Wilder Research

Evaluation ethics Evaluation resources from Wilder Research

Before you start collecting data, one very important issue cannot be overlooked or overstated. Strategies to protect the rights and dignity of those who participate in the evaluation should be incorporated into the way that you design and carry out your project. It is also important to consider safeguards that may be needed when your participants are youth.

Many professional organizations have ethical guidelines (e.g., the National Association of Social Workers, the American Psychological Association, and the American Counseling Association). While their details vary, most guidelines address these four over-arching issues:

- Help or benefit to others acting in ways that promote the interests of others, by helping individuals, organizations, or society as a whole.
- Do no harm the corollary principle is not bringing harm to others, including physical injury and psychological harm (such as damage to people's reputation, selfesteem, or emotional well-being).
- Act fairly treating people in ways that are fair and equitable, including making decisions that are independent of race, gender, socioeconomic status, and other characteristics.
- Respect others respecting the rights of individuals to act freely and to make their own choices, while protecting the rights of those who may be unable to fully protect themselves.

Key ethical issues related to program evaluation

Consideration of risks and benefits

Your evaluation can benefit program participants and others. In some cases, there may be benefits to an individual who participates in an evaluation, such as receiving a gift certificate or other incentive in exchange for completing an interview. Other benefits emerge as a result of changes made at the program or agency level – for example, the evaluation may guide strategies for improving a program's impact, leading to more positive outcomes for current or future participants.

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However, associated risks can come with these benefits. You should carefully consider any harm that may result from an evaluation, and take steps to reduce it. With evaluations of ATOD prevention programs, or any programs, potential risks may include:

- Sacrificing time and energy to participate
- Emotional consequences (e.g., participating requires them to answer questions about their experience with ATOD).
- Social harm (e.g., confidentiality breaches result in people learning about their ATOD use).
- Youth may disclose dangerous or unhealthy family situations, and program staff may need to report situations to authorities.

In weighing benefits relative to risks, you want to make sure you maximize the resources used to conduct your evaluation (e.g., time and money) and the involvement of your participants. Strategies to do this include targeting your evaluation to the key questions you have, carefully reviewing and discussing findings, and effectively using your results.

Informed consent

Everyone who participates in the evaluation should do so willingly. In general, people participating in any research project, including a program evaluation, have the right to:

- Choose whether or not they want to participate without penalties (e.g., participation in the evaluation should not be a mandatory requirement for program participation).
- Withdraw from the evaluation at any time, even if they previously agreed to participate.
- Refuse to complete any part of the evaluation including refusing to answer any questions.

The word "informed" is important – in addition to choosing whether or not to participate in the evaluation, people have the right to understand all implications of participating. To ensure that potential participants can make an informed decision regarding their involvement, you should:

Provide potential participants with information about the evaluation, including why it is being done, what you are asking them to do, how you will you use the information, and how long it will take.

- Describe both the potential benefits of participation and any foreseeable risks, including possible discomfort due to participation.
- Share this information using language all participants can understand avoid jargon and translate if needed.
- Allow the participant the opportunity to ask any questions about the evaluation.

When working with youth under age 18, parental consent might be required. In addition to parental consent for minors, youth should also be asked for their assent to participate. Youth who have been given permission from their parents to participate in the evaluation can still decline participation. Youth over the age of 18 provide their own consent to participate, and therefore parental consent is not necessary.

Participants may not need to sign a consent form if they are adults capable of making decisions, have not been coerced, and will not be put at significant risk by participating in the evaluation. For example, if you want participants to fill out an optional anonymous survey asking them if they were satisfied with specific elements of a program, the fact that they complete and return the survey can be construed as providing consent. Signed consent forms may be necessary in other situations, however, especially if you plan to:

- Include children or others who cannot provide their own consent (in which case you will need to obtain consent from a legally authorized person, such as parent or guardian).
- Collect very personal or sensitive information.
- Use the results for purposes other than program improvement, such as publication, training activities, or participation in a larger research project.
- Gather information about participants from other third parties, such as program staff, teachers, family members, or others.
- Require significant time or effort on the part of participants, such as asking them to participate in multiple or time-consuming interviews.

If you are unsure as to whether or not consent is necessary, please consult your Wilder consultants.

Confidentiality

It is not always possible for evaluations to be conducted anonymously, without collecting identifying information such as a participant's name or social security number. However, all information gathered should be considered confidential and not shared with others. To ensure confidentiality, consider these strategies:

- Collect data in a private location where surveys cannot be seen and interviews cannot be overheard.
- Do not discuss information about individual participants with other people. Findings should generally only be discussed at an aggregate level or with identifying information disguised.
- Keep completed surveys or interviews in a secure location where they cannot be seen by other people.
- Shred or securely dispose of completed evaluation materials when they are no longer needed.

You may encounter situations in which you believe that it is important to disclose confidential information. In some cases, this may be due to a legal requirement (e.g., a mandated reporter of child abuse). In other cases, you may learn through the evaluation that someone is intending to cause harm to themselves or others, or is at risk of harm from others. To the extent possible, consider in advance the types of disclosures that may be needed and develop a plan to handle these situations. Provide information about possible disclosure of confidential information with the consent instructions.

Ensuring safety

In some cases, you may have concerns for the safety of your participants. Be thoughtful about participants' needs and take care to protect participants as much as possible. In the course of collecting information you may learn that one of your participants is abusing drugs or living in an unsafe situation. While your ability to intervene may be limited depending upon the level of imminent risk that the person is experiencing, it may be appropriate for your evaluation staff to be prepared with information about how to refer participants for assistance if they desire it.

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Federal privacy laws

There are a few federal laws that serve to protect the privacy of research participants, including the Federal Educational Rights and Privacy Act (FERPA) and the Protection of Pupil Rights Act (PPRA). No elements of your current evaluation are subject to any federal privacy laws, but it is good to be aware that such laws do exist. The following briefly describes the policies that could potentially affect future evaluation efforts of the current project or future projects. If you are concerned about any of these laws, feel free to visit the <u>www.evaluATOD.org</u> website (available summer 2009) or contact your Wilder consultant.

Health Insurance Portability and Accountability Act (HIPAA) – HIPAA is a federal law enacted in 1996 designed to protect the privacy and security of health information. This could include information collected about chemical health or mental health. For information about HIPAA, please contact your Wilder consultant. Or, you may choose to go to <u>http://www.hhs.gov/ocr/hipaa/</u>.

Institutional Review Boards (IRBs) – An IRB is a federally-recognized committee authorized to review research projects and ensure that procedures comply with ethical standards. Many colleges, government offices, hospitals, and research agencies have established IRBs. IRB approval is generally not required for program evaluations. In rare instances it may be required, especially with some types of federal funding. Evaluations may also require IRB approval when the evaluator intents to share the results outside of the program being evaluated, such as published articles or journals. Some typical evaluations that might require IRB approval are:

- Evaluations that use sensitive health information, such as information from medical records
- Evaluations where you contract or work with a faculty member or student from any academic setting

More information about IRBs and research with human subjects can be found at: <u>http://www.hhs.gov/ohrp/</u>.

Addressing ethical challenges

It is important to note that this evaluation was designed to be one of high quality and ethical. You can feel confident that you are approaching this evaluation ethically. In some cases, however, you might face situations in which the ethical direction is not clear. Ask yourself the following questions when faced with an ethical challenge:

- What does my intuition tell me? Am I feeling stress or self-doubt about a direction that has been chosen?
- Is there an established way that my colleagues would act in the same situation?
- Does my profession have a set of ethical codes or guidelines? If so, do they suggest a course of action?
- Are there existing laws that apply to this situation? If so, what requirements do I need to follow?
- Which overarching ethical issues apply to this situation (e.g., helping others, doing no harm, acting fairly and being respectful)? Does a clear solution to the challenge emerge when considering these principles?
- What are my personal values and beliefs? What guidance do they provide?

If you are unable to decide the best course of action, consult with others as needed, including colleagues, supervisors, your coalition, DHS staff, or your Wilder consultant.

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For more information To learn more about evaluation <u>www.wilderresearch.org</u>

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