

Exploring the representation of disabled children  
and their childhoods in occupational therapy  
literature from India: A critical interpretive  
synthesis

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# Background

## India and Disability:

### Pre-colonial

- Differences marginalized.
- E.g. caste one is born into
- Disability as a difference.
- Disability represented as evil, ritually impure in Hindu scriptures.

(Ghai,2015)

### Colonization

- Traditional beliefs and systems were disregarded.
- Establishment of medical-oriented institutions.
- Shift to institution-based care
- Hegemony of Western knowledge and the medical model
  - informed policy and service development

(Ghai,2020)

### Post-colonial

- Focus on welfare and nation building (Mehrotra,2011)
- Establishment of Occupational Therapy in a medical institution in the year 1949 (Murthi,2019)
- Charity/pity/religious, medical and social models intertwined(Staples,2012).

# Disabled children's childhood in India (Ghai,2015)



\*Photo for illustration purpose only

- Within the medical institutions, the discipline produces and shares knowledge about disability and disabled children that seems to reflect a true understanding of what needs to be governed (Laliberte Rudman, 2010).
- In the postcolonial Indian context, the identities of the disabled and children are evolving through neo-liberalization and globalization (Chaudhary, 2018; Dar & Kannan, 2023).
- Although the majority of the disabled population lives in the Global South, concepts and theories on disability have been produced through Western logic. (Meekosha, 2011).
- This calls for a critical turn inwards (Farias & Laliberte Rudman, 2016) to the “injustices in [the discipline’s] its own backyard” (Owens, 2017, p.195) in producing particular versions of subject positions as ideal and marginalizing others (Laliberte Rudman, 2010).

# Aims of the study

- To identify and critically analyze
  - how the subjectivities of disabled children and their childhoods in India have been produced through the dominant Western-centric and biomedical lenses and,
  - how their identities are negotiated at the intersection of multiple contextual factors of difference and marginalization.
- To examine why it is problematic to assume a homogenized understanding of disabled children and their childhoods in local imaginaries.

# Theoretical underpinning

Disabled children's childhood studies



Childhood studies from Global South



Postcolonial theories

- Trouble the **binary of disabled and non-disabled**
- Challenge the **construction of disabled childhood as deficient and abnormal** (Curran,2013)
- **Re-presentation of disabled childhood in its own authenticity.** (Curran-Runswick Cole,2014)
- **Starting point to think about disabled children and their childhoods beyond impairment, inequality and abuse.**
  
- Challenge the **dominance of ethnocentric child development theories and assessment measures** (Hogan,2005)
- **Problematize construction of the Other “weird” Southern child vs “ideal” Western child** (Araneda-Urrutia,2022)
- **Edward Said- How disabled children in India are represented as the Other through Western models and theories** (Gandhi,1998).
- **Spivak- Highlight the intersection of oppression**(Balagopalan,2023).

# Methodology

- Critical interpretive synthesis (CIS)
- Methodology that considers literature as an object of inquiry
  - To expand beyond compiling and summarizing data
  - To produce new insights and alternate ways of thinking about the construct or phenomenon (Dixon-Woods et al., 2006; Farias & Laliberte Rudman, 2016)

# Research Questions

1. How are disabled children and their childhoods represented in occupational therapy literature from India?
2. How have biomedically oriented and/or Western occupational therapy models influenced the representation of disabled children and their childhoods in occupational therapy literature from India?
3. What assumptions, values and norms underpin the dominant notions of disabled children and their childhoods in occupational therapy literature from India, and why are these assumptions problematic?

## Inclusion Criteria

- Studies conducted in India
- Published in English since the year 2016 [signifying the year when the Persons with Disabilities Act was re-drafted from welfare to rights focus (Department of Empowerment of Persons with Disabilities, 2024)]

## Exclusion Criteria

- Conference abstracts
- Research on interventions for parents of disabled children (e.g., intervention for parental stress) with a lack of representation of disabled children

## Data Analysis

- **Analytic guide as compass** to identify patterns of representation and to construct themes.
- **Collaborative reflexivity** (Finlay,2002) with the third author to examine the data set from different points of view.

## 1. Remediation as a requirement for social inclusion

- Most studies focused on finding the effectiveness of occupational therapy interventions.
- Disability as a deficit to be ‘fixed’.
- Children represented through the dominant age and stage based developmental models, labelling them as deviant and deficient.
- The problems were located *in* the children, which justified the remediation or need for the intervention.
- Sustains the dis-abling factors existing in the system.
- Overlooks possibilities for alternative ways of doing and being (Gerlach et al.,2018).



“Take people who are broken by [the] broken system, fix them... send them back to the same system to continue doing what they were doing” (Ramugondo, 2018, p. 88)



## 2. Othered children with Other childhoods

- Disabled child participants were represented using different labels:
  - children with disabilities/ special needs,
  - children with ‘a diagnosis’ (e.g., children with Autism)
- Non-disabled children were represented as normal or typical.
- The Othering of the children labelled disabled as ‘abnormal’ and ‘atypical’ works
  - as a discursive practice to maintain the ‘normal’ (Watson, 2018 )
  - shape the assumptions of what they can and should do, that is their occupational possibilities (Laliberte Rudman, 2010)..
- “portrayals of the ‘disabled’ as ‘normal’ and ‘ordinary’ persons are rarely found” in any discourse (Singh & Ghai, 2009, p. 135).

[Labels] and categories are never neutral; they have effects, whether intended, obvious or hidden (Mosleh & Gibson, 2022, p.124)

### 3. Unseen and unheard children and childhoods

- Children who were **not represented in the literature**:
  - Female disabled children
  - Disabled children from *lowered* class and caste
  - Disabled children from rural areas
- The absence **could be because of the prevalence rate of disabilities**.
- Is the absence of children with intersecting identities deliberate, preferred or unintentional?
- Questions the **system that produces and sustains social inequalities**, leading to inadequate and inaccessible health care facilities.



“There’s no such thing as the voiceless. There are only the deliberately silenced or the preferably unheard”.(Arundhati Roy)



## 4. Indian children labelled disabled as valued family and community members

- Disabled children are often constructed as a ‘burden’ for the family.
- Interventions are mostly aimed at reducing caregiver burden when the family is involved.
- The caregivers or the parents of disabled children dominantly positioned as
  - unaware, careless or incapable of identifying their children’s needs
  - especially if they belong to the *lowered* strata of the social hierarchy
- Culture and carelessness as reasons for disability individualize the disabled children and their families for the injustices they experience (Staples, 2012).

“it is simply about giving back these families [in Global South] the same agency, heterogeneity, resilience and humanity awarded to (or taken for granted among) Western families. It is about making sure that these strengths are understood, learnt from and built upon, and never ignored or trampled on, whether discursively or materially”  
(Grech, 2012, p. 60).

# Implications And Future Research Directions

- Take a **critical turn inward** into the practice and research of occupational therapy in India,
  - if and how we are producing, (re)producing and sustaining injustices against disabled children and their families
  - by uncritically aligning with the dominant and received ideas.
- Calls for **critically interrogating the conditions of possibility** (Laliberte Rudman, 2021),
  - such as ableism, middle-class and upper-caste perspectives,
  - that are underpinning occupational therapy research with children in India.
- **Not proposing to abandon the existing theories, models or interventions** but,
  - to **reflexively interrogate** if there are alternative ways to understand disabled children and
  - **possibilities for “shared exploration of needs and hope”** (Gibson, 2016, p.85) with disabled children and their families.
- For **future research**
  - Include **therapists working across different regions of India** to add more nuance and situatedness to the analysis.
  - Include **disabled children and their families as co-researchers**

# References

- Araneda-Urrutia, C. (2022). The invention of the “weird” Southern child: Mapping coloniality in the political problematization of disadvantaged children’s lives in the global South. *Childhood*, 29(3), 292–306. <https://doi.org/10.1177/09075682221108025>
- Chaudhary, V. (2019). Disability in and through rural worlds. *Somatosphere*. <https://somatosphere.com/2019/disability-in-and-through-rural-worlds.html/>
- Curran, T (2013 ). Disabled children’s childhood studies: Alternative relations and forms of authority?. In K. Runswick-Cole & T. Curran (Eds.), *Disabled Children’s Childhood Studies: Critical Approaches in a Global Context* (pp. 121-135). Palgrave Macmillan.
- Curran, T., & Runswick-Cole, K. (2014). Disabled children’s childhood studies: A distinct approach?. *Disability & Society*, 29(10), 1617–1630. <https://doi.org/10.1080/09687599.2014.966187>
- Dar, A. & Kannan, D (2024). Introduction: Children, youth and modernity in the ‘everyday urban’. In A. Dar & D. Kannan (Eds.), *Childhood and youth in India. Engagements with modernity* (pp.179-200). Palgrave Macmillan. <https://doi.org/10.1007/978-3-031-31820-7>
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6(1), 35. <https://doi.org/10.1186/1471-2288-6-35>
- Farias, L., & Laliberte Rudman, D. (2016). A Critical Interpretive Synthesis of the Uptake of Critical Perspectives in Occupational Science. *Journal of Occupational Science*, 23(1), 33–50. <https://doi.org/10.1080/14427591.2014.989893>
- Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209–230. <https://doi.org/10.1177/146879410200200205>
- Ghai, A (2020). Ignorance of disability. Some epistemological questions. In N. Mehrotra. (Ed.), *Disability studies in India. Interdisciplinary perspectives* (pp. 75- 92). Springer. <https://doi.org/10.1007/978-981-15-2616-9>

- Gibson, B. (2016). *Rehabilitation. A post-critical approach*. CRC Press
- Goodley, D., & Runswick-Cole, K. (2010). Emancipating play: Dis/abled children, development and deconstruction. *Disability & Society*, 25(4), 499–512. <https://doi.org/10.1080/09687591003755914>
- Grech, S. (2012). Disability and the Majority World: A Neocolonial Approach. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and Social Theory* (pp. 52–69). Palgrave Macmillan UK. [https://doi.org/10.1057/9781137023001\\_4](https://doi.org/10.1057/9781137023001_4)
- Hogan, D (2005). Researching ‘the child’ in developmental psychology. In Greene, S., Hogan, D. Researching children’s experience: Approaches and methods. Sage Publications.
- Laliberte Rudman, D. (2021). Mobilizing Occupation for Social Transformation: Radical Resistance, Disruption, and Re-Configuration: Mobiliser l’occupation pour une transformation sociale : résistance radicale, perturbation et reconfiguration. *Canadian Journal of Occupational Therapy*, 88(2), 96–107. <https://doi.org/10.1177/00084174211020836>
- Laliberte Rudman, D. (2010). Occupational terminology: Occupational possibilities. *Journal of Occupational Science*, 17(1), 55–59. <https://doi.org/10.1080/14427591.2010.9686673>
- Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, 26(6), 667–682. <https://doi.org/10.1080/09687599.2011.602860>
- Mosleh, D., & Gibson, B. E. (2022). Abnormal-Becoming-Normal: Conceptualizations of Childhood Disability in Children’s Rehabilitation Textbooks. *Scandinavian Journal of Disability Research*, 24(1), 122–135. <https://doi.org/10.16993/sjdr.877>
- Owens, L (2017). Our professional existence is political: Critical reflections on seeing white in Occupational Therapy. In Sakellariou, D., Pollard, N. (Eds.) *Occupational Therapies without borders: Integrating justice with practice*. (pp.194-202). Elsevier
- Ramugondo, E. (2018). Healing work: Intersections for decoloniality. *World Federation of Occupational Therapists Bulletin*, 74(2), 83–91. <https://doi.org/10.1080/14473828.2018.1523981>
- Staples, J. (2012). Culture and Carelessness: Constituting Disability in South India. *Medical Anthropology Quarterly*, 26(4), 557–574. <https://doi.org/10.1111/maq.12007>



Thank you.

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Questions and Feedback