

UTAH SSDI '1 FOR 2' PROJECT

INFORMED CONSENT

Name _____ Social Security # _____ Date of Birth _____

- The Utah SSDI '1 for 2' Project is a Social Security Administration (SSA) research study. The study will look at the effect of changing the rules about work activity for people receiving Social Security Disability Insurance (SSDI) benefits.
 - SSA has contracted with the Utah Department of Health (UDOH) to conduct and evaluate the '1 for 2' Project in Utah. UDOH has contracted with Utah State Office of Rehabilitation, University of Utah and Utah State University to assist.
 - Participation in the Utah SSDI '1 for 2' Project is voluntary.
- You need to sign three forms in order to participate in the Project. One is this Informed Consent document. The second is called the Authorization to Disclose Information. The third authorizes the release of IRS data by Social Security. By signing these forms, you agree to participate in the Project and to release information about yourself to the SSDI '1 for 2' Project team.
- Project participants will be randomly assigned to either a **Current Rules Group** or a **Pilot Rules Group**.

Current Rules Group

If you are assigned to the **Current Rules Group**, your benefits will be administered under current rules for SSDI. You will not be eligible for the benefit offset or other SSDI rule changes being tested in this Project. Your participation in the Project will not affect your rights and responsibilities under the SSDI program.

Pilot Rules Group

If you are assigned to the **Pilot Rules Group**, the following rules will apply to you.

- After completion of your Trial Work Period and Cessation and Grace period, for every \$2 you earn over the Substantial Gainful Activity (SGA) amount your cash benefits will be reduced by \$1. This is called a benefit offset. In 2006, the SGA amount is \$860 per month, or \$1450 per month if you are blind. In 2005, the SGA amount was \$830 per month, or \$1380 per month if you are blind. This benefit offset is available even if you are participating in SSA's "Ticket to Work" program.
- This benefit offset will be in effect for a 72-month Extended Period of Eligibility (EPE) following completion of your Trial Work Period. The benefit offset may begin no earlier than the month after the month you enroll in the Project.
 - Medical Continuing Disability Reviews (medical CDRs) will not be conducted from the time you enroll in the '1 for 2' Project through the end of your 72-month EPE. If a medical CDR has been started at the time of enrollment, it will be completed.

- Any Social Security benefits for your dependents will not be reduced based on your performance of SGA while the benefit offset is in effect.

If you are assigned to the Pilot Rules Group, these SSDI rule changes will be available to you as long as you remain eligible for the Project and continue to be eligible for SSDI. Your continued eligibility for SSDI benefits may be affected by other changes in Social Security law.

Except for these SSDI rule changes, your rights and responsibilities under the SSDI program will not be affected. All other provisions of the Social Security program will continue to apply to you and to your dependents, if applicable.

REPORTING WORK ACTIVITY AND EARNINGS

You have a responsibility under the SSDI program to report your work activity and earnings to SSA. If you enroll in the Project and are assigned to the Current Rules Group, you will be responsible for reporting your work activity and earnings directly to SSA.

If you enroll in the Project and are assigned to the Pilot Rules Group, the Project team will coordinate the reporting of your work activity and earnings to SSA. You will be required to provide estimates of your earnings periodically and to report your actual earnings at least annually, or more frequently if your earnings change. You will provide these estimates and reports to SSA through the Project team during your participation in the Project.

PARTICIPATION IN RESEARCH

By signing this Informed Consent form, you agree to participate in a research and evaluation Project. This means you agree to complete surveys for the Project regarding your work history, plans and concerns you have about working, general health status information and comments on the Project. You are not required to work.

The surveys will include:

- Intake interview and survey
- 6-month written survey
- 12-month telephone survey

If you consent to participate in the Project and do not volunteer the information requested for the research, or refuse to complete the research surveys, your eligibility for the Project will terminate. If you are assigned to the Pilot Rules Group, you will be subject to the usual SSDI program rules beginning with the first day of the month following the month in which your eligibility for the Project terminates.

By signing the Authorization to Disclose Information form, you are agreeing to release information about yourself to the Project team. This will allow the Project to collect data about you from public programs for which you give specific consent for

release. The information that will be collected includes data about program services you have received, and employment history and wage data from your jobs. Your Social Security Number (SSN) will be used to collect the public program data and the wage data.

CONFIDENTIALITY

The information about you that is collected by the Project is confidential and will be protected under the Privacy Act. Each survey will have an ID number that will link your name and address to send out follow-up surveys. The ID number will also be used to link survey responses to public program data. All identifying information will be kept in locked filing cabinets. Electronic data will not be transferred over the Internet unless it is encrypted. Neither your name nor your identity will be used for publication or publicity purposes. At the end of the Project, all personal identifiers in the data such as your name, address, and SSN will be destroyed.

Social Security Administration Privacy Act Statement

SSA is allowed to collect the information asked for while you participate in the Utah SSDI '1 for 2' Project under section 234 of the Social Security Act. The information requested from you as a participant will be used to evaluate the Project. While you do not have to give us this information, your failure to do so will result in the termination of your eligibility for the Project. This means that if you are assigned to the Pilot Rules Group, you will no longer have the SSDI rule changes applied to you. Also, the Project will use the information asked for while you are a participant to decide what services would best help you. Giving us this information is voluntary. However, without it, the Project will be unable to offer you services.

There are certain situations authorized by Federal law in which SSA may release the information you give us through this Project. For example, SSA may release the information to a congressional office in response to an inquiry that office may make at your request, or to any entity hired by SSA to evaluate the Project. Explanations about these and other reasons why information you provide us may be used or given out are available in Social Security Offices. If you want to learn more about this, contact any Social Security Office.

The Project team is required by federal and state law to report to the authorities any actual or suspected abuse, neglect or exploitation of a child, disabled adult or elder adult.

BENEFITS

Everyone who participates in the Project will be offered and encouraged to take advantage of benefits planning services. This will help you understand how working

could affect public benefits you get. You do not have to participate in the Project to get these benefits planning services.

Everyone in the Project will receive a gift card for a small amount of money to a local grocer for completing the telephone survey.

If you are in the **Pilot Rules Group**, you will be able to increase your income from working and have your SSDI benefit gradually reduced for income over SGA. In addition, the starting of medical CDRs will be suspended from enrollment through your extended period of eligibility and there will be no loss of dependent benefits, if these apply.

If you are in the **Current Rules Group**, you may or may not personally benefit from participating. However, by participating, you will be helping to create knowledge which may benefit SSDI beneficiaries in the future.

RISKS

Whether or not you enroll in the Project, you run the risk of an overpayment if you do not report earnings to SSA. If you increase your earned income, you could lose benefits from some of the programs for which you are presently eligible such as housing, food stamps or childcare. In addition, any earned income is taxable.

If you are assigned to the **Pilot Rules Group**, you will be required to report earnings estimates to SSA through the Project team, including estimates of your annual earnings. You will need to report your actual wages to the Project team at least annually, or more frequently if your income changes. You run the risk of an overpayment if you significantly underestimate your annual earnings or you do not provide timely reports of your actual wages for the preceding year or of changes in your income.

Once you are enrolled you will encounter minimal risk in this Project. There is a slight risk to you if someone outside the research team illegally obtains your public program or survey data thereby breaking confidentiality. If confidentiality is broken, there is an extremely small risk that information provided to us could be used improperly. We will take every possible measure to protect your privacy and confidentiality.

WITHDRAWAL FROM PROJECT

If you do not want to participate in this Project, you do not have to. This is a completely voluntary Project. If you do enroll, you may choose to withdraw from the Utah SSDI '1 for 2' Project at any time. If you would like to withdraw, a Project team member can provide you with a form. If you are assigned to the Pilot Rules Group and you withdraw from the Project, your enrollment in the Project will end, and you will be subject to the usual SSDI program rules, beginning with the first day of the month following the month you sign the form to withdraw.

COSTS

There are no financial costs to you for participating in this Project.

QUESTIONS ABOUT PARTICIPATION

If you have questions regarding this Project, please contact the Work Ability Project at 877-246-9675. You may also contact Sara McCormick, University of Utah, at 801-585-7764.

CONSENT

By signing this consent form, I confirm I have read and understand the information presented in it. I have had the opportunity to ask questions. I understand that my participation is voluntary, and I am free to withdraw at any time without giving a reason and without cost. I understand that I will be given a signed copy of this consent form to keep. I voluntarily agree to take part in this study.

Participant's Signature

Date

Street, City, State, Zip Code

() -
Telephone

Parent/Guardian's Signature (if applicable)

Date

Street, City, State, Zip Code

() -
Telephone

Consent by legal guardian

I confirm that I have read and understand this Informed Consent document. I understand the participant's involvement is voluntary and that they are free to withdraw at any time, without giving a reason and without cost.

Legal Guardian's signature (if applicable)

Date

Enrollment Specialist's signature

Date

Individuals needing accommodations to participate in this Project please contact the Work Ability Project at 877-246-9675.