

**PEOPLE WITH DYSLEXIA IN WINNIPEG:
EXPERIENCES AS CHILDREN AND ADULTS**

BY

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A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES OF THE
UNIVERSITY OF MANITOBA

IN PARTIAL FULFILMENT OF THE REQUIREMENTS OF THE DEGREE OF
MASTER OF ARTS

DEPARTMENT OF DISABILITY STUDIES

UNIVERSITY OF MANITOBA

Winnipeg

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Abstract

Most studies on dyslexia have been conducted by individuals who are not dyslexic. This research study identifies and reflects on the experiences of adults with dyslexia “through the eyes of a dyslexic.” This study concentrates on emotional and psychological outcomes experienced by adults with dyslexia as they navigate adulthood as dyslexics, as well as coping strategies they employed, both in their everyday life as well as the work-place. This study utilized qualitative research methods. Six participants (3 males and 3 females) between the ages of 21 years to 55 years, who were assessed with dyslexia, participated in this study. Qualitative data was analysed using NVivo data analysis software. By including findings of this study in a Powerpoint/video format, adults with dyslexia are more able to access and engage with this research.

This study addresses the gaps in the literature by exploring the experiences of adults with dyslexia and their challenges. Results of this study indicates that the emotional experiences of adults with dyslexia were negative. Findings show that adults with dyslexia struggled with the formal education system, as children and as adults. Some participants felt embarrassed being an adult with dyslexia while others felt they had a close-knit of friends to rely on at the workplace. The results of this study show that adults with dyslexia struggled with the formal education system, as children and as adults. The study also illustrates the coping strategies employed by adults with dyslexia.

Acknowledgements

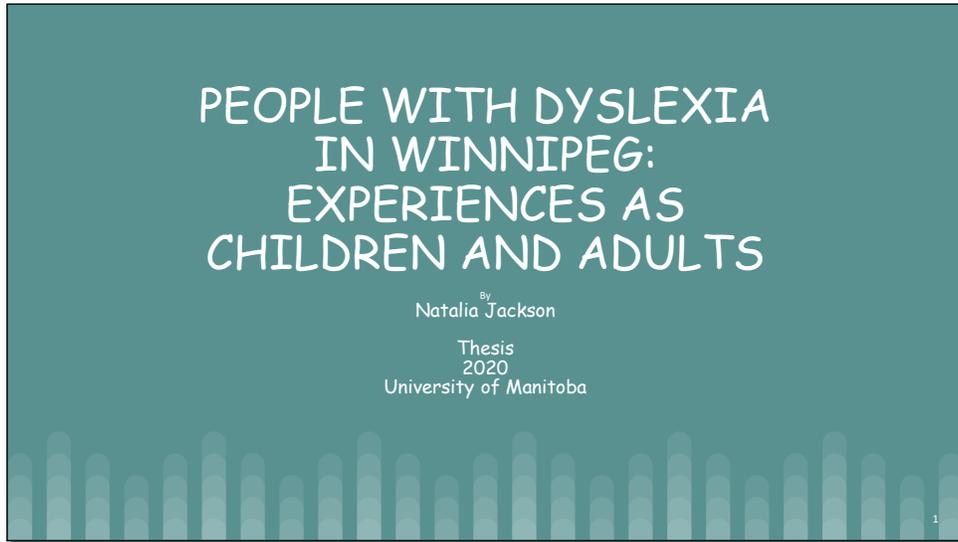
- My advisor: Professor Deborah Stienstra
- My committee members:
 - Professor Rick Baydack
 - Professor Diane Driedger
- Participants: Issac Friesan, Tess Dzogan, Jennifer Cloutier, Heather Greidanus and those who wished to remain anonymous
- Video editor & interviewer of Reflection piece: Teddy Zegeye-Gebrehiwot
- Research assistant: Banke Oketola
- Tutor
- My first born for giving me time to work on this.
- My family both in Trinidad & Canada
- My friends both in Trinidad & Canada

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PowerPoint Presentation

Slide 1

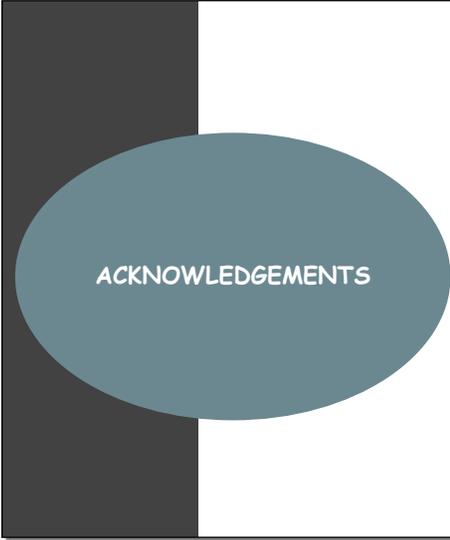


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By
Natalia Jackson

Thesis
2020
University of Manitoba

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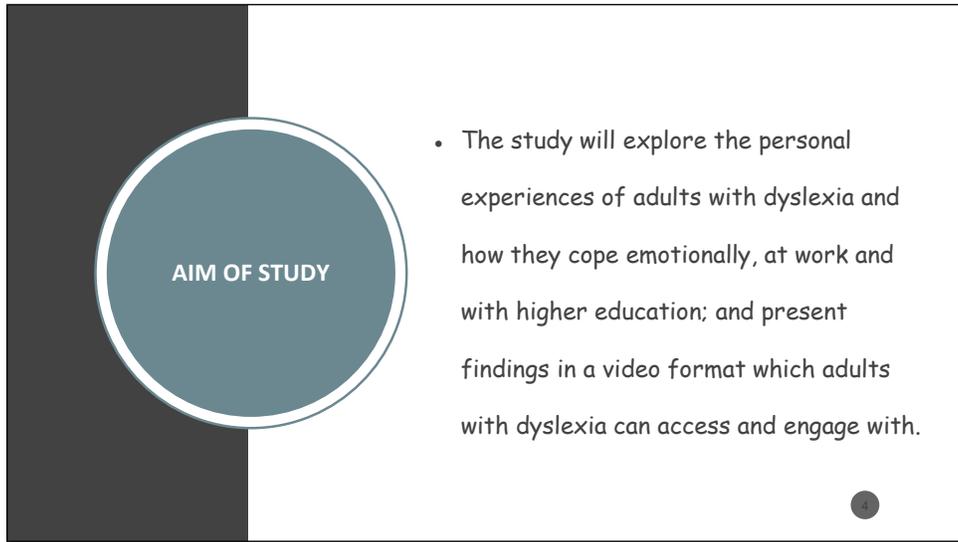
ACKNOWLEDGEMENTS

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AIM OF STUDY

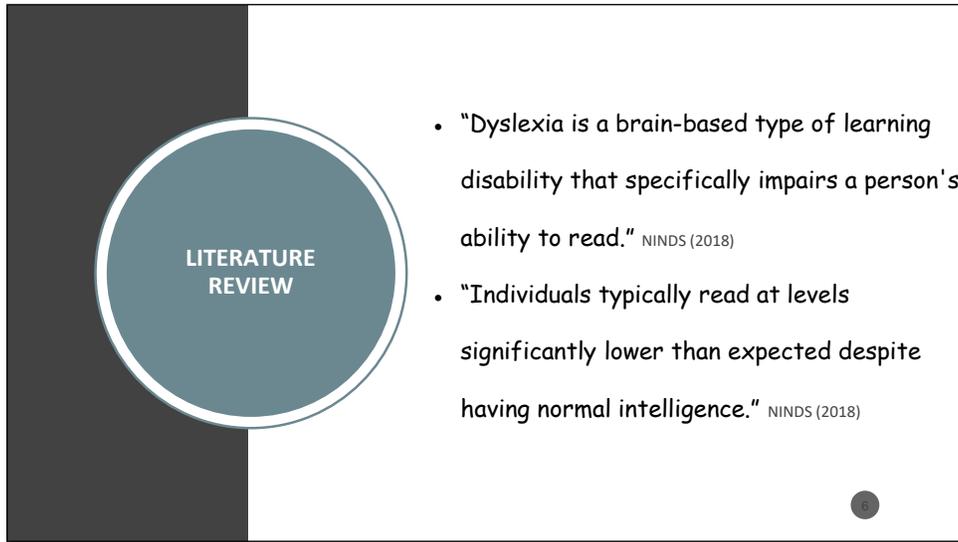
- The study will explore the personal experiences of adults with dyslexia and how they cope emotionally, at work and with higher education; and present findings in a video format which adults with dyslexia can access and engage with.

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RESEARCH QUESTIONS

1. What are the emotional & social experiences of adults living with dyslexia in Winnipeg, Manitoba?
2. What are the strategies adults with dyslexia utilize to navigate daily living in Manitoba, Canada?
3. What resources are currently available for adults living with dyslexia in Manitoba, Canada past and/or present?

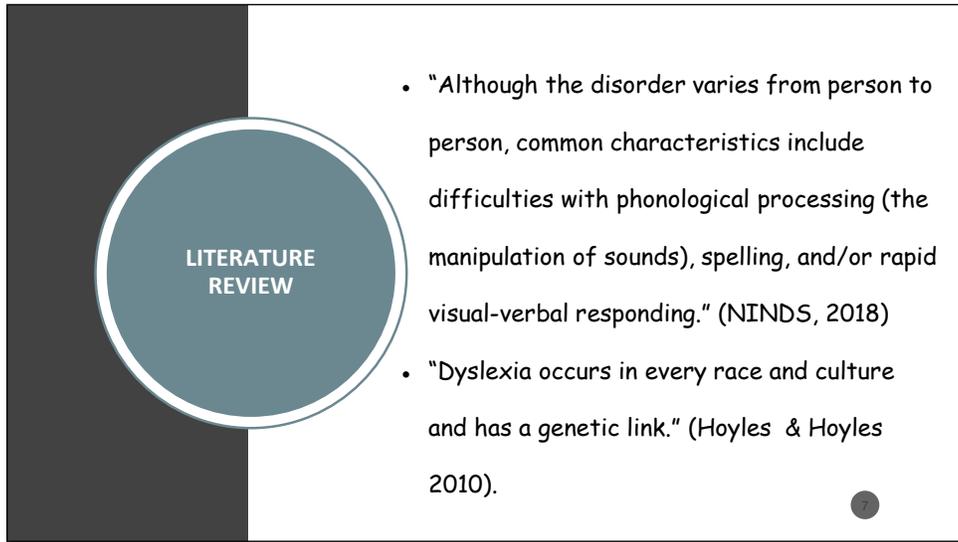
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LITERATURE
REVIEW

- "Dyslexia is a brain-based type of learning disability that specifically impairs a person's ability to read." NINDS (2018)
- "Individuals typically read at levels significantly lower than expected despite having normal intelligence." NINDS (2018)

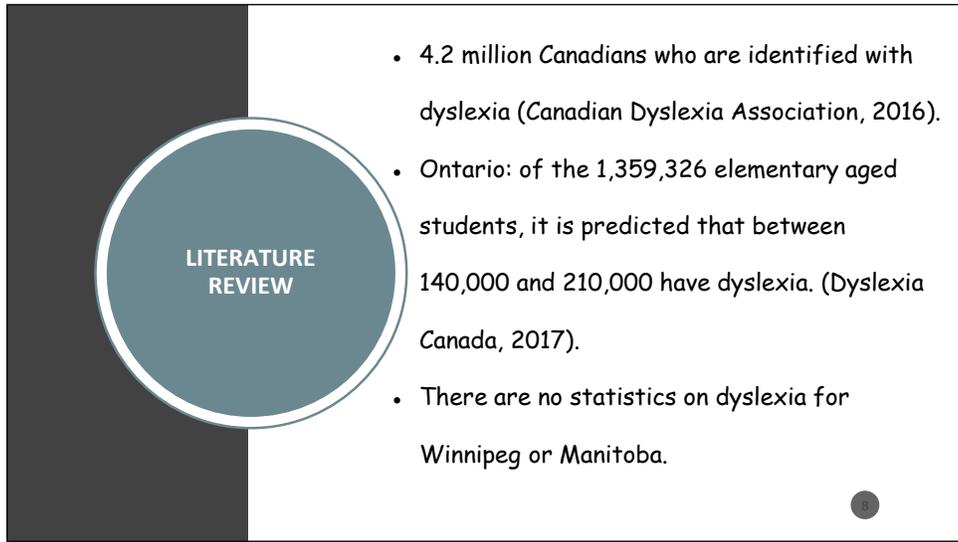
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LITERATURE
REVIEW

- "Although the disorder varies from person to person, common characteristics include difficulties with phonological processing (the manipulation of sounds), spelling, and/or rapid visual-verbal responding." (NINDS, 2018)
- "Dyslexia occurs in every race and culture and has a genetic link." (Hoyles & Hoyles 2010).

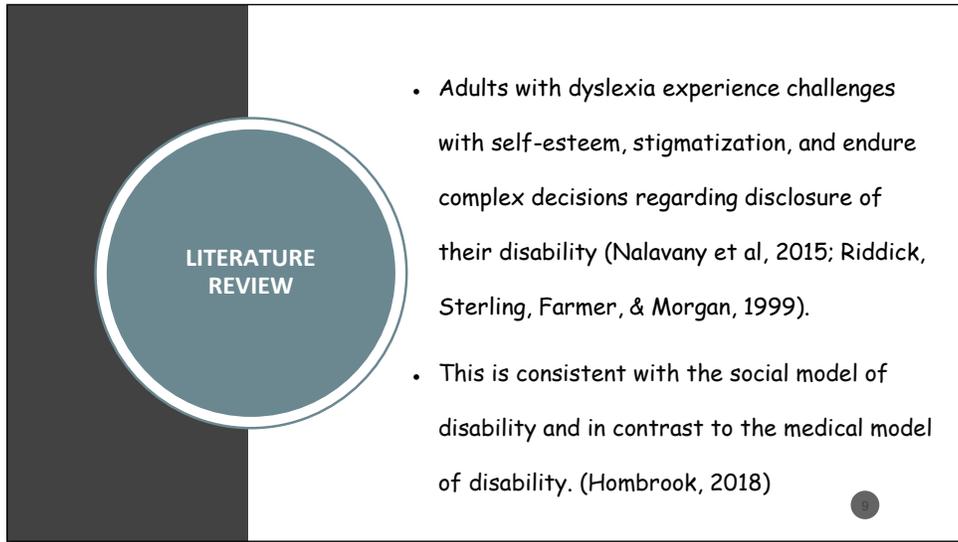
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LITERATURE
REVIEW

- 4.2 million Canadians who are identified with dyslexia (Canadian Dyslexia Association, 2016).
- Ontario: of the 1,359,326 elementary aged students, it is predicted that between 140,000 and 210,000 have dyslexia. (Dyslexia Canada, 2017).
- There are no statistics on dyslexia for Winnipeg or Manitoba.

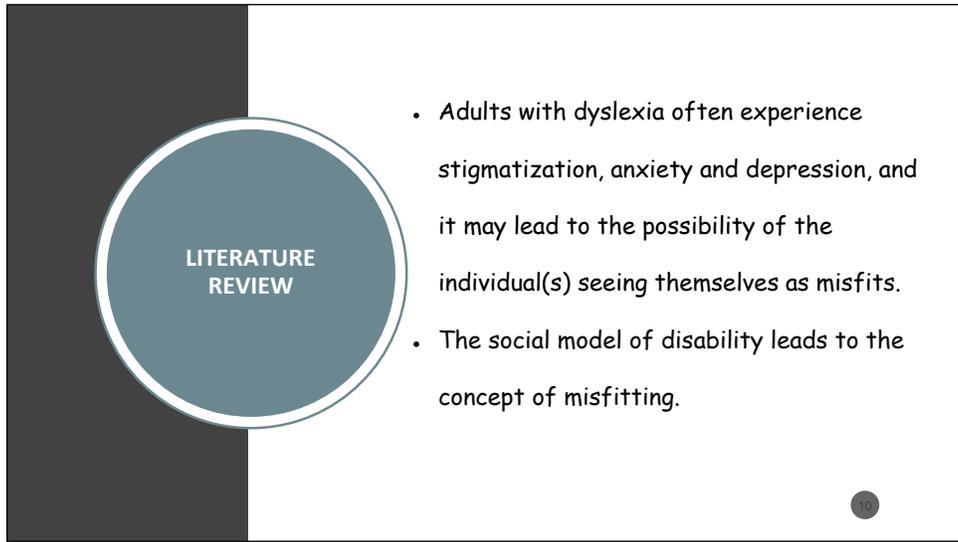
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LITERATURE
REVIEW

- Adults with dyslexia experience challenges with self-esteem, stigmatization, and endure complex decisions regarding disclosure of their disability (Nalavany et al, 2015; Riddick, Sterling, Farmer, & Morgan, 1999).
- This is consistent with the social model of disability and in contrast to the medical model of disability. (Hombrook, 2018)

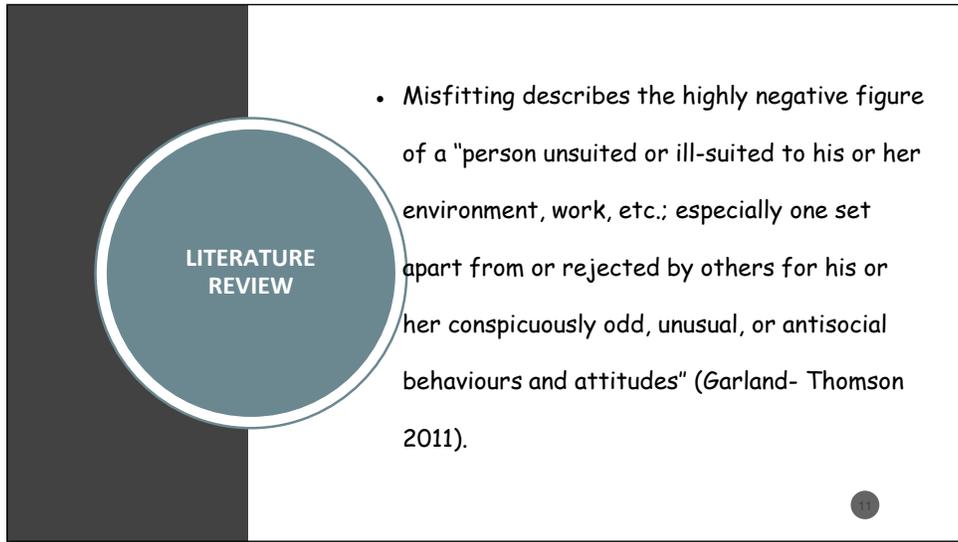
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LITERATURE
REVIEW

- Adults with dyslexia often experience stigmatization, anxiety and depression, and it may lead to the possibility of the individual(s) seeing themselves as misfits.
- The social model of disability leads to the concept of misfitting.

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LITERATURE
REVIEW

- *Misfitting* describes the highly negative figure of a "person unsuited or ill-suited to his or her environment, work, etc.; especially one set apart from or rejected by others for his or her conspicuously odd, unusual, or antisocial behaviours and attitudes" (Garland- Thomson 2011).

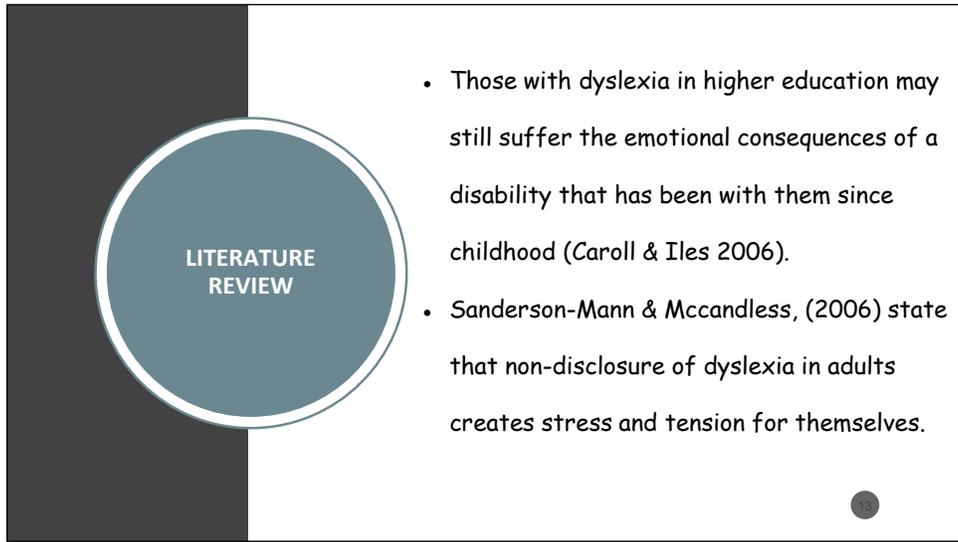
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LITERATURE
REVIEW

- Adults with dyslexia often have to extend more effort for sometimes basic tasks, and are easily intimidated by successful persons. (Reid and Kirk 2001).
- Morris & Turnbull (2006) explain that dyslexia continues to attract an unwarranted stigma in adulthood and can adversely affect the learning experience in higher education.

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LITERATURE
REVIEW

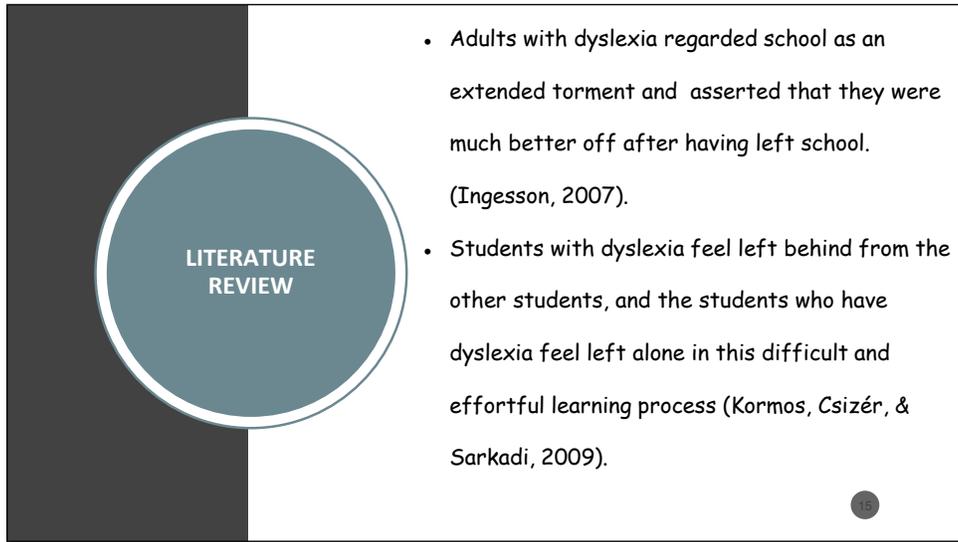
- Those with dyslexia in higher education may still suffer the emotional consequences of a disability that has been with them since childhood (Carroll & Iles 2006).
- Sanderson-Mann & Mccandless, (2006) state that non-disclosure of dyslexia in adults creates stress and tension for themselves.

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LITERATURE
REVIEW

- They further concede that some adults who are dyslexic may feel that being labeled as dyslexic means that others are making assumptions about what they can or cannot do, often to their detriment.

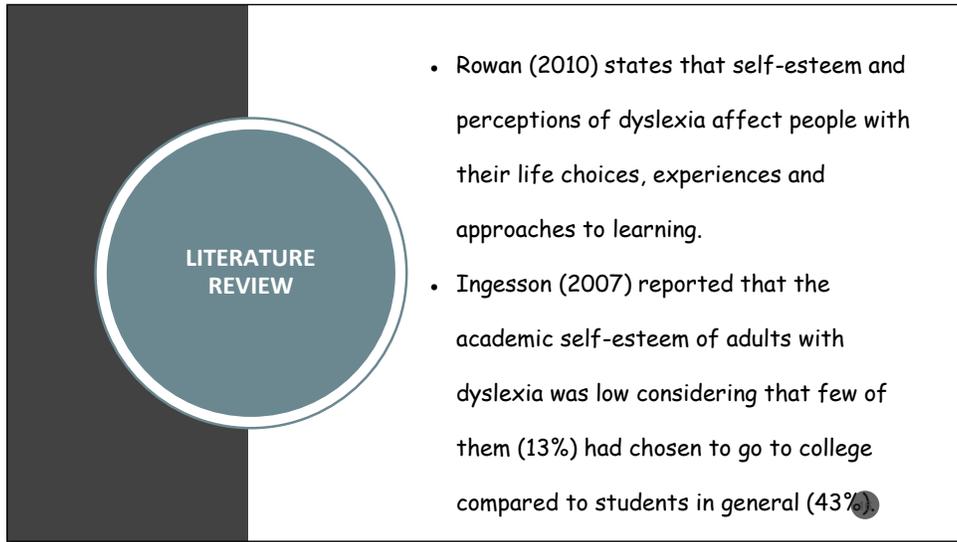
14



LITERATURE
REVIEW

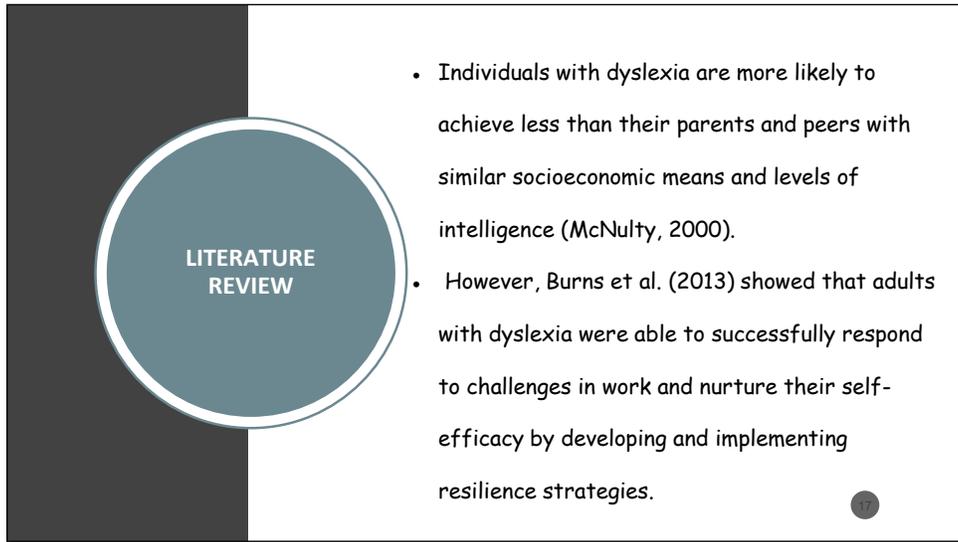
- Adults with dyslexia regarded school as an extended torment and asserted that they were much better off after having left school. (Ingesson, 2007).
- Students with dyslexia feel left behind from the other students, and the students who have dyslexia feel left alone in this difficult and effortful learning process (Kormos, Csizér, & Sarkadi, 2009).

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LITERATURE
REVIEW

- Rowan (2010) states that self-esteem and perceptions of dyslexia affect people with their life choices, experiences and approaches to learning.
- Ingesson (2007) reported that the academic self-esteem of adults with dyslexia was low considering that few of them (13%) had chosen to go to college compared to students in general (43%).



LITERATURE REVIEW

- Individuals with dyslexia are more likely to achieve less than their parents and peers with similar socioeconomic means and levels of intelligence (McNulty, 2000).
- However, Burns et al. (2013) showed that adults with dyslexia were able to successfully respond to challenges in work and nurture their self-efficacy by developing and implementing resilience strategies.

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The slide features a dark grey vertical bar on the left side. A teal circle with a white border is positioned on the bar, containing the text 'RESEARCH METHODS' in white, uppercase letters. To the right of the bar, a bulleted list describes the research methodology. A small teal circle with the number '18' is located in the bottom right corner of the slide content area.

RESEARCH METHODS

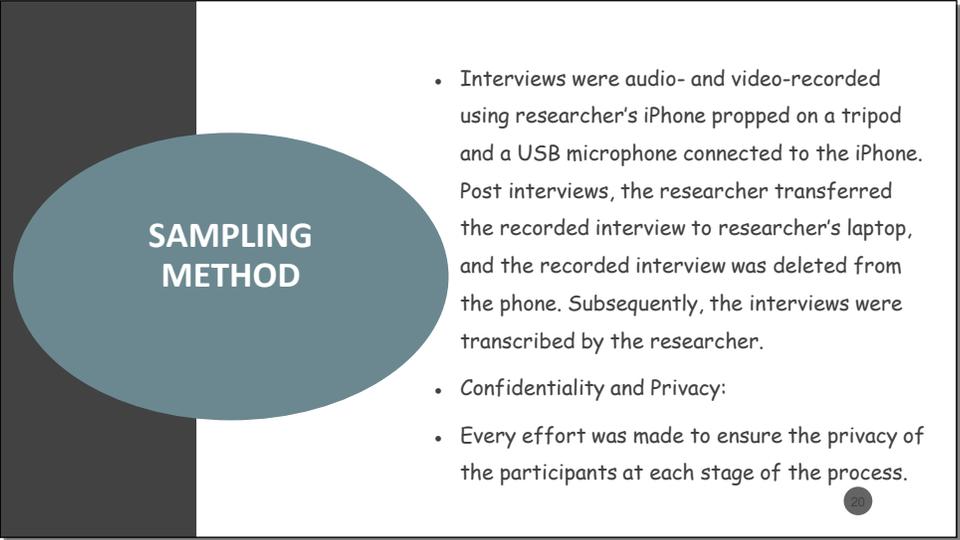
- Data was obtained by interviewing adults with dyslexia in Winnipeg, Manitoba, in both personal and social settings in order to examine their coping strategies, social and emotional experiences, and discern the current resources available in Winnipeg for adults with dyslexia.

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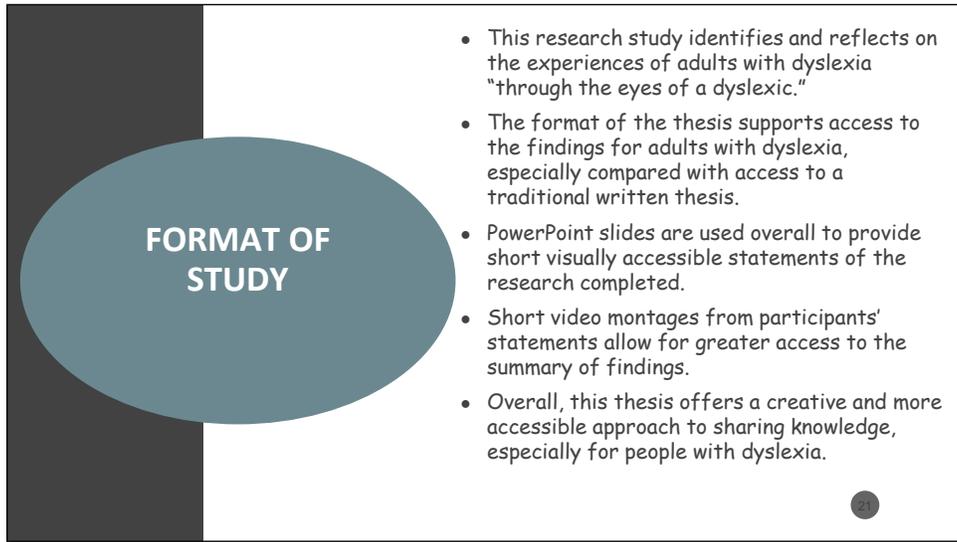
**RECRUITMENT
CRITERIA**

- Participants were persons of either gender, 21 years and older, who identify themselves as living with dyslexia and live within 200 km of Winnipeg, Manitoba. They were selected using the snowball method.



SAMPLING METHOD

- Interviews were audio- and video-recorded using researcher's iPhone propped on a tripod and a USB microphone connected to the iPhone. Post interviews, the researcher transferred the recorded interview to researcher's laptop, and the recorded interview was deleted from the phone. Subsequently, the interviews were transcribed by the researcher.
- Confidentiality and Privacy:
- Every effort was made to ensure the privacy of the participants at each stage of the process.



FORMAT OF STUDY

- This research study identifies and reflects on the experiences of adults with dyslexia "through the eyes of a dyslexic."
- The format of the thesis supports access to the findings for adults with dyslexia, especially compared with access to a traditional written thesis.
- PowerPoint slides are used overall to provide short visually accessible statements of the research completed.
- Short video montages from participants' statements allow for greater access to the summary of findings.
- Overall, this thesis offers a creative and more accessible approach to sharing knowledge, especially for people with dyslexia.

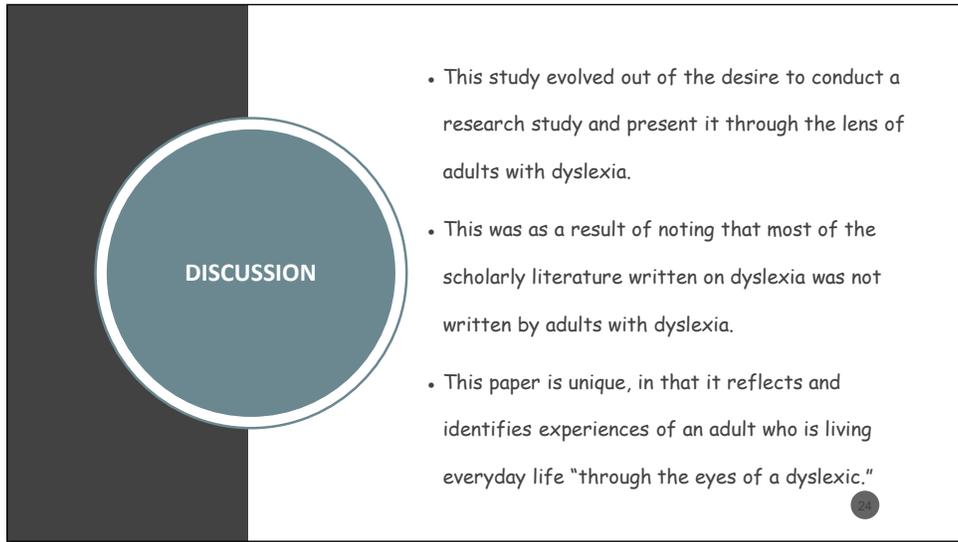
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RESULTS OF STUDY

- <https://vimeo.com/398413495/7223a6a4e5>

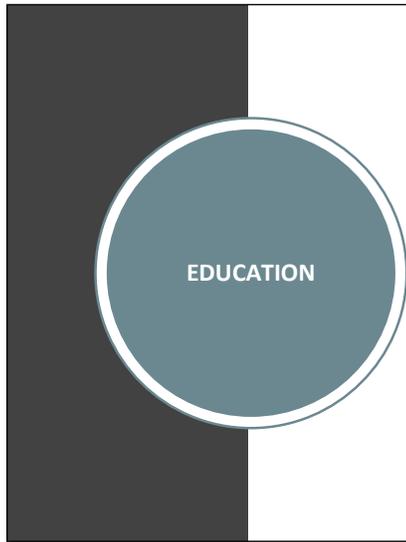
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DISCUSSION

- This study evolved out of the desire to conduct a research study and present it through the lens of adults with dyslexia.
- This was as a result of noting that most of the scholarly literature written on dyslexia was not written by adults with dyslexia.
- This paper is unique, in that it reflects and identifies experiences of an adult who is living everyday life "through the eyes of a dyslexic."

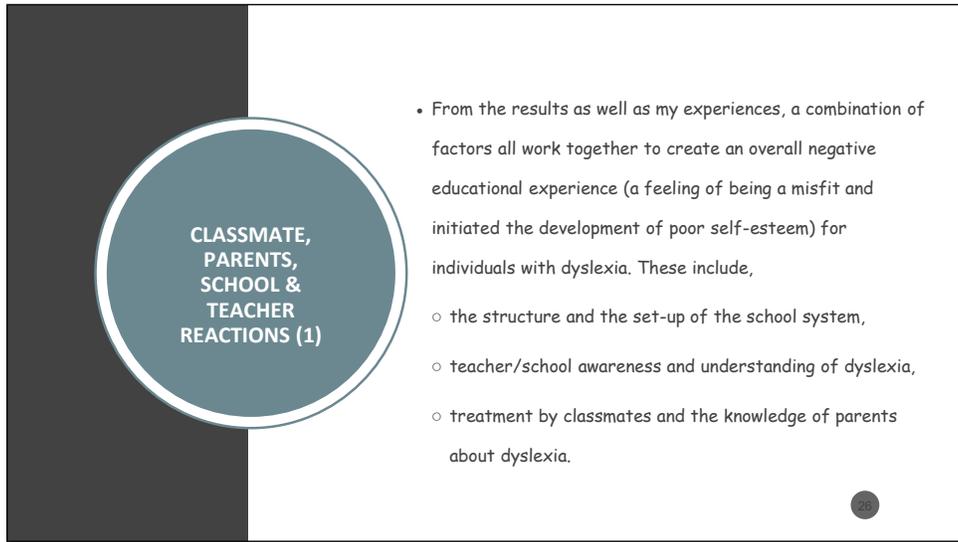
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EDUCATION

- The results of this study show that adults with dyslexia struggled with the formal education system, as children and as adults.
- Adults with dyslexia are generally not successful in academic achievement. (Collison & Penketh, 2010; Ingesson, 2007; Hoyles & Hoyles 2010; Kormos, Csizér, & Sarkadi, 2009).
- However, I agree with the findings of Reilley (n.d), in that once dyslexia is recognized and individuals received guidance, modifications and remedial help they became more proficient and were successful academically.
- This was my experience as an undergraduate.

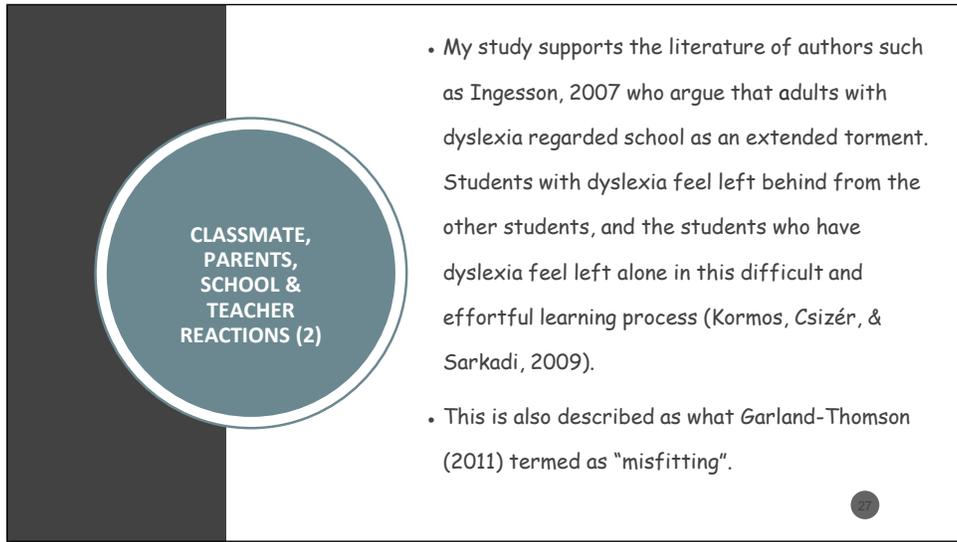




CLASSMATE,
PARENTS,
SCHOOL &
TEACHER
REACTIONS (1)

- From the results as well as my experiences, a combination of factors all work together to create an overall negative educational experience (a feeling of being a misfit and initiated the development of poor self-esteem) for individuals with dyslexia. These include,
 - the structure and the set-up of the school system,
 - teacher/school awareness and understanding of dyslexia,
 - treatment by classmates and the knowledge of parents about dyslexia.

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CLASSMATE,
PARENTS,
SCHOOL &
TEACHER
REACTIONS (2)

- My study supports the literature of authors such as Ingesson, 2007 who argue that adults with dyslexia regarded school as an extended torment. Students with dyslexia feel left behind from the other students, and the students who have dyslexia feel left alone in this difficult and effortful learning process (Kormos, Csizér, & Sarkadi, 2009).
- This is also described as what Garland-Thomson (2011) termed as "misfitting".

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EMOTIONAL EXPERIENCES (1)

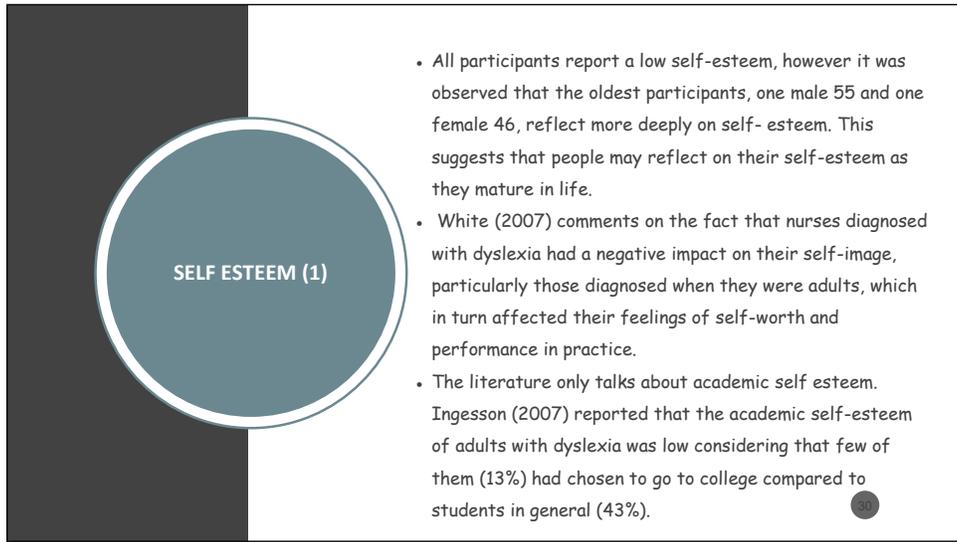
- In this study all participants, three males and three females, reflected on negative emotional experiences of feeling stupid, awkward, inadequate, depressed, frustrated, annoyed, angry, scared.
- The literature does not clearly define emotional experiences for adults with dyslexia, but Kormos, Csizér, & Sarkadi, (2009) stated that dyslexics experience feelings of failure, which often leads to extreme bouts of depression, alienating them from peers and those in the school environment. My findings agree with Kormos, Csizér, & Sarkadi, (2009) in that participants in the study reflected on the fact that they experience depression, frustration and generally low esteem throughout their life.

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EMOTIONAL EXPERIENCES (2)

- My findings support Reid & Kirk, (2001) who argue there is a need for more emotional support interventions for adults with dyslexia.
- My experience, as well as the participants, indicate that there are no resources, support systems or groups in the province for adults with dyslexia.

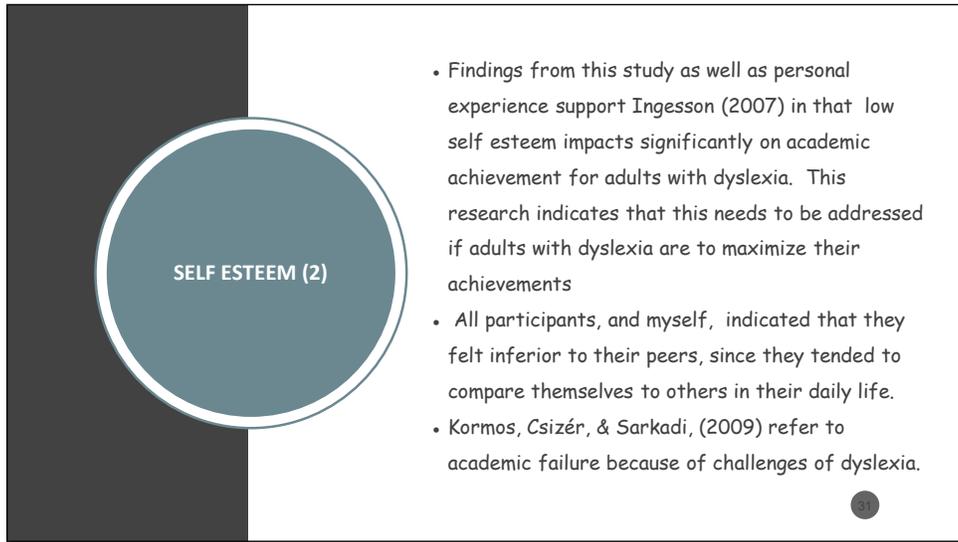
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SELF ESTEEM (1)

- All participants report a low self-esteem, however it was observed that the oldest participants, one male 55 and one female 46, reflect more deeply on self-esteem. This suggests that people may reflect on their self-esteem as they mature in life.
- White (2007) comments on the fact that nurses diagnosed with dyslexia had a negative impact on their self-image, particularly those diagnosed when they were adults, which in turn affected their feelings of self-worth and performance in practice.
- The literature only talks about academic self esteem. Ingesson (2007) reported that the academic self-esteem of adults with dyslexia was low considering that few of them (13%) had chosen to go to college compared to students in general (43%).

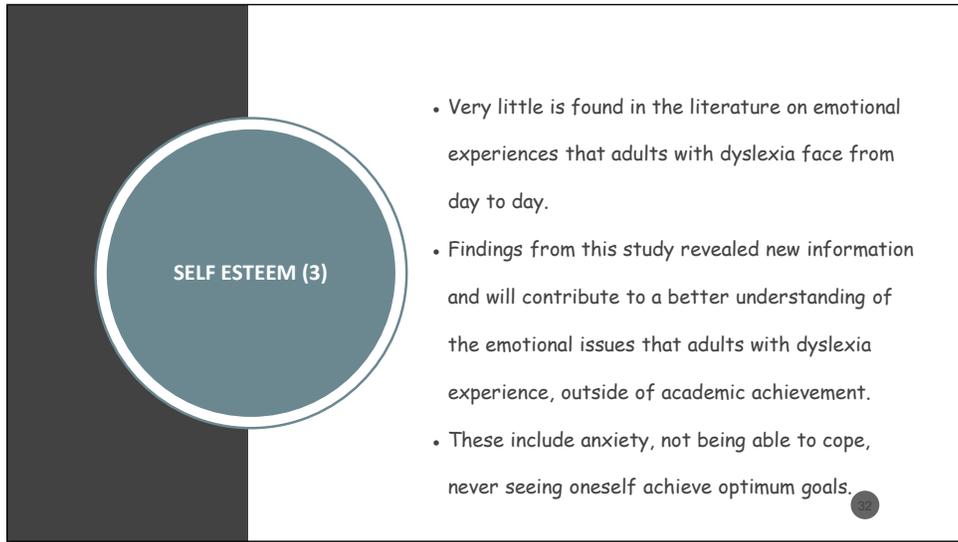
30



SELF ESTEEM (2)

- Findings from this study as well as personal experience support Ingesson (2007) in that low self esteem impacts significantly on academic achievement for adults with dyslexia. This research indicates that this needs to be addressed if adults with dyslexia are to maximize their achievements
- All participants, and myself, indicated that they felt inferior to their peers, since they tended to compare themselves to others in their daily life.
- Kormos, Csizér, & Sarkadi, (2009) refer to academic failure because of challenges of dyslexia.

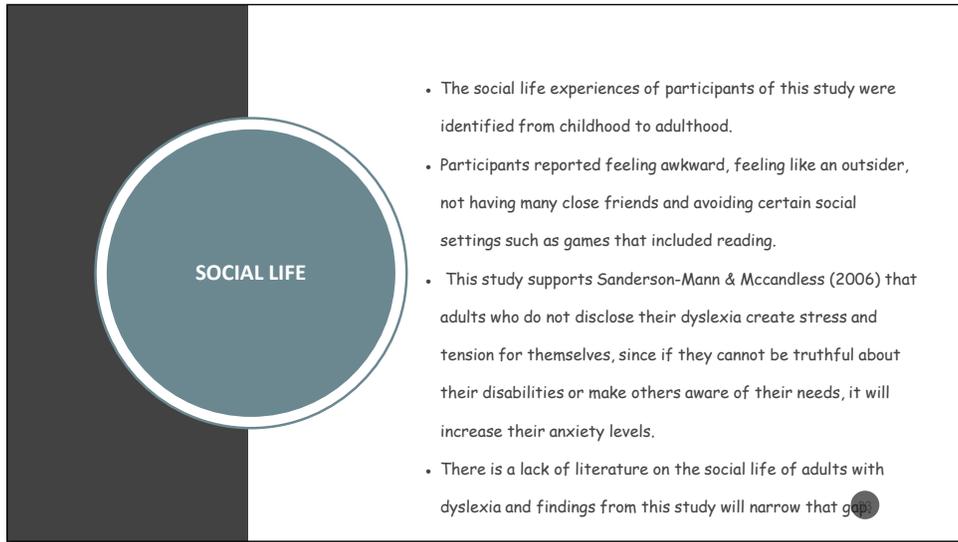
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SELF ESTEEM (3)

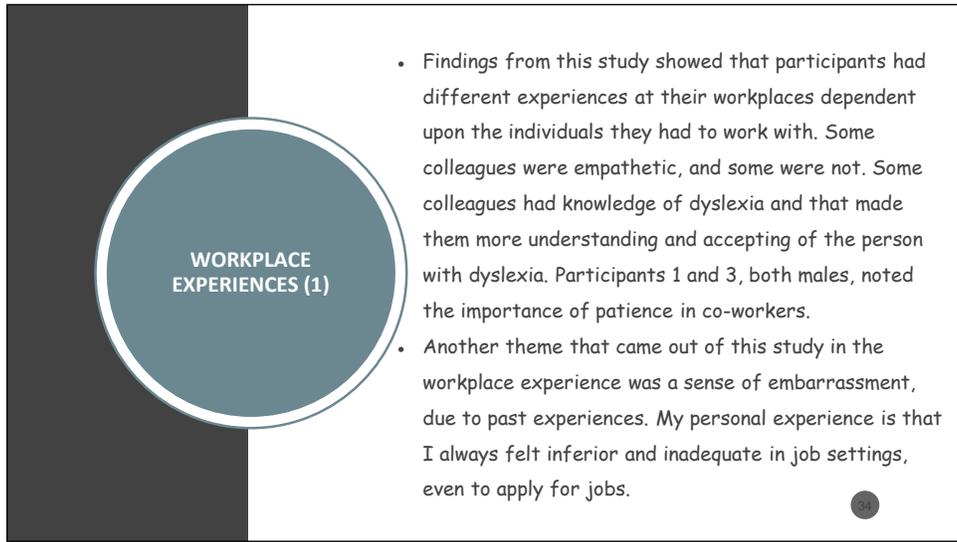
- Very little is found in the literature on emotional experiences that adults with dyslexia face from day to day.
- Findings from this study revealed new information and will contribute to a better understanding of the emotional issues that adults with dyslexia experience, outside of academic achievement.
- These include anxiety, not being able to cope, never seeing oneself achieve optimum goals.

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SOCIAL LIFE

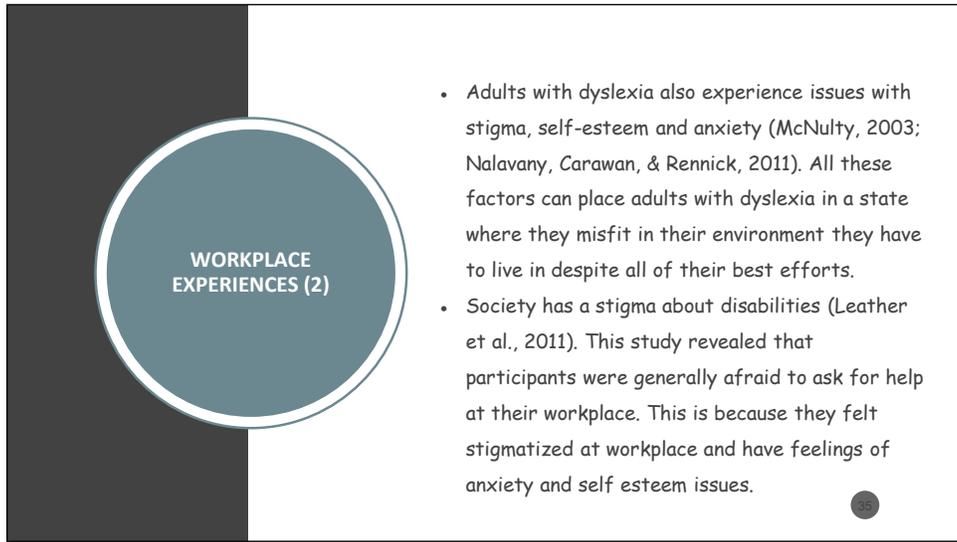
- The social life experiences of participants of this study were identified from childhood to adulthood.
- Participants reported feeling awkward, feeling like an outsider, not having many close friends and avoiding certain social settings such as games that included reading.
- This study supports Sanderson-Mann & Mccandless (2006) that adults who do not disclose their dyslexia create stress and tension for themselves, since if they cannot be truthful about their disabilities or make others aware of their needs, it will increase their anxiety levels.
- There is a lack of literature on the social life of adults with dyslexia and findings from this study will narrow that gap.



WORKPLACE EXPERIENCES (1)

- Findings from this study showed that participants had different experiences at their workplaces dependent upon the individuals they had to work with. Some colleagues were empathetic, and some were not. Some colleagues had knowledge of dyslexia and that made them more understanding and accepting of the person with dyslexia. Participants 1 and 3, both males, noted the importance of patience in co-workers.
- Another theme that came out of this study in the workplace experience was a sense of embarrassment, due to past experiences. My personal experience is that I always felt inferior and inadequate in job settings, even to apply for jobs.

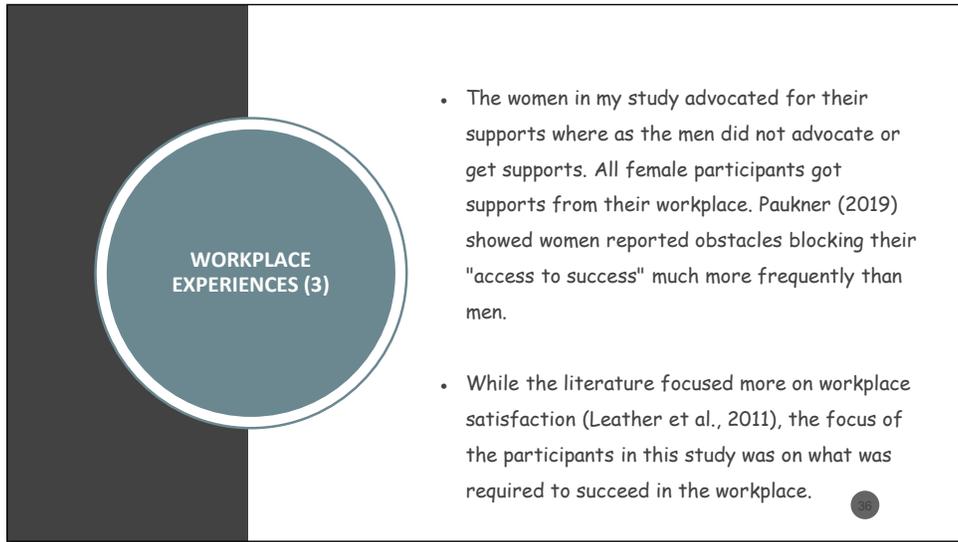
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WORKPLACE EXPERIENCES (2)

- Adults with dyslexia also experience issues with stigma, self-esteem and anxiety (McNulty, 2003; Nalavany, Carawan, & Rennick, 2011). All these factors can place adults with dyslexia in a state where they misfit in their environment they have to live in despite all of their best efforts.
- Society has a stigma about disabilities (Leather et al., 2011). This study revealed that participants were generally afraid to ask for help at their workplace. This is because they felt stigmatized at workplace and have feelings of anxiety and self esteem issues.

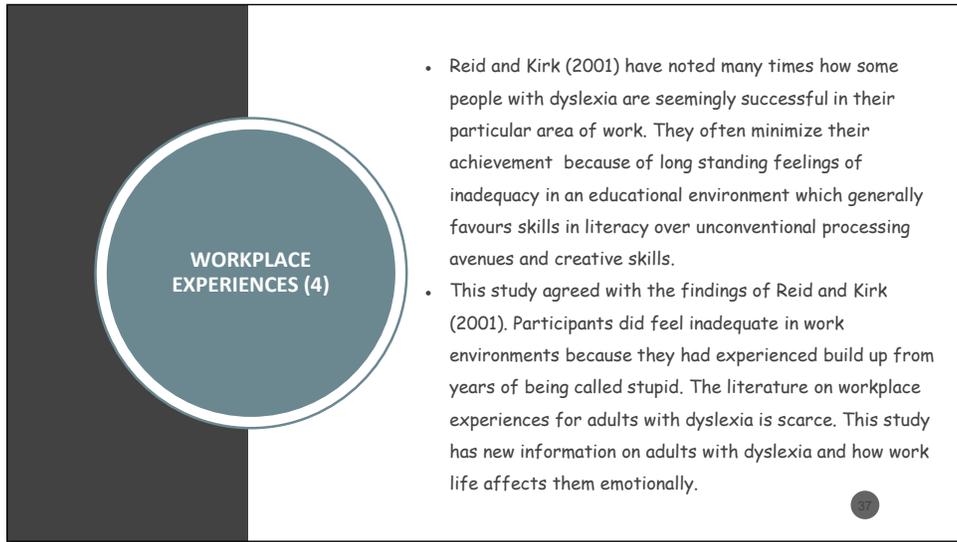
35



WORKPLACE EXPERIENCES (3)

- The women in my study advocated for their supports where as the men did not advocate or get supports. All female participants got supports from their workplace. Paukner (2019) showed women reported obstacles blocking their "access to success" much more frequently than men.
- While the literature focused more on workplace satisfaction (Leather et al., 2011), the focus of the participants in this study was on what was required to succeed in the workplace.

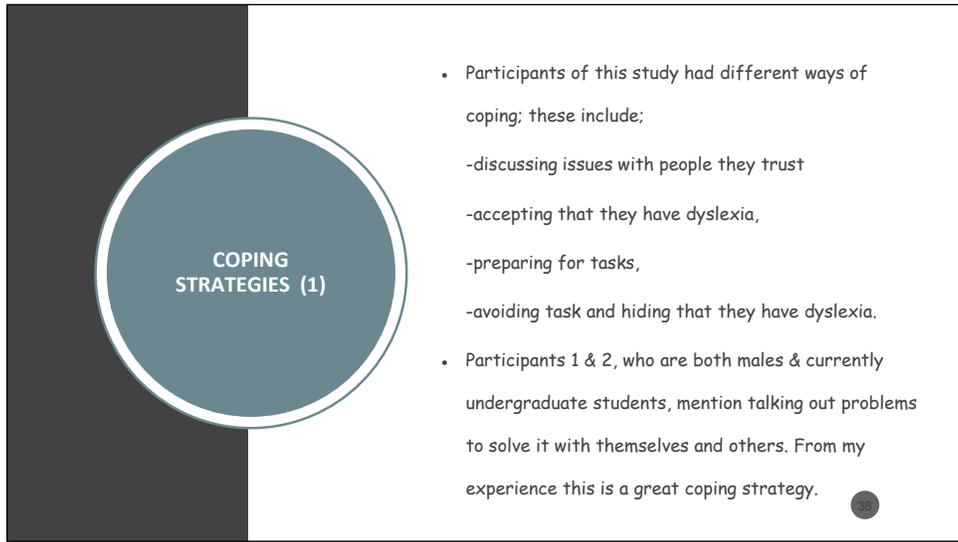
36



WORKPLACE EXPERIENCES (4)

- Reid and Kirk (2001) have noted many times how some people with dyslexia are seemingly successful in their particular area of work. They often minimize their achievement because of long standing feelings of inadequacy in an educational environment which generally favours skills in literacy over unconventional processing avenues and creative skills.
- This study agreed with the findings of Reid and Kirk (2001). Participants did feel inadequate in work environments because they had experienced build up from years of being called stupid. The literature on workplace experiences for adults with dyslexia is scarce. This study has new information on adults with dyslexia and how work life affects them emotionally.

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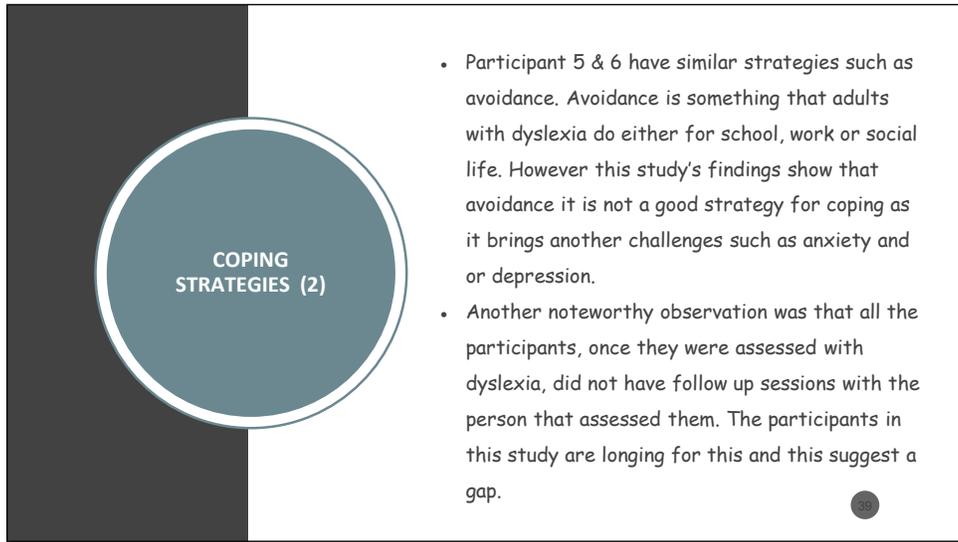


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COPING STRATEGIES (1)

- Participants of this study had different ways of coping; these include;
 - discussing issues with people they trust
 - accepting that they have dyslexia,
 - preparing for tasks,
 - avoiding task and hiding that they have dyslexia.
- Participants 1 & 2, who are both males & currently undergraduate students, mention talking out problems to solve it with themselves and others. From my experience this is a great coping strategy.

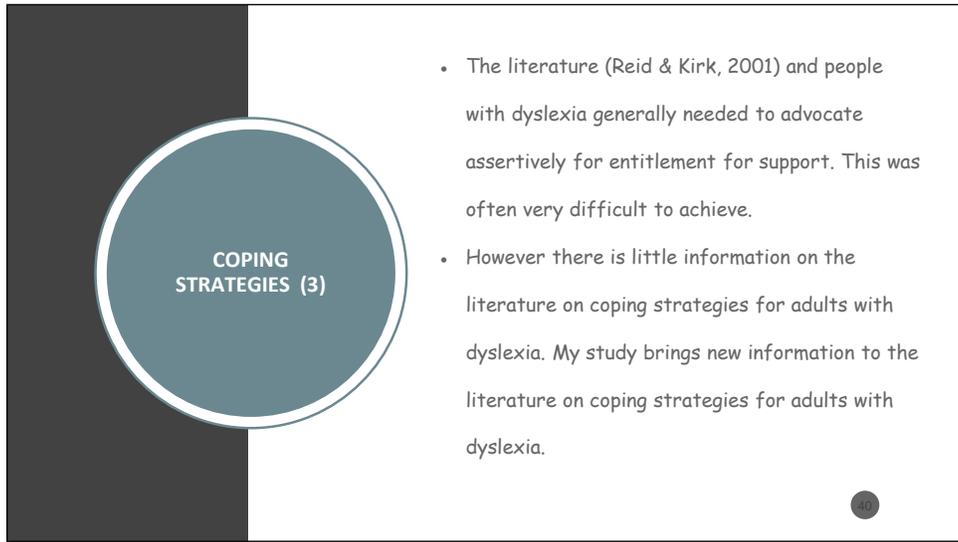
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COPING STRATEGIES (2)

- Participant 5 & 6 have similar strategies such as avoidance. Avoidance is something that adults with dyslexia do either for school, work or social life. However this study's findings show that avoidance it is not a good strategy for coping as it brings another challenges such as anxiety and or depression.
- Another noteworthy observation was that all the participants, once they were assessed with dyslexia, did not have follow up sessions with the person that assessed them. The participants in this study are longing for this and this suggest a gap.

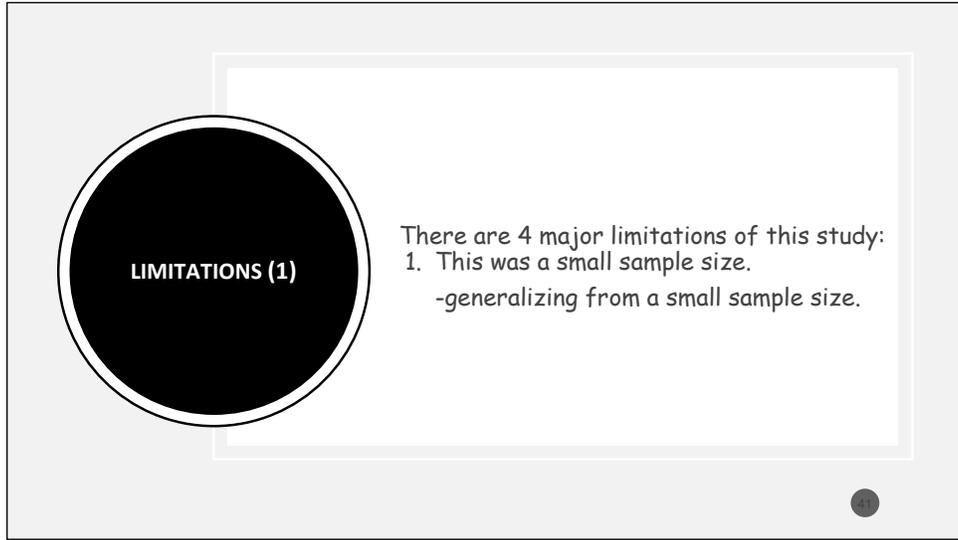
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COPING STRATEGIES (3)

- The literature (Reid & Kirk, 2001) and people with dyslexia generally needed to advocate assertively for entitlement for support. This was often very difficult to achieve.
- However there is little information on the literature on coping strategies for adults with dyslexia. My study brings new information to the literature on coping strategies for adults with dyslexia.

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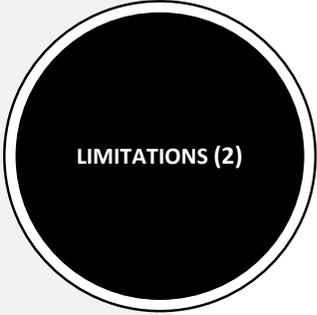


LIMITATIONS (1)

There are 4 major limitations of this study:

1. This was a small sample size.
-generalizing from a small sample size.

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LIMITATIONS (2)

2. There was little to refer to since it was a unique study.
3. Difficulty in recruiting individuals to be interviewed.
 - challenges in conducting videos for interviews.
4. Participants only interviewed once
 - No opportunity for follow up to clarify or expand thoughts.

RECOMMENDATIONS (1)

- Elementary and secondary schools should ensure students with dyslexia have access to remedial classes (Reilley, n.d.).
- A person with dyslexia needs access to smaller classes (Reilley, n.d.).
- Teachers should be trained about dyslexia and how to help students from primary to tertiary education.

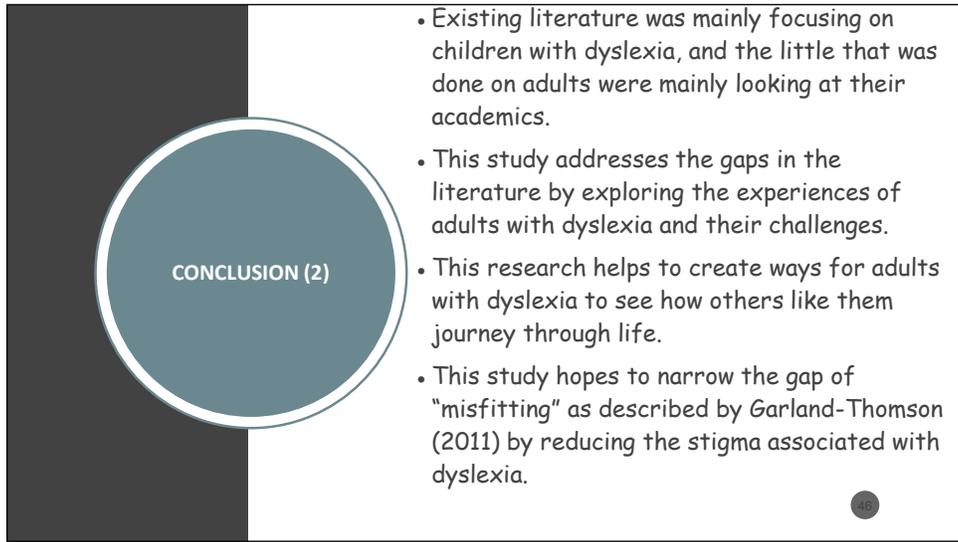
RECOMMENDATIONS (2)

- Having support groups with the same experiences makes people with dyslexia feel less of a misfit and build self esteem.
- Having a mentor really helped having someone to guide you and bounce ideas.

CONCLUSION (1)

- Research is mainly to educate and increase the awareness of people without dyslexia about the experiences of people with dyslexia.
- This study revealed that the emotional & social experiences of adults with dyslexia in Winnipeg, Manitoba were mainly negative.
- Strategies that adults with dyslexia in this study used for coping include discussing their ideas with someone they trust, using extra time for tasks, using technological accommodations.

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CONCLUSION (2)

- Existing literature was mainly focusing on children with dyslexia, and the little that was done on adults were mainly looking at their academics.
- This study addresses the gaps in the literature by exploring the experiences of adults with dyslexia and their challenges.
- This research helps to create ways for adults with dyslexia to see how others like them journey through life.
- This study hopes to narrow the gap of "misfitting" as described by Garland-Thomson (2011) by reducing the stigma associated with dyslexia.

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Appendices

APPENDIX I

Room 128 Education Building

University of Manitoba

Winnipeg, Manitoba

Canada R3T 2N2



UNIVERSITY
OF MANITOBA

Disability Studies

An Interdisciplinary Program

INFORMED CONSENT FORM

Research Project Title: People with dyslexia in Winnipeg: experiences as children and adults

Principal Investigator and contact information: Natalia Jackson, email address

Research Supervisor and contact information: Prof. Deborah Stienstra, email address

Sponsor: NA

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Background: I am Natalia Jackson, MA. student in the Department of Disability Studies, University of Manitoba, Winnipeg, Manitoba. I am doing a research on the past and present experiences of adults with dyslexia in Winnipeg, Manitoba. I am going to give you information and invite you to be a part of this research. You are being asked to participate in the research because I believe you are able to give insider information on this issue and your opinions can contribute to our understanding of the subject. You do not have to decide today whether or not you will participate in the research, and you can talk to anyone you feel comfortable with about the research.

Purpose: The purpose of this research is to find out the past and present experiences of adults with dyslexia, and present the information in a manner that adults with dyslexia can access and consume. You will be asked to answer questions about your current experience as an adult living with dyslexia as well as your experiences growing up with dyslexia; which will include emotional, social, work, and educational experiences.

Methodology: This research involves an interview, which will be conducted once. The interview will take about forty-five minutes to one hour and you have the option of asking for a copy of the interview schedule prior to the interview. The interview will be audio- and video-taped using an iPhone7 mounted on a tripod, and a USB microphone will be connected to the phone to improve the quality of the recording. The interview will be video recorded because we hope to develop a final thesis using video clips that adults with dyslexia will be more drawn to and willing to interact with. I will ask you to choose a public library of your choice to have the interview, as well as a date and time that is most convenient for you to have the interview. I will book a private room in the public library of your choice, with your preferred date and time. The expert information you provide will assist in getting a better understanding of the lived experiences of

adults with dyslexia from the experts themselves. This information will also assist in providing resources that will be effective for individuals with dyslexia as they navigate and cope through their adult life. After the interview, the recorded interview will be transcribed, and a copy of the transcript and well as the video recording will be sent to you to verify for accuracy. This is to ensure that we did not misunderstand anything you shared; and if there is anything in the transcript or video you find you are not comfortable sharing, it will give you an opportunity to let us know so we can delete it from your final data.

Benefits: The benefits to you by participating in this research is that you will get the opportunity to have your voice heard regarding the realities of an adult with dyslexia. I believe speaking out will help reduce the stigma associated with dyslexia as well as let other adults with dyslexia and their families know that there are also other adults coping with dyslexia (me) and they are not alone. In addition, participating in this research gives you the opportunity to share your story with another adults with dyslexia, who can report this story to the academic community from the perspective of someone on the inside. Participating will also afford you the opportunity to give expert advice on policy changes that will in fact benefit adults with dyslexia.

Cost: Participation in this research is at no monetary cost to you. As compensation, you will be given a gift card valued at \$20CAD. If any parking costs are accrued during your visit to the public library, the researcher will be responsible for them.

Confidentiality: The interview you will participate in will be video recorded and some parts of the video will be included in the final thesis and other publications or videos coming from the thesis. To keep you anonymous, the video will be recorded in low lighting, your face will be blurred and your voice will be distorted. However, absolute anonymity cannot be guaranteed. This means your participation in this study, as well as your stories may be linked to you. The risk

of this is that people you have not disclosed to about having dyslexia may be able to identify you as an adult with dyslexia. To minimize this risk to you, aliases will be used to identify you in the videos; and neither your workplace nor job title will be used to identify you in the videos.

However, you have the option of choosing to be named for your contribution to this study. If you so choose, the video will show your face and your name will be used to identify you in your videos. Otherwise, we will ensure to keep you and your information as anonymous as possible.

The information you provide will be stored anonymously, that is, your name, age, gender and your workplace will not be used to store your data. Instead you will be allocated a number which will be used store your transcripts, videos and consent form.

Immediately after the interview, the recorded interview and video will be moved from the researcher's phone to the researcher's personal computer. The researcher, research supervisor, research assistant and video editor are the only people that will have access to the interviews before it is edited. Also, your transcribed interviews will be emailed to you to verify accuracy, as well as your video will be edited to reflect the changes you identify in the transcript. The knowledge obtained from this research will be made available to the public and some of your comments may be presented in the publications verbatim. But your name will not be identified with your comments and contributions; unless you choose to be named.

Consent: Your participation in this study is voluntary and you may withdraw at any time without any negative consequences whatsoever. If at anytime you choose to withdraw your consent, please contact the researcher via the contact information in this consent form. Your videos, transcripts and informed consent form will be deleted. This however might not be possible if the thesis has been submitted to the Faculty of Graduate Studies.

Follow-up: You will be sent an email right after the interview to thank you for your time and effort. A copy of the transcript and video will be emailed to you within two weeks of the interview, to verify for accuracy and to confirm you are comfortable with the information you shared. If there is any information in your video and transcript that you are not comfortable with or that you do not want us to share in the final publication, please let us know and we will remove them before storing your final data. You will also receive a brief (1-3 pages) summary of results of the research approximately six months after the interview via email, but if you would prefer to receive it via another method, you are free to inform the researcher and you will be sent the summary that way. The data from the study will be kept for two years after completion of the study. This is because it might be necessary to refer to original data during the process of data dissemination.

Data Dissemination: The findings of this study will be disseminated initially through the thesis. Efforts will be made to also publish research findings in an academic journal, as well as to be presented at a conference and workshops. The videos will be utilized during the process of data dissemination. All participants will be asked to sign a separate video release form.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Fort Gary Campus Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above - named persons or the Human Ethics Coordinator at 204-474-7122 or send an email to *humanethics@umanitoba.ca*. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Name: _____

Email Address: _____

Participant's Signature _____

Date _____

Named for contribution Yes No

Researcher and/or Delegate's Signature _____

Date _____

APPENDIX II

INTERVIEW SCHEDULE

Opening: “My name is Natalia and I will be interviewing you today. And I just want to say thank you so much {name} for willing to be a part of this study.”

{Response}.

“Much of the information we have in literature on dyslexia has been focused on education. But as an adult with dyslexia myself, I know that navigating education is just one part of living with dyslexia. Dyslexia affects all aspects of our lives including work, social life, relationships and all these have emotional and psychological implications for us. So, my hopes are that the information you will provide here today will help us to learn more about the lived experiences of adults with dyslexia.”

{Response}.

Purpose of interview: “Just to clarify, the purpose of this research is to contribute to the academic community, in a non-traditional way, of the reality of the life of adults with dyslexia from the perspective of those who are living with dyslexia. This might bring more clarity on this issue and assist in developing policies and services that will be more appropriate to the needs of adults with dyslexia. I also believe further research might be built on the findings of this study.”

{Response}.

“So, basically, I will be asking you questions pertaining to your experiences as an adult with dyslexia, how you navigate work life, social life, stressors, emotions, and the likes.”

Importance of interview: “I hope this information will give the academic community as well as the policy makers, an insight into the actual reality of what it entails to be an adult with dyslexia.”

Time Line: “This interview should take approximately forty-five minutes, at the most one hour. We might finish before then, but we will definitely not spend more than one hour. Hope that is okay by you?”

{Response}

“Thank you”.

Body:

Starting with Introduction

- “Allow me to start by asking you to tell me a bit about yourself.”
 - How old are you?
 - Are you working right now?
 - How long have you been employed?
 - Are you married?

Knowing about Dyslexia

- “I am very interested in your experience with dyslexia. But we need a little bit of your background in order to understand your experience. ”
 - When did you realize that you were dyslexic?
 - When do you think your parents learned about it?

- When was your school made aware of it?
- When were you assessed with dyslexia? By who (assessed you), I mean like a psychologist, speech pathologist, reading clinician, teacher, etc.?
- Can you tell me about your supports, in the school setting? Did it change over the years of school? Did it change when you left school?
- Did you have any support outside of school? For example when you were looking for work.

Education Experiences

- Can you tell me about one situation where your education was affected by dyslexia?

What did you do?

- What did your teacher do?
- What did your classmate do?
- What did your parents do?
- Follow up: How did you feel in this situation? Can you tell me a little bit more about how you felt in that situation?

- Can you tell me about another situation where your education was affected by dyslexia?

What did you do?

- What did your teacher do?
- What did your classmate do?
- What did your parents do?
- Follow up: How did you feel in this situation? Can you tell me a little bit more about how you felt in that situation?

Transition to Social Life

- Can you tell me about one situation where your dyslexia shaped you as a child playing with others? How did this make you feel? What made you feel better? What made you feel worse?
- Can you tell me about another situation where your dyslexia shaped you as a child playing with others? How did this make you feel? What made you feel better? What made you feel worse?
- Can you tell me about one situation where your dyslexia shaped your social interactions as an adult? Example in a party? In a social gathering, going for dinner with friends?
- Can you tell me about another situation where your dyslexia shaped your social interactions as an adult? For example in a party, at a social gathering, going for dinner with friends?

Transition to Work life.

- Can you tell me a bit about a time about when you were out looking for work and your dyslexia affected it?
 - How did this situation make you feel? Follow up: What made you feel better about this situation? What made you feel worse about this situation?
 - What supports, if any, did you have access to? Did your family play a role? How so?
- Can you give me a situation at your work place (if you are working right now) where your dyslexia affected you?
 - How did this situation make you feel? Follow up: What made you feel better

about this situation? What made you feel worse about this situation?

- Can you tell me about a time at your workplace where you had to disclose or request support for your dyslexia?
 - How did this situation make you feel? Follow up: What made you feel better about this situation? What made you feel worse about this situation?

Transition to Emotional life

- Does dyslexia affect you on a daily basis? Follow up: If so, in what way does it specifically affect you?
 - How does all that make you feel?
- Can you give me an example of a situation where having dyslexia changed your mood?
Follow up: Perhaps due to your dyslexia there was a drastic mood change?
 - How do you think your dyslexia was related to this situation? How did this situation make you feel? Follow up: What made you feel better about this situation? What made you feel worse about this situation?
- Do you ever compare yourself to your friends who do not have dyslexia?
 - How does that make you feel?
- When was the first time you met another person that also has dyslexia?
 - How did meeting the person make you feel?

Transition to coping strategies

- Do you attend any follow up sessions with the person who assessed you?
 - If so, does that help?
- Do you have a support group that you talk with about dyslexia?

- How does the support group help you deal with dyslexia?
- Do you experience stressors due to dyslexia?
 - Can you give examples?
 - How do you cope with these?
- If given the choice, would you want to keep being dyslexic or give it up?
 - If yes, why?
 - If you could give some advice to adults with dyslexia what would it be?
- Do you have an example of when you felt your dyslexia was to your advantage? Or can you describe a positive experience where your dyslexia was a major strength in the situation?

Closing:

“That about rounds it up. I appreciate your time and patience in this interview. I thank you very much for giving us an opportunity to know all these things about you. And I hope, in the near future, changes will begin to happen that will be as a result of what you have contributed to the academic world today.

You will get an email from me shortly, and you will also receive a written draft of this conversation within the next two weeks. I want to be sure I did not misunderstand anything you said, so when you receive it, kindly go through it to be sure it is accurate.”

{Response}

“Wishing you all the best and thank you again.

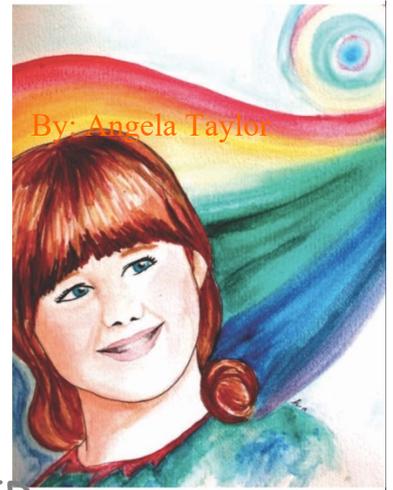
Bye.”

APPENDIX III

PARTICIPANTS NEEDED!

Dis-lex-e-uh

Let's DYScuss DYSlexia TOGETHER



We are looking for adults with dyslexia ages 21 and above who will be willing to be interviewed & video recorded for a research project.

The Joint- Faculty Research Ethics Board of the University of Manitoba has approved this research study.

Contact information:

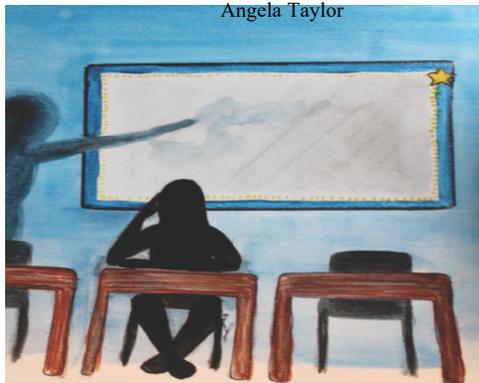
Pinar Eskicioglu, B.Kin, M.Sc.

Human Ethics Coordinator

Office of the Vice-President (Research and International)

Picture done by:

Angela Taylor



APPENDIX IV



UNIVERSITY
OF MANITOBA

Research Assistant Pledge of Confidentiality

I, _____, agree to maintain full confidentiality of any and all research data received by me in the course of my involvement in the study entitled **People with dyslexia in Winnipeg: experiences as children and adults**. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual(s) that may be revealed during the collection or handling of research data, or in any associated documents.
2. To store all research data and materials in a safe, secure location as long as they are in my possession.
3. To delete all electronic files containing data from my computer hard drive and any back-up devices after I no longer need this information as directed by the study principal investigator.
4. To destroy as confidential waste, any hardcopy research data in my possession after it is no longer required by me as directed by the study principal investigator.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred to individuals if I violate this agreement.

Research Assistant's Signature

Study Principal Investigator's Signature

Research Assistant's Name (printed)

Study Principal Investigator's Name (printed)

Date: _____

Date: _____

APPENDIX V



UNIVERSITY
OF MANITOBA

Video Editor Pledge of Confidentiality

I, _____, agree to maintain full confidentiality of any and all research data received by me in the course of my involvement in the study entitled **People with dyslexia in Winnipeg: experiences as children and adults.**

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual(s) that may be revealed during the collection or handling of research data, or in any associated documents.
2. To store all research data and materials in a safe, secure location as long as they are in my possession.
3. To delete all electronic files containing data from my computer hard drive and any back-up devices after I no longer need this information as directed by the study principal investigator.
4. To destroy as confidential waste, any hardcopy research data in my possession after it is no longer required by me as directed by the study principal investigator.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred to individuals if I violate this agreement.

Video Editor's Signature

Study Principal Investigator's Signature

Video Editor's Name (printed)

Study Principal Investigator's Name (printed)

Date: _____

Date: _____

Room 128 Education Building

University of Manitoba

Winnipeg, Manitoba

Canada R3T 2N2



UNIVERSITY
OF MANITOBA

Fort Garry Campus Research Ethics

Boards Crop Technology Centre

208 - 194 Dafoe Road

APPENDIX VI

VIDEO RELEASE FORM

I hereby give my consent to use my image and video for the purpose of the research study titled
“People with dyslexia in Winnipeg: experiences as children and adults.”

This consent includes, but is not limited to:

(a) Permission to interview, film, photograph, tape, and make a video reproduction of me and/or record my voice.

(b) Permission to distort my voice and image in the process of dissemination and publication of research findings to ensure my privacy.

(c) Permission to use quotes from the interview(s) (or excerpts of such quotes), the film, photograph(s), tape(s), and/or recording of my voice, in part or in whole.

By signing this video release form, I understand that I do not waive any legal rights I have to confidentiality and anonymity as a research participant nor release the researcher and her team from their legal and professional obligations.

I understand that I can change my mind about my participation in this research study at any time and request my video and/or photographs be removed from the research study.

Participants Name : _____

Signature: _____

Date: _____

Researcher's Name: _____

Signature: _____

Date: _____

Researcher's Name: _____

Signature: _____

Date: _____

APPENDIX VII
ETHICS APPROVAL



Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Email: humanethics@umanitoba.ca

RENEWAL APPROVAL

Date: August 29, 2019

New Expiry: September 25, 2020

TO: Natalia Jackson
Principal Investigator

(Advisor: Deborah Stienstra)

FROM: Julia Witt, Chair
Joint-Faculty Research Ethics Board (JFREB)

Protocol #J2018:043 (HS22007)
“People with Dyslexia in Winnipeg: Experiences as Children and Adults”

Joint-Faculty Research Ethics Board (JFREB) has reviewed and renewed the above research. JFREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Any modification to the research must be submitted to JFREB for approval before implementation.
2. Any deviations to the research or adverse events must be submitted to JFREB as soon as possible.
3. This renewal is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
4. A Study Closure form must be submitted to JFREB when the research is complete or terminated.

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