OMB # xxxx-xxx
Expiration date: xx/xx/20xx

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE OF RESEARCH STUDY: Youth Transition Exploration Demonstration

RESEARCH STUDY NUMBER: IRB protocol number

WHAT AM I BEING ASKED TO DO?

I am being asked to consent to participate in a research study led by Mathematica and implemented by the Pennsylvania Office of Vocational Rehabilitation (OVR) and the Center for Transition and Career Innovation at the University of Maryland (UMD). I understand that taking part in this research study is completely voluntary; I do not have to be part of this research study unless I choose to be. I am free to leave the research study at any time if I change my mind.

The information provided in this form may contain words I do not understand. I will ask the research study staff to explain anything I do not understand.

WHY IS THIS RESEARCH STUDY BEING DONE?

For many youth ages 16 to 24, obtaining employment is an important goal. Though there are employment services to help youth, the best ways to coordinate and deliver these services are not yet known. This project will compare the current way of coordinating and delivering employment services for youth with a new approach.

Mathematica, OVR, and UMD are working together on this project. Staff at OVR will provide employment services to participants in this research study in partnership with other community partners. As explained in the next section, some participants in this research study will also receive additional services from OVR staff as part of the new approach this research study is testing. UMD will train OVR staff on how to provide these additional services. Researchers at Mathematica will evaluate the effects of the new approach to services. As part of that evaluation, Mathematica will obtain data from organizations that store and manage data related to my employment, my earnings, and the benefits that I receive.

WHAT WILL HAPPEN DURING THIS RESEARCH STUDY?

While I am a part of this research study, I will be asked to do the following:

Enrollment Survey

At the beginning of the research study, I will complete a survey about my personal characteristics (such as age and race/ethnicity), health and well-being, employment history, earnings, education, family situation, and expectations. This survey will be completed during an in-person interview or a phone interview.

When I enroll in the research study, I will also be asked to provide my Social Security number (SSN) and other information that identifies me (referred to as Personally Identifiable Information or PII). This information is needed to accurately collect information about me from state and federal databases and to help enroll me in services that I am eligible to receive. As will be discussed further below, many procedures are in place to ensure my information is kept secure.

Program Participation

I will be randomly assigned (like a coin flip) to participate in one of two groups as part of this research study.

- Group 1: In this group, I will receive information about how to apply to OVR for employment services or continue my OVR application. I can apply to OVR at any time.
- Group 2: In this group, OVR will help me complete an application for OVR services. If I qualify for services from OVR, I will receive services from an OVR counselor with additional training called a youth transition exploration counselor. The youth transition exploration counselor will help me develop my career goals and then coordinate various services to help me achieve those goals. These services may include referrals to other programs that provide employment services. My case file with OVR will remain open if I receive services from other programs to which I am referred.

Both groups can apply to OVR for services. If I apply and am eligible, services I receive may include:

- Advice and guidance from professional counselors,
- Help completing applications for services,
- Training or education services,
- Assistive technology to help address barriers to employment,
- Assistance communicating with others about my needs and ways to accommodate them,
- Referrals to and services from other services providers, and
- Assistance with job placement.

Database Information Collection

Information about my earnings, benefits, and services received will be collected from state and federal program databases by using the consent provided below. My SSN and other PII will be used to ensure that the correct information is collected.

One Year Follow-Up Survey

I will be asked to complete a survey about one year after enrolling in the research study. The survey will ask me about employment, job satisfaction, satisfaction with services received, health and well-being, and other outcomes related to my pursuit of employment.

Follow-Up Interview

I may be asked to participate in an interview about my experiences after enrolling in the research study. The interviewer will ask me to describe the services I received and my experience with my OVR counselor.

WHAT RISKS ARE ASSOCIATED WITH PARTICIPATING IN THIS RESEARCH STUDY?

The research study described above may involve the following risks and/or discomforts:

There are no physical or medical risks associated with this research study. As with all research studies that involve collection of personal information, there is the risk of a breach in confidentiality, but Mathematica has extensive procedures in place to prevent this from happening. These include collecting this information in private settings (to prevent what I share from being overheard or seen) and storing this information in secure databases that can only be accessed by authorized personnel. I will be informed immediately by Mathematica of any specific threat to my privacy.

I understand some research study questions will ask about my financial status, health, and well-being. It is possible these questions may make me feel uncomfortable. If this happens I understand I may take breaks or decline to answer questions that make me feel uncomfortable.

WHAT WILL BE DONE TO PROTECT INFORMATION ABOUT ME?

Mathematica will make every effort to maintain the privacy of my research study records. Mathematica will protect my information consistent with applicable Federal laws, regulations, and directives.

Protected Health Information and Personally Identifiable Information

Mathematica would like to use information about my health ("Protected Health Information") as well as information that identifies me ("Personally Identifiable Information"). My Protected Health Information (PHI) is given special protections under The Federal Health Insurance Portability and Accountability Act (HIPAA) of 1996. The researchers must obtain my approval to use PHI and PII.

If I participate in this research study, health information that will be used may include the following:

- Information from my OVR case record, such as my diagnoses, services I am receiving, program milestones, outcomes at case closure, and other observations made by OVR staff as part of the services I receive.
- Surveys about my health and well-being, employment history, earnings, job satisfaction, education, family situation, expectations, and satisfaction with services received.
- Other observations made by Mathematica during the course of the research study.

If I participate in this research study, PII that will be used may include, but is not limited to, the following:

- My SSN and date of birth (which is needed to determine if I qualify for certain services and to accurately collect information about my earnings, benefits, and services received).
- My name, phone number, email, address, or other information that allow Mathematica to contact me as needed during the research study.
- The information I consent to be disclosed by third parties, including the information listed in the Consent to Disclose Social Security Administration Records below.

Mathematica takes several actions to safeguard PHI and PII. These actions comply with applicable Federal laws, regulations, and directives that protect this information. These actions include (but are not limited to) staff training and signed confidentiality agreements, use of appropriate technology, strict control of access to records, use of encryption (a way of preventing unauthorized viewing of information) while information is being stored or shared, and secure methods of disposing data when they are no longer needed.

Sharing PHI and PII

My health information and information that identifies me may be shared with Mathematica to conduct this research study and with OVR to provide employment-related services to me.

I have the right to look at my information at Mathematica and to ask Mathematica (in writing) to correct my information that is wrong in its study records.

Mathematica will not identify me by name in any findings published on this research.

Sharing PII with the Social Security Administration

Mathematica will share a copy of this consent form with the Social Security Administration (SSA) and will provide SSA with information that identifies me that may include, but is not limited to, my name, date of birth, and SSN. SSA will share PII listed in the Consent to Disclose SSA Records below with Mathematica. If the consent is signed by a parent or legal guardian, SSA will only be able to disclose non-medical personally identifiable information, and only if the parent or legal guardian is acting on the minor's behalf.

Information shared with SSA for this research will be used for limited purposes consistent with applicable Federal law, regulations, and directives. No information provided for this research study will be used to determine current or future benefits.

Withdrawing Consent

I can change my mind at any time and withdraw my consent for my information to be used in the research. If this happens, I must withdraw my consent in writing. Beginning on the date I withdraw my consent, no new information will be collected about me if I revoke consent for those activities. However, Mathematica may continue to use any information that was collected before I withdrew my consent.

After signing this form, if I want to withdraw my consent, I can contact the person(s) below. They will make sure the written request to withdraw my consent is processed correctly.

Karen Katz
Senior Managing Consultant
Mathematica
1100 First Street, NE, 12th Floor
Washington, DC 20002-4221

Tel. (312) 585-3352

Consent Expiration

This consent has no expiration date, except that the end date of my consent to allow SSA to release information to Mathematica for purposes of this research study is January 1, 2030, as noted below. However, as stated above, I can change my mind and withdraw my consent at any time.

WHERE ELSE CAN I FIND INFORMATION ABOUT THIS RESEARCH STUDY?

A description of this clinical trial will be available on http://www.clinicaltrials.gov/. This website will not include information that can identify me. At most, the website will include a summary of the results. I can search this website at any time.

WILL IT COST ANYTHING TO PARTICIPATE IN THIS RESEARCH STUDY?

There will be no cost to me for my taking part in this research study. However, some of the services I may be offered may have costs associated with them. These costs may be paid by a combination of my own funds or other sources. The cost for these services is the same as would be the case if I were not participating in this research study.

WILL I BE PAID FOR PARTICIPATING IN THIS RESEARCH STUDY?

I will receive a total payment of $55 in appreciation of my completing the one-year follow-up survey ($5 cash before completion and $50 gift card after completion). I will receive an additional payment $50 if I participate in an interview.

CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THIS RESEARCH STUDY?

I understand that taking part in this research study is my choice and I may stop taking part in the research study at any time without penalty or loss of benefits to which I am otherwise entitled. I also understand the investigator has the right to withdraw me from the research study at any time.

If I choose to withdraw from the research study, Mathematica will ask if I want to withdraw consent for organizations as identified within this consent to disclose information about me. Mathematica will also ask whether I still want to participate in the one-year follow up survey. Mathematica will retain access to any data collected about me before my withdrawal from the demonstration.

WHO CAN I CONTACT FOR MORE INFORMATION?

If I have any questions about my treatment or the research procedures, I can contact:

David R. Mann, Ph.D.
Principal Researcher
Mathematica
600 Alexander Park, Suite 100
Princeton, NJ 08540

Tel. (609) 275-2365

I will receive a copy of this consent form if I agree to take part in this research study.

WILL INFORMATION ABOUT ME BE USED FOR OTHER RESEARCH STUDIES IN THE FUTURE?

The information collected in this research study may be useful in future research studies.

Mathematica may want to use my information in ways that identify me in future studies. This information includes my name, contact information, SSN, or other data that reveal I am the person the information describes. If Mathematica wishes to use information that can identify me in the future, it must obtain my written permission.

Mathematica may also want to use my information in a way that does not identify me. In this situation, Mathematica does not have access to my name (or other identifying information) and would not know that I am the person who provided the information. As part of my agreement to participate in this research study, I authorize Mathematica to use my information in ways that do not identify me until July 31, 2032.

CONSENT TO DISCLOSE SSA RECORDS

As part of my agreement to participate in this research study, I authorize SSA to disclose the following information to Mathematica for purposes of this research study:

- The diagnoses/impairments used to determine my eligibility for benefits,
- My applications for benefits and eligibility,
- How long I have been enrolled in benefit programs,
- Benefit amounts I received,
- Employment support I received, and
- Employment milestones I reached.

Information released by SSA under this consent will be released electronically to Mathematica, which is located at the following address:

Mathematica
600 Alexander Park, Suite 100
Princeton, NJ 08540

The end date of my consent to allow SSA to release information to Mathematica for purposes of this research study is July 31, 2030.

YOUTH SIGNATURE PAGE

A. SIGNATURE OF YOUTH (ALL YOUTH; IF YOUTH IS YOUNGER THAN AGE 18 OR OTHERWISE CANNOT GIVE CONSENT, PARENT OR LEGAL GUARDIAN SHOULD ALSO SIGN THE PARENT OR LEGAL GUARDIAN SIGNATURE PAGE)

I have read this entire form, or it has been read to me, and I understand it completely. All of my questions regarding this form or this research study have been answered to my satisfaction. I understand what this study is about and what I am being asked to do. I understand the risks and benefits of being part of this study. I volunteer to take part in the research. I make this choice freely. I authorize the release of information by the Social Security Administration as described above.

Please check (✓) one of the following boxes and sign the form:

If you want to be in the research study, check (✓) this box

☐ YES, I agree to be in the Youth Transition Exploration Demonstration.

If you do not want to be in the research study, check (✓) this box

☐ NO, I do not want to be in the Youth Transition Exploration Demonstration.

Youth name: _____

Youth signature: _____

Date of signature: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

B. PROVIDE SOCIAL SECURITY NUMBER AND DATE OF BIRTH OF YOUTH IF CONSENT TO PARTICIPATE HAS BEEN GIVEN

Social Security number: |__|__|__| - |__|__| - |__|__|__|__|

Date of birth: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

WITNESS SIGNATURE PAGE IF YOUTH SIGNATURE PAGE WAS COMPLETED WITH A MARK (X)

If the Youth Signature Page above was completed with a mark (X) rather than a full signature, please have two witnesses complete the section below. Please print the signee's name next to the mark (X) on the signature line above.

Signature of Witness 1:

Name: _____

Signature: _____

Mailing address: _____

_____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

Signature of Witness 2:

Name: _____

Signature: _____

Mailing address: _____

_____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

PARENT OR LEGAL GUARDIAN SIGNATURE PAGE

A. SIGNATURE OF PARENT OR LEGAL GUARDIAN (IF YOUTH IS YOUNGER THAN AGE 18 OR OTHERWISE CANNOT GIVE CONSENT)

I am the parent or legal guardian of the youth being asked to participate and have provided proof of my relationship to the youth. I have read this entire form, or it has been read to me, and I understand it completely. All of my questions about this research study have been answered to my satisfaction. I understand what this study is about and what I and my youth are being asked to do. I understand the risks and benefits of being part of this study. I volunteer and I volunteer my youth to take part in the research. I make this choice freely. I authorize the release of my youth's non-medical information by the Social Security Administration as described above.

Please check (✓) one of the following boxes and sign the form:

If you want the youth to be in the research study, check (✓) this box

☐ YES, I agree the youth can be in the Youth Transition Exploration Demonstration.

If you do not want the youth to be in the research study, check (✓) this box

☐ NO, I do not want the youth to be in the Youth Transition Exploration Demonstration.

Parent or legal guardian name: _____

Signature: _____

Date of signature: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

WITNESS SIGNATURE PAGE IF PARENT OR LEGAL GUARDIAN SIGNATURE PAGE WAS COMPLETED WITH A MARK (X)

If the Parent or Legal Guardian Signature Page above was completed with a mark (X) rather than a full signature, please have two witnesses complete the section below. Please print the signee's name next to the mark (X) on the signature line above.

Signature of Witness 1:

Name: _____

Signature: _____

Mailing address: _____

_____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

Signature of Witness 2:

Name: _____

Signature: _____

Mailing address: _____

_____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

RESEARCH STUDY REPRESENTATIVE AND WITNESS SIGNATURE PAGE

A. VERBAL CONSENT IF THE YOUTH, PARENT, OR LEGAL GUARDIAN LACKS UPPER LIMB FUNCTION TO COMFORTABLY WRITE

The youth, parent, or legal guardian, _____, is unable to sign the consent form due to impaired arm function. I certify that I have carefully explained the purpose and nature of this research to them in appropriate language and they have had an opportunity to discuss it with me in detail. I have answered all of their questions and they have consented to participate in this research study. I am signing this form to document that they have given their consent to participate in this research study and authorization for the release of information by the Social Security Administration as described above. If a parent or legal guardian is consenting on behalf of a minor, the authorization is for release of the minor's non-medical information by the Social Security Administration.

Signature of Research Study Representative:

Name: _____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

Signature of Witness 1:

Name: _____

Mailing address: _____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

Signature of Witness 2:

Name: _____

Mailing address: _____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

TRANSLATOR SIGNATURE PAGE

A. SIGNATURE OF READER/TRANSLATOR IF THE YOUTH, PARENT, OR LEGAL GUARDIAN DOES NOT READ ENGLISH WELL

The person who has signed above, _____, does not read English well. I read English well and am fluent in *(name of the language)* _____, a language this person understands well. I have translated the entire content of this form for them. To the best of my knowledge, they understand the content of this form, have had an opportunity to ask questions regarding the consent form and the research study, and have had their questions answered.

Name: _____

Signature: _____

Date: |__|__| / |__|__| / |__|__|__|__|
Month Day Year

Privacy Act Statement
Collection and Use of Personal Information

Sections 205 and 1110 of the Social Security Act, as amended, allow the Social Security Administration (SSA) to collect this information, which SSA will use to evaluate the Youth Transition Exploration Demonstration research study. Providing this information is voluntary; not providing all or part of the information will not affect any SSA benefit. As law permits, SSA may use and share the information you submit, including with other Federal agencies, contractors, cooperative agreement awardees, and others, as outlined in the routine uses within System of Records Notices 60-0089, 60-0218, and 60-0320 available at www.ssa.gov/privacy. The information you submit may also be used in computer matching programs for Federal benefits eligibility and to recoup debts under these programs.

Paperwork Reduction Act Statement - This information collection meets the requirements of 44 U.S.C. § 3507, as amended by section 2 of the Paperwork Reduction Act of 1995. You do not need to answer these questions unless we display a valid Office of Management and Budget control number. The OMB control number for this information collection is XXXX-0XXX, expiring xx-xxx-20xx. We estimate that it will take about 10 minutes to read the instructions, gather the facts, and answer the questions. You may send comments about our time estimate above to: Social Security Administration, 6401 Security Blvd, Baltimore, MD 21235-6401. **Send** only **comments relating to our time estimate to this address, not the completed form.**