Human Rights and Persons with Intellectual Disabilities: Historical, Pedagogical, and Philosophical Considerations

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ABSTRACT
Persons with intellectual disabilities are more likely to experience victimization and have their rights infringed upon than are people without such disabilities. While legislative and policy interventions have afforded a certain degree of protection against such rights violations, people with intellectual disabilities continue to experience restrictions of their basic human rights. This article describes the development of a Human Rights Project being developed in Canada and aimed at promoting human rights awareness in individuals with intellectual disabilities. Following a brief history of the project, we focus on its current phase: the development of a multimedia human rights training CD. We address the empirical and pedagogical foundations for the use of simulated instruction, aspects of the project that reflect its participative orientation, and the use of dramaturgical methods for training persons with intellectual disabilities to be actors in the video scenarios that appear on the training CD. We conclude by highlighting the importance of a systemic approach to human rights training, as well as the implications of such an approach for understanding the relationally and situationally emergent nature of human rights knowledge.

Key words: Human rights; Intellectual disabilities; Simulated instruction; Participatory research; Dramaturgical methods; Systems perspective
de este enfoque a la hora comprender el sentido relacional y la situación emergente que tiene el conocimiento de tales derechos.

**Palabras clave:** Derechos humanos; Discapacidades intelectuales; Instrucción simulada; Investigación participativa; Métodos de dramatización; Perspectiva sistémica

**RÉSUMÉ**
Les personnes ayant des désabilités intellectuelles sont plus exposées à faire l’expérience de représailles et à voir leurs droits enfreints que les gens n’ayant pas ces désabilités. Bien que les interventions à leurs droits, les personnes ayant des désabilités intellectuelles continuent à subir des restrictions à leurs droits humains fondamentaux. Cet article décrit le développement d’un Projet sur les droits humains en cours au Canada, visant à promouvoir la conscientisation au sujet des droits humains chez les individus qui ont des désabilités intellectuelles. Après un bref historique du projet, nous nous concentrons sur la phase actuelle: le développement d’un DC (disque compact) multimédia sur l’entraînement aux droits humains. Nous abordons la question des fondements empiriques et pédagogiques de l’usage de l’instruction simulée, les aspects du projet qui en reflètent l’orientations participative et l’usage de methods dramaturgiques pour entrainer les personnes ayant des désabilités intellectuelles à entrer en participation active aux scenarios du video qui paraît sur le DC. Nous concluons en soulignant l’importance d’une approche systématique à l’entraînement aux droits humains ainsi qu’aux implications d’une telle approche pour comprendre la nature émergente, relationnelle et situationnelles, des connaissances sur les droits humains.

**Mot-clés:** droits humains; désabilités intellectuelles; instruction simulée; recherché participative; methods dramaturgiques; perspective de programmation

**Introduction**

It is well documented that people with intellectual disabilities are much more likely to experience victimization than are people without such disabilities (Davis, 2000; Mazzucchelli, 2001; Sobsey, 1994). Historically, services offered to people with intellectual disabilities have been characterized by serious human rights abuses, including incarceration, overmedication, mass sterilization of women and men (Radford & Park, 1999; Scheerenburger, 1983; Sobsey, 1994; Wolfensberger, 1972), euthanasia, and the eugenics movement (Sobsey, 1994; Stratford, 1991). Moreover, people with intellectual disabilities were often denied the right to live in the community, marry, procreate, work, receive an education, and in some cases have access to life-saving medical treatment (Griffiths et al., 2003). In this regard, people with intellectual disabilities may not fully comprehend that it is their right not to experience abuse and neglect and may feel powerless when their rights are being violated (Mazzucchelli, 2001).

Certainly, recent history has witnessed an increasing concern for the way in which people with intellectual disabilities have been treated. The principle of equal rights for all citizens, regardless of disability, has been enshrined in the United Nations Declaration on the Rights of Disabled Persons (1975). The growth of the Community Living movement in the 1960s also helped to promote acceptance of differences among human beings and increased the opportunities for people with disabilities to have access to education, recreation, and social relationships, and the opportunity to make independent decisions (Radford & Park, 1999; Sobsey, 1994; Wolfensberger, 1972). Similarly, the emergence of self-advocacy groups, such as People First, at the local, national,
and international levels, has established a prominent forum for the promotion of human rights for people with intellectual disabilities.

Nevertheless, despite these major advancements and the significant protections they have afforded, people with intellectual disabilities continue to experience violations of their basic human rights, including invasion of privacy, lack of autonomy, financial and sexual exploitation, unwarranted removal of parenting rights, and unjust incarceration. An issue of particularly longstanding concern is the availability of and accessibility to medical and health care among persons with intellectual disabilities. It has been argued, more specifically, that equitable access to medical treatment represents a notable area of rights violations for persons with disabilities, one that has been documented extensively in both Canada and the U.S. For example, persons with intellectual disabilities are often not aware that they are being given medical treatments without their consent, are discriminated against, and their right to adequate medical treatment is often withheld (Driesfeld, 2001). These rights violations are especially concerning given that persons with intellectual disabilities are at an increased risk for epilepsy, dental problems, skin disorders, fractures, diseases related to poor nutrition, infections, poisoning, choking, sensory disorders, dementia, and behavioural/psychiatric disorders (Jansen, Kroll, Groothoff, & Post, 2004; Lennox & Kerr, 1997; McCarthy & Boyd, 2002).

While we cannot offer a detailed account of the sources of such rights violations in this paper, we do note that the broadly prevalent presumption of incompetence of persons with intellectual disabilities is certainly among them. It is a bias reflected routinely, for example, in the determination of health care providers that individuals with intellectual disabilities are unable to “handle” certain activities; and it is a bias that is no less evident in court decisions that fail to recognize these individuals’ rights violations (Feldman, 2002). Lester (1998) has identified this discriminatory bias as “ableism,” or the view that individuals with disabilities are inferior and, therefore, lack entitlement – rights being pre-eminent among those aspects of “the good life” to which persons with intellectual disabilities are often barred. Clearly, a service system that expressly or unwittingly supports such views can be a haven for people with a predisposition to abuse (Owen, Sales, Griffiths, & Richards, 2001).

The ableism of which Lester writes is perhaps itself rooted in more fundamental philosophical assumptions associated with individualism. These assumptions are elucidated, for example, in Edwards’ (1997) account of the modernist philosophical supports for the claim that individuals with intellectual disabilities are accorded a lesser moral status than individuals without such disabilities. As Edwards argues, these supports are rooted more specifically in ontological and normative dimensions of individualism. In its ontological guise, individualism suggests that the integrity and authenticity of selves is premised on the self’s complete independence from social contexts and relationships. Hence, if it assumed that the only legitimate self is a socially independent self, and, moreover, if independence is valued over dependence, then a person with intellectual disabilities – who may be characterized as dependent or as “less able” – will be seen to possess a less authentic self: in effect, given the assumptions
of ontological individualism, he or she will be judged to be less of a person, less impor-
tant. On the normative side, individualism sees the ideal moral agent as “one who is
fully autonomous: one who is able to make her own decisions and choices concerning
what the good life is for her” (p. 35). Here, too, people with intellectual disabilities may
be seen as falling short. Ultimately, according to Edwards, it is these commitments to
individualism in both its ontological and normative aspects that support many of the
morally evaluative attitudes toward persons with intellectual disabilities.

Disabilities and Human Rights: The Canadian Context

Canadians, like citizens of many countries around the world, have come to assume the
protection of certain rights and freedoms. These rights are largely articulated in decla-
rations and conventions of law (Brabeck & Lauren, 2000). In Canada, the institutiona-
lized protection of human rights is guaranteed, in principle, through vehicles such as
the Canadian Charter of Rights and Freedoms, the Canadian Human Rights Act, and
the provincial/territorial Human Rights Codes (Rioux & Frazee, 1999). Rights are fur-
ther protected through international agreements that Canada has signed, including
the United Nations Universal Declaration of Human Rights (1948), the United
Nations Declaration on the Rights of Mentally Retarded Persons (1971) and the De-
claration on the Rights of Disabled Persons (1975). (See Baker [1993] for a more
detailed discussion of universal rights for persons with disabilities.)

In 1985, Canada became the first nation in the world to declare within its constitu-
tion the right to equal protection and equal benefit of the law to persons with disabili-
ties (Rioux & Frazee, 1999) and to guarantee protections against discrimination for all
citizens, including those with a disability (Neuman, 1984). Declaration of the rights of
persons with disabilities within the country’s Charter of Rights ensured that the law was
inalienable, and as such that persons with intellectual disabilities should have access to
these rights by virtue of their being; they should not, in other words, be forced to earn
their rights. Human rights implies the inalienable entitlement to certain universal natu-
ral rights such as food, shelter, a non-threatening physical environment, security,
health, knowledge, work, freedom of conscience, freedom of expression, freedom of
association, and self-determination – rights that, under most conditions, cannot be
lost. Rights, however, are not absolute: they do not necessarily override other considera-
tions (Bayles, 1981). As framed by Accreditation Ontario (2000), “Individuals can ... by immoral or illegal conduct, forfeit and lose certain of their rights” (p. 7). A bona fide
justification for restricting a person’s liberty is based on the notion of prevention of
harm to self or others. Other principles in whose name rights have traditionally been
denied, but which do not constitute defensible justifications today, include immorality
or offense to others (Accreditation Ontario, 2000).

The observation that “The history of services for people with disabilities reveals
many examples of less than equal treatment in relation to rights” (Accreditation
Ontario, 2000, p.1) may be explained, at least in part, by the tendency within the ser-
vice arena to justify human rights restrictions as means of protection for the individual
or others. Schultz (1996) cautions, however, that when service providers justify their
decisions because they “know what’s best,” there is a degenerative potential for needs to become separated from rights and for care providers to do things for people rather than with them. To offset these potentials, the Canadian Human Rights Act (1977) prohibits service providers from discrimination on many dimensions, including physical or mental disability. According to Section 2 of the Act,

all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on . . . disability.

Moreover, in 1978, the Canadian Human Rights Act established the Canadian Human Rights Commission to provide a mechanism and process to 1) prevent discrimination through education, 2) promote understanding of rights and the mechanisms for protection, and 3) restore rights when discrimination has occurred. Indeed, in Canada, people with intellectual disabilities not only have the right to be treated in the same way as anyone else, but a provision in the constitution allows for special laws or programs to be established to assist individuals in overcoming structural barriers to the exercise of their rights (Rioux & Frazee, 1999). Finally, at the provincial level, Accreditation Ontario (2000), the body that accredits community services for persons with intellectual disabilities, suggests that service providers have a responsibility both to affirm and protect rights through education, removal of systemic barriers, and through establishing processes that will ensure that individuals have the same opportunities to exercise their rights as people who do not have disabilities.

In recent years, Canadians have also gained a growing awareness of the need for community agencies and other organizations to develop proactive policies to ensure that the rights of people with intellectual disabilities are respected and protected. The majority of community-based service agencies in Canada that support persons with intellectual disabilities fall under the umbrella of the Canadian Association for Community Living (CACL) and its provincial and local bodies. In keeping with governmental objectives, the CACL aggressively promotes a national profile which, through educational efforts and advocacy, aims to ensure that the rights of persons with intellectual disabilities are acknowledged and respected. Local associations for Community Living throughout Canada largely endorse the principles defined by this national organization.

Challenges, however, do remain. These challenges pertain not so much to the principled legal or philosophical affirmation of rights, but rather to the actual practice of ensuring that rights are protected within the service process. In this regard, specific policies are especially vital in ensuring that there is a consistent and responsible atmosphere in which individuals may learn about their rights. Unfortunately, at present no universal mechanism exists to monitor and review rights restrictions that may be imposed specifically within the care systems provided by Canadian service agencies for persons with intellectual disabilities. In the absence of clear guidelines for service
providers regarding individual rights, each service staff member becomes, de facto, a policy maker. Under such circumstances, clearly, the rights of individuals would be inconsistently understood, and measures to protect them inconsistently applied. In short, certain rights might be respected at certain times and at other times restricted, depending on which staff member was at hand. Understandably, the specter of this type of inconsistent treatment creates an environment in which it is very difficult for people to become empowered to take responsibility for their own lives.

The Human Rights Project

Over the past 25 years many persons with intellectual disabilities have enjoyed living more independent and inclusive lives within their communities, and this has in large part been the result of major advancements in the effective training of community living skills. Curiously, however, while general educational curricula exist that include a focus on human rights (e.g., Amnesty International, 1997; Buckingham, 1998; Pike & Selby, 1997), there is very little evidence of training programs designed specifically for persons with intellectual disabilities that might allow them to fully access the rights and activities available to all citizens. In particular, areas such as human rights abuse prevention and self-advocacy have received little systematic attention, despite the prevalence of human rights abuses in persons with intellectual disabilities. Accordingly, programs are needed that train persons with intellectual disabilities to recognize and respond to human rights violations, particularly as many may lack the knowledge to identify such violations and to exercise their rights to choice-making and self-determination.

The need to inform individuals with intellectual disabilities about their rights is receiving increasing attention from professional groups such as Accreditation Ontario (The Council, 2000). What is currently lacking, however, is an understanding of the nature and scope of system-wide restrictions of human rights, such as access to religious practice, freedom of association, and so forth. In 2000, in response to the growing recognition of the need for systemic approaches to affirm and protect the rights of individuals within their service delivery system, members of our research team, in partnership with Community Living Welland Pelham (CLWP), located in southern Ontario, initiated a Human Rights Project. The project, called 3Rs (Rights, Respect and Responsibility): Training for Individuals in Agencies Supporting Persons who have Intellectual Disabilities, was conducted in conjunction with the local university (Brock University). The project’s emphasis on rights, respect, and responsibility reflects the assumption that people (with or without disabilities) develop a sense of self-realization and self-determination in the context of social relationships – that is, in a context of respect for and responsibility to others.

The project has been through several stages. In the summer of 2001, the initial phase of the project (Stage 1), the team developed and conducted a human rights awareness survey to examine the nature and breadth of human rights restrictions currently existing within CLWP (Gosse et al., 2002a, 2002b; Griffiths et al., 2003). The survey items were derived from rights statements contained in the Canadian Charter of
Rights and Freedoms (1982), the UN Declaration on the Rights of Disabled Persons (1975), and other rights documents, as well as from statements about rights made during focus group sessions with agency staff, managers and supervisors, and individuals supported by the agency. A total of 22 fundamental rights were identified. These were divided into four factors: 1) Access and Autonomy (e.g., right to freedoms of conscience, religion, opinion and expression); 2) Relationships and Community Support (e.g., right to income support, education, sexual expression); 3) Safety, Security and Privacy (e.g., right to privacy, adequate health care and security); and 4) Control and Decision Making (e.g., right to vote, right to liberty). The content of the survey was validated through focus groups held with agency staff and individuals with intellectual disabilities, and will be externally validated by a variety of community agencies, legal experts, and ethicists.

Initiated in the summer of 2002, subsequent phases of the project (Stages 2 and 3) involved the development, implementation, and evaluation of an agency-wide human rights training program for staff and for individuals with intellectual disabilities who were consumers of the services of CLWP (Stoner, Gosse, Vyrostko, Griffiths et al., 2002; Stoner, Gosse, Vyrostko, Owen et al., 2002). The training program consists of 22 lessons, each based on one of the rights identified in the initial phase of the project. The program designed specifically for individuals with intellectual disabilities involves 8-10, 2-hour group training sessions with a maximum of 10 people per group. The program begins with the teaching of the core concepts of rights, respect, and responsibility. Using scenario discussion, storytelling, games, and role playing, participants then receive instruction in how to use these concepts in situations related to their daily lives (e.g., food choices, voting, dating, community access). Participants are also taught to discriminate between rights violations and non-violations, and between responsibilities and limitations to rights (as, for example, when people’s actions put them or someone else at risk of harm), and are instructed in appropriate actions to redress rights violations (cf. Sievert, Cuvo, & Davis, 1988). To date, several training manuals have been developed and field tested (Gosse et al., 2002a, 2002b; Johns, Owen, Stoner, Gosse, & Moyer, 2003; Stoner, Gosse, Vyrostko, Griffiths et al., 2002; Stoner, Gosse, Vyrostko, Owen et al., 2002) and the results are encouraging (Owen et al., 2003).

Stage 4 of the project involved the development of the CLWP Human Rights Commission. Typically in this context, human rights committees are composed of a group of citizens who serve to ensure that due process is implemented when intrusive therapeutic intervention is proposed. The CLWP Human Rights Commission, in contrast, is composed of community members, professionals, staff members, and individuals with intellectual disabilities whose collective task is to review any and all rights restrictions that are brought forward by individuals with disabilities, by staff, or that are identified through routine agency reviews.

The data from the training ventures demonstrated that individuals with intellectual disabilities were interested in, and enthusiastic about, receiving training in human rights and responded positively to the training activities provided (Owen et al., 2003). However, it was difficult to determine their level of understanding of the training material since some individuals had difficulty understanding and responding to the human rights
scenarios used in the staff version of the training program. These scenarios had to be read aloud to participants who were unable to read. In response to this program evaluation problem, the research team developed a short amateur videotape that appeared to provide material in a manner that was more understandable for participants. This video was produced hastily and with little opportunity for refinement, and was used with a relatively small number of participants. Nevertheless, anecdotally, individuals appeared to respond with somewhat higher levels of understanding to the video-based scenarios than to the orally-presented test vignettes. This observation prompted the team's current focus on the development of video and interactive CD materials to support human rights training for persons with intellectual disabilities and their care providers. It is to this most current phase of the project (Stage 5) that we now turn.

Development of an Interactive Multimedia CD Human Rights Training Program

In the following sections, we wish to highlight three key features associated with the development of the CD human rights training program. We begin by briefly examining the empirical base and pedagogical arguments for the use of computer-based instruction for persons with intellectual disabilities. We then consider the participatory dimensions of the project, with a view to foregrounding the active role that individuals with disabilities and their support staff have played in the development of the multimedia training program. Finally, we describe the use of dramaturgical methods in training individuals with disabilities to be actors in the video scenarios contained in the CD.

Simulated Instruction

Several technologies have been successfully employed for teaching both functional (e.g., self-care, social, and domestic) skills and more complex conceptual (e.g., self-advocacy) skills to persons with intellectual disabilities. These have included task analysis, modelling, prompting, pictorial and audio materials, feedback, positive reinforcement, role playing, and drama (Bolton, 1979; Feldman, 2004; Feldman & Case, 1997; Herman & Smith, 1988; McClintock, 1984). More recently, increasing attention is being given to the use of multimedia computer-based instruction to teach a variety of skills. For example, studies have demonstrated gains in independence, self-determination, and self-esteem for persons with intellectual disabilities when multimedia computer-based training is used to teach skills related to vocational tasks (Davies & Stock, 1994, 1997, 1999; Morgan & Salzberg, 1992), language acquisition (Holzberg, 1995), the management of money (Davies & Stock, 1995), independent Internet access (Davies, Stock, & Wehmeyer, 2001), and anti-victimization awareness (Holzberg, 1994). Studies have also demonstrated the effectiveness of a computer-mediated, self-directed approach to teaching basic computer skills to adults with mild intellectual disabilities (Davies, Stock, & Wehmeyer, 2004).

More recently, research has focused on the effectiveness of simulated multimedia technology in the training of more complex skills and knowledge needed for inde-
pendent and inclusive community living (Langone, Clees, Rieber, & Matzko, 2003; Mechling, Gast, & Langone, 2002; Standen, Cromby, & Brown, 1997). Simulated instruction involves training using computer-based video re-enactment of events that would normally take place within the target or natural setting (Langone et al., 2003). For example, studies have demonstrated the effectiveness of simulated instruction in teaching grocery shopping skills to persons with moderate (Langone et al., 2003; Mechling et al., 2002) and severe (Standen et al., 1997) intellectual disabilities. The appeal of simulated instruction continues to grow, as community-based instructional activities are not always feasible and/or remain costly, and as research findings continue to show promise for this instructional approach (Langone et al., 2003).

The effectiveness of simulated instruction in training persons with intellectual disabilities rests on several key characteristics that are unique to this type of learning environment. In addition to allowing the user to work at her own pace and be exposed to a virtually unlimited number of instructional trials, the use of simulated instruction encourages the user to take a more active role in her own learning (Hawkridge & Vincent, 1992; Standen, Brown, & Cromby, 2001). With regard to the interactive CD that the project team is currently developing and testing, active involvement in learning (without the need for reading) is promoted in at least two ways: first, through interactive game-like activities designed to facilitate the acquisition of the concept of human rights, as well as related concepts and conceptual distinctions, such as that between needs and wants and between rights and responsibilities; and second, through the use of audio and video prompts that allow the learner to choose among several possible courses of action for the protagonist depicted in the video-based human rights scenarios on the CD. We feel this sort of interactive platform is especially important for people with intellectual disabilities who may otherwise approach learning tasks in a passive, deferent manner (Standen et al., 2001). Of course, this enhanced interactivity speaks also to the motivational components of CD-based instruction: the interactivity element, along with the incorporation of audio, video, and graphics, means that it is likely to be for many an engaging learning experience.

According to Standen et al. (2001), at least three other characteristics of simulated instruction contribute to the effectiveness of this approach in educating persons with intellectual disabilities. First, simulated instruction allows users an opportunity to make mistakes during the learning process, without experiencing any of the potentially dangerous and embarrassing consequences of their mistakes. Second, simulated instructional environments can be altered in ways that the real world cannot be. Thus, the user can begin an instructional lesson with the assistance of various supports, such as accompanying audio materials or manuals. Over repeated lessons, these supports or scaffolds could be gradually removed until the user performs the lesson successfully without their assistance. Third, because the use of expressive language is not a necessary component in simulated instruction, abstract concepts (e.g., human rights) can be conveyed through more direct, concrete means. In the case of the interactive CD at hand, this has meant the inclusion of detailed exemplars of human rights violations and of strategies for exercising rights in the context of respect and responsibility. Finally, it is noteworthy that simulated instruction encourages face-to-face, collaborative inter-
actions between the learner and her tutor. This is in keeping with the role of instruction as highlighted by Vygotsky (1978) and Bruner (1968), where learning is said to take place within a shared social context and to be heavily guided by more experienced mentors or peers (Langone et al., 2003). This last point expresses a caution against the belief that unguided interaction with computer-based training materials is the most effective means of exploiting their educational potential (Standen et al., 2001). We realize, in short, that individuals' navigation through the material on the CD has to be scaffolded in some way. We think it equally important, however, that we reframe the human tutor's role and that we come to see the tutor, more specifically, as a participant in the joint exploration of human rights, rather than as an infallible authority and transmitter of knowledge (Young, 1993). This is all in keeping, of course, with the hope that individuals will take more responsibility for their own learning.

Clearly, simulated instruction provides a unique learning environment for persons with intellectual disabilities. A question that remains concerns whether skills, concepts, and language acquired through simulated instruction will generalize to other, real world settings. Defenders of simulated instruction regularly assume that such transfer will indeed occur (Langone et al., 2003). Extant literature often suggests, however, that generalization of skills, competencies, and knowledge of persons with intellectual disabilities to non-training settings is often difficult to obtain (Feldman, 1994). Research also suggests that training effects generalize more readily when the training occurs in the natural environment or in settings that closely simulate real-life situations, when training includes the use of sufficient and relevant exemplars, and when caregivers prompt and reinforce appropriate responses (Griffiths, Feldman, & Tough, 1997; Horner & Albin, 1988; Miltenberger et al., 1999; Neef, Lensbower, Hockersmith, & DePalma, 1990).

Considerations about factors and conditions most likely to promote learners' active appropriation and application (generalization) of training materials were critical in the design of the interactive video CD. For example, the theoretical constructs of situated cognition and anchored instruction – concepts that stress the importance of delivering instruction in the context of meaningful activity and around specific problem-oriented concerns, and under the guidance of more knowledgeable mentors or tutors (Langone et al., 2003) – figured prominently in its development. We also feel that the video scenarios incorporated into the CD satisfy two of the more specific conditions that the training literature suggests are important in promoting the application of learned concepts. First, as intimated above, research suggests that transfer or generalization is most likely to occur when instructional simulations are similar to target (or everyday, real-life) settings. By incorporating extensive video material in the CD – material which depicts settings and scenarios that closely resemble target settings in terms of both social and physical stimuli – we feel that we have gone some way toward satisfying this condition. Being able to film on location (e.g., in group homes), replicating language that might reasonably be used by staff and individuals with intellectual disabilities, using situations that individuals are likely to encounter in their everyday lives (e.g., going to a movie or staying at home to keep a sick friend company) have all been helpful in this regard. It is our hope, too, that the video scenarios, because they present
information contextually or in a manner that relates to learners’ daily functioning, will encourage a more contextually sensitive understanding (and self-understanding) of human rights – that they will encourage an appreciation, more specifically, of the fact that human rights should be exercised responsibly, with an awareness of and sensitivity to the ways in which one’s actions and choices affect others.

Second, research also suggests that generalization of skills is facilitated by the depiction of naturally occurring consequences for one’s actions (Langone et al., 2003). With regard to the CD at hand, we have used a series of video scenarios that allow the learner to make choices about the video protagonist’s courses of action, and that also illustrate the possible consequences to the protagonist of pursuing these courses of action. Ultimately, what we hope to encourage here is individuals’ realization that they have options, that they can actively decide among possible courses of action, and, in keeping with the focus on the exercise of rights in the context of respect and responsibility, that their actions have consequences for others as well as themselves.

**An Emergent Participatory Paradigm**

In the traditional social science model, a firm line of demarcation is established between researchers and those researched: researchers are ultimately those who control the funding, who devise the research questions, who make the methodological decisions, who analyze and interpret the data, and who disseminate the findings of the research; research participants, in contrast, emerge as (often voiceless) “objects” of inquiry. Increasingly, however, research in the area of intellectual disabilities is challenging the nature of the research relationships inscribed in this traditional model, with some investigators in fact arguing that participatory paradigms represent the most ethical choice for research in the area (Stalker, 1998). Consistent with this call for greater involvement, investigators in both North America and Europe (and especially in the United Kingdom) have begun to establish a clearing within which persons with intellectual disabilities can assume a more active, even controlling role in the planning, design, implementation, and dissemination of studies (Chappell, 2000; Kiernan, 1999; Ramcharan & Grant, 2001; Sample, 1996; Walmsley, 2004). As Walmsley (2001) notes, the advent of such inclusive, participatory approaches has been fostered by a variety of ideological frameworks, including the social model of disability, feminist epistemologies, and normalization. These frameworks have been important, more specifically, in fostering the general societal climate within which persons with intellectual disabilities can “speak out” and have their voices heard. The local, national, and international rise of self-advocacy groups, such as People First, was certainly one manifestation of the nascent empowerment of individuals with intellectual disabilities. Another related development was the move toward inclusion of people with intellectual disabilities as collaborators, co-researchers, consultants, and evaluators in the research process.

Our own 3Rs Human Rights Project is perhaps best characterized as an emergent participatory research project. We use the qualifier “emergent” to signify two things. We use it, first, to acknowledge that in its current manifestation the project falls considerably short of some of the participative features that characterize strong versions of the
inclusive research paradigm, such as individuals’ participation in the research planning process. Second, our self-understanding as a project whose participatory dimension is emergently participatory is meant to suggest that the project is in its formative stages in this regard, and more importantly, that we are committed to building on the participative aspects that define the project in its present phase. This important qualification aside, we now describe those participative aspects in greater detail.

Through all phases of the project, the participation of individuals with intellectual disabilities has been critical in identifying urgently felt human rights concerns. Through unstructured individual interviews and focus group discussions, we have attempted to provide participants with opportunities to share personal narratives that addressed human rights issues. The experiences recounted in these narratives served as foundational in the development of the initial human rights awareness survey and training materials, and, as described in greater detail below, in the design and content of the video scenarios contained in the interactive CD. However, for those of us on the multidisciplinary research team who joined the project in its later phases, and who had little or no experience working with individuals with intellectual disabilities, participants’ personal narratives went far beyond serving simply as “data.” They were, for several of us, the stuff out of which sympathetic alliances were formed, defining moments in our own self-understanding as researcher-advocates.

While limited, the participation of individuals with intellectual disabilities has also been enlisted at the consultative and advisory-group levels. With regard to their role as consultants, participant focus groups comprised of individuals with intellectual disabilities have had the opportunity to provide comments on and express concerns about the training material contained in the pilot version of the CD. These comments, which addressed both aesthetic and pedagogical issues, have been critical in informing the design of subsequent versions of the CD. At the advisory-group level, progress reports on the development of the CD are presented to the Human Rights Commission affiliated with CLWP. This committee, which consists of members of CLWP, members of the community, and one individual with intellectual disabilities who is supported by the agency, meets regularly to discuss human rights concerns, to address specific human rights complaints that have been filed by individuals supported by the agency or by their staff, and to comment on developments associated with the CD training program. While the use of this committee in an advisory capacity goes some way toward ensuring accountability, we acknowledge the need in future phases of the project to include people with intellectual disabilities on advisory groups with the dedicated task of monitoring all aspects of the project.

Perhaps the most notably participative feature in the video CD’s year-long production history involves the contributions made by participants – as actors – in designing and depicting some of the everyday human rights dilemmas faced by people with intellectual disabilities. By all indications, individuals’ participation in the making of the video scenarios, no less than in the preparatory work that preceded their creation (addressed below), has been well received. Recently, in fact, participant-actors had the opportunity to talk about their participation in the project – about the challenges and
rewards they experienced during the process of creating the video scenarios – at the annual International Certificate Programme in Dual Diagnosis at Brock University. From the vantage point of participatory models, such opportunities are critical for ensuring that persons with intellectual disabilities are afforded an active role in the dissemination of ideas related to the research projects in which they are involved.

As a final note on the participative dimensions of our project, we should like to stress that since its inception, the project has been a fully collaborative undertaking between faculty members at Brock University and the staff and supervisors at CLWP. Indeed, the Human Rights Project received its initial impetus outside academia, and more specifically from the Executive Director and managerial staff at CLWP. This community agency has been integral in the process of securing the granting agency funds that have made this work possible. In addition, through their participation in focus groups, members of the supervisory staff have provided critical feedback on all aspects of the training program, through all phases of its development.

Equally critical is the participation of family members of individuals with intellectual disabilities. In addition to receiving training that informs them of the rights of individuals supported by CLWP and of the procedures that the Human Rights Commission associated with the CLWP follows, future work will involve family members in focus groups designed to assist in the development of new training packages for families and family home providers. Toward this end, family members will be asked, for example, to describe human rights restrictions they have encountered in their child’s life or in the life of the person they support, as well as restrictions they anticipate their child will encounter in the future; and, in post-training sessions, family members will be given the opportunity to share their perceptions of the training program (e.g., how informative it was, the degree to which the scenarios used in training are representative of the types of situations that occur with families, suggestions for improvement of the scenarios, etc.).

**Dramaturgical Methods**

As noted previously, individuals with intellectual disabilities were enlisted as actors in the human rights scenarios depicted on the video CD. Over the course of CD production, and in particular during the process that involved training the actors to appear in these scenarios, it became increasingly clear to us that the use of various dramaturgical methods, while originally conceived as a means to an end, may in and of themselves a powerful tool in teaching human rights. Because of their immediacy, and because drama methods require participants to actively work through questions, problems, obstacles, concerns, and relationships, it is argued they provide a form of “rehearsal for life.”

Preliminarily, as a basis for constructing the video scenarios that captured these dilemmas, drama students enrolled in Brock University’s Department of Dramatic Arts conducted informal individual and group interviews with participating individuals to establish what issues were most pressing, what events occurred around these issues,
and what outcomes – both positive and negative – could occur in these situations. A second step of the plan involved training the actors to appear in the scenarios. The drama students’ first task in this regard was to demystify the idea of acting and increase participants’ confidence level by running a series of “drama days.” They conducted these sessions like theatre improvisations, which, rather than involving the pursuit of a fixed, predetermined agenda, with solutions worked out in advance, involved building dialogically on the responses given by the participants – whatever they might be. The aim here was to get to know the participants, to animate them into responding to conversations, and to encourage dialogue in open and unguarded ways – in short, to assist participants in discovering and enjoying their own points of view, attitudes, feelings, and ideas. At all points, the drama students were careful to incorporate group reflection and gently initiate self-reflection into the discussion. In this way, the students were able to anchor the participants’ gains in confidence and willingness to articulate personal feelings and challenge them to continue to advance in exploring these new, more kinetic, emotionally open ways of communicating.

The theoretical support for these dramaturgical strategies came from several sources. Because the work in his seminal first book, Theatre of the Oppressed, involves introducing and exploring human rights with whole communities, Augusto Boal’s (1985) “Forum Theatre” approach provided an excellent basic foundation for the drama students’ decision to interweave theatre presentational work with the more reflective drama-in-education strategies. The drama students also drew on the work of Boal (1992) and Bolton (1979), and in particular on their use of games, discussion, charades-like role-play, and storytelling, to prepare individuals with intellectual disabilities as actors, asking individuals for help in “dramaturgy,” or input in devising appropriate and meaningful scenarios through which to demonstrate human rights issues. Additionally, American literacy expert Jerome Harste’s (1997) work on “transmediation” – the interchangeability of symbol systems – provided a helpful theoretical support for the filming sessions. Similarly, Lecoq’s (2001) approach to the use of the body for communication, meaning, and nuance provided a foundation for the use of mime and gesture work to coach and aid line delivery for the actors.

The atmosphere of exploration and positive energy that characterized the “drama day” sessions carried over into the filming of the video scenarios. For the drama students, the scenarios, which they had laboured to create out of the issues given to them by participant-actors, were simply a stepping stone. They were to be used as guideposts to the desired length of the scenario, the theme, and the relative trajectory of the plotline. However, as with all theatre improvisation, the art (and heart) of improvisation exists in the moment. What is done spontaneously, at the moment, but based on the preparation (the scenario) and the training (the rehearsals), is what is most definitive about improvisation. Each of the filmed scenarios relied extensively on these improvisational, unscripted moments. Indeed, in our estimation, the resulting realism of the depicted scenes owes much to the actors’ initiative and creativity in making the roles their own in this manner.
Human Rights Training in Systemic Perspective

Our own experience has certainly emphasized the fact that human rights training must not be seen as a one-time, strictly individual-based activity needed to satisfy an evaluating body. Indeed, experience tells us that organizations which pursue training in this narrow fashion may in fact abuse the very people they purportedly serve: first, by raising their awareness of human rights and their expectations for action attendant on the violation of those rights, and then by failing to respond to human rights concerns that are brought to their attention. To obviate these potential problems, a training approach must be supported systemically. We realize, of course, that breaking down the barriers to self-determination includes challenging many of the historic ways that services have been delivered for people with disabilities. To be sure, such challenges can be difficult to initiate and, sometimes, more difficult to sustain. The difficulty lies in part, we imagine, in the fact that approaches to the delivery of services have traditionally been ideologically supported by pre-eminently individualistic, medicalized discourses of impairment or disability – discourses in which, typically, the individual tout court emerges as the unique site of the “presenting problem,” and as the singular locus of educational, remedial, or therapeutic interventions.

An alternative, systems-oriented view forces us to rethink not only the traditional practices of service provision, but also the persistent philosophical assumptions upon which such practices have, more or less consciously, been based. First, at the level of practice, we recognize that all levels in the community organization must be involved in supporting human rights training initiatives. In keeping with this systems focus, and as intimated above, we have developed a human rights training program for community agency staff and managers, and will be developing a training program for families to support individual-based instruction. For staff and supervisors, the training mirrors that of persons with intellectual disabilities but also addresses potential conflicts between protecting the health and safety of the people they support and respecting individual rights. Staff members are also shown how to support the skills, awareness, and understanding of rights demonstrated by individuals with intellectual disabilities who have experienced rights training (cf. Griffiths et al., 1997). In addition, managers and supervisors within each agency are trained to monitor program implementation and outcomes. Finally, we recognize the importance of instituting a human rights commission within the supporting agency as a mechanism for responding to day-to-day human rights concerns raised by individuals served by the agency and its staff. In arguing for these and other systemic supports, we echo the claims of others who have emphasized the need to approach the facilitation of choice-making and self-determination from a broad systemic perspective (e.g., Robertson et al., 2001).

With regard to assumptions surrounding individual functioning, a systems perspective encourages us to re-examine the philosophical grounding of notions like self-determination or, more generally, individual competence. Earlier, we had occasion to reflect briefly on the individualism that underlies “ableist” attitudes toward persons with intellectual disabilities. More specifically, we suggested that the devaluation of the
“dependent self” is premised at least in part on a set of ontological and normative assumptions that define authentic selfhood in terms that, ultimately, establish an existential cleavage or antinomy between the individual and the social (between self and other). Left unspecified in that brief discussion was an alternative, social ontology – one that challenges the propriety of this prototypical modernist dichotomy. From the vantage point afforded by this social framework, selfhood is achieved not by virtue of our separation from others and from social contexts, but precisely through and with these others – in short, relationally and dialogically.

What might self-determination mean in light of this social ontology? In keeping with our preceding argument, an individual’s sense of self-determination can be understood not as a property or possession of the individual as such, but rather as an accomplishment that emerges relationally – that is, through the supportive relational networks in which the individual is implicated. The emphasis placed by our 3Rs program on the individual’s exercise of rights in the context of responsibility to and respect for others is certainly consistent with this relational perspective, as is our emphasis on the importance of systemic supports for individual training.

What this alternative ontological space suggests, finally, is that regardless of one’s level of ability, human competencies, such as awareness and understanding of one’s rights, cannot be thought of as objectively specifiable skills which, once acquired, are simply deployed methodically in (or generalized to) situations that call out for them. Human rights awareness, and actions based on that awareness, are not like other so-called “skills” in that regard. Awareness of human rights has perhaps less to do with what Aristotle called technï, or procedural/technical knowledge, than with phronïsis, or moral/ethical knowledge. While human rights awareness may contain procedural elements (e.g., knowledge of the sequence of actions required to formally lodge a human rights complaint), it differs from technical expertise in that it does not, from one situation to the next, call out for the application of the self-same elements. The elements involved in knowing how to act with self-determination, for example, may involve defending one’s rights as well as deferring to others. In other words, whereas the actions performed in the service of technical knowledge can be specified more or less in advance of the task that calls out for them, actions that moral knowledge involves are not so given and ready-made, but rather depend to a far greater extent on the concrete particularities of individual circumstances.

While it is certainly true that acquired concepts or principles of human rights provide a guide for action – provide, in other words, the normative, paradigmatic image of what one ought possibly to do – that guiding image does not, like the image or blueprint of the technician or artisan, fully determine what courses of action one is to pursue, nor indeed what moral action is, in any given situation (Gadamer, 1989). Again, self-determination is not fully specifiable independently of the situation that demands it; that is, human rights principles are never applied as is – in their normative or paradigmatic aspect – but always must be fitted to individual circumstances. If it is true, as we stated above, that practical knowledge of human rights emerges relationally, then it is equally true that it emerges situationally, in the process of populating a general right with a par-
ticularized, situational meaning. “Practical knowledge,” explains Warnke (1987), “affects the norm and paradigm in question. It is not just a matter of fulfilling the norm … as best one can but rather of filling in what the norm actually means” (p. 93). This process of “filling in,” of applying general principles to different specific situations, is the hallmark of phronesis. It is a process, moreover, that invariably involves not the mechanical and methodical application of a “skill,” but the reflective, deliberative consideration of possible courses of action in light of a normative idea, principle, or concept.

In many respects, our emphasis on the 3Rs represents an affirmation of this hermeneutical insight about the situated, contextual nature of the meaning. To be exercised wisely – indeed, ethically – rights need to carry an appreciation of or orientation toward the individual circumstances in which they are exercised. It is our hope that the interactive CD training program, in tandem with the broad systemic supports noted above, will encourage the sort of deliberation and reflection required for this responsible exercise of human rights knowledge by people who have intellectual disabilities, and by those who support them.

References


Canadian Human Rights Act (1977), c. 33, s. 1.


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This research was supported by grants from the Ontario Trillium Foundation, Human Resources and Skills Development Canada, Community Living Welland Pelham, and Brock University. The authors wish to acknowledge the contributions of the following research assistants: Stephen Agnew, Julia Course, Krystine Donato, Leanne Gosse, Raymond Johns, Lauren Kennedy, Nicolina Lanni, Andrea Moyer, Elizabeth Penic, and Alana Taylor. Special thanks to Barbara Vyrostko, Executive Director of Community Living Welland Pelham, and Frances Chandler, Office of Research Services, Brock University.

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