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TITLE: Transforming life : fragile X syndrome between molecular diagnosis and biosociality

ABSTRACT

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ABSTRACT (max 300 words)

This paper addresses issues of molecular diagnosis as a pivotal *life* reconfiguration factor, defined both as life forms ("naked life") and as forms of life (Wittgenstein). Drawing on a multi-site ethnographic study carried out from mid-2002 to mid-2003 in the French speaking part of Switzerland as fieldwork for my MA thesis, I describe how these two interrelate in the context of a particular disease, termed "fragile X syndrome", for which a molecular testing routine was proposed since the 90's. It is portrayed in biomedical literature as one of the most common inherited causes of "mental retardation". Its symptomatology, including some physical and behavioral features (e.g. facial dysmorphy), was gradually linked, from the end of 60's to the 90's, to a single genetic causal explanation, first in terms of "chromosome fragility" and further as the fully mutated FMR-1 gene.
Molecular diagnosis usually comes after a clinical and family history investigation trajectory. I focus on this "moment" and show that the intervention (engineering) upon "naked life" in the testing lab, its specific products (among others the degree of gene mutation, ie no mutation, pre-mutation or full mutation) and the syndrome inheritance patterns affect the way the syndrome becomes known, experienced and "practiced" by the patients and their families, taking part in their life as "the embodiment of fate, the evil locus" and the "site of hope" (Rabinow, 1999). The biological and the social are re-framed to produce what Rabinow termed "biosociality". In this context, the FMR-1 gene creates not only sociality and inclusion but also new boundaries between "we" and "the others" and new intra-categories in the fragile X communities, (re)shaping identities according to detailed knowledge and articulation between molecular *and* phenotypic differences.