

# **Between World Borders: Situating the Reality of a Child Labelled Schizophrenic as Real**

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## **Abstract**

*This paper explores from a mad studies perspective the under-investigated relationship between madness and childhood. Through analyzing a video published by the Oprah Winfrey Network on YouTube, where the host conducts an 'interview' with a young girl named Jani labelled with 'childhood schizophrenia,' I argue that mad experiences of children are doubly characterized as dubious. Beyond dubious, they are conceptualized as a form of human experience so unfamiliar to sane adult perception they become online entertainment. Following Butler's theory of gender performativity, I propose mental performativity where, like the gendered body, sane and mad bodies also have no true internal essence and instead are made sense of through cultural interpretation of what constitutes in/sane mis/conduct. Moreover, I propose that mad children's art may serve as a mode in which to communicate between mad and sane realities, if child artists are provided with artistic autonomy. Lastly, I contend that viewing the 'mental topographies' or non-omnipresent world(s) of mad people as disordered is problematic as it excises these realities are in fact real to those experiencing them. I propose towards the end of this paper that in order to fully understand mad children's subjectivity, scholarly analysis must consider the existence of a diversity of mind/body systems, including the ways in which socio-cultural conventions of identity shroud an understanding of them. What mad positive futures can be imagined if we dare to consider Jani as Jani and not a 'crazy' little girl?*

**Keywords:** childhood madness, child mental health, mad studies, child schizophrenia, critical disability studies

## Introduction

Children are often considered credulous for believing in their imaginations. This disparagement is exacerbated for children who hear voices, whose ‘hallucinations,’ or rather, non-conventional multiple perceptions and realities, are pathologized as a disorder. The Hearing Voices Network, an organization promoting self-advocacy for people labelled with schizophrenia, argues that instead of primarily seeing the phenomenon as a biological defect, hearing voices might at times be seen as personally valuable (Blackman, 2016). For example, some conceive ‘hallucinations’ like voice hearing to be a coping strategy that facilitates survival during adversity such as domestic abuse (Mills, 2009). Often in mad studies, ‘disorders’ like schizophrenia are approached through a constructionist perspective to negate the pathologizing effect of diagnosis, seeing mental ‘illness’ as socially sourced. This is not an argument negating biological predispositions for specific symptoms, but one that emphasizes the influence of culture in shaping how madness is perceived and shaped negatively by the socio-cultural environment in which it emerges. For instance, if schizophrenic symptoms are assessed cross-culturally, mental illness is easily identifiable as socially constructed, with *some* voice hearers in India and Ghana being reported to enjoy or not mind the phenomena, unlike their American counterparts, whose voices are often distressing (Luhmann et al, 2015). However important, a constructivist approach cannot fully explain the existence of children who are thought to be born with “rare childhood schizophrenia,” as is the case below with Jani (OWN, 2018). As mad studies scholars devoted to the “critique and transcendence of psy-centered ways of thinking, behaving, relating and being,” how do we conceive of such realities? (Menzies, LeFrancois, & Reaume, 2013, p.13). Without engaging in the conventional ‘nature versus nurture’ debate, I believe the only way to make sense of child voice hearing is to utilize a phenomenological approach. It is important to note that for the purposes of this paper I conflate voice hearing with schizophrenic diagnosis, which, although separate, often overlap. In what follows, I argue via critique of a YouTube video that understanding the behaviours of children labelled schizophrenic through a non-pathologizing perspective can illuminate marginalized ways of experiencing the

world. To do this I draw from theories of phenomenology and performativity to carve out mad child subjectivity from within its social representation.

## **The Mad Child: A Theoretical Framework**

Merleau-Ponty conceptualizes “sense-data” as the “phenomenological qualities of the world experienced prior to being incorporated into an associated matrix of meaning . . . becoming an object intervening into the field ruled over by common sense” (cited in Richter, 2017, p. 327). Through a reading of the philosopher, artist-scholar-activist Zahari Richter suggests there is worth in investigating the desires, motives, being, movement, feeling, and thought that motivate and exist within mad behaviour, before such behaviour is consumed and made sense of by sanist regulation of what is proper and perverse in/sane mis/conduct (2017). Concomitantly, through disrupting cultural Merleau-Ponty’s ‘fields of common sense,’ feminist philosopher Judith Butler’s thinking on gender performativity disentangles normative notions that bodies dictate internal subjectivities, like one’s gender or mind. Butler declares that “the occasion in which we come to understand what we take to be real.’ What we invoke as the naturalized knowledge of gender [or madness] is, in fact, a changeable and revisable reality” (Butler, 1990, xxiv). What Butler means is that through the repetition of gendered (or mad) behaviour, a hegemonic understanding of reality is solidified, constructing gender to be a natural phenomenon rooted in sex (or the brain). Following Butler’s theory of gender performativity, I propose mental performativity, where, like the gendered body, sane and mad bodies also have no true internal essence and instead are made sense of through cultural interpretation. Mental performativity as a theory reveals that acts of sanity create only the illusion of an internal mental stability, which is maintained for the regulation of mental normalcy, building and stratifying cultural conceptions of who is or is not crazy. This regulation of normalcy is vital to the construction of sane subjects, and sane belief systems, including theories focused on ‘correct’ child behaviour and development. This construction evolves through the embodiment of sanity, which like the gender binary becomes accepted as *bona fide* by the repetition of sane behaviour and agreement that such behaviour in a child demarcates ‘healthy’ human development. For example, stimming, a form of repetitive motor movement, is a symptom used for diagnosing Autism Spectrum Disorders. Such movements are aimed to be eradicated in early childhood

interventions using approaches like applied behavioural therapy, despite Autistic self-advocates asserting that stimming, like autism, represents a natural form of human difference (Lynch, 2019). Indeed, this is supported by recent research by Kapp et al., whose study of 31 autistic adults' perspectives on stimming revealed it is "a useful behaviour, serving to contain or control excess emotion" (2019, p. 7). Within the sane regulation of mental normalcy, stimming, through its repetitive opposition to compliant, still, un-repetitive movement, is perceived to be an indication of inner mental disorder and improper child development. Such regulation creates the perception of a subject whose performances need to be fixed and aligned with healthier sane parallels in order to nurture an internal sanity.

Through displaying mad behaviour, the child is contrasted as an anomaly that deviates from the figure of the 'perfect' child that each new generation of parent guardian constructs, partially through a recollection of their personal childhood (Stockton, 2009). Not having personal experience with childhood madness, parents who cannot accept as normal their children's performances of voice hearing, or stimming, are forced to come to the "concept of [child] pathology," an action based on fear of mental illness, "prior knowledge of the corresponding normal state" of their own nostalgic childhood, and mainstream knowledge of normative child development (Canguilhem in Castaneda, 2002, p. 25). Rather than looking at children's mad behaviour as a subjective yet legitimate way of being, mad children's performances are forcibly constrained and subjected to neurological explanation. This is not to say that such ways of being should be viewed as completely devoid of distress or impairment, but rather the lens of mental disorder makes impossible conceptualizing individuals as more than sick. Parents and medical professionals become obsessed with the "process of brain function and its consequences of subservient bodily function," which leaves little interpretation of the child's performance as agentive and meaningful (Smith, 2016 p. 187). Mad child performance becomes construed as needing assimilation into sane childhood rather than being understood as a unique individual aspect of being in and navigating the world. This creates a discourse of mental difference within wider cultural thought. Such discourse proliferates through mediums of knowledge, like media representing mad children as oddities (as seen below) or literatures of child development that use the mad child figure to differentiate between sane (normative) and abnormal children.

## **Gawking into Calalini: The Schizophrenic Child as Entertainment**

On August 30th, 2018, the Oprah Winfrey Network (OWN) published a video on YouTube titled *Oprah Meets a Schizophrenic Child with Over 200 Imaginary Friends*. In this look back on an earlier interview conducted by the host, Winfrey initiates the segment by comparing the few imaginary friends a 'normal' child has to the 200 encountered by Jani, a seven-year-old girl labelled with "rare" childhood schizophrenia (OWN, 2018). Oprah further introduces Jani to the audience by describing schizophrenia as a "chronic mental illness" where "reality gets interpreted abnormally, causing psychosis". Both Jani's parents and Oprah repeatedly refer to the task of raising a schizophrenic child like Jani as "frightening" and "exhausting," demonizing her madness and confirming psychological models of grief parents are expected to feel when their progeny live with 'severe' disabilities (OWN, 2018; Mallet & Runswick-Cole, 2015). What is most frightening, however, is Oprah's intrusive probing into Jani's madness. Oprah constantly follows the young girl, asking her to explain who her 'imaginary' friends are, where they live, and if they are dangerous, all while Jani becomes increasingly visibly frustrated by the attempts to expose her. During questioning about where her friend "Cat 400" is, Jani reveals that Cat 400 lives in Calalini. What transpires is a discussion about this world between the host and Jani:

O: Aaand 24 Hours, who's 24 Hours?

J: She's actually a person.

O: She's a person ... and she lives in Calalini too? Now where is Calalini?

J: Well ...

O: Where is it?

J: I can't tell you.

O: Why?

J: Because ... because Wednesday lives there and she's the worst one.

O: What is she?

J: Calalini is on the border of my world and ... your world.

O: Meaning this world? [referring to omnipresent reality]

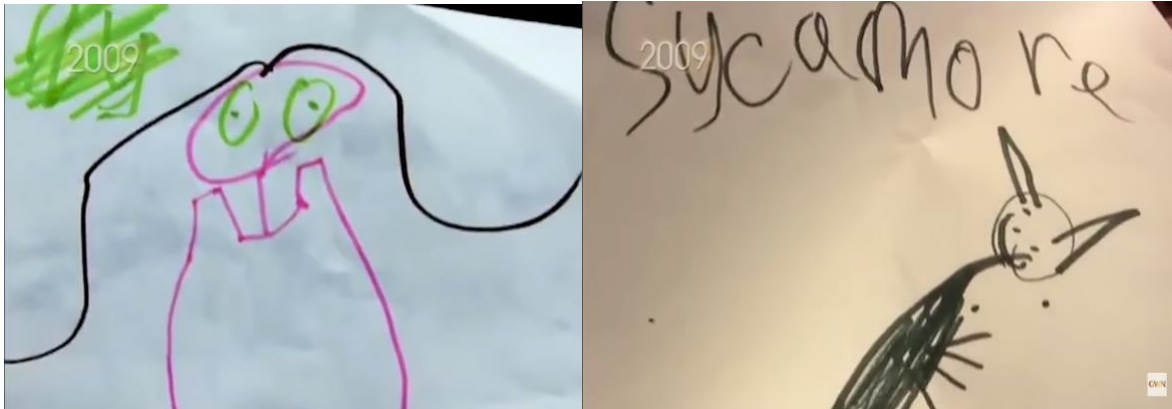
J: Yeah!

In a style reminiscent of patient porn, where institutionalized mad people are gawked at for their 'oddities,' Oprah insists that Jani let her, the camera, and an at-home audience into her world of Calalini (Costa et al, 2012). By reason of Oprah initially describing Jani's experiences as 'disordered' and 'hallucinatory,' the video encounter is meant to teach audiences the horrors childhood 'schizophrenia' presents, meanwhile, portraying Jani's world and acquaintances as a fictitious plot, ignoring their real-ness from Jani's perspective. Jani is repeatedly asked to perform her madness on camera without fully understanding the repercussions that come with being gawked at; that this is not a story about Jani, but a story about how strange Jani is. Through the interviewer's insistence that Jani perform her madness within the demeaning context that schizophrenia is a human horror, audiences are taught to feel sympathy for her parents and the stigmatizing fear that voice hearers and people labelled schizophrenic are dangerous. Finally, audiences are encouraged to feel comfort that they themselves can perform life sanely. This is an insight made possible through the construction of voice hearing as a behaviour in direct contrast with the constructed, stable, rational, and safe confines of only hearing one's own voice or internal narrative within the mind.

### **Mad Child Art: Exploring communicatory potential**

Jani's drawings of her 'imaginary' friends (see below), "24 Hours" (Fig 1, 03:10) and "Sycamore the Rat" (Fig. 2, 03:16), are used as devices to convince the young girl to provide her 'crazy' story to Oprah via use of them as prompts to begin conversation (OWN, 2018). Because her on-camera performances do not suffice in validating to the sane eye what exists under Jani's external madness, Oprah's use of her drawings constitute a form of 'cognitive injustice,' where because Jani is both a child and mad, hard evidence of her supposed illusionary world is necessary for sane consumption (Visvanathan, 2009). Such evidence provides a *total image of insanity*, the pre-conceived notions of what it means to be crazy as they exist in the dominant cultural imagination (Barnes in Day, 2018). Observing the mad body in performance does not suffice in conveying Jani's 'total image' because it is not material enough, it is not a brain scan depicting her 'abnormal' neurological structure. Thus, sane audiences require a holistic picture of childhood 'schizophrenia' that complements the performance. In lieu of a brain scan, child drawings, which are thought to provide native perspectives on the child psyche, are used by Oprah to translate Jani's 'delusionary' being to sane viewers (Mitchell, 2006). Jani's

performance of madness, her stories, her non-conventional somatic existence, her knowledge and self-expertise, become somewhat legible through the adult's viewing of her art, unfortunately in a pathologized manner.



Figures 1 & 2. OWN. (2018, August 30). *Two drawings by Jani on white paper of her Calalini acquaintances*. Figure 1 features 24 Hours, a pink anthropomorphic entity with large green eyes and two black long flowing lines emerging from side of head. Figure 2 depicts Sycamore the Rat, drawn with a white circular face and black oval body plus large triangular ears. Retrieved December 2018, from <https://www.youtube.com/watch?v=vJpiAQThmFA>. Screenshot by author, 03:10 & 03:16.

Jani's words and art never make it beyond the sane conceptualization of 'schizophrenic child' words and art. Oprah's failure to recognize Jani's subjectivity is representative of the overall failure to recognize the harm labels like schizophrenia create for children, who under adult control are often powerless. The biologisation of Jani's 'illness' objectifies her for the purpose of providing provocative entertainment for sane consumption, also reifying sanity as normative. As LeFrancois points out, "the very act of diagnosing children with a mental disorder immediately renders the children into a position where their own agency is considered lacking or undesirable" (cited in Mills, 2009, p. 254). Although asked questions, Jani is not expected to practice agency within this celebrityised encounter. In the circumstance of the YouTube video, she is expected only to be a young schizophrenic subject who speaks when spoken to, and who solely speaks about child 'schizophrenia.' If Oprah had asked "how do you feel about me asking you these questions?" would it perhaps have prompted Jani to speak outside her imposed framing as a 'crazy little girl'?

Conversely, an investigation into how art could be used in non-pathologized contexts as a form of communication between neurodiverse children and adults is promising. Mitchell writes

that through drawings “children may make visible the details of place and self that have escaped the [sane] adult gaze” (2006, p. 70). In the case of Jani and other children like her, the use of art creation to facilitate understanding of non-omnipresent realities shows promise. With decades of experience researching the relationship between disabled youth and art education, Margaret Taylor writes that art allows disabled (and I argue mad) youth a mode in which to feel empowered and resist negative tropes of disability that define them. This is in addition to being a medium in which to include their “lived experience of impairment and disability as part of a multi-identity perspective of shared concepts, in ways that are not pitiable or tragic and that they can share through the images that they produce” (2005, p. 777). To Taylor, art acts as a “visual voice” that can “facilitate students, disabled and non-disabled, in the expression of human diversity and can promote an inclusive approach through the recognition that we are all part of a spectrum of difference” (2005, p. 777). Oprah’s use of Jani’s art to facilitate understanding of Calalini was not inherently problematic. What distorted the potential of Jani’s art to communicate her world to the world was the contextualization of her from the beginning as ill and thus objectively unintelligible. The absence of Jani’s authority to narrate her work through the interview, which largely depended on Oprah’s interpretation of it, is what stripped Jani of her “visual voice,” denoting her work as merely a sick child’s unnuanced scribbling.

Further, as a critical consideration, future scholars, policy makers, and practitioners interested in utilizing art to truly engage with mad children should reflect on the adult colonisation of disabled children’s play, which, unlike that of their able-bodied and -minded counterparts, is often therapy in disguise, as it “lack[s] spontaneity and is adult directed” (Goodley & Runswick-Cole, 2010, p. 503). Goodley & Runswick-Cole explain that play is often utilized as a therapeutic means in which to mould disabled children’s ‘un-productive’ recreational activity into one that is productive, assimilating and aligning behaviour to match that of able-bodied and sane children. Therefore, for mad children’s art to fully be a meaningful and agentive means of communicating different states of being, they must be given the freedom to design not as a means to become normative, or in the aforementioned celebritised encounter a means to exemplify abnormality, but as a venue in which to communicate as agents of their own realities. I am not arguing art therapy cannot co-exist with independent art creation. For example, in a study of 5 adult women labelled schizophrenic, art therapy was shown to be effective in allowing participants to make sense of their different realities and cope with the mental distress



arising from them, cultivating a “mastering of their psychosis” (Hanevik, Hestad, Lien, Tegljaerg, & Danbolt, 2013, p. 318).

## **Towards a Study of Mental Topography**

In the geographical sciences, topographical study involves documenting and analyzing the features of land. Social topography refers to the “material, symbolic, and discursive practices” that “mold the physical landscape so as to reflect and reproduce status hierarchies, creating a sociospatial distribution” (Richer, 2015, p. 252). Building from this concept, I suggest scholarly attention turn to a study of ‘mental topographies’ (MTs) which I define as the various abstract spatial realities existing within human minds. These can be: 1) autogenous and arising from within (like Calalini), 2) reflective of an omnipresent reality (what is believed to be objectively perceivable), or 3) both. An example of a reflective mental topography is how one envisions one’s neighbourhood within one’s mind. Reflective mental topographies become privileged through their omnipresent status, accessible to the minds of any person through sensory perception, like seeing a community centre or smelling a bakery, whereas autogenous MTs are constructed as disordered due to their limited access. That is, no one has perceptory access to them, except for the person whose mind possesses them.

Through utilizing the concept of mental topography, I now return to the 2018 OWN YouTube video to demonstrate how the mental topographies of mad people become disenfranchised. Jani’s position as a child labelled with schizophrenia warrants her accounts of reality being seen as mythical. As mentioned, Oprah begins the segment by comparing Jani’s over 200 ‘imaginary’ friends with the few that a ‘normal’ child has. In the video, childhood imagination and schizophrenic hallucination merge to cast Jani as a dubious subject. Although, as Jani asserts, Calalini lies on the border between her reality and omnipresent reality, it is never attended to in a serious manner. The gawking supersedes wanting to understand Calalini. It fails to humanize Jani and instead condemns her to be consumed on television as ‘psychotic.’ Nadesan writes that scientific “discourse is a group of statements and practices that define and constrain how a particular phenomenon gets identified and articulated at a particular historical moment” (Nadesan, 2002, p. 2). Discourse like that of Oprah’s prior to, and during her meeting with Jani is shaped by psychocentric ideology that produces a form of psychiatric “cultural domination,” privileging the sane universe at the expense of deriding mad ones (Gruson-Woods,

2016, p. 42). Sane philosophy does not have the faculty nor desire to comprehend knowledge beyond what is readily available in omnipresent reality. Thus, subjugated realities become constituted as connate pathologies of the mind, rather than different yet real ontologies. After Jani briefly provides an account of her other world Oprah casts her as abnormal, questioning "Do you think sometimes, that maybe you're different?" which leads to Jani getting up. This prompts Oprah to assert, "Hello, come back for our interview, would you mind?" In response, Jani screams, "No, I don't want to talk!" and continues walking away, which to the adults around her, marks the young girl as a 'difficult' subject. Jani's father then asks what her friend named 400 is doing, and she angrily responds, "No, 400 just left." The camera pans back to Oprah still sitting in the shade upon a concrete ledge, smirking as if she is about to start laughing. In this same moment, Oprah raises her hand to the camera and in a demeaning manner mimics Jani's response, "400 just left." Here the talk show host makes a mockery of Jani's mad perceptions, her other world of Calalini and those living within it. By the end of the six-minute segment Oprah relegates Jani's 'temperamentality,' her refusal to purge the craziness as requested by the camera, to the realm of psychological disorder.

Calalini exists as a distorted reality within the omnipresent geography claimed by sane philosophy to represent the only real objective space. By this I mean that in a mentally topographical sense where sane perception is viewed to be 'truer' or more rationally tangible via shared conception of a shared perception, places like Calalini exist as 'regressive' in that they are not seen as adult-like or sane, and thus merely the immaterial and imaginary world of a child. Calalini is conceived as a mentally geographic oddity that cannot be, insofar as it only belongs to Jani. This is problematic as it assumes that children's, especially mad children's, subjectivities are just delusions of youthhood and the brain. Blackman calls for:

trans-subjective conceptions of what it means to hear voices, which exceed individualistic notions of the clearly bounded and separate psychological subject. This includes more mediated and distributed forms of perception, which can attend to the signalling of 'environments', which extend across space and time, and are experienced in registers which exceed conscious perception. This includes developing the means to 'see' what cannot be easily spoken, shared or articulated and yet are carried in embodied

experiences that usually signify as abnormal perceptions, signs of psychopathology, or at best as curious puzzles and anomalies (2016, p. 259).

Thus, what is needed is a critical and respectful acceptance and analysis of mad children's performances as they make legible the borders that exist between different realities. What I propose is not meant to be a practical solution to how we assist disabled and mad children struggling to stay grounded within omnipresent realities. Instead, I suggest that mad children's worlds be seen not solely through the lens of abnormal psychology, but through that of humanism, an acceptance of the neuro-socio-phenomenological diversity that constitutes living. There must be collaboration amongst such children, parents, and professionals who are willing to work from a social model of disability (Oliver, 2013). We need to imagine accommodations that respect different worlds, not make a mockery of them on YouTube. As noted by Lührman et al., people around the world who hear voices in environments where such a phenomenon is not pathologized are generally more likely to experience them as positive or neutral (2015). Such an outlook for Jani could have involved learning about the Hearing Voices Network, the social versus medical definitions of madness and disability, and both the struggles and gifts that hearing voices can bring.

### **Conclusion – Foster Mad Children's Voices**

In citing the Deleuzo-guattarian philosophy of 'smooth and striated spaces,' Smith argues that a direct study of autistic children's identities does not truly explore their subjugated experiences. The author paraphrases that striated spaces are disciplined "spaces of hierarchy, binaries and normative meanings in which a body can be known" (Smith, 2016, p. 185). Smith argues that to truly know who the autistic child is, beyond their autism or status as child, one must seek smooth spaces of becoming that "go beyond the knowable and appearing subjectivated autistic child and into spaces of exploring the potential of what a body can do [or be]" (2016, p. 185). Like the figure of the autistic child, the imposed identities of mad children must be dissected, and each piece of identity must be set apart so that the individual can come forward and express true subjectivity "beyond the governed, performatively formed subject" (2016, p.185). Beyond biomedical and social models of childhood disability, perhaps a phenomenological approach can offer the individual a voice. A phenomenological approach would seek to understand mad children as they see themselves, as neither completely social nor

biological beings. After all, if one were to ask a 7-year-old child “who are you?” it is unlikely they would respond, “I am a schizophrenic child!” Returning to Merleau-Ponty’s concept of ‘sense-data,’ we must begin seeing young people’s madness for what it is, a ‘pure’ phenomenon, existing before cultural meaning can even be attached (as cited in Richter, 2017). Titchkosky describes how we are all embodied beings, and that “to be embodied means to be conditioned by societal interpretations of bodily existence” (2011, p. 15). Nonetheless, even social interpretation of children’s bodily existence may override their own ontological sense of self. Of course, children’s language is constructed by the society in which they learn, and their ways of meaning-making will thus be influenced by the social ideals belonging to this society. However, in engaging with children, especially mad and disabled children, we need to allow them to define themselves and their bodily phenomena, rather than structuring their perspective as disorder. This approach could potentially be established through collaboration with mad people to reform therapies as mad-friendly, allowing for the transference of intergenerational mad expertise between older and younger generations of mad people.

I wish to mention that Jani does not to my knowledge self-identify as mad. Rather, I chose to replace ‘mentally ill’ with the political mad in order to move away from the pathologization of her experiences. I must acknowledge referring to Jani as mad is still an imposition of identity. Neither I, nor Oprah, nor people working within the psy-disciplines can speak for Jani. Although I self-identify as mad, I must acknowledge a major limitation of this paper. It serves as a critique and analysis, not response. A truly critical response to how children who hear voices are represented and made sense of within and outside media like YouTube would be most significant if initiated from the perspective of Jani, or a person who self-identifies as schizophrenic or as being labelled with schizophrenia.

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