Strategies To Engage Families in Research

I would like to become involved with research (i.e. biomedical or clinical research) related to my child's diagnosis.

I would like to involve family partners in my clinical and/or biomedical research project.

 Contact biomedical and clinical researchers to see who you could work with

WHO should I contact?

Contact provincial/national childhood disability networks to connect with

 Advertise your research at local conferences, and institutional newsletters

- Learn about the skills required to conduct research
- Create a 1-page letter outlining your interests and skills
- WHAT should I do?

Have an open mind with honest communication

- Provide regular project updates
- Value your family partner's opinion!

- Explore support groups for families on Facebook who are interested in research
- Ask about project timeline
- Share your availabilities
- To learn the behind the scenes of research
- To broaden your understanding of your child's disease
- Talk with biomedical and clinical researchers about their research

WHERE should I go?

Local conferences, Facebook groups, university websites or childhood disability research networks such as CHILD-BRIGHT, CanChild, & KBHN

WHEN should I start?

At any point of the research project!

- Attend community events to reach out to family partners interested in research
- Involve your family partner in all project stages

WHY should I partner up?

Bridge the gaps between research, either clinical or biomedical, and families

HOW can I find a partner?

Contact people who have experience in family engagement
Schedule a first meeting to discuss what this partnership could look like

- To learn new strategies to disseminate results
- To ensure findings are meaningful
- Partner with a researcher familiar with family engagement to help you build such a relationship

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