**PARTICIPANT INFORMATION STATEMENT**

*The Perspective and Experiences of Families Raising a Child with a Neurodevelopmental Disorder*

Student Investigator: Rebecca Bobin (Master of Clinical Psychology, Australian Catholic University, email: rebecca.bobin@myacu.edu.au)

Staff Supervisor: David Hamilton (Deputy Head of School of Psychology Melbourne, Australian Catholic University, email: david.hamilton@acu.edu.au)

This project investigates the broader contributions of individuals with Williams syndrome (WS), and other neurodevelopmental disorders (NDDs), to family life and society. We are seeking individuals to participate and have outlined to specific inclusion criteria below.

**What are the aims of the study?**

The aim of the current study is to elucidate the perspective and experience of family members of persons with a NDD. To this end, the study aims to explore what opportunities and rewards (personal growth, resilience, appreciation, support) are experienced by having a family member with a NDD and what impact having a family member with a NDD had on the lives of family members (positive and negative).

Participants are encouraged to share perspectives, stories, and anecdotes. Broad questions may include: What is important to you as a family? What things or issues are you most concerned about? What sorts of things do you celebrate? Have your family values, priorities or worldviews changed over time?

**Who is conducting this study?**

This study is being conducted by Dr David Hamilton and Rebecca Bobin (Master of Clinical Psychology Student). We have listed our contact details above.

**Who is funding this study?**

We are conducting this study independently, independent of external funding, and we are free to report the results of this study accurately and without restriction.

**What does this study involve?**

Participation involves completion of an online questionnaire which requires approximately 30 minutes.

**Who is eligible to participate?**

Parents, siblings, and grandparents (of individuals with a NDD aged 8-20) are invited to participate.

**How will the information be used?**

We will analyse the questionnaire responses and the results will form part of a Master’s thesis. The results may be published in a journal article.

**How will my identity be protected?**

Questionnaire responses will be stored on a password protected server and will not be identifiable. Paper copies of signed consent forms will be kept for 5 years, as required by law, and will be appropriately disposed after that.

**Will I receive any benefits for participating in the study?**

The findings of the current study can be used to inform practitioners about the nature of potential positive experiences that can be shared with families starting out on their journey, allowing families to recognise the positive dimensions of raising a child with a NDD in addition to the hardships.

**Are there any risks associated with participating in the study?**

There is minimal risk involved in participating in this study.

**What are your rights?**

Participation in this study is completely voluntary. You have the right to withdraw from active participation in this project at any time and, further, to demand that data arising from your participation are not used in the research project provided that this right is exercised within four weeks of the completion of your participation in the project. To do this, you may complete the “Withdrawal of Consent Form” or to notify the investigator by e-mail or telephone that you wish to withdraw your consent for your data to be used in this research project. There are no disadvantages, penalties, or adverse consequences for not participating or for withdrawing prematurely from the project.

**How do you ask a question about this study or make a complaint?**

If you have any comments or concerns regarding this project, please contact the project supervisor (Dr David Hamilton). If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Senior Human Ethics Officer, Ethics and Integrity, Research Office, Australian Catholic University, (P: 02 9739 2646, E: res.ethics@acu.edu.au). Please quote the application reference number 2016-289H.