

EDITORIAL

NARRATIVE IMAGINATION

Methodological Imperative for Understanding Mental Disability

Mental health is not a destination, it's a journey, narrative imagination makes it worth the effort.

I saw him as a toddler, cuddled in his mother's arms. He appeared as normal as any other child could be and his mother looked elated with happiness and hope. Two years went by, and the family moved to London. After few months, I received a distressed call from the distraught mother that her son was diagnosed with Autism and given a 50% disability certificate. She¹ was pursuing her Ph.D. at that time, and I had known her as one of the most committed diligent researchers deeply engrossed in the study of ethnomedicine. That day her life changed forever!! Her only priority in life was her son and how she would be able to give him physical, emotional and moral support to become 'independent adult'. Few years later, family moved back to India and struggled to provide special education to their son to make him socially empowered and physically independent. For the last forty years, I am a witness to their physical, emotional journey that inspired me to study mental health issues and how it impacts families living with these children.

In the year 2012, with one of my former research scholars, who was researching disability in family settings, we decided to examine the lived experiences of individuals diagnosed with mental health issues living in traditional family settings. We located 15 individuals diagnosed with mental health disorder² of them nine were males and six were females. Three of them were diagnosed with autism and were given 50 to 80% disability certificate. Five were diagnosed with learning disability. They were given disability certificates specifying degree of their impairment from 50 to 100%. Six were simply classified as mentally retarded and were mostly given 100% disability certificate, except for one that received 80% disability certificate. In this research sample, only one individual was diagnosed with cerebral palsy and had a 100% disability certificate. Socio-economic profiles of the study families showed that five heads of household were daily wage earners, three were farmers, five were self-employed or working in small private enterprises, only one was a government employee and one was a practising neurosurgeon. All the women in the sample were housewives, but not necessarily out of choice but of necessity to provide primary care to their mentally disabled child. Disability certificates in India are awarded two years after the diagnosis of the impairment and after six months of medical supervision. It is true that most of these impairments are generally not visible at birth and late diagnosis makes therapies much less effective. In the absence of the state support, children identified with mental ailments are left in lurch and become victims of apathy and abuse.

This brief socio-economic profile of the sampled populations suggests that most of the families in the sampled population were poor and in no position to provide required care and rehabilitation therapy for their mentally disabled wards. Most of them needed institutional care but in the absence of adequate facilities, they lived at home with their families³. On enquiry, we found that only six of them were ever sent to institutional care just for few months as the cost of commuting to institutional care centres was prohibitive and care staff was insensitive to their needs. The process of getting disability certification and related pension benefits was audacious to say the least. Classification of disability and award of disability certificate⁴ is an arbitrary construct, and far more complex because mental disability is a social construct (Oliver 1990, 1996).

My reflexive understanding⁵ of what Nila (Pseudonym) and other fourteen families in the sample were experiencing, challenged my forty years of theoretical and methodological learning in anthropology. It was at this juncture that I came across famous philosopher Martha Nussbaum's (1997, 2010) concept of “narrative imagination” that she simply describes as “the ability to be an intelligent reader of another person's story”. Inherent in this statement is a call for creating an enabling environment to comprehend differing voices and behavioural specificities. Rehabilitation policies for the disabled are determined by the extent of empathy that society and state experiences towards them. If disability is regarded as a personal misfortune, then policy interventions become restrictive. From the outset, we noticed that beginning with diagnosis to providing a disability certificate, state and its agencies lacked “narrative imagination”. Mental Health policy document (2014) recognized dependence of these people on families but makes no provision for providing financial assistance to the families with mentally disabled persons. One of the primary care providers in our sample was forced to drag her fourteen years old son with a 100% disability certification to the third floor of a building to verify his disability status to get meagre benefit of disability pension⁶. When a mother of the mentally challenged daughter asks for the family pension to be credited to her account, narrative imagination demands that planners view it from her perspective. But data documented in our research showed that none of the study participants received any support from any of the intermediary agencies. Special schools had staff that was indifferent to their needs and lacked narrative imagination. Mother of a girl child diagnosed with 80% learning disability was forced to sit under a tree in peak summer months to take her child to the toilet as school refused to provide a caretaker.

When we study mentally disabled, there are no primary co-research participants but others who live with them and experience their lived existentiality. We thus generate *narrative imagination* and not narratives per se. Inherent in this understanding is love and compassion that narrator has for the mentally challenged ward under his care and protection. When Nila talks about Nirvan, she epitomizes an identity that is enmeshed into herself. But there is also a sense of fear and insecurity that emanates from perpetual uncertainty asking what happens to them after me/us'. There is

unknown future and a social system not sensitive to the needs of not only those suffering physical and mental challenges but also of the families. These families live in a disabling environment experiencing 'othering' and exclusion at every step (Oliver,1990; 1996). They abstain from social interactions and have no social networks as they are afraid of exposing their impaired child to relatives and friends.

Narrative imagination extends beyond the narrator and requires empathy and sensitivity from the researcher in the interactive process. Researcher is expected to have the ability to imagine what it would mean to be living like the 'other' (Von Wright, 2002). The process requires empathic resonance⁷ (Docety and Meyer, 2008) and empathetic reasoning⁸ (Von Wright 2002). There is conscious subjectivity involved in generating narrative imagination for research. Acceptance of this subjectivity without questioning narrator's positionality is the key to designing policies that provide mentally disabled friendly programmes. In India disability continues to be recognised as physical and mental incapacity and not viewed as a matter of political power, oppression and deliberate neglect. It remained confined to the domain of medical professionals, welfare and non-government organizations and suffering families. Community and state remained nearly absent. It's time that we iterate million times that *You are not alone. You are seen. I am with you. You are not alone- Shonda Rhimes.*

End Notes

¹I will name her Nila and her son Nirvan in the editorial to maintain confidentiality.

²*The Diagnostic and Statistical Manual of Mental disorder* (5th edition, DSM-5) defines mental disorder as “a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning”. WHO in its definition includes Anxiety and depressive disorders, schizophrenia, bipolar disorder, Dementia and then there are Neurodevelopment disorders that includes intellectual development, autism spectrum disorder, and attention deficit hyperactivity disorder (ADHD) to name just a few conditions. In its recent two report *World mental Health today* and *Mental Health Atlas 2024*, says that more than one billion people across the world are living with mental health disorders and recognising it as the 2nd leading cause of long-term disability (cf. *The Hindu*, Sunday, September 14th, 2025; also see <https://www.who.int/news-room/fact-sheets/detail/mental-disorders> accessed on 29.10.2025)

³National Health Mental policy documents that 70 to 80% persons with mental health disorder live with their families and this is true across all socio-demographic variables. It also acknowledges the fact that once the primary caregiver in the family is dead or incapacitated due to age or infirmities, mentally disabled are often deprived of food, hygiene or care. https://www.nhm.gov.in/images/pdf/National_Health_Mental_Policy.pdf accessed on 2nd October 2025

⁴In India *The RPWD* (2016) Act mandates that mental illness must persist for at least two years before a permanent disability certificate is issued vis-à-vis west where a disability certificate is given based on an individual's ability to participate in daily activities and full participation in society.

⁵Lincoln & Gauba, (2000:183) define reflexivity as “the process of reflecting critically on the self as researchers”.

⁶I was informed that the third-floor office of the disability commissioner handling grievances neither had a lift nor a ramp

⁷It is a subconscious response, instinctive reflection of being in the same position

⁸This reflects a conscious cognitive effort 'assuming to be in the same position/ wearing the same shoes'.

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