

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

Parent/Guardian 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 a 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 your child. The job training programs are in a high school or a community business.

You are being asked to consent to your child's involvement in this study because:

1. He/she has the disability of Autism Spectrum Disorder
2. Attend a Henrico, Hanover, or Chesterfield County High School or a Southeastern Cooperative Educational Program (SECEP) Classroom
3. Is between the ages of 18 and 21.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to consent for your child 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 him/her.

If your child meets the requirements and you decide to allow him/her to participate in this study, he/she will be asked to take part in an assessment before the start of his/her last year in high school. During this assessment, we will ask for your child's or ward's name, address, date of birth and ask you and your child/ward 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 him/her to internships and determine the level of support he/she will need during the course of the study. The assessment will occur at a place and time fitting to you and will take approximately three (3) hours to complete. Once in the study, he/she will receive job training in one of two programs. The first job training program is in your child's high school. The second job training program is a 9 month internship in a community business. Project staff will assign your child to one of the two job training programs. Neither you nor your child will have a choice of the program to which he/she is assigned. Project staff will make program assignments by chance. If your child is able to participate in the study, he/she 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. Your child will attend the program when school is in session, and will be off when school is not in session. If your child is assigned to receive job training in high school, your child will attend school for the entire school year. If your child is assigned to the community business internship, he/she will attend school at a community business. You are responsible for finding and arranging your child's way to and from the community business. If you would like, we will help your child learn how to use public transportation before the internship program begins. If your child is assigned to the high school job training program, he/she will use school's bus or car to get to and from high school. Your child's school day in the community business internship will start and end at the same time as his/her high school does. Once your child completes either job training program, he/she will graduate from high school.

As a part of this research study, we will stay in touch with your child for a period of one year after the end of the school year. Your child 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 your child to continue to taking part in this study.

RISKS AND DISCOMFORTS

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

BENEFITS TO YOUR CHILD AND OTHERS

We will provide you with compensation for your time during the interviews and surveys. Taking part in this study may help your child find a job faster than if you were not part of the study. It may help your child get a job more to his/her liking than if he/she were not part of the study. It is also possible that your child will not get or keep a job. Even though he/she may not get a job from this study, the information we learn from 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 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 he/she is not able to bring a lunch from home

Also, part of the cost will be the time you and your child 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, your child will receive his/her education as usual.

CONFIDENTIALITY

In this study, we will gather information about your child's job history. Your child's 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 your child. 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 child's name will not ever be used in these presentations or papers.

If your child ever says that he/she may hurt him/herself 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 child's name
2. Your child's address
3. Your child's date of birth
4. Application
5. Assessment forms
6. The Individualized Education Plan
7. Interview notes or recordings
8. Photos.

It is possible that others might identify your child 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.

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

You can decide to have your child 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 your child is injured during the course of the study. If your child is injured because of being in this study, he/she or you should 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 company. 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 consent for your child to participate in this study. If you choose to consent to participation, you may withdraw your consent at any time without any penalty. If you decide to withdraw your child from the study, he or she will return to the high school program which they would normally attend. Your child's 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 child's health or safety;
- your child has not followed study instructions;
- the sponsor has stopped the study; or
- Administrative reasons require your child's withdrawal.

If your child leaves the study before the final regularly scheduled visit, you must notify VCU staff.

QUESTIONS

In the future, you may have questions about your child's 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)828-6979
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
Telephone: 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 your child being photographed or videotaped.

I consent to my child being photographed and/or videotaped during this study.

I do not consent to my child being 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