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# Confidentiality and Disclosure in Non-Intervention Adolescent Risk Research

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Non-intervention research on adolescent risk often uncovers evidence of threats to the welfare of participants or others that may be unknown to adults in a position to protect youth or provide appropriate services. Whether to keep such information confidential or disclose it to guardians or professionals is a daunting ethical challenge that requires investigators to balance tensions between scientific responsibilities to produce well-controlled studies and humanitarian obligations to protect the welfare of vulnerable youth. This article discusses the ethical dimensions of such decisions and provides a decision-making strategy for developing ethically appropriate confidentiality and disclosure policies.

The 21st century has witnessed increased public anxiety over the growing tide of conditions threatening the development of our nation's youth. Empirical information on the individual and contextual factors contributing to developmental risk and resilience is an essential precursor to the design and evaluation of effective preventive interventions (Benson, Leffert, Scales, & Blyth, 2012; Fisher, Busch, Brown & Jopp, 2012; Lerner, 2010). To meet this need, social-behavioral scientists use interviews, surveys, and other non-intervention research methods to generate critical knowledge on adolescent mental health problems, substance abuse, peer and family violence, delinquency, and sexual and other health compromising behaviors (Hepburn, Azrael, Molnar, & Miller, 2012; Schwartz et al., 2010).

Obtaining such information challenges traditional views of confidentiality in research (Fisher, 1994, 1999; Lothen-Kline, Howard, Hamburger, Worrell, & Boekeloo, 2003; Moolchan & Mermelstein, 2002). First, at-risk youth studies can elicit information about serious threats to participant welfare or harm to others which parents, counselors or other adults in a position to help are unaware. Second, the types of behaviors in which participants are engaged, if reported, could place participants, their family members or peers in social, physical, or legal

jeopardy. Third, the disclosure obligations of non-intervention scientists working with such high-risk populations are less clear than the ethical responsibilities of those conducting clinical trials where medical or mental health assessment, referral or intervention are available and expected. Researchers studying high-risk youth are thus faced with a critical ethical question: *Under what conditions should non-intervention developmental scientists report or refer for help adolescent research participants whose data indicate they or others are at risk of serious harm?*

The purpose of this article is to illuminate the ethical dimensions of this question. The article begins with an articulation of the scientist-citizen dilemma and the ethical arguments for and against disclosing research-derived confidential information. This discussion is followed by a summary of legal requirements impacting disclosure decisions. The article concludes with a decision-making model to guide investigators in identifying when it is necessary and how to develop confidentiality and disclosure procedures that protect participant welfare and scientific integrity.

## THE SCIENTIST-CITIZEN DILEMMA

The *Code of Federal Regulations for the Protection of Human Subjects* (DHHS, 2009) permits disclosures of confidential information when mandated by law or to

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protect participants or others from harm. However, it is silent on when disclosures are ethically justified. Adolescent risk investigators are thus left on their own to determine how to resolve the scientist-citizen dilemma--the tension between their scientific obligation to the implementation of well-controlled research designs with their humanitarian responsibility to protect the autonomy and welfare of vulnerable youth (Fisher & Goodman, 2009; Fisher & Rosendahl, 1990). For example, what should an investigator conducting a longitudinal study on school bullying do if data reveal a participant or another adolescent is in immediate danger of physical harm? Will reporting the danger to a parent or school counselor diminish the scientific rigor and ecological validity of subsequent data collection? Will failing to report the danger result in a preventable harm? Will participants perceive disclosure as a moral obligation or a betrayal of trust? Will it jeopardize future research participation of other adolescents? The next sections articulate the ethical arguments brought to bear on these important questions.

### SCIENTIFIC RIGOR AND RESPONSIBILITY

Strict confidentiality policies reflect non-intervention scientists' legitimate concerns that reporting research-derived information may be outside the boundaries of the responsible conduct of research. First, the science establishment has traditionally viewed interference in the psychological and behavioral phenomena being studied as contrary to accepted principles of well-controlled and objective research design (Boys, Marsden, Stillwell, & Hatchings, 2003; Duncan, Drew, Hodgson, & Sawyer, 2009). Second, the majority of hypotheses and measures administered for non-intervention studies on adolescent risk are designed to test significant relationships among group means or other population-based statistical associations and are not constructed to determine the accuracy of an individual participant's response (Fortenberry, 2009). Thus, non-intervention scientists maintain a healthy skepticism that behaviors measured exclusively for research purposes may not have "diagnostic" validity for individuals to ethically justify disclosing to others a particular adolescent's responses (Fisher, 2002, 2013; Hoonard, 2001).

Third, most developmental scientists who have received rigorous training in non-intervention research designs did not receive training in the clinical skills necessary to administer a diagnostically valid post-experimental assessment if a participant's responses or demeanor unexpectedly suggest the need for services. Moreover, to do so might violate the initial informed consent agreement for the scope of confidentiality and the nature of data to be collected. Finally, developmental scientists

whose research is focused on description and explanation of factors influencing adolescent risk and resilience may lack familiarity with school or community-based services leaving them uninformed as to whether providers will react competently in response to the information disclosed by the participant. The ethical decision-making model presented at the end of this article offers a blueprint for responsibly addressing the ethical complexities arising from these scientist-citizen dilemmas.

### PARTICIPANT AUTONOMY AND WELFARE

The decision to take no action when potentially harmful information is revealed during research is supported by the importance federal guidelines and professional codes of conduct place on the maintenance of confidentiality for research-derived information (American Psychological Association, 2010; DHHS, 2009). Implicit in these rules are two assumptions: (1) research participants have a fundamental right to protection of their privacy and (2) rigorous rules against disclosure avoids granting undue authority to researchers to decide which problems should be reported. A strict non-reporting policy also reflects justified concern that disclosures can create stressful or harmful consequences for teenage participants, especially if adults react punitively.

#### What Do Adolescents Want?

Another assumption underlying confidentiality policies is that teenagers value autonomy and would feel betrayed by an experimenter if information was disclosed (Brooks-Gunn & Rotheram-Borus, 1994). This assumption has prevented scientists from asking two critical questions: *What moral role does an adolescent research participant expect of an investigator and what are the consequences of failing to fulfill this role?* In many instances, the research context may be the first time a teenager has disclosed high-risk information to an adult.

Consider the following. During an interview study on peer relationships several participants spontaneously describe their discomfort with aggressive sexual advances made by an older student; and this is the first time the youth has disclosed these concerns. If interviewers do not respond to these revelations, the youth may conclude that adults think this problem is unimportant, that no services are available to help them stop such advances, or that knowledgeable adults cannot be depended on to help youth in need (Fisher, 1994, 1999, 2003).

In a series of studies, Fisher and her colleagues asked youth and parents what investigators should do if during the course of a non-intervention study they found an adolescent's welfare to be in jeopardy (Fisher, 2002, 2003; Fisher et al., 1996; Fisher & Wallace, 2000; Masty &

Fisher, 2008; O'Sullivan & Fisher, 1997). In most instances, both teenage and adult respondents viewed a policy of referring the participant to appropriate youth services most favorably. Contrary to expectations, they often viewed strict confidentiality policies negatively, and thought researchers had a moral obligation to disclose information if they learned a participant was a victim of sexual harassment, indicated suicidal ideation, or engaged in other dangerous behaviors. Moreover, parents were just as likely to say they would consent to a procedure that provided adolescents with a direct referral to a service provider as they were to a policy of directly informing parents. Such studies underscore the need to situate decisions surrounding confidentiality and disclosure policies within specific research contexts and the perspectives of the specific population considered for investigation (Fisher, 1999; 2002; Fisher & Wallace, 2000; Fisher & Goodman, 2009).

## LEGAL OBLIGATIONS

Confidentiality and disclosure decisions must take into account legal reporting requirements (Becker-Blease & Freyd, 2006; Lamb & Molloy, 2012). All states have laws mandating educators and health care workers to report suspected child abuse and neglect. In some states researchers are included in the list of mandated reporters. Consequently investigators must review state laws to determine their personal responsibility to report child abuse and the responsibility of other professionals (e.g., pediatricians, school psychologists) who are members of their research team. In addition, psychologists conducting research over the Internet need to be familiar with state laws governing mandatory reporting in jurisdictions where participants reside (Fisher, 2013; Stern, 2004).

### Duty-to-Protect Laws

“Duty-to-protect” state laws require health care providers to inform third parties of a client’s threat against them if the provider has (a) a “special relationship” with the prospective assailant, (b) the ability to predict violence will occur, and (c) ability to identify the potential victim (*Tarasoff v. Regents of the University of California*, 1976). Scientists studying violence-prone individuals may also have a duty-to-protect potential victims from a research participant’s threats (Appelbaum & Rosenbaum, 1989). For example, researchers conducting a longitudinal study on gang violence may have (a) an ongoing direct scientific relationship with participating gang members; (b) the expertise to predict a violent threat will be carried out; and (c) know the identities of potential victims (e.g., see Taylor, et al., 2002a, 2002b, for examples of such research). In designing confidentiality and disclosure

procedures for such research, investigators are wise to consider in advance whether they have a legal or moral duty to protect, and if the answer is affirmative to communicate this to prospective participants during informed consent.

In the wake of highly publicized incidents of school violence, many states require or permit school personnel to detain, question and report students suspected of planning acts of school violence. Criteria for reporting threats include the type of data investigators studying this problem may collect including a student’s past violent, menacing, or stalking acts and the cognitive and physical capability of following through on violent intentions (Jacob & Hartshorne, 2007). Thus, investigators studying school violence within educational settings should learn whether state laws apply to research-derived information relevant to pupil safety and the reporting obligations of school personnel who may collaborate in the research (Fisher, 2013).

### Certificate of Confidentiality

The *Public Health Service Certificate of Confidentiality* gives researchers immunity against subpoenas for participant information when data collected that, if released, could result in stigmatization, discrimination, or legal action (<http://grants2.nih.gov/grants/policy/coc/>). It does not, however, prevent scientists from deciding they have an ethical responsibility to disclose harmful or illegal behaviors to relevant authorities. Researchers who believe they may have an ethical responsibility to report to authorities any potentially lethal or criminal participant behaviors should ensure that informed consent procedures clarify this distinction for prospective participants and their guardians.

## STEPS FOR DETERMINING RISK-DISCLOSURE PROCEDURES

Every research project requires a series of decision points that build to the construction of best ethical practices for the particular population and research context. In determining confidentiality and disclosure procedures for studies on adolescent risk and resilience, investigators need to consider the extent to which reporting to adults who can assist the youth will compromise the scientific integrity of the study, result in social or legal harm for the youth and his or her family, or provide a better form of protection than taking no action. The following steps can assist investigators in making these important decisions.

1. Anticipate disclosure challenges. Draw upon published data and one’s own investigative experience with high-risk youth to evaluate: (a) the range and

severity of risk responses expected during data collection and (b) the probability that some participant responses might require a disclosure procedure.

2. Evaluate the diagnostic validity of risk measurement. Determine whether the data collection measures have sufficient psychometric properties to conclude that an individual participant is at high risk for harm to self or others. This determination includes examining the cultural validity of the measures for the population studied (Fisher et al., 2002). If the measures *do not* have diagnostic validity, maintaining confidentiality or providing all participants with a list of community-based youth services may be the most ethically appropriate policy. If measures *do* have diagnostic validity, investigators should identify the threshold at which scores or interview responses would trigger a disclosure obligation.
3. Investigate legal responsibilities. Determine whether state or local reporting laws pertain to the youth risk behaviors studied, the legal obligations of members of the research team, and the educational or healthcare professionals at the settings in which the research is conducted.
4. Engage in community consultation. Identify and develop a working relationship with youth-oriented community health, social, and legal services to maximize the probability that disclosures, if necessary, will adequately protect a participant or others from harm. Seek parent and youth perspectives on expectations regarding the investigator's protective role and risks and benefits of alternative ethical procedures including: maintaining confidentiality, referring participants to available youth services, or reporting information to appropriate adults (Anderson et al., 2012; Fisher, 2002; Flicker & Guta, 2008; Spencer, 2011).
5. Select a policy that appropriately balances youth welfare and scientific validity. Based on Steps 1–4, generate alternative confidentiality, referral and disclosure policies and select the policy that (a) most accurately reflects the probability that participant responses will pose a disclosure dilemma; (b) is supported by the nature and validity of risk information that will be obtained during the course of research; (c) meets the legal obligations of research team members; (d) best fits the availability and adequacy of community resources; (e) is compatible with the values and expectations of prospective participants and their guardians; and (f) preserves the scientific integrity of the study.
6. Train research team members and formalize relationships with appropriate referral or reporting agencies. Establish procedures to be followed by

research staff when a potential disclosure responsibility is triggered. If confidentiality is to be maintained, debriefing at the end of a survey or interview session might include discussion of the high-risk nature of behaviors studied and a list of local youth-friendly services. If disclosure is an option, staff must be trained in accessing levels of risk and steps to take if a participant meets reporting criteria. This step may include explaining the process to the participant, determining whether the participant is already receiving services for the problem and contacting the principal investigator, the participant's guardian, a designated healthcare provider or legal services.

7. Communicate the policy during informed consent. Ensure that guardian permission and adolescent assent procedures explicitly communicate the extent of confidentiality protections and the rationale and procedures to be followed if referral or reporting is judged to be in an adolescent's best interest.
8. Monitor, Evaluate and Modify if Necessary. The most appropriate confidentiality and disclosure policies are neither singular nor static. Continuous monitoring of policy consequences can help ensure that (a) risks are neither under- or over-reported, (b) disclosures result in positive rather than negative consequences for participants, (c) the internal validity of the study is maintained, and (d) the research retains the trust of participants, their families, and communities.

## CONCLUSIONS

Non-intervention studies illuminating factors potentially compromising adolescent health and safety bring to the surface potentially conflicting confidentiality and disclosure obligations because of the important public health benefits of producing well-controlled scientific studies on adolescent risk and resilience and the humanitarian obligation to protect the welfare of participants whose life situation may place themselves or others in jeopardy. There are no cookie-cutter solutions to confidentiality and disclosure policies, and each investigator needs to weigh the costs and benefits of alternative policies to participants, research team members, and the integrity of the research design. As the primary training ground for student socialization in the responsible conduct of research (Fisher, Fried, & Feldman, 2009; Fisher, Fried, Goodman, & Germano, 2009), applied developmental science programs can enhance the future responsible conduct of adolescent research through engaging students at the outset of training in the identification of ethical issues as they arise across diverse research context and providing opportunities to

seek and incorporate the perspectives of participant populations in research ethics planning. Exploring the ethical dimensions of adolescent risk research provides an opportunity to envision research ethics as a process that draws upon investigators' knowledge as scientists of the human condition, their responsiveness to others as members of society and to discover new means of resolving obligations as scientists and citizens.

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