

# A Scoping Review of Promising Practices for Engaging Families in Childhood Disability Research

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## Background

- Family engagement in research involves the meaningful inclusion of families in research processes to **improve study designs, enhance analyses, and to help mobilize knowledge**
- There is still relatively little known about the most effective ways to engage families of disabled children in research processes<sup>1</sup>
- Understanding promising practices for engaging families in research can help to:
  - Ensure that studies are meaningful/helpful to families
  - Account for families' needs and preferences in study participation processes

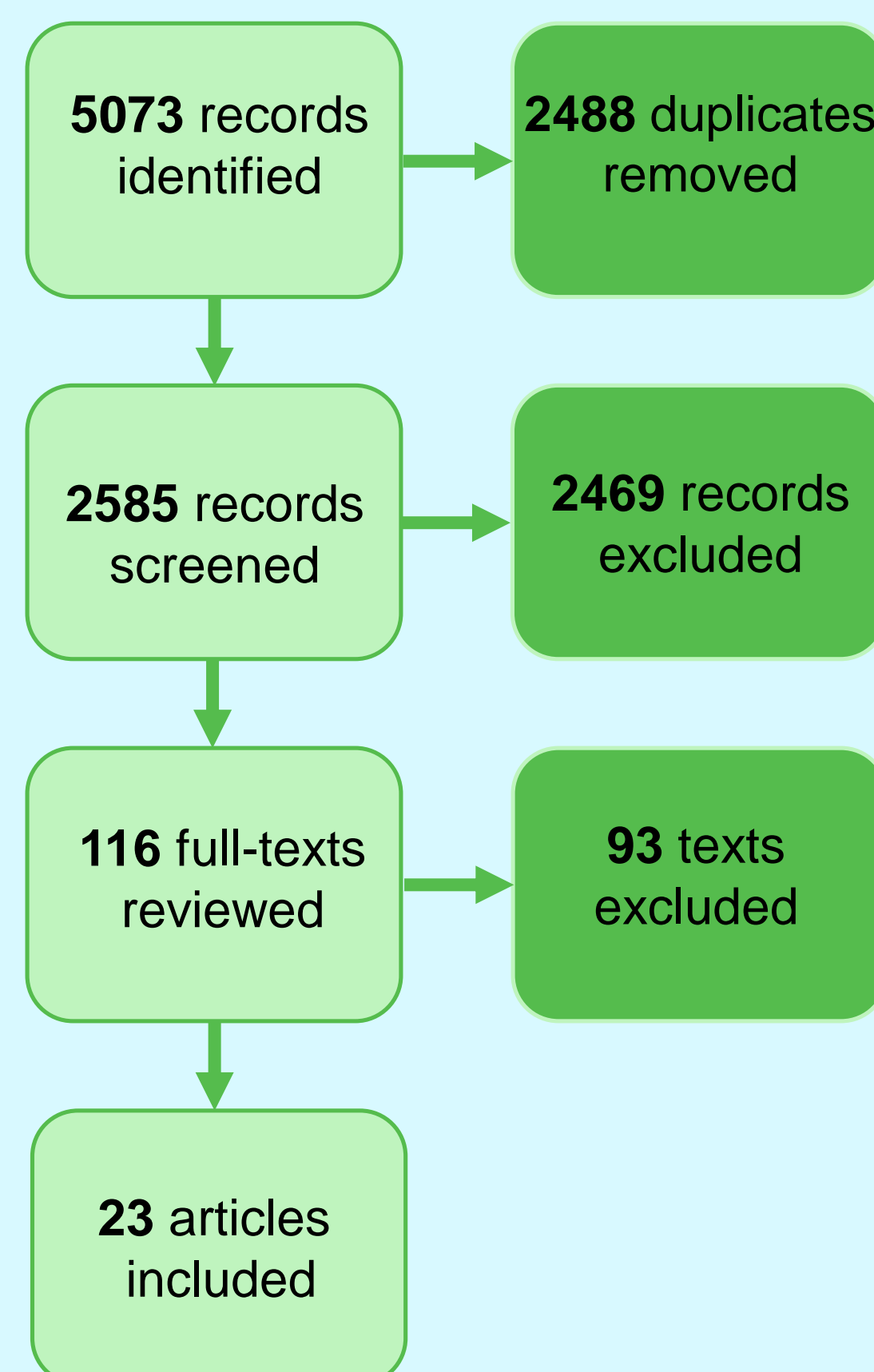


## Objective

To understand useful policies and practices, and opportunities and challenges associated with meaningfully engaging families in childhood disability research.

## Methods

- Six databases searched to identify articles intersecting **family engagement** and **childhood disability** using scoping review approach<sup>2</sup>
- Sought input from two HBKRH Family Leaders on our initial analyses and discussion points



# How Can We Meaningfully Engage Families in Childhood Disability Research?



## Results

### Culture of Openness

- Cultivate an open, trusting, reciprocal relationship before and throughout the course of the research
- Flexibility in research design processes is needed to allow for changes based on family input



### Time Considerations

- Lengthen project timelines to allow for meaningful family engagement and changes based on their input
- Be flexible with scheduling to account for and prioritize families' availabilities
- Minimize/streamline work for partner families as much as possible



### Clear Roles and Expectations

- Address power imbalances to ensure families' contributions are equally heard/valued<sup>3</sup>
- Clarify families' level of involvement and what exactly is being asked of them early on in research



## Conclusion and Next Steps

- Family engagement must be more than "ticking the box" in research design and requires ongoing consideration
- A relationship of trust and mutual respect is needed to engage families and create meaningful outcomes
- Researchers should value families' time and input, and continuously consider how they can streamline families' work/time commitments on projects
- Research institutions should consider existing engagement frameworks to advance family engagement policies and practices across their research projects



## Acknowledgements

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## References

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