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Latin American Interdisciplinary Perspectives on Bioethics and Disabilities

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Editors

Latin American Interdisciplinary Perspectives on Bioethics and Disabilities

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Foreword

Disability studies are about what we are, as human beings and as beings *simpliciter*. To write about disabilities is to write about the *condition humaine*: a variety of philosophical and theoretical perspectives are needed to do justice to this complex subject. Seen from Europe, the creativity, innovativeness, and diversity of Latin American discourses on this topic are striking. The present volume, *Latin American Interdisciplinary Perspectives on Bioethics and Disabilities*, edited by Ana Paula Barbosa-Fohrmann and Sandra Caponi, bears impressive witness to this.

Capturing what we are is necessarily an interdisciplinary project. This volume brings together 15 authors from jurisprudence, sociology, philosophy, history, pharmacy, occupational therapy, and psychology, who develop a variety of complementary, overlapping, mutually reinforcing (and sometimes mutually irritating) perspectives in 10 chapters. There are many common grounds in disability studies – authors such as Michel Foucault, Emmanuel Lévinas, Maurice Merleau-Ponty, and Alasdair MacIntyre form points of reference on both sides of the Atlantic. A particular strength of the present volume, however, lies in the philosophical perspectives drawn from Brazil's, Argentina's, and Chile's own debates. This is far more than just the reception of an international discourse context since thinking about disabilities always is situated in specific cultural context, including historical path dependencies and shared social experiences.

The authors offer a rich selection of objects of investigation. The basic questions dealt with range from criteria for human flourishing to questions of philosophy of mind, from neuroethics to phenomenological and aesthetic approaches to intellectual and psychosocial disabilities. The legal and political investigations explore the rights of those affected and the processes of their self-organization; they ask about the dynamics of medicalization and demedicalization, about the practices of

psychiatric institutionalization and the treatment of children with antipsychotics. Finally, they examine the sociocultural premises of legislation, as well as historical cases that shed light on the path we have already traveled and the road ahead.

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Part I
Subjects with Intellectual and Psychosocial
Disabilities

Chapter 1

Empathizing with the Intellectually Disabled



Claudia Passos-Ferreira

Abstract This chapter is devoted to reflecting on the role of empathy in interactions with people with profound intellectual disabilities. We have a duty to respect people with intellectual disabilities. Respect involves identification with a point of view. We owe them an effort at identification with their perspective. However, if intellectually disabled people's communicative abilities are impaired, our apprehension of their point of view might be limited, reducing our ability to identify with them and respect them. To answer this challenge, I appeal to empathy. Through imaginative empathy, we can learn to identify with their perspectives. I argue that empathy is a good moral guide and can be helpful in developing respectful attitudes toward people with profound intellectual disabilities.

Keywords Intellectually disabled · Identification · Respect · Care · Empathy

1.1 Introduction

We have a duty to respect intellectually disabled people. We owe them a kind of respect and care that we owe to all fellow human beings – a kind of humanistic respect. This duty might be stronger for those who care about them, including their parents, family, and caregivers. However, ultimately, any normal adult human being has a duty to treat intellectually disabled people humanely and respectfully.

One major challenge arises from people with especially profound intellectual disabilities. A common view is that these people do not have a point of view with which we could identify with in order to relate to them. If having a point of view with which others can identify with is required for being morally respected, and people with profound intellectual disabilities do not have a point of view, then respect for people with profound intellectual disabilities is compromised.

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To answer this challenge, I will argue that we should distinguish different sorts of points of view. It may be that people with profound intellectual disabilities lack a *reflective* point of view. But a reflective point of view may not be required for identification and respect. Profoundly intellectually disabled people may still have a *pre-reflective* point of view, and this point of view may ground identification and respect.

There remains a challenge. If intellectually disabled people's communicative abilities are impaired, our apprehension of their point of view might be limited, reducing our ability to identify with them and respect them. To answer this challenge, I will appeal to empathy. Empathy plays a key role in enhancing our understanding of profoundly impaired people. Through imaginative empathy, we can learn to identify with their perspectives.

It's often accepted that empathy is a good guide for caring relationships. I will also argue that empathy is a good moral guide and can be helpful in developing respectful attitudes toward people with profound intellectual disabilities.

1.2 Dehumanization and the Intellectually Disabled

There is no consensus about how to define intellectual disability. For my purpose here, I consider people with intellectual disabilities in functional terms as proposed by the last edition of the *Diagnostic and Statistical Manual of Mental Disorders 5 TR* (American Psychiatric Association (APA) 2022). According to the *DSM-5-TR*, intellectual disability "is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (APA 2022). People with intellectual disabilities vary in a large spectrum, from mild to severe and profound cognitive impairment. I will be mainly concerned here with people with severe and profound intellectual disabilities, although some of my claims might apply to mild and moderate cases too. People with profound intellectual disabilities have disabilities in conceptual, social, and practical domains, impairing their ability to adapt to and undertake everyday tasks. They have limited capacity for memory, language, and practical knowledge. They have impaired awareness of others' thoughts and few interpersonal communicational skills. Their learning and self-management capacities are impaired. They require support for all aspects of daily life and are highly dependent on caregivers.

Historically, the intellectually disabled have been the target of disrespect, abuse, and immoral treatment. Public perceptions of the intellectually disabled as 'sick', 'subhuman', 'menace', 'object of pity', 'burden of charity', and 'developing individual', have contributed to dehumanizing treatment (Keith and Keith 2013). Public policies of institutionalizing and confinement for care and treatment of individuals with intellectual disabilities have immensely contributed to disrespect and lifelong segregation (Keith and Keith 2013). It is well-known that people with disabilities suffered a process of eugenic dehumanization during the Nazi period. Under the

Nazi regime, people with disability, in particular those with intellectual disabilities and mental illness, “were deemed to be less than fully human” and were the target of a persistent eugenic campaign “aimed at eliminating people *like them*” (Wilson 2021, p. 174).

In *Making Monsters* (2021), David Livingstone Smith describes the psychology of racial dehumanization, particularly of Jews and Black people. According to Smith, dehumanizing others involves conceiving of them as subhuman creatures, belonging to inferior species, like non-human animals or supernatural creatures (monsters). However, it also involves conceiving of them as humans. The process of dehumanization involves metaphysically contradictory beliefs or representations of the other as both human and subhuman. As a consequence, Jews and Black people are seen as cognitively threatening, making people into ‘monsters’ (Smith 2021, p. 255).

Eric Schwitzgebel and Amelie Green (2022) suggest that the racial dehumanization process described by Smith (2021) can be extended to the cases of cognitive disabilities. Dehumanization is also present in caregivers’ attitudes toward the intellectually disabled. Caregivers, and even family, frequently abuse, disrespect, and dehumanize the severely intellectually disabled. There is a sort of *metaphysical discomfort* in seeing the intellectually disabled as unnatural and threatening – they might seem “creepy, occupying a gray area that defies familiar categories, at once both human and subhuman.” Caregivers seem to attempt to resolve this conflict “by symbolically degrading their clients”, and by “implicitly asserting their clients’ sub-humanity” (Schwitzgebel and Green 2022). By this symbolic degradation, they can justify their sadistic abuse, their acts of purposeless cruelty, and convenient mistreatment. As Smith (2021) points out, dehumanization often facilitates abuse, violence, disrespect, atrocities, harm, and degrading behavior. Schwitzgebel and Green (2022) argue that caregivers often have dehumanizing representations. They refer to their clients as non-human animals; they refer to them using the ‘it’ pronoun – a verbal symptom of the dehumanization. At the same time, they also refer to their clients as humans with rights. As Schwitzgebel and Green point out, it is relevant to solve this metaphysical dissonance of conflicting representations, if we are concerned with the ethical treatment of the cognitive disabled. They suggest that we should develop a more capacious understanding of humanity where high levels of cognitive abilities are not essential for being or being perceived as fully human. A more inclusive notion of humanity can be a remedy against dehumanizing attitudes toward the intellectually disabled.

How can we treat the intellectually disabled humanely? There have been more inclusive types of treatment that go beyond the past practices of institutionalization and isolation of the intellectually disabled from social activities. There have been legal protections and human rights protections, such as the right to receive public education with individualized educational programs, for example, the Declaration on the Rights of Mentally Retarded Persons in 1971, and the Declaration of Intellectual Disabilities in 2004, demanding basic human rights and freedom from discrimination (Keith and Keith 2013, p. 153). There has been also public awareness

of adopting a more inclusive language. Categories and labels used to describe people affect the way we think about them. Recently, there have been attempts to avoid dehumanizing and demeaning labels historically used, such as *mental retardation*, *mental deficiency*, *idiocy*, or *imbecile*; and the introduction of less stigmatizing categories such as *intellectual* or *cognitive disability* (Keith and Keith 2013).

One aspect of the dehumanization process involves regarding others as having no worth, or as being unworthy of equal moral standing or full respect as persons. One important way of humanizing the intellectually disabled is to extend to them the attitudes we have toward persons. One important attitude is showing respect to someone. Respect involves valuing an object from a moral point of view.

Respect is an attitude, a way to treat and value someone. It has cognitive (beliefs, judgments, deliberations), affective (emotions, feelings), and conative dimensions (motivations, dispositions to act, and forbear from acting) (Dillon 1992, 2021). Treating someone with respect means paying attention and perceiving the person as worthy; it involves the belief that the person is worthy of attention. As Robin Dillon points out, respect involves a judgment that the object has “a feature which makes it worthy of respect”; so, respect is grounded in “those features of an object that make it worthy of attention and appropriate response” (Dillon 1992, p. 113). Respect for persons involves “recognizing that a being is a person”, and “appreciating that persons as such have intrinsic moral value”, that is, they matter morally in their own right (Dillon 1992, p. 112). In this sense, the features which make something a person are the features that make persons matter morally (Dillon 1992, p. 113).

On a Kantian view, what grounds the value of a person is their capacity for rational autonomy and self-reflection. So, respect for persons involves respecting their capacity for rational autonomy.¹ However, if respect is grounded wholly in persons’ rational and self-reflective capacities, this might entail excluding the profound intellectually disabled as deserving respect. The scope of the concept of a person constrains or expands the class of human beings who warrant respect. A broader conception of persons, where rational capacities are not required for being an object of respect, might yield a more respectful and humane attitude toward the intellectually disabled. In the next section, I examine a more inclusive approach to respect.

1.3 Identification with a Point of View

A common idea of what constitutes respect for others is that respect involves *identification with a point of view*; that is, showing respect to someone requires taking into consideration the way they see and experience the world around them (Dillon

¹As Dillon (1992) points out, there are different ways of respecting persons, for example, respecting their moral and legal rights. I will be most concerned here with respecting in the sense of caring or having concern for others.

1992; Vorhaus 2020). Persons have desires, goals, and life purposes. Respect for others involves an understanding of an individual's life goals and purposes; it involves an understanding of what the person really wants and desires. It is through an identification with your perspective that I can understand how my actions might affect your life purposes and intentions, and what I am expected to do to cultivate a respectful relationship with you. For example, I should not unjustifiably interfere with your actions and decisions; I should give you space to exercise your rational capacities.

What is to have a point of view? On one conception, this requires a conscious and autonomous individual who acts for reasons and has purposes in life; they are conscious of themselves and their situation, and the world around them. Having a point of view involves being capable of rational autonomy, the ability to act on the basis of reasons and make evaluative judgments, and to be concerned with one's future.

However, the capacities required for having this sort of rational point of view seem not to be present in some human beings, such as neonates, patients in vegetative states, and people with severe or profound intellectual disabilities. These people have no (or little) self-consciousness and self-reflection, they cannot reason about their future or make decisions, and they have reduced capacity for communication. It's arguable that they are not capable of rational autonomy. If so, they lack a point of view as traditionally conceived.

According to John Vorhaus (2020), this poses a challenge for respecting people with profound intellectual disabilities. If respect involves identification with a point of view, and a person lacks a point of view, there is no perspective with which we can relate and identify with – even if we are willing to respect them. If this is right, identification-based respect might not be possible for the profound intellectually disabled, among others individuals.

If we should treat all persons with identification respect, how can we identify with the intellectually disabled who lack higher cognitive capacities? Does this mean that they have no point of view at all? An alternative proposed but not developed by Vorhaus (2020) is to ground respect in a less demanding account of what is to have a point of view. I suggest that what matters for respect of personhood is a *pre-reflective point of view*.

On the traditional account, a point of view requires rationality, complex narratives, deep interpersonal relations, and a perspective on ourselves and the world. In this sense, having a point of view is being capable of having beliefs and representations of ourselves, others, and the world, and being aware of their continuing existence over time. This is actually the point of view of a cognitively abled adult human with the capacity for self-consciousness, self-reflection, for acting on the basis of reasons, interpersonal relations, and linguistic communication.

In a broader sense, any conscious being has a point of view that is intrinsically associated with being conscious. Conscious creatures have a perspective on the world around them. Every conscious being has a minimal pre-reflective