



APPENDIX D

**Midwestern University**  
**Research Study Information Sheet**  
**Preferences for PFL and IFL within the Autism and Autistic Communities**

**Principal Investigator:** RaMonda Horton, Ph.D, CCC-SLP

**Student Investigator:** MacKenzie Smith

**Address and Contact Information:** [E-mail-rhorto@midwestern.edu](mailto:E-mail-rhorto@midwestern.edu) or  
[msmith66@midwestern.edu](mailto:msmith66@midwestern.edu)

Midwestern University  
Speech-Language Pathology Program  
555 31<sup>st</sup> St  
Downers Grove, IL 60515

You are being asked to participate in a research study. Participation in this study is voluntary. You may refuse to participate or stop participating at any time without any consequence. Please read the information below and ask the researcher any questions that you have.

<b>WHY IS THIS STUDY BEING DONE?</b>	<p>The purpose of this study will be to describe and understand the preferences for Identity First Language (IFL), such as “autistic”, and Person First Language (PFL), such as “person with autism”, in parents and individuals within the autism and autistic communities.</p> <p>Information obtain from this study may be used to guide clinical practice by allowing service providers to understand factors that influence preferences for IFL and PFL, and therefore make inferences about a client’s preferences in order to provide services that better align with their values and belief.</p>
<b>WHAT WILL I BE ASKED TO DO DURING THE STUDY?</b>	<p>Over the course of two months caregivers of children with autism and individuals diagnosed with ASD who are over the age of 14 will be asked to complete an anonymous survey. Individual child participants will be prompted to complete a 25 item survey about their perspectives on living with ASD. Parent participants will be prompted to complete a 25 item survey about their perspectives on raising a child with autism and submit the survey. It is estimated that the survey will take 15-20 minutes to complete</p>
<b>WILL THIS STUDY BENEFIT ME?</b>	<p>There are no financial benefits for participating in the study, however, individuals may find value in sharing their experiences as a person with autism</p>
<b>ARE THERE ANY RISKS?</b>	<p>Participation in the study carries minimal risks. These risks included fatigue and boredom.</p>
<b>WHAT ABOUT MY PRIVACY &amp;</b>	<p>The survey is anonymous but consent and assent forms are collected from those under the age of 18. However, anyone who submits a consent/assent form and completes the survey</p>



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<b>CONFIDENTIALITY?</b>	will be assigned a unique ID number to ensure that their responses are not identifiable. For all adult and child participants individual survey responses will be combined and any identifying information will be removed when disseminating findings to protect anonymity
<b>WHAT IS AN IRB?</b>	IRB stands for “Institutional Review Board.” It is a committee made up of researchers and non-researchers at a University and its job is to protect the rights of people involved in research. The Midwestern University IRB reviewed this research study.
<b>QUESTIONS ABOUT THE STUDY?</b>	You can contact the researcher at the top of the form. If you have any questions about your rights as a research participant, please contact Dr. James Woods, the Director of Research at Midwestern University, at: 630-515-6173

