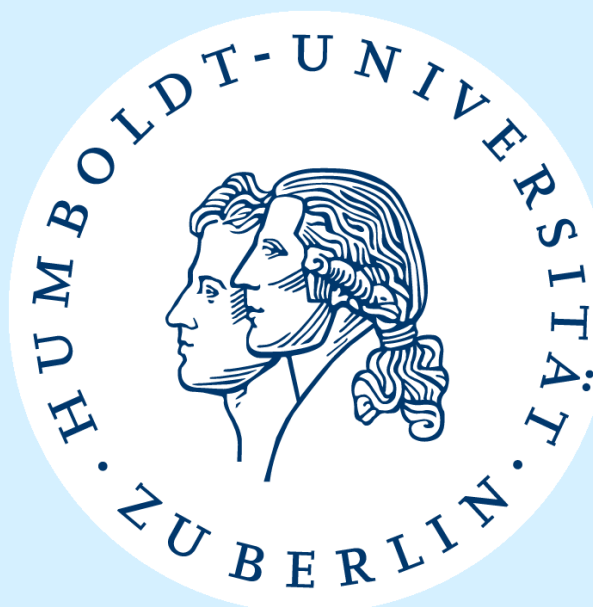# School-Age Boys with Fragile X Syndrome in Educational Settings: An Ethnographic Approach

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Introduction

This project investigates the following topics:

- What is everyday school life like for school-age boys with Fragile X Syndrome (FXS)?
- What do pupils with FXS do at school and how do they do it?
- How do the often described behavioral features („behavioral phenotype") present themselves in everyday school life? Are there patterns for specific classroom behavior?

Method

Qualitative research:

To investigate the daily routine of students with FXS at school in a systematic way, I adopted a qualitative research approach based on an *ethnographic participant observation methodology*.
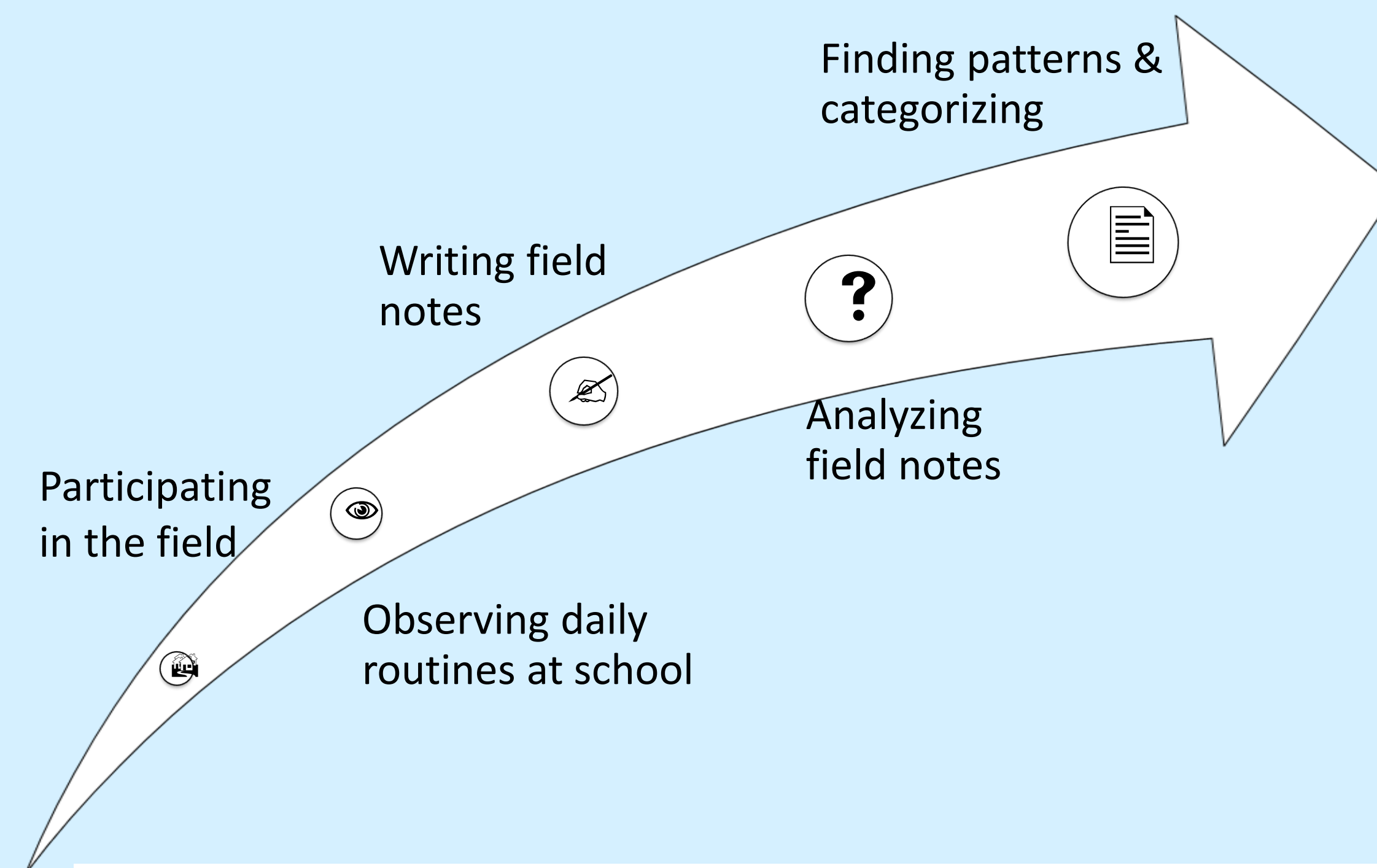
The analysis and interpretation of field notes, drawing on *Grounded Theory* (Glaser & Strauss 2010), offers insights into the social interaction and "performance" of both students with FXS and their teachers. As simple as the research questions might sound, it is difficult to evaluate them in a non-biased way. It seems that psychological as well as educational approaches have different perspectives and aims. Psychologists utilize theories about genetic syndromes and their medical and genetic background regarding the etiology and behavioral phenotypes, whereas educators mainly consider the academic abilities and degree of intellectual disability of students and often consider etiological diagnoses as irrelevant.

Ethnography

Finding patterns & categorizing

Writing field notes

Analyzing field notes

Participating in the field

Observing daily routines at school

Sampling

Participant observation involved three individual boys with FXS (8, 10 and 12 years old) in their special education classrooms over a period of two years (2011-2013).

Goals

- Understanding the participants in the context of their social world.
- Analyzing how students with Fragile X Syndrome manage their daily lives at school.

This is not based on assumptions about how education should be, but rather how it actually is.

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Analysis

Excerpt from field notes

„His teacher is standing at the other pupils´ desks, leaning forward towards them and talking quietly. Simon calls to her, but so quietly and softly spoken that she does not react. „Mrs. Hanke, Mrs. Hanke". Maybe she doesn´t even hear him. His voice turns whiny and he starts ripping his laminated photo off the folder in front of him. He bites it with his teeth in order to tear it apart, but without success, then takes the photo in his mouth and chews on it. At that point the teacher comes to him and announces with a firm voice that he will get a red dot in his token system."

(Field note S2.2)

What is happening here?

Simon´s practice seems to be an automatic response. He is not asking how to gain attention, he just demands it. His behavior could be the result of frustration when other actions are not noticed anymore.

The teacher on the other hand interprets this as deliberate provocation and responds to it negatively. Thus his inability to communicate leads to a misunderstanding.

Keywords/Themes
- Misunderstanding/Miscommunication
- "Performative acts" (non-verbal communication)

Student with FXS: Potential for different classroom behaviors

"Performative acts" – e.g. seeking attention by destroying something

Student´s act provokes patterns of interpretation by the teacher

Potential interpretations: positive, negative, misbehavior, provocation, …

Teacher´s misunderstanding provokes specific behavior of the student

„cycle of misunderstanding"

Focus

- Identification and analysis of situations, mutual understanding and misunderstanding
- Transitions, rituals, interactions, structure of daily routines, pedagogical situations,
- Which questions do teachers have to ask themselves when working with students with FXS to enable the most successful, effective learning?