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Editorial

Yves Lachapelle

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Autodétermination et technologies de soutien des personnes ayant
des incapacités

Self-determination and Support Technologies for People with
Disabilities

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Editorial

For over two decades, promoting self-determination has become an important dimension of discourse and missions pursued especially in the field of disabilities. For example, the *Office des Personnes Handicapées du Québec* which, in its policy *À part entière : pour un véritable exercice du droit à l'égalité* (OPHQ 2009) emphasizes that one of the major challenges ahead, is to ensure a society oriented towards an optimal response to the essential needs of people with impairments and disabilities. In this context, improving self-determination is a widely and highly valued goal which influences the establishment of policies and intervention practices considering their importance for improving the quality of life of these people.

However, realizing this vision requires not only a reorganization of the services offered by our society, but also improving people's abilities to participate actively as they should possess and demonstrate self-determined behavior which is unfortunately often not the case. Self-determination can be viewed as the skills and abilities required in a person, allowing him/her to act directly on his life by choosing freely without being exaggeratedly influenced by external agents. In this perspective, several studies have made it possible to develop conceptual models, measuring instruments and intervention programs to promote the emergence of self-determined behavior in people with disabilities.

This quest for innovative solutions has, in the last decade, attracted particular interest in the development and testing of technological solutions specifically designed and tailored to the needs of people. This type of technology is now known under the name of self-determination support technologies (SDST). For many people with disabilities, the use of such technologies greatly facilitates the realization of several daily tasks (meal preparation, time management, budget planning), reduces the number of errors, promotes learning new skills

and facilitates their integration and participation in the community.

Well aware of the benefits of SDST, the Americans drafted and endorsed a statement of the "Rights of people with cognitive disabilities to technology and access to information" (colemaninstitute.org/declaration). The declaration states that 28 million Americans with cognitive disabilities such as intellectual disability, severe persistent mental health illness, brain injury, stroke and neurodegenerative disorders. It adds that access to understandable and usable technologies is necessary for anyone in our society, especially those with disabilities, to promote self-determination and enable them to engage meaningfully in key aspects of his life. The declaration also states the importance of developing technologies based on the principles of universal design, which guide best practice standards and ensure security and privacy.

The following texts target very well the extent and diversity of those challenges. Some propose definitions and conceptual models which will surely feed our reflections on the nature and meaning of self-determination; we shall stop doing for the people or in order to avoid them potential difficult situations, and start doing with them, supporting them in their quest for exerting greater control over their lives. In addition to developed and offered support, we believe that SDST represent a new set of innovative and promising approaches which will better prepare people with disabilities to cope with their daily challenges. Several technological solutions have been the subject of rigorous experiments that have demonstrated their usefulness. For example, researchers pursuing the objective of supporting people who want to participate directly in the various investigations concerning them have developed an easily navigable interface survey on an iPad which will enable them to participate more actively in the design of support measures, services and environments that have an impact on their lives. Other studies have demonstrated the usefulness of tasks completion apps for programming, in vivo, every steps of a task combining photos, video and audio comments. Furthermore, in order to support students with

learning disorders, experts suggest scanning and optical character recognition, screen reading, audio text format, voice dictation, spell checkers and grammar as well as concept mapping as potential useful solutions. However, although there is a wide variety of these technologies available, results show that students choose to use less specialized technologies such as smart phones and MP3 files.

This leads us to believe that simply developing and providing access to technological solutions for people with disabilities will not be enough to guarantee their efficient use. Despite the great interest and practical approaches to acquire technologies, many services providers admit having difficulty implementing these technologies in their clinical practice due to obstacles in their management process in addition to some ethical issues. To address these challenges, a tool for reflection on ethical issues as well as technological innovation management model that takes into account the clinical components, technology and management are proposed. Based on these observations, some questions have no reason to be anymore. Are support technologies useful for people with disabilities? Affirmative! Should these people have access to such technologies? Affirmative! Can those technologies support these individuals in the acquisition of self-determined behaviors and promote their social participation? Yes, yes and yes again! Well then, what are the bugs? First I think we need to revisit our preconceptions, beliefs and values. Their natures are directly responsible for our perceptions about the capacities of these people and consequently the opportunities we offer them or not to express them or to acquire new ones! Also, I believe we are severely limited by a social context where human and material resources are becoming increasingly rare due to the economic context. Moreover, such a change calls many ethical, personal, professional, organizational and societal challenges.

Thus, despite the growing popularity of the principle of self-determination and SDST, much remains to be done to develop a common terminology, improved means to assess their emergence and apply them in all spheres of

intervention. Obviously, this will not happen smoothly. Human and material obstacles will stand in front of us, but SDST are demonstrating, slowly but surely, their usefulness. It is now up to us to ensure that we “Walk the talk!”

Yves Lachapelle, Ph.D.
Guest Editor

Full professor
Department of Psychoeducation
Université du Québec à Trois-Rivières
Québec, Canada

