



## ENVISAGE Participation Information Letter

<b>Project Title</b>	<b>ENabling VISion And Growing Expectations: Online Workshops, Surveys and Interview</b>
<b>HiREB Number</b>	#5769
<b>Local Principal Investigator</b>	Professor Peter Rosenbaum: <i>CanChild</i> , McMaster University
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<b>Co-Principal Investigator</b>	Dr. Laura Miller: Australian Catholic University
<b>Associate Investigators</b>	Professor Jenny Ziviani: Children's Health Queensland
	Professor Christine Imms: Australian Catholic University
	Dr. Andrea Cross: <i>CanChild</i> , McMaster University
	Dr. Kinga Pozniak: <i>CanChild</i> , McMaster University
	Ms. Rachel Martens: <i>CanChild</i> , McMaster University, Parent Researcher
	Ms. Monika Novak Pavlic: <i>CanChild</i> , McMaster University, PhD student
	Ms. Debbie Hughes: <i>CanChild</i> , McMaster University
	Ms. Vicki Cavalieros: Cerebral Palsy Support Network, Parent Researcher
	Ms. Abha Balram: Australia Catholic University
	MS. Alison Stokes: Australia Catholic University

Thank you for taking the time to read this Participant Information Statement and Consent Form. We would like to invite you to participate in a research project, explained below, that we think you might be very interested in.

IT IS OK TO SAY NO!

### What is an Information Statement?

These pages tell you about the research project. They explain to you clearly and openly all the steps and procedures of the project. The information is provided to help you decide whether you would like to take part in the research. Please read this Information Statement carefully.

Before you decide if you want to take part, you can ask us any questions you have about the project. You may want to talk about the project with your family, friends or health care

workers.

### **Important things to know**

It is your choice whether you take part in the research. You do not have to agree if you do not want to.

If you would like to take part in the research project, please select the "I agree" button at the end of this letter. By clicking "I agree" you are telling us that you:

- Understand what you have read
- Have had a chance to ask questions and received satisfactory answers
- Consent to taking part in the project

If you do not wish to participate select the "I do not agree" button and you will be exited from the screen.

### **1. What is the research project about?**

We wish to engage with parents who are raising children with developmental challenges. Our goals for this project are to empower parents and caregivers by sharing with them some of the new and different ways we are thinking and talking about childhood 'disability'. 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 competent and empowered.

### **What is ENVISAGE?**

ENVISAGE stands for "ENabling VISion 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, 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's the issue?**

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.

### **What's new?**

The field of childhood disability has changed a lot – and we strongly believe that these changes are for the better. ENVISAGE aims to share new ideas with parents and provide helpful information and support as they start on their journey as parents of a child with developmental challenges.

What are these ideas?

The five ENVISAGE online workshops will discuss:

1. The World Health Organization's way of thinking and talking about 'health', and how the 'F- Words in Childhood Disability' have taken these ideas to families.
2. The importance of development – of children and of families – as a key way to think about everything we all do in our work together with children with developmental challenges.
3. Parenting as "a dance led by the children", and how to dance when the partner doesn't know the steps.
4. Being kind to yourself and your family – because that's good for your kids and the important people in your life!
5. Focusing on Communication, Collaboration, Connection – strategies about how to belong to the community and be an effective advocate and connector to services.

### **2. Who is funding the research project?**

This project is funded by a grant from the Canadian Institutes of Health Research (CIHR).

### **3. Who is undertaking the project?**

Our ENVISAGE team is made up of Canadian and Australian parents, clinicians and childhood disability researchers. This project is being led by Professor Peter Rosenbaum at CanChild at McMaster University in Canada, and Dr. Laura Miller at Australian Catholic University in Brisbane. Professor Rosenbaum is the cofounder of CanChild Centre for Childhood Disability Research. He has more than 45 years of experience as a developmental paediatrician and health services researcher. His special interests include how services are offered to families of

kids with impairments, parent and family wellbeing, and how to focus on the 'positive'. Dr. Miller is an occupational therapist with 20 years of clinical experience in paediatric rehabilitation. She has extensive experience working with children with disabilities and their families. Her research interests focus on motivation and engagement, parent empowerment and enablement and models of service delivery. Associate investigators include Professor Christine Imms (ACU); Professor Jenny Ziviani (Children's Health Queensland); Dr. Andrea Cross (CanChild); Dr. Kinga Pozniak (CanChild); Ms. Vicki Cavalieros (Cerebral Palsy Support Network, Parent Researcher); Ms. Rachel Martens (CanChild, Family Engagement Facilitator, Parent Researcher); Ms. Monika Novak Pavlic, CanChild (doctoral student); Ms. Debra Khan (Children's Health Queensland); Ms. Grace Nickson (ACU Honours Student); Ms. Abha Balram (ACU).

#### **4. Who can participate in the project?**

We are asking parents raising a preschool child with a disability to participate in this research project. We would like to know if our five workshops improve outcomes for families new to the journey as parents of a child with developmental challenges and to ensure the workshops are useful for these families.

To be eligible for this study we have some specific criteria for participants:

- 1) caregivers of children with an early onset disability (that is, any disability that began in the preschool years and affects a child's functioning)
- (2) caregivers from Canada or Australia
- (3) your child with a disability is under 6 years of age

At this time, we discourage families from participating if they are currently going through the diagnostic processes and their child has not yet been formally identified as having a disability.

You can discuss these criteria with the research team if you have any questions:

Dr. Peter Rosenbaum: Phone: 905-525-9140/27834 Email: [rosenbau@mcmaster.ca](mailto:rosenbau@mcmaster.ca)  
Dr. Laura Miller Phone: 08 3623 7843 Email: [laura.miller@acu.edu.au](mailto:laura.miller@acu.edu.au)

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

This research project involves your participation in several stages outlined below, and further details of each stage are provided following this list:

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

**Stage Two:** Participate in a series of FIVE online workshops. Each workshop will take about 2 hours: approximately 60 minutes to review materials on your own time, plus a 60-minute online discussion. 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 post workshops (45-60) mins each time point)

**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.

**Total** time commitment for this study is approximately 15 hours (plus 2 more hours if you agree to be interviewed post intervention)

**Here are some details:**

**Stage One: Completion of pre-workshop online questionnaires**

In this first stage, you will be allocated a unique code that is specific to your information and responses. This code enables us to remove your name and personal details from your data. You will be asked to provide some information about your child and family (e.g. your child's age, child's diagnosis, etc.). You will also be asked to complete several online questionnaires which we call 'baseline' measures. These have been chosen to help us work out if the five workshops are effective in improving outcomes for families. To help us do this we will ask you to complete these questionnaires again later (in stage three).

The online questionnaires include the following measures, and will take you approximately 1 hour to complete. There are no right or wrong answers!

- a. Demographic Questionnaire: General information about your child and your family.
- b. About My Child: Seeks to understand the functional needs of children and priorities of their families.
- c. Family Empowerment Scale: Measures parents' sense of empowerment in families of children with disabilities
- d. Family Hardiness Index: Explores patterns of family functioning
- e. PROMIS: Global Health Scale: Assesses general domains of health and functioning.
- f. Measure of Processes of Care: Evaluates parents' perceptions of the family-centredness of their services

**Stage Two: Engagement in a series of five online workshops – Online Resources and Online Discussion**

During this stage, you will be asked to take part in five ENVISAGE workshops, which will be available to you online using a password. These workshops will include resources for you to save and download if you wish. The resources are videos, written materials, activities and presentations for you to do and watch. We anticipate it will take you approximately 60 mins to review the resources for each workshop. You can do this at times that are convenient to you in the week before the online workshop discussion. The online workshop discussion will be approximately 60 mins in duration and will be held using ZOOM – an online videoconferencing service. We will provide you with technical support to access the workshop resources and Zoom if you require this support or assistance. The online workshop discussion will be held with up to 10 other parents who are participating in the research project. These discussions will be facilitated by two or more members of the ENVISAGE research team and will include a parent

collaborator. The purpose of these discussions is to explore the workshops in more detail and answer questions you may have about the workshop resources and materials. We will always encourage questions and ideas from you!

These online discussions will be recorded, as will any text in the 'chat' boxes and discussion board.

Before each workshop we will ask you to identify what you hope to gain from attending the workshop. Following each workshop, we will ask you what you found useful in the workshop and what you would like included or excluded in future workshops. These questions will be answered online and will help us to refine workshop content for other families, based on your feedback.

### **Stage Three: Completion of post-workshop online questionnaires**

As outlined in Stage One, you will be asked to complete the online questionnaires again immediately following the completion of the workshop series, and then again at 3 months after the start of the workshops, 6 months after the start of the workshops, and 12 months after the start of the workshops. This allows us to explore possible later effects of the workshops.

### **Stage Four: Online interviews (optional extra)**

Within 3 months following the completion of the workshops you will be asked if you wish to participate in an interview for approximately 60 minutes to discuss your ENVISAGE experiences in more detail. Interviews will be online using ZOOM videoconferencing. We will then invite you for another interview at 12 months. **You do not have to participate in an interview if you do not wish to, and you can still participate in the previous stages of the project (the workshops) even if you do not do the interview.** You will be asked about your interest to participate in an interview at the end of this letter, and then again at completion of the workshop series. It is OK if you change your mind.

The project will be entirely online. Participation in the questionnaires, workshops and interview is voluntary and all information will be confidential and never revealed outside the study.

Since this is a joint study between Canada and Australia, the information you provide will be analysed in both countries. Anonymized data will be shared using the confidential and secure online platform called CloudStor. This platform is approved by Australian universities for storing and sharing confidential data.

The research team listed on this application will have access to the information described above. In addition, information technology support services for REDCap and Moodle will have access to data since these are information gathering services. These staff are employees of ACU

and McMaster and are bound by research integrity, ethical codes of conduct and confidentiality requirements of the universities.

## **6. What if I wish to withdraw from the research project?**

If you decide to participate, you are free to withdraw your consent and to discontinue your participation at any time. No one outside the research team will know you have withdrawn. The decision to withdraw from the study will not affect your child's medical or health treatment, or their relationship with the people treating them.

When you finish the questionnaires, you will be asked again whether you want to submit your responses. At that time, you can choose to submit your response or you can exit and not submit your data. You can choose to withdraw your data up to the point that we begin our data analysis. Once we have begun analysing our data we will not be able to remove your data/information/responses, as it will be combined with other participants' data, and all will then be anonymized.

## **7. What are the possible benefits for my child and other people in the future?**

There are no direct benefits to you from participating in this study. You will be contributing to the small body of research on interventions that aim to support parents and families of children with an early onset neurodisability. You may hopefully find the information presented helpful to you and your family. Findings from this study will assist us to know how best to empower and enable families new to the journey of parenting a child with a disability. The perspectives of people like you may be very useful to future families.

## **8. What are the possible risks, side-effects, discomforts and/or inconveniences?**

Participation involves time and effort, with participation in 5 online workshops, reviewing related materials, completing surveys, and participating in an online interview. Most people find these tasks interesting, however there is the possible inconvenience of a time commitment and effort required in doing these tasks.

Additionally, some of the issues raised during the workshops may be distressing as we will be asking you to reflect on your own journey in childhood disability and your experiences with health professionals and service providers. We will do everything we can to ensure that being involved is a positive experience for you. We will help you find support if the workshops, surveys or interviews make you feel distressed, upset or uncomfortable.

Participating in all parts of this study is optional and you may withdraw at any time. If you feel any level of distress as a result of this, please feel free to contact the primary investigators.

Canadian families can contact:

Dr. Peter Rosenbaum, 905-525-9140 ext 27834.

## **9. What will be done to make sure my information is confidential?**

### ***Online Questionnaires:***

You will be asked to complete questionnaires before starting the workshops and after you complete the final workshop. You will be asked to provide your name and email address to receive the link for the online workshops. This information and any other identifying information will be collected and stored separately, away from your questionnaire answers. Your questionnaires will be given a unique identifying code so your responses are not stored with any personal identifying information.

### ***Workshops and Discussion:***

All information shared by participants in the workshops is confidential. Participants will be asked to agree to a workshop charter at the beginning of the online workshops discussions to ensure confidentiality, and that people follow group rules (such as listening to all participants, respecting participants' confidences). As it is an online workshop you may choose to use a pseudonym rather than disclosing your name. The written 'discussion board' and online 'chat' that workshop members may participate in during the discussion will be saved. The workshops will be audio and video recorded and transcribed so the researchers have a copy of what people say. The recordings, transcriptions and written discussion board will only be available to the research team. What you tell the research team will remain confidential. Nothing that you say or write will be shared or reported in a way that will identify you, except as required by law.

### ***Interview:***

All information shared by participants in the interview is confidential. The interview will be videotaped and audio recorded and transcribed, so the researchers have a copy of what people say. The recordings and transcriptions will only be available to the research team. What you tell the research team will remain confidential. Nothing that you say will be shared or reported in a way that will identify you, except as required by law. You will be provided a copy of your interview transcript following the interview and you can choose to edit or take out any information that you do not wanted included in the analysis.

Please note that, as with any research study, research data may be accessed by auditors, ethics committee or regulatory authorities as part of research compliance. All data collected will be stored in a de-identified format. Email addresses remain identifiable; however, these will be stored separately from any data collected as part of the research project. All data will be stored on a secure, password-protected computer and de-identified data will be shared using the secure platform Cloudstor.

Research data gathered from the study may be published in peer-reviewed journals or



presented at conferences. However, no identifying data are used and only summary information will be published. Your individual responses and personal information will remain confidential.

**10. Will I be able to find out the results of the project?**

We will send every participant in the study a plain-language report of what we learn in this research project.

**11. Whom should I contact for more information?**

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

CANADA

Name: Peter Rosenbaum  
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Name: Debbie Hughes  
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AUSTRALIA

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This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB) and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

Office of the Chair of HiREB  
Telephone: (905) 521-2100 ext. 42013