Chapter 7
Broadening the Lens: Genetic Manipulation

This book has so far focused on the so-called traditional bodily practices, commonly understood as “longstanding, resisting to change, and embedded within the cultural fabric of a community.”¹ This concentration followed the address the Monitoring Committee under the Children’s Convention (Children’s Committee or Committee) and the other international bodies gave to harmful traditional practices particularly under Article 24(3) of the International Convention on the Rights of the Child (Children’s Convention or Convention).² It has been argued that this analysis is lacking, as biomedical practices are not carried out only on children belonging to long-established minority groups. Alternatively, considering the indisputable role the family and the community play in the construction of children’s views and autonomy, as well as the mutual sense of belonging, connectedness, and, ultimately, identity, a child-centered approach has to view all children as belonging to minority, and particularly, indigenous groups.³

In this chapter, “invented traditions” in the genomic era are considered. The focus is on disability-related practices, specifically, genetic manipulations that are carried out in fetuses in utero and on preconception zygotes with the goal of bringing them to full maturation as human subjects.⁴ Although there has been ample literature on the moral, legal, and other challenges that the genetic revolution has created, there has been strikingly scant work on the (future and present) children as the subjects of observation. The goal of this discussion is to fill in some of the gap by formally bringing to the international surface these children’s interests, rights, and voices. It should be stated from the outset, however, that bearing in mind the limited information in this particular aspect of bioethics, the chapter is mostly speculative. Working within the framework of analysis proposed in Chapter 6 to examine children’s bioethics, this chapter builds on the literature that exists in various disciplines, particularly disability studies, to highlight some of the main dilemmas and to suggest possible future paths for investigation.

This chapter begins with a brief introduction to the new scientific technologies in the context of genetic manipulation and explains the relevance of

³ Regarding the conceptualization of children as a minority and as an indigenous group, see Chapter 6.
⁴ Discussion on research using tissues from aborted fetuses is beyond the scope of this study.
disability-related practices to the study. This is followed by an examination of the right to procreative freedom and family autonomy that have been the leading arguments raised in this context, and some critiques are provided. The rest of the chapter refocuses the discussion on children’s bioethics. Different from research that has been conducted so far, here scientific developments from the point of view of the (future) children that are involved and in view of the children’s right to identity are examined. In this context the status of fetuses under international law is explored, and the question whether the scientific developments gave rise to the child’s “right to a sound mind and body” is explored. Finally, the chapter draws conclusions and proposes some paths for future inquiries.

A. GENETIC MANIPULATIONS

Progress in the study of human genetics occurred at a remarkable rate over the course of the past decade. The completion of the Human Genome Project, particularly the international effort to map and sequence the entire human genome in 2003, has played a central role in this development. It led to increased scientific endeavors to devise effective interventions to treat or cure some disabling conditions, both before and after birth. An array of gene carriers for major disorders (such as cystic fibrosis and Tay Sachs) as well as the genetic propensity of developing major disorders later in life (such as heart disease, cancer, and Alzheimer’s Disease) can now be identified both before and after birth. The newly developed technologies of assisted reproductive methods made it possible for scientists to determine the sex of a fetus post- and preconception, either in vivo (in the body) or in vitro (out of the body). It also opened the door for future enhancement efforts in the form of improving genetic endowment and cloning. Thus, while the genome era has been applauded by some as proffering significant potential remedies, it has also posed substantial challenges to the moral, legal, political, and social understanding of human’s lives.

The scientific revolution clearly bears a significant impact on children in an array of biomedical fields. This includes medicalization, research with children, children as organ and tissue donors, and others. This chapter discusses one of these fields: prenatal genetic manipulations, referring to interventions aimed at the avoidance of specific disability-related conditions.

---


8 The terms genetic manipulation, genetic procedures, and genetic interventions are used intermittently throughout the chapter, all referring to the general practice of genetic manipulation.

9 The literature often makes a distinction in this context between a few types of genetic