65; Nelkin, 101; Wynne, “Frameworks of Rationality,” 34;
CHAPTER EIGHT: RISK BIOGRAPHY, RISK SOCIETY

A friend of mine has a great analogy. Its like a swamp. You get a stick and you shove it in there and you stir it around and it all bubbles and all the foul gas comes up and it all looks fermented and then you stop and it all settles back to the same level again and nothing happens.692

Risk positions in this sense are springs from which questions rise to the surface, to which the victims have no answer.693

SCIDS was a social problem contested in the public domain. It was finally deemed to be an “imaginary” problem, since it did not exist, at least according to the scientific and medical evidence. Nor could the causative role of environmental toxins claimed by the SCIDS group be scientifically verified. There is no doubt of ongoing degradation of air and groundwater quality in the Valley. Nonetheless, the evidence that illustrated this degradation could not be scientifically linked to a disease that could not be diagnostically defined. However, the concern incited by the SCIDS group’s vocality required managing and putting to rest. This was implemented through provincial government response to the voiced concerns in the community, and completed with the short-term program, Project Enviro-Health. To all intents and purposes, SCIDS had now vanished. Not so however, for the 500-plus people whom it was reported continued to experience symptoms.694 How do we, in conclusion, explain this dysjuncture?

Collective hysteria
In recent years there has been a return to the old idea of ‘hysteria’—public hysteria—as an explanatory device to explain and contain collective responses to perceived risks. Leiss and Chociolko in Responsibility and Risk suggested that SCIDS was just such a case, that of public

692 Interview with local orthopaedic specialist, 1995.
693 Beck, Risk Society, 54.
hysteria, incited by unfounded and unreasonable fears. It was the local orthopaedic specialist’s diagnosis that inflamed such panic, they said. Although government responded, a local group brought in their own “expert” from Florida who, according to Leiss and Chociolko, made alarming statements about a substance banned five years earlier which he claimed was present in the groundwater samples he had taken. He provided no evidence in support of his claims. The hysteria dissipated, Leiss and Chociolko maintain, when government was able to show with its own research that the syndrome, SCIDS, did not exist.\textsuperscript{695}

Panic or hysteria is noted by Blumer as a form of collective behaviour in which one individual influences another, not through interpersonal dialogue and discussion, but as a reaction. Such behaviour occurs in large groups, for example, crowds, and is not culturally prescribed or pre-established but is a response to undefined or unstructured situations.\textsuperscript{696} Hatty and Hatty have suggested that the uncertainty and anxiety that accompany the end of the millennium provide just such an unstructured situation. The trajectory of technological and social “progress”; the commercial practices of the West in light of economic, social and environmental problems; the promise of science and medicine to provide an improved standard of living; and the authority, relevance and usefulness of the dominant social institutions are all under question. Cynicism and disengagement have replaced optimism. The individual is in retreat, Hatty and Hatty suggest. Isolation seems the best solution for survival. Contagion is to be avoided at all costs, both of disordered bodies and of the body social.\textsuperscript{697}

This millennial angst has produced a wide range of hysterical syndromes, Showalter suggests. Hysteria eventuates when “someone expresses stress, powerlessness and unhappiness through physical or sensory symptoms which have no clinical explanation.” An epidemiologist in the SCIDS conflict considered stress the cause of physiological symptoms in those with SCIDS.

Um, I would say what they're showing is the definition of stress...they're showing a physiologic response to stress..I mean, I have no...there's no question that these people have...illness...in...in anybody's definition of illness. [...] I think their causation is stress...now the stress itself is probably external to a certain extent, but their handling of that stress is internalized and its coming out in this

\textsuperscript{695} Leiss and Chociolko, 267.
\textsuperscript{697} Hatty and Hatty, 233 & 234.
particular way.

While psychological pain and discomfort are experienced by the individual, the causes of such conditions are cultural, Showalter posits. A physician who diagnoses the illness and a patient who believes they are suffering the symptoms, as well as a culture of self-help and confession and the mass media to spread the information provide just the right climate for hysteria, according to Showalter. And hysteria is highly contagious, she asserts.

Social contagion refers to “the relatively rapid, unwitting, and nonrational dissemination of a mood, impulse, or form of conduct.” It is the pronounced unreflective responsiveness of one individual to another, attracting and infecting even detached and indifferent bystanders. Infected with the spirit of excitement, onlookers engage in the behaviour. A lowering of social resistance occurs and individuals react to the impulses awakened in them. “Spread[ing] like wildfire,” social contagion becomes a social epidemic. The epidemiologist suggested that the presence of the group, SCIDS, and the local orthopaedic specialist’s clinic acted as the loci of infection.

...if you look at where these people are from geographically, they're not clustered particularly...they're sort of...they have come from as far away as the North Shore, we had people from Tsawwassen, I mean quite a large geographic area, and what the support clinic does, is that it has attracted a group of people who have a syndrome, causally unknown...but that...so they're...so they're almost a self-help group and its...they're there because of the support group, they're not there because the area has the causative factor involved in it versus other areas...and that's at least our view of it.

The logic of contagion shapes and guides social relationships in contemporary society, Singer suggests. Social problems are perceived as contagious in the turn of the century “age of epidemics.” Attributing the term epidemic to the problem legitimizes the introduction of more intrusive and extensive measures by the state, and suggests that problematic individuals are “diseased.” Intervention becomes possible.

Epidemics of hysteria, however, locate explanation at the level of the individual. It is irrational individuals reacting without reflection to unfamiliar situations who are responsible for mass hysteria. Social contagion is the result of socially/behaviourally infected individuals. Fears

699 Singer, 29, quoted in Hatty and Hatty, 237-239.
are considered unfounded, simply a response to the contagious activities or beliefs of others. However, in the SCIDS case those pointed to as inciting fear, panic and hysteria were not alone in terms of the claims made. Other individuals besides the local orthopaedic specialist and the SCIDS group founder focussed on a degrading environment. Individuals who could speak with some authority, who were experts in their field and embodied the authority of science, had warned provincial government of a deteriorating environment. Both government hydrogeologists and toxicologists, at local, provincial and federal levels, as well as non-government hydrogeologists had been drawing attention to the degradation of the local aquifer for some years. A Ministry of Agriculture agrologist had stated that they also knew of the degradation. For their part, the local orthopaedic specialist and his patients with SCIDS drew attention to this health problem and its possible cause in a degrading environment not to inflame fears but to alert those with responsibility for population health. The fears of those with SCIDS were not unfounded as claimed by Leiss and Chociolko, but based upon an experienced, and at times frightening, symptomatology. Although the syndrome SCIDS was declared not to exist by the epidemiologists and the Ministry of Health, the symptoms did not disappear, nor those suffering from SCIDS. They were quite simply silenced, no longer a public presence with the SCIDS group’s demise, nor visible through the mass media with the creation of Project Enviro-Health and the project director’s substantive degree of control of local environmental and health news.

A social movement?

While a theory of an epidemic of hysteria cannot satisfactorily explain the SCIDS conflict, it can suggest another explanation. Blumer suggested that what begins as primitive forms of collective behaviour such as fear and panic can be organized and take the form of a social movement. More specifically, in discussing the toxic waste movement and its departure from the structure and organization of other environmental movements, Brown and Masterton-Allen suggest that rage, stemming from personal experience, may be the instigation for involvement of individuals in organized collective activity.\(^\text{700}\)

It has been suggested that groups such as the SCIDS group are part of a social movement

known as the toxic waste movement. This movement is concerned about the waste left in the wake of industrialism, particularly industrial toxic waste dumped illegally or surreptitiously by corporations and often buried beneath new housing developments. The movement is characterized by a proliferation of groups dedicated to the prevention and/or remediation of localized and immediate threat of toxic waste. Highly decentralised and with no national organization, their focus is local causes, impacts and solutions. Not assembled by professional organizers, groups spring up spontaneously, often in response to rage or personal loss and without the likelihood of specific rewards. Citizen groups against toxic waste represent a powerful grassroots movement which has grown exponentially since the Love Canal incident, 1978. The primary participants are the lower middle class and working class, politicized by the perceived danger to their families' health.

Government intervention is sought by the toxic waste movement. Acceptance of responsibility on the part of government or corporations is expected. However, uncertainties regarding the negative health effects of toxic substances, the futility of epidemiological studies in determining associations between exposure and disease incidence, together with the class orientation and composition of the toxic waste movement contribute to a negative or neutral response to activists by government and experts alike. Concerns of the toxic waste movement are simultaneously personal and intimate as well as economic and industrial. Economic crises remain a challenge and a reality for toxic waste movement members. Loss of homes, loss of health, and inability to work bring into focus the mode of production and distribution of wealth of a capitalist/industrial society.

Many of the facets of the toxic waste movement apply to the SCIDS group. The group's concern however was not the mass dumping of toxic waste but the production of environmental toxins as an insidious by-product of industrial progress. Murphy has suggested that the many unrelated and unconnected Multiple Chemical Sensitivity (MCS) groups form an MCS movement which is part of a larger alternative health movement. Fragmented, generally not political, with no over-arching goals nor a single charismatic, visionary leader, this movement consists of sick bodies reacting to the built environment. Geographically scattered, cut across class and social

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groupings and consisting mostly of women, and with participation that at best may be described as partial, the movement is held together by a multitude of names and explanations given to sick bodies. Unlike the many new social movements that have proliferated in late capitalism, such as those organized around AIDS and Gulf War Syndrome, the MCS movement lacks a coherent identity politics based on gender even though most of its members are women; has no obvious target, since chemical exposures are not centralized around a single product or polluter but are ubiquitous and ordinary; and has strategies of a different tenor than most social movements, these being organized around regimes designed to cope with rebellious bodies in the everyday.\footnote{Murphy, 93-96.}

Murphy does not address the toxic waste movement literature, nor appear to consider the links, if any, between it and the MCS and alternative health movements. This could fruitfully be explored in the future. An important addition a consideration of the MCS movement makes to the study of the toxic waste movement is the incorporation of the biomedical frame. Certainly the SCIDS group fits the parameters of the toxic waste movement, the MCS movement, and quite possibly the alternative health movement, as this quote from the SCIDS founder illustrates:

...he uses fluorescence as a treatment, where I go to a native healer.

The SCIDS group founder, however, never conceived of the group as part of a social movement. The group’s role was first, to provide assistance to those with SCIDS and second, to raise public awareness.

The group was basically there as a help group, a sounding board for other people. It was basically two reasons, the main one in my mind was a sounding board for people who had all these things that doctor didn’t know what it was, to say, to hear how other people were dealing with it, how other people are coping with it, cause I mean, it got you through the next day and you, you had to have that, um and the other was public awareness, you know, if you drink city water and you break out in mouth blisters afterwards, maybe its not your body, maybe it’s the water.

Her own activism she describes as part of her character, and as a need to discover what her symptoms were.

I guess in that way I’m my dad’s daughter. My dad always taught me if you want something bad enough you’ll go out and fight for it. I needed to know what
was wrong. Long before anything else I was phoning the Ministry of Health saying, there's got to be something. I was phoning the Ministry of Environment, I was, I mean, Public Health...

The SCIDS group networked with other groups such as AGES (Advocacy Group for the Environmentally Sensitive), an Ottawa based group, and the Women's Health Action Network based in Vancouver, but had little success in networking with local environmental groups who remained uninterested in their cause. The group perceived other social movement organizations as radical, and turned down an approach by GreenPeace to become involved. Not prepared to undertake the tactics in which GreenPeace engaged, the SCIDS group founder declared their interest as working with government to find a solution and did not want this objective jeopardized. Other “softer” forms of social movement action were of interest, but could not be seriously entertained.

We used to look at the AIDS walk, you know, yes, we gotta walk in Victoria, right, and its like none of us can walk on this. Alright, so we'll hobble on Victoria.

Although the SCIDS group founder did not consider the group part of a social movement, nonetheless they did correspond to the type of local movement that Brown and others, and Murphy have suggested constitute the decentralized toxic waste and the fragmented MCS movements.

Collective behaviour and its management

Social movement researchers have investigated many communities where residents have organized to bring about change in some aspect of community life. Much of this research is an account of success. Models have been developed to describe the sequence of events. Both Brown\textsuperscript{703} and Couto\textsuperscript{704} have developed separate models that outline the process of collective action which occurs in a community faced with environmental risk. I have amalgamated both models into one scheme and use it to describe the SCIDS conflict once more.

At the very earliest stage in the career of a social movement, prior to action, individuals

\textsuperscript{703} Brown, “Popular Epidemiology,” 267-281.
\textsuperscript{704} Couto, 55-62.
become aware separately of health effects and pollutants. This stage of awareness precedes any thought of action.

One day a teenage girl is racing around the school track—for no apparent reason her knees buckle in pain—she's sidelined. Meanwhile, searing pain strikes the shoulder of a middle-aged woman—her back tightens into a rigid grid like a two-by-four plank. Before long she too is incapacitated. Diagnosis for both are still question marks. What is causing the seemingly unrelated ailments? No-one knows.\(^5\)

Wildlife service logs 20 years of birds falling prey to pesticides
The Canadian Wildlife Service has a two-decade history of confirmed pesticide poisonings of birds in the lower Fraser Valley.

For example, in December 1979, a pesticide killed 120 ducks; in August 1989, another pesticide poisoned 40 Canada geese.

During the 1980s, the largest bird kill in the valley from a single pesticide poisoning was the previously unpublished death of an estimated 1,000 sparrows in August 1986. […]

Government records show instances of large numbers of pesticide-killed ducks and other waterfowl in a single farm field, but birds of prey die alone.\(^6\)

That this is something out of the ordinary is hypothesized, and an intuitive judgement is made by someone that the health problems are related to the pollution.

[the local orthopaedic specialist] became suspicious when he saw the same medical problems cropping up time and again in his Abbotsford practice, yet they defied any known diagnosis. […]

It appears something in the environment may be to blame. Insecticides? Pesticides? Malathion? Dioxins? Dinoseb? No-one knows, but [local orthopaedic specialist] has some ideas about it. “Think about it. First the Germans invented nerve gas...a deadly effective neurotransmitter inhibitor. From there the first generation of insecticides were created. The toxicology research tells us what happens to people in cases of acute poisoning...but what about chronic poisoning?” He postulates that residue from some toxins may be locking into the


\(^{6}\) Glenn Bohn, “Wildlife service logs 20 years of birds falling prey to pesticides,” _The Vancouver Sun_, Friday, January 24, 1992, sec. B. p.5.
fat soluble tissue in the central nervous system of some of his patients.  

Knowledge of common health effects in the community and of environmental contamination create a common perspective. The community within which this process takes place is a “community at risk.” Based on the judgement that health problems in the community share a common source such as environmental contamination, a few people organize, begin to take action and undertake research, convinced that they are dealing with a potentially serious problem. Now a more cohesive group, they read, talk to government officials and scientific experts about the health effects and the putative contaminants.

[the local orthopaedic specialist] met with [the Central Fraser Valley medical officer of health] in 1989 and told him he was concerned about a recurring illness striking mostly teenage girls, but also later linked to older patients. Then in July 1990, [local orthopaedic specialist] and five of his patients shared their stories with Abbotsford Alderman [ ], a Dewdney Alouette Regional District representative, [Upper Fraser Valley medical officer of health] and some people who were starting an environmental group. He showed those present the patients’ muscle weaknesses.

This brings the community at risk into contact with the “community of consequence calculation,” the officials who allocate resources related to environmental health risks. The opposition of the community of consequence calculation is experienced. There is denial that there is a problem, then denial that the problem is serious.

Up until recently, little action had been taken by the public health department, other than giving advice to [local orthopaedic specialist] on how to do the research. [. . .]

But [medical officer of health] and [medical officer of health] both state that valid scientific research has to be undertaken to determine there is, in fact, a problem and then a step-by-step approach to proving it. The variables in the patients’ symptoms are too wide to be taken seriously by epidemiologists.

Attribution of the problem to the lifestyle of the people at risk follows.

The issue is attribution here. Their attribution is external, and that’s a well recognised phenomena in our field. I don’t think their causation is external at all.

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709 Ibid.
We don’t have any evidence that there is more people with this syndrome in Abbotsford than any place else.\textsuperscript{710}

This response by the community of calculation stimulates a radical reaction by the community at risk in defense of other values. They take direct action to acquire a response to their initial requests from local officials. Violence may occur. They enlist other allies, form networks, share experiences and lessons learned, may form coalitions, and seek the assistance of professionals from outside the community. National and international media may be involved.

**Ottawa told of enviro-disease**

News of the valley’s mysterious “enviro-disease” has made it to the floor of the house of Commons and the ears of federal politicians. Fraser Valley East MP Ross Belsher rose in the House on Friday to speak on what he called “a matter of extreme urgency to the residents of the Fraser Valley.”\textsuperscript{711}

In response to pressure from the community at risk, government officials conduct research.

**Disease probe begins**

Sherlock Holmes, he’s not. But [epidemiologist] is a white-cloaked sleuth who uncovers medical mystery clues. He has been named as the researcher who will look into a baffling medical condition striking about 120 people (documented so far) in the Central Fraser Valley.\textsuperscript{712}

Usually no association is found between the contaminants and health effects.

**Valley mystery sickness debunked**

Fraser Valley residents who feared they all had a disease linked to pesticide poisoning in fact suffer from a variety of ailments, a B. C. health ministry investigation has found.\textsuperscript{713}

**SCIDS—what SCIDS?**

UBC scientists’ study shows there’s no common link joining people suffering from muscle ailments.

There’s no denying 250 people are sick, but there is no proof that they all suffer

\textsuperscript{710} Interview with epidemiologist, November 1994.


from the same thing, UBC scientists said Wednesday.\textsuperscript{714}

The community at risk bring in their own experts to conduct a health study and to investigate pollutant sources and pathways. These assessments are considered anecdotal by government officials and the communities of calculation, and corroboration of findings is demanded.

**Toxicologist tests air, soil**
Hired by group to search for link to chemical poisoning.\textsuperscript{715}

**[Florida toxicologist's] remarks rankle scientists**

Tearful doctor says Valley people have been ‘poisoned’. […]

[Florida toxicologist] made some dramatic statements in his presentation in Abbotsford—but he found little agreement with local or provincial health officials.

 […] “He made unfounded allegations, and my concern is that he has engulfed [sic] a great deal of fear in the community—and quite unnecessarily.”\textsuperscript{716}

If successful, the link between the pollution problem and its threat to health are recognised. Litigation and confrontation may ensue. Victories for the community at risk may include out-of-court settlements and a new water supply, for example. However, neither litigation and confrontation nor out-of-court settlements marked the closure of the SCIDS conflict. The difficulty in litigating was pointed out by the SCIDS founder.

…so if you do a blood test and you found malathion, you’re going to go after the company that made malathion right? With the Canadian law there’s not a lot of lawyers who are willing to take on a case that’s never been tried [here] before. Simply showing that you’ve got the chemical doesn’t do much, you also have to show intent. They intended you to get sick. Ignorance isn’t the grounds for a lawsuit, but I mean the companies here don’t have to tell you, they don’t. It took me three months to find a lawyer who would be willing to sit down and examine everything, ‘cause everyone was scared. I finally ended up going to one of the Teamster lawyers. And I mean, I meet a lot of people who say, I hope you sue. I mean who do you sue? You can sue Public Health for having destroyed your water, you can sue the Ministry of the Environment, you can sue, but in the end


\textsuperscript{715} Petra Kossman, “Toxicologist tests air, soil,” *Abbotsford Times*, Wednesday, February 12, 1992, 3.

it's the manufacturer, it's the guy who doesn't have to tell you, right? But nobody intentionally did this.

Closure was precipitated with the results of the epidemiology study which declared SCIDS was not an entity, and was completed with the work of Project Enviro-Health.

The social movement literature is replete with stories of success. A social movement may disappear from view, expire, following victory. Litigation, out-of-court settlements, re-settlement of part of a community, or incorporation of the social movement in the new state of affairs at the local or governmental level are stories of success. The defeat of a social movement is seldom told. This dissertation, however, is the not-oft-told tale of defeat. It is a tale of disillusionment, disenchantment, and containment for the sufferers, but one of 'sound practice' and success for the authorities charged with managing the environment and public health.

Cycles of Protest and Master Frames

Snow and Benford point out the importance of frames in the life of a social movement. Drawing upon Tarrow's concept of cycles of protest, they suggest that master frames are an important component in escalating sequences of more frequent and intense collective action together with new techniques of protest and organization. Mobilisation will not take place in the absence of a master frame, they suggest. Adapting the idea of cycles of protest and master frames, and drawing upon the social problem literature to do so, I suggest that the cycles within which the SCIDS conflict took place were first, naming the social problem, second, contesting the social problem and third, owning the social problem. Science was the frame within which the cycles took place.

SCIDS was named with the demand from the provincial Ministry of Health in response to the local orthopaedic specialist's requests for government to undertake its responsibility and research this problem. In naming the symptoms, a causal link was hypothesised between body, health and environment, challenging government's ability to protect both environment and health and instilling doubt in the lay public as to their safety. Conflict ensued and SCIDS became a political contest.

All parties to the conflict accepted the science frame. The founder of the SCIDS group

717 Snow and Benford, 133-155.
combined scientific and medical knowledge with her own experiences; the experts in the conflict were from specialties in which science was the basis. Of note, however, was that the experts seeking the overthrow of SCIDS were predominantly what I shall call “research scientists.” Research, discovery and publication were important to their careers. They had a vested interest in portraying the objectivity of science to the wider public. They were skilled and experienced at “science-speak,” that is, they were familiar with and could manipulate scientific jargon in a way the experts associated with the SCIDS group could not.

The local orthopaedic specialist and the Florida toxicologist were not research scientists. The local orthopaedic specialist had approached the epidemiologists, the medical officers of health, and government researchers for assistance to undertake research into the syndrome, SCIDS. He was primarily a surgeon and physician, who by his own admission was interested in healing and rehabilitation of his patients, rather than research. In undertaking research into SCIDS, he was treading new ground. The Florida toxicologist was first and foremost an attorney who undertook research for evidence, not for publication. The research scientists had certainty and surety, a “comfortableness” with science which the local specialist and the Florida toxicologist lacked. The research scientists were able to manipulate the scientific authority with which they were embued. They could decry the emotion shown by the Florida toxicologist in his report back to the community; even the lay public expect science to be delivered without passion. They could also, and did, discredit him as less credible because he had no publications. The local orthopaedic specialist was discredited by a complaint to his professional body for having overstepped the bounds of his discipline. A credible scientist does not intrude into areas where his knowledge is lacking. A credible scientist would recognize this lack. In addition, his diagnostic test for SCIDS could not differentiate those with SCIDS from those without. Tested scientifically, SCIDS was declared not to exist. The founder of the SCIDS group, with faith in science, and as a member of the epidemiology community advisory group, had agreed to the level of excess\(^{718}\) at which SCIDS would be considered to exist prior to the testing. She could do little but agree with the finding that SCIDS, indeed, did not exist.

\(^{718}\) The level of excess refers to the percentage of the control group who must exhibit the muscle weakness before SCIDS could be said to exist. This percentage must exceed that found in the wider population in order for the muscle weakness not to be a common factor of the population generally.
At the point of ownership, the problem was no longer SCIDS. SCIDS had been declared not to exist. The problem that was owned was the residue of the environmental conflict. Ownership implied management, and a program was developed to do just this. Project Enviro-Health was birthed to manage the residues of the SCIDS conflict using the science frame. Irrational fears spread through the media by the SCIDS group were to be replaced by the rationality of science. The concerns of residents reported to Project Enviro-Health's local committees were framed in terms of science; scientific research was undertaken if the concern was deemed important; and local news on the environment and health was provided as scientific fact by the director of Project Enviro-Health.

As science was the dominant frame within which health and the environment were understood, the SCIDS group and the local specialist had no option but to engage it. However, resonance with existing popular understandings is important to the success of a frame. Frames that propose a new framework of interpretation are much more easily overthrown. The lack of expertise of the SCIDS group and the local specialist in playing the "science game" meant they could not develop a master frame of resonance that could match or out-do that mobilised by those who had a vested interest in overthrowing the idea of environmental illness.

Cycles of protest with escalating periods of action are based on a normative frame of healthy individuals engaged in collective activism. Such cycles become problematic when the individuals participating in collective action are ill. In order to undertake everyday activities, individuals must be able to take the body for granted. Where the body cannot be forgotten and intrudes into all activity rather than being passed-over-in-silence, escalating collective action cannot be sustained unless by able-bodied champions—for instance in a well established environmental group. But this option the SCIDS group members had disavowed, at least as far as GreenPeace was concerned. And there was a dearth of environmental groups locally. The fear of radicalism (found more generally in the Abbotsford population) denied the SCIDS group the possibility of sponsorship or support by strong environmental groups with access to credible scientific experts and skill at managing the media. And as the SCIDS group founder pointed out, a debilitating and progressively weakening illness makes maintaining one's own health difficult, not to mention leading and maintaining a self-help group.

The loss of the SCIDS founder as leader of the group came at a time that was crucial in the
cycles of protest. If there was to be a challenge mounted against the now-dominant frame that stated that SCIDS did not exist, she was crucial to that challenge. With the loss of identity together with an implied characterization of herself as a trouble maker with the extinction of the name and the diagnosis that explained her symptoms, she relinquished the fight and ownership, and retired to the needs of her family for a functioning mother and wife. The new leadership of SCIDS re-focussed the group’s concerns to their individual pain and suffering by bringing in speakers and workshop leaders in alternative therapies such as acupuncture to deal with these issues. Introspection at the group and individual level replaced the previous outward-looking, external, environmental focus.

Cycles of protest and master frames, however, are embedded within a society, a culture, and an historical period. The juncture of these aspects also determine the success of a social movement and any counter movement.

Socio-historical factors

Some social movements have been instrumental in the classification of a previously unaccepted illness by biomedicine. Why did the SCIDS group not succeed similarly? Post Traumatic Stress Disorder (PTSD), for example, was classified in the DSM-III in 1980 in the face of opposition. Vietnam War veterans advocated vociferously together with a group of sympathetic psychiatrists for a classification that would recognize their symptoms and discontinue the misdiagnoses of stigmatizing disorders that resulted in inappropriate treatment. Unemployability, inability to have a normal social life, and maladaptive social and psychological responses resulted in high rates of suicide, parasuicide and self-dosing with drugs and alcohol among the veterans. These social and historical factors contributed to the decision to classify PTSD.719

The Women’s Health Movement is another social movement that has been instrumental in improvements in women’s health, the medical classification of disease and the removal from medicalization of some symptoms such as pre-menstrual syndrome (PMS). A key characteristic of both movements that saw the classification of PTSD and improvements in women’s health was

the inclusion of a group of professionals (rather than a single professional) who adhere to the biomedical model and who could argue their case in terms of that model.

The naming of SCIDS, however, occurred at a time when the focus of biomedicine, and particularly etiology, was becoming increasingly refined. It was the microscopic genetic structure in which cause for human ills was now to be found. The human genome project provided a new lens through which to see not only disease, but also social suffering. The genetic frame grew in strength in the past decade both within biomedicine as well as generally at the lay level. This focus on a firmly individualized and internalized disease etiology has resulted in an increase in genetic explanations for human problems.\textsuperscript{720}

Further, the number of people in the community susceptible to SCIDS was small. Women were found to have a higher ratio of susceptibility than men, as is the case with environmental illness generally. In addition, within the community of Abbotsford, it was those wells in a narrow strip close to the airport that were the most contaminated, well sampling showed. Given this narrow susceptible population of women and a particular confined area of wells, there was no need for the general community to be concerned. Residents could ignore the fact that their own wells drew from the same aquifer, and that the public water supply also included groundwater content.

This lack of concern by the general community was also endemic in relation to environmental problems generally in Abbotsford. Although people in the Valley did voice concern about environmental problems when asked, this concern was not sufficient to motivate environmental activism, lifestyle change, or a shift from economic to environmental sustainability.\textsuperscript{721} Visible pollution was more likely to be recognized than the invisible scourge of groundwater contamination that remained unseen. Yet even then, Abbotsford residents were less likely than B.C. residents generally to support individual measures to combat visible pollution.\textsuperscript{722} Apathy towards environmental and associated health problems was also found in the Valley by other UBC researchers.\textsuperscript{723}

\textsuperscript{720} Conrad, 139-154.
\textsuperscript{721} Simpson, 291-294.
\textsuperscript{722} Urmetzer, Blake and Guppy, 345-359.
\textsuperscript{723} Alldritt, 1.
The lack of an infrastructure for a citizen response may have interacted with the apathetic and unmotivated response towards change found among community members. McKinnon found environmental groups in Abbotsford smaller and less influential than those in neighbouring municipalities. An independent and self-reliant environmental public sphere which would provide a platform from which community groups could take off was absent.\textsuperscript{724}

The community itself was largely a community of self-sufficient and self-sustaining smaller communities, particularly those organized around a religious culture (for example, the Mennonites) or a church organization (for example, the United Church). Members of these communities were insulated from events in the rest of community. Well-organized and catering to their members every needs, community members did not need to concern themselves with wider community problems.

At the provincial government level in Abbotsford, there was no single department with overall responsibility for groundwater quality. While the spread of responsibility across at least three government departments might suggest increased stewardship of this resource, in fact it was much easier for the decline in water quality to go unnoticed with each department assuming another was dealing with the problem. Restructuring, shedding of personnel and the drive towards bureaucratic efficiency in government in the 1980s and early 1990s simply meant increasing levels of contamination just did not get dealt with.

At the national level, by 1992, the salience of environmental issues that had peaked in the late 1980s was in decline. With an economic recession taking its toll across Canada, the focus of public concern was on economic rather than environmental problems.

These social, historical and geographical factors, together with the science frame and cycles of protest were instrumental in the outcome of the SCIDS conflict. However, the very foundation of society was under attack with the naming of SCIDS. In locating the origins of this set of complaints within the biosphere, chemicals, the by-products of production processes, were to be understood as pathological agents. Participating in a capitalist society in which the accumulation of wealth is accompanied by the accumulation of toxic waste was portrayed as hazardous to health.\textsuperscript{725} Environmentally ill patients remove themselves from such an

\textsuperscript{724} McKinnon, 81-109.
\textsuperscript{725} Kroll-Smith and Ladd, 20-24.
environment, or are removed by their symptoms from the productive process, and generally do not return after treatment as productive workers since the conditions causing their symptoms continue to exist and exacerbate. It is biomedicine’s task to fit the body to society, to legitimate the removal of the sick body from important social obligations just as it is the sick person’s responsibility to get well in order to return to those obligations, namely to productive work. Environmental illnesses such as SCIDS provide a challenge to capitalist production processes.

Acknowledging the role of environmental toxins in the SCIDS conflict would be tantamount to economic and political catastrophe. Such a causal link would admit fault in the setting of acceptable standards for pesticides and nitrates, for example. This is recognised by the founder of the SCIDS group.

They were scared I think, and that to this day is my opinion as to why this has never gone any further. Its because they’re scared that if they acknowledge it’s a problem, they have to accept responsibility. And that is, in my mind too, the sole reason why we, we have the problems that we do. It can’t be fixed.

To admit a causal link between illness and the environment would be to admit that science was implicated in the creation of the problem, in its inadequate monitoring of the problem and apparent inability to solve it. And it would question an economy based on the production of risk.

Risk Society

In consumer driven Western society, progress is measured in techno-economic terms. Modern industrial society, based on technological innovation and progress, is characterized by increasing wealth, although not necessarily in terms of more equitable wealth distribution. Techno-scientific development has been proffered as the key to concealed sources of wealth, the escape from poverty and dependence in the “‘dictatorship of scarcity’.” The key has turned out to be that to Pandora’s Box however, as the sources of wealth are accompanied by hidden hazards. The price of progress has been to unleash increasing risk. It is not that risk has not been ever-present, it is that the nature of risk (as modernity has progressed) has changed dramatically. In

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726 Beck, Reinvention of Politics; idem, Risk Society; Beck, Giddens and Lash, Reflexive Modernization.
previous times, generally not too far distant, risk and danger have been recognized by the senses: the pungent smell of stagnant, putrid water, the smarting eyes from gas-bearing fog. These same risks were localized and temporal. Today, risk and danger remain largely invisible, unheard, without smell or feel. To be recognized and/or visible as hazards, the 'sensory organs' of science (experiments, measuring instruments) are required. Risks today reside in “physical and chemical formulas,” the residues of the technological-scientific progress that now stimulates industrialism. We require that same technological-scientific paradigm to uncover the residues. And herein lies the problem.  

The sciences that developed out of hazard and risk in the nineteenth century continue to respond to the risks present in the late twentieth and early twenty-first century. These same sciences respond as though there has been no change in circumstances in the past one hundred or more years. Scientists insist on objectivity and value-neutrality as the basis for the quality of science, however these same standards of science minimize the visibility of risk while allowing their multiplication. Scientifically-determined acceptable levels of risk, for example the Canadian Guidelines for Drinking Water Safety, determine also the numbers of people who will be afflicted. Victims increase or decrease as standards are raised or lowered. Scientifically-based decisions about risk are also decisions about who shall be afflicted.

The gap between scientifically calculable and non-calculable threats continues to increase as a result of the production decisions of a high-technology based industrialism. Two of the groundwater experts in the SCIDS conflict pointed out that now, the instruments of their trade can measure more and more minute quantities of chemicals. However, as fast as the sampling schedules for groundwater list the pesticides to be tested, these are replaced by new products as research indicates the deleterious effect of the now-banned pesticides on the environment. Both technology and products move ahead of the research practices of science.

The economy benefits from the industrialized processes of modernization. Risk society arrives on the back of such modernization processes, unheralded, silent. At first, as a reflex action, rather than reflective, risks related to the products of capitalism accumulate unnoticed, as latent by-products. Then the realization that the effects of progress can no longer be managed and

\[\text{\textsuperscript{(727) Ibid.}}\]
assimilated by the industrial system leads to a reflexivity on the part of both institutions and the public. Reflexivity ensures the production of new and more products. Products that pollute are eliminated, replaced by new and supposedly better products. The reflexive nature of risk society requires products and services that are less harmful to the environment: the range of “green” cleaning products; recycling, and its products of recycled paper, tyres, plastic; deliveries of organic produce and so on. Yet the risks are never eliminated. They multiply with the introduction of new products, since new products bring with them chemicals about which little is known. Take the case of pesticides. There was a time when we dusted our favourite rose bush with DDT. When this was banned, Captan was favoured. With its ban, Vapam is now the pesticide of choice. Yet Vapam is not tested in ground water sampling. Sampling has not yet caught up. No standard level of ‘safe’ concentration has yet been established. Pesticides, as do other products, become part of systematically produced endangerment in a society characterized by multiplication and economic exploitation of hazards. Threats, hazards, risks become more and more incalculable.

A market in risk exists. Dangers have become market opportunities, and antagonism occurs between those afflicted and those who profit from its production. Although there are regulations designed to protect the public, a much stronger set of rules exists to protect those who create the risks. Both formal and informal regulations of the market protect those who profit and endanger those who do not. Pesticide sales, for example, are considered private trade information. Chemical companies do not want their competitors to know what their market share is, and thus argue that this information should stay outside the public domain. Government organizations that have data related to market information cannot release that information. In addition, government agencies who receive provincial pesticide sale figures, such as Pesticide Management of the B.C. Ministry of Environment, claim they don’t have the finances to compile totals. Market opportunities thus conceal and reveal risk. Risk is at one and the same time a problem and a solution.

728 Giddens, “Replies and Critiques.”
729 Beck, Giddens and Lash, Reflexive Modernization.
Risk drives the economy. Varying definitions of risk create new demands and hence new markets. The demand for avoidance of risk is very powerful, and radical activism is a powerful source of advertisement as well as a creator of future markets for risk-avoidance products. One of the successes of the SCIDS group was the installation of purified water coolers in public places which inadvertently increased sales for such products. Seemingly a preventive measure, it turns out to be merely cosmetic, reducing the symptoms and pollutants while the source of risk is retained.

The SCIDS conflict was a definitional struggle over the scale, degree and urgency of risks. As a threat to a society based on the production of risk, this struggle required managing. As the SCIDS group discovered, their proclamation of environmental degradation and its possible link to experienced health effects was managed in a variety of ways. Defamation of key players occurred and the threat of the same continued to silence others long after SCIDS’ extinction. The hazards pointed to in the environment by the SCIDS group were illustrated by those in authority as unproven. Research was used to monitor the environment and additional studies were undertaken in response to the ‘alarmist’ notions of the SCIDS group. The environment was declared safe. The community’s trust in science and research was re-invoked, first, with the finding that SCIDS did not exist, and second, with the implementation of Project Enviro-Health as a communication and education strategy. This rational scientific research approach was able to illustrate that risk was an accepted part of progress for which science and research would find solutions. Project Enviro-Health was a behaviour-modification project of the Skinnerian type. The anxiety-ridden irrationality of the SCIDS group and any contagion to the community was eliminated by these means.

At the level of the individual, the personal trouble which became a public issue was returned to the person as a private trouble. The management of the SCIDS conflict occurred at the level of the individual as well as at the structural level. Returning the public issue to the person was effectively implemented in a process of individualization.
The Individual: Outside In

Personal biographies are shaped by historical and social circumstances. The structural, historical and personal biography outlined by C. Wright Mills is the individualized standardized biography in Beck's risk society. In contemporary society, the consciousness of class and family recede into the background as biography takes centre stage. Changes in class consciousness, in the workplace, in family structures and in gender expectations have dissolved the traditions of old. Now the individual finds him or herself cut loose from tradition, liberated from collective conscience, with the freedom to devise a biography that distinguishes him or herself from others of their cohort. Yet while advanced modernity allows for a wide range of individuality, it is at the same time constrained by the requirements of social structures. It is not collective conscience nor class consciousness but the regulations and standards of the institutions of society, such as the market, the workplace, education, and the welfare state that impose themselves upon the individual. The biography is standardized predominantly by the requirements of the labour market. Institutions of education, finances, and law become paramount when the individual must depend upon the labour market and the idiosyncracies of recruitment and dismissal. Personal biographies are molded by the regulations and standards of these institutions. The stamp of tradition is replaced with the stamp of institutional patterns. "The outside of institutions become the inside of biographies." 

Private situations are no longer private but simultaneously public (institutional). Individual situations are subject to the external control of social policies which regulate entry in to and out of institutions of education, training and work. In contrast to this however is the sense of control of the individual over their life course, over their biography with the loosening of the ties of tradition, of collective and class consciousness. It is not that tradition and collective consciousness have entirely disappeared. They have not, however the lived experience for one generation can no longer be taken for granted for another. Dysjunctures that result from this lack of correspondence between generations cannot be comforted or compensated for in the common understandings of family, class or society. Self-reflexive biographies replace the formally socially determined biography.

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The individual is now responsible for making decisions, decisions about education, marriage, jobs and careers, families and progeny, and retirement. Decisions cannot be postponed, nor left to the determination of social or class position. "Choice has become obligatory." There are consequences for not making decisions. The individual is required to be the centre of action in relation to his or her biography or reap permanent disadvantage. Opportunities, decisions and arrangements that are presented by society must be grasped and used to shape the individual biography. Disappointments and disadvantages are considered to be personal failures for decisions taken or not taken. A new kind of risk accompanies responsibility for one's own biography, "the risk of chosen and personal identity."  

With the outside become inside then, personal troubles are already public issues. If the social policies of institutions today shape individual biographies, if the private sphere is "the outside turned inside and made private, of conditions and decisions made elsewhere," then it is apparent that the private trouble of environmental illness or SCIDS is already a public issue. It never did require amplification through the media, through self-help groups and through the dialogue of experts to become so. It is already the public turned private, the outside turned inside, the institutional embedded in the personal. In the SCIDS case, the demands of agri-business for production, the need to spray fields and orchards and cane crops with herbicides and pesticides become implicated in personal biographies at varying levels. The founder of the SCIDS group was accidentally sprayed with Malathion. The requirements of the market were now embodied. The private trouble, even though it had not yet emerged, was already a public issue. Similarly with the contamination of the aquifer with nitrates and pesticides. The surpluses and residues of the industry upon which the community relied for its wealth as well as its existence seeped into the aquifer and via the household tap into the private lives of individuals who relied upon that water source.  

Managing of the SCIDS conflict also brought the regulations and policies of institutions into the personal biography. SCIDS became embedded in the identity of those suffering the symptoms of Somatic Chemically Induced Dysfunction Syndrome. Wanting and accepting a medical diagnosis, the biomedical paradigm became part of the personal biography of the SCIDS

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732 Giddens, "Post-traditional Society," 76.
733 Beck, Risk Society, 136.
founder. Practical epistemologies and ontological narratives are the self-reflexive means by which institutional regulations and standards, including classifications, are brought into the personal biography. The later declared non-existence of SCIDS following the epidemiology study, and with it the annihilation of an identity does not free the individual from the standardization of individualization. The doubts about oneself, the need for a medical diagnosis to legitimately be sick, the need to access compensation from an institution that insists on a medical diagnosis, these all ensure the continuation of the outside inside. And Project Enviro-Health, with its message that a group of individuals were not fully informed and educated to make the links they did between health and the environment, re-embedded a technical-scientific knowledge through a program of education and communication that was institutionally controlled yet individually accessed and received. Information available to the community about issues of the environment and health was standardized, controlled by Project Enviro-Health, the director of whom wrote articles for the newspaper, hosted a radio show, produced a video for public communication about the Project, and occasionally made local television appearances.

People with SCIDS believed they were ill and looked to the traditions of medicine to solve their mysterious ailments. The realization that medicine did not take their symptoms seriously but considered them to be aspects of individual character furthered the loss of trust in systems of expertise and authority. However, disenchantment also had liberating effects. Together with the accessibility of medical and science texts and journals, of various experts, and of community groups plying some expertise in environmental concerns the SCIDS group was able to undertake background research and discussion with knowledgeable others and draw its own conclusions with respect to their illness. And despite the declaration that SCIDS did not exist, the SCIDS founder still fields calls from individuals seeking a name for their medically unknown symptoms.

Perhaps though, SCIDS is the illness, par excellence, of the risk society. Following the epidemiology study, persons with the symptoms of SCIDS were told that although they did not
have SCIDS, they were ill, each with individualized symptoms. Murphy draws attention to the "biochemical individuality" that undergirds multiple chemical sensitivity (MCS). The term, as used by the MCS movement, comes from clinical ecology which, while not accepted by adherents of the biomedical paradigm, nonetheless incorporates biomedical techniques to both assist persons with MCS and gain scientific acceptance.\textsuperscript{734}

Biochemical individuality of response is the individual's uniqueness. This uniqueness of response depends on the differing quantities of carbohydrates, fats, proteins, enzymes, vitamins, minerals, immune and enzyme detoxification parameters with which an individual is equipped to handle pollutants' insults. These variations determine an individual's ability to process the noxious substances he [sic] encounters...Thus, a group of individuals may be exposed to the same pollutant. One person may develop arthritis, one sinusitis, one diarrhea, one cystitis, one asthma, and one may remain apparently unaffected.\textsuperscript{735}

The concept of biochemical individuality is not unlike that discussed by Calabrese from a biomedical perspective. He suggests that specific genetic factors may predispose the individual to environmentally-related disease. He concludes that genetic differences appear to contribute in important ways to individual responses to environmental agents. The percentage of the total variability in disease incidence that can be explained by genetic factors is uncertain, however. Other biological variables such as age, gender, nutrition, pre-existing diseases, and lifestyle also contribute to the body's susceptibility to environmental insults.\textsuperscript{736}

Clinical ecologists, however, consider health as the interaction between the individual and his or her environment.

A human being, for example, is not only a hierarchical system composed of organs, cells, enzymes systems, and genes as subsystems, but is also a component of supra-individual hierarchical systems such as populations, cultural systems, and ecosystems.....An important consequence of hierarchical organization is that as components or subsets are combined to produce larger functional wholes, new properties emerge that were not present or not evident at the next level below.\textsuperscript{737}

The individual is embedded in, and a product of, social, cultural and ecological systems.

\textsuperscript{734} Murphy, 100-104.
\textsuperscript{735} Rea et al, 171, quoted in Murphy, 103.
\textsuperscript{736} Calabrese, S65.
\textsuperscript{737} Odum, 1289, quoted in Murphy, 101.
Parallels have been suggested by others between social systems and systems of disease. History and biography are implicated in the popular and technical construction of biomedical, biotechnical bodies and selves.\textsuperscript{738} In risk society where institutions are embedded within individual biographies, where individualization is standardized, will we increasingly see emerge individual symptom profiles, many of which do not meet any biomedical disease classification?

**Individual symptom profiles, collective solutions**

Individuals with environmental illness, with medically unknown symptoms,\textsuperscript{739} however, do not sit idly by, accepting that they have individualized symptom profiles for which there is no medical solution or diagnosis. Growing collective action on the part of those with environmentally-sourced medically unknown symptoms is increasing. Solutions are increasingly being demanded from within the medical model. Individuals are themselves pursuing the use of medical technology, such as PET scans, as a means of demonstrating environmentally caused symptoms.\textsuperscript{740} Protest drawing upon medical techniques and measures is growing. What is it that is required for more effective protest, more effective collective action in the face of increasing activism around matters of the environment and health? In retrospect, what might have turned the demise of SCIDS into a success?

The SCIDS group espoused ideas similar to those of the ecology movement. However, in the interview with the founder of the SCIDS group mention was not made of contact with clinical ecologists or others who might be members of such a movement. The local specialist, on the other hand, communicated with clinical ecologists at the environmental health clinic in Dallas, Texas. Greater use of the literature and research undertaken by clinical ecologists by both the SCIDS group and the local specialist may have provided more legitimation to the master frame with which they and their supporters were arguing and contesting their case.

Support within the biomedical frame for the greater susceptibility of some individuals to toxic substances has slowly grown in the 1990s with the growing doctrine of the genetic basis of disease. Human genetic diversity has largely been ignored and remained a small field until

\textsuperscript{738} Haraway, *Simians, Cyborgs and Women*, 203-230.

\textsuperscript{739} Sabo, Joffres and Williams, 128.

\textsuperscript{740} Dumit, 226 & 227.
recently. Vogel, for example, coined the term “pharmacogenetics” in 1959, drawing upon Motulsky’s earlier work to explain specific types of drug toxicity as caused by genetic disorders which affect drug-metabolizing enzymes. Brewer, in 1971, extended the concept of pharmacogenetics by suggesting that genetic variation was not only relevant to drug action but needed to be considered in response to any type of environmental agent. Brewer replaced the term pharmacogenetics with “ecogenetics.” These ideas, had they been known to the SCIDS group, would have helped develop a master frame of resonance.

A coalition with the environmental movement was not likely, given the different focus of both the SCIDS group and the environmental movement generally. As with the toxic waste movement, the SCIDS group focussed on local, not global issues, and rage, personal loss and grievances were the initiator of their activism. Environmental justice, rather than the environmental reform sought by the environmental movement, and citizen-initiated responses at the failure of the state to protect community well-being were demanded. Coalitions with local groups, however, may have been productive for the SCIDS group had they been pursued. A barrier to any involvement with local environmental and social justice groups however may have been the idea that SCIDS, and environmental illness generally, is no more than “all in the head,” a psychiatric disorder. In addition, there was the problem of sick people having the energy to reach out to make the contact with local groups on a regular basis and to persuade them of the legitimacy of their claims.

Coalition of ideas is also important. Making alliances in the community with those whose ideas were compatible with those of the SCIDS group may have led to more effective protest. For example, local environmental groups, such as the Central Fraser Valley Environmental Health Group, believed government to be responsible for a clean environment. In addition, the Chamber of Commerce at the time was seeking new business for the district and new residents. A healthy environment into which to attract newcomers should have been an attractive proposition to the Chamber of Commerce. Instead, they viewed the SCIDS group as “airing dirty laundry” that was detrimental to the Chamber’s primary purpose. A group’s affiliations and connections lend authority to the claims made. Alliances with local groups, especially those respected in the

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741 Vogel, 52-125; Motulsky, 375-385; Brewer, 92-94; Calabrese, S58-S67.
742 Driedger and Eyles, 1591.
community, and with some groups of power might have added to the legitimacy of the protest.

Participation by the public is seen as a simple way to stem discontent and reactionism. The method of participation is important. Although Project Enviro-Health sought grass-roots involvement, it attempted this in a top-down manner that neither respected the concerns of those with SCIDS or the ability of those in the community to understand local concerns. Had grass-roots participation really been the goal, then addressing the concerns of the SCIDS group in the first instance would have demonstrated that commitment. However, perhaps what is needed is more than merely getting the public involved. Thinking differently about science may be required. Looking outside the narrow lens of science, understanding the lay point of view from that point of view, not from the condescension of the “correct” view of science, and recognizing that the practical epistemologies, the environmental knowing of lay people, may hold many viable solutions to problems as does science. The challenge to science by the SCIDS conflict was the confluence of scientific knowledge, the borrowed languages of expertise, with the narrative knowledge of bodies to form new paradigms of knowledge. These new paradigms of knowledge, however, do not seek to replace expertise or expert systems. Expertise is recognised as essential in the problem solving required around matters of the environment and health.

These suggestions for more effective protest are not new, and draw upon already existing stocks and practices. It is easy in retrospect to see what might have been done on the part of both the SCIDS group and those who would manage it. In the midst of the conflict, tempers ran high, confrontation occurred and distancing and looking in from the outside was difficult. However, there are lessons to learn from disillusionment and disenchantment.

**Back to the fugue**

There is an old joke which states that “a fugue is a composition where the voices or instruments come in one by one and the audience goes out one by one.” The challenge to the composer is to develop the material in the most inventive and clever way possible when once the voices have stated the fugue theme. Recurrences of the theme may alternate with passages derived from fragments of the theme and its countersubject, providing variety and leading to new statements of the theme. With the fugue, it is said that the most important and difficult task is to maintain variety and hold interest without throwing in extraneous material that is unrelated to the
fugue theme.\textsuperscript{743}

Centred on the SCIDS conflict, the main theme of the dissertation has been the science frame. As with the fugue, the challenge has been to not become (too) repetitious by simply restating the theme. The science frame has been woven throughout most chapters, its threads developed by the voices of the specific chapter and built upon the threads of the previous chapter(s). I have attempted in the dissertation to develop a conversation between the melodies of the different voices, each commenting on what the other is saying while retaining their individual characters.

There have been some voices that have not been heard in this environmental conflict, however. They are the voices of the SCIDS group itself. Future directions for this research are to include the narratives of persons with SCIDS. Further, the tension between the critique and yet the desire to be included in the biomedical paradigm by both those with environmental illness and the physicians and clinical ecologists constitute grounds for further study. The cross-cutting grids of the farming industry, the pesticide industry and environmental illness are further avenues for investigation. The process of nosological classification, and of boundary shifts with the challenge of environmental illness and clinical ecology to the biomedical paradigm are but two additional aspects that will be clarified with future research on this topic. For now, however, this dissertation contributes to the literature on social movements, illustrating a case study that did not “succeed” in the usual social movement fashion; to the literature on environmental illness, providing an account of the involvement of experts and their attempts to understand this (non)disease category as well as their use of science to convince others of the (non)existence of symptoms and their links to the environment. Steven Epstein, in a review of Kroll-Smith and Floyd’s \textit{Bodies in Protest} suggested that the view of other actors who contribute to the creation of the social problem, such as medical researchers, would have been a useful addition to their account and analysis of the experience of those with environmental illness.\textsuperscript{744} This dissertation goes some way to providing that account.

\textsuperscript{743} Matyas, 1
\textsuperscript{744} Steven Epstein, 381.


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APPENDIX 1

ETHICS COMMITTEE APPROVAL
APPENDIX 2

DESCRIPTION OF QUALITATIVE SOFTWARE

ATLAS/ti (version 4.1)

ATLAS/ti was developed as an interdisciplinary project which included computer scientists, linguists, psychologists and future users.¹ The methodological influence upon the design was grounded theory. Designed to support qualitative researchers, automation of analysis has never been considered, and the program leaves the intellectual, interpretive work of research with the researcher.²

ATLAS/ti "methodology" has been termed VISE (Visualization Integration Serendipity Exploration) by the developer, referring to the function of ATLAS/ti tools to assist in the creative visualization of data, integration of data in terms of a whole by means of the Hermeneutic Unit or project container in ATLAS/ti, an intuitive or serendipitous approach, and a systematic but exploratory process leading to discovery in the data.³

A Hermeneutic Unit is an entity which refers to all aspects of one project regardless of where they reside in the electronic environment: primary documents (textual, graphical and audio documents), quotations (coded chunks of text, graphics or audio), codes, comments, memos, hyperlinks, concept networks and so on. Data can be exported to quantitative programs such as SPSS or to other programs such as Corel Draw or Word.⁴

ATLAS/ti facilitates a working back and forth between textual⁵ and conceptual⁶ levels. Coding and retrieval of text, text searches, the generation of memos and comments about the data, and the hyperlinking of chunks of data facilitate the analysis. Grouping of codes and memos, and

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¹ Future users views were incorporated via the results of a survey to potential users asking about their needs related to current and future computer application to qualitative text analysis (Muhr, "ATLAS/ti—A Prototype," 350).
⁵ By textual level I refer to the use of the text, audio and visual data.
⁶ The conceptual level refers to the development of ideas, theories and concepts.
linking of various entities such as text or video data with memos and codes in a graphical 
"playground" encourages the construction of concepts and theories based on relationships. Links 
can also be made between different entities, such as quotes, codes and memos. Linked codes can 
be visually displayed in a semantic network, allowing further creative exploration and analysis of 
data. Graphic views of linked entities can be hierarchical or flat, and relationships (for example: 
'is a part of', 'is a cause of') defined between items. The software also assists in the testing of 
hypotheses and the asking of questions across data with a number of boolean, semantic and 
relational functions.10

QSR NUD*IST (revision 4)

NUD*IST stands for Non-numerical Unstructured Data * Indexing Searching and 
Theorizing. The software enables the indexing of textual data, search and retrieval of coded and 
raw data, and supports theorizing through the use of memos, search and retrieve functions and a 
hierarchically ordered coding structure.

NUD*IST operations are structured in three systems: the document system, the indexing 
system, and the analysis system. The document system provides for processing and maintenance 
of internal (on-line) and external (off-line) textual documents which are the raw data of the 
research project. A hierarchical indexing system includes a database of coded (or indexed) data 
and functions that create, modify and inspect that database. An analysis system, its strength, is a 
set of operations or functions for manipulating the indexing database for category creation, 
definition and exploration of research ideas, find and retrieve text relevant to complex ideas, the 
pursuit of wild hunches, formulation and testing of hypotheses.11

Project management is assisted with NUD*IST’s progress-tracking facilities with the 
ability to date memo’s and automatic tracking logs for many of the functions that change or alter 
the indexing structure. Data can be linked by case, and longitudinal data analysed by time or date

7 Boolean operators allow combinations of keywords using AND, OR, AT LEAST ONE OF, and 
NOT.

8 Semantic operators allow the connected codes in the graphic network to be exploited.

9 Relational functions are used to analyze proximity or spatial relations between coded data.


of collection. Facilities are available for importing and exporting data from/to quantitative spreadsheets such as SPSS or Excel, as well as to graphical and semantic mapping programs such as Inspiration and Decision Explorer. Multiple researchers on the same project are facilitated by an accompanying software that enables the combining of more than one version of a project into a larger project. Sophisticated search operations allow the data to be cut on any number of dimensions, encouraging exploration in depth. Parts of the coding and search and retrieve processes of a project can be automated.\footnote{Ibid.}
Coding and the coding structure

I began the analysis process by developing a project in the software QSR NUD*IST 4. A project consists of the raw data, codes, the coded data assigned to the codes, and memos containing the researcher's thinking about the data. The raw data consisted of transcribed interviews and written summaries of documents that had been formatted and entered into the software, and newspaper articles that were off-line and entered as external documents. The software enables documents that are not able to be transcribed or scanned and that sit external to the computer (for example on a shelf in the office) to be noted within the program and coded along with documents that have been transcribed and imported into the software. Examples of external documents are legislation, policy documents, reports or newspaper articles. Codes are tags or labels assigned to data. Memos are akin to field notes, and are the researcher's thoughts and ideas about the data in relation to the research question.

Conceptual codes were developed out of the data. That is, as the raw data was read, codes as tags or labels for chunks of text were created. Conceptual codes were those where an interpretation of the data was made, the code emerged from the data. Two types of conceptual codes were developed. These were sociologically constructed codes and in vivo codes. The latter derive from the language used by the research participants. An example is the code 'gag orders'.

In contrast to the conceptual codes, data management codes were an organizational tool in the software for housing the data in different groupings. Data management codes did not emerge from or require any interpretation of the data. For example, the code, Experts & Professionals contained all the documents of all the experts and professionals. These were split into sub-groupings as well, so that the documents for the two epidemiologists interviewed were contained at a code, Experts & Professionals/Epidemiologists. To say that documents were housed or contained at a code, while an easy shorthand for thinking about coding at a code, is incorrect, however. I am going to use the term "index" to refer to coding for two different reasons. First, when text is coded in the software, it is referenced to a code rather than being physically moved to
the code as might happen with a manual copy-and-paste method. The text is being indexed to the 
code in much the same way that books are indexed in a library. When the retrieval of text at a 
code is requested, the software retrieves the text from the document referenced at the code. Text 
physically remains located in the original document. Second, since I am referring to codes, the use 
of the term coding together with code becomes awkward.

All codes were easily re-named, moved to a different location in the coding structure or 
deleted as necessary. The coding structure was not constrained by size or complexity and codes 
could be continually altered and restructured.

In the early stages of the research, the coding structure reflected my initial interests and 
research questions. Over time, as more interviews were completed, as I worked through the 
newspaper articles in a more thorough fashion, and documents in the form of reports of research 
associated with the study came to light, the coding structure began to reflect the patterns in the 
data, in response to my initial question, “What is going on here?” Table 1 provides a view of the 
changing coding structure over time. Codes could be assigned in a hierarchical relationship to 
each other within the coding structure, allowing the links between codes to be identified, although 
not named. I refer to the codes to which other codes are hierarchically related as “upper level 
codes” and to codes which “hang” below the upper level code as “attached codes.” Essentially, 
the upper level code acts as a hanger from which the related (and hence attached) codes hang, 
visually analogous to the hanging mobiles that were popular for young children. In addition, an 
area of the coding structure free from such hierarchical and relational links allowed some codes to 
be explored and developed. Later, the association with another code(s) might be made and the 
code assigned a location in the hierarchical structure. Alternately the code might remain unrelated 
to any other codes. For example, the code objectivity began unrelated to any other code. As more 
interviews were coded, it became apparent that the concept of objectivity was a theme running 
through all the interviews and the code was attached to the upper level code discourse which also 
had the attached codes: gender, health-illness, and environment. The code, blame the victim, on 
the other hand, remained unrelated and unattached hierarchically to any other codes.

13 The November 1999 project is used in the table as the organizing column. That is, the June 
1998 project columns have been sorted in relation to the November 1999 columns so as to provide an 
idea of how the structure of the project changed in light of my changing thinking about the data.
All data entered into the software in the form of on-line documents were indexed by

Table A1. The changing shape of the coding structure in QSR NUD*IST: conceptual codes

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<td>Precautionary principle</td>
<td></td>
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<td>Soil absorption</td>
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<tr>
<td>Soil absorption</td>
<td></td>
<td></td>
<td>Checks and balances</td>
</tr>
</tbody>
</table>
highlighting a selection of text and applying a code. There was no restriction on the number of codes that could be applied to any text selected. While the text of external documents could not be indexed directly in the software as the documents were off-line, the title of the external document could be indexed to the appropriate code to direct the researcher to the document later.

Indexing was a means of organizing the data. Stretches of data relating to the same concept could be brought together, a preliminary to a more detailed analysis. The codes developed however are not necessarily the final method for examining and exploring the data. The coding structure provides a description of the data, however in order to develop and explore more complex ideas further interaction with the data is necessary. One approach is to use the codes and their indexed text to think with, rather than remaining anchored in the documents alone.

**Beyond coding**

When the indexing of the documents was completed, each of the codes was examined by reading the text referenced at the code. This took the researcher away from the documents and now provided distance from the data. Indexing of a document gives a sense of closeness to the data. The context of the interview places the researcher back into the interview experience. In contrast, examining the text indexed to a code lacks the context of each individual interview but provides the context of the concept that is coded. Reading the indexed text provided an overall understanding of each concept. It narrowed the view, so-to-speak, to just that concept as it had emerged from the data, allowing it to be defined and understood.

This process of examining, defining and attempting to understand every code raised a number of questions and ideas which could be followed up. Some codes were fractured, split apart to further define the concept. For example, farming practices in relation to storage of manure and its application to berry fields was originally coded amongst the text assigned to both

<table>
<thead>
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<th>June 1998</th>
<th>November 1999</th>
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<tr>
<td><strong>Upper level codes</strong></td>
<td><strong>Upper level codes</strong></td>
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<td><strong>Attached codes</strong></td>
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<tr>
<td>contradiction</td>
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<tr>
<td>blame the victim</td>
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</table>
raspberry farming and agri-business codes. Since these farming practices were important in terms of groundwater degradation and the Ministry of Agriculture’s Code of Practice, a new code, farming practices, was developed and text from the two previous codes re-indexed there.

My interest in what experts had to say about risk could be met by intersecting the codes to which the text from the interviews with experts was indexed with the code, Risk. Risk was a conceptual code to which all text where research participants had discussed the concept of risk was indexed. An intersection of this code with the documents of the experts provided what the experts (and no-one else) had said about risk. I was able to further define experts’ concepts of risk by looking at what just the hydrogeologists or the epidemiologists, for example, had to say by intersecting Risk with the documents from the hydrogeologists only, or the epidemiologists only. Further, if it was important to know what any one person had said about the concept of risk, this could be retrieved by intersecting the documents from that one person with the code, Risk. The results from the intersected codes provided the answer from the data to my question, “what do experts have to say about risk?”

In addition, to continue with the same example, what experts had to say about risk was reported in the newspapers and news magazines. Together with the indexed text from interviews with experts was reference to off-line articles which reported experts discussing risk. Therefore when reading the text indexed at the code Risk it was also necessary to retrieve the articles from the media file in the filing cabinet and include those too in the examination if my interest was in more than the expert’s own words about risk.

Memos written within the software kept track of my thinking about the data and about the developing concepts that would inform the dissertation. In terms of the larger question about “what was going on here,” memos described my emerging understanding, especially in relation to how individual experts defined the situation. Here is the memo written describing my understanding of how the hydrogeologist saw the problem. The shorthand “T/U” refers to the location of text in the specific interview document to which I can return to retrace my construction of understanding through the data.
Memo: [Hydrogeologist's] definition of the social problem
7:10 pm, Nov 14, 1999.
Experts have knowledge of the historical and ongoing demise of the aquifer by nitrates and pesticides, yet government will not respond with policy's that will see any preventive measures put in place, or education of the public with regards use of manure and pesticides.

Also, little fires are being fought in the sense that small areas of wells in an aquifer are being examined, but what is government doing with regards the whole picture, where these little areas of contaminants are actually spread over a wide area (T/U327-329).

Where contamination can be monitored, or the finger pointed and legislation brought to bear, then local, provincial and national govt, corporations and even individuals will ensure all the correct precautions are put in place, but where regulations, standards, and/or monitoring are lacking and it can never be proven where the contamination originated, they will not be worried about it (T/U492-500).

Don't have proof that any of the chemicals are carcinogens or mutagenes, work is on-going, so why not have people take precautions and make sure the chemical doesn't get in there (T/U454-467).

Sees self and his company as the watchdog of the people, constantly asking Govt and corporations with regards their actions and decisions around water and contamination (T/U560-571). States that they try to work with Government and corporations first and then let the public know of the issue too, by writing position papers through the association of engineers for newspapers. See themselves as information brokers? (T/U578-582 & 587-594)

Memos too were a description of my emerging understanding of various concepts. As mentioned previously, the concept, “objectivity,” became a central theme in the research. Here is a memo written early in the coding process.

Memo: Objectivity-Subjectivity
9:35pm, 18 January 1999
I notice a theme coming through the interviews with regards objectivity versus subjectivity. [Agrologist] talks about the truth being objective. The literature on environmental illness also distinguishes between the two--biomedicine as being an objective view, not subjective. Historically, the belief was in illness/disease as
being outside the body, external, in fog, air, the environment. This view was overthrown by biomedicine in the 19th century as being located in the body (See Kroll-Smith and Floyd: Bodies in Protest).

Need a node to collect the subjective/objective speech and information. How does it impinge upon the production and reproduction of collective identity? In terms of the 3 discourses--gender; health; environment? Are these discourses still appropriate or should they be different? And where does technology come into all this?


[Epidemiologist] also talks about objectivity and subjectivity. The symptoms of SCIDS he sees as subjective, [local orthopaedic specialist's] test as an attempt by him to put those symptoms into an objective framework, which fails of course. External causation also seen as linked to the subjective-objective framework, but in ways I haven't yet pulled apart.

In ATLAS/ti, a hermeneutic unit was created to analyze the digitized video. A hermeneutic unit consists of the raw data, codes, the coding referenced to the codes, and comments and memos reflecting thinking and ideas about the raw data or the unfolding analysis. It is the equivalent of a project in QSR NUD*IST 4. The digitized video data was indexed by time segment in ATLAS/ti. Each second of the video was able to be indexed. Coded time segments are called quotations in the software, reflecting its earlier rendition as a text-based program. Each quotation was tagged with a code, and comments or memos were written about quotations and codes. Following indexing, by selecting the code of interest, indexed video frames could be observed and examined in a similar manner to the intensive examination of text at codes in the other two software. With the context of the whole video removed, a focused understanding of the code based on only the video segments indexed there could be gained. This combination of the visual with reading of the hard copy reports and association with codes of indexed text in the other two software provided some useful insights. Visuals of cows chewing their cud in the fields beneath a backdrop of mountains or of raspberry canes laden with berries in sunlit fields provided a stark contrast with text indexed at codes for raspberry farming and farming practices for example, in which participants discussed manure storage, fertilizer and pesticide practices which
leached into and contaminated the aquifer. The discussion in the video of contamination of the aquifer expanded beyond problematic farming practices to show that fertilization of lawns by property owners, pesticide and insecticide use in house gardens, oils from industrial sites and the use, storage and disposal of chemicals by both industries and households contributes to such contamination. The contrast of the "balanced" view of Project Enviro-Health’s education and publicity tool was considerable compared to the "one-sided" view of not just the lay public but also many of the experts interviewed for the dissertation research. By and large however, the video reiterated what was written in Project Enviro-Health’s reports.

Table 2 provides a comparison of codes used in ATLAS/ti and NUD*IST for video and text data respectively.

Table A2. Comparison of codes developed in the two qualitative software.

<table>
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<tr>
<th>ATLAS/ti</th>
<th>NUD*IST</th>
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<tbody>
<tr>
<td>Abbotsford</td>
<td>agri-business</td>
</tr>
<tr>
<td>Abbotsford airshow</td>
<td>Agrologist</td>
</tr>
<tr>
<td>aerial view</td>
<td>Alderman</td>
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<td>agricultural products</td>
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<td>community-expert link</td>
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<tr>
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<td>berry festival</td>
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<td>costs</td>
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<td>Chilliwack</td>
<td>discourses/gender</td>
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<tr>
<td>coal/sulphur dust</td>
<td>discourses/health-illness</td>
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<tr>
<td>contamination</td>
<td>farming/raspberry farming</td>
</tr>
<tr>
<td>ATLAS/IT</td>
<td>NUD*IST</td>
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<td>discourses/environment</td>
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<td>discourses/objectivity</td>
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<td>international treaty</td>
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<td>SCIDS/improvement</td>
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