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1 PURPOSE

1.1. This guidance outlines the additional obligations of investigators conducting ED research.

2 GUIDANCE

- 2.1. For research funded by the National Institute on Disability and Rehabilitation Research, when the IRB reviews research that purposefully requires inclusion of children with disabilities or individuals with mental disabilities as research subjects, the IRB includes at least one person primarily concerned with the welfare of these research subjects.
- 2.2. The Family Educational Rights and Privacy Act (FERPA) applies when investigators obtain student records or personal education information from an education program as defined as any program principally engaged in the provision of education, including, but not limited to, early childhood education, elementary and secondary education, postsecondary education, special education, job training, career and technical education, and adult education. FERPA requirements include:
 - 2.2.1. An educational agency or institution may disclose personally identifiable information from an education record of a student without consent if the disclosure is part of an agreement between organizations or subjects conducting studies for, or on behalf of, educational agencies or institutions to:
 - 2.2.1.1. Develop, validate, or administer predictive tests
 - 2.2.1.2. Administer student aid programs
 - 2.2.1.3. Improve instruction
 - 2.2.2. A school district or postsecondary institution that uses this exception is required to enter into a written agreement with the organization conducting the research that specifies:
 - 2.2.2.1. The determination of the exception
 - 2.2.2.2. The purpose, scope, and duration of the study
 - 2.2.2.3. The information to be disclosed
 - 2.2.2.4. That information from education records may only be used to meet the purposes of the study stated in the written agreement and must contain the current requirements in Department of Education regulations on redisclosure and destruction of information
 - 2.2.2.5. That the study will be conducted in a manner that does not permit personal identification of parents and students by anyone other than representatives of the Organization with legitimate interests
 - 2.2.2.6. That the Organization is required to destroy or return all personally identifiable information when no longer needed for the purposes of the study
 - 2.2.2.7. The time period during which the Organization must either destroy or return the information
 - 2.2.3. Education records may be released without consent under FERPA if all personally identifiable information has been removed including:
 - 2.2.3.1. Student's name and other direct personal identifiers, such as the student's social security number or student number
 - 2.2.3.2. Indirect identifiers, such as the name of the student's parent or other family members; the student's or family's address, and personal characteristics or other information that would make the student's identity easily traceable; and date and place of birth and mother's maiden name
 - 2.2.3.3. Biometric records, including one or more measurable biological or behavioral characteristics that can be used for automated



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2.2.3.4. recognition of an individual, including fingerprints, retina and iris patterns, voiceprints, DNA sequence, facial characteristics, and handwriting.

- 2.2.3.5. Other information that, alone or in combination, is linked or linkable to a specific student that would allow a reasonable person in the school community, who does not have personal knowledge of the relevant circumstances, to identify the student with reasonable certainty.
- 2.3. For certain types of research directly funded by ED the Protection of Pupil Rights Amendment (PPRA) applies.
 - 2.3.1. PPRA prohibits students from being required, as part of any research project, to submit without prior consent to surveys, psychiatric examination, testing, or treatment, or psychological examination, testing, or treatment, in which the primary purpose is to reveal information concerning one or more of the following:
 - 2.3.1.1. Political affiliations or beliefs of the student or the student's parent
 - 2.3.1.2. Mental or psychological problems of the student or the student's family
 - 2.3.1.3. Sex behavior or attitudes
 - 2.3.1.4. Illegal, anti-social, self-incriminating, or demeaning behavior
 - 2.3.1.5. Critical appraisals of other individuals with whom respondents have close family relationships
 - 2.3.1.6. Legally recognized privileged or analogous relationships, such as those of lawyers, physicians, and ministers
 - 2.3.1.7. Religious practices, affiliations, or beliefs of the student or student's parent
 - 2.3.1.8. Income (other than that required by law to determine eligibility for participation in a program or for receiving financial assistance under such program
 - 2.3.2. For certain types of research projects not directly funded by ED and conducted in a school that receives funding from ED: Policies and procedures include a process to verify compliance with ED regulations that schools are required to develop and adopt policies in conjunction with parents regarding the following:
 - 2.3.2.1. The right of a parent of a student to inspect, upon the request of the parent, a survey created by a third party before the survey is administered or distributed by a school to a student
 - 2.3.2.1.1. Any applicable procedures for granting a request by a parent for reasonable access to such survey within a reasonable period of time after the request is received
 - 2.3.2.2. Arrangements to protect student privacy that are provided by the agency in the event of the administration or distribution of a survey to a student containing one or more of the following items (including the right of a parent of a student to inspect, upon the request of the parent, any survey containing one or more of such items):
 - 2.3.2.2.1. Political affiliations or beliefs of the student or the student's parent
 - 2.3.2.2.2. Mental or psychological problems of the student or the student's family
 - 2.3.2.2.3. Sex behavior or attitudes
 - 2.3.2.2.4. Illegal, anti-social, self-incriminating, or demeaning behavior

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2.3.2.2.6.		Critical appraisals of other individuals with whom respondents have close family relationships Legally recognized privileged or analogous relationships, such as those of lawyers, physicians, and ministers					
	2.3.2.2.7. 2.3.2.2.8.			Religious practices, affiliations, or beliefs of the student or the student's parent Income (other than that required by law to determine eligibility for participation in a program or for receiving financial assistance under such program)			
2.3.2.3. 2.3.2.4. 2.3.2.5.	p	The right of a parent of a student to inspect, upon the request of the parent, any instructional material used as part of the educational curriculum for the student					
		2	2.3.2.3.1.		procedures for granting a reques onable access to instructional ma		
	2.			tion of physical e cy may administe	xaminations or screenings that t er to a student	he	
	2.	3.2.5. T fi ir p p	The collection, from students for information (or purpose), include	disclosure, or us or the purpose of otherwise provid ding arrangemen	e of personal information collector f marketing or for selling that ing that information to others for ts to protect student privacy that vent of such collection, disclosur	that are	
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- 2.4. Access to instructional material used in a research or experimentation program:
 - 2.4.1. All instructional material, including teachers' manuals, films, tapes, or other supplementary instructional material, which will be used in connection with any research or experimentation program or project must be available for inspection by the parents or guardians of the children engaged in such research.

2.5. Definitions:

- 2.5.1. "Prior consent" means:
 - 2.5.1.1. Prior consent of the student, if the student is an adult or emancipated minor
 - 2.5.1.2. Prior written consent of the parent or guardian, if the student is not an emancipated minor
- 2.5.2. "Research or experimentation program or project" means any program or project in any research that is designed to explore or develop new or unproven teaching methods or techniques.
- 2.5.3. "Children" are persons enrolled in research not above the elementary or secondary education level, who have not reached the age of majority as determined under state law.



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- 2.5.4. "Psychiatric or psychological examination or test" means a method of obtaining information, including a group activity, that is not directly related to academic instruction and that is designed to elicit information about attitudes, habits, traits, opinions, beliefs or feelings (34 CFR §98.4)
- 2.5.5. "Psychiatric or psychological treatment" means an activity involving the planned, systematic use of methods or techniques that are not directly related to academic instruction and that is designed to affect behavioral, emotional, or attitudinal characteristics of an individual or group (34 CFR §98.4)

3 REFERENCES

- 3.1. 34 CFR §98
- 3.2. 34 CFR §99
- 3.3. 34 CFR §356