

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

Student Consent

TITLE: Facilitating Employment for Youth with Autism: A Replication Study of an Internship Model to Identify Evidence Based Practices

VCU IRB NO.: HM15031

SPONSOR: National Institute on Disability and Rehabilitation Research (NIDRR)

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research is to understand how two different types of job training programs work for young people like you. The job training programs are in a high school or a community business.

You are being asked to take part in this study because you:

1. Have Autism Spectrum Disorder diagnosis
2. Attend a Henrico, Hanover, or Chesterfield County High School or a Southeastern Cooperative Educational Program (SECEP) Classroom
3. Are between the ages of 18 and 21.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to agree to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

If you decide to take part in this study, you will be asked to participate in an assessment before the start of your last year in high school. During this assessment, we will ask for your name, address, date of birth and ask you to complete four questionnaires. The questionnaires are; the Support Intensity Scale, The Social Responsiveness Scale, the ARC Self Determination Scale and the Your Health and Wellbeing Scale. The assessment will be done by trained staff. We will use the information to determine skills, abilities, and support needs so that we can best match you to internships and determine the level of support you will need during the course of the study. Once in the study, you will receive job training in one of two programs. The first job training program is in your high school. The second job training program is a 9 month internship in a community business. Project staff will assign you to one of the two job training programs. Neither you nor your parents will have a choice of the program to which you are assigned. Project staff will make program assignments by chance. If you are in the study, you will have an equal chance of being in either program as anyone else in the study.

Both job programs will begin on the first day of school in the fall and last until the last day of school in the spring. Both job training programs will follow the Henrico, Hanover, Chesterfield County, or SECEP Public Schools calendar. You will be required to attend the program when school is in session, and will be off when school is not in session. If you are assigned to the community business internship, you will attend school at a community business. If you would

like, we will help you learn how to use public transportation before the internship program begins. If you are assigned to the high school job training program, you will use school bus or car to get to and from your school. If you are assigned to the high school job training program, your school day will follow the school's schedule. Your school day in the community business will start and end at the same time as your school. Once you complete either job training program, you will graduate from high school.

As a part of this research study, we will stay in touch with you for a period of one year after the end of the school year. You will take part in assessments and be asked to complete a survey about your job and job training. The assessments and surveys will be collected four different times from the beginning of the program till one year after it ends and will take approximately 2 hours to complete.

We will share with you important findings that we learn during this study. These findings may affect your decision whether or not you want to continue to taking part in this study.

RISKS AND DISCOMFORTS

There are no risks beyond what you would encounter in a normal high school or work place. These are examples of issues that you may come across: scheduling changes, and stress from peer and/or boss interaction.

BENEFITS TO YOU AND OTHERS

We will provide you with compensation for your time during the interviews and surveys. Taking part in this study may help you find a job faster than if you were not part of the study. It may help you get a job more to your liking than if you were not part of the study. It is also possible that you will not get or keep a job. Even though you may not get a job from this study, the information we learn from people in this study may help us design better ways to help people with disabilities get jobs in the future.

Please be aware that the University may receive money to conduct this study.

COSTS

The cost for taking part in the high school job training program includes any high school fees you would normally pay to the school. The cost for taking part in the community based job training program include:

1. Getting to and from the business daily
2. Buying appropriate clothing (which may include buying uniforms)
3. Buying lunch if you are not able to bring a lunch from home

Also, part of the cost will be the time you spend in the study itself. The University will not charge you anything for taking part in this study.

ALTERNATIVES

The only alternative to this study is to not take part. In such cases, you will receive your education as usual.

CONFIDENTIALITY

In this study, we will gather information about your job history. Your information will be added with the information from the other people in the study. We will compare the job training programs with each other. Information that you give us may be looked at by the staff who pay for this research or by the University staff for research or legal reasons. The name of the group paying for this research is the National Institute on Disability and Rehabilitation Research (NIDRR). With your permission we might send reports and other information to other agencies that serve you. We will only do this if you have given us permission by signing the application on page 6.

What we find from this study may be presented at meetings or published in papers. Your name will not ever be used in these presentations or papers.

If you ever say that you may hurt yourself or others, by law we have to report that to people or agencies that might help.

The paper or computer information we collect in this study includes:

1. Your name
2. Your birthdate
3. Your address
4. Application
5. Assessment forms
6. The Individualized Education Program
7. Interview notes or recordings
8. Photos.

It is possible that others might identify you from this information. We will keep this information in a locked area, or in a password protected computer. We will erase or destroy all personal information once the study is finished. Access to all data will be limited to study staff.

You may be videotaped or photographed while at your internship site. Video and photographs may be used in meetings where the study staff present the findings from this study.

You can decide to be videotaped or photographed if you want. Please put a check mark by the statement that best matches your decision about video and photographing at the end of this form then sign on the line below the statement.

IF AN INJURY HAPPENS

Virginia Commonwealth University and the VCU Health System do not have a plan to give long-term care or money if you are injured because you are in the study. If you are injured because of being in this study, tell the study staff right away. The study staff will arrange for short-term emergency care or referral if it is needed. Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. If you decide to withdraw from the study, you will return to the high school program which you would normally attend. You may also choose not to answer

particular questions that are asked in the study. Your participation in this study may be stopped at any time by the study staff or the sponsor without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions;
- the sponsor has stopped the study; or
- administrative reasons require your withdrawal.

If you leave the study before the final regularly scheduled visit, you must notify VCU staff.

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Carol M. Schall, PhD
Virginia Autism Resource Center
Virginia Commonwealth University
Richmond, VA 23284-2020
(804)828-4523
cmschall@vcu.edu

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
(804) 827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed

Participant signature

Date

Name of Person Conducting Informed Consent
Discussion / Witness
(Printed)

Signature of Person Conducting Informed Consent
Discussion / Witness

Date

Principal Investigator Signature (if different from above)

Date

Please check the statement that reflects your opinion about being photographed or videotaped.

I consent to be photographed and/or videotaped during this study.

I **do not consent** to be photographed and/or videotaped during this study.

Participant name printed

Participant signature

Date

Name of Person Conducting Informed Consent
Discussion / Witness (Printed)

Signature of Person Conducting Informed Consent
Discussion / Witness

Date

Principal Investigator Signature (if different from above)

Date