## *Kulasová, Hana: Kapka kámen vyhloubí. Deník odvážné mámy o autismu a socialismu [A Drop Wears away a Stone. A Courageous Mom's Diary of Autism and Socialism].*

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The history of disability is full of explanations concerning the driving forces of discrimination; much less work has been done on the history of fighting for justice. The reflections of parents of people with disabilities represent unique sources that problematize the historicizing of disability as one of the crucial prerequisites for practicing justice.[1] In this context, the publication of the diary of Hana Kulasová, whose son Jiří was among the first children to officially receive a diagnosis of autism in Czechoslovakia, is a rare event in the post-socialist space. The diary challenges disability studies not only at the local but also at the transnational level, and reading it inevitably leads to recognition of the discrepancy between different trajectories for practicing justice: (1) the transitional – searching for the proper space for those oppressed during and because of socialism; (2) the epistemic – providing options to produce knowledge and evidence for those who have disabilities and their families; and (3) the historical – examining historic wrongs in terms of their continuities.

For those familiar with the global history of autism, Kulasová's story resonates with that of Bernard Rimland, the author of *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* (1964), historically one of the most influential publications concerning assistance for children with autism. As the father of Mark, an autistic boy born in the same year as Jiří Kulas, Rimland – a professional psychologist – generalizes his experiences, including the use of self-help tests for parents. He challenges the existing approaches, like the idea of the "refrigerator mother" (with a cold, uncaring demeanor that traumatizes children) as a primary source of children's autism. Instead, Rimland introduces one of the first complex explanatory models for autism.

The work of both Rimland and Kulasová has become a unique source of support for parents of children with autism spectrum disorder (ASD). Kulasová's activities were directly responsible for the establishment of a parents' movement in the 1970s as a result of her presentations on the broadcast *Hovoříme s rodiči* (We talk with parents) as well as her multiple streams of communication with parents in Czechoslovakia and other countries. Rimland's publicity led Leo Kanner, one of the pioneers of institutionalizing assistance for people with ASD, to apologize to parents at a conference for implying that they were somehow responsible for their children's autism.[2] This engagement and conflict with professionals is one of the predominant topics in Kulasová's reflections.

The diary presents multiple examples of pathologization of families of children with disabilities. Raising two sons, one with autism and one without any special diagnosis, Kulasová made considerable efforts to resist health professionals' recom-

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[1] *Wright,* David Downs: The History of a Disability. Oxford 2011.

[2] *Edelson,* Stephen M.: Bernard Rimland's "Infantile Autism". The book that changed autism. In: Autism Research Review International 28 (2014) 1, 1-8.

mendations to prioritize taking care of her healthy child, as this would offer the better perspective: "Today I was at Dr. Nesnídalová's with Vášek again. She said that there was nothing wrong with him […], and that I would take it too far. And that because we have a sick Jiří, I have lost the idea of what a normal boy is." (p. 99) Later, when Vášek's difficult behavior inclined a psychiatrist to diagnose him with "light epilepsy and encephalitis" and prescribe an antipsychotic drug, chlorprothixene (p. 103), Kulasová adamantly ignored this diagnosis.

The mother's response often shifts from irony to sarcasm when her own expertise is disavowed by experts. Kulasová describes several attempts to perform electroencephalography on both her and her sons, along with the very vague answers from specialists to her question about what they managed to find out:

> On the second of October, I went to the examination alone again. Dr. Uttl still found nothing, although he tried hard, because the EEG had shown something. But he didn't say what, so I asked if he thought Jiří took after me. He replied that he did not want to claim that, and that if EEGs were routinely performed on people, something interesting might be discovered. That was it. (p. 80)

In contrast to Rimland's book, Kulasová's diary remains completely sterile with regard to her reflections concerning the different approaches to autism. Such approaches were undoubtedly familiar to her, as she subscribed to professional journals from Switzerland, Germany and France and was acknowledged by her peers as an expert in autism.[3] This gap raises questions concerning the choice of materials for the published diary and the impact of cliches in shaping an image of a brave mother of a child with a disability. Throughout the text, Kulasová appears as a modest woman, a refined musician who has acquired a unique assemblage of personal qualities and social predispositions, including her parents' ability to help and maintain a non-socialist way of life as long as possible.

By reproducing this "disabling opposition between civic and species being,"[4] the editors of the diary not only add fuel to the tropes regarding motherhood of children with disabilities but also reinforce one of the speculative approaches to historicizing disability in socialist Czechoslovakia – namely, the consistent heroization of parents as people who opposed the totalitarian regime. This approach either relegates the role of professionals to the margins of historical justice[5] or presents the activities of psychologists and psychiatrists as being on the side of resistance to the communist obsession with residential care.[6] Neither people with disabilities and

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[3] *Trusina,* Tadeáš: Podoby advokační činnosti rodičů dětí s mentálním znevýhodněním za státního socialismu na příkladu organizace Sdružení pro pomoc mentálně postiženým [Advocacy activities of parents of mentally handicapped children under state socialism using the example of the Association for Assistance to the Mentally Handicapped]. Prague 2024, 8.

[4] *Rose,* Jacqueline: States of Fantasy. Oxford 1994, 132.

[5] *Mužáková,* Monika: Koexistence solidarity a nesvobody. Každodennost člověka s mentálním postižením v totalitárním Československu [The coexistence of solidarity and unfreedom. Everyday life of a person with mental disabilities in totalitarian Czechoslovakia]. Prague 2018.

[6] *Geisler,* Michal: Historická sociologie autismu v České republice [Historical sociology of autism in the Czech Republic]. Prague 2018, 53.

their communities nor professionals become "the beneficiaries of particular renderings of historic wrongs".[7]

Nuancing the role of professionals, a key aspect of connecting transitional and historical justice, calls for a more consistent application of the intersectionality between ableism and patriarchy. The analysis of Jiří Kulas' case by Růžena Nesnídalová,[8] the first Czechoslovak expert in autism, whose presence in Kulasová's diary reminds readers of the duel between the mother and the professional, illuminates this point. Besides her obvious and somewhat wary admiration of Kulasová, Nesnídalová reproduces a typical mixture consisting of a utilitarian view of emotional attachment and an accusation of society's insensitivity towards people with disabilities due to the prevalence of selfish consumer values. It is noteworthy that Nesnídalová, with whom Kulasová shared her notes, selected the following excerpt from the diary:

> To tell you the truth, when raising Jindra, I get the most tired when I have to convince someone that it is worth teaching Jindra, because […] it is only fair if we give him time to at least partially catch up on what is delayed by the illness. […] It is generally considered natural for people to sacrifice all their strength to acquire all kinds of comforts, such as a car, a cottage, etc., but it seems abnormal to them that I strive to help my own child. Don't you think that the pursuit of technical conveniences dehumanizes people?[9]

This tropism, recorded in the films of Kurt Goldberger and Zdeněk Matějček[10] and aimed at promoting family care as the unique source of proper mental development, significantly diverges from what, in Kulasová's own opinion, challenges her intention to save her son.

Kulasová's fear of placing her son in a residential care institution and the fact that she viewed her efforts as a "rescue mission" beg the question what parents of children with disabilities knew about institutional care. But this is not the only vexing question. The systematic juxtaposition of poor residential care with perfect family care, which evidently permeates the selection of materials for the diary's publication as well, ignores the historical connection between the two forms of care despite their entangled history of pathologizing people with ASD and their families. Neglecting this connection precludes deeper understanding of the changes in perception regarding the side effects of treatment with antipsychotics, other forms of invasive therapies, and general strategies of assisting people with ASD, as well as how the relevant debates circulated between West and East. Bringing together historical, transitional, and epistemic justice remains an unachievable task without recognizing and accepting the shared and individual responsibility of powerful actors in the politics of disability – first and foremost, experts and practitioners. A critical reading of documents such as Kulasová's diary represents a clear step toward practicing justice.

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[7] *Neumann,* Klaus: Historical Justice. London 2016.

[8] *Nesnídalová,* Růžena: Extrémní osamělost: autistické projevy u dětí a "pseudoautismus" dospělych [Extreme loneliness: Autistic symptoms in children and "pseudo-autism" in adults]. Prague 1973.

[9] *Ibid.* 63-64.

[10] Děti bez lásky [Children without love, 1963] and Lidé [People, 1964].