Virtual Knowledge Network for Human Rights Monitoring

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Abstract

Disability rights monitoring is essential in order to translate rights on paper into rights in reality for people with disabilities. This article focuses on the design process of a complex 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.

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

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).

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). Mobilization and dissemination of evidence-based knowledge produced through monitoring processes represent the keystone of a holistic approach to monitoring; though integrating different facets of monitoring requires collaboration among a broad range of individuals (including people with disabilities) and organizations. This paper proposes an operational tool that enables dynamic collaboration among project's participants and knowledge creation and sharing.

2   Background

2.1   Framework of Disability

Systemic human rights violations against people with disabilities are usually interpreted as issues of service provision rather than being recognized as fundamental rights in order to achieve a society in which people with disabilities are free to fully and equally participate. This requires

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a conceptualization of disability within a human rights framework that looks at how society marginalizes people, and what strategies are needed to address existing inequalities. It involves moving away from viewing people with disabilities as anomalies towards viewing them as rights holders and equal citizens (Quinn & Degener, 2002).

Rights monitoring is the first step in making this shift possible. While there are a number of international and Canadian human rights commitments and rights monitoring initiatives in the international arena(Disability Rights Promotion International (DRPI), 2003; International Disability Rights Monitor (IDRM), 2004), Canada lacks comprehensive and multi-level analysis of disability rights violations. DRPI-Canada project takes a significant step forward in developing a system to monitor the human rights situation of people with disabilities.

2.2 Mobilization and Dissemination of Evidence-Based Knowledge – Essential process to the sustainability of disability rights monitoring

Holistic disability rights monitoring is grounded in on-going communication and sharing of resources, training and methodological approaches among the four themes. Furthermore, it is essential to build capacity, leadership and knowledge development within the disability community in order to promote greater awareness of disability discrimination and to enable people with disabilities themselves to take ownership of disability rights monitoring. In this context, a complex system is required to facilitate the collaboration of a full range of project participants – researchers, representatives of disability community, policy makers, and general public – and support capacity building within disability community through access to online tools and training resources.

3   Methods

This paper describes the design and development process of a Virtual Knowledge Network (VKN) to support the holistic disability rights monitoring.

3.1   Virtual Communities

VCs received a visible level of attention from the research community in Computer Science, Sociology, Psychology and other disciplines (Preece, 2000). A virtual community is a form of social system; it inherits some of the social system's characteristics (Weissman, 2000) such as causal reciprocity, purpose, design, roles, circumstances, officers, passion, needs, loyalty, and access. There are different perspectives and different classifications of VCs (El Morr, 2007; El Morr & Kawash, 2007; Stein, Hawking, & Sharma, 2005); though, VCs can be constructed to form a knowledge network (KN). Knowledge networks are communities where participants capture, access, use, create, and define knowledge (Merali & Davies, 2001). Our purpose is to design and implement a VC for Knowledge Mobilization, i.e. for knowledge generation and dissemination, in the context of DRPI.

Our VC-KM platform is a hybrid model that supports different complexities (Jansen, Steenbakkers, & Jägers, 2000). In all DRPI research teams the researchers and community

members manage highly complex activities with high variability, while we anticipate that knowledge dissemination communities (dissemination of fact sheets, policy briefs, etc.) - which are open to the public or to private partners - will have a low complexity and low variability. On the other hand, we anticipate that some communities will be based on an e-learning model and therefore will have a high complexity and low variability.

While several virtual communities platform exist, none are adapted to our research team objectives in terms of creating dynamic relations among team members, enabling particularly each member (and not only administrators) to create folders and upload/download documents, to co-edit documents and to share files across communities in different levels of granularity: share with one person, one group of people and a whole community. Besides, none of these sites is fully accessible to people with visual disabilities, while accessibility is an essential objective that we strive for in our project. The VKN is described in detail in the next sections of the paper.

3.2 Platform Design and Implementation

3.2.1 Community Design

In the field of disability, tools and training resources for evidence-based data collection are scarce as are tools and methods for multiple levels of analysis (i.e. individual, systemic) and particularly those tailored to the Canadian context. Development and *dissemination* of these tools incorporating an e-learning component to a virtual knowledge community in order to support continuous training to develop monitoring skills (online manuals, course guides, books, tools…). Internally, the VKN should enable researchers to *communicate* and *cross-check* their findings, and to *collaborate* around subjects of interest during the research activities. Therefore, members will need a component allowing collaboration to facilitate knowledge *creation*. Finally, the VKN needs to facilitate the **search** for information for communities' members. Consequently the VKN was designed into four components allowing (1) knowledge *creation*, (2) knowledge *discovery*, (3) knowledge dissemination and (4) VKN management. The VKN platform was designed to comprise functionalities that support all four components.
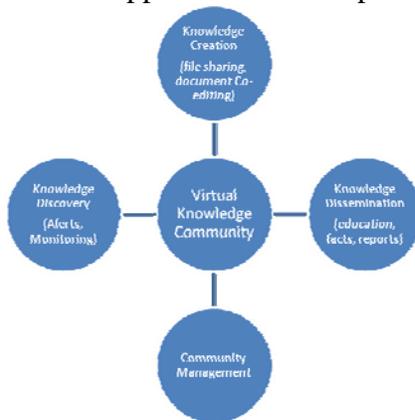

Figure 1. A high level view of the components of the collaborative platform

3.2.2 Community Platform Implementation

Open source material has been used throughout the development of this model. The VC platform allows two major **roles** to be played: *Administrator* and *Member*; the members can play two possible roles: *consumers* and *producers* of information.

Five communities have been created; four of them deal with the four substantive themes of research and one is public. The portal allows a person to connect to the portal and to create his/her own profile. In order; to simplify information dissemination, we decided that the *public community* allows people to join without administrator approval since it is designed to disseminate knowledge (research findings, articles, reports, etc.) to the public in the society at large. Members of the *public community* can play the role of *information.* Members of communities, other than the public, are mainly information producer (e.g. upload documents); nevertheless, they are also information consumers of information exchanged inside their community (e.g. download documents).

The administrator is concerned with the maintenance of the VKN (community and member management), such as creating a new community (figure 4).

Figure 2. Creating a new community

Administrators and members of the themes communities can upload and assign each file a "visibility" right (figure 6); that is a member can decide if his/her file is visible by a whole community or a specific person in that community, or any combination of these two possibilities.
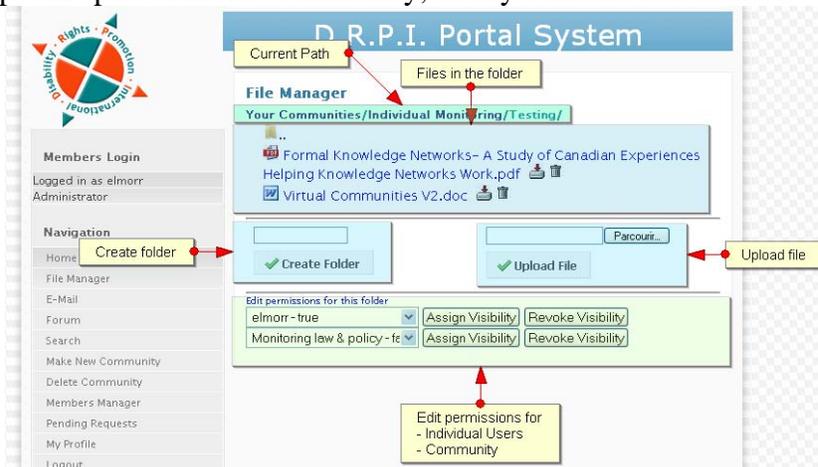

Figure 3. A member assigning "visibility" right (i.e. access rights) to other specific members and/or while communities.

3.2.3   Usability and accessibility

To ensure the usability of the portal, we took into account relevant guidelines (U.S. Department of Health and Human Services, 2008) and decided to use a light XHTML W3C compliant template for the layout, with few pictures, to reduce users waiting time and enhance accessibility. The layout is light and easy to scan by the users, a menu on the left gives access to all the features of the portal in one click. The navigation was designed to minimize users' interaction to access information. Fonts and colors have been chosen for their clarity for people

who are not visually impaired. To avoid accessibility issues, we use a layout with few pictures. Thus, most of the content being readable text, accessibility features were implemented easily. We followed the Web Content Accessibility Guidelines (World Wide Web Consortium, 2008) from the W3C; thus, for example, we made menu items accessible using keyboard shortcuts. Activity and outcome monitoring.

3.2.4   Knowledge Management

3.2.4.1 Knowledge Management on the Platform

Nowadays, there are 2 main KM trends: People centered and Information Management and Information Technology Centered KM. Using previous experiences (Davenport, De Long, & Beers, 1998), we used several relevant guidelines to develop our approach in this healthcare related platform. As our initiative focuses more on the technical purpose than on a human approach, guidelines regarding technical support were taken in account. Flexible knowledge structure and good usability are important for the success of the initiative. During the development of our platform, those basic guidelines were taken in account, from early specification to late implementation.

Within the platform, numerous users, i.e. ***producers,*** will share large amount of documents within and between the communities for **consumers**. We identified two major issues and defined features to address them. First, searching through a *large* number of documents; therefore, finding relevant documents in the platform regarding to the users interest is identified as of utmost importance. Second, as the information producers are mainly researchers, this platform offers a great opportunity to create cross-theme synergies, open new collaborations or enforce the existing ones. Besides, the platform is designed for the public, and other researchers and organizations at a later stage. The large number of potential contributors will make the discovery of potential common interests between members difficult. Consequently, it is important to facilitate this discovery process.

To address these two issues, we designed a matching feature that enables the system to describe users and documents using metadata in order to (1) notify the user when relevant information has been added to the platform and (2) match users having a "similar" profile. We identified four sequential steps in the process: Information gathering, information extraction, matching, and push mechanism.

During information gathering we gather all the information concerning each member. While during i**nformation extraction,** keywords are extracted from documents using a text-mining library: RapidMiner (rapid-i.com, 2008). These keywords will complete the documents metadata. These extraction will take place for both documents uploaded by users and the publications they entered to complete their profile. Navigation will also be mined to extract relevant topic of interest (Widyantoro, Loerger, & Yen, 2001; Xiaobin, Jay Budzik, & Kristian, 2000). We trained the RapidMiner model with more than 50 documents related to healthcare. Using this healthcare dedicated text-mining model gives impressive results for keyword extraction. Once the keywords automatically extracted, the owner of the file can decide to manually edit, add or remove keywords from this list (figure 7).
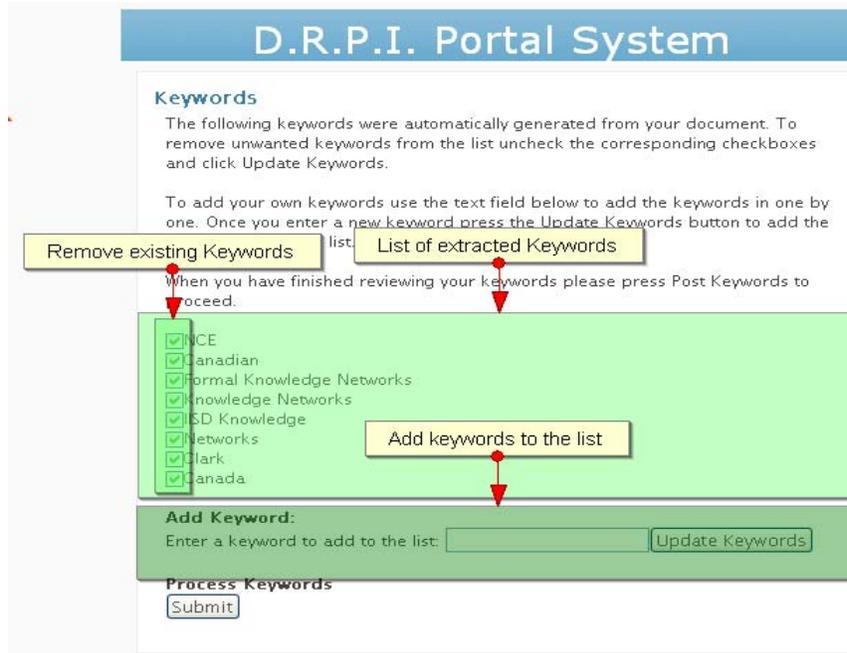
Figure 4: Keyword editing after extraction

Afterword, matching algorithms allowed us to provide a user to document and user to user matching. Both matching algorithms follow the same principle of computing a distance between the gathered metadata. Yu et al. (Yu, Al-Jadir, & Spaccapietra, 2005) presented an algorithm for matching demands and supplies of profiles using a description logic based approach, a similar approach can be used for the user/documents matching.

Multiplying channels of exchanges enhance the global performance of knowledge dissemination; therefore, we've build a forum and a mail system for users. Those communication channels are complementary. Users interaction is thus enhanced, discussion on a paper uploaded in the repository can start and lead to a better understanding or constructive critics.

4   Conclusion

We have created a sustainable disability rights virtual knowledge network to (1) support its research findings, and (2) continue to mobilize community members, academics, students, as well as the media and policy makers around disability rights and (3) to empower the users in the development and use of the network. A public subscription to a public community has been provided. Members are provided tools to publish (upload) and read (download) information (articles, fact sheets, policy briefs, etc.); to communicate to each other in synchronous (chat) as well as in an asynchronous way (email, bulletin board). Work is underway to ensure all parts of the system are accessible for people with disabilities (Alison & David, 2006; Boldyreff, 2002). And a search capability is built into the VKN.

We believe that the VC will make a significant impact on the training and development of students and individuals affiliated with disability community organizations, by enhancing critical

disability studies curricula and by providing the academic and disability community with evidence-based knowledge and new tools for on-going disability rights monitoring.

5   Acknowledgements

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