

## PARENT INFORMATION LETTER

Dear parents and caregivers,

Parenting is a tough task! Parenting a child whose development might be complicated by a disability can be even harder. We know that parents want to do a good job with their kids. We also know that there can be a lot of extra stress and strain on parents as they work to do all the right things when their child has a disability.

We wish to engage with parents raising children with developmental challenges. We want to find out if our planned series of five weekly online interactive workshops, called **ENVISAGE**, improves parents' mental well-being and helps them feel more confident, competent and empowered. Let us explain briefly.

### **What is ENVISAGE?**

**ENVISAGE** stands for **ENabling VISIONs And Growing Expectations**. It involves five caregiver-friendly online workshops for parents/caregivers of young children new to the journey of parenting a child with a neurodisability. The workshops aim to provide early exposure to modern thinking about childhood disability. Our aim is to empower caregivers to take a strengths-based, 'developmental' approach to their child and family's situation.

### **The overall aims of ENVISAGE are to:**

- Enhance caregivers' understanding of their own capacities, competence and capabilities to parent their child with an early-onset neurodisability successfully and with confidence;
- Promote caregivers' understanding of their lived experience of family-centred service, strengths-based approaches and contemporary views of childhood disability; and
- Empower caregivers to be confident in decision-making regarding their child's development and the services they access.

### **What will I be asked to do?**

This research project invites your participation in several stages of the project, as outlined below. Further details of each stage are provided following this list:

**Stage One:** Complete a pre-workshop online questionnaires (approximately 1 hour)

**Stage Two:** Participate in a series of FIVE online workshops. Each workshop will take approximately 2 hours: approximately 60 minutes to review materials on your own time, plus a 60-minute discussion with other parents. Total time commitment for the workshops is approximately 10 hours over the 5-week duration.

**Stage Three:** Complete post-workshop online questionnaires immediately following completion of workshop series, then again at 3, 6 and 12 months after the workshops (45-60 mins each time)

**Stage Four:** If you agree: participate in an online interview approximately 3 months after the workshops and then again at 12 months. Each interview will take approximately 1 hour. THIS STAGE IS VOLUNTARY AND YOU DO NOT HAVE TO PARTICIPATE.

The project will be done entirely online. Participation in the interview will be voluntary and confidential.

**Who is funding the research project?**

This project is funded by The Canadian Institutes of Health Research. This project has received ethical approval from Hamilton Integrated Research Ethics Board (#5769) and Children's Health Queensland Human Resources Ethics Committee (#2019-18H) and is supported by *CanChild* Centre for Childhood Disability Research, and the Cerebral Palsy Support Network in Australia.

**You can access information about this study at:**

<https://www.canchild.ca/en/research-in-practice/current-studies/enabling-vision-and-growing-expectations>

**You can access the Participant Information Letter and Consent form at the following link:**

[https://www.canchild.ca/system/tenon/assets/attachments/000/002/893/original/ENVISAGE\\_McMaster\\_Letter.pdf](https://www.canchild.ca/system/tenon/assets/attachments/000/002/893/original/ENVISAGE_McMaster_Letter.pdf)

After consenting to participate, a member of our research team will provide access to the Envisage Program.

We are very interested to know what you think – so your advice is really valuable.

If you have any questions, please do not hesitate to contact:

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