Under the direction of Isabelle Hachez and Nicolas Marquis

Repenser l'institution et la désinstitutionnalisation à partir du handicap
Actes de la Conférence Alter 2022

Deinstitutionalizing for inclusion?

Isabelle Hachez and Nicolas Marquis

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Isabelle Hachez,
professeure de droit à l'UCLouvain Saint-Louis Bruxelles,
CIRC (Belgique)
Nicolas Marquis,
professeur de sociologie à l'UCLouvain Saint-Louis Bruxelles,
CASPER - ERC Starting grantee (Belgique)

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1. AN INVITATION

"Rethinking the institution and deinstitutionalization from the perspective of disability" is the invitation that presided over the 10th Alter conference that took place at Université Saint-Louis – Bruxelles (Saint Louis University — Brussels, which has since become UCLouvain Saint-LouisBruxelles) on 6-8 July 2022. The choice of this theme was a natural must after the COVID-19 crisis that had exacerbated an already divisive debate, for residential and home services alike were greatly disrupted by the crisis, at the same time as they came in for renewed attention[1]. The context of tension between the protective institution and the institution that imperilled its residents, the institution that cut ties and the institution that (re)created community led the various parties to take up new positions on deinstitutionalization.

How does one take up this invitation to rethink institutions and deinstitutionalization from the perspective of disability? This proposition may seem paradoxical in several respects. On the one hand, it might appear to be comfortable, even soothing, for the debates around institutions and deinstitutionalization are old, now well-ensconced (even institutionalized, we might dare to say) in the scientific and activist fields. As proof of this take the fact that the theme is never totally absent from the conferences that have been organized yearly since 2012 by the European Society for Research into Disability, ALTER, in partnership with a hosting university. On the other hand, this same invitation might appear provocative, even counterproductive, to those who are working to draw closer to deinstitutionalization. Must we really take up again a matter that should have been settled long ago, given the obvious limits of institutionalization, provided, of course, that the remarks of the principal people concerned, i.e. people with disabilities, be taken seriously[2]?

In a word, what is the relevance of "rethinking the institution and deinstitutionalization from the perspective of disability"? The wager of this collective volume is to show that whilst this problem *seems* to make do with a relatively unequivocal answer (taking the form of "deinstitutionalization is of course a *must*!" or "of course the disabled *should* be deinstitutionalized, but it is currently not *possible*", or even "there is no salvation outside institutions!", although this last position is put forward much more seldom today), it is truly indispensable both to step back from the issue and to include more complexity in treating it.

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1 — See i.a. G. Quinn, « Covid-19 and Disability: a War of Two Paradigms », Covid- 19 and Human Rights, M. Kjaerum, M. F. Davis et A. Lyons (eds.), London, Routledge, 2021, chapter 8 ; I. Hachez et L. Triaille, « Covid et handicaps au prisme des institutions et de la désinstitutionalisation », online review *Droits fondamentaux et pauvreté*, 2021/4, p. 140 à 180 et cited references.

2 — See i.a. : G. Quinn and S. Doyle/Regional Office for Europe, *Getting a Life. Living Independently and Being Included in the Community. A Legal Study of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities*, Bruxelles, 2012, 90 p.

2. DID YOU SAY "INSTITUTION"?

We have no definite, commonly accepted definition of what an institution is, and this is perhaps a good thing. There are huge differences between the total institution topicalized by Goffman and the essential therapeutic role that institutional psychotherapy confers on the institution. There are also huge gaps between the institution understood to be a closed space within walls, as a routine, as a formal legally codified system or as a "collective cognitive scheme" ("dispositif cognitif collectif") to take Olivier Favereau's expression[3]), that is to say, a set of rules that, following the example of language, is essential for human life[4].

Despite this polysemy, when we think about institutions or deinstitutionalization, we quickly end up referring to social representations in which the floating term of "institution" takes on negative connotations because it is associated with other terms such as power and constraint, bureaucracy and oversight, separation and exclusion, and non-respect for the person and dehumanization. These representations can arise from experiences (be they personal, second-hand or even spread by culture) of what an institution is. They are also forged by contact with scientific or activist studies, for example by those of (post-)Foucaldian inspiration that fuelled most often and for decades a thoroughly argued critique of the institutional phenomenon. More generally, these imaginative worlds or social representations belong to the context of individualistic societies that tend to pit the individual, with the individual's freedom and potential, against the community and rules and norms, which are perceived more often in terms of the constraints that they impose than in terms of the resources that they offer[5]. This is the moral environment from which citizens, professionals, and communities draw elements of answers to some difficult fundamental questions, such as, "What is a life worth living? What should we do about the differences between humans? What is an inclusive society? What is a good, legitimate way to intervene in the life of or with someone else?" The ways that people tackle these questions trigger animated discussion, for they affect what the philosopher Iris Murdoch calls the "texture of being"[6].

Now, one of the striking characteristics of individualistic societies is to consider people to be equal before the law. Individualistic societies value autonomy, along with everyone's right (and ability) to lead their existence[7]. What is more, individual autonomy is no longer or should no longer be a distant horizon for

3 — O. Favereau, "Marchés internes, marchés externes", *Revue économique*, March 1989, pp.273-328.
4 — See points 1.2. and 2.1.2. of the conclusions of this volume, as well as cited references.
5 — N. Elias, *La société des individus*, Paris, Fayard, 1990.
6 — I. Murdoch, "Vision and choice in morality", in *Proceedings of the Aristotelian Society: Dreams and Self-Knowledge*, vol. 30, 1956 ; republished in *Existentialists and Mystics, Writings on Philosophy and Literature*, edited and prefaced by P. Conradi, with a foreword by George Steiner, London: Chatto & Windus, 1997, pp. 76-98.
7 — A. Ehrenberg, *La société du malaise*, Paris, Odile Jacob, 2010 ; N. Marquis, *Du bien-être au marché du malaise. La société du développement personnel*, Paris, PUF, 2014.

any and all individuals. Whilst it may be temporarily reduced or obliterated (due to age, the ups and downs of life or an environment that is not adapted to the person's characteristics) and, in such cases, be the subject of work or support, autonomy must *never* be considered to be totally absent or lost. The idea that each individual, even the very young or old, even the "disabled", contains a potential, possibly a potential that is hidden because of an inappropriate environment but one that will flower in a propitious context that respects the diversity of forms of life, is currently a crucial element to take account of if one wishes to understand how most of the actors of society (social, political, legal, scientific, etc.) have gone in less than a century from one set of facts to the other, from accepting as obvious that to be able to treat "abnormality", to correct it, to care for and protect (the individual and society), *separation* is required (that is to say, one must isolate and collect people on the basis of common characteristics and remove them from an environment that they disrupt or that upsets them) to accepting as obvious that to cope with and care for differences the people concerned must be *included* in society, especially in their own network of affiliation. Despite the volatility of the concept itself, inclusion is thus the normative horizon to reach for, at least in theory. This takes the shape of combating all forms of discrimination, of providing outpatient care and setting up so-called "individualized" support services, of promoting models such as the "recovery model"[8] and, more generally, of calling for "deinstitutionalization"[9].

3. REVEALING THE TENSIONS AROUND/IN DISABILITIES

"Rethinking the institution and deinstitutionalization from the perspective of disability" is a vital problem, first of all because it is a major human, social and political stake that concerns "the largest minority in the world", that is, people with disabilities along will their relatives, professionals and, more generally, all the actors who construct the ways in which societies treat or do not treat the matter of disabilities. However, this problem is also an unrivalled laboratory for making the social, moral and legal world in which we live intelligible, whether or not we are concerned personally by the matter of disability.

To understand this, let us start with a given: The worlds of disability are currently locked in a strange middle ground between a push towards systematic deinstitutionalization advocated by the body charged with overseeing the treaty specifically dedicated to disabilities and an extreme diversity of situations encountered on the ground.

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8 — P. Deegan, "Recovery as a journey of the heart". *Psychiatric rehabilitation journal*, 1996, vol. 19, no 3, p. 91-97.

9 — On the polysemic aspect of the notion of « inclusion », see the conclusions of this volume, especially points 1.3. and 2.1.3.

On the one hand, with the adoption by the UN of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 and the success of its ratification by 190 parties to this categorial treaty, a decisive step seems to have been taken. Why is this treaty vital? First of all because it enshrines in law what is known as the "social" (and not "medical") model of disability in which the problem concerns not so much the particular profile of the person as the inability of the environment to adapt thereto[10]. Next, because this text gathers together under the term "disability" a large number of situations of environmental inadaptation to people's particular features[11], including, for example, not just the traditional sector of disabilities, but the worlds of mental health as well[12]. Finally, because Article 19 of the Convention gave rise to the call for deinstitutionalization put forward by its oversight body, the Committee of the Rights of Persons with Disabilities, which has given this notion a maximalist, if not radical, form. According to the Committee, respecting the rights of persons with disabilities that are set out in Article 19 "means that States parties need to phase out institutionalization" and the public authorities are henceforward refraining from building or even renovating institutions[13]. And the Committee adds "Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization.[...] Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings."[14]

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10 — See i.a. J. Damamme, « Projecteurs sur une notion énigmatique. Le 'handicap' en droit de l'égalité : spectre ou entonnoir ? », *Les grands arrêts en matière de handicap*, I. Hachez et J. Vrielink (dir.), Bruxelles, Larcier, 2020, pp. 121 et s., and cited references. About the difference between the social model and the human rights model of disability, see also Th. Degener, « A new Human Rights Model of Disability », *The United Nations Convention on the Rights of Persons with Disabilities. A commentary*, V. Della Fina, R. Cera, G. Palmisano (eds.), Springer, 2017, p. 41 à 59 ; R. Kayess, « The CRPD and Segregation: a framework for transformation», Forthcoming in the special issue of Alter : « Repenser l'institution et la désinstitutionnalisation » (2024).

11 — According to the second paragraph of the CRPH, Article 1, three conditions must be met to come under the scope of the Convention, namely: (1) the person must have a physical, mental, intellectual or sensory impairment (2) that is long-term and (3) the interaction of this impairment with various barriers may hinder the person's full and effective participation in society on an equal basis with others. This third condition marks a turnaround from an exclusively medical model of the disability (based on the person's deficiencies alone) to a social model (which also allows for the barriers erected by society and recognises the latter's share of responsibility in creating situations of disability). The legal grasp of the category of disabilities thus rubs shoulders with the anthropological understanding of disability seen as a universal experience.

12 — See M. L. Perlin and E. Szeli, « Article 14, Liberty and Security oh the Person », *The UN Convention on the rights of persons with disabilities. A commentary*, I. Bantekas, M. Stein et D. Anastaiou (dir.), Oxford University Press, 2018, p. 402 à 425 ; I. Hachez, Y. Cartuyvels et O. Nerderlandt, « Internement (civil et pénal) des personnes souffrant d'un trouble mental », in *Les grands arrêts en matière de handicap*, *op. cit.*, p. 757 à 781.

13 — Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on Article 19 – the right to live independently and be included in the community, (https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/88/PDF/G1732888.pdf?OpenElement) §§ 49 and 51.

14 — Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on Article 19 – the right to live independently and be included in the community, CRPD/C/GC/5 (www.documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/88/PDF/G1732888.pdf?OpenElement), §16.

The paradigm shift to which this categorial treaty gives rise and the interpretations thereof by the Committee on the Rights of Persons with Disabilities warrant its central place in the structure of this volume as well as in several of its chapters. Of course, other sources of law can be mobilized in the presence of situations of disability and not all of them necessarily converge in the directions indicated. Of course, the CRPD remains largely foreign to mental health field workers, who as a rule are familiar only with the fundamental rights spelt out in the European Convention on Human Rights. Yet it is no less true that in a context in which fundamental rights law is written more and more in networks (the levels of protection offered by one group having as their calling to influence those offered by other groups) on the one hand and the European Union, which is a party to the CRPD, is quite receptive to the deinstitutionalization promoted under the United Nations, on the other hand, we cannot thumb our noses at the horizon painted by the CRPD system. Once we agree that this treaty, as interpreted by the Committee, could end up filling a central role in the ways of running society that will come about, we must delve into it to decode its main stakes.

On the other hand, it is striking to see that in the series of documents that it has produced the Committee is stressing more and more the need for complete deinstitutionalization, pointing to the insufficiencies of the intermediate forms that are currently in place in many States (as well as in the 2022 Guidelines[15]). Like the Committee, many actors coming out of civil society, amongst others, and some of whom have written chapters in this volume, feel that a long journey has yet be taken before one can truly talk of deinstitutionalization in the conventional field of disabilities or in the areas that the extensive definition offered by the CRPH wants to encompass.

How does one understand this hiatus between a horizon that today seems to be completely accepted by the Committee on the Rights of Persons with Disabilities and a social reality that is clearly lagging behind? Can this situation be attributed solely to a matter of insufficient financial means? In other words, would it vanish if, by waving a magic wand, the States had infinite resources? Or is it explained by the persistence of care and assistance models characterized by paternalism, even conservatism with professionals and users put on unequal footing? In other words, would it be set to rights if, by a second wave of the magic wand, we were to finally do justice to the demand "Nothing about us without us" and persons with disabilities were given the full possibility and responsibility to decide what was good for them or not?

The problems of financial resources and the ideological and organizational remanence of “institutional” models are two vital elements that absolutely must be taken into account to home in on what the deinstitutionalization process is currently coming up against. However, we hypothesise that they are not the only ones.

15 — Committee on the Rights of Persons with Disabilities, Guidelines on deinstitutionalization, including in emergencies (2022), CRPD/C/5 (https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including).

Whilst, according to Camus' famous pronouncement, "to name things wrongly is to add to the misfortune of the world", one is forced to admit that the conceptual, legal and political blurriness that surrounds the three key notions of disability, institution and deinstitutionalization – but which also plagues many other terms that belong to the language game, such as autonomy, independence, empowerment, aid, mobility, project, inclusion, diversity, and so on – is problematic. Indeed, whilst this vagueness may have the advantage of making a series of superficial agreements possible (who is "against" autonomy or "for" discrimination?), it can also spawn many difficulties when it comes to turning these notions into appropriate public policies, professional practices and personal experiences. With its sixty-odd contributions, this volume is trying to tackle head-on these problems, which are actually much more cleaving than they appear for, provided that they are taken seriously, they force one to rub up against an apparently paradoxical question, to wit, "What are the institutional conditions for deinstitutionalization to occur in the areas of disabilities?"

4. A BOOK: WHY AND FOR WHOM?

This open-access book, available both online and in print, will interest both scientists and activists by offering them a broad overview of ongoing research and the positions defended. It also addresses readers from civil society, professionals who work with disability, persons with disabilities and their relatives and, more globally, all stakeholders in disability matters, regardless of the type of connection. It is an attempt first of all to give them conceptual keys rather than definitive answers, a basic grammar that allows one to have a better grasp of the diverse, but not haphazard, core notions with which we are working and the tensions with which they are fraught. By stepping back and looking at where we have come from, it then gives historical, legal, sociological, political science and philosophical depth to the texts that count today, to their implementation, to the reality of practice on the ground and to experiences inside and outside institutions. Finally, this volume looks to the future. It strives to shed light on concrete ways to surmount the aforementioned tensions by bringing up experiences from various sectors (great dependence, mental health, internment, education, etc.) in various national contexts (France, Belgium, Austria, Great Britain, Italy, Japan, etc.). Let us wrap up by noting that these proceedings are also aimed at raising awareness of the humanity of the issue of disabilities. Some people may not necessarily see the interest of that. However, this volume can nevertheless show them in what ways this issue is such an extraordinary laboratory for understanding what living in an individualistic society means.

As the editors of these proceedings, our primary perspective is scientific. To take the title of a *carte blanche* published ahead

of the 2022 Alter Conference, it consists in "speaking calmly about institutions"[16] without jumping straight into the ring. However, this scientific perspective presents in this case the specificity of resulting from the various pluralities expressed both during the conference and in the chapters of this volume: a plurality of attitudes (scientific, activist, artistic, political, etc.), a plurality of knowledge (experiential, professional and academic) and the plurality of positions regarding institutions, the ways they operate and how they should be treated in the future. Each of the terms in these pluralities is considered in this volume, in the sense that they are thoroughly explored. It is up to the readers to take positions on how worthwhile it is to give reason to some perspectives over others.

In putting this volume together from the various contributions received, we tried to open a window, to shed light on the issues, whilst simultaneously re-injecting friction and complexity into the mix. We believe that that is the way to understand each other better, to agree on what we disagree about but above all to increase the information at our disposal regarding the tensions that seem to be inherent in the disability-institution-deinstitutionalization problem set. We believe that that is the way it will be possible to identify the contours of the frame created by the international law on fundamental rights and within which national lawmakers must position themselves by adopting public policies to incarnate the notions of human dignity, equality and inclusion, to mention only a few of importance in the field of disabilities. In the concluding essay we shall return to some of these tensions, now armed with the information provided by the various chapters. If, at the start of these proceedings, we had to mention just one of these tensions, it could be expressed in the terms of the pragmatist philosopher William James: the One and the Many. Is it indeed possible to speak of persons with disabilities as a group, as is done in many legal texts, as if they were a vague, cohesive whole, or should we settle for abandoning all forms of totalization that would obviously trample the specific differences of each individual, whether with or without a disability? And does something like "the institution" or "institutions" exist, or are we dealing with a quasi-infinite diversity of configurations that would likely make any form of generalization just as dangerous? Consequently, is there any sense in studying or in demanding such a massive process as "deinstitutionalization", or are we faced rather with always situated rearrangements in which one institutional banner is replaced by another?

16 — https://www.lesoir.be/449966/article/2022-06-25/carta-academica-peut-parler-calmement-des-institutions, consulted on 21 November 2023.

5. A VOLUME BORN OF A CONFERENCE OF A DIFFERENT STRIPE

In the series of chapters of which it is composed, this volume extends and deepens the thinking that began at Alter conference 2022[17]. It takes the best of what was, for Saint Louis University-Brussels (which has since become UCLouvain Saint-Louis Bruxelles), a key moment in pursuing the inclusive heading that it has taken. More than sixty of the 100 speakers at the conference contributed to this volume. They include the four keynote speakers, each of whom did us the honour of making a presentation and giving us a text[18]; the founder of the magazine *La Revue ALTER*, Henri-Jacques Stiker; and the Doctor *Honoris Causa* of Saint Louis University – Brussels, Lisa Waddington[19].

The volume also gives an important place to the unique melding of science and art that both enlivened and educated the conference and its 300 attendees in an inclusive environment. It does so through photographs of the artwork given centre stage in the "Alternate Worlds" exhibition put on by the non-profit association FACE B and its co-founder, Assal Sharifrazi, in partnership with Ateliers Indigo, the Art et Marges Museum and "S" grand Atelier *;* by going back to the showings of the film *« Fils de Garches »* ("Fixed Kids") in the presence of its director Rémi Gendarme-Cerquetti and of the short film "Comme ça, tu sais" ("Now you know") by Cédric Guénard and Jean-Philippe Thiriart; and by publishing the text of the artist No Anger's show entitled " Quasimodo aux miroirs" – all events that took place during the conference in July 2022[20].

Born in the wake of the Alter Conference, the volume gradually spilled over these initial boundaries by turning most of the oral presentations into rich written contributions thanks to the review work of the editors and the generosity of their authors. Whilst they are all characterized by their top quality, they differ by the styles that they take: often scientific and in line with the conventional canons, sometimes more along the lines of an essay or defence of an asserted position.

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17 — The call for papers can still be seen online: https://alterconf2022.sciencesconf.org/

18 — They were Rosemary Kayess (an Australian lawyer and current vice chair of the Committee on the Rights of Persons with Disabilities), Paul Lemmens (a former Belgian judge at the European Court of Human Rights), Eva Kittay (an American philosopher) and Olivier Giraud (a French political scientist with the CNRS).

19 — The title of Doctor *Honoris Causa* is a prestigious distinction that a university gives to figures that it wants to single out for to their major contributions to a specific field. On 16 May 2023 Saint Louis University-Brussels thus honoured Lisa Waddington by conferring the title on her for the absolutely crucial contribution that her scientific studies and commitment have made to anti-discrimination law, especially as related to disabilities. The conference may be viewed, in English or French, by clicking on the following link: https://youtu.be/4yJYBVo1rTM.

20 — All of these elements can be found in the conference programme, which is available online: https://alterconf2022.sciencesconf.org/data/pages/LIVRET_FR7.pdf. The conference was also in tune with the inclusive society aim by relying on the talent of the Cap Event team, products from Nos Pilifs (a non-profit farm for the insertion of persons with disabilities), the help of the caterer Le Sésam' (a social enterprise) and the tasty dishes of the restaurant 65 degrés, all of which contributed greatly to the success of this event.

6. STRUCTURE OF THE BOOK

These proceedings may be read from start to finish, but the chapters have also been organized to facilitate a personal journey in line with one's particular interests. The volume is thus divided into five parts, wrapped up by a concluding essay.

The first part sounds the start of the journey, through institutional (Caroline Gaussin) and political (Valérie Glatigny) openings that hark back to the inauguration of the Alter Conference, but above all a scientific horizon with Henri-Jacques Stiker's chapter, which underlines the inextricable links between institutions and deinstitutionalization, especially when it comes to disability.

The second part is entitled "Independence and disability, institutions and deinstitutionalization: key elements". Far from claiming to be exhaustive, it nevertheless provides crucial markers for understanding the stakes. This part is further broken down into three subsections.

The first subsection gives resources and position statements about two key legal instruments: the Convention on the Rights of Persons with Disabilities (Rosemary Kayess, Nadia Hadad & Corinne Lassoie; Véronique Ghesquière) and the European Convention on Human Rights (Paul Lemmens).

The second subsection proposes some conceptual landmarks by taking up an essential issue, to wit, how to envision autonomy and dependence together? Several views of what might be called relational forms of independence are proposed, first from the standpoints of sociology and experience (Benoît Eyraud & the CapDroits movement, Paul Van Walleghem), and then stemming from philosophical resources (Valérie Aucouturier & Miranda Boldrini, Rosanna Wannberg).

The third subsection considers some of the individual and social actors who play decisive roles in the matters of import to us. The transformations that the worlds of disability and institutions are undergoing are tackled first from a macro perspective through the prisms of public policy and social movements (Olivier Giraud, Luke Beesley, Mabel Giraldo). They are then examined from the micro perspective of the actors who are closest to disabilities, be they family, close care-givers or peer support workers (Eva Kittay, Clémence Merveille & Arnaud Picqué, Deborah Lutz, Antoine Printz, Aurélien Troisoeufs). Some readers might be surprised not to find a subsection devoted specifically to the actual experiences of persons with disabilities, especially in such persons' own words. We deliberately did not set apart a specific section for this perspective, for it irrigates all of the sections that make up this volume, as do the other attitudes and points of view.

The third part of this volume launches the discussion about institutions, their diversity, characteristics and limits when they claim to fill the role of homes for persons with disabilities, who thus find themselves "institutionalized".

The first subsection in this part challenges the possibility or impossibility of institutions to be "home-care centres". It does so through multidisciplinary examination of situations of great dependence (Cinzia Agoni, Grégory de Wilde d'Estmael, Vincent Fries, Isabelle Hachez, Gisèle Marlière, Louis Triaille), of women with disabilities who are victims of marital violence (Lisandre Labrecque-Lebeau, Martine Lévesque, Merna Abouseffien, Yolanda Muñoz, Linda Gauthier & Line Bergeron) and finally of elderly persons with cognitive issues (Claire Rommelaere, Caroline Guffens, Charlotte Bréda & Cesar Meuris).

The second subsection concerns institutions as places undergoing reforms for both moral and economic reasons. These reforms give rise to consequences that often differ from expectations either because they are less visible than foreseen or because they give rise to a removal or to the creation of new institutions. Different forms of institutions are analysed based on the transformations that they undergo: institutions for homeless people with mental disorders (Christelle Achard), care establishments for the elderly (Iris Loffeier & Célia Poulet) and psychiatric hospitals (Tonya Tartour, Sébastien Saetta, Éric Fakra, Maël Pulcini & Yvonne Quenum).

The third subsection reports on the experiences of people leaving institutions in highly contrasted contexts, with a focus on both the challenges encountered and the sources of satisfaction ascertained. The subjects covered include the deinstitutionalization of persons with mental handicaps in Italy (Ines Guerini, Carla Gueli & Fabio Bocci), the different deinstitutionalization policies implemented in the different parts of Austria (Melanie Schaur & Angela Wegscheider) and two service schemes to support people leaving institutions in the French-speaking part of Belgium, namely, access to digital resources for persons with disabilities (Elisa Boissézon & Basil Gomes) and the development of inclusive mutually-supportive housing (Laurence Braet, Nathalie Dandoy, Anne Ketelaer & Ghislain Magerotte).

The fourth part of this volume focuses on five key sectors in which the stakes and tensions amongst disabilities, institutions and the possibility of leaving an institution crystallize.

Education – an institution composed as much of norms and symbols as of buildings – is the first sector. Today it faces the challenge of "inclusive" thinking that, whilst

overwhelming, is particularly clear. The possibility of a "society without schools" is questioned from the perspective of the philosopher Ivan Illich (Quentin Landenne) and that of setting up a truly inclusive school is put to the test in the Brussels-Wallonia Federation (Ghislain Magerotte, Jean-Pierre Coenen & Dominique Paquot). The relevance of maintaining separate scholastic institutions is also challenged in light of the experiences of learners with disabilities, especially in the case of the deaf (Carlos Dindin), the visually impaired or persons with various "dys" issues (Célia Bouchet).

The second sector – that of work, occupations and leisure activities – is broad and multifaceted. The question systematically treated, be it directly or indirectly, is to what extent (and for whom?) it is worthwhile to maintain spaces and procedures for persons with handicaps that are separate from those deemed "ordinary". This question regarding the workplace is tackled by an international panel taking up cases in Japan (Anne-Lise Mithout), the United States (Marie Assaf) and France (Mathéa Boudinet). The exemptions obtained or not obtained by deaf airplane pilots provides a counterpoint in the area of leisure activities (Antoine Février).

The third sector – one at the centre of Alter Conference 2022 – is none other than that of culture, and more specifically the relationship between social norms and artistic expression. Visual artists who presented their artwork during the conference explain their approaches (Coline De Reymaeker, Antoine Leroy), as do the makers of the short and feature films that were projected (Jean-Philippe Thiriart, Rémi Gendarme-Cerquetti interviewed by Miranda Boldrini). No Anger, who is both a PhD in political science and an artist, reveals the scientific backdrop of the lecture-performance that closed Alter Conference 2022 whilst raising questions about the invisibilization of disabled bodies on stage.

The fourth sector is that of mental health and psychiatry, which has seen its distance from the worlds of disabilities narrow, especially since the surge in references to psychic disabilities along with the encompassing definition of a disability given by the Convention on the Rights of Persons with Disabilities. These movements have given rise to changes in mental health care that emphasise the acquisition of competencies by people with serious mental disorders (Baptiste Moutaud) whilst challenging the status of mental health institutions as places where human rights

infringements may occur (Sébastien Saetta *et al.*). The caregivers in these institutions, which must prepare their patients for release, are often forced to work without any certainty as to whether the persons will relapse after their release (Nicolas Marquis).

The fifth and last sector is that of the deprivation of liberty in the context of mental disorders or, in other words, the problem of internment. This sector on the fringes of medicine and criminal justice has long crystallized the crucial problem of knowing whether, when and to what extent persons with mental disorders may be held responsible for any offences that they commit. A first light is shed on the issue from an historical perspective (Samuel Dal Zilio). The internment sector, which itself is affected by the call for if not deinstitutionalization, at least forms of care and treatment that prefer outpatient to residential solutions, faces new challenges at the intersection of the texts that govern it as well as that of its practices. These challenges include risk management and the construction of "care pathways" (Yves Cartuyvels, Sophie De Spiegeleir, Mathieu Galmart & Tarik Oudghiri Idrissi, Ciska Wittouk).

When put end to end, the contributions yield a nuanced panorama composed of the various positions present in the debate about deinstitutionalization. These positions occupy the entire spectrum opened by the debate and mobilize the various meanings of the trilogy upon which we worked, namely, institutions, deinstitutionalization and disability. Rather than trying to "land the plane", the fifth and last part of the proceedings "reopens" horizons by stating in very different ways the stakes riding on the connections between disabilities and institutions. In the concluding essay, No Anger shares with us the script of her lecture-performance of July 2022. Vanessa Chapelle of the association Mouvement Personnes D'abord shares with us how persons concerned by the issue saw the conference. Finally, Lisa Waddington, who received the title of Doctor *Honoris Causa* from Saint Louis University—Brussels this past 16 May, evokes the prospects of opening up to the situations of disability of our own university institution, which she has since supported with the heart and expertise for which she is known.

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