

When Women Paint a Story:
Participatory Action Research, Indigenous Ways of Knowing, and
Stories of Culture and Community

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Leah Purcell, Australian author of *Black Chicks Talking*, has said that in her Aboriginal culture, "it is not my place to sit down and talk in-depth with the men about issues; that's men's business. If the brothers come up and said, 'Leah, we would like you to do it, I might, but I still wouldn't feel right.' . . . I sort of work on the theory that you do what you know. At the moment, I know the stories that I'm doing" (Capp & Villella, 2002, pp. 2, 4). Following

Purcell's lead, we know that the stories we can tell are:

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based on our experiences as rehabilitation researchers and practitioners in the field of disability.

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influenced by our role as women—women with a desire to use our research findings to improve conditions in the workplace and in the larger community.

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based on our commitment to a pluralistic society and to research that is both community-driven and culturally appropriate.

We live and work in a world that typically recognizes only the majority, the greater number, "the most" of anything, including "the most powerful". Yet, as researchers devoted to equitable rehabilitation services and to ensuring access of all citizens to publicly available health and human services, we are concerned about the lack of focused and sustained attention to the experience of Indigenous people with disabilities. Although the number of people with chronic illnesses and disabilities in Indigenous populations may be small relative to non-indigenous numbers, the incidence is too often excessive in proportion to the population. Social justice demands that we

look beyond economies of scale in research (i.e., only researching those areas where there are sufficient numbers and sampling convenience). We must devote attention to documenting the issues faced by relatively small populations that demonstrate high levels of need for improved services. Sharing our combined experience has affirmed our belief that this lack of attention to the needs of Indigenous people with disabilities may actually be a global phenomenon.

In the same way as Purcell chose to explore the stories with which she was familiar, we have elected to explore the stories we have learned as women researchers in the field of disability and rehabilitation. We have networked with Indigenous women who share our concerns, and offer our collective experiences as a contribution to relevant global community action. We begin with what we know and where we live, the United States and Australia.

In health and human services, culturally appropriate practices are most likely to be those that are designed and staffed at a local level based on sound local knowledge. However, as a result of the relatively small numbers of Indigenous people with disabilities, populations with larger numbers gain the most attention. Ironically, then, the drive for both cultural awareness and localized responses to the needs of small populations may come from global cooperation among Indigenous people and professionals—scholars and researchers, psychologists, other service providers, and policy makers.

We are not the first to identify commonalities among Indigenous peoples. According to Young (1994), “From a global perspective, the health experience of the Native Americans of North America is comparable to that of aboriginal and Indigenous populations on other continents” (p. 3). Serious health problems such as obesity, diabetes, and alcoholism, deaths from cirrhosis, and traumatic injuries affect the lives of American Indians and Alaska Natives at disproportionate rates compared to other groups in the United States. However, American Indians and Alaska Natives are not alone among Indigenous peoples who face significant health concerns. Aboriginal people in Australia face similar significant health concerns (Kunitz, 2000).

The motivation for our efforts to document and understand the commonalities between our countries is our firm belief that global co-operation can contribute to the redress of health and disability concerns among Indigenous peoples. For example, we believe that global efforts in communicating the extent to which Indigenous women with disabilities have been marginalized, both by culturally inappropriate services and insensitive or unhelpful research practices, can lead to unified representation so that their issues are taken seriously at local and national levels. We also believe that women, both as researchers and as community members, can take a lead role in designing community health programs and rehabilitation solutions based on research, evidence-based practice, and practice-based evidence.

Effective solutions to health disparities are likely to come from a belief in and support of the pluralistic nature of our global society, as well as knowledge produced through culturally-appropriate, community-based research practices. In terms of solutions, the promotion of appropriate research methods in Indigenous communities will lead to the ability to better address health problems. For service providers and policy-makers, addressing the methodological challenge may provide new direction in research that uncovers new knowledge or may provide practice-based evidence from effective health and health service programs that already exist.

The fact that Indigenous people are simultaneously “amongst the most researched and the most disadvantaged peoples on Earth” (Scougall, 1997, p. 460) indicates the failure of conventional research to address disparities in health, well-being, and socio-economic development. Conventional research methods have perpetuated colonial domination of Indigenous people, symbolizing an ongoing form of discrimination. It is time for all researchers in disability and health arenas to consider the implications of “Indigenist”(Rigney, 1997) and “Post-Colonial” methodologies (Smith, 1999) in their own efforts. Our effort to do so serves as a medium to progress the important work that has been achieved by these Indigenous researchers, as well as by non-Indigenous researchers who seek to ensure that research gives full respect to Indigenous

cultural values in disability and rehabilitation research. Services based on culturally appropriate research are likely to be in a better position to address the needs of Indigenous women with disabilities.

Cultural Traditions and Influence on Research Design

One lesson we have been learning in conducting rehabilitation research and an area that needs to be further explored is the extent to which traditions, one example of which is oral communication, in given Indigenous communities may inform research methods and design. Specifically, what do Indigenous and traditional ways of thinking and communicating mean for how research should be conducted in communities with these kinds of values and communication processes? In a community-based, participatory action research process (Bruyère, 1993; Marshall, Johnson, Kendall, Busby, Schacht, & Hill, 2002) would oral traditions lead to the use of qualitative research methods? Would such a match of research method to a community's historical way of sharing knowledge, that is, a "culturally anchored" method (Hughes, Seidman, & Williams, 1993), allow for needed rigor and produce valid findings? These questions led us to network with Aboriginal women. Our first meetings were modeled on interactions with the women as research participants, key informants or "subjects". However, we later joined with these women again, but our interactions were modeled on women as peers, co-participants, and co-facilitators in a global networking forum and as ongoing collaborators.

Ensuring that the research designs utilized by researchers working in Indigenous communities are both appropriate and rigorous is essential for 1) better understanding health disparities and disparities in access to health and human services, and 2) the design and evaluation of evidence-based interventions to eliminate such disparities (e.g. improved access to appropriate health and human services). It is clear that more and better research is needed in the area of Indigenous health and disability, but we must also understand why the existing research has failed

to make a difference in eliminating the marked and alarming health disparities that exist between Indigenous cultures and dominant societies. It may be that Western research methods simply interpret Indigenous knowledge and data from a Western conceptual framework, effectively distorting reality; it may be that how we collect data yields information that cannot be used. Alternatively, the methods we use (e.g., experimental research) may be inappropriate for obtaining the data we need. Too frequently the definition of what constitutes acceptable options for research design rests squarely in the camp of academic researchers, for whom methods that do not conform to the “gold standard” of experimental design can be considered questionable in rigor and value. To solve this problem from a statistical perspective, practitioners and researchers have recommended strategies such as over-sampling (Murray, 2003) and pooling of data (Marshall & Largo, 1999); we certainly support these recommendations. However, remedies need to be sought also at the level of conceptualization and research design.

How we go about conducting research in Indigenous communities—i.e., how we go about knowing—is as critical, if not more so, for eliminating health and access disparities as is researching a given health or disability-related problem. Conventional research designs have often proved injurious or unacceptable to Indigenous communities (Davis, Erickson, Johnson, Marshall, Running Wolf, & Santiago, 2002). We can learn from Indigenous scholars such as Dr. Linda Tuhiwai Smith (Ngati Awa and Ngati Porou), Director, International Research Institute for Maori and Indigenous Education, University of Auckland, New Zealand, who specializes in Indigenous research methods, health research, and asthma research. In her *Decolonizing Methodologies: Research and Indigenous Peoples* (1999), Smith identifies Indigenous research practices, noting that “story telling, oral histories, the perspectives of elders and of women have become an integral part of all Indigenous research” (p. 144). Similarly, in Australia, Rigney (1997) has written extensively on “indigenist” research, which critiques western methodologies and proposes methods that concur with Indigenous traditions.

In Australia, funding for research involving Indigenous people was historically tied to quantitative methods and randomized, controlled trials; but, recently, funding bodies have recognized the value of qualitative research as a more appropriate method given the culture (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2000). It is time we focussed attention on how science is practiced in Indigenous communities, seek evidence for why certain designs work better than others, and use that evidence to revise our research policies and practices. As Harding (1986) argued, those who refuse to question the way science is practiced are avoiding the “scrutiny that science recommends for all other regularities of ... life” (p. 56).

Contributions to the Greater Scientific Community

Professionals in human services have long drawn on psychology as a research base from which to inform interventions. However, psychologists have been advised to consider the influence of culture on science:

To what degree and with what effects is psychological science itself a cultural manifestation? ... It is immediately apparent that the science is largely a by-product of the Western cultural tradition at a particular time in its historical development. Suppositions about the nature of knowledge, the character of objectivity, the place of value in the knowledge generating process, and the nature of linguistic representation, for example all carry the stamp of a unique cultural tradition (Gergen, Gulerce, Lock, & Misra, 1996, p. 497).

Mays, Rubin, Sabourin, and Walker (1996) expressed similar concerns that unless U.S. psychology is willing to learn from other nations “the result will surely be an increasingly fragmented U.S. psychology that is at risk for failing to meet the psychological needs of its own U.S. population, with its rapidly growing multicultural, multinational, and multiracial population”

(p. 486). From various fields of study challenges are arising as to how science is defined and the nature of science itself is seen as a “cultural manifestation”. Du Bois (1983), for example, initiated her exploration of science by stating that "Science is *not* 'value-free'; it cannot be. Science is made by scientists, and both we and our science-making are shaped by our culture" (p. 105).

To address these challenges, we need to value the contributions and insights of community partners in our research. Research methods that resonate with the cultural traditions are likely to have particular value in a given community, as Marshall and her colleagues found in conducting research with Eastern Band of Cherokee communities (Marshall, Sanders, & Hill, 2001). Therefore, we need to understand and document how Indigenous cultural traditions, such as oral communication, dramatic expressions or paintings, can influence our choice of research methods and allow for authentic partnerships in participatory research (Davis, Erickson, Johnson, Marshall, Running Wolf, & Santiago, 2002).

Using Research Findings to Generate Community Solutions

Before embarking on a global solution, however, we need to better understand the tensions, cultural factors, and key elements influencing the relationships between women researchers and community-based research partners who likely would bring different values/interests to the partnership than those trained in the research traditions of the dominant culture. The research processes and practices of psychologists and other human service professionals who work with Indigenous people with disabilities must be, and indeed are, influenced by their cultures. Awareness of this influence and adoption of appropriate research procedures ensures “enhanced validity” of our research. We trust that our research can then demonstrate its value and usefulness to the people whom we aspire to serve.

The need to develop true collaborations with Indigenous people has no boundaries. International collaborations that focus on the intersections found among Indigenous issues,

disability, and research are needed; researchers, psychologists, and health and human services professionals in the United States can learn from the experiences of the world's Indigenous peoples and researchers in other countries as they work to define methods that incorporate culture as an essential context in research. Such research can only positively affect professional practice. Regarding practice, Usdane (1993) observed:

Boundaries persist, in no small measure, because public funding has a hard time keeping up with the elastic needs of people; . . . It is still almost universally the case that funding sources tend not to reflect the wide variety of needs within the system. Instead, they maintain extremely specific eligibility requirements. . . . Such boundaries can easily lead to decisions that people with disabilities are ineligible for this or that service, creating widespread potential for people to fall through cracks and receive services that are poorly suited to their needs or worse, no services at all (p. 31).

The importance of cross-cultural and international collaboration is highlighted by the fact that we are all, to a greater or lesser extent, culture bound—that is, we all view the world through the lens of our own culture, and this reality affects our science (Du Bois, 1983; Gergen, Gulerce, Lock, & Misra, 1996; Hughes, Seidman, & Williams, 1993). That lens, our cultural bias, operates “as both window and blinders,” giving us distinct and valuable perspectives and insights while at the same time obscuring our ability to perceive and comprehend in terms other than our own (Caldwell et al., 2005). We believe that understanding how we go about knowing—i.e., conducting research in Indigenous communities—is critical if health disparities are to be eliminated. This issue is especially fundamental when the research design may not be acceptable to the community of interest (Davis & Keemer, 2002). However, to complicate this picture, Harding (1986) made the important point that women's ways of knowing may also be at odds with the traditional empiricist approach, creating a second layer of culture:

Feminists point to a set of conceptual dichotomies within which enlightenment science and

epistemology are constructed: reason vs. emotion and social value, mind vs. body, culture vs. nature, self vs. others, objectivity vs. subjectivity, knowing vs. being. In each dichotomy, the former is to control the latter lest the latter threaten to overwhelm the former, and the threatening ‘latter’ in each case appears to be systematically associated with ‘the feminine.’ . . . Observers of social hierarchies other than that of masculine dominance have pointed to these very same dichotomies as the conceptual scheme that permits these other kinds of subjugation: Russell Means contrasts Native American and Eurocentric attitudes toward nature in these terms (p. 165).

In the last decade or so, it has been recognized that “if we take women’s knowledge contributions for granted or ignore them . . . we have a half-economy” (Adelman, 1991, p. 31). Further, as noted by a Tohono O’odham elder in Arizona, “women not only hold up half the sky, they are the carriers of the future—only strong women can support the movement toward liberation of the native people” (cited in Marshall, Martin & Johnson, 1990). There is evidence that Indigenous women already take responsibility for the design and implementation of successful community and health services. An excellent example of this potential is the initiatives taken by women in several Aboriginal communities in Australia to eliminate alcohol and substance abuse from their communities (Clendinnen, 1999). Similarly successful activities initiated by women in Indigenous communities can be found across the world.

“If we were to abandon the dogmas of empiricism, we could adopt the alternative view that science is a fully social activity—as social and as culturally specific as are religious, educational, economic, and family activities” (Harding, 1986, p. 56). Harding’s observation places research in its context and highlights the futility of forcing knowledge into a particular framework rather than trying to understand relevant ways of knowing.

Conclusions

Irrespective of their country of origin, neither people with disabilities nor Indigenous people are likely to have full and equal access to health and human services. Women also often have unenviable social positions that lack power and respect. Consequently, Indigenous women with disabilities can confront a triple disadvantage. Across the world, access and equity for Indigenous people with disabilities are hindered by the failure and reluctance of the dominant culture to understand the vast differences between European and Indigenous cultures, the prevalence of popularized stereotypes of Indigenous people and the lack of locally-developed services that respond appropriately to the unique needs of local Indigenous groups and communities.

According to Peters-Little (1999), the prevailing opinion that all Indigenous people or communities are homogenous and that solutions can be developed for the entire nation has been detrimental. She noted that throughout the history of Indigenous cultures, viable solutions have not been developed at a national level. Instead, solutions were developed locally, preferably at the level of the family, and in response to immediate local problems. However, in terms of disability concerns, local solutions are hindered by the small numbers of affected Indigenous people, and the lack of power or influence associated with such small numbers. For women, this situation is even more crucial.

As a percentage of the population, Indigenous people represent a small proportion of their respective countries. According to Sanderson (2001), the population of American Indians, including Alaskan Natives and Aleut, is 2.3 million according to the 2000 U.S. Census. However, this population still only represents 0.9 percent of the total U.S. population. The Aboriginal and Torres Strait Islander population is 2.2 percent of the total population in Australia (Australian Bureau of Statistics, 2001). These percentages, both in the U.S. and in Australia, represent numbers that are simply too few for meaningful comparisons or to be acknowledged and addressed by majority culture service providers and policy-makers. The even smaller proportion of

Indigenous women with disabilities in Australia and in the United States means that these women's needs are often overlooked (Australian Bureau of Statistics, 2001). However, when considered globally, the numbers are greatly enhanced, thus demanding greater respect and attention.

While no attempt is being made to state that Indigenous peoples have the same cultures, values and needs throughout the world, similarities do exist. As only two examples, values associated with the collective are often found among tribal people and histories of colonization may result in some form of intergenerational stress (Stone, 2002). Given the similarities in the proportion of Indigenous people in most western countries, and the prevalence of serious disabilities and illnesses among them, it is likely that there is benefit in examining the issues addressed in this paper.

Clearly, research designed to identify needs at the level of the individual community is crucial in Indigenous populations because of the diversity across tribes and regions (see Marshall, Johnson, Martin, Saravanabhavan & Bradford, 1992). Such research ensures local relevance and community empowerment as well as avoiding the problem of overgeneralization of results. Nonetheless, it is also clear that understanding the experience of a given Indigenous community, or nation, can only be enhanced by broadening the context and looking at similarly situated Indigenous persons in other countries (Marshall, & Largo, 1999). Adequate recognition and the development of solutions may be gained through global co-operation across these countries. Most importantly, global cooperation can address the extent to which Indigenous women with disabilities can move from a position of disadvantage due to their relatively small numbers to one of unified representation where their issues are taken seriously within the global community.

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