

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

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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