



Under the direction of Isabelle Hachez and Nicolas Marquis

## Repenser l'institution et la désinstitutionnalisation à partir du handicap

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# A unifying inclusion, a divisive institution? For a grounded, pragmatic and gradual reading of deinstitutionalisation

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### Abstract:

This essay starts with the idea that a healthy and calm debate on the notions of institutionalisation and deinstitutionalisation in the field of disability cannot be achieved without first clarifying these conceptually, nor without linking them to the background of the underlying ideas/values (inclusion, autonomy), in particular in the context of individualistic societies. We will begin our discussion by clarifying our position, we will then divide our subject into three parts. The first part gives a succinct overview of the system of the UN Convention on the

Rights of Persons with Disabilities (that is, the Convention itself and the interpretation suggested by the Committee on the Rights of Persons with Disabilities) based on three pairs of key concepts: disability and equality, institutions and deinstitutionalisation and autonomy and inclusion. In the second part we suggest putting the Convention system into perspective, first by returning to the text and then by expanding the focus to include other legal interpretations in addition to the rights of other actors. In the third and final part, we consider the future by proposing an approach to deinstitutionalisation that is not radical but pragmatic, gradual and grounded, and that seriously considers the indeterminacies attached to words and the diversity of situations in which people live. In short, by attempting to formulate questions and avenues, this essay aims to strengthen and make practicable the pursuit of an essential normative horizon: the fight against all unacceptable forms of segregation and intervention in the lives of others.

## 1. INTRODUCTION<sup>1</sup>

While the notion of inclusion seems recently to be gaining ground as the dominant paradigm for public action<sup>2</sup>, the notion of institution continues to divide – at least in the field of disability<sup>3</sup>. Enriched by contributions in this book, the debate about institutionalisation and deinstitutionalisation is nothing new<sup>4</sup>: the institution has long since been questioned and unpacked. However, this debate is far from exhausted, as shown by both the interest and the tensions it continues to generate. The principle of inclusion, however, is not considered much in this book<sup>5</sup>. Nonetheless, it is the overarching principle of the deinstitutionalisation process, which aims precisely to establish this principle socially as the normative and ethical horizon in the treatment of disabled people. Is this because it is a normative horizon that is shared and obvious? One in which institutions divide and inclusion brings them together? On the face of it, the proposition is probably true. However, it is not certain that it stands up to an analysis of the concepts. Inclusion can be seen as unifying as long as no attempt is made to define it, whereas an institution divides on the basis of meanings that do not necessarily overlap.

### 1.1. *Inclusion and institution, at the heart of analytical and normative tensions*

Inclusion and institution, but also disability, deinstitutionalisation, equality or autonomy: the meaning of these polysemous concepts change according to the systems and the players that use them in timeframes and contexts that are themselves significant. It ultimately appears essential to reconnect the conceptual grammar of the theme under consideration (disability-institution-deinstitutionalisation) with the notions that enshrine it within a set of values (equality-autonomy-inclusion). Behind their apparent self-evidence, these values also generate their own tensions, at once moral, intellectual and practical.

First, tension between the one and the many<sup>6</sup>, the particular and the universal, diversity and generality: rethinking institution-alisation and deinstitutionalisation beginning from the perspective of the disabled person, thinking about equality means accepting the

1 — Our warmest thanks to Miranda Boldrini and Louis Triaille for the critical reviews they offered us in a limited timeframe while making sure to specify that the content and framing of the following comments are the sole responsibility of their authors.

2 — In this respect, see in particular the text by Olivier GIRAUD [13] in this book, and S. EBERSOLD, “Inclusif. Vous avez dit inclusif? L'exemple du handicap», *Vie sociale*, 2015/3, no. 11, pp. 57 to 70.

3 — Understood as covering, at least in part, the field of mental health (see the text by Yves CARTUYVELS *et al.* [49]).

4 — Cf., for example, the thematic file « Institution, alternatives, faut-il choisir? », *L'Observatoire*, no. 71/2011, pp. 2 to 73.

5 — However, see in particular the contributions by Christelle AGHARD [24], Ines GUERINI, Carla GUELI and Fabio BOCCI [28], Laurence BRAET, Nathalie DANDOU, Anne KETELAER and Ghislain MAGEROTTE [31].

6 — Echoing the main tension identified in the introduction to this work (under point 4, *in fine*).

complexity inherent in the polysemy of the concepts being studied and the diversity of the realities covered. Second, the tension between the individual to be included and the society, which certainly (de)institutionalises, but also institutes: setting up an inclusive system involves not only granting rights to individuals but also giving institutional expression to a certain way of doing society (“being included in the community,” as described under Article 19 CRPD)<sup>7</sup>.

In our view, these tensions do not arise solely from differences of positions and perspectives, competing visions of the good life and the good society – all perfectly legitimate sources of disputes about ways of thinking and doing. These tensions also feed on a conceptual indeterminacy and a confusion between two levels, analytical and normative, clearly never perfectly airtight. This confusion crystallises in a particularly visible and problematic manner where the category of institution is concerned. In fact, in individualistic societies, there is a tendency to pit the individual (with a potential and particularities that make him or her unique) against a society that is essentially perceived as standardising, with little capacity to recognise individual differences<sup>8</sup>. In this normative representation, the institution is itself associated with the idea of constraint, of barrier to inclusion, of crushing individuality, of obstacles to overcome for access to a good life: failing agreement on its definition, it is readily regarded as an obstacle to the achievement of autonomy, equality and inclusion. Depending on the moral environment of societies, this representation is much more marked in Anglo-Saxon contexts than in Latin, and in particular in French<sup>9</sup>. However, from the analytical perspective of humanities and social sciences, an understanding of the institutional fact cannot be reduced either to the existence of walls and buildings, or to the mere exercise of constraint. As we shall see, the institution is a logical and organisational given of any form of social life, even if this form of life includes, in the case of individualistic societies, a moral critique of the institution. The values of autonomy, equality and inclusion are – along with suspicion of the institutions themselves, of social institutions, of ways of being in society – important elements that generate agreements and conflicts, permissions and prohibitions.

In what way does this shift in focus make it possible to question what it means conceptually and what it means in practice to talk about deinstitutionalisation in the field of disability? How does the difficulty of agreeing on what an institution is and what it is worth relate to the tensions that accompany the implementation of the ideals of equality, autonomy and inclusion? These questions are addressed below.

7 — From this we can see that the right to inclusion, as enshrined in article 22ter of the Belgian Constitution, conceals the tension between the individual perspective (a prerogative recognised for each disabled person) and the collective perspective (to be effective, recognised inclusion presupposes that the social institution itself is in a position to create society).

8 — See N. MARQUIS (ed.), *Education, parenting and mental health care in Europe. The contradictions of building autonomous individuals*, London, Routledge, 2024 (in press), and, in particular, in this collective work, N. MARQUIS and E. LENEL, «Puzzling autonomy».

9 — See A. EHRENBURG, *La société du malaise*, Paris, Odile Jacob, 2010.

## 1.2. *Structure of the subject*

One of the main advantages to this Alter Conference and its follow-up acts is that it has brought together a plurality of viewpoints that, in relation to the concepts described, may be normative or analytical or even somewhere in between. Taken together, these viewpoints are, in our view, sufficiently representative of the state of debate to attempt, based on them, a nuanced synthesis in the form of this concluding essay.

Our discussion is divided into three parts. The first offers a brief overview of the system of the UN Convention on the Rights of Persons with Disabilities (i.e., the Convention itself and the interpretation offered by the Committee on the Rights of Persons with Disabilities) based on three pairs of structuring notions: disability and equality, institution and deinstitutionalisation, autonomy and inclusion (2). It aims to show how, if the principle of equality is central in this system the starting point for which are people with disabilities and their rights (2.1), the systematic deinstitutionalisation, for which the Committee is calling, is based both on equating the institution with the exercise of constraint (2.2) and on an ideal typical figure of the disabled person, with decision-making autonomy that he or she is willing and able to activate (2.3). Implementing an inclusive approach lies in the social environment's obligation to respect the diversity of individuals while creating conditions so that the disabled people can exercise this decision-making autonomy, which implies eliminating all forms of institutions.

The second part suggests putting the Convention's system into perspective (3). By returning first to the text of the CRPD, it shows that the interpretation of the three pairs of concepts analysed in the first part (3.1) can differ from that of the Committee. In terms of equality and disability, we suggest that it is possible to accommodate the tension between singularity and universality, sometimes opening the door from the outset, under strict conditions, to a form of substantive equality that takes into account individual particularities, even if they appear in a person's body (3.1.1). As concerns institutions and deinstitutionalisation, the text of the Convention that guarantees freedom of choice in matters of independent living and inclusion can be read not so much as calling for the complete closure of institutions, but as inviting us to improve as much as possible the conditions for this choice made by individuals, notably by creating a broad range of positive possibilities rather than solutions of last resort. In this context and under certain conditions, it would seem appropriate to have specific formulas that are aimed at disabled persons who want to benefit from the possibilities. Both practically and conceptually, any institution can be understood as a configuration of constraints and possibilities (3.1.2). As regards autonomy and inclusion, it seems appropriate, in order to achieve an inclusive perspective, to consider a relational reading of autonomy, going beyond the classic atomistic liberal conception of autonomy, which paradoxically runs the risk of stifling a diversity of forms of self-determination and once again result in exclusion (3.1.3).

The second part of the paper then continues by showing the relationship between the CRPD with other significant elements (3.2) that enrich its reading: first, with the surrounding context and, amongst other issues, the other forms of inclusion and exclusion that go beyond the issue of disability (3.2.1); second, through the essential consideration of the (private and professional) environment of disabled people which is directly affected by the form taken by the process of deinstitutionalisation (3.2.2); third, through the recognition of rhizomatous nature of fundamental rights law, in which the CRPD system is a source that interacts with other sources, amongst which the European Convention on Human Rights (3.2.3).

The third and final section takes a risk to look ahead, proposing an approach to deinstitutionalisation that is pragmatic, gradual and grounded rather than radical and that takes seriously the indeterminacy of words and diversity of situations (4). It first calls for taking account of the various lessons learned both from international law on fundamental rights and from national experiences as regards interests, promises, limits and setbacks of a process of deinstitutionalisation, as illustrated by the contributions to this book (4.1). The paper then goes on to underscore the role played by actors at the national level, civil society and the authorities: positioning themselves within the framework established by international law, while making informed choices about different experiences, justified in the light of conceptual uncertainties and accompanied by a phased action plan (4.2). Finally, this concluding essay presents a number of suggestive avenues, not to resolve the tensions mentioned in the introduction but rather to hold the terms together: first, by pluralising both deinstitutionalisation and the institution; second, by continuing to reflect on the institution's markers and indices and on the degrees and levels at which it operates. The finer granularity of this respectful apprehension of a diversity that can never be grasped in the impersonal singular (the disabled person, the institution, etc.) could make it possible not only to discuss more openly what we consider more or less acceptable in the ways of managing difference, but also to put in place action plans that do not overwhelm the variety of configurations (4.3).

### 1.3. *Warnings*

The passionate and fascinating nature of the issue that we are dealing with is commensurate with the stakes involved: quality of life, forms of suffering, injustice or domination, recognition of and respect for difference, the ability to speak for oneself and to experience the feeling of belonging to the society. Consequently, investigating controversies in which positions are often clear-cut and terms are always polysemous is not without danger.

To limit the risks, first and foremost those of being misunderstood or of erring on the side of ethnocentrism, it is important to be specific about how we position ourselves. From a disciplinary point of view, first of all, our approach is rooted in and stands at the crossroads of our respective disciplines: law and sociology. But, in reality, this concluding

essay bears, above all, the interdisciplinary mark of the various contributions that make up this book and to which it seeks to pay tribute.

From a spatial perspective, then, we are speaking from within the Belgian legal order, considering not so much the standards that originate within it as the international sources that are binding on the Belgian State amongst which the CRPD is given primary consideration because of its centrality in matters of disability. The following lessons also go beyond the Belgian legal system, since they draw on sources of international law as well as other national experiences brought together in this book.

Finally, and this is the crucial factor, we have to position ourselves in an epistemological perspective and clarify what we are trying to do in this text. For the above-mentioned reasons and because of its significance which is also reflected in many contributions, the CRPD system and, in particular, the clear-cut positions that the Committee on the Rights of Persons with Disabilities takes on systematic deinstitutionalisation form the starting point and the first object of our reflection. However, our analysis aims to go beyond the CRPD system, beyond simply taking into account the rights of people with disabilities. We seek to increase the complexity of the question of institutionalisation and of deinstitutionalisation, based on disability, by placing it in a broader context. In fact, from the perspective of the society called upon to position itself in relation to the theme of deinstitutionalisation, the issues to consider are many: from the rights and interests of the disabled person to those of third-party carers, from evolution (and indeterminacy) of fundamental values to economic constraints, from respect for individual differences to respect for the general interest in what Norbert Elias calls a “society of individuals”<sup>10</sup>.

This shift inevitably leads us to assess aspects of the CRPD system, and even to question certain elements of it, in particular the above-mentioned positions of the UN Committee on deinstitutionalisation. It is essential to underscore that in this pragmatic and forward-looking perspective we are taking, the intention is in no way to prove right or wrong the actors, which include the Committee on the Rights of Persons with Disabilities, who make pronouncements on the rights of disabled people. The aim is not to validate or invalidate this or that position, but to put forward for discussion elements for a grounded, gradual and pragmatic approach to deinstitutionalisation with a view to a twofold clarification.

On the one hand, expanding the focus, we would like to draw attention to the effects that, regardless of the intention of their authors, certain interpretations of the need for radical and systematic deinstitutionalisation may produce as concerns freedom of choice for disabled people, with respect to recognition of the needs of third-party carers and above all with respect to public policies that have to establish the deinstitutionalisation process in contexts that are always unique.

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10 — N. ELIAS, *La société des individus*. Paris, Fayard, 1990.

On the other hand, in our view, the shift away from the CRPD system is driven by both the conceptual and ethical intuition that, in focusing on the institution and its abolition, there is a risk of occasionally losing sight of the issue at the heart of the theme under consideration: the disappearance of all unacceptable forms of segregation of groups or individuals, in this case disabled people, from the rest of society, and the abolition of all forms of intervention in the affairs of others deemed contrary to fundamental rights. It is the conviction of the authors that by questioning the balance, apparently so obvious in the context of individualistic societies, between institution on the one hand and the exercise of unacceptable constraint on the other, we are not distancing ourselves from this fundamental issue. We are instead strengthening its scope and making it potentially practicable.

On the whole, it is not the intention of the authors to conclude this work with general conclusions, but rather to take a risk and conclude with an essay that is open to dialogue and questioning. The structure we have chosen (placing the focus on the CRPD system before offering other interpretations of it) and the option taken (distinguish and compare perspectives, at the risk of caricaturing them) can only be understood in the light of this objective. Under no circumstances is the discussion that follows to be used to call into question what, in our view, is not open to debate, that is, as mentioned above, the elimination of every unacceptable form of separation from others or intervention on others.

## 2. IN THE CRPD SYSTEM

The UN Convention on the Rights of Persons with Disabilities (CRPD) was born out of the realisation that the universal protection of human rights was inadequate, to the detriment of people with disabilities<sup>11</sup>. Logically, in the specific context of the CRPD, the disabled person is the entry point of a catalogue of rights that are entirely dedicated to him or her, without paying any particular attention to the rights of the family or third-party carers, which is not the purpose of the Convention<sup>12</sup>.

Entering into force on 3 May 2008 and having been ratified to date by 190 parties, including the European Union, the CRPD has become a key reference for anyone who is interested in matters of disability. This is a legally binding treaty, entrusted to the care of

11 — See the study commissioned by the UN Commission on Human Rights: G. QUINN and Th. DEGENER, with the collaboration of A. BRUCE, Ch. BURKE, J. CASTELLINO, P. KENNA, U. KILKELLY and Sh. QUILLIVAN, *Human Rights and Disability. The current use and future potential of United Nations human rights instruments in the context of disability*, February 2002, 307 pp. (available at the following address: <https://www.ohchr.org/Documents/Publications/HRDisabilityen.pdf>).

12 — R. KAYESS and P. FRENCH, "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities", *Human Rights Law Review*, vol. 8, no. 1, January 2008. Cf. also in this work the text by Paul LEMMENS [8, point 3] who sees in this circumstance an explanation of a few discrepancies between the Committee on the Rights of Persons with Disabilities and the European Court of Human Rights. As noted by Nadia HADAD and Corinne LASSOIE, the focus on people with disabilities also meets a need, in light of the abuse sometimes suffered in the family home [6], point 5.1.4.

a supervisory body: the Committee on the Rights of Persons with Disabilities, which expresses itself through instruments that have no binding legal force<sup>13</sup>.

Both the text of the Convention and the Committee's interpretation of it follow a systemic logic<sup>14</sup>. Both create an ideal image that holds together the various elements structuring the CRPD and ensures its overall coherence. Whether in its wording or in the meaning the Committee has given it, an analysis of a particular right cannot ignore the cross-cutting principles that run through the Convention (equality, autonomy, inclusion, participation), or the other rights it guarantees. In this case, it is mainly Article 19 of the CRPD which is the focus of attention ("Living independently and being included in the community"), but also, and in particular, Articles 12 ("Equal recognition before the law") and 14 ("Liberty and security of the person").

In connection with the theme we are considering, the CRPD system – through which we mean the text of the Convention, as interpreted by its supervisory body, the Committee on the Rights of Persons with Disabilities – can be briefly presented using the following three pairs and the meaning associated with them from within the said system: disability and equality (2.1); institutionalisation and deinstitutionalisation (2.2); autonomy and inclusion (2.3).

### 2.1. *Disability and equality*

In contrast to the medical model, which sees people with disabilities primarily as beneficiaries of care, the CRPD views people with disabilities as subjects of rights, providing leverage to break down barriers of all kinds created by the social environment. With the CRPD, we are moving away from a medical approach to disability towards a social approach to disability or, from a legal perspective, to a model based on human rights<sup>15</sup>.

Article 1.2 of the Convention reveals this shift from a medical to a social model when it underlines that it is the "various barriers (that) may hinder the full and effective participation of (disabled people) in society on an equal basis with others". Although it also refers to "long-term physical, mental, intellectual or sensory impairments", no direct legal consequences are drawn from this. In line with the social

13 — Cf. for e.g. I. HACHEZ, «Le métissage des sources, *hard ou soft*» *Les grands arrêts en matière de handicap*, under the supervision of I. Hachez and J. Vrieling, Brussels, Larcier, 2020, pp. 27 to 43.

14 — Cf. R. KAYESS, «The CRPD and Segregation: a framework for transformation», to appear in the special edition of the *Alter* journal: "Repenser l'institution et la désinstitutionnalisation à partir du handicap" (2024), developed at the same time as and to complement this work.

15 — See, in this work, the text by Rosemary KAYESS [5], including the distinction made between *impairment* and *disability*, and, for further developments, her contribution to appear in the special edition of the *Alter* journal: "Repenser l'institution et la désinstitutionnalisation à partir du handicap" (2024). *Add.*, on the human rights model: 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, pp. 41 to 59.

model, the differences between disabilities, just like the “degrees of disability”, “take a back seat to the challenges shared by disabled people (their oppression and their exclusion) and the same duties that public authorities have towards them”<sup>16</sup>. It could be said that it is at a second stage, in addition to the common basic theme, that disabled people who “require more intensive support”<sup>17</sup> may benefit from a differentiated scheme depending on their support needs.

In this human-rights based model, the central principle is thus equality and of which the starting point is, at least in the mind of the Committee of the Rights of Persons with Disabilities, a formal equality: the same regime for all, with no possible exceptions. In this respect, all disabled persons, just like “able-bodied” persons, benefit from legal capacity and the right to vote; following this same logic, there is no question of committing them, of providing them with specialised education, of having them work in sheltered workshops or of housing them in collective accommodation, even under the pretext of providing care. If a form of substantive equality is invoked in the Convention system, it will complement this common regime, when specific regimes – like positive action or social benefits intended solely for disabled people – help to guarantee the effectiveness of the principle of equality. Substantive equality is also the channel through which the diversity of individual disability situations is considered, with reasonable accommodation and individual support designed to individualise universal and based on sectorial measures. The Committee on the Rights of Persons with Disabilities appears to reflect this alliance between formal equality in principle and substantive equality pushed to its limits when it is people with disabilities who benefit, with the new concept of “inclusive equality”<sup>18</sup>.

## 2.2. Institution and deinstitutionalisation

Since people who do not fall within the scope of the Convention are not separated from the rest of society in an institution, then by virtue of the principle of equality, nor should disabled people be treated in

16 — Isabelle HACHEZ and Louis TRIAILLE [21], point 2.2.2.

17 — CRPD Preamble.

18 — On the notion of inclusive equality as coined by the Committee, see General Comment no. 6 (2018) of the Committee on the Rights of Persons with Disabilities on equality and non-discrimination, CRPD/C/GC/6; R. KAYESS, “The CRPD and Segregation: a framework for transformation”, to appear in the special edition of the *Alter* journal: “Repenser l’institution et la désinstitutionnalisation à partir du handicap” (2024); I. HACHEZ, L. TRIAILLE and J. VRIELINK, « Conclusions. Dessine-moi des handicaps – Dessine-moi une société », *Les grands arrêts en matière de handicap, op. cit.*, pp. 783 to 812, spec. pp. 792 to 797, including footnote 65. See moreover, on reasonable accommodation, the paper by X. DELGRANGE and V. GHESQUIERE in *Les grands arrêts en matière de handicap, op. cit.*, p. 322 to 343; and on positive actions: I. HACHEZ and J. RINGELHEIM, « Les actions positives », in *Les grands arrêts en matière de handicap, op. cit.*, pp. 350 to 377; I. HACHEZ, J.-F. NEVEN and J. RINGELHEIM, « L’action positive en droit belge : au cœur du principe d’égalité. Etat des lieux, limites et perspectives sur le marché de l’emploi », *Redynamiser la lutte contre la discrimination. Een hernieuwde impuls voor de strijd tegen discriminatie*, under supervision of J. Ringelheim, S. van Drooghenbroeck, J. Vrielink and P. Wautelet, 2023, pp. 319 to 354.

this way<sup>19</sup>. Legally, this principle of formal equality makes it possible to encompass the mosaic of demands that have led to the process of deinstitutionalisation as carried forward by the Committee mainly under the banner of Article 19 of the CRPD. Dedicated to independent living and inclusion in society, this provision recognises “the right of all persons with disabilities to live in the community, with choices equal to others”, in particular “the opportunity to choose their place of residence and where and with whom they live”, with “access to a range of in-home, residential and other community support services”. This right is itself closely linked to the other prerogatives enshrined in the Convention (including Articles 12 and 14) and is permeated by the principles of equality, autonomy, inclusion and participation.

The Committee on the Rights of Persons with Disabilities set out its interpretation of Article 19 of the CRPD in its General Comment No. 5, in 2017, and then in its Guidelines on deinstitutionalisation, in 2022<sup>20</sup>. It is to this body, and not to the CRPD, that we owe the term “deinstitutionalisation”. The Committee reintroduced the term in the context of Article 19, on the basis of the characteristics attributed to institution(alisation)<sup>21</sup>, such as residents sharing the services of several assistants, imposing a strict routine on people with disabilities that does not take account of their wishes or preferences, or bringing together a disproportionate number of people with disabilities in the same environment...<sup>22</sup> The Committee sees these characteristics as the vectors that shape the segregation or exclusion of people with disabilities – and therefore the opposite of treatment based on equality as intended by the Convention. But what the calls for deinstitutionalisation primarily target are obviously the unacceptable consequences of the forms of institutionalisation that the Committee has documented in the course of its work: the brutality of collective organisation with no regard for individual needs, the paternalistic attitude of certain staff, the fact that people in institutions are potentially unable to see anyone other than their co-residents whom they have not selected to be co-residents, the obligation to attend to their basic needs at set times or to have them ignored, the possibility that they may find themselves tied to their seat or bed for hours on end, visiting times regulated without being able to give their input, and so on.

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19 — It is, in fact, partly because this category of people is subject to diverse forms of segregation that the existence of a specialised human rights treaty dedicated entirely to them is justified.

20 — Committee on the Rights of Persons with Disabilities, General Comment no. 5 (2017) on independent living and social inclusion, CRPD/C/GC/5 (<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/88/PDF/G1732888.pdf?OpenElement>); Guidelines for deinstitutionalisation, including in emergency situations (2022), CRPD/C/5 ([https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/5](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/5)). *Add* the text by Nadia HADAD and Corinne LASSOIE [6] in this book.

21 — On the semantic field of institution(alisation), see the contribution by B. EYRAUD and L. TRIAILLE “Désinstitutionnaliser le handicap, instituer l’autonomie. Une mise en perspective socio-juridique de l’avènement du droit onusien des personnes handicapées”, to appear in the special edition of the *Alter* journal: «Repenser l’institution et la désinstitutionnalisation à partir du handicap» (2024).

22 — Above-mentioned General Comment no. 5, §16; above-mentioned guidelines, §14.

In the Committee's opinion, the characteristics and phenomena presented above are primarily the result of living in specialised residential establishments, but they can also be found in the home. In this sense, deinstitutionalisation means not only closing collective care facilities but also opposing support methods that do not respect individual choices. In the same way that governments are called upon to remove the barriers that place people with disabilities at a disadvantage, they must, *in casu*, break down the walls and other institutionalising practices to ensure inclusion in society. Two contributors to this book summarise deinstitutionalisation "[as] therefore a process of redirecting the policies and resources of institutional care towards supporting the rights of people with disabilities in the community"<sup>23</sup>.

According to the Committee on the Rights of Persons with Disabilities, deinstitutionalisation is aimed at all people with disabilities, regardless of the nature and degree of their disability, on the understanding that the provision of services and personal assistance must be calibrated accordingly. It is in this way that the attention paid to the diversity of people with disabilities is reflected: by modulating the intensity of an otherwise unified system – deinstitutionalisation – that concerns all people with disabilities<sup>24</sup>. Following the Committee's reasoning, people with disabilities do not have a choice as to whether they prefer to stay in an institution<sup>25</sup>. This is a significant difference between the text of the Convention (which explicitly recognises freedom of choice of living environment) and its interpretation by the Committee, which some have for this reason described as radical<sup>26</sup>.

In the CRPD system, institution(alisation) is therefore being given a meaning that is at once very narrow and very broad. It refers, on the one hand, to collective establishments for people with disabilities and, on the other hand, to any form of support that separates people from society and/or deprives them of their ability to make choices on a day-to-day basis. Clearly, the scope given to the concept of institution by the Committee can only be conceived and understood in the context of the deinstitutionalisation it seeks.

23 — Nadia HADAD and Corinne LASOIE [6], point 3.3.3.

24 — Isabelle HACHEZ and Louis TRIAILLE [21].

25 — Guidelines, spec. §§ 8 and 29. See in the same vein: G. QUINN and S. DOYLE/Regional Office for Europe of the United Nations High Commissioner for Human Rights, *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*, Brussels, 2012, 90 pp.

26 — Cf. esp. Gisèle MARLIÈRE, CSNPH (for *The (Belgian) National High Council for Disabled Persons*) [21].

### 2.3. *Autonomy and inclusion*

Both the Convention and the Committee work with an ideal-typical figure of the disabled person<sup>27</sup>, endowed, in all circumstances, with legal capacity and capable of deciding what he or she wishes for him- or herself<sup>28</sup>, whether he or she is made aware of this potential<sup>29</sup> and whether he or she is assisted by a third party<sup>30</sup>. For the Committee, independent living, which is at the heart of Article 19 of the CRPD, should not be interpreted solely as “the ability of carrying out daily activities by oneself” but “should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy”<sup>31</sup>. This means decoupling the possibility of choice from the aids required to support everyday life. This is why, in the wake of the recognition of legal capacity, independent living and inclusion in society, the Convention and the Committee stress the right of access to support services and personal assistance, which are the only ways to guarantee their effectiveness.

The difficulty here arises from the conceptual ambiguity that surrounds the use of the notions of autonomy, self-determination and independence, which some have distinguished without always providing a precise determination of their respective boundaries, while others have regarded them as wholly or partially interchangeable<sup>32</sup>. However conventional it may be, the distinction between decision-making autonomy and executive autonomy as proposed in this book seems to us to be key to understanding the meaning conferred on autonomy in the Convention system<sup>33</sup>. Bearing in mind this distinction, decision-making autonomy (or self-determination) refers to choices relating to one’s own life, while executive autonomy (or independence) refers to the ability to implement the choices made on one’s own<sup>34</sup>. If we keep this in mind while reading the Committee’s recommendations, independent living does not so much mean the independence

27 — See N. MARQUIS, «Le handicap, révélateur des tensions de l'autonomie», *Revue interdisciplinaire d'études juridiques*, vol. 74, no. 1, 2015, pp.109-130. See also N. MARQUIS, “Getting out of mental health institutions: from the clarity of texts to the uncertainties of practices”, to appear in the special edition of *Alter journal*: “Repenser l’institution et la désinstitutionnalisation à partir du handicap” (2024).

28 — See, on the distinction between legal capacity and mental capacity, the texts by Rosemary KAYESS [5] and Claire ROMMELAERE, Charlotte BREDÁ, Caroline GUFFENS and César MEURIS [23].

29 — L'autonomie s'apprend et s'expérimente: Nadia HADAD and Corinne LASSOIE [6]; Giséle MARLIÈRE, CSNPH [21].

30 — Cf. Rosemary KAYESS [5] and Claire ROMMELAERE, Charlotte BREDÁ, Caroline GUFFENS and César MEURIS [23].

31 — Above-cited General Comment no. 5, § 16, a), emphasis added.

32 — See, for example, Nadia HADAD and Corinne LASSOIE [6, point 3.3.1] (where the authors distinguish between autonomy, independence and power to act); Eva KITTAJ [16, point 3] (on the meaning given to the notions of *independence, self-sufficiency and self-determination* following Judith Heuman). See, moreover, Paul VAN WALLEGHEM [11] on the distinction between autonomy and independence.

33 — Claire ROMMELAERE, Charlotte BREDÁ, Caroline GUFFENS and César MEURIS [23, point 2.2]. See also the distinction between the subjective and functional poles of autonomy proposed by Lisandre LABRECQUE-LEBEAU, Martine LEVESQUE, Merna ABOUSEFFIEN, Yolanda MUNOZ, Linda GAUTHIER and Line BERGERON [22, point 2.2].

34 — Claire ROMMELAERE, Charlotte BREDÁ, Caroline GUFFENS and César MEURIS [23, point 2.2] – and the authors add that “in healthcare relationships, the issues surrounding respect for decision-making autonomy traditionally centre around the issue of informed consent”. Cf. also on this issue the texts by Paul VAN WALLEGHEM [11] and of Vincent FRIES and Giséle MARLIÈRE, CSNPH [21].

of the disabled person as it does his or her self-determination, which can be supported if necessary<sup>35</sup>. An autonomous person is one who is able to determine his or her own life, without external coercion, either on his or her own or with the assistance of a third party. In the view of the CRPD and its Committee, all disabled people are autonomous, in the decision-making sense of the term – albeit by fiction we would add, when assistance is so consequential that it becomes substitutive. That is, decision-making autonomy is considered as having already been given, as is currently the case for other people<sup>36</sup>. Executory autonomy is that which must be improved by social intervention, with the ultimate aim of promoting decision-making autonomy. The disabled person has the right to set his or her own goals, and society has the responsibility to put in place the means to achieve these goals. In practice, however, autonomous decision-making may prove less obvious and more complex than it appears, as in the case of serious mental health problems<sup>37</sup>.

How, in this system of representations, are autonomy and inclusion interwoven? Inclusion refers to the collective dimension of the autonomy of each individual<sup>38</sup>, shaping a society that respects each person's way of being. In its General Comment No. 5 on independent living and inclusion in society, the Committee does not define inclusion. However, in its General Comment No. 4 on the right to inclusive education, the Committee defined the term to distinguish inclusion from exclusion, from segregation and from integration<sup>39</sup>. In line with the human rights model, the Committee believes that inclusion should

35 — In this respect, see the different understandings of decision-making autonomy developed by Claire ROMMELAERE, Charlotte BREDA, Caroline GUFFENS and César MEURIS [23, point 2.2].

36 — For several decades now, the child has been at the heart of controversies similar to those encountered in the case of disabled people or people suffering from mental disorders: is decision-making autonomy preordained or something to be constructed? In the moral environment of individualistic societies where autonomy is a condition, there is a tendency to see this autonomy as preordained, but possibly made invisible or diminished by someone in the immediate (parents, carers, etc.) and social environment which, because of a lack of recognition of this capacity, assumes the right to intervene in the lives of others. In the ideal of this moral environment, the individual is responsible for (and the only legitimate actor to do so) defining his or her own *purposes*. The task of the immediate or social environment is to provide the *means* necessary to realise these purposes, which implies that recognition of the individual as a legitimate entity and, when necessary, support the expression of these purposes when the individual is unable to make him- or herself clearly understood. In practice, this distinction is obviously soon undermined. See on this topic: N. MARQUIS, «Making People Autonomous: A Sociological Analysis of the Uses of Contracts and Projects in the Psychiatric Care Institutions», *Cult. Med. Psychiatry*, 2022, no. 46, p. 248 to 276. On the topic of the figure of the child, see A. EHRENBURG and N. MARQUIS, «Quel rétablissement pour la psychanalyse? L'enfant-individu et ses troubles à l'âge de l'autonomie normative», *Nouvelle Revue de l'Enfance et de l'Adolescence*, 2023, no. 8, pp. 67 to 85.

37 — See the text by Rosanna WANNBERG [12].

38 — General Comment no. 5, §19, cited above.

39 — “Exclusion occurs when students are directly or indirectly prevented from or denied access to education in any form. *Segregation* occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities. *Inclusion* involves a process of systemic reform, embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences.” (General Comment no. 4 on the right to inclusive education (2016), CRPD/C/GC/ https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx).

be understood as the right of people with disabilities to participate in society on an equal footing with other citizens, and as a correlative obligation for society to adapt the environment to this end<sup>40</sup>. This highlights the link between the social conception of disability, inclusion and deinstitutionalisation, as interpreted by the Committee<sup>41</sup>. The rights of people with disabilities are matched by the obligations of society, which is responsible for this situation, has control over it and, as a result, is called upon to take action to restore the disrupted equality between people with disabilities and the so-called able-bodied, by treating both equally in the heart of the city, including in terms of accommodation. Thus, whereas integration would correspond more closely to the medical model of disability, seeking to repair in order to normalise according to the dominant collective model, inclusion would change perspective, starting from situations of disability to reform, by their yardstick, the functioning of society so as to make it capable of respecting the infinite diversity of individuals and their characteristics. In general, the CRPD system would have seen us move from a model in which society, identified with the ableist norm<sup>42</sup>, predominated and saw disability as a difference to be treated by and in institutions, to a model based on the autonomous individual and rights designed to ensure that he or she is treated equally in all respects, outside specialised institutions<sup>43</sup>.

In this system, autonomy and inclusion are both first and foremost considered from the perspective of the disabled person, seen as having capacity and being endowed with rights. “Social cohesion [lies] in the individual’s ability to build the sense of relationship that underpins social belonging”<sup>44</sup>. Inclusion refers both to the duties and responsibilities of the social environment towards individual citizens, and to a society based on the recognition of and contributions generated by potentially infinite diversity.

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As capable and autonomous members of society, people with disabilities have the right to be included in society, which must treat them in the same way as it does the other members of that society, given the common humanity they share. In a nutshell, this is the message delivered by the

40 — See, in support of this understanding of inclusion, the papers by Christelle ACHARD [24] and by Gisèle MARLIÈRE CSNPH [21]. On some of the digital dimensions of the challenge of inclusion, see Elisa BOISSEZON and Basil GOMES [30].

41 — See, in the paper by Rosemary KAYESS [5], the link between the institutions, deprivation of freedom and substitute decision-making.

42 — See the paper by Nadia HADAD and Corinne LASSOIE [6] for the scope of this concept, also used by Vincent FRIES [21] and Rémi GENDARME-CERQUETTI [43], and present under the expression “*ableist world*” in the paper by Ines GUERINI, Gueli CARLA and Boccì FABIO [28, point 1]. Lisandre LABRECQUE-LEBEAU, Martine LEVESQUE, Merna ABOUSEFFIEN, Yolanda MUNOZ, Linda GAUTHIER and Line BERGERON [22, point 1] speak of capacitism, while the notion of ageism is raised by Iris LOFFEER and Célia POULET [25, point 3].

43 — Cf. the paper by Olivier CIRAUD [13, point 2.3]. See also the paper by Christelle ACHARD [24], where the author addresses inclusion “as a desire to welcome/keep disabled people in an ‘ordinary environment’”.

44 — S. EBERSOLD, «Inclusif. Vous avez dit inclusif? L'exemple du handicap», *Vie sociale*, 2015/3, no. 11, p. 69.

Convention and its supervisory board, and it is essential to understand it correctly, both in its scale and in its political origins<sup>45</sup>. This understanding requires us to challenge what has been described as an ableist stance and to deconstruct stereotypes<sup>46</sup>, coupled with a firm determination to see the realities and hear the truths that all too often remain invisible and kept out of the way. “Without a cross-cutting, cross-sectoral policy strategy, without “freedom of choice and control”, without support for decision-making, without individual support, without personal assistance, without local services available and accessible in society, people with disabilities continue to live in confinement. Not for living, but for surviving.” Nadia Hadad and Corinne Lassoie conclude their contribution with these words<sup>47</sup>, which can leave no one indifferent.

However, once this message has been heard, and heard properly, it is possible to continue the intellectual and political path onto which the CRPD system has invited us by placing the options taken or translated through interpreting into a broader perspective. As will be demonstrated, this work almost necessarily involves putting into perspective the process of deinstitutionalisation as promoted by the Committee.

### 3. LOOKING BEYOND THE CRPD SYSTEM

The CRPD focuses on the rights of people with disabilities, within the framework of a specialised human rights treaty which, in the Committee’s view, prioritises the similarity between situations of disability over the individual person based on his or her specific characteristics. With the UN Convention, the relationship between the specific and the general – in other words, between the individual and society – is considered from the point of view of “the” disabled people, and, according to the Committee, primarily from the perspective of the general and abstract category of “disabled persons” who, as such, are granted rights, and also identical capacities and desires, undifferentiated in the ideal-typical image of “the” disabled person; it is only later that individual preferences are considered in support of these rights, capacities and desires. We would like now to demonstrate that, even if the focus is on the rights of people with disabilities, the text of the Convention allows for a reading of the guaranteed prerogatives that may differ from those proposed by the Committee (3.1). It will then be clear that this different understanding is essential when the rights of other actors are taken into account (3.2) and, more generally, other international legal sources (3.3). Contextualising in this manner leads to the rethinking of the process of deinstitutionalisation against the backdrop of a broader understanding of the notion of institution(alisation).

45 — Cf. the above-mentioned contribution by B. EYRAUD and L. TRIAILLE, «Désinstitutionnaliser le handicap, instituer l'autonomie. Une mise en perspective socio-juridique de l'avènement du droit ouisien des personnes handicapées», to appear in the special edition of the *Alter* journal (2024).

46 — See, in this regard, the paper by Anne-Lise MITHOUD [36] in the work environment, and, as part of artistic performances, the two texts from No Anger [40] and [50].

47 — Nadia HADAD and Corinne LASSOIE [6].

### 3.1. *Rereading the Convention Text*

While continuing to take the CRPD and the rights of people with disabilities as the sole perspective, the aim now is to question the assumptions of the UN Committee's interpretation so as to highlight what, under the guise of inclusion and in the context of individualistic societies (in the sociological sense of the term), could, if care is not taken, generate forms of exclusion of some of the people who are nevertheless beneficiaries of the rights enshrined in the Convention, including the most vulnerable among them<sup>48</sup>. The aim is also to show how an analytical reading of the concept of institution which, contrary to a normative perspective, no longer automatically and necessarily associates it with separation, exclusion, barriers and constraint, can enrich the understanding of the process of deinstitutionalisation for which the Committee, like other actors, is calling.

At the same time, the Committee's interpretation should be seen in relation to the letter of the Convention, showing that this latter also allows for readings and/or applications other than those suggested by the Committee. To this end, and at the risk of overstating the situation<sup>49</sup>, we will deliberately use again as our starting point the three pairs of concepts mentioned above, which were initially deployed in the UN Convention system, at the outset of the interpretation reserved for it by its supervisory body – namely, disability and equality (3.1.1), institution(alisation) and deinstitutionalisation (3.1.2), autonomy and inclusion (3.1.3). Here again, these concepts are all connected, but from a perspective that is more attentive to diversity and otherness than that suggested by the Committee which operates above all for the benefit of the disabled people considered *in abstracto*. What follows is an attempt to highlight the explicit occurrences of this diversity and to reveal its hidden manifestations, whether in relation to the concepts of disability, equality, institution(alisation), deinstitutionalisation, autonomy or inclusion.

#### 3.1.1. *Disability and Equality*

The emphasis could be focused, as the UN Committee had done, on the constructed nature of disability, attributing its origins to the barriers society has put up and considering the diversity of disabilities through support needs. The equality advocated by the Convention under the new label of “inclusive equality” could be revisited, also as the Committee had done, combining formal equality in principle (same regime for all, with no possible exception) and a real equality pushed to the limit (which includes positive actions and reasonable adjustments)<sup>50</sup>. There is, however, another possible reading.

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48 — See in particular in this sense: Christelle ACHARD [24]; Célia BOUCHET [33]; Mathieu GALMART and Tarik OUDGHIRI IDRISI [49].

49 — In this respect, we refer the reader to the epistemological clarifications that appear at the end of the introduction to this concluding essay, which delineate the object assigned to it. (cf. *supra*, point 1.3).

50 — Cf. *supra*, 1.1.

Article 1 of the CRPD touches on long-term physical, mental, intellectual or sensory impairments, and it also mentions barriers likely to hinder the participation of people with disabilities in society which places disability at the intersection of these issues. In this reading, disability is certainly a social construct, but only partially, since interaction with personal characteristics plays a key role. From this perspective, society's environmental responsibility is recognised, but disability is nevertheless not seen as completely distinct from the individual who experiences it. This reading supports the idea that, in some cases, correcting the environment is not enough to remove the disability that may remain, even if only to a lesser extent<sup>51</sup>. In other words, this reading assumes there is tension between the disabled person and the society responsible for the situations of disability it creates. It recognises the intrinsic vulnerability of the individual as much as it considers the conditions outside likely to emphasise it.

The UN Convention is a specialised human rights treaty that protects the rights of the disabled minority, which at the same time recognises the diversity of disabilities in its preamble. Taking both characteristics seriously (a specialised human rights treaty but open to diversity) might, if necessary, lead from the outset to a break with purely formal equality, to reinject attention to individuality between people with disabilities and those who do not fall within the personal scope of the CRPD, or within the general and abstract category of people with disabilities. This would allow for accommodating the tension that cannot be eliminated between universality, reduced, if necessary, to the level of minority, and singularity through differential treatment if it is duly justified<sup>52</sup>. In other words, substantive equality would no longer simply complement formal equality from the outset, but could, in some cases, constitute the primary translation of the principle of equality in respect of specific disabled people. From this perspective, exceptions to formal equality would thus be possible. For example, under strict conditions, in the context of precise procedures and for clearly identified purposes, confinement could be a solution of last resort for people with mental disorders. Similarly, if their choice is made based on a world of enlightened possibilities<sup>53</sup> and the institution is reformed from within, people with disabilities could legitimately prefer to live in collective accommodation rather than at home, even if the preferred option differs from that chosen by the so-called able-bodied person and from the choice made by other people with disabilities.

51 — In some cases, this is particularly true in the field of mental health, where the tension is between the right to put oneself in danger (including by not taking prescribed medication), the duty to treat others well and assist those in danger, and the duty not to up others in danger. For care teams this tension can manifest itself in seemingly innocuous, mundane aspects, like the policy on patient smoking, as shown by Sébastien SAETTA et al. [47]. On the subject of non-apparent disability and the boundary between disability and personality, see the short film "Comme ça, tu sais": J.-Ph. THIRIART [44].

52 — On the tension between general and specific, cf. D. LOCHAK, *Le droit et les paradoxes de l'universalité*, Paris, PUF, 2010.

53 — That is, not predetermined by a context or a culture that *de facto* reduces it to the only option available: that of the institution.

Playing with the full spectrum of the variations on the principle of equality from the outset is one way to address, at the very least, the “dilemma of difference”<sup>54</sup>. The principle of equality certainly will not provide an *a priori* solution to the tension between identity and difference, nor does it provide public authorities with a set of instructions or, if nothing else, replace public policy. It does, however, provide a grammar, broader than the variations used and the perimeter assigned to the notion of inclusive equality and a framework within which there is a call to design appropriate legal regimes<sup>55</sup>.

### 3.1.2. *Institution(alisation) and deinstitutionalisation*

It is a given that the Committee reads into Article 19 of the CRPD and other provisions of the Convention a right to deinstitutionalisation, with a correlative obligation on States to close collective establishments for disabled people, on the one hand, and to dispense, wherever they occur, with all forms of institutionalisation that would keep persons apart from society and/or deprive them of their ability to make choices in their daily lives, on the other<sup>56</sup>. Here too, however, the text of the Convention is open to a different interpretation.

Article 19 of the CRPD guarantees freedom of choice as regards independent living and inclusion in society but it does not refer to or enshrine as such a right to deinstitutionalisation, nor does it specify beforehand what is meant by institutionalisation. It does, however, guarantee freedom of choice: Article 19(a) of the CRPD provides that States must ensure that “disabled people have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”.

Rather than programming the systematic closure of collective accommodation facilities, one way to take freedom of choice seriously would be to ensure that this is not translated into imposing a dilemma constituted of second-best options: living in an institution in the absence of a credible home alternative or living at home in the absence of adequate institutional provision. It is in fact possible to understand the freedom of choice guaranteed by the CRPD as allowing for coverage of both accommodation at home and life in a collective residential facility, from the moment it is devoid of a depersonalising

54 — The disabled person is located «at the crossroads of identity and difference» (M. MERCIER and R. SALBREUX (dir.), *Ethiques et handicaps*, Namur University Press, 2018, p. 16. See also: J. KRISTEVA and J. VANIER, *Leur regard perce nos ombres*, Paris, Fayard, 2011). Embracing the dilemma of difference means, at once and depending on the characteristics and circumstances, ignoring differences while responding specifically to them (M. VANDERSTRAETEN, “Définir, c’est exclure : le cas du handicap”, *R.I.E.J.*, 2015/1, p. 103). Cf. on the Committee’s vision on the subject of the “dilemma of difference”, its General Comment no. 6, cited above, § 10.

55 — For an explanation of the grammar of the principle of equality and non-discrimination in the field of disability, cf. in particular, V. GHESQUIÈRE, I. HACHEZ and C. VAN BASSELAERE, “La discrimination fondée sur le handicap”, *Comprendre et pratiquer le droit de la lutte contre les discriminations*, under the supervision of J. Ringelheim and P. Wautelet, CUP, Anthémis, 2018, pp. 72 to 134.

56 — Cf. *supra*, 1.2.

culture<sup>57</sup>. Of course, it is then necessary to ensure that the choice is *real*, that is, on the one hand, that the different options exist *de facto* and, on the other hand, that the conditions for making a choice free of constraint connected to the absence of an alternative are met. Encouraging freedom of choice by identifying biases and contextualising it in the light of the principles underlying the CRPD, but leaving unrestricted the freedom to choose (favouring living at home or in collective residential facilities) is an option that seems in any case to follow to the letter of Article 19 of the Convention.

Moreover, the CRPD text itself recognises the prevalence of certain forms of specialised institutions, which, in our view, clearly shows that the institution which the Committee on the Rights of Persons with Disabilities opposes is similar to any form of segregation or intervention on others that is deemed unacceptable, without extending to other forms of institutions that might, in certain cases and under certain conditions, appear justified because they are beneficial to people with disabilities<sup>58</sup>. Two examples illustrate this point.

First, with respect to participation in sports, Article 30.5 of the Convention acknowledges the parallel, complementary and subsidiary existence of specific formulas for people with disabilities in relation to ordinary sports activities, the existence and development of which are otherwise required. In other words, the Convention's text recognises the existence of ordinary and specialised sports institutions and the practice of the Committee also seems to be established in this sense<sup>59</sup>. This specificity of the CRPD system, which, contrary to a logic of complete deinstitutionalisation, recognises the coexistence of ordinary and specialised activities, is undoubtedly due to the specific nature of sport, which requires a form of equality of bodies<sup>60</sup>: "Disabled participation in competitive sports is meaningful only if persons with similar types and degrees of disability compete against each other"<sup>61</sup>. It should also be noted that this question of the equality of bodies in sport does not allow for a purely social or constructivist interpretation of disability<sup>62</sup>.

57 — Cf. in particular, in this respect, Eva KRITAY [16] and Giséle MARLIÈRE, CSNPH [21].

58 — Or at least «acceptable» to them according to the concept defended by the Committee, on the basis of the principle of formal equality – cf. in particular the case of prison mentioned in §18 of the above-mentioned Guidelines of the Committee on the Rights of Persons with Disabilities, spec. §15.

59 — Cf. R. BEEKMAN, «Een juridisch onderscheid tussen personen met een fysieke en verstandelijke beperking in internationaal perspectief. De sportwereld als voorbeeld of als uitzondering?», Master's thesis submitted in the final examination for the degree of master in law, KU Leuven, 2021-2022, 89 pp, spec. pp. 17-18, no. 27. On disabled sports, see Valérie Clatigny [3].

60 — With the whole issue of rectifying bodies using prostheses, considered by Christophe LAZARO in his doctoral thesis: *La prothèse et le droit. Essai sur la fabrication juridique des corps hybrides*, IRJS Editions, 2016.

61 — I. BANTEKAS, P.Y. STEPHENSON CHOW, S. KARAPAPA et E. POLYMENPOULOU, «Article 30. Participation in Cultural Life, recreation, Leisure, and Sport», I. Bantekas, M.A. Stein and D. Anastasiou (eds.), *The UN Convention on the Rights of Persons with Disabilities. A commentary*, Oxford University Press, 2018, p. 914.

62 — On the difficulty of holding a completely constructivist position in establishing and dealing with forms of difference, see N. MARQUIS, A. MAIGNAN and C. DAELMAN "Voice-Hearers and Highly Sensitive People Reversing the Stigma of Madness: Dissolving, Stating, or Valuing the Difference?", in N. MARQUIS (ed.), *Education, parenting and mental health care in Europe. The contradictions of building autonomous individuals*, London, Routledge, 2024 (in press).

Second, the full deinstitutionalisation for which the Committee advocates makes it difficult to uphold the dual reality of deafness, between disability and culture<sup>63</sup>, which is difficult to reconcile with the places where the linguistic and cultural identity of young deaf people is formed. However, several material provisions of the CRPD recognise both the dimension of the disability and the cultural dimension of deaf duality<sup>64</sup>.

Ultimately, there is no need to adopt such a narrow definition of institution as that provided by the Committee, with the paradox that it is, at the same time, all-encompassing in the extreme if one considers everything that the move to deinstitutionalise brings with it<sup>65</sup>. The concept of institution does not necessarily refer to facilities, segregated walls and buildings or to support methods that do not respect the individual choices that necessarily characterise them while at the same time going beyond them. Some therapeutic choices, like institutional psychotherapy, consider the institution a therapeutically effective way for people to be together<sup>66</sup>. In the humanities and social sciences, the idea of institution also includes language<sup>67</sup>, shared values and meanings, in short, “any relatively stabilised way in which humans organise their collective life and recognise it as such”<sup>68</sup>. Human life in society logically presupposes the existence of institutions. The individualism that characterises our societies is also an institution, insofar as it involves a collectively accepted enhanced appreciation of the individual, of his/her autonomy or even of his/her potential. The difficulty in seeing that individualism or the call for deinstitutionalisation are also institutional forms lies in the fact that both are critical of the institution, which they identify with the exercise of constraints and the

63 — Hearing impairment is unique in that it can be corrected using devices, implants and lip-reading aids (medical approach) and/or by adapting the environment using sign language translation (social approach).

64 — Article 24(3)(b) of the Convention requires States to “facilitate the learning of sign language and promotions of the linguistic identity of deaf people” (cultural dimension), while article 25(b) imposes on them the obligation to carry out tests that detect hearing loss early (disability dimension). In its sections 1 to 4, Article 30 of the CRPD expressly embraces the deaf duality: the right of all deaf people to access and contribute to the cultural life of their choice, whether hearing or deaf; the right to support and recognition of the identity and the culture of signing persons, whether they are deaf or hearing. See, on this, Basil Gomes’s thesis in the process of being finalised, titled «Entre accès à la diversité culturelle et protection de l’identité culturelle : le droit de participer à la vie culturelle des personnes sourdes», and funded by a grant from FSR at the Université Saint-Louis – Bruxelles, now UCLouvain Saint-Louis Bruxelles.

65 — The above-mentioned guidelines of the Committee on the Rights of Persons with Disabilities, spec. § 15. The family environment can thus become an institution, in the sense that the Committee confers on this notion (Nadia HADAD and Corinne LASSOIE [6, point 3.2.2]).

66 — On this subject, see the text by Antoine LEROY of the Ateliers Indigo [42], and still on the understanding of the institution by institutional psychotherapy: M. BLOOR, N. MCKEGANEY et D. FONKERT, *One foot in Eden: A sociological study of the range of therapeutic community practice*, Routledge, 2018; N. MARQUIS, «Making people autonomous: a sociological analysis of the uses of contracts and projects in the psychiatric care institutions», *Culture, Medicine, and Psychiatry*, 2022, vol. 46, no. 2, p. 248-276.

67 — In the way they structure our societies, language and speech are institutions stress Valérie AUCOUTURIER and Miranda BOLDRINI [10], point 2. See also the contribution by Paul VAN WALLEGHEM [11], in which the hypothesis is that “severe dependency” is a performative statement.

68 — N. MARQUIS and L. VAN CAMPENHOUDT, *Cours de sociologie*, Paris, Dunod, 2020, overbo «institution», p. 337. See also Iris LOFFEER and Célia POULET [25, point 2], who distinguish the concept of institution in sociology from the term institution in the everyday sense.

non-recognition of individual specificities. From a humanities and social sciences perspective, the institution is always both a constraint and a room for manoeuvre, a value and a norm<sup>69</sup>.

Following this approach, there is no society that does not have institutions, but these institutions are constantly transforming and reinventing themselves<sup>70</sup>. Enshrining standards or values, introducing new procedures, other methods for broaching the subject of disability in society are institutions. To include is to institute. Deinstitutionalising is instituting: it is valuing and seeking to share certain ways of doing things, certain definitions of what constitutes a life worth living, by differentiating them from the others that are considered ineffectual or disrespectful, contrary to certain values... instituted or in the process of being institutionalised. Undoing and doing: between these two actions, there is a continuous back-and-forth. According to Castoriadis's point of view<sup>71</sup>, "the 'social-historical' (the production of societies in history) is characterised by the constant movement of institutionalisation, which is a permanent ebb and flow of creation and self-alteration. Never stopping, the instituting forces alter the instituted forms, before in turn stabilising their imaginary projections"<sup>72</sup>.

As with any social institution, deinstitutionalisation, in addition to being a vector of potential, inevitably brings with it its share of constraints (ways of doing things and speaking, organisational models) – constraints that are more or less socially acceptable and accepted. The introduction of "quality policies" in new forms of care which, like peer support, advocate being part of a certain deinstitutionalisation, is a good example of this, as it bears witness to this double movement: centrifugal (new possibilities for intervening on others) and centripetal (formalising and structuring these possibilities)<sup>73</sup>. In this sense, enriching the notion of institution with the way it is understood in humanities and social sciences makes it possible to de-idealise the deinstitutionalisation advanced by the Committee, just as it makes it possible to perceive that deinstitutionalisation goes beyond the suppression of collective places and "works on all institutions, both those created as an alternative to forms that are contested, and those that

69 — Thus language allows us to speak but by naming certain things and not others. On the ambivalence of the emancipating and constraining role of the institution, see, in particular, the papers by Henri-Jacques STIKER [4], CAPDROITS [9], Célia BOUCHET [33]. It was also with this in mind that the Université Saint-Louis - Bruxelles (now UCLouvain Saint-Louis - Bruxelles) awarded Lisa Waddington the title of Doctor Honoris Causa, and that, thanks to her support, a dynamic "institution of inclusion" (as a meaningful frame of reference) was created. See Lisa WADDINGTON's concluding remarks [51].

70 — Fr. DUBET, verbo «Institution», *Le dictionnaire des sciences humaines*, under the supervision of S. Mesure and P. Savidan, Paris, PUF, p. 635.

71 — C. CASTORIADIS, *L'institution imaginaire de la société*, Paris, Seuil, 1975.

72 — Fr. OST, *A quoi sert le droit ? Usages, fonctions, finalités*, Brussels, Bruylant, 2016, p. 138 (on double institutionalisation, see in particular pages 139 to 169 of this book). See also the papers by Henri-Jacques STIKER [4, point 3], CAPDROITS [9], Ines GUERINI, Carla GUELLI and Fabio BOCCI [28]. On the implications of the deinstitutionalisation process for the labour market and specialised institutions, see Mathéa BOUDINET's paper [37] and Coline DE REYMAEKER [41].

On the blurring of boundaries generated by any process of deinstitutionalisation, also see the papers by Mathéa BOUDINET [37] and Coline DE REYMAEKER [41].

73 — See Aurélien TROISOEUF's paper [20].

already exist”<sup>74</sup>. Conversely, looking at the institution in all its plurality and complexity in ordinary practices in the field helps to highlight not only that institutionalised life can, under certain circumstances, generate unacceptable consequences that need to be combated, but also that, under other conditions, collective living spaces can be the subject of an enlightened choice and generate potentially beneficial effects. Thus, it can be seen how introducing conceptual and empirical nuance into a call for radical and systematic deinstitutionalisation should certainly not be read as a gesture in favour of institutionalisation. The issue is not to be “for” or “against” institutions, but to understand, on a case-by-case basis, what institutional forms are or are not acceptable for each person and the life they wish to lead.

### 3.1.3. *Autonomy and Inclusion*

In its understanding of autonomy and inclusion, the Committee sees all people with disabilities as capable of self-determination – but not by opting for a collective institution for people with disabilities, as evidenced by the inverted commas it places in its 2022 Guidelines around the term “choice” of a life in an institution – and led to live in the heart of the city – at home, with the help of assistance services. What the Convention’s monitoring body has in its sights are ways of living that impede free individual choice and life in society, and in so doing deny the human dignity of people with disabilities<sup>75</sup>. In the view of some, however, the Committee’s understanding is based on an atomising conception of autonomy and an individualistic reading of inclusion, and they propose, as a counterpoint, a relational apprehension of the notions of autonomy and inclusion, imbuing them with a collective dimension<sup>76</sup>.

The classic liberal conception of autonomy<sup>77</sup>, which likens it to “self-governance” and freedom that is essentially negative, implies non-interference by others and society in the choices made and the goals pursued. It is true that subjective autonomy may, where appropriate, be assisted by a third party, but in the Committee’s view this assistance appears to be incidental or secondary, the focus remaining on the disabled person, who is called upon to determine his or her own life. In this sense, when taken in a disembodied way, such a conception of autonomy can lead to obscuring “the socially situated and relational dimension of individuals”, just as much as it risks “rendering invisible relations of dependence in action and everyday life”<sup>78</sup>. Nonetheless, the free agent exists only as an abstract, disembodied ideal<sup>79</sup>. This is no

74 — Henri-Jacques STIKER. See also Quentin LANDENNE’s paper [35] who, at the heart of Ivan Illich’s thinking, underlines the idea of a threshold beyond which any institution (even the ordinary educational establishment) runs the risk of turning against its emancipatory purpose.

75 — Cf. *supra*, 1.3.

76 — Cf. in particular Valérie AUCOUTURIER and Miranda BOLDRINI [10]. In this text, the authors also highlight the similarities and differences between *disability studies* and the *ethics of care*, under point 4 “autonomy and vulnerability”.

77 — In the subjective sense of the term, to echo the distinction made above.

78 — Valérie AUCOUTURIER and Miranda BOLDRINI [10].

79 — Valérie AUCOUTURIER and Miranda BOLDRINI [10].

different for people with disabilities than it is for anyone else<sup>80</sup>. In this respect, the CapDroits team stresses the complexity of support relationships insofar as they can just as easily support autonomy as well as impede it<sup>81</sup>, while, in line with the ethics of care, Jean-Louis Genard draws attention to situations “that require (...) a solicitude that expects nothing in return” and “appears to be the exact opposite of the neo-liberal demand for maximum empowerment of beings”<sup>82</sup>. As promoted by the Committee, autonomy postulates that everyone would like to be active and would cancel the universal experience of dependence.

Nothing in the CRPD text conflicts with a relational understanding of autonomy<sup>83</sup>, taking into account both the disabled person and the intervention of a third party. There is no need to confine oneself to a classic liberal conception of autonomy, which would take account first and foremost of the perspective of the atomised disabled person. Nor is there anything to prevent us from seeking to place the CRPD more firmly in a collective perspective, rather than running the risk of feeding into an excessively individualistic reading of this treaty<sup>84</sup>. Far from being merely a right for people with disabilities to participate in society, inclusion then becomes a genuine choice for society, legally enshrined, which commits society as much as it does the person with the disability. While inclusion embodies the collective dimension of autonomy, it also lends itself to a relational understanding, emphasising the rights and responsibilities of disabled people and the rest of society, and recognising the diversity of each of its members. “Inclusion,” as M.C. Haelewyck and M. De Schepper point out, “implies (...) a dialectical process in which, on the one hand, the disabled person seeks to adapt as much as possible to social norms and, on the other, social norms adapt to accept differences”<sup>85</sup>.

80 — Cf. Fr. OST, *op. cit.*, pp. 278-279.

81 — CAPDROITS [9], points 2.2 and 2.3. According to the authors, this applies equally to the subjective and functional aspects of autonomy.

82 — J.-L. GENARD, «Glissements anthropologiques et déplacements institutionnels : les nouvelles coordonnées des politiques sociales», *L'Observatoire*, no. 71/2011, p. 18.

83 — See, in support of a relational understanding of autonomy, papers by CAPDROITS [9], Valérie AUCOUTURIER and Miranda BOLDRINI [10], Paul VAN WALLEGHEM [11], Claire ROMMELAERE, Charlotte BREDA, Caroline GUFFENS and César MEURIS [23] and Quentin LANDENNE [35]. On the factors that are likely to influence the relationships between the carer and the disabled person and adversely affect [the latter's] freedom of choice, see the text by Deborah LUTZ [18].

84 — It is not so much a question of denouncing an ideological version of fundamental rights (M. GAUCHET, «Les droits de l'homme ne sont pas une politique», in *Le Débat*, no. 3, 1980 and by the same author, «Quand les droits de l'homme deviennent une politique», in *Le Débat*, no. 110, 2000) which, in the words of Marcel Gauchet, would tend to set up “the individual as the exclusive focus of reference” (*ibidem*, p. 283) and, in so doing, would contribute dangerously to “the collapse of the collective in the face of the affirmation of individuals” (*ibidem*, p. 284). This worrying perspective, which sees deinstitutionalisation as the driving force behind the disintegration of society, is widely shared today (see: S. EBERSOLD, «Inclusif. Vous avez dit inclusif? L'exemple du handicap», *Vie sociale*, 2015/3, no. 11, pp. 57 to 70. *Addé*, from another angle of study: J.-P. LEBRUN et J.-L. RENÇON, *Où va la famille? Droit et psychanalyse*, Toulouse, Erès, 2023). The risk of an individualistic reading of the CRPD mentioned here stems from a failure to recognise the institutional aspect – as a way of making society – of the inclusive perspective being promoted and the fact that, in practice, this perspective is always part of a network of social relationships that must be taken into account if this perspective is to become a reality (see, in this book, Henri-Jacques STIKER [4]).

85 — M.C. HAELEWYCK and M. DE SCHEPPER, «De l'exclusion à l'inclusion sociale dans le champ du handicap mental», *Ethica Clinica*, 64/2011, p. 9. See B. BOUQUET, «L'inclusion : approche socio-sémantique», *Vie sociale*, 2015/3, no. 11, pp. 15 to 25.

The Committee's vision is based on a practical anthropology of the disabled person who wishes to live as independently as possible and prefers social inclusion<sup>86</sup>. But is this in reality always the case? Does this vision not tend to value a single way of being in the world, and in the process stifle other ways of living? Rather than overturning the norm, does deinstitutionalisation simply move it to the margins, re-enacting, even more invisible ways, the exclusion of those who fundamentally aspire to a different normality, or who simply function differently?

Eva Kittay stresses that true inclusion presupposes an awareness of a common humanity that makes all members of society responsible for and supportive of each other, and therefore attentive to the dignified treatment of the most vulnerable among them, in institutions or elsewhere<sup>87</sup>.

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In summary<sup>88</sup>, there can be an interpretation of the CRPD that differs from the Committee's, revisiting the social dimension of disability by taking greater account of personal incapacities; one that, from the outset, incorporates the full range of variations on the principle of equality and recognises differences; one that recognises the plural nature of institutions and not just their perpetual questioning; one that places autonomy more fundamentally in a relational perspective, which takes freedom of choice seriously right up to the end, by accepting the diversity of life trajectories and the maintenance of certain forms of establishment as part of the deinstitutionalisation process, which understands inclusion as a process of mutual adjustment and not primarily as a personal right, which openly registers again the fundamental individual rights in a collective perspective.

### 3.2. *Connecting the CRPD*

From within the CRPD, it is possible to create more room for third parties and diversity, as we have just attempted to show. By zooming out from a perspective focused in essence on the CRPD and the rights of people with disabilities, it is clear from the outset that the adoption of the CRPD and placing disability on the agenda are themselves the result of a third party's intervention, in society, just as it is grafted onto an underlying context influencing its understanding (3.2.1). Connecting the CRPD also means taking into account that the rights it guarantees are not absolute<sup>89</sup>. In practice, they come into conflict with

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86 — On the practical anthropology underlying this conception of autonomy, see N. MARQUIS, «Le handicap, révélateur des tensions de l'autonomie», *R.I.E.J.*, 2015.74, pp. 109-130.

87 — Eva KITTAY [16], point 5, with a reference to Dworkin's writings and a clarification on this subject in footnote 3.

88 — And as the CSNPH has shown so clearly [21].

89 — Which the CSNPH has clearly understood [21].

the prerogatives equally enjoyed by other actors (3.2.2), just as in the era of lawmaking in network, the Convention is called upon to come to terms with other systems to protect fundamental rights (3.2.3).

### 3.2.1. *By taking into account the social institution of the issues involved*

Whether taking an exclusively social conception of disability, attributing it to society alone, or a more nuanced approach operating at the convergence of personal incapacities and collective behaviours, it is important to acknowledge that, in either case, disability only exists because it is recognised and made visible by the social institution that agrees to consider it as much as it creates it in whole or in part<sup>90</sup>. This is the first reason for connecting the CRPD to the legal recognition of disability that it represents with society.

A second related reason to broaden the perspective is the need to consider the underlying structures of exclusion at play and made visible in institutions<sup>91</sup>. As Edouard Delruelle asks “If the *inclusion* of disabled people is so difficult, is it not because we are living in a society of exclusion?”<sup>92</sup> Deinstitutionalising, without connecting this movement with the systematic framework for leaving and reforming the institution, would then appear to be a dead end<sup>93</sup>. The treatment of people with disabilities depends on the global social context within which it operates. “The first condition of any deinstitutionalisation”, the author continues, “is the existence of strong structures of solidarity at the level of society as a whole”<sup>94</sup>.

Again, the purpose of fundamental rights is not simply to meet personal needs. Guaranteeing them is also the condition for the possibility of a society whose shared project extends beyond the mere addition of individual interests. This is a third reason for seeking to contextualise the rights in question.

### 3.2.2. *By recognising the rights and interests of family members and third-party carers*

A relational reading of the autonomy guaranteed by the CRPD means that the rights it enshrines must be seen from a perspective that goes beyond the people with disabilities whom the Convention primarily addresses to include in its consideration the rights of third-party carers. The shift we are now suggesting is more substantial in that it includes taking as a complementary starting point (for example, in the analysis of the ins and outs of systematic and radical deinstitutionalisation) the rights recognised

90 — Cf. the conclusion offered by Quentin LANDENNE [35], who moreover highlights the doubly instituted nature of disability as evidenced by the etymology of the term.

91 — E. DELRUELLE, «Quelle 'déinstitutionnalisation' ? Pour une approche politique des institutions», *L'Observatoire*, no. 71/2011, p. 6

92 — *Ibid.*, p. 7.

93 — *Ibid.*, p. 9.

94 — *Ibid.*, p. 11.

for people other than those in situations of disability, but involved in and by these situations of disability. These include, in particular, the rights of family members, especially parents, who are often the first to be involved, and those of carers, who may be third-party caregivers. Each of these carers has rights that are likely to be in relation to, or even at odds with, those of the disabled person. Each of them is potentially involved in the deinstitutionalisation process called for by the Committee. They are also likely to be primarily affected by its limitations<sup>95</sup>.

Who can fail to see that these actors will bear the brunt of poorly managed deinstitutionalisation in the absence of sufficient resources or budgetary investment<sup>96</sup>? In this respect, Eva Kittay clearly demonstrates the need to re-assess the status of carers, including a need to ensure that the rights of people with disabilities are effective<sup>97</sup>. Of course, the recent COVID crisis has highlighted the totalitarian aspect of shelters when they close in on themselves. However, it has also (and once again) put under the spotlight the need of institutions for which some parents were crying out. Many associations had not waited for the consequences of the pandemic to denounce the inadequacy of institutional provision, particularly for people with a high level of dependency<sup>98</sup>. In the field of mental health, too, families are demanding (more) institutional support<sup>99</sup>.

It should be noted that, beyond family and friends, other considerations may be in conflict with the individual prerogatives of the disabled person. For example, when it comes to committing someone to an institution, safety considerations on the part of members of society, not to mention the safety of the person with disabilities, may come into play<sup>100</sup>.

### 3.2.3. *By integrating the Convention into a network of legal sources*

Contextualising the prerogatives ensured by the CRPD may thus be initiated by relating them to the rights granted to other beneficiaries. It may also be done by looking at other legal sources and, more broadly, other systems for protecting fundamental rights.

95 — Olivier GIRAUD [13, point 3]; Eva KITTAY [16]; Clémence MERVEILLE and Arnaud PICQUE [17]. For the views of different mothers of disabled children, see also C. FREMAULT, *Paroles de mères-veilles*, Waterloo, Renaissance du Livre, 2023. See also Isabelle HACHEZ and Louis TRIAILLE [21].

96 — Mabel GIRALDO [15]; Clémence MERVEILLE and Arnaud PICQUE [17].

97 — E. KITTAY, “When Caring is just and Justice is Caring: Justice and Mental Retardation”, *Public Culture*, October 2021, pp. 557 to 579. See also Clémence MERVEILLE and Arnaud PICQUE [17], especially on the concept of “droits de tirage sociaux” [social drawing rights], an expression the authors have borrowed from Alain Supiot.

98 — While distancing ourselves from the idea that we need more “institutions”, or at least working on what the term “institutions” means. See in particular the paper by Cinzia AGONI [21].

99 — Antoine PRINTZ [19]; Nicolas MARQUIS [47].

100 — See the papers by Y. CARTUYVELS, Sophie DE SPIEGELEIR, Mathieu GALMART and Tarik OUDGHIRI IDRISSE, Ciska WITTOUK [49]. See also the paper by Antoine FEVRIER [39] in the context of aerial practice, regarding deafness.

First, there are fundamental rights treaties other than the CRPD that benefit, universally, disabled people and any other person. Second, the CRPD may itself be considered an “external source” by supervisory bodies other than the Committee on the Rights of Persons with Disabilities<sup>101</sup>. Fundamental rights law tends to be written in a network, drawing on different sources, which does not preclude trouble spots, or even differing opinions between the various supervisory bodies that use them. For example, the position of the European Committee of Social Rights on care solutions for people with severe dependency needs is difficult to reconcile with that of the Committee on the Rights of Persons with Disabilities, even though its interpretation is based on the CRPD<sup>102</sup>. As regards internment, the European Court of Human Rights has explicitly distanced itself from the level of protection offered by the CRPD system, and the same has been true, more recently, as regards the right to vote<sup>103</sup>. In the field of education, however, the international law of human rights seems to converge in favour of the requirement of inclusive education, although the modalities of this have yet to be fully specified<sup>104</sup>.

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By taking some distance from the rights of disabled people, who are, understandably, the only ones considered in the CRPD system, it is possible to take the measure of the necessary contextualisation and almost inevitable reappraisal of the prerogatives enshrined to their benefit as soon as they are returned to a relational perspective. In principle, the freedom of one person ends where the freedom of another begins, as the general theory on fundamental rights teaches us.

101 — On the concept and taking into account outside sources, see Fr. TULKENS, S. VAN DROOGHENBROECK and Fr. KRENC, “Le *Soft Law* et la Cour européenne des droits de l’Homme. Questions de légitimité et de méthode», *Les sources du droit revisitées*, vol. 1, *Normes internationales et constitutionnelles*, under the supervision of I. Hachez, Y. Cartuyvels, H. Dumont, Fr. Ost and M. van de Kerchove, Brussels, Publications des Facultés universitaires Saint-Louis, Limal, Anthémis, 2012, pp. 381 and 462; D. STAES, *When the European Court of Human Rights refers to External Instruments. Mapping and Justifications*, doctoral thesis, Université libre de Bruxelles and Université Saint-Louis – Bruxelles (now: UCLouvain Saint-Louis Bruxelles), June 2017.

102 — Isabelle HACHEZ and Louis TRIAILLE; Cinzia AGONI [21]; Laurence BRAET, Nathalie DANDROY, Anne KETELAER and Ghislain MAGEROTTE [31], including references to Belgian national decisions [31] under point 2.2.

103 — On the respective regimes guaranteed by the CRPD and the ECHR with respect to commitment, cf. Yves CARTUYVELS [49]. On the points of divergence between the two systems, which he is careful to put into perspective, cf. Paul LEMMENS [8]. See also C.C. TRUE-FROST, “Listening to Dissonance at the Intersections of International Human Rights Law”, *Michigan Journal of International Law*, vol. 43/2, 2022, pp. 361 to 421, spec. pp. 402 to 408.

104 — See for example: European Committee of Social Rights, decision of 9 November 2020 in response to collective complaint no. 141/2017, *FIDH and Inclusion Europe v. Belgium*; ECHR, decision *G.L. v. Italy*, 10 September 2020. Compare with the way inclusive teaching is experienced and applied in the Wallonia-Brussels Federation: Ghislain MAGEROTTE, Jean-Pierre COENEN and Dominique PAQUOT [32]. Finally, see the notion and practice of “reverse inclusion” in the field of deafness: Carlos Stéphane DINDIN [34, conclusion].

#### 4. TOWARDS A GROUNDED, PRAGMATIC AND GRADUAL APPROACH TO DEINSTITUTIONALISATION

As regards ideas, no one, at least not among the authors of this book, would dream of defending the total institution as understood by the Goffmanian use of the term. Everyone agrees on the challenge of moving away from an “institutional culture that brings people together and isolates them on the basis of disability, that deprives them of freedom and choice of lifestyle through a depersonalising hospital routine, and that gives them little or no recognition of their (legal) capacity to make decisions and manage their lives independently”<sup>105</sup>. When the possibility of maintaining institutional structures is recognised under certain conditions, the authors generally see specialised places for disabled people as an alternative to another possible choice that must be initiated and awareness of which must be raised. When inclusion is discussed, it is never to challenge the fight against exclusion but to caution against the potential collateral effects of certain translations of the inclusive paradigm. The call for inclusion for all, which seems obvious as long as it remains abstract, is countered by the insistence on *real* participation by disabled people about issues that concern them, particularly in the context of the discussion on the process of deinstitutionalisation<sup>106</sup>.

Everyone, even advocates of a complete deinstitutionalisation<sup>107</sup>, admits, albeit implicitly, that the institution is intrinsic to society. Deinstitutionalising does not mean, to their way of thinking, moving away from the idea of an institution as we propose to conceive it from a perspective informed by humanities and social sciences. For them, deinstitutionalising means rejecting collective living facilities for disabled people and institutionalising practices, wherever they may operate, because, all too often, these practices continue to shape the daily lives of people with disabilities and/or the elderly. Indeed, one might think that the issue of deinstitutionalisation, as positioned in particular by the Committee on the Rights of Persons with Disabilities, embodies above all an attempt to politicise the oppressive dimensions of collective living environments, and this is something that must be heard. It is believed that all the authors who have contributed to this book have heard it.

Where the disagreement essentially lies is not on the issue highlighted by the Committee (the need to move away both from a logic of segregation and from a depersonalising culture) but on how to give it substance. In other words, the consensus is dissolving on the appropriateness of embarking on a path as radical as that pointed out

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105 — V. GHESQUIERE, I. HACHEZ and C. VAN BASSELAERE, *op. cit.*, p. 83.

106 — See the papers by CAPDROITS [9], VANESSA CHAPPELLE [52], VINCENT FRIES [21] and of the CSNPH [21]. See also, for an emphasis on the participation and involvement of families: Ciska WITTOUK [49].

107 — See, for example, the papers by Rosemary KAYESS [5] and by Nadia HADAD and Corinne LASSOIE [6], or the positions defended by the Committee on the Rights of Persons with Disabilities.

by the Committee, denying the very possibility of collective living spaces and, in so doing, limiting a freely-made choice to a supervised life at home<sup>108</sup>. What remains unclear, in the background to the debate on the scope of deinstitutionalisation, is the meaning and, even more so, the consequences attached to concepts like disability, equality, autonomy and inclusion. Should the general, abstract category of disabled people take precedence – or not – over the singularity of certain forms of disability and incapacity? Does equality primarily mean equal treatment of disabled people and non-disabled people, on the one hand, and between people with disabilities on the other? Is autonomy best understood primarily from an individual perspective or also from a relational one? Is inclusion primarily a one-way process, from society to the disabled person who enjoys a subjective right to participate in the life of the community or is it a dialectical process from the outset, involving mutual adjustments between the disabled person and his or her fellow citizens? Does inclusion in society mean being at the heart of it, in the geographical sense of the term, or, more fundamentally, reconsidering the common humanity and responsibility of all individuals towards one another<sup>109</sup>?

International law on fundamental rights provides a framework for these issues, without necessarily settling them, while national experiences reveal the potential and the limits of the process of deinstitutionalisation as it is taking shape (4.1). Aware of the range of possibilities and the options that have already been tested, it seems to us that it is ultimately up to the various legislators to take a position and be accountable for the way in which the deinstitutionalisation process is carried out (4.2). We can at most, in this perspective, sketch out some evocative routes that outline a possible approach (4.3).

#### *4.1. Drawing on the international framework and national experiences of deinstitutionalisation*

While the CRPD is undeniably a key element in the legal understanding of disability situations, it is not the only lever that can be used in such situations, which often involve players other than disabled people. At the level of the Council of Europe, both the European Convention on Human Rights and the Revised European Social Charter continue to be used in cases involving long-term dependency, persons in care or other disabilities which, in whole or in part, overlap with or give rise to situations of disability within the meaning of Article 1.2 of the UN Convention. Their respective jurisdictions may converge when the level of protection offered by the CRPD inspires the interpretation of European treaty texts, but they may also diverge on certain points, in particular, on the issue of the scope of deinstitutionalisation under the CRPD. Between the letter of the Convention and its interpretation by its authorised supervisory

108 — Compare, for example, the texts by Nadia HADAD and Corinne LASSOIE [6], on the one hand, and of the CSNPH [2], on the other.

109 — Eva KITTAY [16, conclusion].

body, the Committee on the Rights of Persons with Disabilities, there is, moreover, a margin likely to give rise to other interpretations of the Convention than that of a radical deinstitutionalisation.

There will be no attempt here to resolve or, *a fortiori*, to settle the conflicting rights which mark international law on fundamental rights on the issue of deinstitutionalisation<sup>110</sup>. We will limit ourselves to noting their existence and the absence of criteria which, as the law currently stands, necessarily and exclusively point in favour of the course of action outlined by the Committee on the Rights of Persons with Disabilities. As a result, therefore, an argument can be made that the States enjoy a degree of flexibility when translating the fundamental rights of people with disabilities into public policy within their national legal systems.

If an attempt were made to create a rough sketch of the framework of possibilities outlined by international human rights law, it would take the following shape: a progressive obligation to deinstitutionalise in the sense understood by the Committee on the Rights of Persons with Disabilities, coupled with, at any rate as long as deinstitutionalisation is not complete (this remains an open question), maintaining and developing sufficient collective accommodation to ensure effective freedom of choice and to meet the diverse needs (of disabled people as well as their families and third-party carers) – it being understood that this institutional supply is itself subject to the general obligation of deinstitutionalisation in its qualitative aspect<sup>111</sup>. In other words, collective accommodation needs to be reformed from within to guarantee the disabled person's freedom of choice on a day-to-day basis, and to ensure that they are not excluded from normal social life.

It is therefore impossible, in our view and in the current state of the law, to ignore the movement towards deinstitutionalisation that was set in motion by Article 19 of the CRPD, but at the same time it is also impossible to ignore the margins maintained by the European supervisory bodies to accommodate the diverse situations encountered<sup>112</sup>.

To a certain extent, the international legal framework outlined in this book draws on the lessons learned in other disciplines (in particular, sociology, political science and philosophy) and from national experiences. As noted above<sup>113</sup>, some authors point to the setbacks of deinstitutionalisation experiences<sup>114</sup>, particularly when the setbacks concern the most vulnerable people and when they almost

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110 — In this regard, we refer the reader to the thesis of Louis TRIAILLE, nearing completion (title of project: "Dilemmes et formes juridiques de la désinstitutionnalisation dans le droit international du handicap" [Dilemmas and legal forms of deinstitutionalisation in international disability law]; prospective public defence in September 2024).

111 — For more information on accommodation, see Isabelle HACHEZ and Louis TRIAILLE [21, point 7]. The same reasoning can be applied by analogy to the other sectors considered in this book. Iris LOFFEIR and Célia POULET [25, point 2.2] refer to this as «symbolic deinstitutionalisation».

112 — Cf. the papers by Paul LEMMENS [8], Isabelle HACHEZ and Louis TRIAILLE [21], Laurence BRAET, Nathalie DANDOY, Anne KETELAER and Ghislain MAGEROTTE [31] and Yves CARTUYVELS [49].

113 — Cf. *supra*, point 2.2.2.

114 — Some people see this as a two-stage process: deinstitutionalisation and new-deinstitutionalisation (Ines GUERINI, Carla GUELI and Fabio BOCCI [28]), while others speak of post-deinstitutionalisation (Mélanie SCHAUR and Angela WEGSCHEIDER [29]).

inevitably come up against budget limits or rationales<sup>115</sup>. As has also been stated<sup>116</sup>, some point to the collateral effects on carers, especially women<sup>117</sup>. Others point to the return of the institutionalising repression at the heart of experiences of deinstitutionalisation (inviting people to take a critical distance from what is being played out)<sup>118</sup>, maintaining collective accommodation institutions (even where there is a claim to “post-deinstitutionalisation”)<sup>119</sup>, processes of “transinstitutionalisation” (moving from one institution to another)<sup>120</sup> or even paths of institutional wandering<sup>121</sup>. Still others emphasise the potentially deleterious nature of the lack of differentiated treatment depending on the type of disability encountered<sup>122</sup> and the long-standing tensions over the appropriate understanding of equality (same treatment or differentiated treatment) and its implications for the preferred form of institution (asylum prison or prison asylum)<sup>123</sup>. Finally, others stress the need to assess, on the ground, the diverse ways in which capacity is recognised and autonomy experienced<sup>124</sup>, as well as the importance of taking into account the impact of the public policies adopted on the understanding of these concepts<sup>125</sup>, and the performative nature of the categories they imply<sup>126</sup>. Overall, many are calling for a nuanced approach to be deployed across the entire institutionalisation/deinstitutionalisation spectrum<sup>127</sup>, or, at the very least, to act in parallel on the different fronts to achieve, ultimately, the desired deinstitutionalisation<sup>128</sup>. In any case, this approach can be credited with allowing national and individual circumstances to be taken into account up to a point.

115 — Luke BEESLEY [4], Mabel GIRALDO [15], Eva KITTY [16], Grégory DE WILDE D'ESTMAEL [21], Lisandre LABRECQUE-LEBEAU, Martine LEVESQUE, Merna ABOUSEFFIEN, Yolanda MUNOZ, Linda GAUTHIER and Line BERGERON [22], Christelle ACHARD [24], Mathieu GALMART and Tarik OUDGHIRI IDRISSE [49]. On the practical limits and ambivalence of deinstitutionalisation, see in particular the papers by Henri-Jacques STIKER [4], CAPDROITS [9], Mabel GIRALDO [15], Vincent FRIES and Gisèle MARLIÈRE for the CSNPH [21], Christelle ACHARD [24], Mélanie SCHAUR and Angela WEGSCHEIDER [29].

116 — Cf. *supra*, point 2.2.2.

117 — Clémence MERVEILLE and Arnaud PICQUE [17], Antoine PRINTZ [19].

118 — Vincent FRIES [21], Ines GUERINI, Carla GUELI and Fabio BOCCI [28].

119 — Mélanie SCHAUR and Angela WEGSCHEIDER [29].

120 — Sébastien SAETTA, Eric FAKRA, Maël PULCINI and Yvonne QUENUM [27]; Sophie DE SPIEGELEIR [49], who also refers to deinstitutionalisation by degrees.

121 — Samuel DAL ZILIO [48].

122 — Célia BOUCHET [33].

123 — Yves CARTUYVELS [49].

124 — Lisandre LABRECQUE-LEBEAU, Martine LEVESQUE, Merna ABOUSEFFIEN, Yolanda MUNOZ, Linda GAUTHIER and Line BERGERON [22], Claire ROMMELAERE, Charlotte BREDA, Caroline GUFFENS and César MEURIS [23], Anne-Lise MITHOUT [36], Mathéa BOUDINET [37], Marie ASSAF [38], Sébastien SAETTA, Eric FAKRA, Maël PULCINI and Yvonne QUENUM [27], Nicolas MARQUIS [47].

125 — Olivier GIRAUD [13], Deborah LUTZ [18], Cinzia AGONI [21], Tonya TARTOUR [26], Laurence BRAET, Nathalie DANDROY, Anne KETELAER and Ghislain MAGEROTTE [31].

126 — Cf. Paul VAN WALLEGHEM [11] on the category of severe dependency in Brussels public policy. See also the notion of «symbolic deinstitutionalisation» introduced by Iris LOFFEIER and Célia POULET (25, point 3.1).

127 — Cf. in particular: Caroline GAUSSIN [2], Henri-Jacques STIKER [4], CAPDROITS [9], Valérie ACOUOTURIER and Miranda BOLDRINI [10], Isabelle HACHEZ and Louis TRIAILLE, Cinzia AGONI, Grégory DE WILDE D'ESTMAEL, CSNPH [21], Quentin LANDENNE [35], Rémi GENDARME-CERQUETTI [43], Mathieu GALMART and Tarik OUDGHIRI IDRISSE [49] (who invoke the “principle of non-education”, which suggests that institutionalisation should be caricatured by limiting it to its restrictive aspect, nor should deinstitutionalisation be glorified by associating it with freedom alone, in favour of a gradual approach).

128 — Véronique GHESQUIÈRE, for Unia [7].

In the future, clarifying the international framework, in the sense of reducing the range of possibilities, could just as easily result from a more in-depth dialogue between the international supervisory bodies dealing with disabilities as from an accentuation of the convergence of views revealed by the analysis of national public policies in this area. In other words, more marked trends, making it possible to position the cursor more precisely between the extremes of radical deinstitutionalisation and maximum institutionalisation, could emerge at international level or among national legal orders and influence both, in particular, the direction indicated by the case-law issuing from Strasbourg<sup>129</sup>, whose privileged authority and receptiveness are well known, at least within the supervisory bodies of the Belgian legal order.

#### *4.2. Preparing, justifying and supporting a position for the public authorities*

Within the framework provided by international human rights law, the States therefore have a certain margin of appreciation as to how to design and implement UN deinstitutionalisation. The freedom of national self-determination is not limited by international law, nor, where Belgium is concerned, is it in Belgian constitutional law, which guarantees the right to full inclusion of people with disabilities, without defining it in any other way<sup>130</sup>. It is only roughly sketched out and it would appear to be wise that this should be the case.

Deinstitutionalisation is a choice for society that cannot, in our opinion, be left in the hands of a single body of experts, regardless of the nature of that expertise, but must, within the framework provided by international human rights law, be invested by the nations and the social bodies of which they are composed. The internationalisation of human rights, of which the CRPD is just one example, must not obscure the inseparable link between human rights and democracy, and the need for national legislators to translate the values they embody into public policies, with a margin of appreciation that allows them to consider certain specific national characteristics<sup>131</sup>. It is therefore up to the national authorities to position themselves within this framework by making informed choices that need to be justified and supported.

To be informed, the choices to be made must from the outset be based on the opinions of those most affected, people with disabilities, in accordance with the motto *'nothing about us without us'*,

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129 — Paul LEMMENS [8].

130 — See I. HACHEZ, «La consécration constitutionnelle du droit à l'inclusion des personnes en situation de handicap (art. 22ter) : de la duplication du cadre juridique au dessin de politiques publiques», *J.T.*, 2022, no. 6882, pp. 17 to 24.

131 — Cf. in particular: H. DUMONT and I. HACHEZ, «Repenser la souveraineté à la lumière du droit international des droits de l'homme», *Liber amicorum Rusen Ergec*, Pasricrise Luxembourggeoise, 2017, pp. 105 to 143 ; *R.B.D.C.*, 2017/4, p. 315 to 363.

which is translated into law by the principle of participation<sup>132</sup>. Both the *peer experience* and the expertise of organisations representing people with disabilities are essential in this respect. These choices should also take account of foreign experience<sup>133</sup>, as well as the societal and cultural context in which they are made. The availability of disaggregated databases on people with disabilities, the mapping of existing institutions and assessing the needs of the population all seem essential in this respect, as do the identification and visibility of pilot experiments<sup>134</sup>. National choices also benefit from being informed by the conceptual shifts in the notions that underlie deinstitutionalisation, and the issues it raises<sup>135</sup>. What understanding of the notions of equality, autonomy and inclusion underpins the public policies envisaged to give substance to deinstitutionalisation? What type(s) of deinstitutionalisation is (are) envisaged, for whom and why? What resources are allocated to support the objectives? What measures are planned to counter the collateral effects identified in comparative law, including within federal states?

While informed, the choices should also be justified, especially in a context where the exact scope of the deinstitutionalisation obligations cannot be fully understood from the various sources of law that define them. The more the national public authorities demonstrate their knowledge of the international context and explain why they have adopted a particular stance in light of it, the less likely they are to have called into question the directions they have taken. It is their task to show, through their actions, that they are aware of the international context, conceptual uncertainties, foreign experience, society's needs and supply and demand.

Although informed and justified, these choices must finally be accompanied by an action plan that phases in the stages and routes to deinstitutionalisation and that identifies the preferred measures for this purpose, which includes sources of funding, which in turn includes mobilising European structural funds. As was emphasised above<sup>136</sup>, supporting these choices also means providing training and raising

132 — See in particular A. BRODERICK, "Article 4", *The UN Convention on the Rights of Persons with Disabilities. A commentary*, I. Bantekas, M.A. Stein et D. Anastasiou (eds.), Oxford University Press, 2018, p. 107 to 139; General comment no. 7 (2018) of the Committee on the Rights of Persons with Disabilities on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation of the Convention and the monitoring of its application; CSNPH position paper on the participation of persons with disabilities in decision-making processes, approved at the plenary session of 21 June 2021.

133 — Or internally in federal states like Belgium, where the Flemish Community seems to have a head start in deinstitutionalisation. Cf. in this respect the text by Laurence BRAET, Nathalie DANDOV, Anne KETELAER and Ghislain MAGEROTTE [31].

134 — On the data deficit within the Belgian State, see: Concluding observations of the Committee on the Rights of Persons with Disabilities of 28 October 2014 on the initial report of Belgium, adopted at its twelfth session (15 September–3 October 2014), §§ 42 and 43. For an example of a cadastre, see G. DELIENS, F. MERKEN, S. JASPARD and M. KISSINE, «Offre et besoins de services pour les personnes en situation de handicap à Bruxelles Lot 2 – Etude des besoins des personnes en situation de handicap à Bruxelles», Final Report, 6 February 2023, [https://acte.ulb.be/images/PDF/ACTE\\_Cadastre\\_PSH\\_Volet2.pdf](https://acte.ulb.be/images/PDF/ACTE_Cadastre_PSH_Volet2.pdf)

135 — Cf. the two extended «conceptual grammars» *supra*, points 1.1 to 1.3, on the one hand, and points 2.1.1 to 2.1.3, on the other.

136 — *Supra*, point 2.1.2.

awareness about disabilities, deinstitutionalisation and freedom to choose. It also means being in a position to assess the effectiveness of the choices made by means of indicators so that the approach chosen can be improved or rectified.

### 4.3. *Suggested paths: markers, degrees and dimensions of the institution and of deinstitutionalisation*

The importance of a democratic debate on the options to be favoured to give substance to deinstitutionalisation is no longer to be underestimated. Within the framework set out under international law on fundamental rights, it is primarily the national legislators who are given the task of taking a stand by involving and ensuring the representation of people with disabilities. The most that can be done in this context is to make suggestions to stimulate debate<sup>137</sup>. These suggestions seem, in our view, to respect the letter of (Article 19 of) the CRPD, to be aware of its inclusion in a broader range of sources, to reconcile it with the rights of other people affected by disabilities and to take account of the tensions and values that underpin the changes in the worlds of disability and mental health<sup>138</sup>. They seek to hold the one and the many together at the crossroads of general trends to be outlined and singularities to be considered, personally, materially or spatially. They assume the will to see the recognition of subjective rights as a collective project for which responsibility is shared.

Essentially, what is being suggested here, for both moral and practical reasons, is extending both deinstitutionalisation and institutionalisation, opening them up to meeting otherness and difference<sup>139</sup>, in other words, to human biodiversity, to quote Josef Schovanec<sup>140</sup>. Extending does not mean forgetting. Of the deinstitutionalisation called for by the Committee on the Rights of Persons with Disabilities, the criteria-based approach to institution(alisation)<sup>141</sup> would in any case be retained, that of the person as a subject of rights, free to determine his or her own destiny based on his or her ways of being and his or her life choices, but, at the same time, greater attention would be paid to diversity, a broader conception of equality and a relational understanding of autonomy and its collective dimension, inclusion. As regards the institution, what would be highlighted is the need to suggest problems about it from a human and social sciences perspective, its polysemic and potentially emancipatory nature, seeking to contain and push

137 — See, moreover, Isabelle HACHEZ and Louis TRIAILLE [2], session conclusions].

138 — So, generally speaking, a care relationship that is too unequal today seems less legitimate in terms of values. See N. MARQUIS (ed.), *Education, Parenting and Mental Health Care in Europe: The Contradictions of Building Autonomous Individuals*, London, Routledge, in press (2024).

139 — Cf. in this respect, the paper by Henri-Jacques STIKER [4]. See also, supporting the inclusion of dependency in a relationship, the papers by CAPDROITS [9], Valérie AUCOUTURIER and Miranda BOLDRINI [10], Paul VAN WALLEGHEM [11].

140 — J. SCHOVANEC, *Nos intelligences multiples*, Paris, L'Observatoire, 2018, spec. p. 73.

141 — Cf. also, in this sense, the paper by CSNPH [21]. Compare with the approach, diverging slightly in terms of content, of the Committee on the Rights of Persons with Disabilities, employed in particular by Nadia HADAD and Corinne LASOIE [6].

back its darkest facets, and, from this perspective, the contribution of the Committee on the Rights of Persons with Disabilities is essential. More precisely, it is suggested that we move forward with the following guidelines in mind.

It would be a matter of favouring a *pragmatic* understanding of the notions of institutionalisation and deinstitutionalisation, rather than seeking to construct a substantial definition that would make it possible to say what an institution or a process of deinstitutionalisation is or is not.

A pragmatic definition would seek to identify the *markers, indices or indicators* of the institutional fact, of the difference that these elements make both in terms of support and constraint, and, as a corollary, of what would be involved in a process that would seek to have them disappear. In other words, whether it is small or large, whether it is an abstract idea or a concrete structure, an institution must always be considered in terms of what it *allows* and what it *prevents*<sup>142</sup>.

A pragmatic perspective on the institution should make it possible to understand institutionalisation and deinstitutionalisation as matters of *degree* in many *dimensions*, by asking what, on both a very microscopic level and a macroscopic level, “makes” an institution<sup>143</sup>. From this perspective, it is easy to understand that leaving the walls does not necessarily mean deinstitutionalisation, for example, if this involves adapting to other organisational forms (out-patient care) or using other support systems (e.g., relatives or peer carers)<sup>144</sup>. In addition to giving substance to the institutional fact at various practical levels (e.g., place of choice, timetable management, geographical mobility, type of authorisation, social contacts, etc.), such an approach would make it possible to broaden our understanding of the deinstitutionalisation process by highlighting how certain structures can make progress in some dimensions and not in others. Deinstitutionalisation, far from being an unequivocal process, would then become a set of configurations.

In short, this pragmatic perspective on the institution could do without the hypostasised version of the notion of institution which, by its generality and its narrowness (cf. *supra*), contributes to obscuring rather than enlightening the debate, for example, by indiscriminately identifying the institution with the exercise of constraint, by carrying a virulent criticism of the institutional fact itself, and by risking maintaining the confusion according to which it would be possible to do without the institution, including in the sense given to this notion by humanities and social sciences. So it is no longer the institution “in general” that is in the spotlight, but rather it is certain criteria, certain connected or unconnected aspects that can be the subject of discussions for and against, by being weighed against values and social norms that are themselves constantly evolving.

142 — Cf. the references cited *supra*, under point 2.1.2.

143 — A parallel may be drawn here with the gradual nature of autonomy and of each individual's vulnerability (Caroline GAUSSIN [2]; Valérie AUCOUTURIER and Miranda BOLDRINI [10]).

144 — See, in particular, the shared experience of Vincent FRIES [21].

It is our view that any public policy would benefit from being based on a gradual (rather than radical) understanding of deinstitutionalisation, in the knowledge that, within the legal framework and given the questions surrounding its true scope, there is room, it should be recalled, for a political stance that is hopefully informed by foreign experience in the field and attentive to the needs of people with disabilities. Developing a grammar for deinstitutionalisation would also benefit from looking at cases where there is doubt that the person would prefer fewer institutions, just as it would benefit from considering cases where fewer institutions would mean shifting a considerable burden onto informal players, putting the persons themselves or others at risk. It would also be useful to examine and set out the aims and presuppositions that its authors attribute to institutionalisation and deinstitutionalisation, or those to which it responds in practice<sup>145</sup>.

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The complex realities of disability<sup>146</sup> could be read in the light of such a grounded, pragmatic and gradual grammar of deinstitutionalisation, which remains to be developed or nuanced, with a view, on the one hand, to determining where to put the focus, between the extremes of total institutionalisation and complete deinstitutionalisation, and, on the other hand, to be able to identify the trends that reflect the international framework to be expanded, and those from which it would be advisable to move away.

These are the institutional conditions for deinstitutionalisation in the field of disability that we have identified so far. They provide the outline for an inclusive society in which deinstitutionalisation is not simply a matter for people with disabilities who, individually or collectively, are claiming rights from the society in which they live, but which also calls into question society's plan for them in a form of dialectical relationship involving all segments of society. As much as possible, they deal with the fundamental tensions that underpin disability issues<sup>147</sup>.

What kind of inclusive society is being discussed? One that can be summarised by the formula "1+1=3" and which requires each of its members to make mutual adjustments to respond to and address the open question "*do I belong?*" It is about putting people and their environment at the heart of our collective destiny and paying attention to the individual.

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145 — Cf. for example the text by Baptiste MOUTAUD [45] or, in a completely different field and in a completely different place, that of Anne-Lise MITHOU [36].

146 — This complexity is particularly well highlighted in the papers by Samuel DAL ZILIO [48] (about an institutional life journey) and Luke BEESLEY [14] (on constructing militancy in Great Britain).

147 — On the constitutive ambivalence of the social and anthropological experience of disability, see the excellent conclusion of Quentin LANDENNE [35], itself echoing the remarkable contribution of Guillaume DE STEXHE, whom he cites. On the tension that characterises institutions, cf. E. DELRUELLE, «Quelle "désinstitutionnalisation?" Pour une approche politique des institutions», *L'Observatoire*, no. 71/2011, p. 11.