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#### ABSTRACT

Based on a conceptual framework that links literacy and communication, this Canadian report reviews four types of policy provisions for their effectiveness in addressing the barriers to literacy and communication that people with disabilities face: human rights instruments, provisions for literacy and communication support to individuals, access to information and communications in alternative formats, and access to information and communication networks. A number of policy issues and directions emerge from the analysis. First, the human rights foundation for literacy and communication needs more explicit articulation. Second, a mandate to refocus literacy policy is needed so that the cross-departmental and cross-jurisdictional implications of the link between literacy and communication can be developed and monitored. Third, a human resource development strategy that focuses on professionals in education, justice, health care systems, and on employers is needed to develop skills in alternative communications. Fourth, a policy and service delivery framework should be formulated that provides incentives for a coordinated approach to designing communication environments and supports. Finally, a process is needed to rethink literacy policy and practice, to develop policy directives and implications, and to do so within the context of the rapidly developing information highway. (Contains approximately 125 references.) (CR)



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## EXECUTIVE SUMMARY

Low literacy levels of people with disabilities and the consequences for social and labour force exclusion, poor health, and poverty are increasingly recognized. This study goes beyond the usual policy response to this problem, that is investment in literacy education, and removing barriers to participation in literacy programs.

A closer examination of the literacy problem for people with disabilities, and others often defined as having low literacy levels, reveals the link between exercising literacy and barriers to communication. Theoretical development in the field of literacy, communications theory, and an emerging human rights framework for a "right to effective communication" all suggest that literacy is not an end in itself. Rather it is a means to the goal of inclusive and open communication processes whether at school, on the job, in a doctor's office or in the courtroom.

Consistent with these shifts in theory and practice, and in recognition of the significant communication barriers that people with disabilities face, literacy is re-framed in this study. No longer viewed only as a set of particular skills, literacy refers to a *status* that accords people the opportunities and supports to communicate, given the skills and capacities they have and can develop:

To be literate is to have status, respect and accommodation from others; to have skills in communication (verbal, written, sign, gestural or other language); and to have access to the information and technologies that make possible self-determined participation in the communication processes of one's communities and broader society.

It is clear that this status is afforded to certain groups and not to others, simply by virtue of what kinds of literacy and communication skills are given currency in any particular communication environment.

Based on a conceptual framework that links literacy and communication, four types of policy provisions are reviewed for their



effectiveness in addressing the barriers to literacy and communication that people with disabilities now face:

- human rights instruments;
- provisions for literacy and communication supports to individuals; to those they communicate with; and for adapting communication environments in workplaces, the health care system, the justice system, and the like;
- access to information and communications in alternative formats; and
- access to information and communications networks.

A number of policy issues and directions emerge from the analysis.

- First, the human rights foundation for literacy and communication needs more explicit articulation. It exists in jurisprudence, proposed conventions and statutory provisions in other nations. It needs to be more clearly articulated and to have explicit guiding principles, including universal design principles, for the Canadian context.
- Second, a mandate to refocus literacy policy is needed so that
  the cross-departmental and cross-jurisdictional implications
  of the link between literacy and communication can be
  developed and monitored. The National Literacy Secretariat
  and provincial/territorial counterparts are well positioned to
  begin playing this role.
- Third, a human resource development strategy that focusses on professionals in education, justice, health care systems and on employers is needed to develop their skills in alternative communication and universal design of communication environments.



- Fourth, a policy and service delivery framework should be formulated that provides incentives and resources for a coordinated and comprehensive approach to designing communication environments and providing needed supports. In reforming service delivery to provide employers, education institutions and other systems with needed resources, the current literacy education delivery system has a key role to play. However, connections with the emerging delivery system for supports in augmentative and alternative communication is needed, as is updating and investment in the literacy education sector's own information and communications technology infrastructure.
- Finally, a process is needed to rethink literacy policy and practice, to develop in detail policy directions and implications, and to do so within the context of the rapidly developing "information highway." It is essential that the knowledge and experience of people with disabilities and their organizations be supported so that they can participate effectively in this process.



## LITERACY, DISABILITY AND COMMUNICATION: MAKING THE LINKS

#### INTRODUCTION

Literacy is a growing issue for people with disabilities, and for many other marginalized groups. The extent of low literacy levels, and consequences for people's health, and social and economic participation has led to the development of literacy policy, provision of literacy education, and development of curriculum resources. There has been increasing attention paid to the particular needs of people with disabilities in literacy education, and to ways of adapting education to encourage greater participation.

This study was designed to go beyond conventional definitions of literacy as a set of reading, writing and numeracy skills, in order to conceptualize it as a means to communication. The impetus for the study grew out of a concern that some people with disabilities would never reach the threshold of literacy skills defined as adequate by those developing literacy measures and assessment tools. The only conclusion to be reached was that people inherently lacked the ability to develop needed skills. The problem with such a conclusion is that it reinforces a deficit model of disability just at the time that a social model of disability is being advanced to guide research, practice and policy in the disability field. The social model is based on an assumption that the limitations of a disability arise less from a person's characteristics than from the social, economic, legal and political structures that limit advantage and access on the basis of individual characteristics.

Further, this study reframes the literacy problem to take account of the communication barriers that people face. Literacy is seen as a means to communication in this study, not as an end in itself. The inquiry is guided



by questions about the capacities of education, justice, health care and other systems to make communication possible given the literacy skills that people do have. Ultimately, the study has sought a reformulation of literacy that moves beyond the focus on skills. The aim has been to make visible the interdependence between available communication opportunities and what comes to count as literacy skills.

Four objectives were identified for this study:

- to provide a demographic profile of Canadians with disabilities who have limited literacy skills and face communication barriers;
- to identify the range of policies and federal-provincial/ territorial arrangements that have an impact on literacy for people with disabilities;
- to examine incentives and disincentives within these policies and arrangements that make literacy skills possible for people with disabilities and to ensure opportunities for them to be understood and to communicate in their social, economic and political environment; and
- to develop policy directions to enable greater achievement of public commitments to enable literacy and opportunities for communication for persons with disabilities.

The inquiry for this study has proceeded along a number of paths. The links between literacy, communication and disability have not been made explicit in either theory or policy, though they are clear in people's experience, and in some literacy education practice. Theoretical and conceptual work was needed to lay the foundation for the linkages. Background literature reviews on disability and communication, and on disability and literacy were prepared to help lay this groundwork. In addition, literature was reviewed in theories of communication—both general theories, and research and theory in the area of augmentative and adaptive communication.



Consultations were held with representatives of literacy and disability initiatives in the Yukon, New Brunswick, Ontario, and Manitoba to explore literacy and communication issues faced by people with disabilities, and the usefulness of a framework that made the linkages more explicit. As well, a community consultation was held in Shediac, New Brunswick, to test the model of literacy that focussed not on literacy education, but on communication opportunities for people with disabilities in a wide range of environments in the community. Participants included people with disabilities, literacy educators, generic and specialized service providers, representatives from advocacy organizations, financial institutions and municipal council. The consultation made clear that the range of communication barriers people faced was extensive, and that literacy education was not designed to address their needs. The consultation also affirmed that a model in which literacy was defined as a relationship of communication and understanding would be a helpful guide in resituating literacy education efforts and in deepening the analysis of exclusion faced by people with disabilities.

Policy documents were collected through requests to provincial and territorial government departments responsible for literacy education. These requests sought information not only on literacy programs, but on other initiatives in government to address communication barriers with individuals. Interviews were conducted with a few government officials to enquire into the extent and application of alternative communications policies.

As the conceptual framework for the study began to take shape, the wide array of initiatives, policy sectors, service providers, demonstrations, and policy instruments that have a bearing on literacy, disability and communication became clearer. Extensive searching on the Internet was conducted to gather information and begin to weave it into a framework of types of policy provisions. Finally, a review was undertaken of statutory human rights instruments, relevant jurisprudence, and some international examples of human rights instruments that provide for a right to communication.

This report is divided into five sections. The first two sections provide a review and critique of the skills-based definition of literacy, and a



theoretical justification for expanding the definition. Drawing on this conceptual framework, the third section examines the demographics of literacy, disability and communication. The fourth section uses the conceptual framework to identify and examine the types of policy provisions that are relevant to making the links between literacy and communication. Key policy issues are identified. The final section points to policy directions that follow from the analysis.



## I. DEFINING LITERACY: LOOKING BEYOND SKILLS

Over the past 15 years, numerous studies and media reports have suggested that a crisis in literacy is in the making. Estimates show that proportions of the adult population in Canada aged 16 and over have the lowest level of literacy skills ranging from 15% in Alberta to over 20% in the Atlantic provinces. Overall, the proportion of the Canadian adult population with the lowest literacy skill level is 22%<sup>1</sup>.

When the reports on literacy levels were first published in Canada and the United States, the "problem" of low levels of literacy, or "illiteracy" began to be constructed. Low skill levels were linked to unemployment, educational failure, ill-health, poverty, criminal activity, poor parenting and a host of other social and economic ills and disadvantage. Factors underlying low levels of literacy include patterns of immigration and the inability to fully communicate in the predominant language; low educational attainment; and a marginalized position in society by virtue of aboriginal, disability, racial, or economic status.

The personal and social costs of low levels of literacy are compounded by the economic ones. A frequently referenced report of the Canadian Business Task Force on Literacy, estimates costs in range of 10 billion dollars annually². In the United States, in the mid-1980s, Kozol estimated the annual cost of illiteracy to be in the range of 20 billion dollars annually³. The Organization for Economic Co-Operation and Development (OECD) and others argue that low literacy levels limit the capacities of nations to participate effectively in the global economy and information age⁴. A recent Conference Board of Canada report points to the payoff to employers of investing in workplace-based literacy education. Their study found that such an investment has a number of positive outcomes for both the employee and the employer: increased earnings; increased ability to handle training on the job; better team performance; improved labour-management relations; increased productivity and quality of work; increased retention and increased profitability, among others⁵.



By defining persistent social and economic problems as one of low literacy skill levels, the needed response seems clear: invest in literacy education. Governments in Canada and around the world have invested in measuring the nature and extent of literacy skills; in researching factors related to low levels of literacy; in providing needed policy and program responses concerning the best practices for teaching literacy skills; and in delivering literacy skill education to adults. In Canada, the federal government, through the National Literacy Secretariat, has played a major role in funding literacy surveys, policy research, curriculum development, learning resources, and training literacy educators. Provincial and territorial governments have taken on the responsibility for funding the delivery of literacy education, usually as part of adult and vocational training. At the local level, school boards have also provided literacy education as part of their adult and continuing education activities. Literacy education has been delivered through community-based programs, often using volunteer tutors; public library programs; community colleges and vocational training institutes; school board programs; union education programs; and through workplace-based literacy programs provided by employers, or in partnership between employers, unions, and community organizations.

Yet, despite the financial investment, the policy development and the literacy programs put into place in the past two decades, the problems of low levels of literacy at an aggregate level seem frustratingly persistent. That is, research points to the difference that literacy education has made in the lives of numerous adults, but the aggregate proportion of the population with low literacy levels persists. A comparison of change in literacy levels in Canada between 1989 and 1994 reveal no change, despite the significant investment in literacy education over that period. In reflecting on these findings a Statistics Canada report suggests simply that "other processes" affecting the development and use of literacy skills must be at play<sup>6</sup>.

The fact that literacy levels in Canada had not changed after five years of investment does not necessarily suggest that a bad investment was made. The successes at an individual level clearly indicate that continued and sustained investment in literacy education is needed. Rather, the failure to make major advances at a national population level lies, at least in significant

part, in how the literacy problem has come to be defined, and the extent to which the "other processes" affecting literacy are incorporated into an understanding of the problem.

Conventionally, the literacy problem has been seen as one of distribution of needed literacy skills in the population, thus the national and international studies to survey and track the development and distribution of these skills across different population groups. This study suggests that only when we go beyond literacy as a skill and link it to an understanding of communication—which is what literacy is supposed to make possible—that the problems and issues of literacy can be more fruitfully addressed. Reframing an understanding of literacy in this way is clearly suggested by recent critical research and commentary on the skills-based definition of literacy.

### Skills-Based Definitions of Literacy

Literacy is usually defined as a set of reading, writing and numeracy skills that people need to participate fully in their society. Gray formulated for The United Nations Educational, Scientific and Cultural Organizaton (Unesco) one of the earliest definitions of literacy to guide policy and public investment. He defined as literate a person who has, "acquired the knowledge and skills in reading and writing which enable him to engage in all those activities in which literacy is normally assumed in his culture or group." This definition provided the foundation for Hunter and Harmon in 1979 to link literacy skills to the exercise of self-determination, thus beginning to make of literacy a human rights issue. They defined literacy as, "the ability to read, write, and comprehend texts on familiar subjects and to understand whatever signs, labels, instructions, and directions as are necessary to get along in one's environment." Further, they defined it as:

the possession of skills perceived as necessary by particular persons and groups to fulfill their own self-determined objectives as family and community members, citizens, consumers, job holders, and members of social, religious or other associations of their choosing.<sup>8</sup>



Hunter and Harmon's definition provided the starting point for much of the investment in functional literacy education in the subsequent two decades, and for designing measures of literacy skill in a series of national and international literacy surveys in the 1980s and early 1990s. Concerned that continued low levels of literacy in industrialized nations risked economic productivity and social cohesion, in 1994 the OECD launched an international survey of adult literacy in cooperation with Canada and other countries to measure the scale of the problem<sup>9</sup>. The International Adult Literacy Survey (IALS) built upon the definitions of national surveys in Canada, Australia and the United States during the 1980s. It moved beyond definitions of literacy as a specific, standardized set of reading/writing skills to focus more on the capacity to use and produce information to function in society. The survey measured knowledge and skills to use information in three "domains":

- 1. Prose literacy—the knowledge and skills needed to understand and use information from texts including editorials, news stories, poems, and fiction;
- Document literacy—the knowledge and skills required to locate and use information contained in various formats, including job applications, payroll forms, transportation schedules, maps, tables and graphics; and
- 3. Quantitative literacy [equivalent to "numeracy" in the Canadian Survey of "Literacy Used in Daily Activities"—the knowledge and skills required to apply arithmetic operations, either alone or sequentially, to numbers embedded in printed materials, such as balancing a chequebook, figuring out a tip, completing an order form or determining the amount of interest on a loan from an advertisement<sup>10</sup>.

The assessment of literacy skills results in scores that place an individual within the range of 1 to 5 for each of the literacy domains. The designers of the survey recognized that other types of knowledge and skill should be reflected in a definition of literacy, including communications skills.

However, it was also recognized that there were inadequate resources to measure these other aspects of literacy.

Definitions of literacy tend to fall into three broad categories: "basic," "functional," and "critical." Basic literacy skills refer to those needed for elementary reading and writing of a "short, simple statement on... everyday life.<sup>11</sup>" In recognition of the limitations of basic literacy skills for adults to function as full participants in social, economic and political life, functional literacy skills were conceptualized by Hunter and Harmon, and those who designed the literacy surveys referred to above.

Functional literacy skills are those determined necessary to meet the demands of written texts and documents that organize much of contemporary work, living and social environments. The IALS divided functional literacy skills into the three domains identified above—prose, document and quantitative. The literature recognizes that, by their nature, what will count as functional literacy skills varies from environment to environment, and over time. The OECD's concern in measuring functional literacy skills was based on an acknowledgement that with increased economic globalization, and the growing importance of information technologies, the continual development of functional literacy skills was needed for productivity growth. Examples commonly used in elaborating a functional definition of literacy include reading technical manuals at the workplace, ordering from a menu in a restaurant, reading road signs, reading medications labels, signing consent forms for health care.

The challenge in developing functional literacy skills is to identify the kinds of environments a person participates in or wants to participate in, to determine the literacy demands that the particular environment imposes, and to assist a literacy learner in developing the skills so he or she can communicate in that environment. From a functional literacy perspective, this means that if a person wants to be able to go to a restaurant and order a meal, he or she needs to be able to read a menu, and communicate with a waiter to place an order. The literacy education task is to learn to read the menu and speak to the waiter about what it is on the menu that the individual wants to order. The same conceptualization of the literacy learning strategy applies to a whole



range of environments—the workplace, the doctor's office, the bank, the government employment office.

Critical literacy skills refer to those skills that break with the dominant tradition of reading and writing. Conceived by adult educators like Paulo Friere and others in Latin America, critical literacy education begins with those who have been marginalized from their society—economically, socially and politically. It starts with their own language, dialect, forms of communication and experiences. It does not take for granted the "functions" that people should develop the literacy skills to fulfill. A critical literacy perspective encourages adult learners, through the development of their own written and other modes of expression to understand, critique and change the sources of their marginalization in society<sup>12</sup>.

The definitions and measures of literacy formulated to date are based on five underlying assumptions:

- Literacy is a behavioural and cognitive attribute of an individual—a measurable quantity of skill.
- Literacy skills involve the understanding and use of written and numerical symbols.
- Literacy skills can be measured to indicate the level of literacy within population groups to provide meaningful information about how to guide investment to improve literacy.
- Some individuals and population groups have deficits in their literacy skills, which, if developed, will lead to measurable improvements in literacy levels in the population.
- What counts as literacy skills changes as the written and textual demands of the environment change.

## Critique of the Skills-Based Definitions of Literacy

An emerging critique of literacy brings these assumptions into question because they leave out of the conception of literacy the wider process of munication. Exercise of literacy skills make possible a process of

communication in which information is exchanged, knowledge is generated, products are created, cultural and national identities are built and democracy is practised. Literacy is not an end in itself; people do not develop literacy skills for the sake of having them. Rather, literacy is a means to a process of communication. It is in exercising literacy skills in a process of communication with others that individuals obtain meaning and value, and participate in the social, economic and political development of their communities.

Willinsky's (1990) study of what he calls "the new literacy" contributes to this re-framing of the skills-based definition of literacy. He writes:

The New Literacy consists of those strategies in the teaching of reading and writing which attempt to shift the control of literacy from the teacher to the student; literacy is promoted in such programs as a social process with language that can from the very beginning extend the students' range of meaning and connection. (p. 8)

Like other critics, Willinsky argues we should focus less on literacy as a skill. In his formulation it is a "social process." The student or learner engages with others through written texts and other forms to make and communicate meaning. Literacy, for Willinsky, is "nothing in itself," (p. 9) outside of this process of communication with others through reading and writing texts, and other forms of communication. Willinsky tends to focus his analysis on the student-teacher relationship, and how students' experience outside of the classroom can be brought into the literacy work within the classroom. However, the implications of his analysis extend far beyond this setting. Once literacy is conceived as a social process, it is more than literacy skills that come into view as the focus of study, and of policy and pedagogical intervention. Certain reading and writing skills used to make the social process of communication possible become part of a much larger picture.

How are we to understand this social process of communication and its relationship to literacy? Most importantly, it is not a singular process with fixed criteria. How communication is made varies among persons, situations, organizations, cultures, social and language groups,



communities and countries. Recognition of this variation has been one of the primary sources of critique of the skills-based definition of literacy. Candace Mitchell has referred to "exclusionary literacy," as a literacy that,

views itself as a universal form of reading, writing, and language use... Those situated outside the confines of the monolithic, exclusionary literacy are designated as the Other, alien and troubled, lawless and frustrated, and marked by an inherent failure to learn to read and write. (1991:xviii)

This critique of standardized literacy tests and skills points to how non-standard ways of communicating, non-standard from the vantage point of the dominant cultural or language group, are read by the dominant group as illiteracy or low levels of literacy skill. In order to limit the tendency of the skills-based definition to define as "deficits" ways of communicating that are outside of the dominant culture, the definition of literacy must take into account the many ways in which people communicate.

Mitchell suggests that a deficit in literacy skills is perceived only from the vantage point of those who have defined what the needed skills should be, and that in fact what is going on is a "mismatch" between the ways in which certain individuals and groups make meaning and attempt to communicate, and the capacities of educational and other institutions to enable and engage in their forms of communication:

Unfortunately, this mismatch often leads to the erroneous reaction on the part of individuals in authority in educational institutions [for example] that students from non-mainstream backgrounds are not making sense, when, in fact, they are. What is occurring is that the sense making is embodied in structures alien to individuals outside the group. The fact that they are perhaps alien does not mean, however, that they are impenetrable. (Mitchell, 1991:xix).

The consequence of leaving the context of communication outside of the conception of literacy is that, as James Gee (1989) suggests, the literacy problem "resides in individuals." The policy and program concern then



becomes one of determining whether or not individuals have the needed skills and, if not, what can be done to inculcate the skills within them. Once a link between literacy and the process of communication is acknowledged, and it is understood that communication processes vary culturally and otherwise, then another dimension of literacy comes into view. That is, literacy is not only about having particular skills, it is also about having the status and opportunity to exercise the skills that one has.

Elsewhere Gee (1991) defines literacy as the "control of secondary uses of language (i.e. uses of language in secondary discourses)." In coming to this more abstracted definition than the skills-based definitions of literacy outlined above, Gee begins with insights of critical literacy. Certain groups in society have the status and power to define what will count as predominant ways of communicating. To be accepted in the culture of the predominant group usually requires being able to speak and act in the discourse of that group. He defines "discourse" as a form of language, and ways of acting that, when used by someone, enable others to recognize and include him or her as a member of a particular social group. Gee refers to "secondary discourses" as those forms of language and acting that are used outside of the "primary discourse" formed among family members and one's intimate circle. Thus, when one participates in the discourse of the workplace, the education setting, and other social situations, for Gee, one is participating in secondary discourses. He argues that unless one has status and opportunity to communicate with others in this wider set of relationships, then one does not have literacy. Having the control and status to use language and ways of acting that give one recognition and membership in different social groups is what literacy is all about for Gee. Again, the link between literacy and communication becomes clearer in this conception. Literacy skills literally "make sense" only when others recognize the exercise of those skills as meaningful. To be literate is to be in relation to others; it requires the interaction with and recognition of others.

"Dialogic literacy" is the term that Linda Brodky (1991) uses to illuminate this relationship of literacy between persons, and she argues that much of literacy theory and education are limited in their skills-based, functional focus. In her conception of strengthening the relationships of



literacy, those conventionally defined as literate, would learn to read how others, defined as illiterate, write and communicate their lives. This approach departs from the usual form of functional literacy learning, which requires that people (defined as the "illiterate") learn to read what others (defined as the "literate") write. When the understanding of literacy is broadened to encompass the process of communication, the implications for literacy education shift as well. If the point of literacy is to make communication possible, then those presumed to have literacy skills must also learn the skills to communicate in the ways, and in the discourses that those usually classed as illiterate have to offer.

Willinsky (1992) makes a similar argument in his call for a "postmodern" literacy, that would focus on problems of "representation" in written texts and cultural products of groups who have been marginalized by virtue of race, gender or other socially constructed differences. The challenge in literacy education, then, is to learn to listen and communicate across the social differences that have taken away from some groups, through labels like illiterate, the status to speak and to be heard.

"Popular" and "emancipatory" literacy refer to an understanding of literacy that focusses on changing the processes of communication that have limited the control and status of certain groups to participate, and have denied others access, often by labelling them as illiterate. In the technologies and methodologies of what has been referred to as popular literacy, the focus is on expression rather than on becoming skilled in the standardized rules of writing and speaking (Willinsky, 1991; Laqueur, 1976). It brings focus to the dialects and forms of grammar, spelling, and speaking that lie outside of the dominant or official forms of communication. The link between popular literacy and the changing process of communication is easily recognized in the development and dispersion of printing press technology in the fifteenth century. As Willinsky (1991) writes,

the printers quickly realized the limits of Latin manuscripts and their highly restricted readership, and they began to look to the much larger market that might be created in the European vernacular languages...a literacy in many of the overlapping dialects and languages that held across the continent...it



was a literacy beyond the reach of the dominant clerical form, in both a religious and bureaucratic sense. (p. 177)

New technology, sanction of particular ways of writing (in this case market sanction), combined to grant control and status in the process of communication to groups traditionally excluded from the public exchange of written texts. To describe these profound societal shifts as newly found literacy skills of particular groups, would be to miss the point. It was changes in the process of communication that made possible the exercise of literacy by traditionally excluded groups.

Those arguing for an emancipatory literacy suggest that the processes of communication need to be changed so that people in all their diversity can begin naming and communicating in the world in their own language, "transforming the social and political structures that imprison [them] in [their] 'culture of silence.' Thus, a person is literate to the extent that he is able to use his language for social and political reconstruction." (Walmsley, 1981, p. 84)<sup>13</sup> The practical and political challenges of creating such diverse forms of communication are immense. The challenges in the education system of promoting bilingualism, "heritage" language programs, and opportunities for First Nations children to be educated in their mother tongue are cases in point. The fact that such policies are challenging in political and practical terms reinforces the argument that communication processes are not given, unchangeable and neutral. We can always question the raison d'être for these processes by asking: Whom do they benefit? Whom do they exclude? Whose communication do they make possible?

Critiques of skills-based definitions of literacy are based on a recognition that literacy is not an end in and of itself, but is rather a means to communication. Literacy skills are an important means in enabling people to communicate in a range of environments. On their own, however, the capacity to read and write does not secure the possibility for relationships in which people feel their voices, struggles and cultures are heard and respected. It is this recognition that has led some researchers, educators and literacy advocates to broaden the conventional view of the literacy issue, to include a focus on the relationship between literacy and communication.



In expanding the understanding of literacy, these critiques also point to how certain technologies, and differences in social, economic and political power combine to establish particular processes of communication. These processes tend to give status and control to exercise literacy, and therefore to communicate, to certain groups over others. In understanding how literacy develops, it is essential, therefore, to look to the processes of communication available to different groups, and to the respect and status their ways of communicating are afforded. Finally, the critiques of the conventional definitions of literacy point to the possibility of reconstructing the existing processes of communication. Changes in the status and control granted to certain groups, in available technologies, or in the means of legitimated communication can challenge "exclusionary literacies," to use Mitchell's term. Their reconstruction can make the process of communication more open, enabling and inclusionary.

## II. RE-DEFINING LITERACY: THE LINK TO COMMUNICATION

Based on a critique of the skills-based definition of literacy, this study looks to a redefinition in which:

to be literate is to have the status, respect and accommodation from others; skills in communication (verbal, written, sign, gestural or other language); and access to the information and technologies, that make possible self-determined participation in the communication processes of one's communities and broader society.

This definition retains the focus on self-determination integral to Hunter and Harmon's skill-based functional definition, but recognizes that self-determination can only be exercised in an enabling communication process. There are three steps in understanding the relationship between literacy and communication that are central to this redefinition:

- 1) situating literacy, not as an end in itself, but as a means to the process of communication;
- recognizing that literacy is exercised within a communication environment that enables certain symbols and signals to act as meaningful communication; and
- 3) seeing literacy as a set of skills that are only useful when there is a communication system in place that makes those skills useful and useable in the process of communicating with others.

## Literacy As a Means to the Goal of Communication

Within the aim to develop literacy skills lies the hope of achieving relationships of communication that bring understanding, respect and value to the parties involved. In other words, literacy is a means to the goal of communication. This goal is being advanced in a number of ways. Governments are now articulating the goal of open and accessible



communication technologies and processes in response to rapidly developing global communications networks. Communication is also considered by some as one of the areas for enhancing international human rights protections where access to communication is seen as a human right. It is being elaborated as a guiding social and political aim in that branch of moral philosophy known as "communicative ethics." The importance of expanding access to communication technologies and processes is now a central feature of social development strategies. Finally, calls for a reinvigoration of civil society and democratic public life hinge on reconstructing the processes of communication between governments and civil society, and between different sectors of civil society.

## Human Rights provisions

While there were some efforts at international literacy conferences in the 1970s and 1980s to articulate a "right" to literacy, it has not been entrenched as such in national or international human rights instruments. In the late 1960s two international human rights statements acknowledged the importance of literacy as a means to social development and the exercise of human rights, but it was not conceived as a right in and of itself. The 1968 Proclamation of Tehran stated that illiteracy was an "enormous obstacle to all efforts at realizing the aims and purposes of the Charter of the United Nations and the provisions of the Universal Declaration of Human Rights." A year later, illiteracy was again acknowledged as a means to the exercise of human rights.

The 1969 United Nations Declaration on Social Progress and Development declared that the eradication of illiteracy was a goal that had to be achieved if human rights and fundamental freedoms were to be attained. However, no human rights instruments have been adopted nationally or internationally that express a "right" to literacy. One of the major difficulties in articulating such a right is that as long as literacy is seen exclusively as an individual skill, protecting a right to acquire it is difficult to justify. People do not have a right to obtain particular skills, though they do have a right to participate in processes and institutions like education and the practice of democratic elections, and to fair process in the justice system.



While a right to literacy has not been codified, there are a growing number of proposals for establishing a right to communication. The context for these proposals is, in large part, the shift toward information-based societies, and information networks and technologies that are global in scope. Concerns about: affordability and access to such technologies and networks; securing respect for diverse cultures and languages; assuring privacy; and regulating commercialization in global information networks underlay proposed provisions such as the Aspen Institute's "Information Bill of Rights and Responsibilities," and the "People's Communication Charter".

Existing human rights provisions can also be interpreted to include a right to communication. Linden (1996) focuses on development issues in third world countries and reviews shifts in human rights laws and their interpretation in recent history. In interpreting international human rights provisions since 1945, he finds that existing instruments do suggest an obligation of state authorities to facilitate the availability of and equal access to the means of information and communication. He also outlines, in the context of international development policy, how a human rights framework can guide strategic planning and policy formulation for information and communication development. (Proposals and provisions for a right to communication are discussed in more detail in Section IV.)

## Communication theory and "communicative ethics"

Central to contemporary theories of communication is a recognition of the moral and ethical aspects of communication processes. Habermas, one of the leading theorists of communication processes, argues that it is through the act of communicating with others that societies work and evolve. What he refers to as communicative action "is not only a process of reaching understanding...actors are at the same time taking part in interactions through which they develop, confirm and renew their memberships in social groups and their own identities. Communicative actions are... processes of social integration and socialization." (Habermas, 1987, p. 139.)



For Habermas, the "life worlds" of people, their particular views of reality and ways of living have become increasingly organized by social and economic systems over which they have little control. As the life world is "colonized" in Habermas' terms the capacity to bring these systems into question, and to change them is increasingly diminished. He argues that it is through communicative processes where there is equal power to speak and to dialogue, and to identify personal and collective interests that agreements can be reached on the rules that should guide communities, governments, and other levels of society. He sees in communication the possibility of affirming the importance of the "life world" of one's social and cultural groups, against the often impersonal systems of the state and the market, and of achieving a "mutuality of reciprocal understanding, shared knowledge, mutual trust, and accord with one another."14 Benhabib (1986) has questioned the emphasis in Habermas' work on reaching consensus in such communicative processes, as the test of a "communicative ethic," on the grounds that not all positions among different groups in society are necessarily reconcilable. She suggests instead that a more adequate test of ethics in communicative processes is the establishment of an equality among speakers where there is an acknowledgement of differences, and a willingness to recognize and learn from other speakers about their aims and needs.

The work of Habermas, Benhabib and other writers in the theory and ethics of communication strikes an affinity with many groups who have been excluded from participating in the communication processes of their societies by virtue of economic status, race, linguistic and cultural differences, sex or disability. Their exclusion rests in the fact that, as Carey (1989) suggests, communication is an inherently political process with

the power to define, allocate and display that scarce resource [reality].... The site where artists paint, writers write, speakers speak, filmmakers film and broadcasters broadcast is simultaneously the site of social conflict over the real.<sup>15</sup>

## Social development strategies

It is in recognition of the inequality in the process of communication that international agencies are looking increasingly to the role of building

communication infrastructure in the development strategies of countries and organizations they support. While the focus is on countries less developed industrially, strategies for "communication and development" are now being applied in more developed countries of the industrialized north as well. UNESCO, for example, established a number of "roundtables" on "communication for development" to identify ways in which grassroots and community organizations, as well as governments, can develop communication processes that promote development, democracy and equity. Strategies identified include funding of community radio, popular video productions, national broadcasting infrastructure, and linkage to global information networks. In an opening address to UNESCO's Sixth Roundtable on Communication for Development, emphasis was placed on the centrality of communication to social, economic and political development, and to the role of all people, "including the illiterate" in the processes of communication that define any particular society. 16

#### **Democratization**

Establishing channels for open, accessible and interactive communication is also recognized as a condition for democratic participation. In a paper titled "Civil Conversation: Communication and Civil Society," Morgan (1996) argues that the idea of communication as a one-way information flow from one person to others is inadequate. He cites Carey (1989) to make the point, similar to Habermas, that it is through communication that social, economic, and political "worlds" are created:

Communication is a form of action—or, better, interaction—that not merely represents or describes but actually moulds or constitutes the world. (Carey, 1989:84)

Given their importance to social organization, economic productivity and governance, Morgan argues that communication processes and technologies should be designed to enable "civil conversation." Democratization, he suggests, will be strengthened to the extent that communication processes allow different cultural groups to express and maintain identity; provide community organizations with new capacities;



and, make possible people's participation in the governing of their communities and society. Similarly, Langham (1994) finds in the "virtual communities" made possible by communication technologies the potential for people to have a voice in how governments carry out their duties. The recent initiative by NGOs and governments to ban landmines is one example of how the global virtual communities that Langham and others envision can bring about political change.

Giroux focusses less on the skills aspect of literacy than on literacy as a capacity to understand the differences of others—differences in culture, language and ways of communicating. For Giroux, it is this capacity to embrace others' differences that makes a re-conceptualized literacy central to strengthening democratic participation:

Literacy is a discursive practice in which difference becomes crucial for understanding not simply how to read, write, or develop aural skills, but also how to recognize that the identity of "others" matter as part of a broader set of politics and practices aimed at the reconstruction of democratic public life." (1991:ix-x).

An advocacy group in the United States, "Computer Professionals for Social Responsibility," also suggest that it is necessary to link our understanding of literacy to available communication technologies. They advocate a set of principles to ensure that communication technologies are inclusive and respectful of different groups in society, principles including: equality of access; freedom of communication; preservation of public spaces; and guarantees of privacy (Langham, 1994).

In summary, the importance and centrality of communication is increasingly recognized as a human right; as a process that both forms the human world and establishes who can participate in it; as a development strategy; and as a condition for strengthening democratic participation and civil society. The changes taking place in the informational and communication structure of societies around the globe, and the emergence of goals to develop more equal communication processes, create a new context for thinking about literacy. Communication processes are not static, requiring a fixed set of literacy skills. Needed and useable skills change as

the environment changes through technological development and other factors. Once oral and gestural communication in a face-to-face relationship were the primary means for communication. Later the printed text changed the environment for communication. In this century, communication has been transformed with telecommunications, new information technologies, and the creation of "cyberspace." The capacity to construct communication environments that allow for many forms of communication suggest that literacy as we have conventionally thought of it is tied as much to the nature of the communication environment, as it is to the particular skills that individuals possess.

#### Literacy within a Communication Environment

The second step in linking literacy and communication is to conceptualize the environment in which a person exercises his or her literacy skills. A theory and ethics of communication point to the importance of equality in communication processes, and existing human rights provisions can be interpreted to protect that equality. However, there is a need to better understand how communication environments work, in order to point to how certain aspects of the environment can present barriers to a person in exercising the literacy skills he or she has.

Any environment in which a person lives, works, recreates, learns, uses services, and so on, is also a communication environment. A person's workplace can be viewed as a physical environment, and can be examined for its physical accessibility. A classroom can be viewed as an educational environment and can be examined for how well it is designed to support a person in meeting learning goals, given his/her particular needs and capacities. These and other settings can also be viewed as communication environments, which structure opportunities and barriers to people's communication with others. In viewing a person's home, workplace, or a service agency, and the like, as a communication environment, Johnson, et al. (1996) suggest that certain aspects of that environment become visible:

• Communication partners are those with whom a person communicates in a particular setting. Partners bring certain



attitudes and capacities in interacting with a person and his or her particular ways of communicating.

- Communication systems are the means by which a person communicates with others (basic systems such as speech, writing, and reading; and alternative and augmentative systems such as blissymbol boards, systems involving computer technologies and personal support to facilitate communication).
- Expectations or norms of the culture affect how communication will take place in a particular setting (e.g., a classroom, a doctor's office). Expectations influencing the communication process include norms of the broader culture about how communication should be managed (e.g., who has authority to speak, in what ways people should address one another, the appropriate forms of speech or other systems of communication that should be used or made available).
- Communication filters through which individuals manage their communication with others in a particular setting is another aspect of the communication environment. Filters include the rules that determine who communicates, when, how, and about what; the time of day, any visual and auditory distractions, the presence of others, and so on.

Many studies point to the communication barriers people with disabilities face in one or more of these four aspects of the communication environment. Others in the workplace, teachers, family members or service providers who support a person in his or her home may or may not believe that a person has a capacity to communicate, and thus their expectations limit the opportunity for communication and for development of literacy skills. The expectations of a teacher in a classroom, and the school board he or she works for may be that students can learn in a range of ways and that the curriculum is infinitely adaptable to accommodate students' different communication strategies. Or they may expect and require that



students have certain cognitive and communicative competencies in order to be "educable" within a regular classroom. 17

While significant research is taking place on developing alternative communications systems and adaptive technologies, a number of technical issues persist in interface and compatibility with existing communications and information technologies. As well, accessible or universal design of technologies has been accepted more as a principle in developing communications systems than as a practice. The consequence is that people may have access to technologies, but they end up confining rather than enhancing their social and technical access to others in their environment.<sup>18</sup> People may not have conventional literacy skills, but may communicate through gesture and behaviour, which may or may not be understood by others around that person. Their behaviours tend to be seen as "problems" rather than as a different set of literacy and communication skills. Developing augmentative communications systems to turn their gestures into communication in school, home and other environments can require extensive planning and supports, which are often unavailable to people.19

One example of a study on people with disabilities and communication barriers, that takes into account all of these aspects of the communication environment, is the Canadian Transportation Agency's (1997) review titled: Communication Barriers: A Look at Barriers to Communication Facing Persons with Disabilities Who Travel by Air. This review was initiated by the Agency after it received a letter from the president of the Canadian Council of the Blind, head of a national consumer group of people with disabilities. The letter expressed a number of concerns about communication with people with disabilities at airports and in air travel. The expression of concern and the Canadian Transportation Agency's response was not couched in terms of literacy skills of people with disabilities; it was recognized that the communication processes of airport terminals and in travel were not designed in ways that enable people to communicate effectively, and to exercise the literacy skills they have. The scope of the Agency's review included communication issues faced by those who are blind or with low vision, as well as those with cognitive, physical and sensory disabilities. The



review included interviews, surveys and focus groups with representatives of airline carriers, airports and consumer groups.

Barriers in each of the four aspects of communication environments in airports were identified and addressed in the Agency's recommendations. For example, the review found that the **communication partners** (e.g., ticket agents and security personnel) required more effective training and quality control in providing service to people with disabilities, in particular sensitivity to needs and skills in communicating with those who are deaf or hard of hearing, and those with low vision. In addition it was recommended that a new **communication partner** be made available to assist people in crossing what was referred to as the "no-man's land" between the entrance to the terminal and the ticket counter. Airport staff monitoring the entrance, or volunteer "ambassadors" were put forward as suggestions. It was also suggested that people with disabilities themselves should be recognized as having expertise and should be included as partners in the design and development of services to better serve people with disabilities.

A change in **communication systems** was also recommended, in particular a comprehensive alternative formats policy, better signage (including pictographs rather than print, increased size, more colour coding, more visually accessible placement of signs), and more TDDs. **Expectations** and the culture of the environment were also questioned through consultation with consumer groups. It was suggested that staff need greater sensitivity to the requirements of persons with "print disabilities." Again, the issue was not low literacy levels and an inability to manage print, but rather one of air travel staff's inappropriate expectations and lack of sensitivity about people's capacity to communicate through print.

Changes to address the **communication filters** in airports were also recommended. For example, the ambient noise, brightness of light, and size of print on arrival/departure video terminals made obtaining such information difficult for people with low vision, and for some people with cognitive disabilities. To reduce these 'filtering' aspects of the environment that make communication more difficult for some people, it was recommended that enclosed information booths be set



up in the terminal. They would include an audio system to report arrival/departure information, and a capacity to repeat information upon request.

Framing the issue of literacy as largely one of barriers in a communication environment helps to generate practical suggestions to improve both access and participation. Communication barriers are pervasive. Their existence helps to explain the social and economic exclusion that people with disabilities face. It was only as the Canadian Transportation Agency more fully explored accessibility issues that the problems with the design of communication environments in the air transportation sector began to emerge. Addressing barriers in the design of other communication environments—whether in the labour market, in education, or in health care and other community services—will improve access and participation in these sectors as well. Such barriers have been long understood to present formidable obstacles to people with disabilities.

### Literacy As a Communication System

A third step in linking literacy and communication is to consider the communication systems through which particular literacy skills come to make communication with others possible. Communication systems entail:<sup>20</sup>

- the various *forms* of speaking, writing, gesturing, vocalizing and the *personal supports and technologies* to use these forms, through which individuals initiate contact with others, express and respond in the process of communicating;
- the *functions* these forms serve in communicating with others such as the role that speaking, writing, gesturing or vocalizing plays in the process of communication (e.g., initiating or ending an interaction with others);<sup>21</sup> and,
- the *symbols* used to communicate particular meanings and intentions (e.g., written and visual symbols that indicate entrances and exits in buildings, or written words or gestures that express certain intentions or reactions).



For many people, there is a taken-for-grantedness about the communication systems they use. They learn to speak, write and read in ways that are understandable to others in their culture and to those who share their language. As "natural" as their communication system may seem, it is only one of an infinite range of possibilities. The reality that one's own communication system both exists, and is limited, is confronted whenever someone is encountered who only speaks, writes, reads and understands in languages different from one's own.

Understanding both the theory and practice of designing communication systems is central to advancing literacy opportunities for people with disabilities. A person's literacy skills are only as effective as the communication systems available. When effective communication systems needed supports, technologies, and responsive communication partners are in place, people's different capacities to read, gesture, make written symbols, and understand others are transformed into literacy skills. Existing legal rights to "effective communication," rest on the extent to which the cost of developing communication systems (e.g., interpreters for those who are deaf; interveners for those who are deaf and blind; facilitators) is understood as a "reasonable accommodation" for education, health care or other institutions. To be considered "reasonable," the purchase and introduction of the communication system must not impose on the institution an "undue burden" in economic costs and in the "costs" of altering the environment to incorporate the system. Some legal cases launched to secure inclusive education for children with disabilities have been lost, in part, on the grounds that the communication system required for a child to participate in a regular classroom was unreasonable—in terms of cost, disruption to other children, and complexity in managing the system.

To conclude this discussion of linking literacy and communication, it is important to reiterate that for many years literacy has been conceived as a set of individual skills that remain significantly underdeveloped in large proportions of the population in Canada and other countries. It is time to step back to view the relationship of literacy to its goal—that of fostering open and accessible communication processes that secure equality for all participants. Communication environments in every sector of society

are undergoing radical transformation. Cultural and language groups in many countries, cities and communities are increasingly diverse. New communications technologies are rapidly developing. Information networks are globalizing. National and international human rights provisions are being interpreted and expanded to secure greater equality in communication processes.

This sea change in the communication environments of our societies has helped to make visible how both limited and adaptable communication systems and environments are. Such a recognition opens up enormous potential for addressing what has been termed the literacy problem. Drawing on the pedagogies and educational resources now available to promote basic, functional and critical literacy, it is possible to begin restructuring communication environments to maximize the literacy skills that people have. Moreover, by adapting environments and designing new communications systems, new forms of literacy skills can be recognized and transformed into tools of communication. Thus, those who have been excluded from the communication processes that are re-shaping social, political, and economic life on a global scale, can begin to participate more fully. Democratic participation, economic and social inclusion and the strengthening of civil society can thereby be advanced.



# III. DEMOGRAPHICS OF LITERACY, DISABILITY AND COMMUNICATION

A re-definition of literacy that incorporates relationships of communication with others raises new challenges in measurement. It requires measuring the status, respect and accommodations that others provide so that individuals can be understood and included when they communicate in unconventional ways (i.e., through sign, gesture or vocalizations that are not widely shared ways of communicating). The definition also looks to the communication processes and environments of one's society (in schools, workplaces, services, leisure and recreation). Ways of measuring access to, participation in, and exclusion from communication environments have not been developed, although communication barriers for people with disabilities have been identified.

Most literacy measures test capacity according to particular languages and written forms, thus selecting particular communications systems over others. In such an approach, people's capacity in relation to selected communication systems is being measured, not literacy and communication more generally. For people with disabilities, who tend to face various communication barriers, such measures incorporate a systematic bias towards culturally accepted norms of communication.

This is not to suggest that reading, writing, and numeracy skills—or prose, documentary, and quantitative literacy to use the terms of the International Adult Literacy Survey (IALS)—are unimportant. Development of such skills and knowledge are required, as much if not more, among people with disabilities than among the general population. However, to restrict an understanding of literacy to these skills is to minimize a much needed focus on creating more flexible and inclusive communication systems. In other words, literacy measurement has not taken existing literacy and communication capacities as given, and therefore has not asked how technologies and ways of providing information might be changed to better support existing capacities as tools for communication.

Redefining literacy thus raises new questions for its measurement. A review of existing statistical sources on literacy, disability and communication



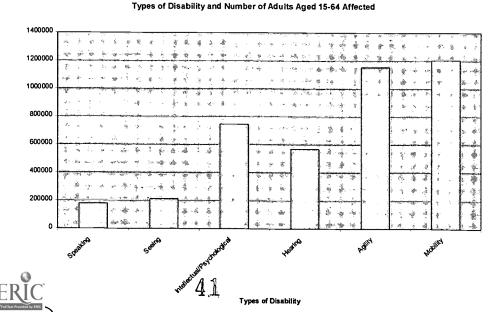
can point to some of the linkages. Such a review also points to the importance of moving beyond a restricted notion of literacy and the policy and program implications it raises.

## Existing Statistical Sources on Disability, Literacy and Communication

While communication issues affect all persons with disabilities, regardless of age, this study looks primarily at the population of working-age people with disabilities aged 15 to 64. This group is the focus of both literacy surveys, and literacy policy and programs. The primary aim of this study is to explore the specific links between literacy and communication for people with disabilities within a framework that would be more widely applicable in the measurement and study of literacy. By focusing on the working-age population of persons with disabilities a comparative body of information for research on literacy can be built.

Types of disability are usually defined for the purposes of demographic surveys as: speaking, seeing, intellectual, psychological or mental, agility, and mobility. **Graph 1** shows the proportion of working age people with disabilities who have at least one of these types of disability; many have more than one.

Graph 1



While speaking, seeing and hearing disabilities are most commonly associated with communication disabilities, all types of disability can lead to literacy and communication difficulties. Those with intellectual or psychological disabilities may have difficulty processing information in the formats in which it is usually provided. Agility and mobility impairments can make access to communication and information technologies difficult without computer adaptations and aids. Moreover, anyone with a disability may require note-takers, readers, interpreters or other personal supports to communicate effectively in education or training. A "communication disability"—a term that is increasingly used—is not a particular type of disability. Rather, it is the outcome of a person not receiving adequate supports to participate in a particular communication environment.

Because existing statistical sources do not measure the link between literacy and communication barriers and opportunities, it is necessary to draw on sources that primarily measure literacy or disability, and see what, if any, connections can be made to communication. Four sources that are key to understanding literacy levels in Canada are:

- Statistics Canada Survey on Literacy Skills Used in Daily Activities;
- The Southam Survey on Literacy;
- The International Adult Literacy Survey (IALS); and
- The Health and Activity Limitations Survey (HALS)

Of these sources, HALS is the only one that addresses the issue of disability. The other surveys vary in their scope of literacy issues and, like HALS, provide insight into not only how we frame literacy, but how we begin to identify connections among literacy and other social factors (i.e., educational attainment; labour force participation; sense of control).

The ability to statistically analyze how issues of literacy affect individuals with disabilities is greatly limited when literacy surveys do not stratify according to disability. Neither the 1989 Southam Literacy Survey, nor the 1989 Statistics Canada Survey on Literacy Skills Used in Daily Activities



stratified their survey sample to measure the level of literacy among people with disabilities. The Southam Survey was administered to 2,398 adults aged 18 and over. Participants of the survey were randomly selected from 148 rural and urban communities across Canada (Calamai, 1987). The 9,500 adult Canadians who were interviewed and tested in the Statistics Canada survey had been recent participants in the Labour Force Survey (LFS), a monthly labour force participation survey of Canadian households. Participants in the Statistics Canada survey were not stratified according to disability because the LFS does not identify individuals according to disability. The International Literacy Survey of Adults (IALS), conducted in 1994, does not include samples of the population who have a disability, because its main study sample was also drawn from the Labour Force Survey.

Analysis of the 1991 HALS indicates that over 425,000 Canadians with disabilities (aged 15-64) rate their reading and writing skills as either not adequate for daily living, or rate their skills as only a 1 or 2 on a scale where 1 represents poor and 5 represents excellent.

Moreover, a large group of working-age people with disabilities (172,000) have significant cognitive limitations as reflected by difficulties encountered in learning three or more basic literacy tasks (i.e., learning how to read, write, spell, add and subtract)<sup>22</sup> and in performing two or more of the following skills essential to daily living such as telling right from left; doing the right thing at the right time; explaining ideas when speaking; performing multi-step tasks such as following recipes; solving day-to-day problems; understanding other people and talking to people who are not familiar acquaintances.<sup>23</sup>

The following analysis provides insight into literacy and communication using HALS' measurement of literacy for four groups of working-age people with disabilities:

• persons who do not have significant cognitive limitations and who believe their literacy skills are adequate for daily living (1,812,284 persons, identified as "other disabilities—adequate literacy" in Graphs 2 to 8);



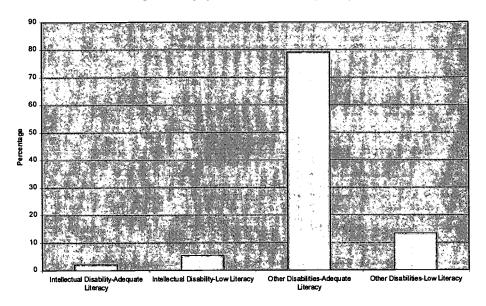
- persons who do have significant cognitive limitations, but who feel their literacy skills are nonetheless adequate (48,885 persons, identified as "intellectual disability—adequate literacy" in Graphs 2 to 8);
- persons who do not have significant cognitive limitations but who believe their literacy skills are inadequate (306,848 persons, identified as "other disabilities—low literacy" in Graphs 2 to 9); and
- persons who do have significant cognitive limitations and who also feel their literacy skills are inadequate (123,115 persons, identified as "intellectual disability, low literacy" in Graphs 2 to 9).

A review of the analysis points to some important findings. First, as reported in **Graph 2**, just over 18% of people with disabilities self-report low literacy levels. This figure is comparable with the national population statistics for Canada in the National Literacy Secretariat (NLS) and IALS. However, unlike these two national surveys where actual literacy tests were administered to the sample, HALS depended on self-reporting. As the IALS data indicate, a high proportion of those whose testing places them in the lowest literacy level, nonetheless self-report much higher literacy levels. This is likely the case with people with intellectual and other disabilities and can be traced to two key reasons. Either people may not want to self-report low literacy levels, or, the demand on their literacy skills may not be that high, given the greater exclusion from the labour market and social participation they are likely to experience. Consequently, they may not experience a lack of literacy skills and the communication barriers they might otherwise confront had they been included in the labour market.



Graph 2

Percentage of Working Age Adults with Disabilities by Literacy Level

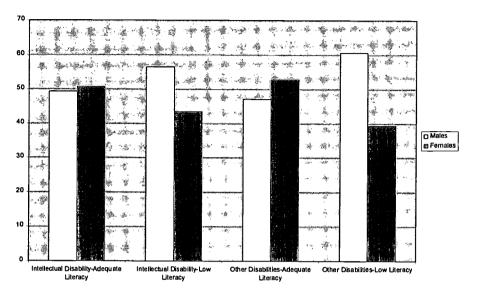


Demographic analysis of literacy and disability reveals the following trends. Men are more likely than women to report low literacy levels (about 60% compared with 40% women. See **Graph 3**.) Those with intellectual disabilities who reported low levels of literacy are twice as likely to be enrolled in a special education program as people with intellectual disabilities who reported adequate literacy levels. They are also much less likely to be enrolled in a regular program at school or community college (50% of those with low levels of literacy compared with over 70% of those with adequate or higher literacy levels). People with disabilities who self-report low literacy levels are much more likely to have completed less than nine years of schooling, and are much less likely to have some post-secondary education. (See **Graph 4**).

Employment status and household income are also related to low literacy levels. While people with disabilities are much less likely than the general population to be employed, those with lower literacy levels are even more likely to be unemployed or not in the labour force. They are more likely to have annual household incomes below \$10,000. (See Graphs 5 and 6.) Because of the greater likelihood of labour market exclusion and

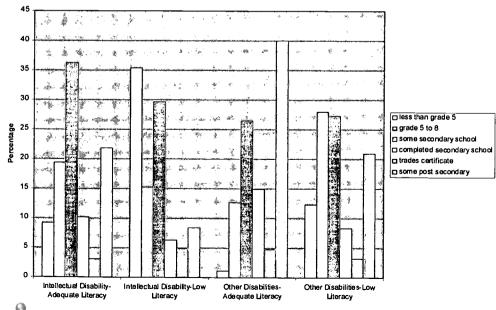
#### Graph 3





### Graph 4

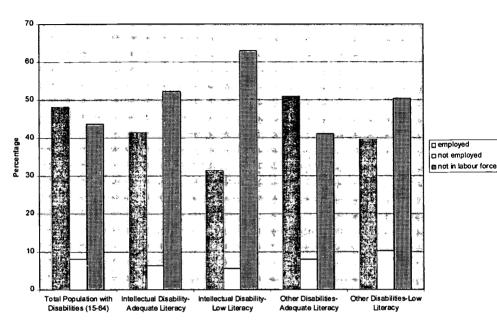
#### Highest Level of Education Achieved





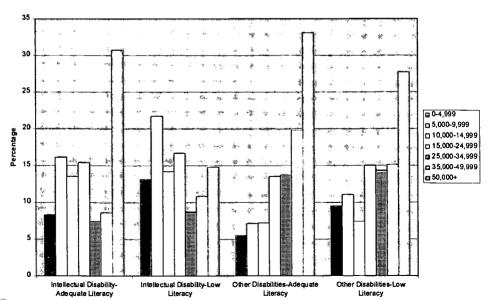
Graph 5





### Graph 6

#### Census Family Income from All Sources (1990)



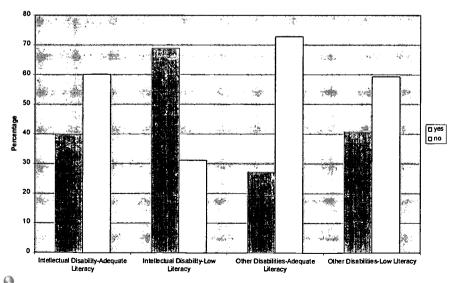


poverty, people with low literacy levels are also more likely to receive social assistance because of a disability. Almost 70% of people with an intellectual disability who report low literacy levels receive social assistance because of their disability, compared with only 30% who do not report low literacy levels. For people with other disabilities who report low literacy levels, 40% receive social assistance because of their disability, compared with under 30% who report their literacy skills are adequate. (See **Graph 7**.)

Statistical evidence of the link between low literacy levels and communication barriers is found, in part, in the fact that people with disabilities who report low literacy levels are more likely to require communication assistance through note-takers, computer access, and so on. (See **Graph 8**.) As well, HALS data indicate that low literacy levels are linked to non-participation in a range of communication environments. People who report low literacy levels are twice as unlikely as others to attend social activities or visit with family or friends; are twice as likely never to go shopping, and are more likely not to participate in education/training. Their exclusion from the labour market and other environments takes a personal toll in a loss of decision-making power. People reporting low literacy levels

Graph 7

Because of Disability - Received income in 1990 from Social Assistance Benefits or Pensions



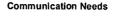


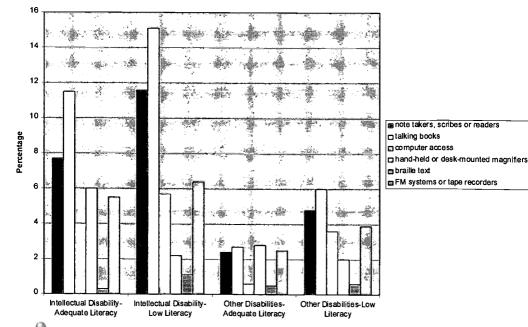
are twice as likely as others to have someone else take care of personal finances, are less likely to feel that they have control in decisions that affect their daily lives, and are more likely to experience depression.

## Inadequacy of Literacy Training as the Only Response

Low literacy levels are a significant and probably under-reported problem for people with disabilities. Linked to low literacy levels are barriers to communication with others in a range of social, educational, and work-related environments. What should the policy and program response entail? Interventions to address the literacy issue have involved investments in literacy education, but as discussed above, these investments on their own have not led to appreciable differences in raising literacy levels generally. They cannot be the only response to the literacy problems faced by people with disabilities either.

#### Graph 8

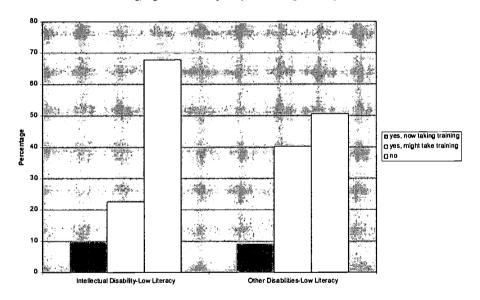




Literacy programs are becoming more inclusive of people with disabilities, and tools to make them more accessible have been developed.<sup>24</sup> However, the reality is that people with disabilities who have low literacy levels tend not to gain access to existing programs. In 1991, almost 70% of those with intellectual disabilities who self report low literacy levels indicate they are not, nor would they likely, take training to improve reading and writing. Fifty percent (50%) of those with other disabilities indicate this as well. Less than 10% of those with low literacy levels are taking training to improve reading and writing skills. (See **Graph 9**.)

Graph 9

Taking, Might Take Training to Improve Reading or Writing Skills



People indicate a number of reasons for not participating such as not being aware of opportunities, lack of available and suitable training, feeling that they are too old or that it's too late, feeling too embarrassed, or finding that it is too costly to participate. Over 50% indicate they are not interested in participating. While more recent data is unavailable, there has been no significant expansion of literacy programs since the early 1990s, and indeed cuts to funding of literacy and social programs, generally, have been introduced in the interim. It is unlikely, therefore, that people with



disabilities are much more highly represented in literacy education in 1998 than they were in 1990.

In summary, like the general population, a significant proportion of people with disabilities have low literacy levels. A number of other social and economic factors combine with low literacy levels to reinforce the disadvantage this group faces, even more so than people with disabilities who report adequate literacy levels. While greater participation in literacy education should be encouraged for this group, there are underlying structural problems in education, the labour market and workplace, and other sectors that lead to the disadvantage associated with the skills that people do have. People with disabilities are much less likely to complete schooling and have access to the social and other opportunities of the regular education system. They are much less likely to have relationships with family and friends, and to have decision-making control in their own lives. Because of their exclusion from the paid labour force, the opportunity to develop and strengthen literacy skills through participation in work environments is restricted.

That individual skill is one part of the literacy problem is clear. But at least, if not more important is how education, work, and other environments have been designed to make communication possible with the literacy skills that people do have. A framework is now needed for understanding how communication environments are designed that are responsive to the skills and ways of communicating that people possess, and that encourage their development. It is to the development of such a framework for policy and program analysis that the next sections in this report turn.



# IV. POLICY AND PROGRAM PROVISIONS FOR LITERACY AND COMMUNICATION CAPACITY

In redefining literacy to make clear its relationship to communication processes and environments, a wider range of relevant policy and program provisions to enable literacy come into view. Both federal and provincial/territorial governments have established literacy policy provisions in recent years. However, the vast majority of these focus on delivery of literacy education, supports to people to participate in programs, and on research in best practices and curriculum in literacy education. In developing a framework for literacy that takes account of how the communication environment affects both the skills and communication processes that constitute literacy, a number of types of policy provisions are important to consider. These are:

- *human rights provisions* to secure access to communication environments and supports;
- provisions for *supports to individuals*, *communication* partners, and environments (e.g., the workplace) in strengthening literacy and communication capacities;
- provisions to ensure access to needed information; and
- provisions for access to and use of information and communication networks.

As the study on communication barriers in air travel makes clear, the real test of the effectiveness of these types of policy provisions is how they work together to create open and accessible communication processes in a range of different environments. Systematic policy analysis of these types of provisions and their inter-relationship in strengthening literacy and communication processes has not been undertaken in the past. The following discussion develops a framework for policy analysis based on the developments in theory and practice outlined in preceding sections. Without providing an exhaustive inventory, it examines the types of



policy provisions that do exist in Canada in each of these areas with some reference to international examples. The analysis looks to particular communication environments to see how these types of provisions are being applied. It considers the impact these provisions have in creating greater literacy opportunities for people with disabilities through more open and accessible communication environments. Finally, the analysis points to the kinds of challenges and barriers to communication that remain.

A matrix to help visualize the following analysis is presented in **Table 1**. The table can be used to identify what provisions exist to shape communication environments in major social, economic, and political institutions such as:

- citizenship and participation (e.g., democratic institutions, public places and services)
- health services
- education
- employment
- the justice system

Numerous communication environments make up each of these institutions. In health services for example, there are doctors offices, acute care hospitals, community health clinics, home care service delivery in individuals' homes, the communication environments of health information networks, and so on. Detailed study of any particular environment in health services is likely to reveal both common and distinct barriers to literacy and communication.

## ANALYSIS OF LITERACY AND COMMUNICATION POLICY PROVISIONS

Literacy and Communication Policy	Human Rights Provisions	Communication Supports to Individuals, Communication Partners, and Environments	Access to Information	Access to Information and Communications Networks
Communication Environments				
Citizenship and Participation				
Health				
Education				
Employment				
Justice System				

The following analysis is guided by a focus on the types of policy provisions and points to general implications for communication environments across citizenship, health services, education, employment and the justice system. These are not the only sectors in which communication barriers arise, but they are sectors in which people with disabilities commonly face significant barriers to inclusion. Consequently, they serve as useful examples in undertaking policy analysis. Viewing these systems from the perspective of enabling literacy and communication helps to reveal the nature of the barriers people face, and the kinds of additional policy provisions that are needed to address them.



#### **Human Rights Provisions**

Barriers to exercising literacy skills and to participating in communication processes arise in part because protections to ensure access to communication are lacking, and because existing provisions are not applied.

#### A "Right to Communication"

Comprehensive proposals for a right to communication are being developed to address the barriers people with disabilities and others face. For example, the Aspen Institute in Washington proposes an "Information Bill of Rights and Responsibilities." It lays out a number of principles related to access, affordability, non-discrimination, participation, and diversity in constructing an information society and communication infrastructure "characterized by the open flow of information among all individuals and institutions." The proposed Bill of Rights makes explicit reference to literacy, but as a means for democratic participation, free expression and "robust civic discourse." At the same time, the bill proposes that "neither skill nor status should bar an individual from full participation in the social dialogue and information transactions of the information society." A proposed international Charter of communication rights, The People's Communication Charter: An International Covenant of Standards and Rights, has been originated through the Centre for Communication and Human Rights (The Netherlands), the Cultural Environment Movement (USA), and others. The proposed Charter draws on provisions in the Universal Declaration of Human Rights, the Covenant on Civil and Political Rights, UNESCO Resolutions on the "Right to Communicate" and "Communication for Development," and the Convention on the Rights of the Child. The Charter asserts the following:

- All people are entitled to access to the resources they need to communicate freely within and between their societies;
- All people need to develop their own communication skills, channels, and institutions through which they can speak for themselves with dignity and respect, and tell their own stories;



 Provisions for all aspects of free, independent and secure communication and culture, and mechanisms for their implementation, must be strengthened.

The proposed *Charter* refers to a "right to acquire skills necessary to participate fully in public communication," along with rights to access local and global networks for communication, to express and have access to information in their own language, and to "universal access to and equitable use of cyberspace."

The one area in which rights to communication have been entrenched at the national level is with respect to people with disabilities. In the United States, the Americans with Disabilities Act (ADA) establishes a right to "effective communication." Places of "public accommodation" are required to provide listening systems and interpreters. Auxiliary aids must be provided unless it would cause undue burden or fundamentally alter the services provided. The Act requires a number of public services and institutions to develop policies, procedures and plans to make needed changes to their services and environments to enable effective communication. For example, Florida Atlantic University established a policy to bring about compliance with the ADA, titled "Policy to ensure compliance with the ADA requiring the provision of effective methods for communicating with people with disabilities," which states:

All communications, printed documents, meetings, activities, etc., offered by the University must be made accessible to people with disabilities. However, no action is required that would fundamentally alter programs or create undue burdens.<sup>25</sup>

In Australia, the *Disability Discrimination Act* provides that "any communications in the course of administering Commonwealth laws and programs must be made equally accessible to people with a disability." Under the legislation "some access" is not to be considered "equal access." For example, provision of some TDDs is not to be considered equal access if they are more limited than regular telephone services.



### The Right to Communication in Canada and the Health Care System

In Canada, there is no statutory right to effective communication. However, recent jurisprudence establishes this right through an interpretation of the section 15 equality rights provisions of the Canadian Charter of Rights and Freedoms. Section 15 provides for equality before and under the law on the basis of disability. The Supreme Court of Canada case Eldridge et al. V. Attorney General of British Columbia concerns access to communication within the health care system. In this case, two British Columbia residents who are deaf contend that the absence of interpreters in the health care system impairs their ability to communicate with their doctors and other health care providers, increasing the risk of mis-diagnosis and ineffective treatment. Hospital services in British Columbia are provided under the Hospital Insurance Act, and medically required services provided by doctors and other health care practitioners are funded by British Columbia's Medical Services Plan, under the Medical and Health Care Services Act. In the ruling, Mr. Justice La Forest found that:

failure of the Medical Services commission and hospitals to provide sign language interpretation where it is necessary for effective communication constitutes a prima facie violation of the s. 15(1) rights of deaf persons. This failure denies them equal benefit of the law and discriminates against them in comparison with hearing persons. Although the standard is set broad, this is not to say that sign language interpretation will have to be provided in every medical situation. The "effective communication" standard is a flexible one, and will take into consideration such factors as the complexity and importance of the information to be communicated, the context in which the communications will take place and the number of people involved. For deaf persons with limited literacy skills, sign language interpretation can be surmised to be needed in most cases. (P. 5)

The Government of British Columbia was directed to administer the Hospital Insurance Act, and Medical and the Health Care Services Act in a manner consistent with the requirements of section 15(1) as interpreted by La Forest. He also held that effective communication was integral to the provision of medical services, and that sign language interpretation for

deaf persons should be viewed as a means for ensuring equality in health care services. Consistent with the analysis in this report, the judgement found in effect that persons who are deaf could not exercise the literacy skills they had because the communication environment was not accommodating. In particular, their *communication partners*, physicians, did not have the skills to communicate, nor were they making available the communication supports needed.

#### Communication in the Education System

Legal cases to secure integrated education for children with disabilities have also been fought, in part, on grounds that children require adaptations in the communication environment of the classroom in order to exercise their right to education. In one case in the mid 1980s, the parents of a child requested that their local school board include their daughter in regular classes. It was argued by the parents' lawyers that the girl could be integrated with an adequate "communication system" involving both adaptive technologies and personal supports, as she did not communicate in conventional ways. Further, it was argued that such a communication system was a "reasonable accommodation" under the provisions of the Ontario Human Rights Code, and that the Board was thus required to provide the system. However, the adjudicator in the case found that the costs of the system, and other changes to the environment of the classroom, imposed an undue burden on the Board.<sup>26</sup>

In a similar case, *Eaton v. Brant County Board of Education*, the Supreme Court of Canada concurred with the finding of the Ontario Special Education Tribunal, which concluded in effect that the school board was not required to accommodate Emily Eaton in a regular classroom because of the extent of her communication and other needs. The judgment read, in part:

Emily's need to communicate is going to be met only with very individualized, highly specialized, extremely intense, one-on-one instruction. Because this need is of such over-riding importance for Emily it makes sense to address it, at least initially, and until she demonstrates minimal competence, in a setting where there will be maximum opportunity for such instruction.



In this case, the issues of communication are viewed as primarily skill-related, thus justifying the placement in a special education setting. Unlike the *Eldridge* case no right to effective communication, and all the accommodations in the form of an alternative communication system that would imply, was inferred.

The argument to include communication systems under a duty to accommodate persons with disabilities is based on prohibitions against discrimination found in all federal, provincial and territorial provincial human rights codes. As well, Codes in both Quebec and Saskatchewan provide a right to primary and secondary public education without discrimination on the basis of disability. The Nova Scotia Code does not apply to youth and senior citizens and therefore public education is excluded from the prohibition against discrimination. The Manitoba Code includes education as one of the services to be covered by provisions of the Code, and in all other jurisdictions application of human rights protections to public education is inferred from provisions such as "services customarily available to the public." Where coverage of education is inferred, then duties to accommodate apply, as well as the defences of "undue hardship" that school boards have drawn upon in some cases.

As well, all jurisdictions except Alberta, Newfoundland, and Nova Scotia provide in their respective Education Acts for a universal right to free public education without exception on the basis of disability. However, it is clear that these rights are not being universally exercised because of current legal interpretations of the nature of the communication barriers that people face, of the duty to accommodate, and of what constitutes undue hardship. Consequently, children with disabilities are being denied the opportunity to communicate with their peers in regular classrooms, and to develop and use the literacy skills they possess.

#### Citizenship and Participation

The exercise of citizenship also requires communication environments that are inclusive. Polling stations used to cast votes in elections are an example. Recognizing the particular needs of persons with disabilities, the federal Elections Act was amended in 1992 to ensure that all people with disabilities



could vote. Attention is given in the legislation to removing physical and other barriers, and to providing needed accommodations so that individuals with disabilities can exercise democratic rights to vote. Under the Act a number of supports can be provided including sign language interpreters, alternative formats for electoral information (braille, audio-cassettes, large print), close captioned public notices, and templates to assist visually impaired persons in marking their ballots. Some provincial jurisdictions have similar statutory provisions. Regulations to the Ontario Municipal Elections Act, for example, requires provision of information in plain language and other formats. Prior to these kinds of accommodations, people with disabilities often had the needed reading, writing, and comprehension skills to participate in all aspects of elections, but lacked the communication environments in which to do so.

Guided by the ADA communication provisions, the "right to communication" is beginning to inform the public policy agenda in the United States for securing citizenship in its broadest sense of full participation and inclusion in society. The Minnesota Governor's Council on Developmental Disabilities, for example, has issued a statement indicating its support for:

the right of all persons, regardless of the severity of their disabilities, to fully participate in and affect, through communication, the community in which he/she lives, works, and recreates. Because communication and a person's successful use of communication affords meaningful and understandable exchanges that recognize and promote the inherent dignity of each person, communication rights should be assured for all persons with severe disabilities.

The Council clearly advocates for communication rights, and promises to "take a leadership role in the development of, access to, and utilization of augmentative and alternative communication systems and services...." They also promise lifelong training for people with disabilities, their families and service providers in alternative communication systems; to provide information, advocacy and/or training or direct services are provided; and to encourage development of new communication techniques and technology.<sup>27</sup>



Another aspect of citizenship is the exercise of individual rights to self-determination, the right to "liberty" in s.7 of the Canadian Charter of Rights and Freedoms. For people with intellectual disabilities, this right has often been removed in full, or with respect to particular types of decisions like health care, on the basis of legal incapacity. Substitute decision-making or guardianship provisions in provincial/territorial statutes are the mechanism by which legal incapacity is determined and decision-making rights removed and vested in a public or private trustee or guardian. A growing critique of these provisions suggests that at its root the determination of incapacity is the failure of others to provide the assistance people need to be understood and to communicate decisions. "Supported decision-making" has been advocated as a legal model to ensure provision of needed communication and other assistance in personal decision-making to prevent the removal of basic citizenship rights.<sup>28</sup> To date, British Columbia, Manitoba and The Northwest Territories have revised their provincial statutes to incorporate provision for supported decision-making, and legislative proposals are being developed in other jurisdictions such as Prince Edward Island.

## **Employment**

In the area of employment, federal, provincial, and territorial human rights codes prohibit discrimination in employment practices, and impose on employers a duty to accommodate, while providing them a defence of "undue hardship" in meeting the costs of accommodation. Research has shown that most accommodations can be made for \$500 or less.<sup>29</sup> However, data on the extent to which alternative communication systems and adaptations also fall within this cost range have not been gathered. Other statutory provisions include the federal Employment Equity Act requiring federally regulated employers to identify barriers to employment of persons with disabilities and to make plans to remove them. Again, the language of the act can be interpreted to include the barriers to effective communication for job applicants and employees. Some provincial jurisdictions also have employment equity legislation, and/or voluntary employment equity programs for the provincial/territorial public service.<sup>30</sup> Despite these

provisions, the Canadian Human Rights Commission has noted in its *Annual Report* in recent years that employment discrimination cases in disability and employment are among the highest caseloads for the agency, and represent the greatest number of outstanding cases. As well, labour force statistics indicate that more people with disabilities are leaving the paid labour force than are being hired.<sup>31</sup>

While employment-related provisions do not make explicit reference to rights to communication and related accommodations, the provisions can be interpreted in this way. The Canadian Transportation Agency's (CTA) interpretation of similar kinds of access and accommodation provisions in the Canadian Transportation Act provided the legal foundation on which it made a series of recommendations to improve the communication environments of air travel. Section 5 of the Act states:

(g) each carrier or mode of transportation, as far as is practicable, carries traffic to or from any point in Canada under fares, rates, and conditions that do not constitute

(ii) an undue obstacle to the mobility of persons, including persons with disabilities.

Existing employment-related provisions could also be explicitly interpreted to bring to light communication barriers in workplaces and other labour market environments (e.g., vocational counselling, information services).

#### The Judicial System

Research has also pointed to the barriers faced by people with disabilities in the judicial system.<sup>32</sup> Problems with physical accessibility and a number



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a safe, economic, efficient and adequate network of viable and effective transportation services accessible to persons with disabilities and that makes the best use of all available modes of transportation at the lowest total cost is essential to serve the transportation needs of shippers and travellers, including persons with disabilities

of communication-related barriers have been identified such as lack of needed interpretive assistance to parties and witnesses in proceedings; exclusive use of oral and documentary forms of communication in proceedings; complex language restricting participation of people with intellectual disabilities; and statutory provisions in most provincial/territorial Jury Acts excluding persons with disabilities from acting as jurors. For example, the British Columbia Jury Act disqualifies a person from acting as a juror where he or she is "is blind, deaf or has a mental or physical infirmity incompatible with the discharge of the duties of a juror." Exclusions are based on an assumption that disabilities related to hearing or visual impairment or intellectual disability by definition incapacitate a person to act as an effective juror. The exclusions from this aspect of citizenship are not considered in such provisions, and their underlying assumption is that the communication environment of a courtroom is designed only for print and oral forms of communication. In such provisions there is no recognition and support of the communication capacities individuals do have.

Section 14 of the Canadian Charter of Rights and Freedoms does provide for a right to interpretive services to assist in communication: "A party or witness in any proceedings who does not understand or speak the language in which the proceedings are conducted or who is deaf has the right to the assistance of an interpreter." Application of this section in a way that addresses fully the communication needs of persons with disabilities has been lacking, as submissions to the 1996 "Federal Task Force on Disability Issues" made clear. In response to a number of barriers to the judicial system, the Task Force called for legislative amendments to

Based on the Task Force recommendations and previous efforts to reform the judicial process, the federal government has proposed amendments to the Canada Evidence Act and the Criminal Code to remove



remove barriers to receiving testimony from persons with a disability, allow witnesses to use the medium with which they are most comfortable when they testify in court, allow individuals with a disability to use alternative methods, such as the voice, to identify the accused, and eliminate any discrimination against persons with a disability in the jury selection process.<sup>33</sup>

barriers to participation in the judicial system. The amendments would provide for communication assistance to individuals including sign language or oral interpreters, alternative communication devices such as a Bliss board or listening devices, and use of auditory and tactile methods for identifying the accused. Amendments to the Criminal Code would allow for the use of videotaped evidence by persons with intellectual or physical disabilities, easier access to jury duty including needed supports for jurors with disabilities.

The courts have made some headway in recognizing that communication and understanding in the judicial process does not rely entirely on the particular capacities of the individual concerned as a witness or an accused. In a 1991 Supreme Court of Canada decision in R. v. Evans<sup>34</sup> the court found that because police had failed to explain the right to counsel to a youth with an intellectual disability, who was later convicted of murder, the youth had not received a fair trial. In the words of Madam Justice Beverly McLachlin:

The purpose of s. 10(b) [of the Charter] is to require the police to communicate the right to counsel to the detainee.... But where, as here, there is a positive indication the accused does not understand his right to counsel, the police cannot rely on their mechanical recitation of the right to the accused; they must take steps to facilitate that understanding.

Recognition of the need for communication assistance in the administration of justice led to the introduction in 1991 by the Nova Scotia departments of the Attorney General and the Solicitor General of a "Protocol for Investigation and Prosecution of Cases Involving Persons with Special Communication Needs." The protocol lays out a number of provisions to ensure that "every reasonable effort" is made by criminal justice officials to accommodate the particular communication needs of individuals. In the protocol people with "special communication needs" can be defined by age, learning or physical disability, level of literacy, and as those who are "unable, without assistance, to fully access the criminal justice system or understand, or be understood by officials thereof." The protocol shifts the focus from the competency, capacity, or reliability



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of victims and witnesses to the communication process. It allows for alternative means of communication to be used including interpreters, signers, video-taped and taped evidence. Assessment of the ability to communicate is done before court, and the witness is to be prepared and supported thoroughly for court proceedings. Research suggests that while the protocol is an important advance in securing individual rights in the justice system, it is used inconsistently, and it has not been adopted in other jurisdictions except for Manitoba (Philpot, 1997b).

In summary, a framework of human rights to secure a right to communication is developing both internationally and within Canadian jurisdictions. This right is being articulated "unevenly"; in Canada it has been clearly expressed by the courts with respect to the health care system, much less so in the area of employment, and increasingly in the justice system. Categorical statutory exclusions based on disability in provincial/territorial guardianship and jury acts reveal that the exercise of citizenship rights does depend on a restricted understanding of literacy and communication skills. In the education system there is a recognition of the need to adapt communication environments to better enable children to exercise their right to education regardless of their particular disability. However, the defence of undue hardship, as set out in the area of employment, may limit the needed adaptations.

Research, jurisprudence, and advocacy efforts by the disability community confirm the "how," and "the extent to which," people understand and communicate is affected by the ways in which communicating is structured. Communication, sharing of information, reaching understanding is the goal; reading, writing, and using numbers are only some means of getting there. Without a more consistent framework of human rights for "effective communication," the predominant means of literacy and communication will continue to restrict social, economic and political participation.

### Literacy and Communication Supports to Individuals, Communication Partners and Environments

A framework for human rights is one of the mechanisms to create open and inclusive communication environments. It is on the basis of such a



framework that governments can provide needed investments to both individuals and to those organizations, agencies and institutions that structure communication environments. As well, a human rights framework can impose obligations on private sector services available to the public to create more inclusive communication environments. Supports for literacy and communication, beyond skills training for those with low literacy levels, can be directed to individuals, to their communication partners, and to the communication environment.

#### Supports to Individuals

Individuals with disabilities that affect their capacity to communicate with others can be supported through a wide and increasing range of technical aids and devices, and through personal supports. Individuals' communication systems are enormously diverse whether or not they have a disability, and vary by culture, language, access to technology, and historical period. Research points to key components in creating individual alternative and augmentative communication systems such as:

- recognition that gestures, behaviours, and facial expressions constitute forms of communication;
- a graphic representational system (e.g., Blissymbolics) when other forms of expression are not available;
- voice and speech recognition devices;
- voice output devices;
- computer hardware and software to adapt voice and other input into written information;
- and interveners and other personal supports.35

For people with disabilities numerous aids and devices to create communication systems are available. Provisions under the Elections Act, the Nova Scotia "Protocol" and other mechanisms for sign language interpretation, audio-cassette, video-taping, and other alternative formats



(e.g., braille, use of Bliss boards, closed captioning, and the like.) indicate a growing recognition of the need for and types of communication supports that can be made available. The National Institute on Disability and Rehabilitation Research in the United States has developed a database of over 23,000 assistive technology items, many of which assist in communication.

As well, new product research and development in communication systems and devices is underway by many private sector firms and publicly funded research consortiums in Canada.<sup>36</sup> The federal Department of Communications has identified a number of research directions in the field of communications and disability.<sup>37</sup> The following list helps to illuminate the range of communication systems possible:

#### For hearing impairments:

- workplace integration and workstation adaptation
- teaching material on videodisc for lipreading, cued speech and la langue de signes québécois
- electronic prosthesis and cochlear implants
- alarm signals

#### For visual impairments:

- optical-tactile converter or braille hard copy
- electrode matrices for vision prostheses
- adapted software and hardware
- braille embossers
- multimedia systems
- integration of braille signs and voice recognition and synthesis in computerized systems



electronic reading and reference systems

#### For motor impairments:

interactive aids for voice recognition users

#### For speech impairments:

- aids to communication by telecommunications
- communications and speech recognition equipment

#### For general impairments:

- voice communication software for persons with communication disabilities
- voice synthesis and recognition
- interactive aids using voice recognition for persons with motor disabilities

Communication supports to individuals are funded in a number of ways in Canada. Provincial and territorial departments of health make certain aids and devices available through Assistive Devices Programs. However, funding limitations, restrictive eligibility criteria, and supply restrict access to needed devices (The Roeher Institute, 1993, 1997). In the health care sector, provincial/territorial medical insurance plans will be required, in the wake of the Supreme Court of Canada's Eldridge decision to make sign language interpretation available. In post-secondary education, the Canada Students Loans Program does provide grants of up to \$3,000 to students to cover the costs of disability-related supports including communication assistance in the form of tutors, technical aids, interpreters, and note-takers. For children and youth with disabilities in the primary and secondary provincial/territorial education systems, some funding is provided through departments of education for components of needed communication systems—teaching assistants, curriculum adaptation,



technical aids and devices. However, as indicated above, no entitlements to needed communication supports exist.

With the current restructuring of labour market programs and services for persons with disabilities, the funding programs for communication supports for participation in training and employment are also undergoing change. With the federal government reducing its role in labour force development, provinces and territories are playing a much more major role in training and employment-related supports. Under bilateral labour force development agreements, the purchase of training and needed accommodations become the responsibility of provincial/territorial labour market development services. The Employability Assistance agreements between the federal and provincial governments, which are replacing the "Vocational Rehabilitation of Disabled Persons" cost-sharing arrangements include some funding for assistive aids and devices for participation in training and employment. As with healthfunded aids and devices programs, there is no entitlement to employmentrelated aids and devices, and access depends on meeting eligibility requirements for training and job readiness. Such criteria have contributed significantly to labour force exclusion of people with disabilities.<sup>38</sup>

In some jurisdictions and institutions a comprehensive approach to assisting individuals in developing needed communication systems is evolving. In Nova Scotia, for example, the Department of Education and Culture provides for a range of services in addition to literacy and basic skills training such as assessment of technology needs, ergonomist services, sign language interpretation, brailled materials, adaptive computer hardware and software, note-taking resources, technical support for specialized equipment, and mediation/dispute resolution services to deal with difficulties in creating effective communication systems that link with existing systems in workplace and educational environments.<sup>39</sup>

At the University of Toronto, for example, the Adaptive Technology Resource Centre provides workshops and training to individuals in developing and using alternative communication systems. Training covers such items as introduction or advanced voice recognition; document processing; access technology and ergonomic work space issues; accessibility to the Internet; screen enlargement; alternative access to reading and writing;



screen reading (speech synthesis and speech output options); learning through electronic media. Another example is the "Manitoba Consortium on Augmentative and Alternative Communication." Formed to support individuals who are unable to communicate with others around them, it provides a framework for clinical service; trains and provide long-term support to users, families and facilitators; and manages allocation of equipment and technologies.

The federal government is playing some role in developing technical communication supports for individuals through Human Resource Development Canada's "Office of Learning Technologies" which has a mandate to expand learning opportunities through the use of technologies. The Office has considered the role of technologies in relation to people with disabilities and funds research and development in this sector.<sup>40</sup>

### Supports to Communication Partners

Supports to individuals is only one part of creating inclusive communication processes. In developing a conceptual framework for understanding literacy as communication, the "communication environment" plays a central role. Without an environmental perspective on communication processes, the issue tends to be individualized into one of low levels of literacy and communication skills, with a need identified for remediation and assistive devices. In bringing the communication environment into view, "communication partners" emerge as critically important in shaping how communication will take place.

There is increasing recognition of the importance of communication partners in creating communication and understanding for individuals who are determined to have low literacy levels. Such a recognition shifts the burden of low literacy levels from the individual who does not measure well on functional literacy assessments, to those with whom he or she communicates. One illustrative example can be seen in the setting up of a 1998 training institute for health professionals sponsored by the New England Office of Continuing Education titled "Low Literacy Communication Skills for Health Professionals." The Institute aims to assist administrators, physicians, nurses and other health professionals in



developing the skills to communicate with people less skilled in managing the printed text that is so pervasive in delivery of health care services.

In responding to the 1992 Elections Act amendments, Elections Canada also began to focus on "communication partners" by developing an accessibility training and awareness program for returning officers. The Canadian Transportation Agency also provides training to ensure that transportation agents can better communicate with people with communication disabilities. Within the justice system, landmark cases like R. v. Evans have helped to shift the focus from accused and witnesses who have been determined to have low literacy levels, to the systems for communication instituted by the justice system. Given the over-representation of people with low literacy levels in the criminal justice system, the John Howard Society of Canada has examined how the communication processes and strategies used by lawyers, police, judges and court staff tend to disadvantage this group. The Society points to the importance of training justice system officials in managing communication with parties in proceedings, in using strategies to better discern the behaviours of those with low literacy levels, and in assisting people to understand the criminal justice and other judicial processes. 41 The Canadian Bar Association reached similar conclusions in its 1992 Task Force Report on legal literacy.<sup>42</sup>

Situating the issue of legal capacity to maintain decision-making rights within a perspective of communication environments assists in redefining the issue. It brings a greater focus on the role of other "partners" in capacity assessment and decision making. Wong (1997), for example, reviews capacity assessments and legal definitions of capacity in the United Kingdom with regard to consenting to medical treatment. She argues that although capacity is composed of several different functioning abilities, it is not a purely internal attribute of the person. Rather, a dynamic interaction takes place between individual "capacity" and the communication skills of others and the processes they establish. She points to ways in which communication partners can shape how a person's capacity for decision-making is understood:

• The simplification of complex tasks, for example, by breaking the decision down into smaller components or steps.



- The treatment provider can ensure that information is given in a way that a person can understand. The use of simple words, short sentences, illustrations, or video material is likely to be helpful.
- The assessor should be used to working with people who have learning disabilities, including knowledge of non-verbal communications systems and to having someone present who is familiar with the individual's communication style.
- Empathy, patience and understanding of the assessor are important in creating an inclusive communication and decision-making process.
- Steps should be taken, where possible, to educate the person about the decision in question, by rehearsing relevant information, showing videos, and so on. They should be encouraged to ask questions and express fears or anxiety.
- The assessment (of capacity) should be done when the person is in an optimal state (e.g., not right after a seizure).
- Individuals are likely to perform better in a capacity assessment when they feel they are in a safe, familiar and comfortable setting.

Research demonstrates the importance of communication partners in transforming existing individuals' current reading, writing, gestural and other skills and behaviours into tools for communication and understanding. Training strategies for communication partners have been developed, and could be usefully applied across the systems considered herein. However, literacy policy has not been expanded to incorporate training of communication partners, and thus no systematic approach is in place. Initiatives by Elections Canada and the Canadian Transportation Agency are instructive examples. However, as the study of communication barriers by the Canadian Transportation Agency suggests, without monitoring and quality assurance programs, such training initiatives do not necessarily translate into changed behaviour on the part of communication partners.



### Supports to Communication Environments

Environmental accommodations have long been understood to be important features of a strategy to enable access by persons with disabilities to workplaces, education institutions, and public services. However, these environments are usually thought of as physical environments requiring adaptations for entrances, accessible washrooms, lifting devices, and the like. With increasing attention to communication rights, workplaces, schools, airports, and other public services are being viewed as communication environments that require adaptation. In part, available communication systems and capacities of individuals' communication partners shape the communication environment. As well, the environment is shaped by statutory provisions, policy incentives, available technologies and organizational strategies.

Telecommunications is one area where technological, statutory and policy developments are having a profound effect on the shape of communication environments. In the "information society" an essential feature of most communication environments in the public realm is telecommunications services and devices. Consistent with the ADA requirements, a new Telecommunications Act was introduced in the United States in 1996. The Act deals primarily with local and long distance telephone service providers, cable providers and broadcasters. The Act requires that all such services and products be accessible to and usable by people with disabilities, if readily achievable. The law also provides that manufacturers of the telecommunications equipment shall ensure that equipment is designed, developed and made in a manner that is accessible and usable by individuals with disabilities, if readily achievable. Whenever these requirements are not readily achievable, they must ensure that the equipment is compatible with existing peripheral devices so that they can be adapted. Research suggests that "readily achievable" can be accomplished with little difficulty or expense (Carroll, 1996).

In order to make the substantial changes required to communication environments, employers and educators require technical assistance. Private sector initiatives, with some public funding, are emerging to play this role. For example, the Alliance for Technology Access, based in San Rafael,



California, is a network of community-based resource centres across the United States, which provides information and support services to people with disabilities and others in increasing access to and use of standard, assistive and information technologies (Alliance for Technology Access, 1997). "Ablecomm" has been formed in the Bell Atlantic Region as a regional information and technical assistance resource project on telecommunications for people with disabilities. It is a joint effort with the Alliance for Technology Access, promotes access for all, and develops awareness of employers and educators about the applicability and low costs of increasing access to communications for persons with a disability through adaptive technology. The service aims to cut through "red tape" for funding and other assistance, and confusion about technologies to bring communications solutions to the workplace, school and community. It has a library and referral service, accessible materials and conducts how-to workshops for employers, teachers and parents (Ablecomm, 1997).

Reconceptualizing environments as communication environments is proceeding in a number of areas. Given the research and technical capacities of post-secondary education institutions, and a growing emphasis on accessibility by students with disabilities, this rethinking is particularly germane in the university and college sector. Traviranus (1997) suggests that a number of trends can support the reconstruction of communication environments at universities to make education more accessible:

The primary activity conducted at any university is information exchange. Traditional methods of exchanging information are highly dependent on both the senders and the receivers ability to hear, see, manipulate objects and get about campuses. An ever increasing amount of information exchange on campus is computer mediated. Because many accommodations for students with print impairments or other disabilities are computer based, this trend can make the educational process more accessible.

However, the development of alternative access systems frequently lags behind mainstream technological innovations. Thus, the latest trends in computer-mediated education may be just as inaccessible as traditional



teaching methods. But computer flexibility in input, output and information processing means that anything entered into a computer in one form (text) can be reprocessed to be accessible in other forms such as voice, braille and so on. Computer-mediated information exchange systems now being developed in the post-secondary education sector include:

- choice of performing administrative tasks such as course information and enrollment over a computer network;
- libraries offering a range of text in electronic form;
- text book stores producing computer generated custom course packs that are processed in print form, but could feasibly be processed in alternative outputs;
- instructors experimenting with fully networked, virtual or online classes. (Studies have found a much larger percentage of students participate in these classes because many more turns are taken communicating with others; topics are explored more thoroughly; class members who are shy are more likely to participate; outside resources can be accessed during class; and students with communication-related disabilities are more likely able to participate.); and
- tutorials and extra-curricular activities can occur electronically.

Three categories of computer-mediated information exchange can assist in the restructuring of communication environments at post-secondary education institutions: 1) electronic text; 2) multimedia and graphical user interfaces; 3) loose grouping of realtime, video conferencing, shared computer work spaces and 3D virtual reality interfaces. Tasks to make the "electronic campus" more accessible have been identified and could be integrated with general services such as:

 Current information directory—students staff and faculty require assistance in finding, keeping current and navigating



through information related to access including listings of texts or course materials in accessible formats; media used in courses; available alternative access systems; available accessible computer labs or public terminals; extra-curricular bulletin boards or listserves; available resources or accessible information sources.

- Policy guidelines for purchasing—the university must be assisted in making decisions that do not adversely affect staff, students and faculty who have disabilities.
- Education—courses should be available to faculty on how to provide course material in e-text form and how to provide accessible instruction. Computer users with disabilities should have access to instruction in how to access computer-mediated information exchange. (Traviranus, 1994)

A profound shift in thinking is needed in the types of accommodations required by students with disabilities if they are to take advantage of the new opportunities in communications in the education sector. Opinions, preferences, policies and guidelines on computer-mediated communication in higher education are largely unformed. One important area is the extent to which accommodations or access features will be incorporated into the information technology itself, following universal design principles, rather than in the student's personal access system. That is, will the issue be framed as one of supports to individuals, or as one of adaptations to the communication environment to make it more accessible. Incorporating technology, for example, like multiple window video-conferencing systems that can display text as well as video has advantages for more than just hearing impaired students. Use of multimedia can accommodate the needs of some students who have difficulty communicating through reading and writing. Without a universal design approach, there is a danger that students with disabilities will restrict themselves to courses that offer such services. As the analysis in this study suggests a strategy that incorporates supports to individuals, and to communication partners, and supports to restructure the environment are all needed.



A similar approach to universal design is being advocated in the employment sector as well. Blanck (1994) examined pre- and post-ADA employment practices at Sears, Roebuck and Co., focusing the relationship of ADA implementation, communications policy, and information technology issues within the organization. As in the post-secondary education sector, he recommends universal design and access to the workplace, not retrofitted technology for individuals:

The rapid developments in electronic information technologies enable people with various disabilities to learn, communicate and experience meaningful participation in the workforce in ways that were not previously available. Sear's success in providing employees who are blind with access to the graphical computing world is an example of universal access solutions that allow all employees to share equally in the benefits of computer and communications technology.

He also recommends "fact-based education" for management and employees who use fact and empirical data to debunk myths and misconceptions about disabilities. However, this has been difficult for Sears because of the difficulty in establishing objective systems to gather and analyze data regarding disabilities, accommodations, costs and pay backs.

Dispute resolution and litigation avoidance are another way Sears responded to ADA requirements to create a more open and accessible communication environment. Through a formal commitment to alternative dispute resolution, which attempts to resolve most employee litigation through mediation an enabling rather than confrontational atmosphere, was fostered for adapting the communications and work environment. "

Preliminary indications are that many employers are using alternative dispute resolution under the ADA to enhance quality of job opportunity. Alternative dispute resolution processes are being used that lead to cost-effective, reasonable accommodations enabling qualified employees with disabilities to work.



Whether in a large university or at a workplace, redesigning communication environments goes far beyond what has traditionally been thought of as accommodations for people with disabilities. Resources are in place through bodies such as the Job Accommodation Network, and Human Resources Development Canada to assist in putting accommodations into place. However, these resources do not address the kinds of comprehensive technological and organizational changes required to reconstruct communication environments to make them more inclusive and supportive of the skills and capacities that people with disabilities possess. Research that shows that most accommodations cost \$500 or less should act as an incentive in many respects to employers, education institutions, and other organizations. However, such information should not be used to minimize the implications of a commitment to creating more inclusive communication processes and environments.

The need to broaden the perspective from individual skill and need for remediation and supports is as true in education as it is in other sectors. As Laine (1992, p. 36) indicates

rather than focus on organizations and their need to work toward change, 90% of the education literature is focussed on the (individual) student with a disability ... or on recommendations to persons with disabilities based on research observations.

Laine argues for more organization-based research to complement the research on individual support and accommodation. He suggests that such research is limited in the post-secondary education sector, but that useful lessons can be drawn from labour-management relations for critical steps in implementing organizational and environmental change designing new shared values; changing the organization's structure to reinforce the new values, developing new vocabulary, retaining organization's members, enforcing new values, and not expecting change overnight. In the field of primary and secondary education, research affirms that a more comprehensive organizational and policy approach is needed to secure inclusive education for children with disabilities than one that relies on introducing particular adaptations for children and youth with disabilities.<sup>43</sup>



### Access to Information

A distinctive aspect of reconstructing communication environments lies in the provision of information. Various technologies have been developed, and are being developed, for people with disabilities to access information through alternative formats to printed text. In many respects, the link between literacy and communication was first recognized in the push to establish plain language formats and policies for information provided by governments. Calls for plain language came from literacy educators, disability advocates and others seeking more open and accessible governments. From the perspective of literacy educators, a commitment to communicating in plain language was a recognition that those writing government communications, policy and program documents, and the like were unilaterally setting the standards for documentary literacy. It was an ever-moving target that literacy learners and educators had to try and keep up with.

The movement for plain language has grown substantially and is an international movement. The "Plain English Campaign" based in the United Kingdom is one of the largest plain language consulting groups with offices in the United States and Canada. In other countries plain language services are set up by governments. In Sweden for example, it is a legal requirement that public authorities express themselves in a way this is easy to understand. The national government established the Swedish Plain Language Group in 1994 to promote clear and simple language in official documents and to encourage government agencies to start plain language projects. (Klarspråksgruppen, 1997)

In Canada, many provincial and territorial governments have established policy for alternative communications formats that go far beyond plain language. The "Alternative Communications Policy" of the Alberta Government is one of the most comprehensive. It requires all provincial government departments to provide government information in alternative communications formats as needed by departments' clients who have alternative communication needs.<sup>44</sup> Alternative communications formats include print materials in plain language, audio tapes, braille, large print, synthesized speech, and the inclusion of open/closed captioning for videotapes. The policy also requires that provincial government

departments provide communications assistance in the form of assistive listening devices, sign language interpreters, oral communications facilitators, readers, or note takers. The Public Affairs Bureau is designated to provide information to departments regarding alternative formats and services, and to assist in implementing the policy. Government departments are required to make alternative formats and assistance available at public consultations and hearings.

As with other communications-related provisions like the Nova Scotia Protocol, or training of transportation or Elections Canada officials, no systematic monitoring of the implementation of alternative communications policies is in place. Such policies usually operate on a voluntary basis by government officials. Moreover, many individuals with disabilities are unaware of the assistance and alternative formats they are entitled to access.

### Access to Information and Communication Networks

In conceptualizing the link between literacy and communication, it is essential to take a broad view of the changes in information and communication networks now underway. Communication environmentswhether in a workplace, university or airport—are not closed systems. They are linked by information and communications networks like the Internet to innumerable sites of information globally. A number of trends make up the shift to the "information economy," the "cabled city," the "global village," the "electronic" and "virtual" university campus. They are advances in communications technologies; globalization of markets, production, finance and communications; the immediacy of information transmission; interconnectedness among differing communication technologies; the increasing role of information and communication technologies in education and economic activity; the increasing dependence of individuals and groups on global communications channels in daily living and in efforts at social and political change; and the commercialization and commodification of information and communication (Webster, 1995; Tremblay, 1994).

The advent of the information society has led to new concerns and responses by governments, such as the Government of Canada's Information Highway Advisory Council and the U.S. Government's response to what



has been termed in that country the National Information Infrastructure (NII) by the President's Information Infrastructure Task Force. In 1994, the Canadian government announced it would develop a strategy to address the challenges of the "Information Highway." It released a report outlining issues ranging from the pace of development and ensuring access at a reasonable cost to promoting economy-wide competitiveness and supporting Canadian cultural content. Policy objectives were identified including job creation through innovation and investment; reinforcement of Canadian sovereignty and cultural identity; and ensuring universal access at a reasonable cost. Four principles for a national strategy on access have been articulated: universal, affordable and equitable access; consumer choice and diversity of information; competency and citizen's participation; and open and interactive networks (Industry Canada, 1996).

The Advisory Council has taken initial steps to explore the relationship of the information infrastructure and issues of disability and communication. As they point out in the Final Report of the Information Highway Advisory Council, for some groups of Canadians, including those with disabilities, the information superhighway can potentially help overcome barriers in society to equality (Industry Canada, 1997). They have begun looking in general at expected impacts on the workplace, employment, health care and education and learning. There are timely opportunities for exploring the ways in which new initiatives related to information and communication technology could remove barriers to full citizenship and participation by people with disabilities in these, and other areas.

The American equivalent of Canada's Information Highway is known as the National Information Infrastructure (NII) and is a similar interconnection of telecommunication networks services and applications. Development and regulation of the NII is being considered by the President's Information Infrastructure Task Force and the Council on Competitiveness. In the NII Virtual Library Publication, The NII Against the Handicap, some of the user implications and NII capabilities as they relate to disability are explored: "These capabilities will be needed to address the national goal of equal accessibility in communications, commerce, and community among people with and without disabilities." The accommodation of people with disabilities is proposed as a tangible

and widely recognized citizen benchmark for responsive and respectful service in achieving the goal of accessible and interoperable communication networks. Such networks are considered to hold considerable potential for greater inclusion of people with disabilities across social, economic and political institutions. Potential impacts envisioned anticipate:

- Commerce, health and manufacturing networks will accommodate business owners with disabilities in their choices in modes of communication in a manner that is transparent and convenient to customers.
- Education networks will accommodate the needs of parents, children and teachers by having available alternative modes of communication and information sharing.
- Citizen expectations for preferred mode of communication will be met at all levels of government service delivery.
- Research and development in advanced communications and information services will account for all user choices of modes of operation.
- Real time captioning through text, visual symbols, and sign language inserts and transmitted texts by braille will be available in standard video conferencing.
- Participants in court room proceedings including judges, jurors, and attorneys will be accommodated for hearing and visual impairment and language differences.
- Electronic town meetings and government provided services will accommodate full participation by all community members.

In order to glean the potential for people with disabilities from the development of communications and information networks, key issues need to be addressed. First, principles of universal design must be incorporated



into technology development. Universal design is defined as "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." (Trace Research and Development Centre, 1995) Principles of universal design that apply to information and communication technologies include:

- equitable use, namely, the design is useful and marketable to any group of users,
- flexibility is use so that the design accommodates a wide range of individual preferences and abilities,
- simple and intuitive use of the design so that it is easy to understand, regardless of users' experience, knowledge, language skills or current concentration level, and
- perceptible information namely, the design communicates necessary information to the user, regardless of ambient conditions or the user's sensory abilities.

As indicated earlier, without a universal design approach, access to information and communication networks will be restricted to those individuals who can obtain the adaptive devices that create links to the technologies.

Second, while universal design is a worthy goal, many people with disabilities will continue to require accommodation and assistive technologies to link to information and communications systems. What is considered a universally accessible system today will undoubtedly pose barriers to some individuals in the future.

A third issue in ensuring access to information and communication networks is making resources available to literacy learners, including people with disabilities. In order to learn how to access and use information and communication networks and technologies, people must have exposure to them. Consultations with literacy education providers indicate minimal computer equipment available to programs in some regions of the country. Where computer access is available, lack of financial resources, inadequate



information about their use, and lack of staff training hamper their productive use and expansion. 45 One proposal to expand electronic infrastructure for literacy education focusses on providing funds for literacy groups to acquire computer equipment; publicly funding stable institutions such as libraries so they could loan equipment to less stable groups; and ensuring that equipment purchased and used is sufficiently sophisticated in order to maximize linkages to communications networks (Consulting and Audit Canada, 1996).

A fourth issue is the limited access by people with disabilities to communication technologies, in large part because of the high proportion of such persons living in poverty, and because of limited access to agencies and institutions that make such technologies available. The proposal to fund public libraries and literacy education providers would go some distance in addressing this problem. However, high rates of poverty and social isolation, and limited access to transportation must be more fully accounted for if proposals for access to communications and information networks are to achieve their goals.

In summary, a framework for policy analysis can be constructed to identify and examine policy provisions that address the communication barriers to exercising literacy that people with disabilities face. Human rights provisions to secure a right to effective communication are evolving nationally and internationally, but as yet a comprehensive and integrated set of provisions do not exist. Moreover, legal obstacles to fully exercising these rights persist. Some provisions are in place to provide supports to individuals, their communication partners, for restructuring communication environments, and for ensuring access to communication in alternative formats. Awareness is developing of what a comprehensive approach to addressing communication barriers would entail in transportation, health care, education, employment, and the justice system. However, policy provisions have not been integrated into a coherent framework, largely because policy issues to date have not been framed to make the link between literacy, disability, and communication.

There is an urgent need to make these literacy/communication links with the development of global communications and information networks



that, more and more, are driving social and economic development. Unless the connection is made that literacy is not an individual skill, the technologies and networks now being designed and installed will not be universal in their application and access. For people with disabilities, this will once again mean that access depends entirely on obtaining the needed technical and personal supports in a restrictive legal, policy and program framework. The result will be further entrenchment of social and economic exclusion and all the consequences that brings.



### V. POLICY DIRECTIONS

The preceding analysis suggests that policy development has not caught up with a shift in thinking about literacy and communication. There have been advances in re-conceptualizing the human rights basis for communication. But the existing set of applicable policy provisions tend to individualize the problem, limit eligibility, and are based on an assumption that it may be too much of a "hardship" to ensure availability of needed communication systems and environmental change. Based on the analysis, a number of policy directions emerge.

# Strengthen the Human Rights Framework for Literacy and Communication

While jurisprudence in Canada has articulated a right to effective communication, the application of this right and its implications have not been fully considered. It is clear from the analysis in this report that a more explicit articulation of this right is required. In other national jurisdictions the right has been articulated in disability-specific legislation. In Canada, the right has been inferred from the equality provisions of the Canadian Charter of Rights and Freedoms, and thereby has been given a constitutional basis. Options for fuller articulation of the right lie in statutory development, or in the establishment of policy based on international proposals for a convention on the right to communication, and on examples from other national jurisdictions. Clear articulation of this right in other jurisdictions has had an impact on considerably heightening the consideration of communication issues in policy development.

This study has pointed to a number of principles that would be consistent with a fuller articulation of the right to effective communication, including those related to universal design. A human rights approach to literacy and communication would not abandon either literacy education or investment in providing accommodations and supports to individuals. But it would compel a shift to universal design as one of the standards for creating an open and inclusive society.



## Mandate Policy Responsibility for Linking Literacy and Communication

To date, the mandate for literacy policy and investment has rested, at the federal level, with the National Literacy Secretariat of Human Resources Development Canada, with some, now declining, investment in adult basic education and training through labour force development provisions. At the provincial/territorial level, the literacy mandate usually rests with departments of education, or advanced education and training. As the link between literacy and communication comes into view, however, a number of departments and agencies have a role in ensuring that communication barriers are removed so that people can exercise their literacy and so that communication environments and technologies now being designed are much more fully inclusive than they have been in the past. At the federal level, additional players include the Office of Learning Technologies and the Department of Communications, both of which have funding and information roles in communication-related supports for people with disabilities. Moreover, accessibility policies of different federal departments can be read, as in the case of the Canadian Transportation Agency, to impose an obligation to consider communication barriers. Similarly, at the provincial/territorial level, policies for alternative communication suggest cross-governmental responsibility.

As an understanding of the link between literacy and communication takes hold, these mandates may need reconsideration. This study does not recommend that literacy policy be replaced by communications and technology policy. Rather, it suggests a need to fundamentally revise the standard notions of literacy and what literacy policy and investment should entail. Given this, there is strong justification for a revised and expanded mandate for the National Literacy Secretariat in conceptualizing and researching the literacy/communication link, and in monitoring the development of a more comprehensive and coordinated literacy and communications policy framework. Without a coordinated monitoring approach, literacy education; supports to persons with disabilities; health care, employment and education policy; and development of the Information Highway will continue to operate in the silos they now occupy.



### Promote a Human Resource Development Strategy to Address Literacy and Communication Issues for a Growing Population

Changing demographics indicate a growing proportion of the population with disabilities given the aging of the population and technological and medical advances. Increasing linguistic and cultural diversity also bears on literacy levels and communication barriers. Both of these trends suggest that literacy and communication issues are going to grow substantially in coming years, as are the barriers to communication processes that are open, respectful and accommodating

One of the major tools for strengthening literacy and communication capacities of those traditionally understood to have low literacy levels is the development of communication skills and capacities by their "communication partners" in health, social service, education, employment-related, judicial and other systems. Incentives are needed to build skill development in alternative and adaptive communication, and training and awareness about disability as a communication issue, into professional preservice and in-service training.

# Foster Policy Development, Implementation, and Service Delivery

There is a growing recognition of the importance of adapting communication environments to make them more accessible to people with disabilities. A set of uncoordinated policies and programs now exist at all levels of government and within services available to the public. Monitoring implementation of current policy provisions is required to determine the extent to which people with disabilities are taking advantage of existing provisions for access to alternative communication formats.

In addition, the current structure of incentives and provisions for accommodations by employers, education, justice, health care and other institutions requires change in order to encourage a more comprehensive approach to creating environments that foster literacy and communication. Those jurisdictions where employment equity provisions are in place could develop protocols to encourage barriers analysis and planning by employers that address literacy and communication barriers in particular.



A framework of investments and incentives, both direct and indirect through the tax system, could eventually develop to assist in making the required changes; and to minimize the need to appeal to "undue hardship" that is now one of the obstacles to change.

As well, existing service delivery to support augmentative and alternative communication is developing, but lack a policy framework and sustaining funding mechanisms to ensure equitable access to services. These services are based in a range of settings—public, private sector, and through public/private partnerships. No single service delivery system would be effective, but networks of community-based resource centres are developing in the United States, a model that could be promoted within the Canadian context. Communications technologies could be drawn upon to create a network of accessible resources on communications systems and adaptations for use by individuals, as well as by employers educators and other providers.

There is an important role for the network of literacy education programs that have developed in making the shift from literacy skills training to literacy fostered through adapting and changing communication processes and environments. These programs have been leaders in many cases in identifying the kinds of communication barriers that people with disabilities face in all aspects of their daily lives. They have also identified practical changes in communication environments in health care and the justice system that can be made through plain language and other formats to expand people's learning opportunities, access, and to make communication with others more possible. Literacy educators have a key training role to play in a human resource development strategy that focusses on communication partners. A more comprehensive and coordinated approach to adapting communication environments would benefit from linkages between the literacy education sector, and the growing number of networks and providers of assistance in augmentative and adaptive communication. Forging a link among these sectors would provide employers, and education and other systems with a strong resource base to undertake the needed analysis and make the necessary changes. However, if the literacy education sector is to play this role, upgrading and investment in its own communications infrastructure will be required, as consultations to date have made clear.

Include People with Disabilities and their Organizations in Policy Development and in Building the Information Highway

Substantial shifts are needed to create a structure of incentives that encourage adoption of an environmental perspective on literacy and communication across, at least, the sectors pointed to in this study. These shifts must be made in light of, and in concert with, the building of the Information Highway in Canada, which is already having a profound effect on the communication environments we inhabit. Making the link between literacy and communication, considering its policy and service delivery implications, and doing so within a period of massive technological change that directly affects the issue at hand, is no easy task. In making the needed shifts, and to build an Information Highway that is universally accessible, the knowledge and perspective of people with disabilities and their organizations are essential. Support and resources to make their participation possible and effective will be essential. Open and inclusive consultation processes for considering the issues and implications are imperative.



### CONCLUSION

This policy study grew out of a concern that the way in which the literacy problem has been constructed, and the solutions it implies for people with disabilities, reinforces a conception that individual skills are the only thing that makes the difference. The model of "disability as individual deficit" provides the bedrock for much of disability-related policy in Canada. This model has, no less, become a foundation for thinking about needed changes in literacy policy and service delivery. There is no doubt that literacy education does make some difference in people's lives and in their capacity to communicate. But the national and international literacy surveys of the past 10 years show that it doesn't make all the difference. Is this only because there are real thresholds to skill development that some people with disabilities and many others face that cannot be remediated by literacy education? Is it because literacy education and the substantial literacy investment in Canada to date have been ineffective? There is too much evidence of their positive impact for such a claim to stand. Or is it because the problem of literacy has been focussed too much on the skills of those with presumed deficits; and too little on what it is that has given certain skills in reading, writing, numeracy and communication such currency? This study answers in the affirmative to the latter question.

In stepping back from the presumption that literacy is an end in itself, this study has brought the link to communication into view. In doing so, it becomes clear that literacy, as it has come to be defined, constitutes a particular, and limited, communication system in an environment of rapid and far reaching technological, social and economic change. If a shift beyond the skills-based definition of literacy is not made, those who have mastered certain skills, and have been afforded particular communication systems, and have had communication technologies and environments designed in their favour, will be the main beneficiaries. In this scenario, which some would argue is now upon us, the polarization between those able to communicate and those denied that ability deepens; it is only the silences between them that grow louder.

Redefining literacy is therefore an essential task. The first step is to acknowledge that literacy is a means, not an end. Like any other "means," it changes as the environment in which it is used changes, and is changed.



As the theorists of literacy and communication referred to in this study make clear, people "read" and "write" the world in many different ways. The issue is whether their different ways will be accorded credence and communication environments designed so that their communication with others is possible. As this study suggests, to be literate is first and foremost to obtain the respect and accommodation from others for one's particular ways of communicating. Second, it is to have the support to develop communication systems (including prose, document, and quantitative literacy skills as they have been defined) and access to technologies that make learning and communication with others possible.

For people with disabilities, and for others, this redefinition of literacy establishes an assumption that they do belong to a society more and more defined by global information and communications networks. Furthermore, it suggests they should have the opportunity to learn and communicate with others—not on the condition of possessing certain skills, but as a matter of right. The redefinition also makes the issue of literacy and disability less one of disability, and more one of the diversity of communication systems to be supported in an environment designed for universal access.

As the research for this study makes clear, forging the links between literacy and communication is now theoretically justified, practically achievable, and a human rights imperative. How is the forging to be done? This study suggests that some critical steps need to be taken.

The process must be guided by a framework on rights to communication now in its formative stage in Canada and internationally, and one that should be strengthened considerably. Recognition is required of the literacy and communication skills needed by those in a position to shape the communication environment for people usually defined as lacking in literacy skills. A policy vacuum, eligibility restrictions, funding limitations and service gaps present significant limitations. Changes are needed to ensure provision of needed communication supports, adaptations of communication environments, and identification of communication barriers. A new role for the literacy sector is needed; one that can draw on its existing resources, infrastructure and networks that can bring leadership for the conceptual, policy, and service delivery shifts now required.



People with disabilities and their organizations can bring knowledge and a perspective that will be integral to a process of change. Their expertise is essential in reconstructing communication environments that now pose such formidable barriers to the literacy they want, rightfully, to express. Taking these steps can make it possible for people with disabilities to access the communication environments now defining the horizons of social, economic and political life. Not to take them would be to unnecessarily restrict the potential for equality and for a democratic, inclusive and productive society.



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### **ENDNOTES**

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<sup>14</sup>In "What is Universal Pragmatics?" in Communication and the Evolution of Society p. 3

<sup>15</sup>Cited in Frank Morgan, "Civil Conversation: Communication and Civil Society," Paper presented at African Council for Communication Education, Capetown, South Africa, November 1996.

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<sup>20</sup>This definition of communication systems is adapted from Jeane M. Johnson, Diane Baumgart, Edwin Helmstetter, and Chris A. Curry (1996). *Augmenting Basic Communication in Natural Contexts*, Baltimore: Paul H. Brookes.

<sup>21</sup>In communication theory, functions are generally divided into "discourse functions"—those that serve to begin, maintain, or end communication; and "pragmatic functions"—those that serve, whether intended or not, as a form of action—eg. greeting, protesting, or requesting something.



- <sup>22</sup>That is, three or more "yes" on HALS variables A22i-iv.
- <sup>23</sup>That is, two or more "yes" responses on HALS variables A23i-vii.
- <sup>24</sup>See The Roeher Institute (1996). Literacy on the Move, Toronto: Author
- <sup>25</sup>See Florida Atlantic University, Policy Memorandum #88—"Policy to ensure compliance with the ADA requiring the provision of effective methods for communicating with people with disabilities."
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- <sup>29</sup>See Canadian Council on Rehabilitation and Work (1997) Http://www.workink.com/workink/index.asp
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- <sup>31</sup>Canadian Human Rights Commission (1998). "Discrimination 'fact of life' for Canadians with disabilities," Http://www.chrc.ca/
- <sup>32</sup>See David Lepofsky, "Equal Access to Canada's Judicial System for Persons With Disabilities—A Time for Reform."
- <sup>33</sup>See Federal Task Force on Disability Issues (1996). *Equal Citizenship for Canadians with Disabilities: The will to act*, Ottawa: Minister of Public Works and Government Services Canada.
- <sup>34</sup>R.. v. Evans, [1991] 1 S.C.R. 869 4 C.R.(4th) 144, 63 C.C.C. (3d) 289, 129 N.R. 278, 3 C.R.R. (2d) 315.
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<sup>37</sup>See J. Robert Dupuy and Marie-Josée Thibault (1993). Communications and information technologies and persons with disabilities, Ottawa: Department of Communications.

<sup>38</sup>For a review of such criteria and their impacts on labour force participation see, The Roeher Institute (1993). On Target? Canada's Employment-Related Programs for Persons with Disabilities, Toronto: Author.

<sup>39</sup>See Nova Scotia Education and Culture (1997). *Adult Learning & Innovation*, Halifax: Nova Scotia Education and Culture.

<sup>40</sup>For a list of published resources on learning technologies and people with disabilities see, The Roeher Institute (1996). "Learning Technologies and People With Disabilities: Annotated Bibliography," Prepared for the Office of Learning Technologies, Human Resources Development Canada, Toronto: Author.

<sup>41</sup>See The John Howard Society of Canada (1996). Understanding Literacy: A Judicial Imperative, and (1996), Literacy and the Courts: Protecting the Right to Understand, Ottawa: Author.

<sup>42</sup>See Canadian Bar Association (1992). Reading the Legal World: Literacy and Justice in Canada, Ottawa: Author.

<sup>48</sup>For a review of some of this research see, Porter, G., and D. Richler (1991). *Changing Canadian Schools: Perspectives on Disability and Inclusion*. North York: The Roeher Institute

<sup>44</sup>The policy defines those with alternative communication needs as "individuals who, because of age, level of literacy, mental, physical, sensory (deaf/hard of hearing, blind/visually impaired) or learning disability, are unable, without assistance, to access government information which would otherwise be available to them, or to understand or be understood by government service providers." See, Government of Alberta (1995). Alternative Communications Policy: Access to Government Documents, Public Meetings and Services, Edmonton.



<sup>45</sup>Both the National Literacy Secretariat and the Ontario Training and Adjustment Board have held consultations on literacy education and electronic infrastructure. See Mike Kelly (1995). Computer technology survey of Ontario Adult Literacy Organizations, Toronto: Ontario Training and Adjustment Board (OATB) Learning and Employment Preparation Branch, Literacy Section.



Literacy is more than individuals acquiring numeracy and reading skills. A broader understanding of the issues makes the connection between literary and people's relationship to society. This study looks at how policy and programs affect people's capacity to be recognized, communicate, and be fully included in seriety. It examines a wide range of policies, including employment, health care, education and justice policy from the perspective of a right to communication.



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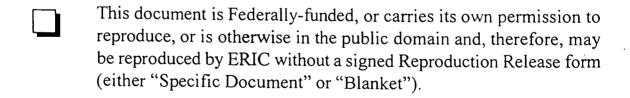
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