

生きられる障害と出生前に検出される障害
—障害のある女性／男性の語る妊娠と出生前検査—

The lived experience of disability and the detection of fetal impairment
: Discourse on pregnancy and prenatal testing by disabled people

論文要旨

(英文)

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While prenatal testing is utilized to confirm the presence of a disability in a fetus, as a matter of course, it is not possible to discover all disabilities. It may be said *disability* as the customary epithet of the prenatal testing as a category or the attribute.

Clearly, the most important participant in prenatal testing is the pregnant woman. Although the pregnant woman may consult with a partner, since it is her body, she has the ultimate decision regarding examination. Moreover, a person with a disability is participant as well because that the attribute was named by the prenatal testing.

Considering progress in medical technology, such as NIPT and PGS, and speed at which these technologies reach application in the market place, the medical profession must take seriously criticism from disabled people and investigate better ways apply medical technology.

Why do people with disabilities criticize prenatal testing? Furthermore, when they became pregnant, what do they think of prenatal testing? These questions are the focus of this study. In order to clarify these questions, this study comprises Chapter 1 and 2 are a review and an analysis of the literature. Chapters 3 to 9 present a summary and the result analysis of the interview investigation for disabled people. Chapter 10 is the conclusions of this study.

Chapter 1 examines the claim of the fetus check opposition movement that the Kanagawa Joint Association of Aoi-shiba presented for the local government carrying out amniotic diagnosis using public money in the 1970s. In Chapter 2, investigates how women who was active in Aoi-shiba faced the Eugenic Protection Act. In addition to the data from Chapter 1 and 2 employ bulletins and notebooks written by members of Aoi-shiba in the examination.

Chapter 3 presents an overview of the interview, including research methods, interview periods and places. Chapter 4 presents discussions on what it connoted to demand the cooperation for an interview about the prenatal testing from the person who is categorized as disabled. Chapter 5 discusses the image of a disabled person embracing a fetus. Chapter 6 discusses the discourse of time of the blank when interviewee are children and I traced how they recognize the disability. Chapter 7 examines an association between gender and disability recognition, Chapter 8 examines the discourse concerned with reproductive rights. Chapter 9 presents a comparison of the discourse of disabled people with the medical professional about *the advantages* of prenatal diagnosis. In the last chapter, conclusions are made based on the examinations from Chapter 1 to Chapter 9.

From the interviews with disabled people alive in the 2010s, I conclude that the concept of disability as used in the context of prenatal testing is not one issue, and I made clear the origins of the fetus image of disabled people. First, previously aware of *I* he or she had been given the name of the impairment that they have nothing to do therewith, I call it as *floating disability*. And in the process of launching *I*, he or she went to know the lived experience of disability, I call it as *retrospective disability*, with and through their body and time. Second, by going piled up such a time, it is formed only of the flow of *I* can be, and retrospective disability come be formed. On the other hand, there is no body also time on floating disability.

If we are to address the social and ethical issues of prenatal testing, our challenges are as follows.

Families with children with disabilities, people who hope to have children in the future, and people who do not plan to have children, how diversely do they define the term disability or fetus? We need to consolidate these terms and share the terminology with others. Differences in image and the definition of the terms make it impossible to share the meaning. We need to build a foundation for discussion which is so far lacking. This study was to clarify a part of the sentiment and the terminology by disabled people of the definition of disability and fetus.