
Gruppenbild mit Mensch mit Behinderungen. Studying life-course of people with ” rare disabilities ” through institutional records

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Abstract

Studying the French category of ” rare disability ” (Winance, Barral, 2013) we analysed 60 records of people for which the assistance of two of the 4 ”national centres for rare disabilities” was required. We made there also numerous observations and had interviews with the specialists that met these persons with multiple deficiencies. But, as the author of the famous *Gruppenbild mit Dame* (Boll, 2001), we didn't meet the persons themselves: we are working on a choir description of peculiar subjects. In our presentation we would like to discuss some features of this record analysis.

Studying records which often have more than hundred pages leads to collect a large amount of information about one person, with various points of view: expertise of the specialized centre, medical records, educative records, mails conversation with family or professionals, generally over several years. We propose to analyse how and to what extent this large amount of objective data is a chance to study meticulously the work of the national centres for rare disabilities, institutional rationales and individual life-courses.

Sometimes the subject makes also his or her way through the record we are studying: graphic traces of a disabled child, pictures, sometimes written message to the professional, emotions of the parents or the professional, in one case a personal diary. These unexpected meetings are a strong reminder of the existence of a subject beyond the objective reports on him or her. They are of importance for the research: it shows that the role of the centres is also to rehabilitate dismissed persons as subjects - notably by building new frames of interaction (Goffman, 1986).

By these reflections we want to discuss how the subject is rendered by objective and subjective materials gathered in the records. This leads to a last question. What do our voice as researchers add to these choir description ? Are we silencing weaker voices ?

Indicative references:

Boll H., 2001, *Gruppenbild mit Dame*, M'unchen, dtv.

Goffman E., 1986, *Frame Analysis: An Essay on the Organization of Experience*

Winance, M. and C. Barral, 2013, ”From ”ineducability” to ”rare disabilities”. Evolution and emergence of political categories involved in shaping the French medico-social sector.” *ALTER* 7(4): 244-259.

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