LOCAL KNOWLEDGE AND INTERNATIONAL COLLABORATION IN DISABILITY PROGRAMS

Patrick J. Devlieger

Disability is a sensitive barometer for local development. How people with disabilities fare immediately reflects their culture. In our global times of information exchange, political, economical and social interdependence, the discourse of disability is constantly taking new turns, primarily based on an ideology of human rights, geared towards community based activities, and support rather than service. In local contexts, the communication and implementation of these ideas have been very varied. In this variation, local knowledge of disability proves to be very resilient. In the past few decades, policy makers and professionals in the South have learnt the international language of bilateral, multilateral, and service development standards imposed by international and national non-governmental organizations. Some of the initiatives resulting from the new language have had tangible outcomes for the lives of disabled people and their families, but others failed to reach out, sometimes due to the intentions of planners, sometimes because of the way international collaboration works in the negotiation and allocation of funds, asymmetrical and inefficient interaction and implementation, and lack of understanding of local knowledge and priorities. In this article, global and local knowledge are considered to be two sides of the coin of disability knowledge. They are considered to be more or less independent developments; one may have developed in capital cities around the world, the other in the course of the history and culture of communities. Yet, in an interdependent world and in the way they become real behavior and initiatives of or for people with disabilities, they become mutually constitutive. For example, the liberation war of Zimbabwe produced a language of liberation and ultimately a new government but also a great number of disabled veterans who created home-grown potential for local cultural change. The language of human rights for disabled people coincided fairly well with this potential and accounts for the leadership Zimbabwe has shown in mounting a disability movement, both locally and globally. The purpose of this article is to explore the two sides of disability knowledge and in particular to explore the importance of local knowledge for international collaboration.

What is global knowledge of disability? In an interdependent world of international relationships and organizations, global knowledge is a layer of standards to which countries and regions refer as they evaluate themselves and each other and seek direction for new development. Global knowledge is developed across cultural and national boundaries. It first becomes reflected in policy statements and new initiatives. Global knowledge creates tensions with what is already known, what is homegrown in languages, cultures, and history. The global discourse of human rights has supported the worldwide recognition of disabled people and provided the foundation for a worldwide movement. Disabled people in many countries, both in the North and the South, have found that it is good to organize themselves. The commonality of disability speaks loud and clear beyond the differences of gender, race, culture, and professional background because the agenda seems quite clear: better lives. Global knowledge is knowledge that easily survives in conferences, policies, and legislation. It becomes local if it survives the stage of reflection and conceptualization and permeates culture and history. Local knowledge of disability is cast in the daily relationships between disabled and able-bodied individuals. It is found in the particulars of languages and cultural capital; in the history of the emergence and disappearance of disabilities; in the social, political, racial, sexual, and ecological environments of individuals; and in the very history of services and supports for disabled people as reflected by the moral and political relationships between a society and its members with disabilities. Local knowledge is not static because cultures and societies are not static; culture is built and built upon (cf. Whyte/Ingstad 1998).

New developments of international interdependence and current understanding of international disability work may lead to a new orientation. Countries in the North and the South are starting to frame their relationships differently. The power relationships of colonialism and post-colonialism have altered in a post-cold war era to make way for more interdependence. This partly emerges from the realization that questions of economic development and international security cannot be solved in a vacuum. Interdependence is also supported by the global market and information industries. The need for local knowledge in order to be effective, and an understanding of the world as interdependent, seem to be the two sides of the coin that may lead to more effective and culturally sensitive work in disability programs. In order to explore the tension between the local and the global, I will first discuss how a new global context may inform international disability collaboration. Then, I will discuss how local cultural, historical, and technological knowledge of disability may be generated and may interplay with global knowledge. My views on these questions are informed by research in African countries, my participation in disability programs run by non-governmental organizations and the United Nations, and my current involvement in the development of disability studies in the United States.

The Voice of Disabled People and the Possibility of International Exchange

The fact that people with disabilities have been organizing themselves in formal organizations and informal networks, both in the North and the South, has developed a new level of consciousness that permeates the way governments, non-governmental organizations, and universities can engage in the *disability business*. The sensitivities of disabled people themselves, as they relate to the cultural understanding of disability, the issue of discrimination, and the services in education, employment, and health care have therefore a greater chance of being included in the knowledge base. Listening to disabled people as part of the planning and implementation process of disability programs seems like a common sense issue. However, much of the international collaboration has failed to see the benefit of including people with disabilities in planning and designing programs. The voice of disabled people is fundamental to the understanding of disability itself. Disabled people have the experience of living in families, communities, and society, and a vision of disability and disability programs must develop in the interaction between disabled and able-bodied people. Both are part of the equation. This principle is now being tried out in some universities in the North. After developing an academic home for cultural minority populations and women, first attempts are now being made at developing training and research programs in disability studies. These programs are based on interdisciplinary collaboration and actively involve people with disabilities as leaders and partners in training and research. This new development will have international ripple effects that extend to international work and disability programs in the South. Enhancing the voice of disabled people in an international context may be facilitated by global developments. First, the organization of international travel, the information networks, and potential of new technological developments in communication make it possible for people with disabilities to be involved more significantly. More important, in the context of North-South relationships, it may also mean that the potential of mutual development between the North and South in the area of disability may be enhanced. The breakdown of old power relationships and the acceleration of exchange have increased the vulnerability of countries in the North. This could mean that the export of development by Northern countries is replaced by mutual development, i.e. collaboration needs to work both ways, and a mode of interdependence is developed. In concrete terms, one may expect that disability program development worldwide may benefit from this development.

Collaborative program development in a global perspective may therefore have the following characteristics. A global discourse on disability will continue to develop. International definitions and standards will remain guidelines on policy and service for organizations and governments. However, the local contexts of countries, including historically, culturally, and technologically situated understandings of disability and economic conditions, will constantly threaten the usefulness and validity of international definitions and standards. More promising is the collaboration between organizations, governments, and universities that examine strategies of mutual development. Program development in the North may benefit developments in the South, but equally now, the reverse needs to be made possible. A number of organizations in the North are starting to develop these strategies. Last but not least, the involvement of individuals with disabilities every step of the way, in program and research design and development, is a matter of principle.

GENERATING LOCAL KNOWLEDGE: THE POWER OF LANGUAGE, HISTORY, AND TECHNOLOGY

Advocating new ways of collaborating assumes that the knowledge base for such collaboration is readily available. This is unfortunately not the case. Only in recent times have initial conscious efforts been undertaken toward systematic research into social and cultural understandings of disability in the contexts of countries of the South (for an overview, see Ingstad/Whyte 1995). Belief systems pertaining to the causality of disability as part of the more global understanding of cosmologies and the implications for care and service have received some attention. Many questions remain. For example: Does this information suffice as a knowledge base for international collaboration? Is this information legitimately produced? What other types of information need to be generated and who needs to be involved?

In the context of mutual development and intercultural understanding, I would like to stress three types of knowledge that constitute the premise for a knowledge base: language use, technology and the history of disability. I emphasize these types of knowledge because of their potential for an impetus for change and development that may indeed result in the improvement of lives of people with disabilities. A cross-cultural understanding of disability is hampered at the outset by a conceptual and a language problem. What is understood by *disability* in countries in the North is informed by cultural differences and historical backgrounds. For example, the idea of disability as a major concept of discourse in the United States is informed by conceptual developments that move away from the term *handicap* and by legal developments, the most important being the Americans with Disabilities Act of 1990, which situate the problem of disability in the environment rather than in the individual with a disability (Devlieger 1997). The concept of handicap or disability as one that is applied to a vast variety of people with many different impairments is one that has been exported from the North to the South and popularized by United Nations initiatives. Yet it remains a concept that is difficult to define in global terms because it means something different for every person so labeled and for people with different cultural backgrounds. This messiness is an invitation to enhance the importance of society and culture in the understanding of disability. There are ways out of the messiness of disability, paradoxically by bringing it to the forefront. In producing and using the knowledge that underlines the complexity of disability in its cultural context, the way may also be paved toward greater cultural sensitivity and efficiency.

Local knowledge of disability is captured in the language of people. This is a vast area that has mostly been ignored in the history of collaboration. Colonial officers, missionaries, government, and development workers have often placed disability on the agenda without finding out what people already knew. They did not see that such information might be available or believed that it would be too hard to obtain or else the colonial language situation simply prevented the exploration of such knowledge. In any event, information in local languages that relates to disability includes the particular terminologies that designate people with disabilities, proverbial language that directly speaks to people with disabilities or uses disability as a metaphor for other situations and fables that include characters who challenge incompetence or limitations. This knowledge was developed over a considerable time and is as old as culture itself. For most people with a disability, it is this knowledge that informs who they are as disabled individuals, i.e., what is expected of them, and how they are valued. There are many possible ways of working with this cultural material. Listening to disabled people and to people in families and communities may quickly yield cultural information captured in indigenous narrative and discourse. A more important challenge, however, lies perhaps in the cultural production of this material. An interesting example of this occurred in Tanzania, where blind people rejected the term *kipofu*, because of negative connotations (Kisanji, personal communication). In the Swahili grammatical structure, *kipofu* is classified among terms that do not usually designate a human category. By requesting that they called be called msiona (plural wasiona), blind people defined themselves in the human category, simply as "the one that does not see". The struggle over terminology designation is not simply a matter of esthetics. It is a political and cultural process that determines how societies relate to their members who are disabled. Engaging in this process may not only clarify important issues that remain under the surface, it may also have important policy and legal implications. Terminology, proverbial language, and fables are the cultural language capital relating to disability in countries in the South. International collaboration has not worked in favor of exploring this information, but rather efforts have been devoted to assuming the various aspects of discourse of the North. The impact of efforts that bring out this information, in the form of research publications and training material, should not be underestimated.

A second proposal that I would like to advance is work on the cultural history of disability in the South. To date, for example, there is very little documentation on the cultural history of disabled people in countries of the South (e.g. Devlieger 1995; Iliffe 1987). Yet to know who you are as a disabled individual is to know where you come from in terms of the history of disability treatment. In the production of this local knowledge, individuals with disabilities, together with their families and communities, need to play extraordinary roles. The social sciences and the humanities departments at universities in the North and South need to take up the responsibility for these tasks. Technology is another very localized knowledge that can perhaps be best examined in an example. In a medical development project in central Zaire, a team of expatriate doctors, missionaries, and the local Catholic church embarked on a project that was nurtured by the spirit of the International Year of Disabled People, by Christian values of justice and the role of the church in development, and by Western ideas of social development. The core of the program focused on surgical operations on children with lower limb deformations resulting from polio, medical rehabilitation that focused on fitting the children with plaster to stabilize the corrective surgery, followed by fitting primitive braces and crutches, produced by local technicians, and instructive physical therapy with its emphasis on the ability to walk. Noble as it was, the project showed many flaws, one of which was the neglect of existing technology. Children and their parents who live off the products of nature in the Kasai region of Congo have become inventive with solutions, in spite of a low level of technology. The standard cultural solution for a deficiency in walking, especially when due to a lack of strength in one of the legs, is to simply cut a stick from a tree that is fit for the weight and length of the individual. The stick is used as a support for the transfer of the weight in walking. This is an ancient method that was also found in ancient Egyptian civilizations, as we know from depictions (see Paul 1971). As it turned out, the stick proved superior to the braces. Local knowledge that surrounded the rehabilitation proved very resilient. First, it was expected from the rehabilitation that a deficient leg was going to regain its strength. Much hope was invested in the white plaster as a substance that would strengthen and would help regain force. Patients after surgery had to wear the plaster for several weeks. When the plaster was removed, some disappointment evolved. The patients were under anesthesia for the operation and had not seen their leg for several weeks. Now that the plaster was removed they discovered that despite the surgery and the plaster the leg was still not *healed*. The same disappointment was extended, but in a lesser degree, with the fitting of the braces. One family stated, at the end of the rehabilitation period, that they would hold off with a big party of celebration until the braces could be taken off after strength in the leg was fully regained. These medical rehabilitation technologies that were meant to stabilize a leg were unable to meet the cultural demand of the Songye and Luba people of the Kasai region to regain strength. Over a period of time, I observed with a number of persons that the braces had been abandoned and replaced by yet another new stick. The reasons were that the braces and crutches needed to be adapted or replaced over time (since children tend to grow!) and the facilities for adapting them may have been too far away, too costly, or too inefficient. While most materials could be obtained locally, such as wood, leather, and iron bars, the supply could be irregular. On the other hand, a stick that matched the length and weight of the individual could easily be cut from a tree at no cost and sufficiently provided the support needed while not leading to culturally informed disappointment. While it did not free the hands while walking as did the braces, this advantage did in general not seem to be crucial. It would have been crucial if the braces could have provided the balance necessary for women to carry loads on their heads as this is a culturally normative expectation. However, the braces, primitive as they were, could not match the superiority of balance that is possible with barefoot walking.

Local knowledge is cultural, historical, and technological. As sources of identity and pride, it also indicates directions for future development. The exchange of such historical knowledge between countries of the North and the South does not need to be unidirectional. Creating cultural and historical knowledge may prevent disability from being dealt with in a vacuum. What does seem to be crucial is the production of knowledge where local and global developments can meet, an intermediary discourse. The non-governmental organizations as the major implementors of development activities and the universities as producers of knowledge have had awkward relationships that sometimes lead to productive results but also stumble over differences in agendas and time perspectives. An evaluation of this relationship seems necessary and the only promise of the development of local and intermediary discourses.

CONCLUSION

Here, I have considered the new global context of international disability collaboration and the role of local knowledge. We can now answer the question, "Is cultural sensitivity possible in international disability work?" The answer is complex and will need to evolve in the practical forms of collaboration; but some directions seem to be emerging. I have furthermore considered two aspects of local knowledge production. First, listen to disabled people, at the very least. Much better even is to place disabled people in central positions of design and implementation. Local knowledge production as it emerges from the interaction of disabled and able-bodied people has the potential to be more genuine, rich, and practical. Second, collaboration has to be a two-way process. For the North it means an openness to welcome the South as a partner in the development processes of the North. For the South it means a responsibility to document local knowledge of disability that can be built upon and to make the North a partner in the process. Bilateral exchanges between peoples of the north, the development of sister organizations. In particular, the universities of the North and the South have important responsibilities and opportunities of collaboration. Finally, globalization processes stimulate the development of interdependence in ways that could not be imagined until recently. For people with disabilities and international collaboration, this means a potential for enablement and mutual understanding. Unfortunately, it may also mean new layers of discourse and discrimination that shift cultural understanding of ability and competence once again. Within these global developments, the challenge will remain to keep in tune with local processes. In meeting this challenge, disability remains a sensitive barometer.

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