

RESEARCH PARTICIPANT INFORMATION SHEET

Acceptability of treatments for autism spectrum disorder: A cross-cultural evaluation
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What is the purpose of this study?

This research project is designed to evaluate the acceptability of various treatment options for children with autism spectrum disorder across multi-cultural populations. Your participation in the study is completely voluntary.

What will I do if I choose to be in this study?

If you agree to take part in this study you will be invited to read short descriptions of different autism treatment options and provide your evaluations of the treatments by completing online questionnaires. Additionally, you will also be required to complete a short questionnaire with questions relating your child’s symptoms and your sense of ethnic identity. Your participation is voluntary and this means that you can choose to stop participating in the study at any time. When the study has been completed, we can send you a summary of the findings if you so desire.

How long will I be in the study?

Reading through the treatment descriptions and completing all the online questionnaires would take approximately 15-20 minutes of your time.

What are the possible risks or discomforts?

The risks involved in taking part in this study are minimal and do not exceed those that are encountered in daily life. We assure you that the highest standards will be maintained in ensuring that all information provided by you is confidential and there is no violation of privacy. However, it is possible that you may face slight distress or anxiety in reading the treatment descriptions and evaluating various treatment options as it may remind you of the issues that you face regarding your child. You may also feel mild discomfort in answering questions about your levels of ethnic affiliation. If you and/or your child do experience emotional distress, please call the Samaritans 24-hour Hotline (toll-free number 212-673 3000); <http://samaritansnyc.org/24-hour-crisis> hotline/) for help. This service provides free, confidential, emotional support to both those in distress as well as family members.

Are there any potential benefits?

Although participating in this study may not have any direct benefits for you, you may find it interesting and educational to know about the various treatment options that are available for children with autism and how you feel about each of these treatment modalities. The results of this study help us understand the treatment preferences that parents of children with autism spectrum disorder (ASD) have across culture groups and can help better modulate treatments according to cultural necessities, so as to achieve best outcomes for children with ASD. Your participation in our efforts would be extremely valued.

Will I receive payment or another incentive?

By participating in this study, you can choose to enter a prize drawing for a chance to win one of fifteen cash prizes up to \$45. We expect around 300 individuals to participate in our study and hence your odds of winning the prize would be around 1 in 20.

Will information about me and my participation be kept confidential?

Your privacy is of prime importance to us and you can be assured of the anonymity of your participation in this study. All identifying information received from you will be stored confidentially in separate password protected files. All survey responses received will be de-identified, letter-number coded and stored in password protected files. Both the identifying information and the survey responses will be accessed only by members of the research team and solely for research purposes. All file sharing related to this project will be conducted through secure file transfer software. Any results published from this study will only be in the form of aggregates of the data collected and will not contain any information that links the results obtained to personal identifying information. Contact information for entering the prize drawing and distributing the prizes will be stored separately and will be in no way linked to your responses. In addition, we will be destroying all identifying information including demographic and contact details within five years of the completion of this study.

What are my rights if I take part in this study?

Your participation in this study is completely voluntary. You can choose not to participate in this study, and even if you participate you can still withdraw your participation at any time without any associated penalty or loss of benefits. Your choosing not to participate will have no bearing on your relationship with the institution you are currently seeking treatment for your child.

Who can I contact if I have questions about the study?

If you have questions, comments or concerns about this research project, you can talk to one of the researchers. Please contact Georgitta Joseph (765-418-2221 or via email at georgia11felicity@gmail.com).

If you have questions about your rights while taking part in the study or have concerns about the treatment of research participants, please call the Human Research Protection Program at (765) 494-5942, email (irb@purdue.edu) or write to:

Human Research Protection Program - Purdue University
Ernest C. Young Hall, Room 1032
155 S. Grant St.
West Lafayette, IN 47907-2114

Documentation of Informed Consent

I have had the opportunity to read this information sheet and have the research study explained. I have had the opportunity to ask questions about the research study, and my questions have been answered. I am prepared to participate in the research study described above.