The Intersection of DISABILITY and Race/Ethnicity/Official Language/Religion

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Intersections: Disability and Race/Ethnicity/Heritage Languages/Religion[1]

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The lives of people with disabilities are shaped by their racial and ethnic status, their religion and their first language. Yet little research has been done on these intersections. What research has been done is primarily from the vantage point of service providers and the need to provide culturally appropriate services. Much research is still required to understand the unique situations of immigrants with disabilities, people of colour with disabilities, Aboriginal people with disabilities and non-English/French speaking people with disabilities.

Simi Linton, in a recent book on the interdisciplinary field of Disability Studies, suggests that there are systematic "faults and fault lines" in how disability is understood in academic research and curriculum. These provide the foundation for what we consider disability research and for identifying where further work is needed to strengthen our understanding of disability. These fault lines also provide a framework within which to consider the intersections of disability and race/ethnicity/heritage language/religion.

$ The current presentation of disability, predominantly in rehabilitation and in special education, individualizes disability -- the curriculum [and research] fosters the idea that disability is the individual's or at most the family's problem. Further, the curriculum

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treats disability as an isolable phenomenon, and ideas about it relate only to it and to people who have particular conditions.

$ As a result of the medicalization of disability in the traditional canon, there occurs a pathologizing of difference; the individualization of disability; a loss of self-definition and self-determination; and a forced reassignment of the roles of patient, client and consumer. Related to this is the conflation of impairment and disability B lack of recognition that impairment and disability should be addressed predominantly in separate realms of discourse.

$ An overemphasis on intervention at the individual level, what Trickett, Watts and Birman (1994, 18) have spoken of as 'person-fixing rather than context-changing'.

$ The preponderance of information on disability in the curricula of the applied fields effectively sequesters the study of disability in those fields, which deal with narrow bands of content and bring to bear a restricted range of methodology on their subjects (Linton1998, 134-5).

What exists, especially in relation to race, ethnic origin and heritage language, mirrors the fault lines identified by Linton. The research is found almost exclusively in applied fields, especially rehabilitation, special education and social work. Much of the research isolates and seeks to treat the individual with impairments rather than addressing the broad context that creates disability. The literature on religion and disability offers a bit more attention to the social context of people with disabilities, but much more research is still necessary in all areas.

Methodology

In undertaking a literature review on disability and identity markers, some terms need to be defined and choices need to be made. Disability refers to the social construction of differences found between people's bodies and/or minds. The physical or mental differences (what some have called impairments) such as the lack of strength in the legs or attention deficit disorder are not significant in and of themselves. They become significant only in the capacity of societies to accommodate or address these differences. People become disabled when they are unable to function within society. They are not necessarily disabled as a result of their bio-medical

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condition. While not all the authors cited here use this distinction, or refer to the social construction of disability, it is the focus of the interdisciplinary field of Disability Studies. The social constructionist approach to disability is in contrast with and opposition to the biomedical/rehabilitation dominated study of impairments and disability. The latter approach is often focused on the physical or mental conditions that create differing functioning within society. As Linton suggests, it privileges work on the individuals and their conditions rather than their social contexts.

Race and ethnicity are also difficult and often contested terms. In this paper, race and ethnicity refer to socially constructed characteristics that may create identities including ancestry, culture, religion, or heritage language (Li 1999). We are not referring to biological or genetic (whether real or perceived) differences between groups. In a socially constructed approach, some groups are perceived to be dominant within a society and others are subordinant and this creates inequality of treatment, access and opportunities.

Gordon and Rosenblum (2001) suggest that the similarity in socially constructed approaches to race/ethnicity and disability, may lead to new and fruitful areas for inquiry. They suggest that through the process of social construction we can see similarities and differences in how people with disabilities and people from other socially constructed groups are named, aggregated and disaggregated, dichotomized and stigmatized and denied attributes valued in the culture. Yet this approach fails to help us understand the intersections between race/ethnicity and disability and neither the social constructionist approach of Disability Studies, nor the biomedical/rehabilitation approach to disability adequately address that intersection. Maria Barile (2000) suggests that we may want to create new analytic tools that concentrate on

exploring those intersections for members of multiple minority groups. Asch (2001) considers critical race theory and feminism with disability in the context of the Americans with Disabilities Act. There is much work yet to be done in developing tools to address these intersections.

It could be appropriate to do an analysis of disability and these identity markers, including those within dominant racial/ethnic groups such as white, Anglo-Saxon Canadians with disabilities. Yet most of the literature on disability fails to be that self-conscious about race and ethnicity. For the most part, when we consider race and ethnicity we find research about those in subordinated or minority groups within society. Thus, for example, we found considerable information about the status of African-Americans with disabilities in the United States that reflected specifically about issues of race and ethnicity. We have focused our attention in this review to literature that addresses those within minority or subordinated racialized/ethnic groups within societies.

We could also consider race/ethnicity on a global scale. For example, we might examine the differences in treatment of people with disabilities in Nepal and Canada. While this would be very interesting, for the most part studies of the status of people with disabilities within a country are not explicit about race/ethnicity. This type of literature review may illustrate cultural and societal differences in the situations of people with disabilities. We have chosen to focus this literature review on research that has explicitly addressed race/ethnicity, or discussed the situation of people who have been disadvantaged by their racialized/ethnic identities. We recognize that this excludes comparisons between countries (unless race/ethnicity has been specifically analyzed) and limits us to research primarily about minority groups within countries.

Finally, in terms of methodology, this review examined literature linked to each of the four identity markers -- race, ethnicity, heritage languages and religion and their connection with disability. Specifically we reviewed academic research, internet sites, government and other reports, dissertation and theses, and other published works since approximately 1990. We also contacted a variety of organizations that are of and for ethno-racial people with disabilities including: the Ethno-Racial People with Disabilities Coalition of Ontario, Association Multi-Ethnique pour l'Intégration des Personnnes Handicapées du Québec and the Ethno-Cultural Program of the Society for Manitobans with Disabilities.

For the first three identity markers (race, ethnicity and heritage languages), our results were primarily related to minority groups. For our search on religion, we found a number of sources that discussed disability and religion without addressing racialized or ethnic minority status. The results discussed under the religion section below are therefore a bit different than the other sections.

General context

Very little is known in general about the incidence of disability among different racial/ethnic communities. In the United States, there is considerable variation in incidence of disability in different racial/ethnic populations. The overall rate of disability in 1991/1992 was reported at 19.4%, but it was higher for Native Americans (21.9%), blacks (20%) and whites (19.7%). For Americans of Hispanic origin the rates were 15.3% and for Asian-Americans it was considerably lower at 9.9% (Bradsher 1996). The Canadian data on disability also dates to 1991, but is not divided by race/ethnicity, except to identify disability among Aboriginal peoples.

(HALS 1991) The overall incidence of disability is 15.5% in the general population and 31% in the Aboriginal populations. Valentine (2001), drawing from literature developed by the Roeher Institute and the Canadian Council on Social Development, suggests that children with disabilities are more likely to be poor than children without disabilities. Prince (2001) indicates that Aboriginal people with disabilities have an even higher rate of poverty. We may have a richer statistical picture of ethno-racial people with disabilities in Canada once the Participation and Activity Limitation Survey (PALS) results from 2001 have been processed, although there is still some question of whether the ethnic and racial markers collected in the regular 2001 Census will be applicable to the PALS respondents.

The literature suggests that while disability is found in all cultures, there is considerable variation in how cultures interpret and address disability. Groce (1999) argues that "the lives of individuals with disability around the world are usually far more limited by prevailing social, cultural, and economic constraints than by specific physical, sensory, psychological or intellectual impairments." Thus, in her view, the social interpretation of disability is the most important factor affecting people with disabilities and "then the issues of interpretation of disability moves from one of health to one of human rights." While this insight is extremely important, it is not widespread in the literature. In the following sections, we will note how much of the literature is taken up in discussion the impairments of people with disabilities and how to provide appropriate services in the context of different cultural communities.

Race/Ethnicity and Disability

Of the identity markers discussed here, while there is still only a small amount of work, race/ethnicity has the largest percentage of the literature in relationship to disability discussed here. This is hardly surprising given that much of the literature addresses disability from an individual and service point of view and is found in very traditional areas associated with disability -- rehabilitation, special education, counseling, and social work. The vast majority of the literature is from the United States.

In some cases, authors are trying to identify the differences in prevalence of an impairment and the usages of services in particular racialized/ethnic groups (Ormel et al 1994, Chapleski et al 1997, Sample et al 1997, Smart and Smart 1997, Tennstedt and Chang 1998, Carrasquillo et al 2000, Johnson 2000, Patterson et al 2000, White-Means 2000, Zsembik 2000). These, mainly quantitative, studies are conducted by professionals, with little obvious consumer input either in to the structure of the research or its analysis.

Other studies address service provision, including counseling, mental health services, cancer prevention, early intervention, to those people with disabilities in minority cultural groups (Nyman 1991, Lieber 1993, Doyle et al 1994, Messier and Toupin 1994, Porter and Beur 1994, Scheller 1995, Hassiotis 1996, Hays 1996, Brown and Sankar 1998, James 1998, Vompe 1998, Bau 1999, Ma et al 1999, Choi and Wynne 2000, Hegarty et al 2000, Lightfoot and Gustafson 2000, Middleton et al 2000, Zhang and Bennett 2001). Again these are studies primarily by professionals, including some organizations, who recognize the cultural diversity among their clients and want to address cultural differences appropriately. They suggest that there is an underutilization of services related to disability by those from racial/ethnic minority backgrounds

as a result of communication barriers, (negative) perceptions about the causes of disability and the inaccessibility and incompatibility of the mainstream service system for these people.

In the same vein, there is some literature examining the context of people with disabilities from particular ethno-racial groups, especially their social support systems (Ronnau and Poertner 1993, Delgado 1996, Begay et al 1999, de Leon et al 2001) Unfortunately most of these works objectify people with disabilities and continue to treat them as the problem, rather than their environment.

At least one study stands out from the others because it addresses disability as a social construct, includes people with disabilities in the research process and promotes alternative approaches to disability. Cook et al (1997) consider service provision for ethno-racial people with disabilities, but approach their research recognizing that the 'subjects' of research were important to the entire process of research. They undertook a participatory action research project "to collect information that could help to devise, implement and evaluate a participatory, culturally sensitive, community-based rehabilitation program in the Chinese community...[and] to raise the understanding and status of disability within the Chinese community through improved family accessibility to supportive programs for children with disabilities and improved education regarding causes, prevention and treatment of disabilities" (Cook et al 1997, 206). The project included families of children with disabilities as partners in all stages of the research process. As well they worked closely with the Chinese community to identify appropriate responses to the needs of both families and their children with disabilities. The key barriers to accessing appropriate supports included language difficulties, time availability, as well as differences in health and illness beliefs. As part of the 'action research', the project shared

findings with professionals and families to transfer what they had learned to those who could then apply appropriate services.

Jones et al (2001) also offers a different perspective on service provision. This study addresses the welfare service needs of South Asian Deaf young people in Britain. Similar issues around access to appropriate services were raised in the interviews and focus groups with South Asian Deaf youth. Additional issues related to being Deaf were also signalled including the assumption that all deaf people share common experiences while for Asian deaf young people this was not true.

> For many Asian young people and their families, the ideas informing 'Deaf identity' could be seen as an extension of the dominant white identity. Asian deaf young people may regard Deaf culture and its support through service delivery, with ambivalence while at the same time recognizing the value of associating with other deaf people. Deaf culture, although empowering young people in relation to the hearing world, can compromise their ethnic and religious heritage. This tension is rarely recognized by service agencies. (Jones et al 2001).

The final results of these two studies do not differ significantly from other studies about service provision in ethno-cultural communities -- they all seek to provide better services and better recognition of the particular concerns of ethno-racial people with disabilities. What Cook et al do suggest is a response that recognizes the real contributions of the people with disabilities and their families to the research. As well, by building links with the families in the context of their own communities, it is likely the services that are provided will be seen more as 'insider' services (or community-based services), rather than those provided by 'outsiders' to the community. This reaffirms the importance of community-based services including community-based rehabilitation. The community-based rehabilitation approach seeks to address "the divergent needs of people with disabilities in the context of a particular community. It is

generally founded on rehabilitation measures taken at the community level that build on the resources of the community, the person with a disability and their family. In this situation, the local people take 'ownership' of their problems and their rehabilitation responsibilities" (Cook et al 1997, 207). This community focus may provide a model for other service areas in addressing the multiple needs of ethno-racial people with disabilities.

Another set of writings addresses the intersection of race/ethnicity and disability from a different angle -- personal experiences and their implications for our understandings of both race/ethnicity and disability. Maria Barile (1998, 2000) offers her experiences as an Canadian woman with disabilities of Italian descent. She suggests the concept of 'multiple minority groups' is one that helps to situate those who experience double, triple or more layers of oppression because of their varying minority statuses. She suggests that those in multiple minority groups experience more severely limiting unequal treatment than those in single minority groups. In addition, they experience discrimination from those within single minority groups as well as the majority groups. The experiences of being from a multiple minority group challenge our theoretical understanding of how to work collectively for change.

> Even with membership in five or more 'groups' the individual does not necessarily get his or her needs met because the groups are designed to address a single, or double identification or minority status. The combination of disabilities, social or ethnic backgrounds, gender or sexual orientation differences, are not addressed by the groups. The individual experiences. The challenge then is to use new analytical tools, or adapt existing ones, to emancipate those experiences multiple levels of discrimination due to their multiple minority status. (Barile 2000, 126-7).

Others (Gordon and Rosenblum 2001, Milian and Erin 2001, Vernon 1998, 1996a) also call for appropriate tools to deal with the intersections of race/ethnicity and disability.

The Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO 2000, 1999, n.d,

1996) as well as the Association Multi-Ethnique pour l'Integration des Personnes Handicapées du Québec (Basuebabu T et al 1993, Penafiel 1999, 2000, forthcoming) have brought forward the voices of their members speaking about their experiences with many different facets of racism, violence against women and access to health care. Demas (1993), the Aboriginal Reference Group on Disability Issues, Burelle (1996), the Assembly of Manitoba Chiefs (1997) and Fricke (1998) offer some insights about the unique situations of Aboriginal Canadians with disabilities. They face different circumstances than many other ethno-racial groups in Canada because on top of lack of culturally appropriate services and information in their original languages, services may not be provided or they have to face jurisdictional conflicts between different levels of governments and they have twice the rate of disability in their communities.

Heritage Languages and Disability

There is very little research available on heritage languages and disability. What exists is found in special education literature primarily from the United States. Several authors review and assess special education for Hispanic Americans with learning disabilities. They suggest that there has been a tendency to misidentify learning disabilities among students with limited English speaking capacity that leads to both an underreferral and overreferral to special education classes (Gersten and Woodward 1994). Ruiz (1995) suggests that the context of the classroom will lead to greater or lesser abilities among students with disabilities. She suggests that the medical model as applied to special education overidentifies children from diverse backgrounds as being disabled and calls for further research on the instructional setting in special education.

Allison and Vining (1999) argue that Native Americans with disabilities may have unique difficulties in accessing appropriate education, including lack of culturally appropriate materials, untrained interpreters, appropriate forms of assessment and jurisdictional issues. They call for the involvement of families and communities in ensuring appropriate and accessible education for disabled Native Americans.

Finally, Germanos-Koutsounadis (2001) illustrates the gaps in special education for non-English speaking disabled children in Australia including lack of statistical data, outreach to community organizations, provision of information in languages other than English, multicultural programming, attitudes of staff, lack of training, lack of knowledge of needs and lack of representation of the children with disabilities in decision-making bodies.

Religion/Spirituality and Disability

The literature on disability and religion or spirituality is a bit broader than the literature related to the other identity markers. Most writings relate to North American, English religions, primarily Christianity. Only a small minority address race/ethnicity in a self-conscious manner. Three areas can be identified in the literature: pieces that use religion as an indicator, literature which explores how religion or spirituality provides services, and literature which explores how religion/spirituality addresses disability.

Selway and Ashman (1998) and Zhang and Bennett (2001) suggest that different religions (as well as different people within each religion) have inconsistent approaches to disability, ranging from acceptance of people with disabilities as a gift from god(s) and therefore special, to rejection of those with disabilities as a punishment from god(s). While this varies by

religion and family, attitudes can also vary by the type of disability. Selway and Ashman argue that people with HIV/AIDS, intellectual disabilities, psychiatric illness and cerebral palsy were the least accepted in all the ethno-racial communities they studied in Australia. As well, the relative stigma varied by ethno-racial group. The data they cite argues that the German-Australian community had the greatest acceptance of disability, followed by the Anglo, Italian, Chinese, Greek and Arabic communities. The religious and cultural acceptance or rejection of disability has implications for accessing health or other support services for family members with disabilities. For example, Zhang and Bennett suggest that where families see disability as a punishment for past wrongs, families may not want to seek early intervention services for children with disabilities. There is no evidence from the literature reviewed here that suggests when a person with disabilities is valued, families or others will be more willing to seek support services.

Some authors regard the religion or spirituality of people with disabilities or the families of people with disabilities as something important to measure in and of itself. Haworth et al (1996) and Idler and Kasl (1997a, 1997b, 1992) examine the trends in religiosity among people with disabilities. Rogers-Dulan (1998) explores the religious connectedness of urban African-American families with children with disabilities. In all of these studies, religious participation was a positive factor in the lives of people with disabilities, although with deteriorating functions, some were less able to participate.

The literature also examines how religion and spirituality provide a service, primarily in terms of coping with disabilities. It builds on the measurement and suggests more about the positive benefits of religion or spirituality. Bennett et al (1995) argue that religion provides a

personal coping resource throughout the life cycle. O'Connor et al (1999) illustrate how faith is a key part of coping with disabilities. Chang et al (1998) describes how religion/spirituality was used as a means of coping by informal caregivers of disabled elders. Nosek (2001) illustrates how spirituality can increase feelings of self-worth or self-esteem among women with disabilities and "is an important tool used by women with disabilities in counteracting overwhelming negative odds imposed by society stereotypes and barriers achieving lives of fulfillment."

A much larger number of authors address how religion or spirituality deals with disability. For many, the research illustrates that the religious experiences of people with disabilities is one of exclusion. Nash (1997) argues that in the 'treetop communities' in Scotland, which practice Anthroposophy, people with learning disabilities are treated in ways that reinforce their marginalization and promote dependency. Elshout (1994) talks with other feminist Christian theologians and identifies that women with disabilities may not find allies with other feminist theologians. She offers the image of the disabled body as a new metaphor for feminist theology. Stiteler (1992) identifies how images of disability within Christian liturgy are most often negative, which contributes to the exclusion of people with disabilities. Swinton (1997) and Bilu and Goodman (1997) both consider how to incorporate people with cognitive disabilities in religion, albeit from different vantage points. Swinton looks primarily at Christianity and the possibilities for inclusion. Bilu and Goodman describe how facilitated communication was used and transformed into a mystic device in an Jewish ultraorthodox community. King (1998) explores how the Black Christian church in the United States has

devalued and excluded African American women with disabilities and offers some recommendations for change.

The literature reviewed here on religion/spirituality and disability suggests that while faith and spirituality can offer positive supports to people with disabilities, their experiences within religious or spiritual communities continue to be of exclusion and marginalization.

Other issues

Several other areas came out in one or two articles in this review -- income, labour market participation and immigration and settlement issues. Bound et al (1996), Santiago and Muschkin (1996) and Wray (1996) examine the links between race/ethnicity, disability and the labour force in the United States. Bound et al suggest that the relatively poor health of black men and women affects the timing of their exit from the labour force. Blacks have less access than whites to the financial resources required to retire early, while at the same time they are more likely to work at jobs that require good health and have few options if their health becomes poor. Santiago and Muschkin illustrate how being black and disabled will more likely also decrease labour force earnings. Wray concludes that health behaviors and conditions, job benefits and workplace conditions were more likely to predict experiences of disability than non-Anglo ethnicity. While much policy research has been done on access to income and appropriate disability supports in Canada (Fawcett 2000, Roeher Institute 2001), there is not sufficient data to develop a sustained analysis of income among ethno-racial people with disabilities.

Several authors also address particular issues related to immigration and settlement for people with disabilities. As early as 1988 the Canadian Task Force on Mental Health Issues affecting Immigrants and Refugees highlighted the ways in which the experiences of persecution and torture may create significant problems for refugees and immigrants and the need for appropriate services in Canada. A decade later Sandys (1998) undertook an exploratory study highlighting some of the key immigration and settlement issues for ethno-racial people with disabilities. The participants made clear they felt Canada's immigration process dehumanizes immigrants and is even more difficult for immigrants with disabilities. They wanted to work but found they faced discrimination on the basis of their disabilities. They found it difficult to access appropriate services, partly because of cultural barriers, but also because of the lack of knowledge about disabilities among organizations that provided immigration services. In addition, for people with disabilities who want to come to Canada as immigrants, there remain significant barriers around perceptions of their undue use of health services (Mosoff 1999; Stienstra forthcoming). There are particular barriers for people with HIV/AIDS seeking admittance to Canada as refugees (Klein 2001), including the possibility of testing potential immigrants for HIV prior to admittance.

A final piece by Fujiura (2000) illustrates how complicated our discussions of race/ethnicity, disability and public policy need to become. Using demographic data from the United States, Fujiura asks and seeks to address the question "are race and ethnicity significant to those of us in the disability community?" He argues that issues related to race/ethnicity are multilayered and that poverty, lack of access and economic inequity complicate discussions of race. He argues, in contrast with much of the literature discussed above, that it is not good

enough policy to train service providers in cultural awareness, but that policy needs to address fundamental inequalities based in disability, race and class. "Professionals in the disability/rehabilitation field must avoid defining the minority agenda in this field only in terms of skin color, which represents the most superficial form of redress. It should be about those persons who are un-served or under-served." "A policy agenda based only on race serves to exclude natural coalitions based broadly on need and inequity -- a more stable common ground for our diverse groups." "The central point is that the core dynamics transcend the disability field itself. It is more than better methods of vocational training or placement services and outreach. Equity demands some hard analyses of the secondary employment market, issues of health care access for the working poor and our social welfare systems for the vulnerable so that a common cause can be found." "Cultural competence, as commonly applied, plays out in our traditional professional-client contexts. We provide culturally competent services. We respect the cultural perspectives of those we serve. However, a competency agenda that does not challenge organizations or individuals to directly address the source of inequity is only half a solution. In this case, one is merely better equipped to deal with the aftermath of those inequities."

At present within Canada, the policy research in this area is bifurcated. The Office for Disability Issues (ODI) in Human Resources Development Canada (HRDC) is the focal point for disability policy research within the federal government. ODI also takes the lead in implementing federal government commitments and actions related to disability, and provides funds for community-based research related to research. The Applied Research Branch, also in HRDC, has undertaken a number of quantitative research projects on people with disabilities, especially related to their connections to the labour market. Recently they funded a small pilot

demonstration project providing money for disability supports to people with disabilities in Vancouver and Ottawa to enhance their employment options. Some research contracts are also available to support the Policy Branch of HRDC in their development of disability-related policies for the federal government. Many of these initiatives may touch upon the diversities of people with disabilities, including those based in ethno-racial identities, however, there has been no sustained policy research on the nexus between disability and race or ethnicity identity markers. Similarly Heritage Canada provides policy and program support around policies related to race and ethnicity markers, but there has been no sustained attention to the intersections with disability.

Fujiura's insights together with Linton's analysis of the disability literature quoted at the beginning of this piece illustrate some clear gaps and necessary future directions for research on the intersections between race/ethnicity/heritage languages/religion and disability.

Gaps and Future Directions

The literature reviewed here is dominated by research undertaken within the context of the United States. The presence of the 1990 Americans with Disabilities Act, the 1990 Individuals with Disabilities Education Act, the history of racial segregation and civil rights based in race all affect the research on the intersections between race/ethnicity/heritage languages/religion and disability. There is much more literature coming from the United States, but much of it follows a very traditional, medicalized, and individualized approach to disability. One theme that comes from this review is that some of the most participatory, engaging studies

on these intersections are already being done by researchers and organizations within Canada. But so little research on these intersections has been done and so much more needs to be undertaken.

Building on the themes outlined by Linton and reinforced by Fujiura, research related to disability should focus on the social, political and economic contexts of how impairment changes into disability. Less attention should be paid to how to provide better 'culturally competent' services, and more paid to what causes the inequities that result in the need for differing services, or services at all. In Canada, this means initially access to data that includes disaggregation by race/ethnicity and disability in a meaningful fashion. In the 1991 Health Activity Limitation Survey, no analysis of such data was published. With the 2001 Participation Activity Limitation Survey we can hope that this data will be available in rich detail so as to allow researchers, policy makers, community organizations to better understand the intersections between these identity markers.

In Canada we also need to develop research that originates from the communities of those who experience the intersections between race/ethnicity/heritage languages/religion and disability. We need to use methods that allow their voices to be heard authentically, and develop research programs together with these communities in ways that will benefit them. One clear gap in this literature was the almost complete lack of research published in French or addressing the situation in Quebec.

For those who are studying majority communities, or are making broad statements about the lives of people with disabilities, we need to be more self-conscious about the generalizations we make about affected communities. Our research needs to reflect the limitations within which

we gathered our data, and needs to be clear about the extent of commentary we can make with those limitations. For example, two recent studies published from Status of Women Canada illustrate these two approaches. Morris et al (1999) state explicitly the ethnic/racialized background of participants (primarily European with some Aboriginal) and outline some of the implications for home care in Winnipeg and St. John's. The Roeher Institute (2001) makes a brief mention of the limited cultural diversity in the communities studied after an extensive discussion of communities and cultures of support. The report also discusses some situations of racism between home support workers and their clients. Yet little mention is made of race/ethnicity in the policy recommendations, including whether the recommendations were limited in scope because of the limited cultural background of the participants.

Much more research is needed to develop our understanding of the different perspectives and inequalities people of colour with disabilities face, immigrants with disabilities face and Aboriginal people with disabilities face. We know little about their experiences of racism as it intersects with their experiences of ableism. The intersections of race/ethnicity and disability however are not only found among ethno-racial people with disabilities, they also intersect for people who provide support or services. We need more research on how, for example, the Live-In Caregiver Program and home care draw in ethno-racial workers, why and the implications of this for all people with disabilities.

Policy research that specifically addresses the social, economic and political contexts of ethno-racial people with disabilities is urgently needed in Canada. Research is required in many areas -- on employment and employment policies, income supports and related policies (including those under consideration in the Social Union Framework discussions), access to

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education throughout the life cycle and policies to address this, legislative frameworks that already or could address these intersections, information and communications technologies, entrepreneurship, and access to health services and related policies.

So much research is needed that it is impossible to prioritize, except to return to the need for research to recognize the full participation of ethno-racial people with disabilities and their communities in the research process, from their vantage point, recognizing and valuing their expertise and addressing their benefit. This will create rich, credible and reliable research that speaks to the inequalities that shape the lives of ethno-racial people with disabilities.

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