Enabling Virtual Knowledge Networks for Human Rights Monitoring for People with Disabilities

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ABSTRACT

Holistic disability rights monitoring is an imperative approach to permit translation of rights on paper into rights in reality for people with disabilities. However, evidence-based knowledge produced through such a holistic monitoring approach has to be accessible to a broad range of stakeholders, e.g., groups such as: researchers, representatives of disability community, people with disabilities, media, policy makers, and the general public. Besides, the collected evidence should contribute to building capacity within disability community around human rights questions. This article explains the design process of a Virtual Knowledge Network (VKN) as an operational tool to support mobilization and dissemination of evidence-based knowledge produced by the Disability Rights Promotion International Canada (DRPI-Canada) project. This VKN is embedded in the more general framework of DRPI, grounded in a human rights approach to disability that acknowledges the importance of creating knowledgeable communities in order to make the disability rights monitoring efforts sustainable.

Keywords: Disability Rights, Disability Rights Monitoring, Knowledge Management, Knowledge Networks, Virtual Communities

1. INTRODUCTION

Disability activists and scholars refer to disability rights as "…the equal effective enjoyment of all human rights by people with disabilities" (Disability Rights Promotion International (DRPI), 2003). The majority consensus is that "disability" is a consequence of negative social conditions rather than an individual's specific medical impairment (Barnes, Mercer,

& Shakespeare, 1999; Fougeyrollas, Cloutier, Bergeron, Côté, & Michel, 1999; Rioux, 1997, 2001; Shakespeare, 1999; Thomas, 2002).

Monitoring or auditing is central to an effective and organized strategy to enforcing the enjoyment of human rights by all people with disabilities on equal basis. Rights monitoring is a research method that involves the tracking, collection, collation, analysis, interpretation and mobilization of data and knowledge about the life situation of people using human rights standards as benchmarks. A review of international human rights literature shows that, unlike areas such as women's rights (Callamard, 1999a, 1999b), disability rights monitoring is relatively underdeveloped (International Disability Rights Monitor, 2004). To date, comprehensive knowledge about the human rights situation of people with disabilities in Canada has not been systematically collected, documented, stored and analyzed. A holistic approach to monitoring is needed to integrate multiple levels of analysis (i.e., individual, system levels) and produce accurate knowledge on the multi-faceted situation of people with disabilities facing human rights violations. Mobilization and dissemination of evidence-based knowledge produced through monitoring processes represent the keystone of the holistic approach to monitoring. Integrating different aspects of monitoring requires fluent collaboration and communication among a broad range of individuals, organizations and policy makers. Furthermore, knowledge produced by the project should be made accessible to people with disabilities and their organizations to build their capacity on disability rights monitoring beyond the life of the project. This paper proposes an operational tool that enables dynamic collaboration among project's participants and knowledge creation and sharing across the four themes of the project and with larger communities to support them in their efforts to improve the life of Canadians with disabilities.

2. BACKGROUND

2.1 Conceptual Framing of Disability

Discourse on disability has been dominated by the perception of disability as an "individual pathology" or a biomedical condition. Being seen as a deviation from a biomedical norm and the result of either a mental or physical condition, as a consequence, disability is assumed to be prevented or ameliorated by situating the individual closer to the established norm through medical, biological, or genetic intervention (Rioux, 1997). Even the broader social approach that places disability at the intersection between individual and environment cannot move beyond the mindset of accommodation in which environments should be arranged to accommodate people's differences. It has to move beyond a call for environmental adaptations to address social and economic conditions that disadvantage people with disabilities.

Individual investigations have uncovered systemic human rights violations against people with disabilities such as significant levels of low literacy (Calamai, 1987; Minister of Industry Canada and Organisation for Economic Cooperation and Development, 2005; Rioux, Zubrow, Miller, & Bunch, 2003), denial of medical care (Frazee, Gilmour, & Mykitiuk, 2005), high levels of poverty (Fawcett, 1996; Torjman, 1996), disproportionately high unemployment rates (Abberley, 2002; Canadian Council on Social Development, 2005; Human Resources Development Canada, 2002; Roeher Institute, 2004), lack of access to income programs and education (Armstrong & Barton, 1999), marginalization and exclusion of disability issues and people with disabilities in civil society organizations (Charlton, 1998; Rioux et al., 2003), and inability to access transportation (Fougeyrollas, Tremblay, Noreau, Dumont,

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