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Prevention and Decision Making in Human Genetic Early Detection in West Germany

In this project we examine the relationship of human genetic counselling, early detection and the concepts of risk and prevention. For the period from 1949 to 1989, concepts and practices in human genetic early diagnosis are examined on the basis of two exemplary case studies: Newborn screening for Phenylketonuria (PKU) and cytogenetic prenatal diagnostics. The project focuses on the historical development of both cases, concentrating on the role played by counselling institutions and platforms. PKU screening is generally seen as an approved method of secondary prevention, which allows timely diagnosis of a severe metabolic disease, before leading to irreversible neurologic damage. As opposed to this, the evaluation of prenatal diagnostics as a method of prevention continues to be controversial, among other reasons because instead of treatment it regularly leads to abortion. Was it the case, that the German Research Foundation had carefully retreated from subsidising research on "Prenatal Diagnosis of Genetic Defects", just at the moment when in 1976 practical consequences of cytogenetic diagnostics could be expected from the amendment to abortion law and when human geneticists propagated the economic benefits of eugenic abortions? How was a professionalization in the field of genetic counselling shaped by specific sponsoring?
Important steps in these developments have already been researched in their basic structures. However, we still know very little about the role of actors *outside* the narrower medical field, about media coverage, processes of political decision making, the role of self-help associations, patient organisations and social organisations for the justification and implementation of state prevention programs. Our project focuses on the early phase of this development in order to reveal, how the expansion of genetic counselling linked to a change in concepts of risk and prevention.

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