"Horrible warning”. How Turner syndrome (re)shapes bodily normativity

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Kasia is a horrible warning on how much parents can neglect their daughter. Just have a look at her webbed neck – it could have been surgically corrected, but they never did it” – this is a way in which Anna, an activist and a mother of a girl diagnosed with Turner Syndrome (TS), described another girl with this condition. Turner syndrome is a chromosomal abnormality that affects exclusively girls and always results in a short stature and frequently with sterility or very limited fertility. This condition often goes together also with specific physical stigmata. Therefore, many girls have short, webbed neck and low hairline, broad chest, scoliosis and down sloping eyes, which may be surgically removed, hidden under clothing or covered with long hair or make up. My informants’ parents usually describe their daughters’ diagnosis as devastating” due to prospect disruption of an imagined normativity related to female body.

My presentation is based on an etnographic research I have conducted together with my colleagues from Childhood Studies Interdisciplinary Research Team since 2016. Our research focuses on narratives and daily lives of Polish girls diagnosed with Turner Syndrome. Deriving from the collected material, I will ask about parental strategies towards bodily manifestations of their daughters’ conditions. How the meanings and practices around attractiveness are being negotiated in the process of socialization of children with TS? Reflecting upon the social lives” of given genotype/phenotype and the definition of normativity, I analyze life trajectories of Kasia and Iza and Nikola, three girls whose families are differently positioned in terms of social class and available resources.

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