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Volume 6

Promoting a More Inclusive Society for Dependent or Disabled People

New Paradigms

Edited by
Corinne Grenier
Elizabeth Franklin-Johnson
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Foreword

Any observer of disability policies will agree that over the last 20 years or so – over a generation – profound changes have taken place. In light of these changes, this volume presents a clear overview of two major, complementary themes.

On the one hand, people with disabilities are affirming their long-standing desire for autonomy and for free choice of their living conditions – in short, their power to act – louder than ever before.

On the other, people with disabilities want to be recognized as full and able participants in society and to make real contributions to social life. In the words of sociologist Serger Paugam, people with disabilities do not wish to only rely *on* others and their support, but, more importantly, they wish to contribute *to* others.

These changes in disability policies clearly reflect a general trend running through society as a whole. Indeed, this shift towards "self-assertion" and the desire for social recognition is simply a feature of our times, as can be seen in the case of social groups who believe that their vulnerabilities have caused them to become marginalized. But the movement for the proud affirmation of differences flies in the face of this, encompassing, for the better, all those thought to be excluded and marginalized.

However accurate this observation may be, can we stop here? Can we simply attribute vulnerable groups' demand for their right to self-determination to a burgeoning movement across society as a whole?

Perhaps, this is the case of its origins, but certainly not its manifestations, as there remains a crucial difference between the agency of an individual without disabilities and an individual living with a physical or intellectual impairment: people with disabilities may require additional care or support in order to exercise

their fundamental right to self-determination, that is, to exercise their freedom to decide for themselves what is best for them.

Clearly, even a vulnerable person deprived of their decision-making autonomy as a result of physical or intellectual impairment should remain, in principle, the author of their choices, except when doing so deprives another. But a decision that would, for example, unwittingly place the individual in danger cannot be regarded as an expression of free will. People with disabilities are therefore not really free in their choices, unless they can be informed and advised with as little interference as possible by one or several "care providers".

It is in this context that we must consider today's broad social movements for emancipation and participation, which impact us all. For the most fragile individuals in our society, this is inseparable from questions of care, support and assistance. Care provision and the immense questions it raises, if it is to be effective and free of coercion, is central to realizing vulnerable individuals' "power to act". In other words, care is at the heart of an inclusive society.

From this, we may note two consequences.

The first is that there can be no care without care providers. An "inclusive" society open to all presupposes the existence – and here we may add in an organized and structured way – of a group of professionals (naturally), family members and volunteers tasked with providing essential care.

This raises the age-old (yet nonetheless controversial) question of "deinstitutionalization".

To ensure that self-determination and social participation for the most vulnerable individuals become a tangible reality, we must improve individuals' living environment. In this regard, "deinstitutionalization", understood as the move away from rigid and imposed ways of living, is essential.

But the freer people's life paths become, more open to new possibilities and the ordinary environment, the greater the need is for care providers to expand their expertise, enhance the cooperation of actors and help bridge the expertise of professionals and peers.

Consequently, it is therefore necessary to structure (a kind of "institutionalization") the joint intervention of care providers, including family members, peers and professionals. In summary, to better "deinstitutionalize" the individuals being supported, it is essential to "institutionalize" the interventions of their care providers deinstitutionalization.

Let us now turn to the second consequence.

In the tradition model of care provision, the vulnerable person is placed in direct contact with the professional team in a closed, "protected environment". An inclusive vision of care invites us to replace the traditional model with what we may call the three-point model, which involves two additional interactions between individuals with disabilities and what is sometimes referred to as the "mainstream" or "ordinary" environment, that is, everyday society shared by everyone.

First and foremost, there is the interaction between the disabled individual and this so-called ordinary environment, which arises from more frequent direct engagement with ordinary spaces, services and professional or interpersonal environments. This contact (perhaps without the need for explanation) calls for the adaptation of society and "rendering society accessible" through its public services (starting with children's schooling and education), work organizations, public spaces, housing, transport and so on. While the list of changes may seem endless, not least regarding physical infrastructure, above all, accessibility depends on shifting people's mindsets if society is to welcome and accommodate people with disabilities.

Within this three-point model, there is another (less mentioned, but equally crucial) interaction: the one between the group of professional and specialized "carers" and other care providers, on the one hand, and the ordinary structures of society, on the other. These care providers can only hope to be able to fulfill their role in supporting the life choices of those they assist if bridges are built between their expertise and the functioning of ordinary services and activities.

Care provision no longer only concerns accessibility, but it is also a matter of shared professionalism. Services need to be coordinated and delivered in tandem; those from the ordinary environment must take into account the expertise of specialized care providers, who in turn must provide these services with the expertise they lack or the one-time support they need.

Consider an everyday sport or cultural activity in which an individual with disabilities wishes to participate. Without close cooperation between the sports instructor or activity coordinator, on the one hand, and the professional care team, on the other, the project is doomed to failure.

To make the ordinary environment more accessible, there is a clear need for organized experts (professionals and peer support specialists) on which it can rely, according to an economic model that is, it has to be said, still wanting. Once again, the "institutionalization" of professionals in the social sector – i.e. their ability to

work in stable organizations and for the same goal – is instrumental for bringing about the "inclusive" transformation of society as a whole.

Thus, the future of "medical–social" institutions is not, as we have briefly outlined above, a matter of "deinstitutionalization". Rather, deinstitutionalization will involve the transformation of medical–social institutions into "medical–societal" institutions, aimed at societal transformation.

Denis PIVETEAU
May 2025

Introduction

Since 2008, KEDGE Business School Healthcare Symposia, co-organized by Corinne Grenier, have examined actors, public-sector organizations, and healthcare and social action authorities from a multi-disciplinary approach in order to better understand their dynamics.

Previous topics have included the care of older adults (2008), innovations in public policy (2009), mutualization and re-grouping (2010), performance and user well-being (2011), healthcare organizations: repositories of injunctions or strategic actors? (2013), healthcare organization governance (2015), sustainable innovation (2017), conceptual and methodological tools for innovation (2019)[1], and patient and user experience (2021)[2]. The 2023 edition was titled *"Inclusion and deinstitutionalization: impeding or promoting new paradigms of innovation in health and society?"*.

The contributions in this book are the result of the lively discussions and debates that took place at the 2023 Healthcare Symposium.

Introduction written by Corinne GRENIER, Elizabeth FRANKLIN-JOHNSON and Giovany CAJAIBA-SANTANA.

1 An edited collection organized by Corinne Grenier and Ewan Oiry and published by ISTE/Wiley (*Altering Frontiers*, 2021) features the contributions of researchers who participated in the 2019 Health Symposium, among others.

2 An edited collection organized by Luigi Flora, Corinne Grenier and Frédéric Ponsignon, published by ISTE/Wiley (*Experience in Healthcare Innovation: Fad or New Paradigm?*, 2024), features the contributions of researchers who participated in the 2021 Healthcare Symposium, among others.

I.1. Inclusion: challenging a social promise

The following terms are commonly used in the healthcare sector: inclusive environments, participative and citizen-based approaches, transformation of medico-social and healthcare sector, deinstitutionalization, self-determination, life projects and the ordinary living environment. These are just some of the terms that have made their way into the healthcare and social sectors in recent years, alongside new forms of support for the older adults, people with disabilities, the frail, the precarious and patients, reflecting the social and political will for an "inclusive society".

According to Sen (2001), "inclusion is characterized by a social experience shared by many, active participation in society, a general equality of possibilities and opportunities in life available to each individual, and a basic level of well-being that is shared by all citizens". Given our focus on the healthcare and social sectors, we will pay particular attention to the following elements: a society (or territory) where everyone must be able to live and exist according to their wishes (e.g. their life project and aspirations); the axiom that all life, with no hierarchy between forms/states of life, is important and necessary to enrich us. Thus, for Gardou (2014, p. 14), "the challenge of an inclusive society is to reunite hierarchical social universes to forge a common us, a common repertoire".

In practical terms, promoting a more inclusive society and living environments may involve a) strengthening people's participation in the decisions and activities that concern them, whether they are in an institution or in their ordinary environment; b) respecting their habits and life projects; and c) undertaking actions for social participation.

This is evident in the work of social and associative movements, which demand a more welcoming, equitable and inclusive society and call on all national and regional institutional actors as well as local collectivities to orient their territorial policies in this direction. For example, in 2007, the international movement for Age-Friendly Cities and the WHO Global Age-Friendly Cities Guide identified a number of crucial action areas to support the social and civic participation of older adults. A similar holistic, intersectoral approach has been taken by Humanicité[3] (northern France), a neighborhood project that provides services, health and medico-social structures, schools and housing for the well-being of "all: for all and with all".

Promoting a more inclusive society and living environments is also a primary concern of health/social care operators, particularly when they embark on a

3 See: humanicite.fr.

process of transforming their medico-social or care service offering via "deinstitutionalization", i.e. moving support and care services delivered within establishments to the ordinary environment. This social aspiration also directly involves the communities concerned – older adults, people with disabilities and those in very precarious situations – who possess experiential knowledge and want to share it (Grenier 2024).

"Deinstitutionalization" gives rise to numerous paradoxes and unresolved issues, including the transformation of a compartmentalized and highly regulated social and healthcare system, and the emergence of diverse social and activist movements and new actors, as well as actors who, like many vulnerable groups, too often face challenges to their legitimacy. For public authorities, "deinstitutionalization" could act as a quasi-injunction, which may run counter to the will of individuals. Or, driven by funded calls for projects, perhaps opportunistic healthcare and social service operators will exploit it (Casseron 2022)?

On the contrary, do we necessarily need to "rebuild institutions" – i.e. "rebuild society?". For Bertillot and Vanneste (2022), the ideal of inclusion consists of three dimensions: the rise of singularities within contemporary societies; subsequent expectations of social recognition; and a political future of societal transformation in the light of singularities (Martuccelli 2017).

In this regard, we cannot avoid certain questions and inquiries, or else deinstitutionalization will remain nothing more than a fantasy of liberation (Castel 1981). Researchers and professionals have raised the following issues:

– Do inclusive environments run the risk of inventing new forms of support and assistance that are cut off from the immediate living environment of the people they are intended to accommodate?

– Does care provision at home risk transferring gerontological expertise to the home, thereby isolating it from other forms of expertise (social, cultural, etc.) that are necessary for healthy aging at home?

– In practice, are professionals able to respond to the demand of civil society to "reach out" to and encourage the participation of vulnerable people, in recognition of vulnerable peoples' power to act and right to self-determination?

– In a context of numerous and sometimes contradictory demands, and in an intervention landscape that remains largely compartmentalized according to discrete interests and institutional prerogatives, are organizations and healthcare and social service operators unable to respond to the values that give meaning to their institutional project and their professions?

– Lastly, while approaches involving people with disabilities are popular across society, several studies (Buffel et al. 2020; Bertillot and Vanneste 2022) show that participatory approaches are not necessarily inclusive in themselves since they can fail to pay attention to the forms of local governance or the ambitions pursued by actors (Buffel et al. 2020).

I.2. Examining the inclusive ideal: three points of entry

This book considers movements for greater inclusion as forms of social innovation (Cajaiba-Santana 2014). In thirteen chapters, it brings together French and Canadian academics from a variety of disciplines to question *the extent to which the concept of inclusion, its associated practices and terminology are all bearers of transformation.*

The first part seeks to clarify the foundations of a more inclusive society. It comprises four chapters that each address issues concerning deinstitutionalization. Chapter 1 presents an analysis of texts, case studies and public policies over the past few years, whereas Chapter 2 examines deinstitutionalization in terms of "inside" and "outside" interpretative frameworks. Chapter 3 builds on this analysis by focusing on the issue of personal autonomy. To conclude this section, Chapter 4 examines approaches to measuring the social impact of changes for greater inclusion.

Part 2 considers recent research on new forms of support and assistance. The first two chapters consider educational (Chapter 5) and professional (Chapter 6) inclusion, respectively. Chapter 7 explores peer support, while Chapter 8 examines the rights of patients and people with disabilities in primary care. Chapter 9 concludes the section with a case study, demonstrating the role played by the Simon de Cyrène (SdC) Association in the institutionalization of inclusive housing for disabled individuals.

Part 3 consists of four chapters which focus on the territory. Chapter 10 analyzes the potential of Living Labs to support the social participation of older adults in rural areas, while Chapter 11 discusses an array of shared housing initiatives in intergenerational neighborhoods. Chapter 12 examines public–private–community partnerships in terms of social geriatrics as a means of providing a more preventive approach to healthcare in territories. Lastly, Chapter 13 examines the role of territorialized platforms in circulating initiatives that support older adults' participation in the community.

I.3. API Territories Chair: promoting enabling and empowering pathways

Many of the case studies presented in this book make use of "intervention" (Hatchuel 2001) and "participatory" (Anadon 2007; Bellot and Rivard 2013) research approaches. These approaches aim to build actionable and transferable knowledge in collaboration with actors, with the aim of designing research projects that can bring about real change. Immersion in the field is intended to encourage the active participation of actors (such as researchers, practitioners, people receiving care and more), who should be identified throughout all of the main phases of the research, from the definition of the research problem, through the research design, implementation and analysis phases, to the evaluation of the results. Yet, does this methodology also fall into the trap of prescriptive participatory and inclusive approaches (Eyraud et al. 2018)?

This is what drives the API Territories (Inclusive and Enabling) Research and Experimentation Chair[4]. We firmly believe that institutions, services and any other support measures aimed at achieving greater inclusion in society and the ordinary environment cannot fulfill their promise if the immediate environment in which disabled people conduct their lives on a daily basis (the neighborhood, the city, etc.) is not welcoming, caring and enabling. We therefore endorse the work of Bauer (2015, p. 74), who states that promoting an inclusive society and inclusive manners of acting requires "a dual approach, aimed at both increasing individuals' capacity to act and enhancing the capacity of environments to accommodate everybody – in other words, accessibility in the broadest sense of the term".

In this way, the territory can be a source of empowerment when it offers resources, mechanisms and systems that enable people in need to draw on them at their discretion, according to their ability and their desire for self-determination, and to make use of what they deem useful for carrying out their activities and projects.

To achieve this, we work on designing and creating API Territories (Inclusive and Enabling) in a way that also challenges this process, so that it can be empowering in itself. If we are to fully live up to our promise of participatory

4 See the API Territories Chair (Inclusive and Enabling) at KEDGE Business School. The Chair is funded by ARS PACA, FIRAH (*Fondation internationale de recherche appliquée au handicap*) and IRESP (*Institut de recherche en santé publique*). It is led by Corinne Grenier and includes Elizabeth Franklin-Johnson, Giovany Cajaiba-Santana, Frédéric Bally and Chloé Vallée (KEDGE Business School). The Chair is organized in partnership with the CIRRIS (François Routhier, Université de Laval, Québec), the *Autodétermination et handicap* Chair (Université du Québec à Trois-Rivières, Martin Caouette) and Karl-Emanuel Dionne (HEC Montréal).

research, we need to ensure that people with disabilities can participate in the process in real terms, by contributing their individual points of view, their wishes, and their fears, and sharing their experiential knowledge. This knowledge is "alternative knowledge" (Baillergeau and Duyvendak 2016, p. 411) as in "a truth learned from personal experience with a phenomenon rather than a truth acquired by discursive reasoning, observation, or reflection on information provided by others" (Borkman 1976, p. 446). This knowledge is emblematic of a humanist approach, which aims to "reaffirm the dignity of and richness of human beings, as well as participatory democracy" (Cartron et al. 2021, p. 78).

But alternative knowledge is not "natural" – it is formed through reflection on experience (Cartron et al. 2021) and is the result of a "long and repeated practice of an activity that allows for the emergence of the experienced individual" (Demailly and Garnoussi 2015, p. 58).

One of the methodological challenges faced by the API Territories Chair is how to involve individuals with disabilities in the main stages of research, particularly in the project design phase and during data collection and analysis, so that informal and formal exchanges with other actors for the "common cause" of collaboratively building an API Territory are in themselves enabling and empowering.

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