

Book Review



Pearson, T.W. (2023) *An Ordinary Future: Margaret Mead, the Problem of Disability, and a Child Born Different*. University of California Press.

What is disability? A limitation? A socially determined personal condition? An identity? Whether it occurs at birth or at some point in life, disability usually arrives unexpectedly. According to Morin,¹ when something unexpected occurs, we should “be capable of revising our theories and ideas rather than force-feeding the new fact into a theory that is unable to accommodate it” (p. 12, my translation). Throughout history, different theories and cultural representations have attempted to make sense of the unexpected quality of disability, within a certain vision of humanity and society.² Although many of these representations are no longer so pervasive, some of them survive today, albeit in ways that differ from their form in the past; however, they retain normative power in that they are able to orient individual and social attitudes and behaviour.

Even though there are approximately 1.3 billion people with disabilities in the world today, according to the World Health Organization,³ disability continues to be a subject of definition, discussion, discrimination, and social injustice. According to the report, 80 per cent of people with disabilities live in low- and middle-income countries, where health services are limited. Although progress has been made in recent years, the report highlights how people with disabilities worldwide experience health inequalities: they die earlier, have worse health, and experience more daily limitations than the rest of the population. But for several decades now, more and more people with disabilities and their families have been writing about their life experiences.

1 Morin, E. (1999) *Sept savoirs nécessaires à l'éducation du futur*. Ed. Seuil.

2 Gardou C. (2006) Handicap, corps blessé et cultures. *Recherches en psychanalyse*, 2(6): 29–40.

3 World Health Organization (2022) *Global Report on Health Equity for People with Disabilities*. www.who.int/publications/i/item/9789240063600.

This self-representation movement makes it possible to relate some of the cultural representations of disability to the voices of people living with this label.

In *An Ordinary Future: Margaret Mead, the Problem of Disability, and a Child Born Different*, Thomas W. Pearson – Professor of Anthropology and Chair of the Social Science Department at the University of Wisconsin – Stout – effectively interweaves different levels of experience and analysis. The experience of the author, the father of Michaela, who was born with trisomy 21, also known as Down's syndrome (the *micro* level), relates to the story of the famous psychoanalyst Erik Erikson (1902–1994), the father of Neil, a son born with trisomy 21 in 1944 (the *meso* level). The stories of these two fathers take different paths and Pearson helps us to understand them through a historical and anthropological analysis of the main cultural representations of disability in the United States and their evolution over time (the *macro* level). The *micro* (intrasubjective), *meso* (intersubjective), and *macro* (trans-subjective) levels are linked together by a key individual: anthropologist Margaret Mead (1901–1978). The scholar, a close friend of Erikson's, advised him to institutionalise his son to protect both Neil and the rest of the family. In the decades that followed, Mead revised her positions on disability, and the evolution of her thinking prompted a broader cultural change in the way disability is represented today.

Pearson's auto-ethnographical approach makes the text much more complex than a biography or an essay because it allows us to grasp relationships and reflect systemically on the impact of the historical, political, and cultural dimensions on individual experience. But it also allows us to see the generative and transformative potential of a life story placed in relation to other stories, helping to illuminate the dominant cultural premises in each context.⁴

The book consists of six chapters, complemented by a prologue and an epilogue. The titles of the chapters bring the focus to certain key words, which Pearson uses to structure the book: *becoming*, *features*, *institutions*, *potential*, *belonging*, and *vulnerability*. In the first chapter – Becoming – the author describes the most significant moments of his daughter Michaela's birth and the days before and after her diagnosis. At the same time, he also introduces Erikson's story and the birth of his fourth child, Neil. Both stories have in common the birth of a child with trisomy 21, but the family paths take different

4 I have myself worked on systemic reflexivity, see for instance: Cuppari, A. (2022) The Transformative Dance of the Crisis to Resignify Social Educational Work: Auto-ethnographical Reflections on Cooperative Enquiry in Northern Italy During the COVID-19 Pandemic. *European Journal for Research on the Education and Learning of Adults*, 13(2): 209–219. See also Jude, J. (2018) The Practice of Systemic Reflexivity. *Journal of Social Work Practice*, 32(1): 45–57.

directions. In Neil's case, the path is one of institutionalisation, which Pearson relates to a key phone call Erikson made to Mead, one which reflects the dominant culture of those years. On the other hand, in the author's story, the unexpected arrival of the diagnosis accompanies a gradual path of awareness of the new situation, crossed by profound "disorienting dilemmas."⁵ "Why was I initially devastated by her Down syndrome diagnosis? Why did I feel an impulse to reject her very humanity, despite my training as an anthropologist?" (p. 17).

The second chapter – Features – goes even deeper into the effects of the diagnosis. One of the main features of Down's syndrome, identified by those who began to study it in the past, was the so-called "simian crease," a single fold running through the palm of the hand. In the late 19th and early 20th century, this characteristic – and others, such as the shape of the eyes – became a pretext for the advancement of anthropometry and racist eugenics. Opposing this current of theory were scholars such as Franz Boas and his students (including Mead and Ruth Benedict), who problematised the concept of normality and criticised the idea of a fixed and inherited "race." Nevertheless, it is interesting to note how Pearson recognises traces of this history in his experience of the diagnosis: "What were they sorry for anyway? Sorry that my child was not perfect? Sorry that we had the wrong baby?" (p. 20). Here, again, the exposure to these dilemmas becomes an opportunity for new awareness: "I thought of a colleague who had recently lost a twin infant during childbirth, and my feelings came nowhere near to the catastrophic anguish he experienced. My loss was that of an imagined future, not a child. I was coping not with loss, but with difference" (p. 41).

The boundary separating normality and difference becomes the subject of the third chapter – Institutions. Racist eugenics, institutionalisation, and sterilisation became part of a strong welfare state system in the United States designed to protect public health and engineer the improvement of society. In the first half of the 20th century, universities generated the rationale to justify eugenicist policies and influence public perceptions of disability by supporting practices of institutionalisation and sterilisation. Terms such as "mentally defective," "feebleminded," "idiot," "moron," "imbecile," "mongoloid," and "insane" were used of people accused of transgressing social norms,

5 "Disorienting dilemma" is a term coined by sociologist Jack Mezirow (1923–2014) in his studies on transformative learning (see one of his most important texts: Mezirow, J. (1991) *Transformative Dimensions of Adult Learning*. Jossey-Bass Inc). The disorienting dilemma is a dilemma that may arise from an unexpected, externally imposed event or other experience. It challenges an established perspective and questions deeply rooted values and the sense of self.

and for decades they informed a medical paradigm aimed at classifying and diagnosing these individuals as sick and as dangerous to the future health of society. In this chapter, Pearson reflects on the power of diagnosis, starting from his personal experience, not only in relation to his daughter Michaela but also in relation to the story of his grandmother, Joan, who was placed in a mental institution. In one part of this chapter, the author writes: “As I absorbed the reality of Michaela’s diagnosis in those initial months, my perception became subject to a history of classifications, and my daughter became the subject of classification” (p. 62). Diagnosis is seen here as an action of signification that goes beyond the description of reality but reflects historical circumstances. As a social worker, I can attest that the diagnosis still represents the label under which a person is taken into care by social services and is a prerequisite for access to certain economic resources and services. However, diagnosis risks creating closed and fixed histories that are saturated by the problem and are incapable of being opened to change.⁶

What is the potential that is excluded from the experience of a person with a disability if the diagnosis does not exhaust it? In the chapter Potential, Pearson analyses how disability has challenged the assumptions of cultural anthropology. If anthropology assumes that all cultures are created by human beings who have the same mental abilities, where should people with cognitive impairments be placed? This assumption of cultural anthropology also concerned Mead when she recommended that Erikson institutionalise Neil. The concept of inclusion, according to Pearson, is opaque if we do not reflect on the premise on which it is – unintentionally – based. In fact, it is not explicitly regulated and it is open to interpretation and differences, depending on the context. While the elimination of architectural barriers is a visible action that generates effects on people, welcoming a person with an intellectual disability or neurodiversity is a more complex challenge because it questions dominant models and individual sensitivities and perceptions. Although raising a child with a disability today is certainly easier than it was a few decades ago, residues of problems in the inclusion of disability in the human experience remain. One example is what Pearson calls “shadow systems” (p. 100): specialised systems

6 To explore decolonial and systemic perspectives applied to the professions of care, see for example Pillow, W.S. (2019) Epistemic Witnessing: Theoretical Responsibilities, Decolonial Attitude and Lenticular Futures. *International Journal of Qualitative Studies in Education*, 32(2): 118–135; Rhodes, P. et al (2014) Transforming Practice in Developmental Disability Services Through Systemic and Dialogical Practice. *Journal of Systemic Therapies*, 33(3): 1–16; Simon, G. (2016) Thinking Systems: “Mind” as a Relational Activity. In Timimi, S., Mallett, R., and Runswick-Cole, K. eds. *Re-thinking Autism: Diagnosis, Identity, Equality*. Jessica Kingsley Publ.

inside existing educational systems specifically designed to work in parallel with people with disabilities, as happens in schools.

As a result, disability is a condition that challenges the sense of belonging in the human being, questions its assumptions, and creates paradoxes. The paradox of belonging is explored in the chapter *Belonging*. In a present that, to a greater extent than in the past, seems to offer better conditions for raising a child with disabilities – where institutionalisation has given way to practices of inclusion in the natural contexts of life, where the paradigm of human rights is protected by laws and international conventions⁷ – ableism (which assumes ability to be the criterion for what it is to be a human) and prenatal diagnosis screening continue to pursue normality, no longer through eugenicist policies but through increasingly accurate prenatal diagnoses aimed at detecting a broader spectrum of genetic or congenital malformations.

The evolution of Mead's thinking was also involved in the change in the representation of disability. Starting in the 1950s and 1960s, she became engaged as a scholar by the movement of family members of people with disabilities, which was in turn inspired by the Civil Rights Movement. As she encountered the life stories of these families, Mead began to see disability as a valuable opportunity for social learning, one that allowed for the cultivation of an ethics of care. The voices of those who experience disability could help us to break open fixed and problem-saturated histories and to consider possible new meanings. This is what happened, for example, to Neil's sister, Sue, who tells another story about her brother in a biography of her father.⁸

In the last chapter of the book – *Vulnerability* – Pearson examines the period of the COVID-19 pandemic, focusing on the concept of vulnerability, of which disability is one possible expression. As a condition of human vulnerability, disability is not merely a form of diversity or another identity in a multicultural world. On the contrary, it constitutes a fundamental and universal reality of human experience and can manifest itself in different ways and at different stages of life. As a universal condition, vulnerability makes it possible to generate new meanings about human experience and to recognise alternative ways of living and of developing a sense of community.

Reading this book helped me to bring into dialogue different parts of myself: that of a scholar of adult learning who is particularly interested in those learning processes that transform the perspectives of meaning with which we usually

7 United Nations (2006) *Convention on the Rights of Persons with Disabilities*. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>.

8 Erikson Bloland, S. (2006) *In the Shadow of Fame: A Memoir by the Daughter of Erik H. Erikson*. Penguin.

interpret ourselves and the world; that of a woman, wife, and mother; and that of a professional working in the field of social inclusion services for adults with disabilities in Italy. I recognised in Pearson's book a narrative capable of moving beyond a rhetoric that often imposes discourses on disability that are remote from the everyday experience of people with disabilities and their life contexts. In this book, life stories and theories on disability, the past and the present, and the micro/meso/macro levels are fluidly but also critically intertwined, in a movement of deconstruction and reconstruction of discourses on disability – one which can never be concluded because it is strictly related to changing ideas of the social world.

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