

Caregiving Together Framework: Optimising the Involvement of Fathers in Caregiving of Children with Disability

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Background

266 MILLION CHILDREN with disabilities worldwide

require special attention to enhance their overall well-being and development.(1) The **active participation of fathers in caregiving of children with disabilities (CWD) is crucial** for promoting their development.(2,3) However, **research on the experiences of fathers in taking care of CWD is scarce**, especially, where mothers are traditionally the primary caregivers.(4,5)



Methodology

Data of this qualitative study were collected in late 2023 **across 8 sites over 5 states** in India in collaboration with project community workers from 7 partner organisations as implementers. Data from fathers was triangulated with insights from mothers to enhance validity.(6)

Parents of CWD

54 Semi-structure Interviews (SSI)

42 males 12 females

9 Focus group discussions (FGD)

7 mix-gender groups 1 male group 1 female group

Objective

This study aims to explore the **lived experiences of fathers' involvement** in taking care of children with a disability, and subsequently **construct a framework** for optimising paternal involvement.



The data was analysed using **inductive interpretative analysis**, specifically **thematic analysis and grounded theory techniques** to construct a framework, with the assistance of NVivo 14 software.

Results

Three major themes emerged. First, the role of father depends on the mindset and emotion, influenced by spatial, relational and capability dimensions. **Second**, fathers feel better and value their children more, the more involved they are, which is influenced by their self-perception (respect and appreciation), self-compassion (collaboration and quality time), and self-regulation (emotional control and rational expectation). **Thirdly**, importance is placed on supportive environments and services such as inclusive public services and support, community sharing and encouragement, and individualised disability services and opportunities. From these themes, **the 3Hs framework is proposed**, consisting of three interconnected principles: **Hand (involvement), Heart (feeling) and Head (mindset)**.

3Hs Framework: Optimisation of Fathers Involvement

External Support

- Inclusive public services & support
- Community sharing & encouragement
- Individualised disability service & opportunity

Positive Mindset & Value (HEAD)

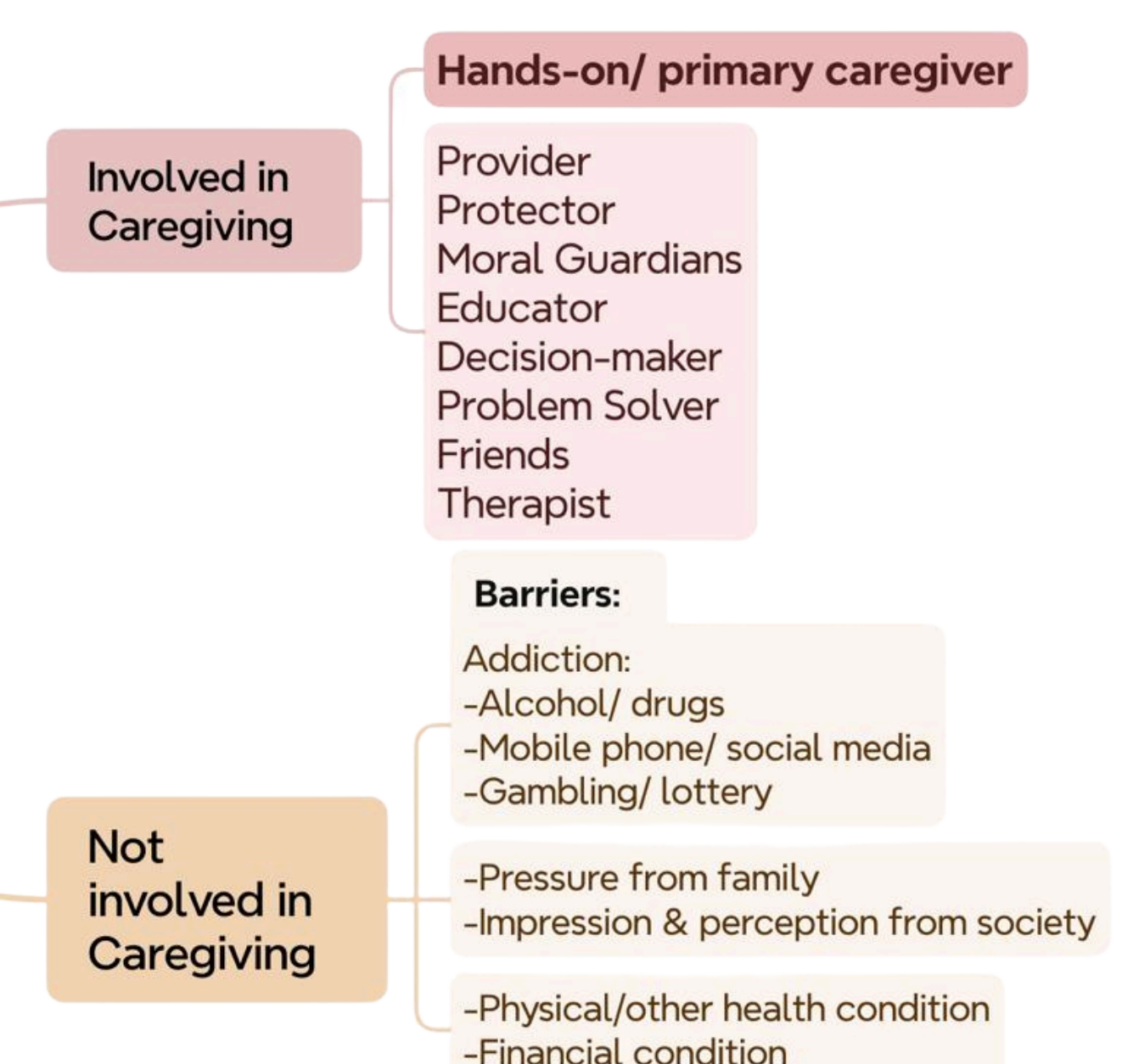
Better Feeling (HEART)

More Involvement (HAND)

- **Self-perception** (Respect & appreciation)
- **Self-compassion** (Quality time & Collaboration)
- **Self-regulation** (Emotional regulation & Rational expectation)

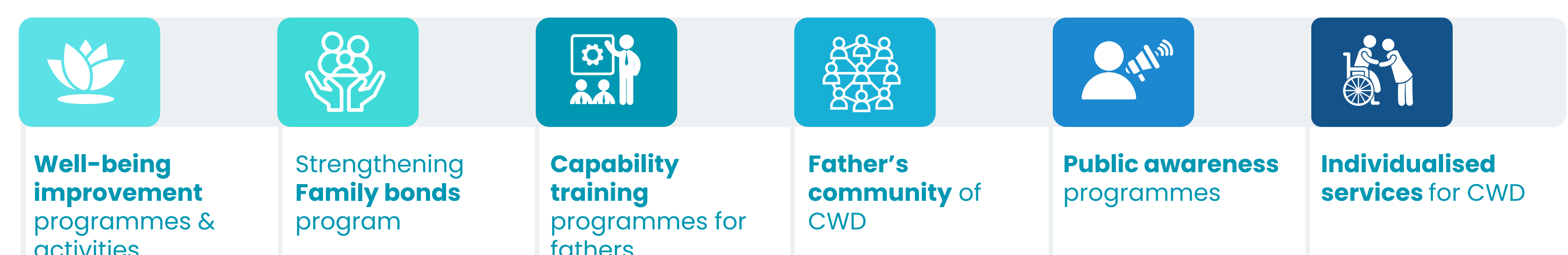
- **Spatial dimension** (Time & opportunity)
- **Relationship dimension** (Trust & connection)
- **Capability dimension** (Knowledge & skills)

Role of Fathers



Recommendations Based on 3Hs Framework

PROGRAMS



POLICY



Conclusion

The diverse role of fathers depends on their mindset and emotions, in which they feel better and value the whole condition more, the more involved they are. External support is important to promote paternal involvement. Framework and comprehension of fathers' roles, impacts, and needs lead to some recommendations for caregiving practices, programmes, and policies.

References

1. UNICEF. Seen, counted, included: using data to shed light on the well-being of children with disabilities. 2021 [cited on 5 April 2024]. Available from: <https://data.unicef.org/resources/children-with-disabilities-report-2021/>
2. Lopez S, McWhirter A, Rosencrans M, Giuliani NR, McIntyre LL. Father involvement with children with developmental delays. *Global Education Review*. 2019 Apr 8(6):140-62.
3. Bronte-Tinkew J, Carrano J, Horowitz A, Kinukawa A. Involvement among resident fathers and links to infant cognitive outcomes. *Journal of Family Issues*. 2008 Sep;29(9):1211-44.
4. Acar S, Chen CI, Xie H. Parental involvement in developmental disabilities across three cultures: A systematic review. *Research in Developmental Disabilities*. 2021 Mar 1;110:103861.
5. Navalkar PG. Fathering a child with a disability in India: A perspective from Mumbai. *Childhood Education*. 2010 Sep 186(6):389-93.
6. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum*. 2014 Sep;41(5):545-7. doi:10.1188/14.ONF.545-547. PMID: 25158659.