

Collaboration as a Method of Support: Investigating Interdisciplinary Facilitation for Caregiver Support Groups Within the Huntington's Disease Community

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Background

- Huntington's disease (HD)
 - Neurodegenerative
 - Hereditary
- Caregivers are often family members
 - Often overlooked
- Support is necessary for well-being of caregivers
 - Caregiver paradox

Background (cont.)

- Virtual support groups = access
 - Many hosted through the Huntington's Disease Society of America (HDSA)
- No research on *who* is facilitating
- Interdisciplinary support is beneficial
 - Tucker-Roghi et al., 2021 - Dementia community support*
 - MacNab et al., 1985 – NICU Parent support group
 - Banach & Couse, 2012 – ASD Parent support group*

Study Aim

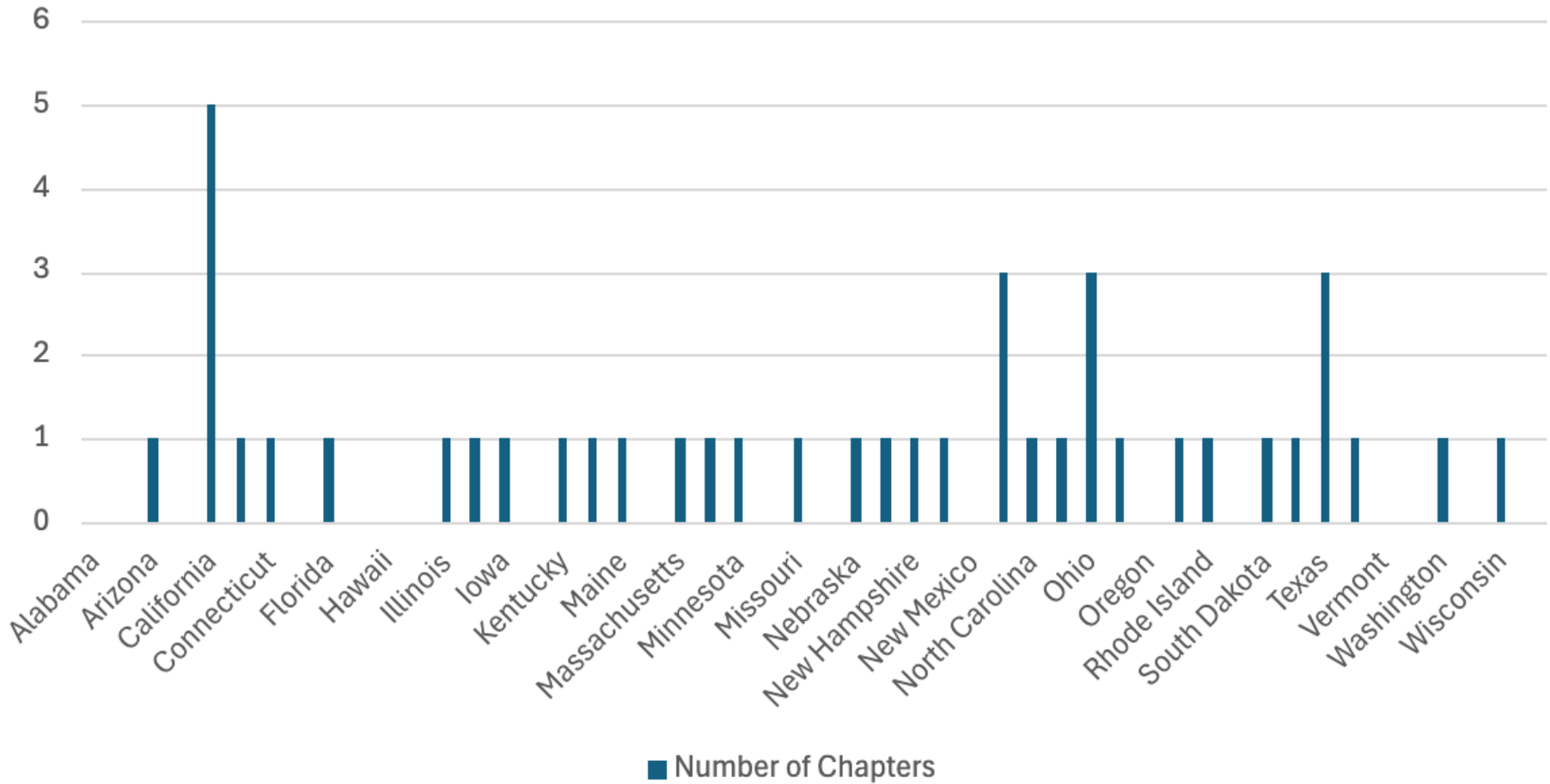
- Identify and describe the facilitation of virtual HDSA support groups for caregivers
- Reasoning: Capstone project, interdisciplinary facilitation was impactful

Methods

- Locate HDSA chapter/affiliate webpages
- Investigate number of chapters/affiliates across all 50 states
- Identify virtual support groups for caregivers specifically
 - Calculate the number of virtual groups
- Collect information on support group facilitators
 - Investigate background, if necessary

Results

Number of Chapters/Affiliates by State



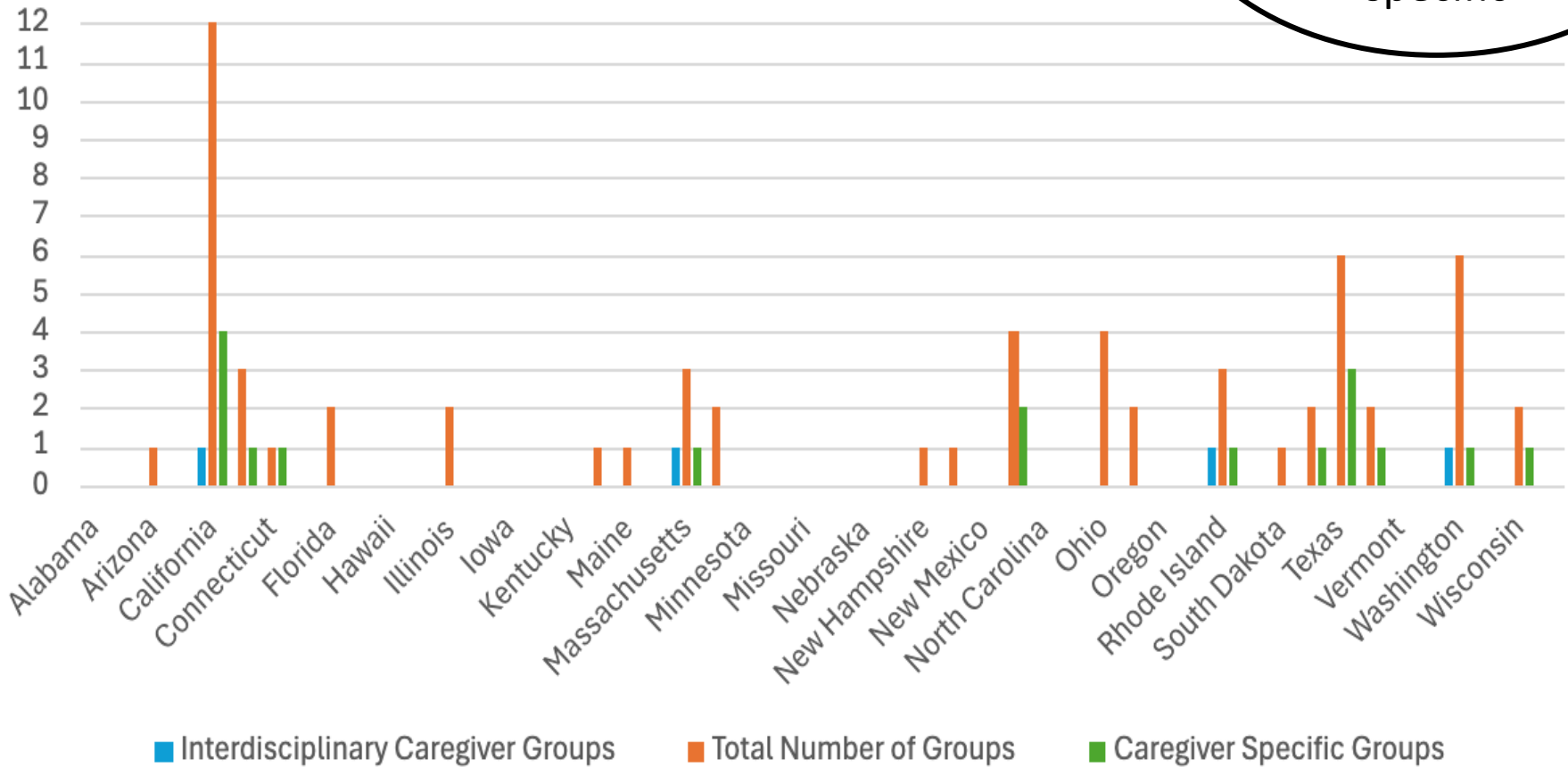
Results (cont.)

- 61 virtual support groups for caregivers
 - 3 (4.9%) facilitated in an interdisciplinary fashion
- Many states had general support groups
 - Caregivers could attend, but not the focus
- Note: Massachusetts and Rhode Island share a chapter

Results

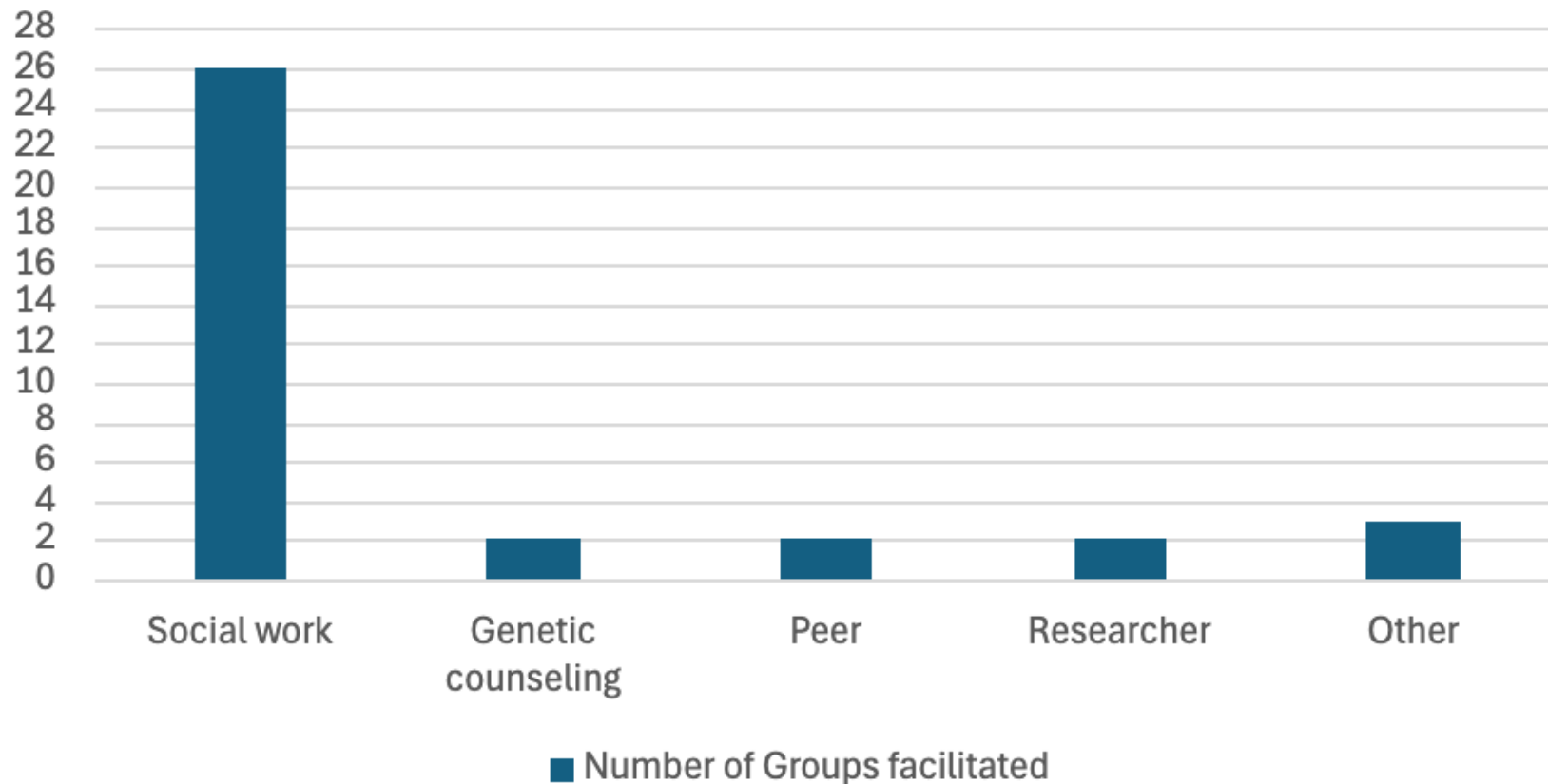
Group Breakdown by State

Florida groups are interdisciplinary, but not caregiver specific



Results (cont.)

Number of Groups Facilitated By Discipline



Discussion

- Lack of interdisciplinary support for caregivers
- Opportunity for personal and professional development
 - (Banach & Couse, 2012)
- Interdisciplinary support is an avenue for improvement

Limitations

- Only HDSA Chapter or Affiliate Groups
 - UConn has an interdisciplinary support group
- Not all webpages had been updated recently
- Some facilitators did not have publically available backgrounds

Implications and Future Directions

- Need to advocate to be in new spaces
- Elevate caregiver voices and needs
- Studies investigating specific interdisciplinary impacts
- Future directions as indicated in my capstone!

References

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver Burden: A Clinical Review. *JAMA*, 311(10), 1052. <https://doi.org/10.1001/jama.2014.304>
- Banach, M., & Couse, L. J. (2012). Interdisciplinary Co-Facilitation of Support Groups for Parents of Children with Autism: An Opportunity for Professional Preparation. *Social Work with Groups*, 35(4), 313–329. <https://doi.org/10.1080/01609513.2012.671103>
- Daemen, M. J. A. P., Boots, L., Oosterloo, M., de Vugt, M. E., & Duits, A. (2023). Facilitators and barriers in caring for a person with Huntington's disease: input for a remote support program. *Aging & Mental Health*, 28(1), 1–10. <https://doi.org/10.1080/13607863.2023.2230949>
- Gina Tucker-Roghi, Jamie Escoubas, Renee Tolliver, Sarah Tucker, Interdisciplinary Community-Based Support for Caregivers of Individuals Living with Dementia, *Innovation in Aging*, Volume 5, Issue Supplement_1, 2021, Page 806, <https://doi.org/10.1093/geroni/igab046.2967>
- Huntington's Disease Society of America. (2025). Chapters and Affiliates. HDSA. <https://hdsa.org/about-hdsa/chapters-affiliates/>
- MacNab, A. J., Sheckter, L. A., Hendry, N. J., Pendray, M. R., & MacNab, G. (1985). Group Support for Parents of High Risk Neonates: An Interdisciplinary Approach. *Social Work in Health Care*, 10(4), 63–71. https://doi.org/10.1300/J010v10n04_07
- Stoker, T. B., Mason, S. L., Greenland, J. C., Holden, S. T., Santini, H., & Barker, R. A. (2022). Huntington's disease: Diagnosis and Management. *Practical Neurology*, 22(1), 32–41. <https://doi.org/10.1136/practneurol-2021-003074>
- Warren, J. L., & Warren, J. S. (2023). The Case for Understanding Interdisciplinary Relationships in Health Care. *Ochsner Journal*, 23(2), 94–97. <https://doi.org/10.31486/toj.22.0111>