



PhiLab

Research Paper

Vulnerability, autonomy, and agency: toward a renewed approach to charitable philanthropy

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Description du réseau PhiLab

Le réseau canadien de recherche partenariale sur la philanthropie (PhiLab), anciennement Laboratoire montréalais de recherche sur la philanthropie canadienne, a été pensé en 2014 dans le cadre de la conception de la demande de financement du projet développement de partenariat CRSH intitulé "Innovation sociale, changement sociétal et Fondations subventionnaires canadiennes". Ce financement a été reconduit en 2018 sous le nom "Évaluation du rôle et des actions de fondations subventionnaires canadiennes en réponse à l'enjeu des inégalités sociales et des défis environnementaux". Depuis ses débuts, le Réseau constitue un lieu de recherche, de partage d'information et de mobilisation des connaissances des fondations canadiennes. Des recherches conduites en partenariat permettent la coproduction de nouvelles connaissances dédiées à une diversité d'acteurs : des représentants gouvernementaux, des chercheurs universitaires, des représentants du secteur philanthropique et leurs organisations affiliées ou partenaires.

Le centre de recherche (Hub) mère se situe dans le centre-ville de Montréal, sur le campus de l'Université du Québec à Montréal (UQÀM).

Le Réseau regroupe des chercheurs, des décideurs et des membres de la communauté philanthropique à travers le monde afin de partager des informations, des ressources et des idées.

PhiLab Network Description

The Canadian network of partnership-oriented research on philanthropy (PhiLab), previously called the Montreal Research Laboratory on Canadian philanthropy, was thought up in 2014 as part of the conception of a funding request by the SSHRC partnership development project called "Social innovation, social change, and Canadian Grantmaking Foundations". From its beginning, the Network was a place for research, information exchange and mobilization of Canadian foundations' knowledge. Research conducted in partnership allows for the co-production of new knowledge dedicated to a diversity of actors: government representatives, university researchers, representatives of the philanthropic sector and their affiliate organizations or partners.

The project's headquarters are located in downtown Montreal, on the Université du Québec à Montréal (UQAM) campus.

The Network brings together researchers, decision-makers and members of the philanthropic community from around the world in order to share information, resources and ideas.

Résumé

Ce rapport de recherche propose une revue de littérature interdisciplinaire sur les notions de vulnérabilité, d'incapacité et de handicap, en croisant les approches ontologiques, relationnelles et structurelles. Il analyse comment ces notions sont définies et représentées dans les discours politiques, juridiques et académiques, en mettant en lumière l'impact des politiques d'équité, diversité et inclusion (EDI). L'agentivité des personnes en situation de handicap est abordée à travers les théories critiques, dont la théorie Crip, et la dimension temporelle des trajectoires individuelles. Le rapport retrace également l'évolution historique des politiques publiques et des mouvements sociaux du handicap au Canada et au Québec. Il dresse un portrait des acteurs impliqués, incluant les organisations communautaires, les chercheurs, les militants et les fondations philanthropiques. Des données statistiques récentes viennent appuyer l'analyse. L'ensemble souligne l'importance de penser les incapacités dans une perspective systémique et inclusive, articulant reconnaissance, justice sociale et pouvoir d'agir. Ce document est le premier rapport de recherche du projet « L'inclusion des personnes en situation de handicap au Canada et à l'international : regard sur la philanthropie en action ».

Mots-clés

Vulnérabilité • handicap • agentivité • politiques publiques • philanthropie • fondations

Abstract

This research report offers an interdisciplinary literature review on the notions of vulnerability, disability and handicap, crossing ontological, relational and structural approaches. It analyzes how these notions are defined and represented in political, legal and academic discourse, highlighting the impact of Equity, Diversity and Inclusion (EDI) policies. The agentivity of people with disabilities is addressed through critical theories, including Crip theory, and the temporal dimension of individual trajectories. The report also traces the historical development of public policies and social movements for disability in Canada and Quebec. It paints a portrait of the players involved, including community organizations, researchers, activists and philanthropic foundations. Recent statistical data support the analysis. The report underlines the importance of thinking about disability from a systemic and inclusive perspective, linking recognition, social justice and empowerment. This document is the first research report of the "Inclusion of people with disabilities in Canada and internationally: a look at philanthropy in action" project.

Key words

Vulnerability • disability • agentivity • public policies • philanthropy • foundations

**Vulnerability, autonomy, and agency: toward a renewed approach to
charitable philanthropy**

Report #1

**Review of writings on vulnerability, disability, and impairment (Part I)
Portrait of the ecosystem surrounding vulnerability, disability, and
impairment (Part II)**

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Introduction

"*Vulnerability, Autonomy, and Agency for a Renewed Philanthropy of Benevolence*" (VAA) is a collaborative research project developed jointly by Humanity & Inclusion Canada (HI) and a team from the Canadian Partnership for Philanthropy Research Network (PhiLab) led by Diane Alalouf-Hall (UQAM) and Jean-Marc Fontan (UQAM). (HI) and a team from the Canadian Partnership Research Network on Philanthropy (PhiLab) led by Diane Alalouf-Hall (UQAM) and Jean-Marc Fontan (UQAM).

HI is an independent and impartial international solidarity organization. It intervenes in situations of poverty and exclusion, conflict, and disaster. Working alongside people with disabilities and vulnerable populations, HI acts to improve their living conditions while promoting respect for their dignity and fundamental rights. The PhiLab team is composed of academic researchers and practitioners from the philanthropic community.

The VAA project examines the actions of "Canadian grant-making philanthropy" with regard to the full inclusion of people considered vulnerable who find themselves in situations of physical or mental disability. Specifically, VAA addresses three major research questions, which were defined jointly with Humanité & Inclusion.

- How do Quebec and Canadian foundations understand and intervene with people considered vulnerable who find themselves in situations of physical or mental incapacity?
- What impact have Quebec and Canadian foundations had so far?
- How could Quebec and Canadian foundations facilitate the structuring of an ecosystem of action for people considered vulnerable who find themselves in situations of physical or mental incapacity?

The originality of this proposal lies in its desire to address the issues of vulnerability, agency, and autonomy with regard to the role of foundations in



social justice. This is all the more important given that the number of people with disabilities in Canada is increasing, while the nature of their disabilities is becoming more complex.

To carry out this project, we have set ourselves three main objectives, which will result in three separate reports.

The first objective is to produce a status report in the form of a literature review and mapping of the philanthropic sector related to vulnerability, disability, or impairment. To do so:

- in the first part of this report, we present a summary of the concepts of vulnerability, disability, and impairment;
- in the second part of this report, we illustrate, using an exploratory portrait of civil society organizations dedicated to the cause of disability, the agency of stakeholders in the emerging ecosystem of disability, incapacity, or handicap.

The second objective will explore the issue of the agency of the philanthropic sector with regard to the cause of vulnerability linked to disability. This will focus specifically on grant-making philanthropy. The second report will present a study of four foundations working on this cause.

The third objective aims to mobilize actors involved in this philanthropic cause with a view to strengthening the innovative and learning-based approaches of this ecosystem. The third report will present a summary of the actions to be taken to strengthen the philanthropic ecosystem dedicated to the cause of disability or incapacity.

Overall methodology of the research project

In line with our objectives and research questions, the methodology we used is based on three approaches. The first consists mainly of gathering data and information. The second approach involves collecting data from various sources



in order to model existing practices on the causes of vulnerability linked to different forms of disability. The third approach focuses on the structuring effect of the knowledge we will have generated in order to promote the development of an ecosystem of innovative actions to support and assist people in situations of vulnerability linked to disability.

In terms of knowledge transfer, we plan to disseminate the knowledge and learning generated in a variety of settings. The knowledge transfer approach is based on a continuous percolation strategy. A variety of means will be mobilized to support both the wide dissemination of the main findings and messages emerging from our research activity and the appropriation of the key findings and messages by the main stakeholders concerned.

Research team and monitoring committee

The research team is composed of the following individuals

- Diane Alalouf-Hall – UQAM / PhiLab Québec
- Janyck Beaulieu – PhD student, University of Ottawa
- Félix Chouinard – Master's student, University of Montreal
- Lucie Dumais – UQAM / PhiLab Québec
- Jean-Marc Fontan – UQAM / PhiLab Canada
- Élisabeth Robinot – UQAM / PhiLab Québec
- Etienne Sinotte – PhD student, McGill University

The Research Monitoring Committee is composed of the above individuals and:

- Anne Delorme – Humanité & Inclusion
- Rabia Kher, National Director, Disability without Poverty
- Sara Krinitzki – Philanthropic Foundations Canada
- Lise Roche – Mirella and Lino Saputo Foundation

Limitations

The research we conducted has several limitations.



The first relates to our positionality as researchers. By positionality, we mean the fact that:

The work of collecting and analyzing data and disseminating results is... undeniably coloured by values, beliefs, ideological allegiances, etc. Researchers analyze and interpret according to their gender identity, historical and geographical situation, ethnic origin, race, social class and status, abilities (or disabilities), etc. Far from hindering the production of knowledge, all these factors determine the conditions under which it is possible (Fabian, 2001). Self-reflection, introspection, and self-evaluation are therefore lexical variants that are corollaries of reflexivity, the objective of which is to clarify the relationship between the researcher's identity and their field of investigation (Gratiollet 2022; Holmes 2020) (Balla, 2024, p. 4).

In response to the impact of this positionality, we adopt a reflexive position.

The researcher's reflexive feedback then leads them to recognize and assume responsibility for their own position, as well as the effect it may have on the people studied, the questions asked, the data collected, and their interpretation. As such, reflexivity challenges the notion that knowledge production is independent of the researcher who produces it (Beaubatie 2023; Berger 2015). Lived experience is thus valued as a relevant source of knowledge, while the researcher's identity is recognized as not being fixed. (Ibid., p. 6)

Taking stock of who we are and our place on the grand stage of social interaction reminds us that we are people with capacity and therefore have an external understanding of vulnerability—disability or impairment. This relative understanding needs to be linked to an internal understanding held by people in situations of vulnerability—disability or impairment—or at least by people or organizations in a position to represent them.



In this sense, we work on the basis of a partnership approach, which embraces the idea that knowledge benefits greatly from the cross-fertilization of knowledge, practices, and powers.

A second limitation relates to the conditions under which this research was conducted. We had resources that, while limited, were sufficient to enable us to carry out exploratory research. By exploratory research, we mean an approach to producing knowledge on a subject with a view to synthesizing existing knowledge, identifying good practices, and proposing courses of action.



Part I – Key concepts, literature review

In order to clarify representations dealing with issues of vulnerability, disability, and impairment, we conducted an exploratory review of the literature on the definitions surrounding these terms.

We chose to address the three concepts simultaneously and complementarily as part of the same family of concepts addressing an empirical reality marked by observable physical and mental differences between a situation that is culturally considered "normal" or "intact" and situations that objectively or subjectively reflect a functional impairment.

For the International Network on the Process of Disability Production (INPDP, supplementary document, <https://ripph.gc.ca/modele-mdh-pph/concepts-cles/>), a person is an organic entity that is "intact," i.e., "unimpaired," or an entity with an "impairment," i.e., one that has "suffered slight, moderate, or considerable alterations" that affect its functioning in society.

In this first section, we will review three models of representation of vulnerability, disability, and handicap. Using language vulnerability as an example, we will illustrate one of the cultural processes at work in fuelling the existing divide between "normality" and "difference" or "deviation" from the latter. We will briefly address the notion of agency and develop a short reflection on the place and importance of temporality in the process of producing vulnerability. Finally, in order to illustrate a critical and political stance on vulnerability, disability, and impairment, we will present a summary of work on the *Crip* stance.

Methodology of the first part of this report

To meet the objective of better understanding the concept of vulnerability, disability, and handicap, a literature review was conducted to explore the existing literature. We consulted scientific documents and "gray literature" on the subject.



Documents were identified using queries entered into the Google Scholar database with the keywords "*vulnerability*" and "disability."

1. Definitions of vulnerability -incapacity-disability

As a starting point for this review of the literature on vulnerability-disability-handicap by Janyck Beaulieu, we have chosen the definition of disability proposed by the WHO in 2001.

Disability is presented as "the product of the interaction of several individual factors (sensory impairments/deficits, cognitive disorders, etc.), sociodemographic factors (age, level of education, etc.) and socio-environmental factors (presence of a support network, access to services, ease/difficulty of travel, etc.)."

"These factors have an 'influence on an individual's ability to perform the daily activities necessary to fulfill their social roles' (WHO, 2021).

This definition addresses different dimensions that refer to a variety of representations of the meaning of vulnerability, disability, and impairment. It is important to examine these conceptualizations. First, it is conceptualized ontologically. This initial representation is complemented by a relational conceptualization, to which a structural representation has been added. The following sections will outline the key elements of each of these representations.

1.1. Ontological representation of vulnerability

The different perspectives on vulnerability that emerged during the second half of the 20th century can be grouped into several approaches. First, there are the so-called ontological approaches, which Armstrong et al. (2022) refer to as "vulnerability-capacity." They suggest that vulnerability is a fundamental, essential, and inevitable part of the human condition (Gardou, 2012).



It therefore represents a "general trait" (Durand, 2018, p. 28) that presents itself "as an intrinsic dimension at a given moment in our lives" (Morrisette and Demazière, 2019, p. 51).

As Valadier (2011) points out, we are flesh-and-blood beings who can be negatively affected at any time by an incapacitating event. According to this representation of vulnerability, as human beings, we are intrinsically and fundamentally vulnerable since we all have the capacity to be diminished or incapacitated.

Although Ennuyer (2017) emphasizes that factors such as age, health status, disability, etc. can influence vulnerability, Valadier (2011) indicates that vulnerability is not just a question of age, gender, wealth, or poverty, since every person is bound to experience one or more moments of vulnerability during their lifetime. According to this view, recognizing the fragility of our bodies and minds, and our potential dependence on others for survival, is both a basic fact and a characteristic of living together (Armstrong et al., 2022).

1.2. Relational representations of vulnerability

In contrast to the ontological conception, other authors suggest a relational conception of vulnerability. For them, the vulnerability of individuals is not generally due to an intrinsic characteristic. Beyond circumstantial vulnerability, there are social contexts that structure the vulnerable situation.

In this sense, Ennuyer (2017) emphasizes that an individual's vulnerability is the result of the interaction between a person and their environment. Environmental factors include physical dimensions, social factors, and cultural norms.

The relational nature of vulnerability, which Armstrong et al. (2022) refer to as "vulnerability-exposure," highlights the fact that some people are exposed to increased risks due to their environment or specific circumstances, which generally leads to injustices.



Martin (2019) points out that this conceptualization of vulnerability first emerged in the fields of environmental science and natural risk management. This conceptualization highlighted the unequal impact of natural disasters on different human groups depending on their *coping capacities* in the face of these risks.

The relational approach perceives vulnerability as an emergent property of interactions between relatively fragile individuals and contexts that expose them to various dangers (Martin et al., 2014; Armstrong, 2017). According to this perspective, vulnerability is both internal and external.

- It is external because individuals are confronted with environmental, social, economic, and political pressures and shocks.
- It is internal because their ability to cope with these pressures and shocks without suffering harm is more or less limited (Chambers, 1989).

According to the relational conception, since ontological vulnerability does not have structural effects, it is important to reserve the notion of vulnerability for situations that lead to injustices (Garrau, 2018). These injustices are observed using a simple formula that links being in a situation of vulnerability to the individual or collective capacity to respond to that situation. When vulnerability is exposed, it may or may not be followed by a capacity to respond, leading to adaptation and resilience.

In this context, vulnerability reveals the potential damage that a particular event could cause to a given population under specific risk conditions (Sirven, 2007). According to Villagrán de León (2006), vulnerability can be seen as a population's predisposition to be affected by external harmful events and its capacity to respond, according to a fairly simple model represented by the following equation.



$$Vulnérabilité = \frac{Exposition}{Capacité de réaction}$$

Figure 1: Formula modeling vulnerability

Unlike ontological vulnerability, relational vulnerability is a phenomenon that reveals potentialities. It is the possibility or otherwise of encountering a risk and being affected by it. A risk that may be permanent (not easily eliminated), have its own dynamics (resulting from a constantly changing situation), and be reversible (if it is possible to influence the determining factors and the situational context) (Brodiez-Dolino, 2016; Sirven, 2007; Soulet, 2005).

1.3. Structural representations of vulnerability

The relational representation has given rise to a structural conception of vulnerability. According to this conception, attention is focused on the specific nature of certain types of social relationships, particularly those that weaken or maintain an individual or social group in a state of fragility, precariousness, or marginality. Vulnerability thus reflects a lack of attention or protection in any societal context that values autonomy above all else and devalues any form of dependence (Soulet, 2005).

From this perspective, Barreyre (2014) suggests that vulnerability leads to a form of social disappearance. Le Blanc (2007) echoes this sentiment, stating that vulnerability generates exclusion and is a source of precariousness, fragility, and social suffering. He evokes the image of an individual or group that has been "disembarked," like a bicycle chain coming off its anchors (Ennuyer, 2017, p. 369). Being vulnerable then corresponds to losing one's place and seeing one's social role diminished.

Now, how does structural vulnerability arise? Soulet (2005) points to the presence of social processes that determine vulnerability. Structural vulnerabilities take the form of injuries caused by an external force acting with the

(conscious or unconscious) intention of harming the integrity of a person or social group. These processes are based on, and find their legitimacy in, individual or collective characteristics (Soulet, 2005), such as the presence of a physical or mental disability or distinct sociocultural characteristics.

Bourdelaïs (2005), in his study on mothers in vulnerable situations, illustrates these discriminatory processes. He notes that vulnerability does not depend on the mothers themselves, but on the social and cultural context in which they live. He emphasizes that the breakdown of intermediary organizations or institutions exposes these mothers to vulnerability by leaving them alone to structure their lives, fuelling, according to Castel (1994), the process that leads to "extreme marginality."

In this context, vulnerability is said to be specific to the discriminatory thought patterns of the social system (Soulet, 2005). Where individuals and groups do not have adequate resources (in the form of different types of capital, including socio-territorial capital), Hill and Sharma (2020) see this as an environment conducive to their vulnerability.

Thus, people who, due to personal deficits or their social and/or economic position (in terms of social class, for example), cannot actively participate in collective life in society, in the modern sense of the term, have a high potential for social vulnerability (Soulet, 2005).

More broadly, individuals and groups who are unable to use their own resources to meet the demands of individual or collective performance required by society in order to take care of themselves and their families—i.e., to promote, manage, and protect themselves—are vulnerable.

The lack of effective responses to socially constructed marginalization leads to a cultural structuring of forms of oppression and discrimination and an increase in various types of violence. In such an environment, the responsibility for not



becoming vulnerable must fall on the individuals and groups that have become the targets of exclusion, marginalization, and discrimination.

Brodiez-Dolino (2016, p. 8) concludes that "it is society that makes individuals vulnerable, not the other way around." For Morrissette and Demazière (2019, p. 65), vulnerability factors are more extrinsic, and therefore systemic and structural, than intrinsic (specific to the individual or group). They do not deny that vulnerability has an intrinsic dimension, but this has fewer negative effects than that induced by social relations. These relations can certainly be changed, calling for a political struggle aimed at reclassifying social relations as social relationships.

The example of language vulnerability, a form of structural vulnerability

Ricoeur (1990) highlights the impact of language impairment and speech in the processes that lead to structural vulnerability. For this thinker, it is in the initial examination of the ability to master the art of communication that we can detect the fabric of vulnerability. When the inability to express one's thoughts leads to effective exclusion from the sphere of communication, it reflects the social environment's unwillingness to compensate for this inability. In a social dynamic filled with dominant cognitive and discursive norms and rules, not possessing these skills has a negative effect, marginalizing and rendering vulnerable individuals and groups who do not have the required linguistic codes.

Linguistic vulnerability is a major component of social vulnerability, highlighting that the ability to be heard by others is a prerequisite for recognition (Le Blanc, 2007). Lacôte-Coquereau (2024), in an article entitled *Epistemic injustices: when autism and dyscommunication combine, how can you make your choices heard?* goes so far as to consider this to be epistemic injustice.

Whether it is an inability to defend oneself with words, a lack of adequate words to explain oneself and be understood (Bentolila, 2012), a deficient voice (not expressing oneself as expected, both in form and content), or a complete lack of



voice (due to a lack of rights, social exclusion, shyness, or physical disability), this creates a social deficit in fully appropriating the basic communication tools needed to be recognized and live well in society.

2. Definitions of vulnerability, disability, and impairment

Diderot, in his *Letter on the Blind for the Use of Those Who See* (1749), was a pioneer in denouncing the failure to recognize people with disabilities as political subjects. His writings marked the beginning of social awareness of disability. In his writings, Diderot demonstrated the real and unrecognized abilities of individuals labelled as "infirm" by society. According to Kristeva (2006), through this critical statement, he empowered people with physical disabilities as political subjects.

Disabilities or handicaps come in a variety of forms: motor, sensory, psychological, and mental. Disability is generally unique in the sense that the person is affected by only one form of disability. However, disabilities can be combined. The terms "complex vulnerability" and "severe disability" refer to situations of multiple disabilities (Brodiez-Dolino, 2016). Whether the disability is expressed in a single form or in multiple forms, each person with a disability presents a unique situation (Kristeva, 2006).

Personal disabilities create situations of deprivation that marginalize these individuals. According to Foucault, this deprivation illustrates "the way in which societies get rid of not their dead, but their living" (cited in Gardou, 2011, p. 24).

For Le Blanc (2007), the more vulnerable an individual is, the less support they receive in their own ways of life and the more ordeal of disqualification, of "disembarkation," exposes them to the denial of their humanity.

According to Kristeva (2006), society's fixation on deficits stems from the archaic weight of a cultural approach that idealizes human beings as autonomous, well-equipped, and highly efficient. This ideological stance stigmatizes incapacity.



Individuals living with one or more disabilities must prove that they have the ability to conform to the law of the strongest, to fight for their existence, even if this fight is distorted by asymmetries and injustices.

At the institutional level, we use the following definitions.

"Disability is part of human nature. An estimated 1.3 billion people, or about 16% of the world's population, currently live with a severe disability. This number is increasing, partly due to the aging population and the rise in the prevalence of noncommunicable diseases.

Disability results from the interaction between individuals with health conditions, such as cerebral palsy, Down syndrome, and depression, and personal and environmental factors, including negative attitudes, inaccessible transportation and public buildings, and limited social support.

A person's environment has a considerable influence on the experience and extent of disability. Inaccessible environments create barriers that often prevent persons with disabilities from participating fully and effectively in society on an equal basis with others. Progress in improving social participation can be achieved by addressing these barriers and making everyday life easier for persons with disabilities" (WHO, https://www.who.int/health-topics/disability#tab=tab_1).

For the Government of Quebec, it is important to distinguish between the terms used and to place them in empirical and relational contexts. Specifically, the government makes a distinction between "impairment" and "disability."

"The term impairment refers to the organic aspect of a part of the body. It is therefore a characteristic of the person.

- Sara has a hearing impairment.
- Hugo has a muscular system impairment.



A disability leads to certain incapacities. Disability corresponds to a person's abilities, i.e., their functioning. It is a reduction in a person's ability to perform an activity or function intellectually, psychologically, physiologically, or anatomically.

- Sara has a hearing impairment. She has a hearing disability.
- Hugo has a muscular system impairment. He has a walking disability. (Government of Quebec, <https://www.quebec.ca/famille-et-soutien-aux-personnes/participation-sociale-personnes-handicapees/definition-personne-handicapee>)

From this perspective, which corresponds to the RIPPH's representation, impairment reflects empirical differences between individuals, while disability reflects a relational difference between individuals in the ways they function in society.

In summary, writings on disability distinguish between two models of conceptualizing disability: an individual model and a social model. The individual model posits that an individual's impairment is the basis on which social disablement occurs/is culturally constructed.

According to the social model, the origin of disability is external to the individual and is rooted in restrictions imposed by the physical, social, and cultural environment (Albrecht et al., 2001).

In both cases, people with disabilities must receive assistance, support measures, or specific services to compensate for their disability.

For Gardou (2011), acting on the living environment of people with disabilities, particularly through an accessibility-focused approach, can certainly eliminate environmental barriers that constitute discrimination in themselves and thus

mitigate the effects of disability. According to this logic, removing the barriers encountered would be sufficient to overcome or at least mitigate disability.

The RIPPH has produced a model that presents an interesting synthesis in which individual and social factors combine to characterize an individual's lifestyle and behaviour in society.



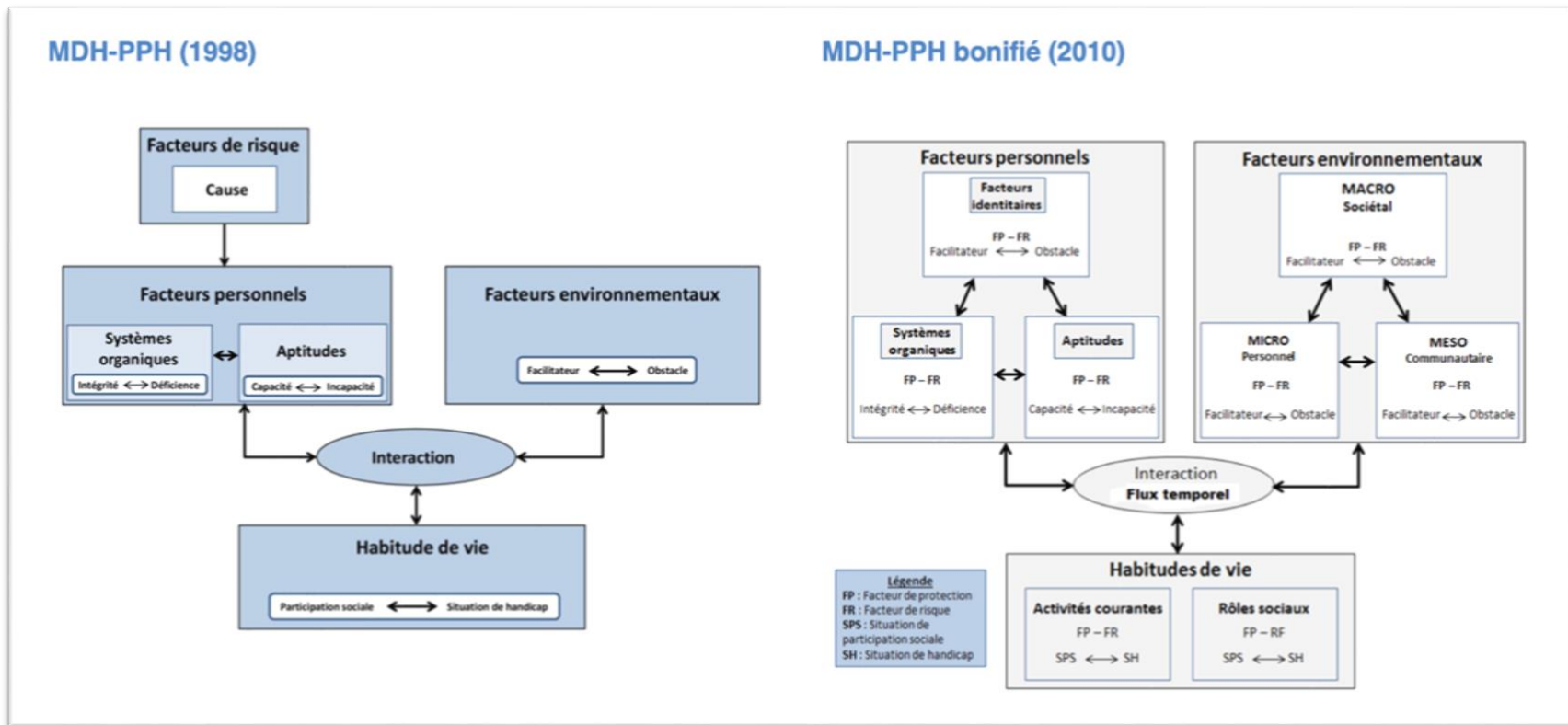


Figure2: Human Development Model – Disability Production Process (MDH-PPH)
 Source: <https://ripph.qc.ca/modele-mdh-pph/le-modele/>

By lifestyle habits, the RIPPH means:

"a routine activity or role valued by the person or their sociocultural context according to their characteristics (age, gender, sociocultural identity, etc.). It ensures a person's survival and fulfillment in society throughout their life. Lifestyles are assessed on a scale ranging from 'optimal social participation' to 'complete disability'." (<https://ripph.gc.ca/modele-mdh-pph/le-modele/>)

The tendency to idealize the ordinary situation means that anything out of the ordinary is categorized as deficient, even abnormal or bizarre. This results in a classification that tends to exclude, leading, in certain societal contexts and at certain times, to an institutional logic of placement, where each deficiency generates a logic of avoidance, exclusion, or placement.

3. Equity, Diversity, and Inclusion (EDI) and its impact on representations of vulnerability and disability

In recent years, there has been much discussion about the recognition of diverse identities and experiences within our societies. These discussions, led by individuals and activist groups, aim to highlight injustices and rethink established practices. Issues of equity, diversity, and inclusion (EDI) are now at the heart of many initiatives, committees, policies, and action plans in various organizations, including universities. These institutions are reevaluating their actions to reduce inequalities.

3.1. Institutional support in Canada and Quebec

3.1.1. Federal laws

The following federal laws play a crucial role in promoting equity, diversity, and inclusion (EDI) in Canada:



Canadian Charter of Rights and Freedoms (1982)

The Canadian Charter of Rights and Freedoms guarantees the fundamental rights of Canadians, including the right to equality by prohibiting discrimination based on race, sex, age, disability, and other grounds. This legal framework requires institutions to respect and promote equal opportunity.

Relevant excerpt: Equality rights

Marginal note: Equality before the law, equal benefit and equal protection of the law

15 (1) The law shall apply equally to all persons, and all persons are entitled to the same protection and benefit of the law without discrimination, including discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

<https://laws-lois.justice.gc.ca/fra/const/page-12.html>

Canadian Human Rights Act (1977)

The **Canadian Human Rights Act** aims to prevent discrimination and promote equal opportunity. It prohibits discrimination in employment, services, and housing. The **Canadian Human Rights Commission** enforces the Act by investigating complaints of discrimination.

Relevant excerpt: Purpose

The purpose of this Act is to supplement the laws of Canada by giving effect, within the sphere of jurisdiction of the Parliament of Canada, to the principle that all persons, in the exercise of their duties and obligations within society, are entitled to equal opportunity for the fulfillment of their potential and to the provision of services to meet their needs, regardless of race, national or ethnic origin, colour, religion, age, sex, sexual orientation,



gender identity or expression, marital status, family status, genetic characteristics, disability, or status as a pardoned person.

*R.S. (1985), c. H-6, s. 2 1996, c. 14, s. 1 1998, c. 9, s. 9 2012, c. 1, s. 137(A)
2017, c. 3, ss. 9 and 11, c. 13, s. 1*

<https://laws-lois.justice.gc.ca/fra/lois/h-6/TexteComple.html>

Employment Equity Act (1986)

This **Act** aims to correct employment disadvantages for women, persons with disabilities, Indigenous peoples, and visible minorities. It encourages employers to create inclusive environments and adopt measures that promote equality.

Relevant excerpts:

designated groups Women, Aboriginal peoples, persons with disabilities, and persons who are members of visible minorities.

visible minorities *Members of visible minorities are persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour. (members of visible minorities)*

persons with disabilities *Persons who have a long-term or recurring impairment of their physical, mental, or sensory abilities, or of a psychiatric or learning nature, and who:*

- **(a)** *consider that they have reduced ability to perform a job;*
- **(b)** *believe that they are likely to be classified in that category by their employer or by potential employers because of such impairment.*

This definition also applies to persons whose functional limitations related to their disability are the subject of accommodation measures for their employment or in their workplace. (persons with disabilities)



Analyses

- **9 (1)** *In order to achieve employment equity, it is the responsibility of the employer to:*
 - **(a)** *in accordance with the regulations, collect information on its workforce and conduct analyses of that information to measure the under-representation of members of designated groups in each occupational category;*
 - **(b)** *review their employment systems, policies, and practices, in accordance with the regulations, to identify any barriers to members of designated groups.*

Plan

- **10 (1)** *The employer shall develop an employment equity plan that includes the following elements:*
 - **(a)** *positive rules and practices to be instituted in the short term with respect to the recruitment, training, advancement, and retention of members of designated groups and with respect to reasonable accommodation for them, in order to correct the under-representation identified by the analysis referred to in paragraph 9(1)(a)*

Accessibility for Canadians Act (2019)

The Accessibility for Canadians Act aims to remove barriers to participation for persons with disabilities in federally regulated sectors. It requires organizations to develop accessibility plans and monitor progress.

Relevant excerpt: Purpose of the Act

Marginal note: Purpose



5 The purpose of this Act is to transform Canada, within the legislative jurisdiction of Parliament, into a barrier-free country by January¹, 2040, for the benefit of all, particularly persons with disabilities, specifically by recognizing and eliminating barriers — as well as preventing new barriers — in the following areas:

- *(a) employment;*
- *(b) the built environment;*
- *(c) information and communications technologies;*
- *c.1) communications, other than information and communications technologies;*
- *d) procurement of goods, services, and facilities;*
- *e) program and service design and delivery;*
- *f) transportation;*
- *g) areas designated by regulation made under paragraph 117(1)(b).*

3.1.2. Provincial laws in Quebec

The following is an overview of provincial laws that serve as a reference for equity, diversity, and inclusion (EDI):

Charter of Human Rights and Freedoms

The **Quebec Charter of Human Rights and Freedoms** guarantees the right to equality and non-discrimination. It establishes the fundamental principles of dignity, equality, and respect for human rights.

Relevant excerpt: 10. Everyone has the right to the recognition and exercise, in full equality, of the rights and freedoms of the individual, without distinction, exclusion, or preference based on race, colour, sex, gender identity or expression, pregnancy, sexual orientation, marital



status, age except to the extent provided by law, religion, political beliefs, language, ethnic or national origin, social condition, disability, or the use of any means to compensate for that disability.

Discrimination occurs when such distinction, exclusion, or preference has the effect of destroying or compromising this right.

Act respecting equal access to employment in public bodies

Enacted to reduce discrimination in hiring, this [Act](#) requires public bodies to analyze their workforce and implement equal access programs for underrepresented groups.

*Relevant excerpt: **3.** Every public body to which this Act applies shall analyze its workforce to determine, for each type of job, the number of persons belonging to each of the groups referred to in this Act.*

Job types are determined by the employer and matched to the basic groups in the National Occupational Classification of Canada, enacted in 1993 by the federal Minister of Employment and Immigration.

Act to secure the rights of persons with disabilities

This [Act](#) aims to promote the educational, professional, and social integration of persons with disabilities by requiring public and private organizations to take measures to improve accessibility and inclusion.

*Relevant excerpt: **1.1.** The purpose of this Act is to ensure the exercise of the rights of persons with disabilities and, through the involvement of government departments and their networks, municipalities, and public and private organizations, to promote their integration into society on an equal basis with all citizens by providing for various measures aimed at persons with disabilities and their families, their living environment, and the development and organization of resources and services for them.*



To this end, this Act aims in particular to enable the Office to effectively fulfill its role in evaluating the integration of persons with disabilities, to ensure compliance with the principles and rules set out in the Act, and to play a decisive role in providing advice, coordination, and consultation with a view to improving opportunities for persons with disabilities.

Act to prevent and combat sexual violence in higher education institutions

This **law** requires higher education institutions to adopt prevention and support policies to ensure a safe and respectful environment.

*Relevant excerpt: **1.** The purpose of this Act is to strengthen measures to prevent and combat sexual violence in higher education institutions and to help promote a healthy and safe living environment for students and staff members. To this end, it provides, in particular, for the implementation of measures for prevention, awareness-raising, accountability, support, and assistance to individuals.*

In this Act, the term "sexual violence" means any form of violence committed through sexual practices or targeting sexuality, including sexual assault.

This concept also refers to any other misconduct that manifests itself in particular through unwanted gestures, words, behaviours, or attitudes of a sexual nature, including those relating to sexual or gender diversity, expressed directly or indirectly, including through technological means.
2017, c. 32, s. 1.

3.1.3. EDI in research

Equity, diversity, and inclusion (EDI) play an essential role in the strategic planning and long-term vision of Canadian universities. These institutions are adopting a fundamental analytical approach to evaluate, guide, and shape their initiatives. As a result, integrating the principles of diversity and inclusion into



their operations and decision-making processes is now an essential priority. Key indicators show significant progress since the 2020 University Canada survey:

- **89%** of institutions explicitly mention EDI in their strategic plans, compared to **77%** in 2019.
- **88%** have a campus-wide EDI definition, compared to **55%** in 2019.
- **83%** have an EDI action plan or are in the process of developing one, compared to **70%** in 2019.

In 2018, the three main federal research funding agencies (NSERC, CIHR, and SSHRC) adopted an EDI Action Plan, recognizing the need to remove systemic barriers in university research. More recently, the Fonds de recherche du Québec implemented an EDI Strategy for 2021–2026. The document "Guidelines for Equity, Diversity, and Inclusion Criteria" states, in particular:

It is therefore important to counter the myth that the principles of equity, diversity, and inclusion (EDI) are at odds with excellence. On the contrary, by addressing the prejudices and systemic barriers that individuals face simply because of, for example, their gender, ethnocultural background, sexual orientation, or disability, we enable the research community to access all of its talent. Furthermore, greater diversity within a community is associated with better performance.

(Excerpt from FRQNT guidelines, 2022)

At the same time, several Quebec universities that are members of the U15 group have adopted their own EDI policies, in line with federal and provincial objectives. For example, the University of Montreal has identified six major areas of research related to EDI: identities and colonialism, displacement and ethnicity, integration and exclusion in the Canadian context, First Peoples, feminisms, and gender studies. These areas reflect current issues of diversity and inclusion in Quebec and Canadian society.



In addition, McGill University and the Université de Montréal are promoting EDI not only in the design of research projects, but also in the methods, perspectives, and corpus used by researchers. At HEC Montréal, a census conducted in 2020 measured diversity among staff and faculty, providing concrete data for the development of inclusive policies.

The Université du Québec à Montréal (UQAM) particularly illustrates its institutional commitment through several flagship initiatives, notably the EDI lexicon:

Accessible via the "Equity, Diversity, Inclusion" portal, this document standardizes vocabulary by defining, for example, equity as "fair treatment that takes individual realities into account to eliminate systemic barriers" and diversity as "the presence of people from diverse backgrounds who enrich the field of research with their distinct perspectives."

3.2. Definition of each concept

According to Verhulst & DeCenzo (2022), the DEI strategy is an organizational framework dedicated to ensuring impartial treatment and active participation of all employees. In other words, DEI brings together three complementary concepts that enable organizations to support diverse groups—whether in terms of ethnicity, race, gender, religious beliefs, or sexual orientation—and embody three essential values for meeting the needs of a workforce with diverse backgrounds (McKinsey & Co., 2022; Tessema et al. 2023).

It is therefore clear that EDI originated in the context of the world of work, and more specifically in human resources management. Its practices and definitions are therefore rooted in a vision that addresses inequalities in employment and organizational structure (Burale 2021). However, the actual use of practices based on equity, diversity, and inclusion extends beyond HR management, particularly in philanthropic practices. In doing so, it is possible to offer definitions

of diversity, equity, and inclusion that take into account their roots in the world of work as well as their broader understanding.

3.2.1. Diversity

Diversity is reflected in the plurality of profiles within a company, including characteristics such as ethnicity, religion, gender, disability, age, sexual orientation, and culture. Different definitions coexist in the literature: Robbins, Coulter & DeCenzo (2020) emphasize that diversity refers to the heterogeneity of origins. Griffin & Phillips (2023) go so far as to distinguish between primary dimensions—shaped from childhood (race, gender, age, etc.)—and secondary dimensions, which are more likely to change, such as level of education, income, professional experience, and religious beliefs.

Definition of diversity from the UQAM lexicon

Diversity refers to the conditions, modes of expression, and experiences of different groups defined by age, education level, sexual orientation, parental status or responsibilities, immigration status, Indigenous status, religion, disability, language, "race," place of origin, ethnicity, culture, socio-economic status, and other attributes. Diversity also refers to gender identity or gender expression.

<https://edi.uqam.ca/lexique/equite-diversite-inclusion/>

3.2.2. Equity

Equity aims to establish fair and transparent HR practices, ensuring that every employee has real opportunities and equitable outcomes (Tessema et al. 2023). It involves implementing policies that compensate for structural disadvantages, thereby ensuring true equality within the organization.

Definition from the UQAM EDI glossary:



Equity is synonymous with justice, meaning that people, regardless of their identity, are treated fairly. This means ensuring that resource allocation and decision-making mechanisms are fair to all and do not introduce discrimination based on identity. Measures must be taken to end discrimination and inequalities that have been reported and documented and to ensure, as far as possible, equal opportunities.

<https://edi.uqam.ca/lexique/equite-diversite-inclusion/>

3.2.3. Inclusion

Inclusion goes beyond simply having diverse profiles. It involves creating an environment in which every individual feels welcome, recognized, and valued. Soda (2023) and Urwin (2023) emphasize that an effective DEI strategy is not limited to displaying diversity, but ensures that all employees are truly "invited to the table" and receive the support they need to reach their full potential.

Definition of inclusion from the UQAM lexicon:

Inclusion refers to the creation of an environment where all people are treated with equal respect and have access to the same opportunities. At the organizational level, inclusion requires identifying and removing barriers (physical or procedural, visible or invisible, intentional or unintentional) that hinder people's participation and contribution. It also requires affirming the values and principles of equity, justice, and respect by being open to different opinions and perspectives, gaining an understanding of other cultures, experiences, and communities, and making a conscious effort to be welcoming, helpful, and respectful to all. **<https://edi.uqam.ca/lexique/equite-diversite-inclusion/>**

These definitions of EDI help to grasp the breadth of its uses. Invested in both human resource management and organizational processes, EDI is understood by Chow (2018) as a lens through which philanthropic organizations can reflect on their practices. Thus, she defines diversity as a measurement tool, equity as



an outcome, and inclusion as a behaviour, all of which can generate concrete changes in philanthropic practices.

4. Temporality: an important dimension of vulnerability, disability, and impairment

In the field of *disability studies*, time is a central research topic. Seymour (2002) addresses the inextricable relationship between time and the body and highlights how the temporal dimension acts as a visible and perpetual reminder of the fragility and vulnerability of the human body.

Beudaert and Nau (2021) examine the vulnerability that arises from the desynchronization between individual time and the normative rhythm of society, a discordance that marginalizes individuals and accentuates their vulnerability. They identify three main effects of time on vulnerability: a problematic individual experience of time; a lack of synchronization with the time of others; and with the time of society.

The actions of people with disabilities often require additional time due to their functional limitations and environmental barriers, which can be perceived as a waste of time within the framework of dominant social norms (Baril, 2017). Tensions between different temporal rhythms can therefore lead to varied and sometimes problematic experiences.

The study by Beudaert and Nau (2021) shows that seemingly minor tasks require a considerable investment of time on the part of people with disabilities. The time required can be a source of frustration, particularly because of unfair social expectations (Baril, 2017).

This slowness, often accompanied by increased fatigue, leads people with disabilities to perceive their time as limited. This time pressure on individuals also generates negative emotions that reinforce their feelings of vulnerability, exacerbated by the physical constraints they face (Beudaert and Nau, 2021).



The temporality of people with disabilities is often determined by that of their caregivers, who are essential in meeting their daily needs. This dependence creates a need for synchronization of temporalities (Southerton, 2006). The synchronization of schedules is often to the detriment of individuals with disabilities, leading to a feeling of disconnect from social norms and the expectations of those around them. Differences in temporality create a feeling of exclusion among individuals with disabilities, depriving them of full participation in society. On the one hand, finding reliable and flexible caregivers who can adapt to their daily lives is relatively difficult. On the other hand, people with disabilities often express regret about the limited time they are given. This time seems insufficient for essential activities and is often lacking for more enjoyable activities, which are nevertheless essential to their well-being and identity (Nau et al., 2016).

The needs of people with disabilities also conflict with the pace of organizations and institutions, requiring the implementation of specific measures to accommodate them. It is clear that organizations and institutions have a limited capacity to accommodate people with disabilities (Beudaert and Nau, 2021; Nau et al., 2016). Beyond the issue of pace, the length of the working hours of organizations and service providers can also be considered restrictive.

Finally, Pavia and Mason (2014) highlight the fact that people with disabilities face chronic time pressure that affects all aspects of their lives and makes their activities particularly time-consuming, even when they are related to their most basic needs.

5. Vulnerability, disability, handicap & agency

Agency, defined as "the socioculturally mediated capacity to act" (Ahearn, 2001, p. 112), can be exercised intentionally and individually, collectively, or societally (Al Zidjaly, 2015).



Agency can be used to resist marginalization or oppression. It can be deployed by people in vulnerable situations, by their loved ones, by their community, or by society.

Ahearn (2001) emphasizes that not all agency is oppositional in nature and is often adaptive. The literature on vulnerability or disability represents agency as resistance in response to the inadequacies of society and the oppressive conceptions to which people with disabilities are subjected.

For example, through art, writing, or various communication processes (Al Zidjaly, 2015; Andrieu, 2012), people in vulnerable situations can construct their own narratives of "disability," moving away from "disabling stigmas" and the medicalization of disability, defining a "standard body" (Andrieu, 2012, p. 52) in their own image.

People with disabilities or in vulnerable situations can also demonstrate agency and resistance by reframing their use of technologies—considered by the traditional medical model to provide "assistance" in order to bring their users closer to normality (Clinkenbeard, 2020)— – by positioning themselves as "agents who advocate for accessible technologies and implement changes in their interactions with and through technologies" (Clinkenbeard, 2020, p. 117).

Over the past 50 years, people with disabilities have come to be seen as more than just "objects of care." A social movement has campaigned for their full recognition as actors in their own right, for whom disability is seen as the result of an impairment that must be accompanied by a social response. Disability thus embodies a "situation" shaped by the way society treats them (Kristeva, 2006).

This agency, which is always under construction, in and through struggles for recognition, fits positively into the relational conceptualization of vulnerability. While disability reflects notable differences between individuals in relation to a certain representation of "normality," living in society makes these disabilities more active or significant, resulting in the crystallization of structural vulnerability.



However, the ability to act to counter, overcome, or mitigate this exclusion through mitigation or compensation measures, or through transformative measures at the social systems level, means that the vulnerability associated with disability can be eliminated, mitigated, or reduced.

6. Vulnerability, disability, handicap & Crip Theory

As an indication of the positions that drive activism for a more politicized agency of persons with disabilities, we present a critical approach to disability studies, namely *Crip* theory. This theoretical approach envisages the deconstruction of norms and the "ableist" system, which are sources of vulnerability for persons with disabilities.

The "non-critical" field of study of disability and vulnerability and disability-related accessibility movements rarely adopt a structural-systemic political stance that places systems of oppression at the heart of the analysis.

This type of conceptualization is gaining ground in other fields of study and activism, such as certain movements for greater social justice, feminist and *queer* movements, and intersectionality theory. The latter offers a relevant perspective and angle for studying discrimination, marginalization, and ultimately vulnerability (not to say "vulnerabilization").

While disability analysis was not at the root of the development of intersectionality theory, as advocated by Kimberly Crenshaw (1989), disability analysis has since been integrated into it, placing ableism as one of the systems of oppression/power, just like racism, sexism (patriarchy), colonialism, etc.

Authors in *disability studies*, faced with a lack of critical thinking when it comes to power dynamics, have proposed a "*Crip*" approach to disability (Kafer, 2013; Baril, 2017).

Crip is considered an inclusive term, representing all disabilities, whether physical or psychological. Crip represents the current movement for the



rights of people with disabilities, and is found in disability culture... In the disability community, the term Crip refers to the reappropriation of a much more pejorative term, "cripple" ("crippled, lame, infirm, invalid"), which not only reduces the person to something repulsive but also excludes those with invisible disabilities from the disability community (free translation, Williams, 2015/2023).

The *Crip* approach promotes alternative representations to the dominant system described as "ableist" (Parent, 2017). Ableist in the sense that it values what corresponds to the performance standards of people described as "able-bodied" and therefore "valid." Such standards are detrimental to people described as "disabled," in other words, those with disabilities.

Ableism, as a system of oppression, is understood as "a structure of social differentiation and hierarchy based on the normalization of certain bodily forms and functions and on the exclusion of non-conforming bodies and the people who inhabit them" (Masson, 2013, p. 115), making bodily normality the best option (Grenier and Fougeyrollas, 2020; Reid and Knight, 2006).

By reimagining our conceptions of time and standardized rhythm, *Crip time* suggests understanding disability time as an alternative to the dominant ableist temporality (Baril, 2017). For Kafer (2013, p. 27), it is a matter of questioning "our conceptions of what can and should happen in time" or "recognizing how our expectations in terms of 'the time things take' are based on very particular minds and bodies."

According to Samuels (2017), the onset of a disability suggests that "*Crip time*" represents a "broken" subjective period of time, characterized by the emergence of new rhythms and the presence of imposed pauses. This conception of time recognizes that individuals, particularly those with disabilities, generally think, speak, and/or move at a pace that is far from the so-called normal pace (Kuppers, 2014).



The *Crip* approach is not so much about proposing specific accommodations and adaptations as it is about challenging the temporal constraints imposed on people with disabilities. In doing so, disability time would no longer be viewed as slow and unproductive, but as an equally legitimate way of doing things. In other words, by seeking to construct a counter-narrative that rejects dominant ableist norms, the aim is to stop subjecting the bodies and minds of people with disabilities to schedules based on so-called valid levels of performance, and instead to subject schedules to individuals' abilities. Moving in this direction would allow people with disabilities to develop a positive representation of their own pace and themselves (Kafer, 2013), reversing the stigma and thereby limiting their vulnerability.

Although very interesting, this critical stance on time, in relation to disability and vulnerability, is rarely taken up by people with disabilities, as demonstrated by Beudaert and Nau (2021). In their study, none of the people with disabilities mentioned the need to build an alternative model that would reverse the ableist temporality that predominates in our society.

Nevertheless, this critical approach remains relevant. As Soulet (2005) points out, there is a danger in resorting to vulnerability, or calls for integration for people with disabilities in a microsociological way, focusing solely on strictly individual aspects and sidestepping the political dimension.

For Goffman (1975), considering the situation from an ecological perspective and calling for a deviation from dominant norms, as emphasized by Bonnicco-Donato (2013), allows us to lay the foundations for ethical reflection on inclusivity, so that any "deviation" specific to a situation of disability is accepted as normal, not exceptional. This would avoid considering it as "individual peculiarities" that lead to stigmatization, questioning what is "normal" and "abnormal" in society.

In the same vein, Kristeva (2006) is wary of calls for the integration of people with disabilities. The psychoanalyst prefers interaction or acting with. This is a more political and ethical stance of welcoming others based on their situation of being



and not on "having to be" in accordance with specific criteria. This stance makes it possible to "change the way we look" at people with disabilities by promoting interaction that respects differences. This makes it possible to move away from the classificatory dichotomies that separate the "able-bodied/normal" from the "disabled/abnormal."

Conclusions of Part I

Based on the literature reviewed, this overview of the concepts of "vulnerability," "disability," and "handicap" informs us about two situations and the importance of positive agency, based on a critical and politicized stance, in terms of full integration and social recognition.

The first situation is cyclical in nature and specific to human biology. Vulnerability is a reflection of health. The optimal and utopian situation of spending an entire life in "perfect health" is a cultural illusion and a myth. In reality, our bodies are constantly shifting between states of good and poor physical and mental health. Reality shows an evolution characterized by constantly shifting balances between better and worse states. As a result, physical or mental fluctuations in our state of health affect our abilities, making us more or less fragile, more or less vulnerable, and more or less capable of accomplishing things properly.

It is therefore important to view the physical and mental condition of each individual as a realistic reflection of their circumstances. These circumstances form the basis of a second reality, one that is determined by cultural markers. Physical or mental fluctuations in our state of health are amplified by cultural factors. These cultural determinants amplify vulnerability by making physical or mental differences structural and difficult to overcome.

These amplification processes, which are embedded in socialization mechanisms, are more or less taken into account, accepted, valued, and discriminated against. They produce an inability to cope, both for the individuals affected and for their immediate environment and society in general. These



incapacities must be dealt with individually, collectively, and socially, and culturally mitigated or eliminated if the principle of social justice for all is to be an essential principle of a society or community.

The vulnerability inherent in disability, through the agency and empowerment of individuals, requires individual, collective, and societal adaptations. Relative well-being, i.e., the level of vulnerability of people with one or more disabilities, will be affected, positively or negatively, depending on whether or not adaptations, consideration, and positive recognition are provided.

The literature converges on one point: sociocultural factors are central determinants of vulnerability, disability, or impairment. This fact leads some authors to state that sociocultural factors are more or less exacerbated depending on the nature of existing social relations, including class relations, and therefore that efforts to reconfigure these relations must be considered in order to address the root causes.

Individual, collective, or societal agency in relation to vulnerability, disability, or impairment therefore appears essential to correcting the situation. It is therefore important, beyond the support provided to people in vulnerable situations, to engage in social struggles for the effective mobilization of resources against integrative approaches that do not respect the levels of vulnerability, incapacity, and disability present.



Part II – Agency and disability, incapacity, handicap

Introduction

This second section is divided into three parts. The first part explains the data collection method. The second section focuses on disability-related agency. It presents a summary of the major phases of the disability-related social movement, an overview of the main public policies related to this cause, and social perceptions of people with disabilities since World War I. This section summarizes the main legal and social advances in the treatment of people with disabilities and the evolution of social perceptions of these individuals.

The third section presents a contemporary portrait of the actors in the disability sphere in Canada. In addition to reviewing the types of actors and specific examples, we compare the data collected with the literature.

Methodology

To complete this second stage of the work, the data presented is based on a literature review and data collection on civil society organizations working in the field of support for persons with disabilities.

Three dimensions are addressed in this second part of the first report.

- A look at the different types of disability.
- The historical evolution of models of action on the causes of disability.
- An exploratory portrait of the actors in the disability ecosystem.

The documentary research was mainly carried out using keywords—disability, incapacity, vulnerability, agency, non-profit organizations—and was conducted using Google Scholar and Sofia. In total, more than 75 reference documents were consulted.

Data collection provided information on civil society organizations working in the field of disability in Quebec. Providing a comprehensive and detailed portrait of



the field was beyond the scope of our mandate. We chose to provide an overview of this agency. Four criteria were used to select the organizations that were included in our database.

- The selected organizations must be non-profit organizations (NPOs), foundations, or associations.
- The head offices of the selected organizations must be located in Quebec.
- The cause of disability must be part of the mission of the selected organizations.
- The scope of action of the selected organizations must correspond to one of the following choices:
 - the province of Quebec (or Canada, including Quebec);
 - the administrative regions:
 - Montreal;
 - Estrie; or
 - Gaspésie-Îles-de-la-Madeleine.

1. Typology of forms of disability: summary of proposals

There is no universally recognized model for classifying disabilities, as there is no unanimous definition of disability (Altman, 2001; Bickenbach, 2019). Several definitional approaches are generally used, including:

- the legal and administrative definition: which focuses on the individual and tends to emphasize the characteristics that identify a person with a given disability;
- the clinical and medical definition: which focuses on diagnosis and pathology;
- The academic definition: it conceives of disability as a continuum of situations and focuses more on social factors than individual factors in its approach (Altman, 2001).

Bickenbach (2019) produced a summary, reproduced in Table 1, of the meaning attributed to the term "*disability*." His summary takes into account the variety of definitions, their components, and their impact on how disability is understood and classified.

It is interesting to note that the key elements of each of the models presented fall on a continuum that emphasizes individual dimensions on one side and combines these with social and cultural considerations on the other. This continuum runs from top to bottom of the table, with representations that focus primarily on individual or physical components of disability located at the top of the table, while broader and more inclusive representations of contextual and structural considerations extend downward from the middle of the table.

This diversity of representations plays a role in the failure to recognize the importance of context and the role played by cultural factors in sidelining the issue of the full integration of people with disabilities.



<i>Model of disability</i>	<i>Components of the model</i>	<i>Conceptual meaning of 'disability'</i>
Nagi (Nagi 1965, 1969, 1977, 1991)	Pathology Impairment Functional limitation Disability	Patterns of behaviour that evolve in situations of long-term or continued impairments that are associated with functional limitations
Social (UPIAS 1976; Oliver 1990, 1992)	Impairment Disability	Limited or loss of opportunities to take part in community life owing to physical and social barriers
Verbrugge and Jette (1993)	Pathology/disease Impairment Functioning limitation Disability	Disability is experiencing difficulty doing activities in any domain of life due to a health or physical problem
Institute of Medicine (Pope and Tarlov 1991; Brandt and Pope 1997; Field and Jette 2009)	Pathology Impairment Functional limitation Disability	The expression of a physical or mental limitation in a social context – the gap between a person's capabilities and the demands of the environment
ICIDH (WHO 1993)	Impairment Disability Handicap	In the context of health experience, any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being
ICIDH-2 (WHO 1997)	Body function and structure (Impairment) Activity (activity limitation) Participation (participation restriction) Contextual factors: environmental and personal	Disability is an umbrella term comprising impairments as problems in body functions or structures as a significant deviation or loss, activity limitations as difficulties an individual may have in the performance of activities, and participation restrictions as problems an individual may have in the manner or extent of involvement in life situations.
Québec (DCP (Fougeyrollas <i>et al.</i> 1989, 1995, 1998)	Risk factors Personal factors: organic systems: integrity/impairment - capabilities: ability/disability Environmental factors: - facilitator/obstacle - life habits Social participation/handicap	No conceptualisation of disability as such, rather a model of the 'disability creation process': 'an explanatory model of the causes and consequences of disease, trauma and other disruptions to a person's integrity and development'.
ICF (WHO 2001)	Body function and structure (impairment) Activity (activity limitation) Participation (participation restriction) Contextual factors: environmental and personal	As in the ICIDH-2; cf. 'Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' (Leonardi <i>et al.</i> 2006).

Table 1: Models of disability and their meanings

Source: Bickenbach, 2019, pp. 58-59



In Canada and Quebec, two models have had a particular influence: the *Human Development Model – Process of Disability Production* (HDM-PDD, also known as the *Quebec Model* in the table) and the *International Classification of Functioning, Disability, and Health* (ICF in the table).

The HMPD was developed by the International Network on the Process of Disability Production (INPDP) and in particular by Patrick Fougeyrollas (Fougeyrollas et al. 1998; Fougeyrollas, 2002; Fougeyrollas et al. 2019; Fougeyrollas, 2021; RIPPH, 2024). The MDH-PPH "presents an understanding of disability that does not place the responsibility for disability and its consequences on the individual, but rather on the interaction between their individual characteristics and those of the environment in which they live" (Fougeyrollas, 2021, p. 16).

Three types of factors are used to qualify and conceptualize a person's disability:

- personal factors: identity, organ systems, abilities;
- environmental factors: a person's physical and social environment,
- as well as lifestyle habits (the individual's social participation and social roles) (Fougeyrollas, 2021).

In addition to presenting a defined concept of disability, the MDH-PPH proposes a "rudimentary" and "untested" classification of types of disability (Bickenbach, 2019, p. 59). Described as the Quebec model, this concept had a "strong influence on the WHO's revision process of the [ICF]" (Fougeyrollas, 2019, p. 27) and guided the development of public policies regarding different types of disability (INSPQ, n.d.).

The ICF, developed by the World Health Organization (WHO) in partnership with researchers, clinicians, and persons with disabilities (Leonardi et al., 2022), conceives of disability as a derivative

from the positive and multidimensional concept of human functioning. The ICF presents the universal human experience of functioning across a



spectrum ranging from the most basic biological function to simple and complex activities, to the most complex and relatively more socially constructed areas of participation (Bickenbach, 2019, p. 57).

In other words, the ICF views disability as a medical problem (the model is based on medical diagnosis) that limits the "normal" functioning of the human body, while also taking environmental factors into account in its analysis (Bickenbach, 2019).

The main advantage of the ICF over other disability classification models is that it is the only model that provides a comprehensive, evidence-based classification of disabilities (Bickenbach, 2019). In Canada, the ICF is used legally as a general framework for policy and regulation development. However, it is not used in a clinical context (Leonardi et al. 2022).

The influence of these two models can be seen in the definitions and classifications of disabilities provided by various Quebec and Canadian government agencies (Table 2). The influence of the MDH-PPH is particularly visible in the Canadian Accessibility Act (2019) and the Canadian Survey on Disability (Pianosì et al., 2023), which incorporate discrimination as an integral component of their definition of disability.

Conception of disability	Classification of disabilities
<i>Accessibility Act</i>	
"Any factor—including one that is physical or architectural in nature, related to information, communications, behaviour, or technology, or resulting from a policy or practice—that hinders the full and equal participation in society of persons with physical, intellectual,	"A physical, intellectual, cognitive, mental, or sensory impairment, learning or communication disability, or functional limitation, whether permanent, temporary, or episodic, whether apparent or not, that, in

<p>cognitive, mental, or sensory impairments, learning or communication disabilities, or functional limitations " (Government of Canada, 2019).</p>	<p>interaction with a barrier, hinders a person's full and equal participation in society" (Government of Canada, 2019).</p>
<p><i>Canadian Survey on Disability</i></p>	
<p>"The [Survey] is based on a social model of disability. The social model is based on the principle that disability results from the interaction between a person's functional limitations and the barriers they face in their environment, including social and physical barriers that complicate daily life. Therefore, disability is a social disadvantage imposed by an unfavourable environment that adds to a person's functional limitation" (Pianosi et al. 2023).</p>	<p>Vision / Hearing / Mobility / Flexibility / Dexterity / Pain / Learning / Development / Mental health / Memory (Statistics Canada, 2022)</p>
<p><i>Quebec – Act to secure the rights of persons with disabilities with a view to their educational, professional, and social integration</i></p>	
<p>"Any person with a disability that results in a significant and persistent impairment and who is likely to encounter barriers in carrying out everyday activities" (LégisQuébec, 2004).</p>	<p>The disability may be motor, visual, auditory, or intellectual.</p> <p>It can also be related to: speech; language; other senses; organic functions; autism spectrum disorder; serious mental health disorder.</p> <p>The term "person with a disability" includes people with significant and</p>



	persistent disabilities. (Government of Quebec, 2023).
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Table2: Concept and classification of disabilities in Canada and Quebec

2. Portraits of disabilities and handicaps

We present two profiles in this section. The first presents the sociodemographic situation in the Canadian and Quebec contexts. The second provides a snapshot of the non-profit component of the ecosystem working on disability issues in Quebec.

2.1. Sociodemographic portrait of disability

The Canadian Survey on Disability (Government of Canada, 2022) revealed that 8 million Canadians (27% of the working population and 21% in Quebec, representing 1.4% of its population) had a disability, representing an increase of 4.7 points compared to 2017.



Table3: Disability rates by province in 2022 and percentage point difference between 2017 and 2022

Of the number of people in Canada in 2022 with at least one disability: 30% were women compared to 24% for men, 20% were young people, and 40% were seniors (aged 65 and over). In Quebec, in 2017, the disability rate was 23.6% for women and 18.2% for men. In the same year, the disability rate was 6.6% among young people aged 15 to 24, 38.9% among those aged 45 to 64, and 68.1% among those over 65.

The 2022 Canadian study indicated that 71% of these individuals had more than one type of disability. More than half of this population had a disability that was considered severe or very severe. Nearly half of these individuals (45%) were living in poverty.

It should be noted that disability is assessed according to severity classes ranging from mild to very severe. Table 4 shows the four classes, the number of people with disabilities, and their respective percentages for the year 2022.

Classe de sévérité	Personnes ayant une incapacité	
	nombre	pourcentage
Classe 1 = légère	3 114 790	39,0
Classe 2 = modérée	1 582 850	19,8
Classe 3 = sévère	1 597 440	20,0
Classe 4 = très sévère	1 682 530	21,1

Note : La somme des valeurs dans chaque catégorie peut différer du total en raison de l'arrondissement.
Source : Statistique Canada, Enquête canadienne sur l'incapacité, 2022.

Table4: Disability, severity classes, and related percentages

In addition, the Canadian IL Survey identifies 10 types of disability. Among the Canadian population as a whole, the percentage distribution of people with disabilities is as follows. We also have indications of the percentage increase compared to the previous study conducted in 2017.



- 16.7% related to pain;
- 10.9% related to flexibility;
- 10.6% related to mobility;
- 10.4% to mental health;
- 7.4% to vision;
- 5.6% to hearing;
- 5.6% to learning;
- 5.0% to dexterity;
- 4.9% to memory; and
- 1.5% to development



Table5: 2017-2022 difference by type of disability for Canada

Based on data presented by the Institut de la statistique du Québec for 2017, Table 6 shows the estimated population and corresponding disability rate for different types of disability. It should be noted that there are relatively significant differences in the percentage of disability types between the situation in Quebec in 2027 and that in Canada in 2022.

Type d'incapacité	Taux d'incapacité	Population estimée
Vision	3,2 %	205 920
Audition	2,8 %	182 830
Mobilité	6,4 %	418 550
Flexibilité	6,6 %	429 520
Dextérité	2,5 %	160 870
Douleur	9,8 %	639 040
Apprentissage	3,5 %	228 570
Développement	0,8 %	55 280
Santé mentale	4,6 %	298 630
Mémoire	2,1 %	139 170
Indéterminée	0,4 %	25 170

Table6: Disability rates for Quebec by type of disability in 2017

Finally, people with disabilities are at a disadvantage in terms of education and their relationship with the labour market. As the situation in 2016 shows with regard to economic activity, people with disabilities are more often unemployed than those considered to be fully able-bodied. It should be noted that the data on this subject for Quebec is just under 10 years old. An update would be important given the impact that COVID-19 and the period of inflation have had on the Quebec and Canadian labour markets.

Situation sur le marché du travail	Taux des personnes avec incapacité	Taux des personnes sans incapacité
Taux d'activité (en emploi et au chômage)	60,1 % (-)	80,4 %
Taux d'emploi	54,7 % (-)	75,3 %
Taux de chômage	9,0 % (+)	6,4 %

Table7: Disability: activity, employment, and unemployment rates in 2016

Faced with the growing complexity of this social issue, the Canadian and Quebec governments are falling short in their responses, hence the importance of mobilizing other social actors.

2.2. Snapshot of the NPO component of the Quebec ecosystem in response to vulnerability, disability, and impairment

In order to develop an exploratory representation of the Quebec ecosystem of action developed by civil society and related to the cause of disability, we decided to focus on 313 organizations. Of these, 140 have a province-wide reach, 103 are dedicated to the administrative region of Montreal, 51 to the Estrie region, and 19 to the vast region of Gaspésie-Îles-de-la-Madeleine.

These organizations were identified through various resources, including L'Accompagnateur (2024), a database of programs and organizations that

provide support to people with disabilities and their families. For each organization, the data identified in Table 8 was compiled in Table 9.

Indicator	Possible values	Details
<i>Profile and head office</i>		
Name of organization		
Type of organization	Foundation; Non-profit organization; Association.	
Municipality		
Administrative region		
Web address		
<i>Mission and scope of action</i>		
Specific disability		Organizations that offer support for more than one disability are classified in the categories <i>All Disabilities</i> if no specific disabilities are mentioned, <i>Multiple Disabilities</i> if the organization targets specific disabilities, or <i>[Category], Multiple</i> if multiple disabilities within the same category are targeted.

Disability category	Pain-related disability // Neurodevelopmental // Multiple // Multiple disabilities and disabling illnesses // Mental health // Sensory // Neurological and memory disorders // Physical and motor disorders.	The purpose of this indicator is to allow multiple disabilities to be grouped under a single banner for trend analysis.
Organization's mission		
Organization family	Accessibility - Universal accessibility and built environment // Financial assistance - Financial assistance for individuals and families // Arts and culture // Education - Access to education and academic success // Grant-making philanthropy // Caregiving and civic sponsorship // Research and service development // Consultation and representation groups // Reception and respite centres // Specific disability representation (SD) - Representation, integration, information, and support // Specific disability support (SD) - Support, quality of life, integration, and social inclusion // Sports and universal accessibility // Access to employment, adapted jobs, and personal and family finances // Service dogs and animal therapy.	The wording for each category was based on the data collected.



Scope of action	Province of Quebec; Montreal; Estrie; Gaspésie-Îles-de-la-Madeleine.	
Financial overview		
Total assets in 2022		Total assets = amount reported by the organization on line 4200 of tax form T3010.

Table8: Data types, possible values, and details
Source: author

Indicateur	Total	Selon le champ d'action				Selon le type d'organisation		
		Province	Montréal	Estrie	Gasp.-IDL	Fondation	OBNL	Regroup.
Nombre d'organisations recensées	313	140	103	51	19	46	250	17
Type d'organisation								
Fondation	46	43	3	0	0			
OBNL	250	83	98	51	18			
Regroupement	17	14	2	0	1			
<i>Total</i>	313	140	103	51	19			
Famille d'organisation								
Accessibilité - Accessibilité universelle et environnement bâti	7	3	2	2	0	1	6	0
Aide financière - Aide financière aux individus et familles	8	8	0	0	0	6	2	0
Arts et culture	7	2	5	0	0	0	7	0
Éducation - Accès à l'éducation et réussite scolaire	8	4	2	2	0	1	6	1
Philanthropie subventionnaire d'organismes	2	1	1	0	0	2	0	0
Proche-aidance - Proche-aidance et parrainage civique	18	8	6	4	0	3	14	1
Recherche - Recherche et développement de services	4	3	1	0	0	3	1	0
Regroupement - Regroupement de concertation et de représentation	9	7	1	0	1	0	1	8
Répit - Centre d'accueil et de répit	17	2	8	5	2	1	16	0
Représentation HS - Représentation, intégration, information et soutien	69	38	8	17	6	2	61	6
Soutien HS - Soutien, qualité de vie, intégration et insertion sociale	129	46	56	18	9	20	109	0
Sports - Sports et accessibilité universelle	16	9	5	2	0	3	13	0
Travail - Accès à l'emploi, emplois adaptés et économie personnelle et familiale	8	4	3	0	1	0	7	1
Zoothérapie - Chiens de service et zoothérapie	4	3	1	0	0	3	1	0
<i>Total</i>	306	138	99	50	19	45	244	17
Catégorie de handicap								
Handicap lié à la douleur	6	2	2	1	1	0	5	1
Neurodéveloppemental	68	26	27	15	0	6	56	6
Plusieurs	102	51	27	12	12	22	72	8
Poly-handicaps et mal. invalidantes	14	9	2	2	1	3	11	0
Santé mentale	49	11	26	10	2	3	46	0
Sensoriel	31	18	7	5	1	4	26	1
Troubles neurologiques et mémoire	13	6	3	2	2	3	9	1
Troubles physiques et moteurs	30	17	9	4	0	5	25	0
<i>Total</i>	313	140	103	51	19	46	250	17
Ressources (actifs totaux)								
Ressources moyennes, tous types d'organisation confondu (en \$)	1,234,727	1,748,200	1,068,239	506,283	557,824			
Ressources moyennes d'une fondation (en \$)	3,819,315	3,883,725	2,939,051	0	0			
Ressources moyennes d'une OBNL (en \$)	729,270	605,764	998,083	506,283	588,289			

Table9: Summary of characteristics for the selected population
Source: author

In order to accurately represent the data contained in Table 9, Figure 1 provides a visual presentation of all the organizations surveyed (NPOs, foundations, and groups combined) according to their organizational family. Figure 2 presents all

the organizations surveyed according to the category of disability targeted in the organization's mission.

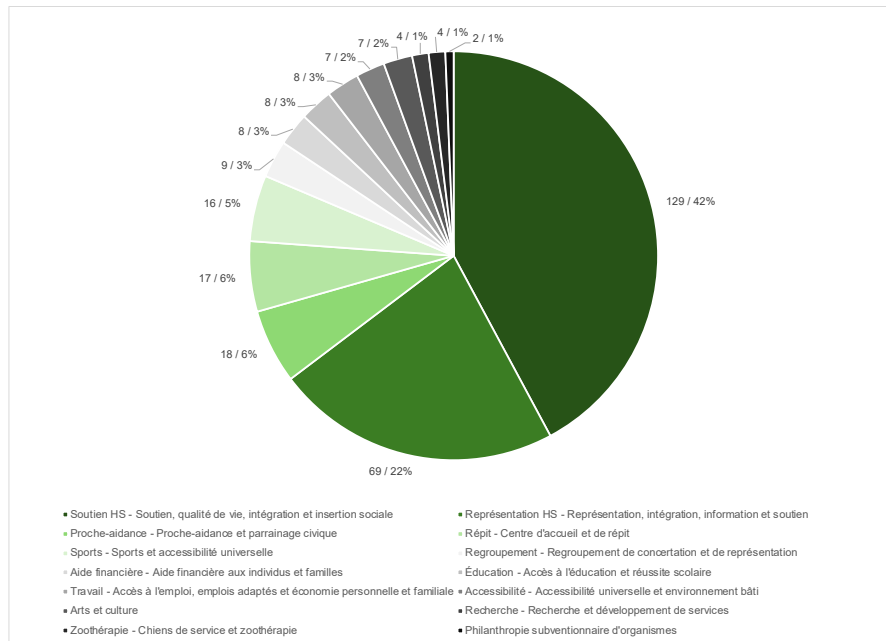


Figure3: Types of organizations for the selected population

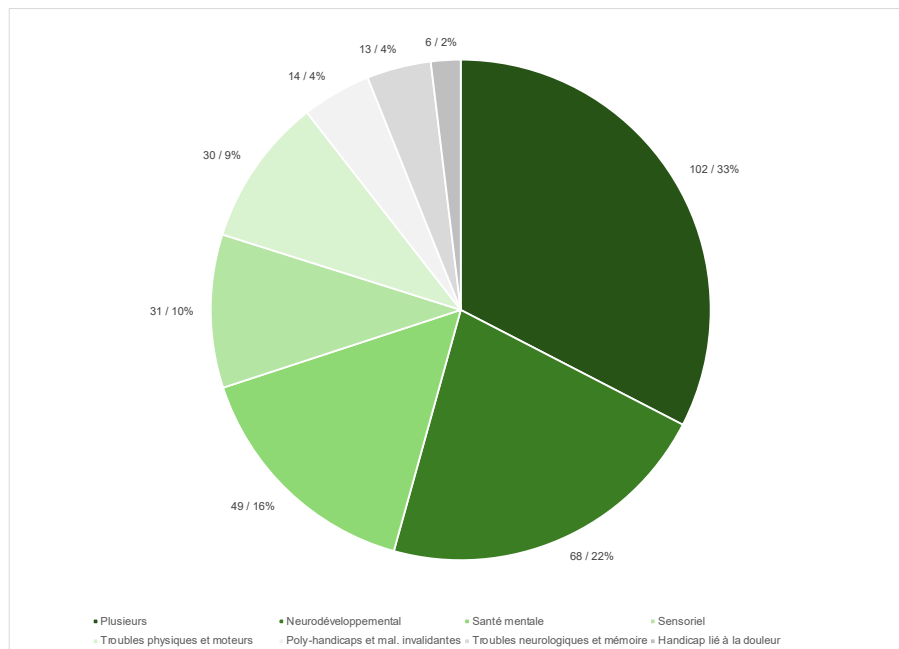


Figure4: Disability category for selected organizations

Figures 3 and 4 highlight several trends.

First, the majority of the organizations selected (64%) belong to two types of organizations:

- *Support for a specific disability or Support, quality of life, integration, and social inclusion; and*
- *Representation of a specific disability or Representation, integration, information, and support.*

A significant proportion of organizations therefore focus on supporting and representing people with *specific disabilities*, while the rest of the organizations are spread across the twelve other fields of action.

This diversification of activities means that there are only a limited number of organizations per field of specialization. As a result, in regions where the population is less dense than in Montreal, certain fields of action are less well represented: 9 for Gaspésie-Îles-de-la-Madeleine and 7 for Estrie. However, all fields are covered by at least one organization at the provincial level.

Second, the majority of organizations (55%) focus their mission on the categories of "*multiple*" disabilities (33%) and "*neurodevelopmental*" disabilities (22%). The latter includes learning and developmental disabilities. It should be noted that mental health organizations are relatively important (^{3rd} place with 16%).

Third, as part of the data collection process, we also looked at the missions of the selected organizations. Common determiners, pronouns, prepositions, and verbs used in the mission statements were removed from the word cloud. The words "people" (265 instances), "mission" (95), and "organization" (70) were also removed due to their low analytical potential and high frequency—after removing these words, the most frequent word is "life," with 70 instances. Figure 4 presents a word cloud representative of the wording of all these missions. There is a greater presence of the words "life," "services," "living," "promote," "mental," "impairment," "disability," and "support."



perfectly representative, as our sample includes only four of the 17 existing administrative regions.

Fifth, in financial terms, the data we have collected has a relative level of reliability, as it comes from returns processed by the Canada Revenue Agency based on T3010 forms provided by charitable organizations. On the one hand, not all organizations dedicated to the cause of disability are necessarily recognized as charities. On the other hand, the quality of the data varies depending on how individuals interpreted the questions on the T3010 questionnaire.

All in all, the data we have indicates that the financial resources available to registered charities dedicated to disability issues average around \$730,000. This means that some organizations have relatively large resources, exceeding \$1 million, while others have relatively smaller resources, less than \$500,000.

The data on foundations surveyed by the Canada Revenue Agency, which we use in this report, are largely incomplete and unclear. They do not provide a clear picture of the percentage of resources that are devoted, in their philanthropic programs, to supporting the cause of disability.

The low level of support observed among the foundations surveyed clearly indicates that the financial resources mobilized by the organizations surveyed come primarily from public funds and, to a much lesser extent, from private sources.

Sixth, the distribution between organizations with a broad territorial scope (provincial level) or a limited scope (regional or sub-regional level) covering one or more areas of activity and working equally on representation and support, and receiving financial support mainly from public sources and to a lesser extent from private sources (from foundations, patrons, fundraising activities, or self-financing).



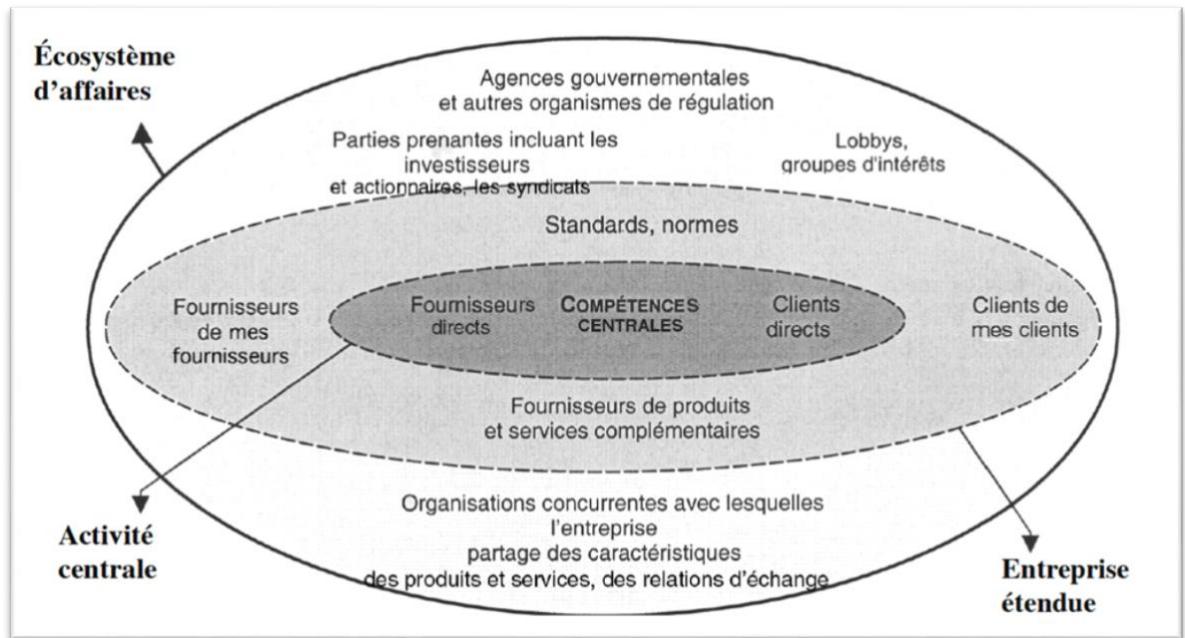


Figure6: Business ecosystem
 Source: Gueguen and Torres, 2024, p. 230

This observation reflects the presence of a miniature ecosystem of action. Our observations simply allow us to sketch out a social ecosystem. Drawing inspiration from the concept of a business ecosystem (Gueguen and Torres, 2004), we understand "ecosystem specific to a social cause" to mean a group of actors engaged in cooperation, coopetition (a form of collaborative competition), and joint evolution with a view to mobilizing resources to meet the needs and defend the rights of people in situations of vulnerability, disability, or handicap.

The literature review on the concepts of vulnerability, disability, and handicap, and the two portraits—sociodemographic and organizational mapping—show the presence of actors, organizations, institutions, and capital flows that form a system around the cause of disability. However, in order to move from a "system" to an "ecosystem," a qualitative leap must be made in terms of dynamism, interconnection, and the distribution of inputs and outputs (distribution and circularity of financial and other resources) between the various components of the system.

The next section of this report focuses on the contemporary social construction of disability issues in Quebec and Canada. It will allow us to add important data on dynamism, interconnection, and resource allocation.

3. Development since World War I of the social movement of persons with disabilities, public policies, and social perceptions of persons with disabilities

Society's and state institutions' perceptions of people in vulnerable situations and with disabilities have evolved since 1945. Indeed, under the impetus of a variety of actors—such as activists, politicians, researchers, and international organizations—the dominant conception of disability in Quebec and Canada has gone through three historical periods, each featuring one or more models of action (Jongbloed, 2003).

- The first period, spanning from the 19th century to 1914, is characterized by the presence of the first model identified and named "*law and order*."
- The second period, between 1914 and 1960, featured an economic model, which coexisted with another model known as the medical model.
- A third period, from 1960 to the present day, is composed of sub-periods featuring a fourth model that we have described as social.

The prevailing perceptions for each of these models gave rise to the formulation and implementation of public policies based on different rationales and distinct objectives (Boucher, 2005; Jongbloed, 2003).

In this section, we will trace the evolution of models of disability perception in Quebec and Canada. In doing so, we will mention the main public policies and actors that have instigated change. We will conclude this section by presenting a summary of the public policies and measures available to persons with disabilities in 2024.



3.1. From the 19th century to 1914: the "*law-and-order*" model

In the second half of the 19th century and early 20th century in Canada, people with disabilities were considered dangerous and disruptive to social order. Society had to protect itself from them (Rioux, 1993). Following what Jongbloed (2003) calls the *law-and-order* approach, people with intellectual disabilities were imprisoned in penitentiaries or confined to homes. People with physical disabilities were more tolerated, as they did not pose a social danger, but they often died prematurely due to the lack of appropriate care available (Jongbloed, 2003).

At that time, there was no public policy to support people with disabilities. On the contrary, several Canadian provinces passed laws restricting interprovincial movement or immigration of people with intellectual disabilities, requiring their internment in mental health institutions or penitentiaries, or mandating their sterilization (Rioux, 1993).

3.2. From 1914 to the late 1960s: coexistence of economic and medical models and the emergence of a new social movement I

Negative perceptions of people with disabilities and the discriminatory policies that accompanied them began to change after World War I (Jongbloed, 2003). At that time, the economic model, which views disability as "the reduction in a person's productive and working capacity as a result of a disability," explored fiscal solutions to disability (*free translation*, Fougeyrollas, 2019, p. 26). The economic model began to establish itself as the dominant paradigm.

During World War I, rehabilitation programs and disability pensions were established for veterans wounded in combat, notably through the Federal Pension Act of 1919 and other provincial laws. These programs aimed to rehabilitate soldiers so that they could quickly re-enter the labour market and be economically productive. They also sought to compensate veterans for income lost due to a disability caused while serving in the military (Jongbloed, 2003).



It is important to note that civilians with disabilities did not enjoy the same benefits (Boucher, 2005). Indeed, disabilities resulting from military service were considered more deserving of government assistance than other disabilities (Hahn, 1985; Jongbloed, 2003). However, there were other determining factors related to illness, workplace accidents, or accidents occurring outside of work. It should be noted that the first occupational health and safety measures, programs, and policies were implemented at the provincial level and then nationally in the first third of the 20th century.

Following World War II, programs based on the economic model were opened up to people whose disabilities were not caused by military service. These individuals became eligible for programs such as the National Employment Service (special placements component) (1940s) and the Canada Assistance Plan (1966) (Boucher, 2005) (see Table 12).

In the post-war period, the development of public policies and social programs for people with disabilities was partly attributable to effective activism. During this period, associations of parents with children with disabilities began to appear, self-help groups for persons with disabilities, and associations founded by wounded veterans who had participated in the two world wars, such as the Canadian National Institute for the Blind (CNIB, founded in 1918) and the Paraplegic Association of Canada (PAC, founded in 1945). The latter engaged in lobbying and public opinion campaigns. The CPA contributed to the adoption of *the Disabled Person's Act* (1954) (Boucher, 2005).

Lord and Hutchison (1998; cited in Boucher, 2005, p. 148) emphasize the importance of these early associations for the cause of people with disabilities:

It was only after 1945, when groups and families began to advocate on their behalf, that the political voice of people with intellectual disabilities began to be heard. Family advocacy groups also helped shape government policy and social change by presenting a vision of what might be possible for people with disabilities.



The economic model described above, which viewed disability as an obstacle to active life and economic productivity, coexisted with a third model, known as the medical model, which also emerged during World War I. The two models coexisted until the 1970s.

The medical model viewed people with disabilities as "functionally limited and biologically inferior" (Jongbloed, 2003, p. 205). These individuals needed to be treated by a healthcare professional (Fougeyrollas, 2019). The medical model was based on diagnosis and assumed a causal relationship between the medical causes of a disability and its consequences in people's lives. This model did not consider the social and structural causes of disability (Hahn, 1985).

In line with the *law-and-order* model, the medical approach led to a certain degree of segregation of people with disabilities, given the "establishment of heavy and specialized institutions" (Boucher, 2005, p. 147) to treat them.

	<i>Pensions Act</i>
1919	Federal law introducing a monthly disability pension for veterans with disabilities and a care allowance (MacLean et al. 2019).
	<i>Bill C-19 (War Veterans Allowance Act)</i>
1930	Federal law aimed at "providing income assistance to veterans deemed unfit for work due to their service" (MacLean et al. 2019).
	<i>National Employment Service (special placements component)</i>
1940	Federal employment program encouraging employers to hire people with disabilities (Boucher, 2005).
	<i>Marsh Report (Report on Social Security for Canada)</i>
1943	Report containing "an initial proposal for a wide range of welfare state reforms, including occupational disability and caregiver support, as well as universal access to medical care" (Stauch and Snowden-Lawley, 2024, p.83).



	<i>Veterans Affairs Act</i>
1944	Federal law mandating the creation of the Department of Veterans Affairs, whose mission is to implement and coordinate programs for veterans, including those with disabilities (MacLean et al. 2019).
	<i>Veterans Charter</i>
1946	Federal law offering veterans wounded during World War II improved disability benefits and priority hiring in the public service (MacLean et al. 2019).
	<i>Universal Declaration of Human Rights</i>
1948	United Nations declaration affirming the equality of all before the law and the right of everyone to equal protection against discrimination (Universal Declaration of Human Rights, 1948).
	<i>Disabled Persons' Act</i>
1954	Federal law promoting the integration of persons with disabilities into the workforce by reimbursing provinces for 50% of the costs associated with their training (Jongbloed, 2003).
	<i>Canada Assistance Plan</i>
1966	Federal law establishing cost sharing for social assistance programs, from which persons with disabilities can benefit (Government of Canada, 2023).

Table 10: Canadian and Quebec public policies relating to disability between 1914 and 1966

3.3. Early 1960s to present: from the sociopolitical model to the social model

3.3.1. From 1960 to 1990: dominance of the sociopolitical model

The sociopolitical model views disability

not "as a physical or mental impairment, but as a social construct shaped by environmental factors, including the physical characteristics of the

environment, cultural attitudes and social behaviours, as well as the institutionalized rules, procedures, and practices of private entities and public organizations" (*free translation*, Scotch, 2000, p. 215).

In *other* words, according to this approach, disability is the result of "a form of social oppression constructed through discriminatory attitudes, representations, and practices rooted in sociopolitical systems that value performance, ableism, and productivism" (Fougeyrollas, 2019, p. 26). This results in a built environment and social norms that are unsuitable and non-inclusive, preventing certain people from using or navigating it adequately (Oliver, 1990).

This model gained popularity in the 1960s and 1970s, both in Quebec and Canada. In Quebec, the 1960s marked the beginning of the development of the Quebec welfare state, accompanied in the 1970s by a growth in "social, economic, and political concerns about disability and its consequences for individuals and society as a whole" (Boucher, 2005, p. 148). Actors with diverse objectives came together in a movement that broke with economic and medical models and promoted the social integration of people with disabilities rather than their institutionalization (Boucher, 2005).

In 1978, a major institution working in the field of disability rights in Quebec, the Office des personnes handicapées du Québec (OPHQ), was created through the adoption of the *Act to secure the rights of persons with disabilities with a view to their educational, professional, and social integration*. Responsible for coordinating all ministries with regard to disability, the OPHQ developed a comprehensive policy for the social integration of persons with disabilities for the Quebec government, published in 1984 under the title *À part... égale* (Fougeyrollas, 2019). The OPHQ also contributed to the development of direct payments to persons with disabilities, a service modality that had been little used until then (Boucher et al., 2011).

In the rest of Canada, the 1970s also saw the creation and rise in importance and visibility of organizations concerned with the human rights of persons with disabilities, such as patient and parent groups. This proliferation led to the creation



in 1977 of the Coalition of Provincial Organizations, Ombudsman for Persons with Disabilities (COPOH), now known as the Council of Canadians with Disabilities (CCD), a coalition of persons with disabilities.

The CCD, together with other organizations, defended the idea that "improving the situation of persons with disabilities required changes to the external environment rather than changes in individual functioning" (Jongbloed, 2003, p. 205), firmly anchoring it in the sociocultural approach.

Partly thanks to this new wave of mobilization, between the 1960s and 1980s, there were numerous regulatory developments in Quebec and Canada with regard to the rights of persons with disabilities (see Table 11). In particular, the adoption of the Charter of Rights and Freedoms in 1982, which identifies persons with disabilities as one of four disadvantaged groups (Jongbloed, 2003), marked a major victory for the associative movement and ensured the lasting political and legal recognition of persons with disabilities (Prince, 2009).

	<i>Declaration of the Rights of the Mentally Disabled</i>
1971	United Nations Declaration Recognizing the Rights of Persons with Intellectual Disabilities (United Nations, n.d.).
	<i>Declaration on the Rights of Persons with Disabilities</i>
1975	United Nations Declaration recognizing the rights of persons with disabilities at the international level (Boucher, 2005).
	<i>Bill 55</i>
1975	Bill that died on the order paper aimed at protecting persons with disabilities by the Quebec government, precursor to the 1978 Act described below (Boucher, 2005).
1978	<i>Act to ensure the exercise of the rights of persons with disabilities with a view to their educational, professional, and social integration</i>

	Quebec law aimed at the social integration of persons with disabilities and mandating the creation of the OPHQ (Fougeyrollas, 2019).
	<i>Creation of the Office des personnes handicapées du Québec (OPHQ)</i>
1978	Quebec government body responsible for coordinating ministries on disability issues (Fougeyrollas, 2019).
	<i>International Year of Disabled Persons</i>
1981	Year chosen by the United Nations to raise public awareness of disability issues and defend the rights of persons with disabilities (United Nations, n.d.).
	<i>Bill of Rights and Freedoms</i>
1982	Charter identifying persons with disabilities as part of a disadvantaged group, thereby enshrining the cause of disability in the Constitution (Jongbloed, 2003).

Table 11: Canadian and Quebec public policies between 1971 and 1982 relating to disability

In the Canadian context, these developments were part of a wave of social and institutional changes in the country, but also part of international progress (Jongbloed, 2003). Indeed, several countries enacted laws promoting independent living for persons with disabilities, such as the United States (*Chronically Sick and Disabled Person's Act*, 1973), the United Kingdom (*Rehabilitation Act*, 1973), and France (*Loi d'orientation en faveur des personnes handicapées*, 1975) (Boucher, 2003).

At the same time, on the international stage, the United Nations adopted the Declaration on the Rights of Mentally Retarded Persons in 1971; in 1975, the Declaration on the Rights of Disabled Persons (United Nations, 2024); and proclaimed, in 1976, that 1981 would be the International Year of Disabled Persons (Jongbloed, 2003).

3.3.2. 1990 to 2025: refinement and fragmentation of the socio-political model and reconfiguration towards a social model

Boucher (2005, p. 150) identifies a third phase, beginning in 1990. According to the author, "society is then driven by a set of social phenomena that are still difficult for social theorists to interpret, but which nevertheless reveal the elements of a process of change."

This new phase is marked by two key elements.

The first is the prevalence of the "*nothing about us without us*" position (Charlton, 1998). Rooted in the sociopolitical model, which promotes social integration and self-determination, this position became the norm during the third phase and propelled people with disabilities to the forefront of the fight for their rights and the co-production of public policies intended for them (Boucher, 2005).

The second element is the popularization of the framework for analyzing social exclusion, an extension that is consistent with the sociopolitical model. As Boucher (2005) points out, social exclusion has become an umbrella term for various phenomena. The adoption of this way of thinking has led to an increase in targeted government interventions in order to respond to the increasingly fragmented demands of specific groups.

Since the beginning of this third phase until 2024, several pieces of legislation strengthening the rights of persons with disabilities or their enforcement have been adopted in Canada and Quebec (see Table 13), including the *Accessibility for Ontarians with Disabilities Act (AODA)*, the first law of its kind in Canada. It establishes robust accessibility standards in the province and stipulates that all buildings and services must be accessible by 2025. Several other provinces, such as Manitoba (2013) and Nova Scotia (2017), have adopted similar laws. The Canadian Accessibility Act of 2019 also embraces similar principles.

On the international stage, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) in 2007. This convention defines



many rights for persons with disabilities, particularly with regard to accessibility. In order to align federal laws with this treaty, which was ratified by Canada in 2010, the Canadian Accessibility Act was adopted in 2019 (Stauch and Snowdon-Lawley, 2024).

	<i>Accessibility for Ontarians with Disabilities Act (AODA)</i>
2005	Accessibility law requiring full accessibility of buildings and services in Ontario by 2025 (Stauch and Snowdon-Lawley, 2024).
	<i>United Nations Convention on the Rights of Persons with Disabilities</i>
2006	International treaty establishing specific rights for persons with disabilities, which led to the adoption of the Accessibility for Ontarians with Disabilities Act (AODA) (Stauch and Snowdon-Lawley, 2024).
	<i>Marrakesh Treaty</i>
2013	International treaty aimed at meeting the accessibility needs of persons with visual disabilities by amending copyright laws (Government of Canada, 2016).
	<i>Canada Accessibility Act</i>
2019	Act requiring federal buildings and services to be accessible by 2040 (Stauch and Snowdon-Lawley, 2024).

Table 12: Canadian and Quebec public policies between 2005 and 2019 relating to disability

3.3.3. From 2005 to today: the Canadian context

Today, people with disabilities in Canada live in an environment where public policies intended for them are fragmented, for two main reasons.

First, the constitutional division of powers in Canada means that these policies and their degree of effectiveness vary depending on the province or territory. The federal government is responsible for employment insurance and old age

pensions, while the provinces are responsible for legislating in the areas of health, social services, and education (Dinan and Boucher, 2023).

This division means that policies adopted at the federal level generally follow the economic model of disability, while programs at the provincial level are more diverse, following economic, medical, and sociopolitical models. This results in "a wider range of measures such as unemployment benefits, employment support, health services, tax credits, and tax exemptions " (Dinan and Boucher, 2023, p. 725). Nevertheless, the significant share of responsibilities left to the provinces and territories creates considerable heterogeneity in public policies for persons with disabilities across the country.

Second, public programs and policies have been developed gradually, in line with changing models of disability and the gradual emergence of demands and needs expressed by different groups. The measures developed in this way often tend to ignore the multidimensional nature of disability—which causes economic, medical, and sociopolitical difficulties—and focus instead on one of these aspects.

Consequently, rather than being a coherent, unified, and comprehensive set of policies, the body of public policies supporting persons with disabilities is an incomplete collection of isolated programs stratified according to their model, their conception of disability, and their views on society's responsibilities toward persons with disabilities (Jongbloed, 2003).

The inconsistency of the public policy system surrounding disability is undoubtedly a challenge for persons with disabilities, who must adhere to different programs with divergent objectives that may not cover all their needs. This inconsistency is also a problem for Canada at the legal level and in terms of its compliance with its international commitments.

In 2007, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD), to which Canada is a signatory. Under this convention,



signatory states are required to systematically collect and report data on public policies relating to disability, a requirement with which Canada still does not comply (Finlay et al., 2020). The absence of such a database not only makes it impossible to verify whether Canada and its provinces are complying with the CRPD, but also complicates the analysis we are attempting to carry out.

3.3.4. 2005 to present: the context of Quebec's

As mentioned above, public policies based on several models of disability coexist in Canada and Quebec. The sociopolitical model, developed since the 1960s, is the main approach guiding interventions for people with disabilities in Quebec. Based on the social integration of persons with disabilities, the Quebec model is "*client-centered* and individualized, and services are generally provided by health professionals" (Dinan and Boucher, 2023, p. 731). The governance structure of the Quebec health care system is multi-jurisdictional and more complex than those of other Canadian provinces, such as Ontario. While, in theory, a more fragmented structure may be more flexible and lead to better social integration of persons with disabilities in contexts where standards are complex and fragmented, this is not necessarily the case in Quebec. For example, a comparative study on the social integration of adults with disabilities in Ontario and Quebec showed that they are socially integrated to a similar degree in both provinces (Dickson, 2022).

In a study on the mechanisms of social participation among working-age people (15-64 years old) with disabilities in Canada, Dinan and Boucher (2023) reveal that more than 90% of provincial public policies implemented in Quebec are aimed at providing financial assistance to beneficiaries to offset the costs associated with disability. Compared to other Canadian provinces, Quebec is an extreme case, as the latter have a more balanced distribution between financial policies, policies providing disability-specific services, and policies providing financial support and services.



Given the absence of a government database listing programs and measures for persons with disabilities, as required by the CPDH, researchers (Finlay et al., 2020) have attempted to compile this information. For the period from fiscal year 1999-2000 to 2017-2018, Quebec spent \$5,892 per person on support programs exclusively for persons with disabilities (Zwicker and Finlay, 2024). This statistic places Quebec in sixth position among the ten Canadian provinces, slightly below the median value (\$6,134 for British Columbia) and above the average value of \$5,552.

The database developed by Finlay et al. (2020), despite its limitations, indicates that many programs are in place in Quebec to assist people with disabilities. During the period covered by their study, the most significant financial measure introduced by the provincial government was the *Solidarité sociale* program. Introduced in 2007 and enhanced in 2008, this program provides financial assistance to people with "severe employment constraints [and promotes] integration and social participation" (Government of Quebec, 2024). This measure increased Quebec's total investment in programs for people with disabilities from \$231 per capita in 2006 to \$269 in 2007 and then to \$417 in 2008. This value continued to grow until 2014, when it reached \$451 per capita, before falling back to \$445 in 2017 (Zwicker and Finlay, 2024).

Over the period studied, the five largest government programs in terms of total investment were *Social Solidarity* (\$15.6 billion), *Intellectual Disability and Autism Spectrum Disorder* (\$13.9 billion), *Physical Disability* (\$8.6 billion), the *Amount for Severe and Prolonged Mental or Physical Impairment* (\$3.9 billion), and the *Paratransit Subsidy Program* (\$1.5 billion) (Zwicker and Finlay, 2024).

Since the Coalition Avenir Québec (CAQ) came to power in 2018, several measures have been put in place to "bring those furthest from the labour market into employment, including people with disabilities" (Dinan and Boucher, 2023, p. 732). These policies, which include the *Adapted Business Grant Program*, the *Work Integration Contract*, the *Adapted Work Premium*, and the *Work Premium*



Supplement, are part of a context of labour shortages and the retirement of large numbers of *baby boomers* (Dinan and Boucher, 2023).

However, the programs mentioned above are only those that have historically received the most funding. In 2024, Quebec has many more programs and measures aimed at people with disabilities. We have identified 42 of them, which are listed in Table 13. In addition to these, there are 10 federal programs, for a total of 52.

Federal measures and programs

Tax credit - Home accessibility expenses

Non-refundable tax credit - Medical expenses (Canada Revenue Agency)

Non-refundable tax credit - Canada Caregiver Benefit for other dependents aged 18 or older with a disability

Disability Tax Credit (DTC)

Deduction for Support Products and Services for a Person with a Disability (Canada Revenue Agency)

Disabled Children's Benefit (DCB)

Special Benefit - Diapers and Incontinence Pants

Employment Insurance Caregiver Benefits

Program - Canada Pension Plan Disability Benefit

Program - Gasoline Excise Tax Rebate

Provincial measures and programs (Quebec)

Non-refundable tax credit - Medical expenses (Revenu Québec)

Non-refundable tax credit - Expenses for medical care not provided in your region

Non-refundable tax credit - Amount for severe and prolonged impairment of mental or physical functions



Non-refundable tax credit - Amount for dependents and amount transferred by an adult child in postsecondary education

Refundable tax credit for caregivers

Refundable tax credit for adapted work premium

Deduction for products and services to support a person with a disability (Revenu Québec)

Exemption from payment of contributions to the Québec Drug Insurance Plan

Act Early Program

Home Adaptation Program (PAD)

Vehicle Adaptation Program (PAV)

Communication Assistance Program (CAP)

Social Assistance and Support Program – Action

Assistance Program for the Purchase of Compression Garments for Lymphedema

Daily Living and Domestic Assistance Program

Hearing Aid Assistance Program

Material Assistance Program for Elimination Functions

Technical assistance program for people with physical or intellectual disabilities or autism spectrum disorder (ASD)

Visual aids program

Special Needs Allowance Program - Adult Component

Special Needs Allowance Program - Youth Component

Physical Disability Assistive Device Program

Orthotic Shoe and Shoe Fitting Program

Walking Aid Program

Adapted Tricycles and Bicycles Program



Three-Wheeled and Four-Wheeled Scooter Program

Financial exemption program for domestic help services

Financial contribution program for adults living in public institutions

Financial contribution program for persons placed in intermediate care facilities

Employability Development Program for Persons with Disabilities (PDEIPH)

Loan and Grant Program - Major Functional Impairment

Loan and Grant Program - Serious Mental or Physical Health Disorder

Ocular Prosthesis or Artificial Eye Program

Reimbursement Program for Expenses Related to the Use of a Mobility Assistance Dog

Social Solidarity Program

Family Support Program

Ministerial Enteral Feeding Program

Ministerial Communication Technology Assistance Program

National Home Ventilation Assistance Program (PNAVD)

National Home Oxygen Therapy Program (PNOD)

Program for devices intended for ostomates

Transportation and Accommodation Program

Table 13: List of programs for people with disabilities in Canada and Quebec in 2024
Sources: Canada Revenue Agency (2024); L'Accompagnateur (2024); Revenu Québec (2024)

Despite these public policies and investments by the Quebec government, they have not yet achieved the desired results in terms of integration and inclusion. For example, despite the inclusion of persons with disabilities in the *Act respecting equal access to employment in public bodies* (adopted in 2001,

amended to include persons with disabilities in 2005), the proportion of civil servants with disabilities in the public bodies covered was only 1% in 2019, well below the target of 4.6% (Dinan and Boucher, 2023).

The built environment in Quebec is also not very accessible for persons with disabilities. In addition to architectural and urban planning practices that are hostile to this group (only 45% of public spaces are accessible, according to B nard (2017)), the harsh winter contributes to reducing the accessibility of public spaces (Bonnell et al. 2021). It should be noted that transportation in general also represents a significant barrier to employment access.

Furthermore, people with disabilities face a higher poverty rate than the general population (Dinan and Boucher, 2023). Poverty, combined with the remaining factors of precariousness linked to disabilities, makes these individuals more vulnerable to social upheaval.

For example, it has been pointed out that the challenges associated with the COVID-19 pandemic and government responses to the virus have exacerbated the inequalities and challenges faced by people with disabilities. Indeed, in addition to experiencing challenges related to mental health and economic and food insecurity, which are widespread among the general population, these individuals "faced difficulties accessing information about health services, lockdown measures that did not take their specific needs into account, and disruptions to essential services and supports" (Shikako et al., 2023, p. 1).

4. Overview of stakeholders in the vulnerability, disability, and impairment sector

Depending on the definition of what constitutes a stakeholder in the disability sector, estimates of the size of the sector in Canada and Quebec vary.

Proulx et al. (2006, p. 18), based on a definition associated with the social economy, identified 1,357 "social economy organizations serving people with

disabilities" spread across all administrative regions of Quebec. These authors used a broad definition of the social economy, "which does not limit the social economy to organizations and businesses that engage in commercial activities (charging for services), and which therefore includes all community organizations, whether they are involved in providing services to the population or defending rights" (p. 10).

The *Canadian Abilities Foundation* (2007, cited in Prince, 2009) identified "more than 5,000 disability-specific organizations" in Canada (p. 113).

Although Prince (2009) does not provide an estimate of the size of the *Canadian disability community*, he does offer a useful classification of the actors in this sector.

The author identifies five categories of actors: citizens; social movements; service providers; pressure groups and interest coalitions; and knowledge production networks.

We will use this typology in the next section and, where possible, the literature on the subject will be linked to the database we have constructed.

In the last subsection, we will present philanthropic actors from the perspective of grant-making foundations, which are absent from the classifications of Prince (2009) and Proulx et al. (2006).

4.1. Citizen action

15 (1) The law shall not discriminate against any person and shall apply equally to all persons, and all persons shall be entitled to the same protection and benefit of the law without discrimination, in particular on the basis of race, national or ethnic origin, colour, religion, sex, age, or *mental or physical disability* (Government of Canada, 1982; Canadian Charter of Rights and Freedoms, s. 15, 1982; emphasis added).

Since 1982, equality for persons with disabilities has been a right protected by the Canadian Constitution under section 15 of the Canadian Charter of Rights and Freedoms. More specifically, the inclusion of the phrase "mental or physical impairment" in the Charter ensures "that disability and persons with disabilities are recognized 'politically' with respect to equality rights and the legitimacy of affirmative action provisions in Canadian public policy" (Cameron and Valentine, 2001, p. 35, cited in Prince, 2009, p. 123).

Citizens with disabilities are an integral part of all the categories of actors presented below. Considering the position of *"nothing about us without us"* (Charlton, 1998), which emerged with the sociopolitical model and has gained importance over the last few decades (Boucher, 2005), these individuals are frequently at the center of social movements, nongovernmental organizations, and interest coalitions for the rights of persons with disabilities (Prince, 2009). The database we have compiled sheds little light on citizen action, as our study focuses on organizations.

4.2. Activism in new social movements

Prince (2009) describes collective action in the disability community as a *new* social movement because "new social movements (NSMs) are organized around diversity to promote social identities that have taken the place of public-oriented collective action in many countries since the 1960s.

They are "new" as opposed to social movements described as old, such as trade unions and working-class pressure groups. As a result, NMSs "focus on quality of life, equality, personal fulfillment, participation, and human rights" rather than on issues related to labour relations (Hutchison et al. 2007, p. 712). The NMS also tends to adhere more closely to the principle that people with disabilities should be at the heart of decision-making, communications, and representation of the movement and its components (Hutchison et al., 2007).



This type of movement, like *disability rights movements* and *independent living movements*, has played a crucial role in securing and implementing rights for persons with disabilities (Genest, 2016). Activists for the rights of persons with disabilities have also participated in other social movements in Quebec and Canada, such as the Quebec student movement in 2012 (Genest, 2016), promoting their vision of equality, accessibility, and citizenship.

The formal and informal organizations that are part of the NMS for the rights of persons with disabilities mainly pursue "state-centered" objectives, aiming for social and economic reforms and the adoption of public policies favourable to their cause. A minority of participants in the movement (Prince, 2009) use demonstrations, marches, rallies, and picketing to put direct pressure on the state, although it is possible to identify numerous instances of demonstrations in favour of the rights of persons with disabilities since the 1960s (Barnartt, 2008).

Since the database we have built focuses on civil society organizations engaged in philanthropic processes, either as funders or funded organizations, we have not included informal groups organizing demonstrations or other methods described above. However, it is safe to say that at least some of the organizations in our database are part of the NMS surrounding disability issues, given their "advocacy" functions.

4.3. The work of service provider organizations

The category of service provider organizations is probably the largest in terms of number of organizations. Organizations belonging to this family provide services to the community, often for people with a particular disability, and sometimes engage in advocacy. There is considerable variation in their organizational identity in terms of their conception of disability, sources and amount of financial resources, staff employed, size, etc. (Prince, 2009).

The formation process and composition of these organizations are also varied: while many older organizations were created *for* people with disabilities, a new



wave of organizations, which emerged in the 1970s, are created and managed by people with disabilities (Hutchison et al. 2007). This model of operation for organizations whose services are intended for persons with disabilities is reminiscent of the "*nothing about us without us*" position (Boucher, 2005; Charlton, 1998) mentioned above. According to Hutchison et al. (2007), this new wave of organizations represents the NMS of disability in the language they use, their values, their leadership by people with disabilities, and their focus on issues of "quality of life, equality, participation, and human rights" (p. 712).

Despite this new wave of organizations, which are closer to the values promoted by the NMS in terms of vulnerability, they do not necessarily adopt a strong activist or politicized approach to achieve their goals. Indeed, the neoliberal management of the Canadian state prioritizes the free market and reducing the size of government, as reflected in service cuts. These policies lead the state to rely on civil society organizations, controlled by restrictive project funding, to fulfill important roles that theoretically fall to public action (Kelly, 2013). In order to obtain public funding, NPOs abandon activism in favour of "supporting people."

Organizations with "political objectives," including efforts to "preserve, oppose, or change the law, policy, or decision of any level of government in Canada or in a foreign country" are not eligible for charitable status in Canada [...], but charitable status is a prerequisite for access to most sources of funding in Canada" (Kelly, 2013, p. 9).

It is interesting to note that the language used by organizations supporting people with disabilities reflects this need to appear apolitical: "Many, if not all, of these organizations will not use terms such as *advocacy*, *activism*, *disability movements*, or *empowerment* in their public documents and mission statements,

preferring to use more neutral terms such as *public education* and *self-advocacy*"¹(Kelly, 2013, p. 10).

Another apparent result of this incentive to adopt a politically neutral position is that "most community organizations are primarily concerned with service delivery" and that only "a few combine service delivery and public advocacy in their mandate" (Prince, 2009, p. 115). However, we found that a large number of service delivery organizations also included advocacy in their mission. In fact, 61 NPOs (25% of the sample) belong to the category *Representation of a specific disability - Representation, integration, information, and support*. Organizations in this category have a mission to represent or advocate for their members, in addition to providing them with services and support².

Although Prince's (2009) definition of service-providing organizations and Proulx et al.'s (2006) definition of social economy organizations do not match—the latter includes businesses, among others—the statistical data provided by Proulx et al. (2006) provide a good picture of this sector in Quebec. The data presented in Table 14 classify the fields of activity of social economy organizations working in three areas of disability—physical, intellectual, and mental health—based on the percentage of organizations working in one of the three identified fields of activity.

¹ Terms in italics are not translated as they refer to vocabulary.

² It is important to note that this representation may be biased, since our review is not exhaustive and organizations whose purpose is to represent and defend the rights of a group may tend to have a greater virtual presence than other types of organizations, such as local associations. Nevertheless, the existence of 69 such organizations in the selected regions of Quebec shows that they are well represented—much more so than other categories of organizations.

In all these fields, the categories of psychosocial support, advocacy, and social, recreational, and cultural activities are the most common.

Physical disability		Intellectual disability		Mental health	
%	Field of activity	%	Field of activity	%	Field of activity
53.3	Psychosocial support	43.8	Social, leisure, and cultural activities	62	Psychosocial support
46.1	Rights	41	Psychosocial support	35.4	Social, leisure, and cultural activities
42.4	Social activities, leisure, and culture	40.7	Rights	30.9	Rights
32.5	Family support	30.9	Family support	23.1	Family support
17.1	Transport	20.4	Transport	18.4	Work and productive activities

Table 14: Social economy organizations working in different sectors of the disability community according to their field of activity

Source: Proulx et al. (2006)

These three fields of action are also prevalent in our sample: the family *Support for a specific disability - Support, quality of life, integration, and social inclusion*, which corresponds to the field of psychosocial support, is the most common: 109 out of 313 organizations are involved in this field, representing 45% of the sample. *Representation of a specific disability - Representation, integration, information, and support*, which encompasses advocacy, is the second largest family, with 61 organizations, representing 25% of the sample. Finally, we divide the field of action, social activities, leisure, and culture into three families: *Support for a specific disability - Support, quality of life, integration, and social inclusion*, which includes organizations working to promote the social integration of people with disabilities through social activities, among other things. *Sports - Sports and*



universal accessibility, which comprises 13 organizations (5%). *Arts and culture*, comprising 7 organizations (3%)³ .

The vast majority of the NPOs surveyed (69%) offer services, support, and represent three categories of disability:

- *Multiple*: 72 organizations, representing 29% of organizations;
- *Neurodevelopmental*: including developmental and learning disabilities, with 56 organizations (22%); and
- *Mental health*: 46 organizations, or 18%.

The average total assets of these NPOs in 2022 were \$729,270. For an organization

- with a Quebec-wide reach, this average was \$605,764;
- focusing on the administrative region of Montreal, \$998,083;
- for the Eastern Townships, \$506,283;
- for the Gaspésie region, \$588,289.

The word cloud created from the missions of NPOs⁴ reveals that the most frequently used words are "organization," "health," "mental," "life," "living," and "services."

³ It should be noted that in our classification, organizations were associated with the main field of action mentioned in the organization's mission statement. Consequently, an organization whose mission is to support social integration, for example, may organize activities in the fields of art and culture, without this being reflected in the classification.

⁴ Common determiners, pronouns, prepositions, and verbs were removed from the word cloud. The words "people" (228 instances), "mission" (75), and "mission" (75) were also removed due to their low analytical potential and high frequency. After removing these words, the most frequent word is "organization," with 66 instances.

4.4. The actions of pressure groups, interest coalitions, and associations

The fourth category, lobby groups, interest coalitions, and associations, consists of organizations whose primary focus is political influence. Representing the interests of their members, clients, or community—in this case, people with disabilities—these organizations present their ideas to and lobby elected officials, members of government, civil servants, or society at large in order to influence the development of public policy or practice (Prince, 2009).

Lobbying groups and interest coalitions can be active within the judicial system. The shift from the medical and economic model of disability to the sociopolitical and then social models has been a factor in the resurgence of legal activism for the rights of persons with disabilities.

This evolution introduced the concept of disability as a human rights, citizenship, and anti-discrimination issue, replacing the old model that viewed disability as a health or social welfare issue.

Once separated by a medical view that tended to classify and divide disabilities, organizations working for a specific disability, united by the universal experience of discrimination of their members, formed coalitions of interest and mobilized the judicial system. In Canada, major organizations associated with this type of advocacy include the *Council of Canadians with Disabilities*, *Inclusion Canada*, and the *Disabled Women's Network of Canada* (Vanhala, 2009). The inclusion of persons with disabilities in the Charter also reinforced the relevance of the legal activism of the disability rights movement (Prince, 2009).

As mentioned above, many of the organizations surveyed have a mission related to representing a specific disability or clientele—69 organizations (22% of the sample) belong to the category *Representation of a specific disability—Representation, integration, information, and support*.

These organizations use a variety of methods to lobby public decision-makers. For example, they may engage in public education and information campaigns



about a disability, such as *the Association des personnes avec une déficience de l'audition* (APDA), part of whose mission is to "[...] defend rights while raising awareness and sensitizing the population to the needs and realities of these individuals" (APDA, 2021). These organizations may also retain the services of a lobbyist consultant to conduct a campaign directly with decision-makers, as many organizations have already done. One example is *the Fédération québécoise des Sociétés Alzheimer* (FQSA), which used the services of a lobbyist to influence legislative developments related to Alzheimer's disease⁵ (Carrefour Lobby Québec, 2024).

Our review also identified groups—i.e., coalitions of organizations (NPOs or foundations)—that do not always have legal personality and are primarily based on advocacy. Of the 17 groups identified, eight belong to the Regroupement family of organizations (*consultative and representative groups*) and six to the *Representation of a specific disability - Representation, integration, information, and support* (the difference with the previous family being that organizations in the *Representation* family also offer information or support, rather than focusing solely on consultation and representation). The majority of groups belong to the *Multiple Disabilities* (eight groups) and *Neurodevelopmental Disabilities* (six groups) categories.

4.5. Knowledge production Scientific s on the sector of vulnerability, disability, or impairment

There is a network of researchers within the ecosystem working on the issue of vulnerability, disability, or impairment. This network creates knowledge and sets

⁵ The mandate posted on Carrefour Lobby Québec is vague: "Advocacy for policies to be adopted and commitments to be made regarding the development of programs to promote disease prevention and the development of means that can be used to relieve people with Alzheimer's disease" (Carrefour Lobby Québec, 2024).

up research mechanisms that can be mobilized by other categories of actors. Research in the field of disability covers a wide range of areas, methods, and topics:

Service delivery and administration, litigation or court hearings, government lobbying and cultural policy [...] clinical and pharmaceutical trials, biomedical studies, engineering research and development, as well as treatments and rehabilitation protocols [...] disability management – in relation to businesses, governments, unions, medicine, and the insurance sector—and addresses issues of recruitment, retention, return to work, injury prevention, and workplace accommodation" (Prince, 2009, p.125).

This category of actors includes *think tanks*, university research groups, and government research mechanisms (OPHQ in Quebec, Statistics Canada at the federal level) (Prince, 2009). These are not included in our database.

4.6. Philanthropic actors: grant-making foundations

The social sector comprises more than 170,000 organizations, 86,000 of which are registered as charities with the Canada Revenue Agency. Of these, 10,844 (8%) were foundations in 2022. They held \$122 million in assets and had expenditures of approximately \$13 million, including \$2 million for charitable activities and \$8 million in donations to qualified donees (Pearson, 2024). Canadian foundations are generally private, public, or community-based. They are small and medium-sized organizations (endowments of less than \$100 million) with few (1 to 6) or no employees. Large foundations are the exception. They have dozens of employees and significant assets: about 30 have more than \$100 million, including 7 with between \$1 million and \$10 million and 1 with between \$4 million and \$40 million (Elson et al., 2020). Foundations are unevenly distributed across Canada, with Ontario having the largest number (40%), followed by Quebec. Together, they account for two thirds of Canadian

foundations. Donations are mainly given to causes related to education, health and social services, religion, and culture, with a minority going to causes related to social injustice (less than 4% of donations) and the environment (around 3%) (Longtin, 2022).

The Longtin report (2022, p. 127) analyzed data from the Canada Revenue Agency to provide an exploratory picture of Canadian foundations' involvement in vulnerability issues.

Some [foundations] support organizations that serve people living with disabilities, intellectual disabilities, autism spectrum disorders, or learning, language, or behavioural disorders (500 [foundations for] 4.61%); supporting people living with mental health disorders, providing psychological assistance services, and promoting mental health (228, 2.10%); or providing addiction treatment services (alcoholism, drug addiction, etc.) (100, 0.92%).

The data presented by Longtin (2022, p. 128) also highlight the intertwining of modes of action when a foundation intends to combat social inequalities. Thus, with regard to the situation of vulnerability linked to social inequalities, he paints the following picture.

Acting more directly on social inequalities, a significant number of foundations seek to help disadvantaged (1,019, 18.43%) or "vulnerable" people by providing for their basic needs (62, 0.57%). Among others, several (559, 5.15%) aim to reduce food insecurity by offering emergency food assistance, meals, cooking workshops, grocery assistance, or promoting and educating about healthy eating habits. Some of these foundations also operate abroad to provide access to drinking water or distribute food in developing countries, particularly during famines. Other foundations (166, 1.53%) support clothing donations or the sale of clothing at affordable prices. Many foundations also work on issues related to access to housing for vulnerable groups. On the one hand, several



organizations (614, 5.66%) offer accommodation services to vulnerable groups (e.g., nursing homes, adapted housing for people living with disabilities or impairments, long-term care or rehabilitation centres, foster families for young people, etc.), provide respite homes for their families and caregivers, aim to increase access to affordable housing for disadvantaged people, or offer support related to housing and maintaining housing. etc.), provide respite homes for their families and caregivers, aim to increase access to affordable housing for disadvantaged people, or offer support related to housing and home care (e.g., home services, donations of furniture or household products, services to residents, etc.).

Scientific literature in Canada and Quebec on foundations active in the areas of vulnerability, disability, or impairment is scarce, if not almost non-existent. Neither the categories of actors proposed by Prince (2009) nor the work of Proulx et al. (2006) give particular importance to philanthropic foundations⁶.

Given their specific characteristics, Canadian and Quebec foundations are "well positioned to bring about social change through innovative tools and strategies and a wide range of roles at their disposal," such as "the autonomy of foundations to address issues that are either controversial or outside the scope of government policy" (Elson and Hall, 2017, p. 58). Several publications provide examples of issues where foundations have had a particular impact, such as:

⁶ The lack of literature on the role of foundations in the disability movement can be explained by the fact that foundations working specifically in the disability field represent only a small proportion of foundations, and that they are difficult for the public to access. Indeed, "it is not easy to conduct research on philanthropy professionals. Private foundations that award grants are notoriously closed institutions, which keep few public records on how programs are developed and decisions are made" (Kohl-Arenas, 2017, p.684).

- the development and adoption of the Registered Disability Savings Plan (RDSP), which provides greater financial security for people with disabilities (Elson and Hall, 2017);
- the McConnell Foundation's funding of *the Planned Lifetime Advocacy Network* (PLAN) to create "a national network to serve, advocate for, and connect people with disabilities" (Pearson, 2022, p. 61);
- The contribution of organizations such as the Canadian Breast Cancer Foundation to raise public awareness about breast cancer and raise funds for its treatment (Quarter et al. 2018).
- the creation of *the Canadian Council for Tobacco Control*, to which the Heart and Stroke Foundation contributed given its concerns about the harmful effects of smoking on health (Quarter et al. 2018); and
- the contribution of various foundations to important organizations in the disability community, such as the Council of Canadians with Disabilities and the *National Network for Mental Health* (Hutchison et al., 2007).

Other publications discuss fundraising methods and, more specifically, the inclusion of people with disabilities. Longmore (2015) has exposed the way in which people with disabilities—especially children—are exploited in telethons that highlight their disabilities and portray them in a negative light in order to elicit pity from viewers.

Despite the virtual absence of scientific literature on the disability sector in Canada and Quebec, our research has revealed that there are a small number of foundations working in this sector in Quebec. The database we have built, although not exhaustive, identifies 46 foundations in the province whose mission relates to disability. Of these, 43 have a province-wide reach, and three focus specifically on the administrative region of Montreal. We did not identify any foundations whose mission specifically focused on disability in the Estrie or Gaspésie-Îles-de-la-Madeleine regions. The average total assets of these foundations are \$3.9 million for foundations with a province-wide reach and \$2.9 million for foundations that focus on the Montreal region.

Among the selected foundations, the three most common types of organizations supported are Support for a specific disability - Support, quality of life, integration, and social inclusion (20 foundations, 44%), Financial assistance - Financial assistance to individuals and families (6 foundations, 13%), Caregiving - Caregiving and civic sponsorship (3 foundations, 7%) (see Figure 6). The most common disability categories targeted are Multiple (22 organizations, 48%), Neurodevelopmental (including developmental and learning disabilities; 6 organizations, 13%), and Physical and motor disorders (5 organizations, 11%) (see Figure 7).

The word cloud created from the missions of the foundations⁷ (see Figure 8) reveals that the most frequently used words are "children," "people," "families," "illness," "life," "support," and "disability."

⁷ Determiners, pronouns, prepositions, and common verbs were removed from the word cloud. The words "foundation" (29 instances) and "mission" (14) were also removed due to their low analytical potential and high frequency.

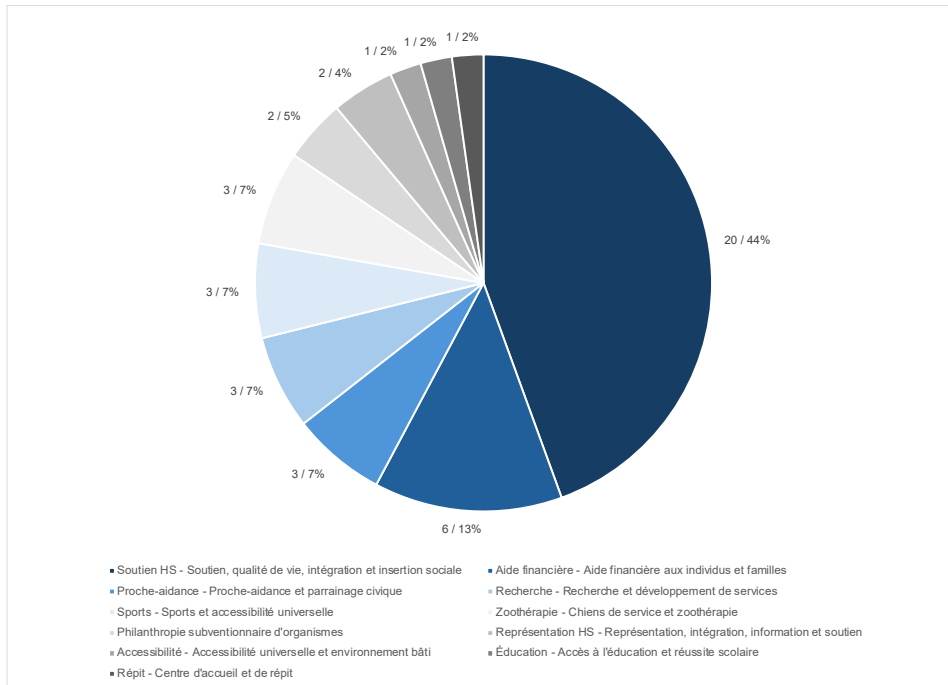


Figure7: Foundations listed by type of organization dedicated to disability

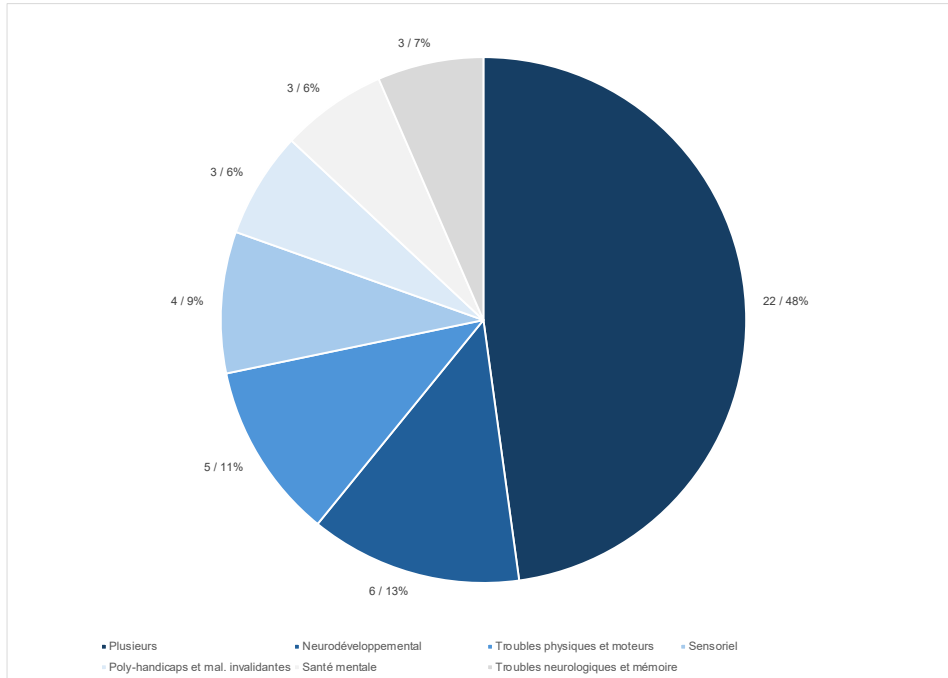


Figure8: Foundations listed according to the category of disability supported

Furthermore, people with disabilities often have multiple types of impairments, which affect their quality of life. In concrete terms, these individuals are more likely to live in poverty than people considered to be fully functional.

Second, an overview of major historical periods shows a gradual opening up of Canadian society to the cause of disability. This openness has been reflected in the adoption of public policies, the development of programs and measures, and the allocation of resources to mitigate the effects of physical or mental impairments. Our exploratory study suggests that adaptations are also taking place in the business world, but we have not been able to identify the advances that have been made in the workplace, whether in the private, social, or public sectors.

Despite the historical development of different models and approaches over more than a century, the authors consulted highlight a dual process of densification and complexification. While densification makes it possible to respond, at least partially, to the problems, needs, and aspirations of people with disabilities, this densification reflects an increase in the capacity for action in terms of representation and advocacy for an increasingly broad range of forms of disability. This densification reflects an increase in the capacity for action in terms of representing and defending an ever-wider range of disabilities, revealing the presence of a well-established network. This densification reflects the availability of greater financial, organizational, institutional, and human resources. Nevertheless, this ecosystem is becoming more complex as it becomes denser, rather than simpler.

Third, we turned our attention to analyzing this ecosystem. We did so by characterizing its various actors, with community actors and civil society occupying a central place. From the limited information we have processed on the various actors that make up the ecosystem of vulnerability, disability, or impairment, the picture that emerges is that of a young, emerging ecosystem, in



the sense that the quality of the interrelationships between its components is more mechanical than organic.

There is therefore room for better organization of the ecosystem, where the roles and functions of the various actors could be better coordinated to generate greater effectiveness and efficiency. From this perspective, the transformative dimension of this ecosystem needs to be strengthened in order to have a direct impact on major institutional systems.

Fourth, we focused our attention on philanthropic actors. Although they are part of the ecosystem addressing vulnerability, disability, and incapacity, these actors are not mentioned in the documentation consulted. Despite the resources at their disposal, philanthropic grant-makers are often overlooked and could be called upon to contribute more.

On the one hand, the resources at their disposal could be better mobilized by support or advocacy organizations, with a view to supplementing government funding or even replacing it when its programs are not accessible to certain causes defended or represented in relation to vulnerability.

On the other hand, although we have not focused much on how the financial resources dedicated to this important cause are distributed between actions to support individuals, families, and communities and actions to represent them, generally more attention is given to support organizations. Given that there is indeed inequality in the distribution of resources, philanthropic actors could facilitate the establishment of a healthy balance between actions to support people in situations of vulnerability, disability, or impairment, and actions aimed at promoting adaptive or systemic change.



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