

Plain Language Statement

Human Research Ethics Approval No. 1238564

Invitation to take part in an online survey as part of a research project:



The experiences and views of parents of a child with dyslexia in Victoria

Purpose of this Project

This project aims to explore the experiences of Victorian parents of children with dyslexia. There is very little known about the experiences of parents of children with dyslexia in Victoria. The researcher would like to hear the voices of parents to help shed light on this important subject and share this information with other researchers, support agencies, parents, and policy makers.

Invitation to participate in the project

Parents or carers of a child aged between 7 and 18 with a child who has been diagnosed as having dyslexia are invited to participate. The research will be conducted via an online survey which will explore parent's experience of:

- the process of discovering that their child is effected by dyslexia
- gaining a formal diagnosis of dyslexia
- finding information, support and resources to assist their child and themselves
- responses to their child's dyslexia
- key challenges they face in supporting their child

In addition, the research will seek parents' ideas regarding current policy and ideal policy in this field.

Before reading the detailed information below, please ensure you are eligible to participate:

- You must be a parent or carer of a child currently aged between 7 and 18 who has a formal single diagnosis of dyslexia from a practitioner qualified to confirm this diagnosis. Please note that a "single diagnosis" of dyslexia means that the child does not have other conditions which could potentially impact on their ability to read, spell and write, such as attention deficit disorder or acquired brain injury.
- You must be currently living in Victoria and also have lived here at the time of the child's diagnosis.

Who is conducting the research?

Katherine Levi is a PhD student at the School of Social Work, in the Faculty of Health Sciences at The University of Melbourne. She is also the parent of a child with dyslexia. Katherine is conducting this research as part of her doctoral thesis. The research is being supervised by Professor Cathy Humphries (Department of Social Work), Dr Nola Firth (Honorary Research Fellow, Melbourne Graduate School of Education and the Murdoch Childrens Research Institute) and Dr David Rose (Department of Social Work).

Why participate in this research?

To date little research has been conducted focussing on the experience of Victorian parents whose children have dyslexia.

There is growing interest from the government in relation to support for dyslexia. We would like to gain a broad snapshot of the experiences and insights of parents' of children with dyslexia and contribute to this discussion.

What are the benefits of participating in this research?

Being a parent with a child who has dyslexia can be challenging. Some participants may find a benefit in having an opportunity to discuss their experiences and feelings. Some participants may also feel positive about the possibility of having their voices heard by policy makers and by other researchers in the field. However, the researcher acknowledges that there may be no direct benefits to participants. The completed thesis will be available for review and an electronic copy of it can be sent to participants if desired.

What will I be asked to do if I become a participant in this research?

If you voluntarily agree to take part in this research you will be asked to read the terms of consent and indicate your consent electronically. The survey should take you approximately 30 to 40 minutes to complete.

The survey will ask questions such as:

- Basic information about you such as age in years, educational level, occupation, marital status, number of children, household income, country of birth and the language you speak at home.
- Background information about your child with dyslexia such as age, gender, age of diagnosis, the type of school they attend.
- Questions about your experience as a parent of a child with dyslexia such as how you have gathered information about dyslexia, from whom you have sought help and advice, resources you have accessed, the response of your child's school to dyslexia, positive experiences, challenges and hopes and fears for your child's future.
- Questions about costs associated with having a child with dyslexia.
- Reflections on what sort of policy in relation to dyslexia you would like to see in the future.
- You will also be given an opportunity to raise any issues you feel are important.

What will the survey information be used for?

The information you provide in the survey will be analysed for themes and statistical data along with all the other survey responses. Individual quotes may be used from your surveys to highlight points in the final report. Please be assured that the research team has no way of identifying you personally and quotes will not be attributed and information you provide cannot be linked to you personally.

The completed research will be submitted for a PhD degree. There may also be articles published and talks given at conferences about the findings from this research.

Will the information I provide remain confidential?

Yes. Your personal information will remain entirely confidential at all times and your answers will remain anonymous. You will not be asked to provide any information that will identify you. Your complete (or incomplete) survey will not be traced to you. The completed survey will be stored securely in a locked filing cabinet and in a secure, password protected computer.

As required by The University of Melbourne regulations this information will be retained for a period of 5 years from when the reports on the research are published.

Do I have to take part in this research?

Your participation in this research is completely voluntary. You can withdraw your consent at any time up until you submit the completed survey online. Once submitted as it cannot be traced to you, it cannot be withdrawn.

Are there any risks to me for taking part in this research?

It is highly unlikely that there is any risk to you in taking part in this research. It is possible that thinking about this topic may cause you some discomfort or mixed feelings by revisiting past negative experiences or fears about your child's well-being.

If you feel at all uncomfortable or concerned following the survey you are welcome to contact the researcher and set up a time for a meeting or have a discussion by phone or Skype. Additionally or alternatively you could contact SPELD VIC who are supportive of this research and employ people skilled at providing information and support regarding dyslexia. If this survey raises difficult material, you may wish to contact Professor Cathy Humphreys for advice and support. (Contact details for these supports are provided at the end of the online survey).

Where can I find the results of the research?

The results of this research will be available in late 2014. A summary of the project will be linked to The Melbourne University Department of Social Work website as well as SPELD VIC's website.

Who can I contact if I have concerns about the research or require further information?

If you have any concerns about the research or would like more information you can contact the researcher or members of the supervisory team at The University of Melbourne as follows:

Katherine Levi: Katherinelevi@optusnet.com.au

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If you have any concerns about the conduct of the research you can also contact:

The Executive Officer

Human Research Ethics

The University of Melbourne

Phone: 83442071

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