Consent Form (Parent)

Title of Research Study: ***Evaluation of a Mentorship Program for Individuals with ASD***

Researchers: ***Rebekah Hudock, PhD and Lindsey Weiler, PhD***

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Why am I being asked to take part in this research study?
We are asking you to take part in this research study because you are participating in the pilot of a mentoring program for individuals with ASD. Your input and feedback will help us understand how the program works, in addition to what works well in the program and where there could be improvements. This information will be used to further develop the mentoring program.

What should I know about a research study?
- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

Who can I talk to?
For questions about research appointments, the research study, research results, or other concerns, call the study team at:

Researcher Name: Dr. Rebekah Hudock Phone Number:612-626-3538 Email Address:kale0040@umn.edu	Researcher Name: Dr. Lindsey Weiler Phone Number: 612-301-9345 Email Address: lmweiler@umn.edu

This research has been reviewed and approved by an Institutional Review Board (IRB) within the Human Research Protections Program (HRPP). To share feedback privately with the HRPP about your research experience, call the Research Participants' Advocate Line at 612-625-1650 or go to www.irb.umn.edu/report.html. You are encouraged to contact the HRPP if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Why is this research being done?

Relationships with caring, non-parental adults (i.e., mentors) are critical to healthy child

development. Mentoring programs can positively influence a range of outcomes for youth, including peer and parental relationships, academic achievement, self-concept, and prevention of problem behaviors, including substance use. Despite the importance of adult youth relationships, mentoring for children with autism spectrum disorder (ASD) has not been described or studied systematically.
The purpose of this study is to gather information about the pilot implementation of the Autism Mentoring Program (AMP). We want to understand how the program works, what works well, and where there could be improvements.

How long will the research last?
Over the course of the next 6-18 months, you will be asked to spend 7-14 hours engaging in evaluation activities:

- At 2-4 different times, you will be asked to participate in a 90-minute focus group, where you will come together with other participants and/or parents to talk about what is going well with the program and what challenges there are.
- At 2-4 different times, you will also be asked to complete a series of surveys/questionnaires.
- At 2-4 different times, you will be asked to participate in a 60-minute interview with evaluation staff.

For Phase 3 of this study (2020-2021), you will be asked to spend about 6 hours over the next 9 months participating in the following activities:

- At 2-3 different times, you will be asked to participate in a 30-60-minute interview about different parts of your life.
- At 2-4 different times, you will be asked to fill out a series of surveys that will take about 60-90 minutes.
- At the end of the 2020-2021 program, you will be asked to participate in a 90-minute focus group, where you will come together with other participants and share your experiences and opinions on the program.

How many people will be studied?
We expect that approximately 50-90 individuals will participate in this study.

What happens if I say "Yes, I want to be in this research"?
If you agree to participate in this research, you will be asked to participate in the following activities:

- Participate in focus groups where you will be asked to answer questions about what worked well in the program and what could be improved.
- Complete up to four interviews/surveys regarding the impact the mentoring program.
- Complete a series of questionnaires before the program begins, during the program, and after the program ends.

What happens if I do not want to be in this research?
You can leave the research at any time and it will not be held against you.

What happens if I say "Yes", but I change my mind later?
You can leave the research at any time and it will not be held against you.
If you decide to leave the research, contact the investigator so that the investigator or a member of the research team can conduct a brief exit interview with you regarding portions of the study that you completed and potential barriers to your participation. No further data will be collected.

Is there any way being in this study could be bad for me?
There is minimal risk to participating in this study. Potential risks may include discomfort from discussing potentially upsetting topics (e.g., anxiety, depression, difficulties with friendships) and participating in social situations, which can be difficult for individuals with ASD.

Will being in this study help me in any way?
We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include contributing to the continued development of a mentoring program for individuals with ASD in your community. You may benefit directly from program itself, which may result in positive social relationships and opportunities to participate in preferred activities.

As part of your participation in the study, you will receive compensation for your time. For the first six months of the study (January 2019 through June 2019), you will receive $10 for each time you meet with researchers for data collection.

If you continue to participate in the 2019-2020 school year, you will receive increasing compensation over the course of the program:

- Beginning of program data collection: $10
- Mid-program interview: $20
- Post-program data collection: $25
- Post-program focus group: $30

If you participate in Phase 3 of this study (2020-2021), you will receive the following compensation for each portion of your participation:

- Baseline assessment: $20
- Pre-intervention data collection: $50
- Mid-program data collection: $30
- Post-program data collection: $50
- Post-program focus group: $50

What happens to the information collected for the research?
Efforts will be made to limit the use and disclosure of your personal information to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of this institution.
An exception to our promise of confidentiality is when we in good faith are permitted by law or policy to report evidence of child abuse or neglect. Similarly, if we learn that you have intent to harm yourself or others, we will help you to contact a parent/guardian or health professional who can help you.

All data will be kept in an encrypted database and/or stored in a locked file cabinet at in a locked office. Only the PI and members of the research team will have access to this data as needed. Data will be retained for up to 7 years.

Will anyone besides the study team be at my consent meeting?
You may be asked by the study team for your permission for an auditor to observe your consent meeting (or a recording of your consent meeting). Observing the consent meeting is one way that the University of Minnesota makes sure that your rights as a research participant are protected. The auditor is there to observe the consent meeting, which will be carried out by the people on the study team. The auditor will not record any personal (e.g. name, date of birth) or confidential information about you. The auditor will not observe your consent meeting (or a recording of your consent meeting) without your permission ahead of time. The auditor will be another member of the study team. Your parent(s)/guardian(s) and/or teacher are also allowed to be present with you during the consent process if you would like.

Will I have a chance to provide feedback after the study is over?
After the study, you might be asked to complete a survey and/or interview about your experience as a research participant. You do not have to complete the survey/interview if you do not want to. If you do choose to complete the survey/interview, your responses will be anonymous.

If you are not asked to complete a survey after the study is over, but you would like to share feedback, please contact the study team or the Human Research Protection Program (HRPP). See the "Who Can I Talk To?" section of this form for study team and HRPP contact information. You may contact the researchers at any time to provide feedback.

Can I be removed from the research without giving my OK?
The person in charge of the research study or the sponsor can remove you from the research study without your approval. However, we will notify you if you will no longer be participating in the study.

What else do I need to know?
Parents please be aware that under the Protection of Pupils Right Act 20 U.S.C. Section 1232 (c)(1)(A), you have the right to review a copy of the questions asked of or materials that will be used with your students. If you would like to do so, you should contact Dr. Rebekah Hudock to obtain a copy of the questions or materials.

You will be able to learn the results of this study through materials published through the Autism Society of Minnesota, Minnesota Independence College and Community, and/or the University of Minnesota at the completion of this study. We also hope to publish the results of this study in professional journals. The results of this study may also be used for teaching, publications, or for presentation at scientific meetings.

Optional Elements:
The following research activities are optional, meaning that you do not have to agree to them in order to participate in the research study. Please indicate your willingness to participate in these optional activities by placing your initials next to each activity.

I agree	**I disagree**	
_____	_____	The researcher may audio record and video record me (mentoring sessions only) to aid with data collection and analysis. The researchers will not share these recordings with anyone outside of the study team.
_____	_____	The researcher may contact me in the future to see whether I am interested in participating in other research studies by the principal investigators of this study.

Signature Block

Your signature documents your permission to take part in this research.

_____ _____

Signature of participant (parent) Date

_____

Printed name of participant (parent)

_____ _____

WITNESS STATEMENT:
For the Consent of Non-English Speaking Participants when a Professional Interpreter is Used:
As someone who understands both English and the language spoken by the subject, I represent that the English version of the consent form was presented orally to the subject in the subject's own language, and that the subject was given the opportunity to ask questions.

_____ _____

Signature of Interpreter Date

_____

Printed Name of Interpreter

OR:

Statement from a Non-Interpreter:
As someone who understands both English and the language spoken by the subject, I represent that the English version of the consent form was presented orally to the subject in the subject's own language, and that the subject was given the opportunity to ask questions.

_____ _____

Signature of Individual Date

_____

Printed Name of Individual

_____ _____

Signature of person obtaining consent Date

_____

Printed name of person obtaining consent