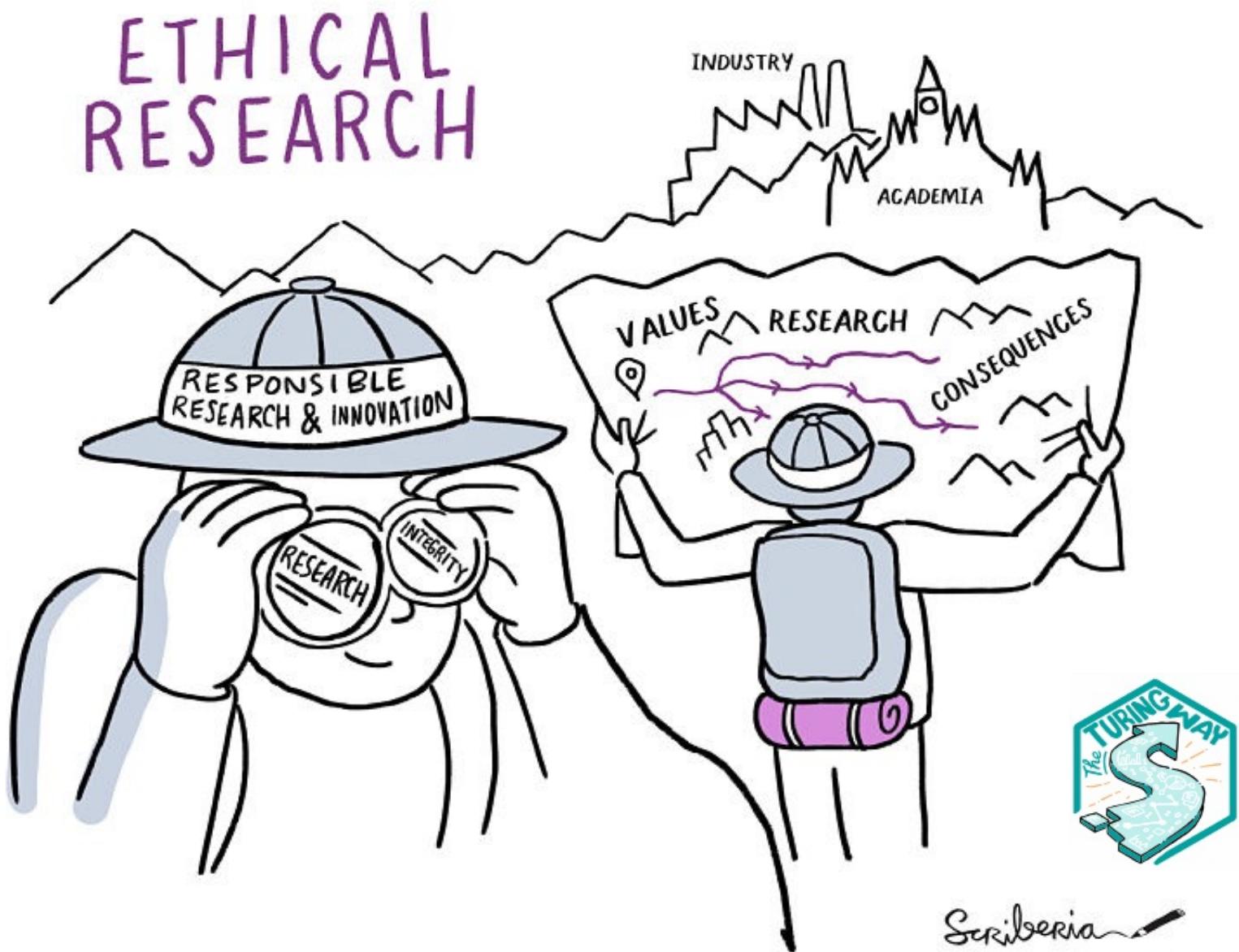


Ethics In Research

HS0.218a

Priyanka Srivastava
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This image is sourced from The Turing Way by Scriberia

When - Ethics?



Psychological harm
& Well-being

Physical harms

Protecting Human Rights

Stress

Beneficence

Risks and Benefits

Deception
&
Debriefing

Information
Withholding
Issues

Justice
Selection of
Subject

Privacy and Confidentiality

**Respect for
Autonomy Individual
Informed Consent**

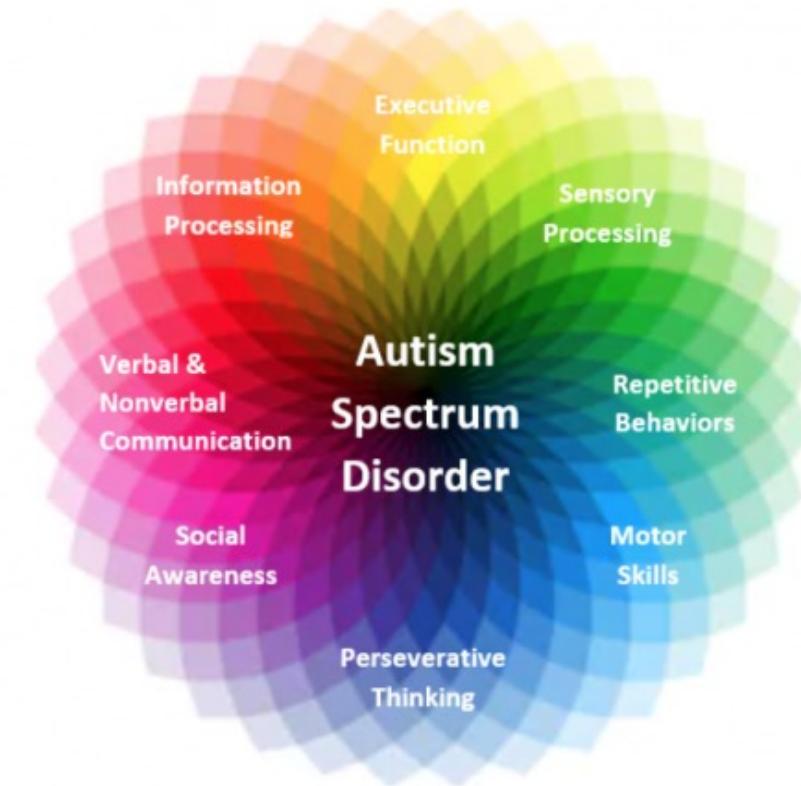
Justice and Equality

Factor	RRI	Research Integrity
Perception of ethical questions	Outward (for example: how does the public perceive scientific output?)	Inward (for example: how do researchers conduct themselves?)
Who researchers interact with	With research subjects (for example: do we treat them with respect?)	With fellow researchers (for example: do we adhere to a code of conduct?)
What shapes research	Shaped by society (for example: how is AI as a solution generally understood?)	Shaped by institutional norms (for example: what research questions are being funded?)



Facilitated Communication Intervention for Autistic Children

Facilitated Communication – infantile Autism and Communication Case study – Jenny (14 year)



Douglas Biklen, Syracuse Uni. **defined autism as motor disorder** than mental disorder – affecting mental processes

Facilitated Communication – infantile Autism and Communication Case study – Jenny (14 year)

- Douglas Biklen, Syracuse Uni. defined autism as motor disorder than mental disorder – affecting mental processes
- Task – Let child write and express their thoughts
 - Facilitator will hold their hand, gently, to support typing as it was computer aided technology
- Measure – Evaluate the writing as content/quantity



Different Supports Used in Facilitated Communication | Practitioners of F.C. steady typers by holding them at the elbow, shoulder or forearm. "It looks like a dance, like you're not doing a thing, but you're really doing five things at once," says Marilyn Chadwick, a master trainer and Stubblefield's own F.C. mentor. Illustrations by Brown Bird Design

Facilitated Communication – infantile Autism and Communication Case study – Jenny (14 year)

- Observation - children with autism, the infantile autism, in which, the child shows social and language development, have not only shown single words but sentences phrased properly
- *“Mommy , I want you to know that I love you even though I can’t speak.”*
- Only short-lived joy of parents, they realized the accusation from their daughter when Jenny types the allegations of brutal sexual abuse against her father.
- Did this really happen to Jenny?

Facilitated Communication – infantile Autism and Communication Case study – Jenny (14 year)

ALARMS ! Who actually typed these messages?

Extraordinary Claim, confirmation bias,
hypothesis testing

Ruling out rival Hypothesis

HOW it has been tested, option of control

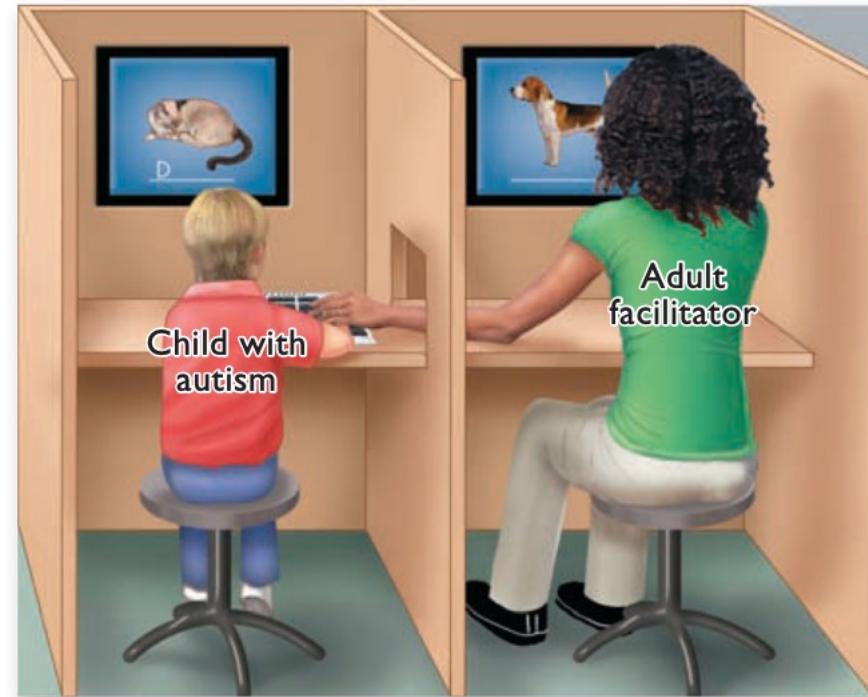
Construct validity, Internal Validity, and
Conclusion Validity - **What about ETHICS?**



Different Supports Used in Facilitated Communication | Practitioners of F.C. steady typers by holding them at the elbow, shoulder or forearm. "It looks like a dance, like you're not doing a thing, but you're really doing five things at once," says Marilyn Chadwick, a master trainer and Stubblefield's own F.C. mentor. Illustrations by Brown Bird Design

Facilitated Communication – infantile Autism and Communication Case study – Jenny (14 year)

Despite the lack of evidence, Jenny was removed from her parent's care, until FC testing revealed unfavorable results.



Testing with Control

Ethical Issues Related to the Use of Facilitated Communication Techniques with Persons with Autism

JOELLE DAYAN
Concordia University

PATRICIA MINNES
Queen's University at Kingston Ontario

Abstract

The use of Facilitated Communication techniques recently introduced and now widely used with persons with autism poses a number of ethical dilemmas for psychologists. These dilemmas stem from the lack of empirical support for the validity of messages communicated with facilitation. Using the *CPA Code of Ethics for Psychologists* (1991) as a guide, this paper will highlight a number of ethical issues pertinent to psychologists working with clients who use Facilitated Communication techniques.

In the past few years, the use of Facilitated Communication techniques (F/C) with autistic individuals has become a topic of considerable controversy (Cummins & Prior, 1992; Prior & Cummins, 1992; Rimland, 1992).

families or caregivers who use this mode of communication.

Since the introduction of F/C in Australia in 1988 by Rosemary Crosley, and then in the United States in 1990 by Douglas Biklen, there have been many reports of autistic individuals who were either mute or echolalic suddenly demonstrating literacy and numeracy skills with the use of facilitated communication (Rimland, 1990). F/C has challenged previous notions regarding the nature of autism, and as a result, has sparked new hope and enthusiasm for parents, caregivers and teachers of individuals with autism. However, the claims made by proponents of F/C also have prompted considerable controversy. Although, calls for controlled evaluations (Cummins & Prior, 1992; Minnes, 1992) have been resisted by proponents of the technique, increasing numbers of cases of alleged abuse communicated through F/C (Rimland, 1992) have resulted in a growing number of research studies.

Three major paradigms outlined by Schwarz and Jacobson (1998) have been used. In the first, questions are posed but facilitators do not have access to information presented to the person being facilitated.



BIOETHICS FORUM ESSAY

Bioethicists Should Speak Up Against Facilitated Communication

by Amy S.F. Lutz and Dominic Sisti

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Published July 29, 2024

Posted in Disability Bioethics, Hastings Bioethics Forum

Last month, Netflix premiered the documentary *Tell Them You Love Me*, the story of former Rutgers University professor Anna Stubblefield, who was convicted of first-degree aggravated sexual assault in 2015 for raping Derrick



American Speech-Language-Hearing Association
Making effective communication a human right, accessible and achievable for all.

Search

A Number of Organizations Caution Against Use of FC and RPM

Following a thorough, year-long, peer-reviewed process based on systematic literature reviews, the American Speech-Language-Hearing Association (ASHA) recently adopted new position statements about Facilitated Communication (FC) (updated from 1995)

FC is a discredited technique that should not be used. There is no scientific evidence of the validity of FC, and there is extensive scientific evidence—produced over several decades and across several countries—that messages are authored by the “facilitator” rather than the person with a disability. Furthermore, there is extensive evidence of harms related to the use of FC. Information obtained through the use of FC should not be considered as the communication of the person with a disability.

and the Rapid Prompting Method (RPM)

Use of RPM is not recommended because of prompt dependency and the lack of scientific validity. Furthermore, information obtained through the use of RPM should not be assumed to be the

Evidence-Based Communication Assessment and Intervention, 2014
Vol. 8, No. 2, 62–101, <http://dx.doi.org/10.1080/17489539.2014.976332>

Routledge
Taylor & Francis Group

The persistence of fad interventions in the face of negative scientific evidence: Facilitated communication for autism as a case example

Scott O. Lilienfeld¹, Julia Marshall¹, James T. Todd² & Howard C. Shane³

¹Department of Psychology, Emory University, Atlanta, GA, USA, ²Department of Psychology, Eastern Michigan University, Ypsilanti, MI, USA, ³Boston Children's Hospital, Boston, MA, USA

Abstract

Communication disorder and mental health professionals may assume that once novel clinical techniques have been refuted by research, they will be promptly abandoned. Using facilitated communication (FC) for autism as a recent case example, we provide evidence to the contrary. Although FC was scientifically discredited by the mid-to-late 1990s, data we review demonstrate that it is still frequently administered in clinical and educational settings. We examine evidence for FC's (a) continued use as an intervention for autism, (b) persistence in academic and institutional settings, (c) popularity in online and print sources, (d) promotion in the media, (e) ongoing risk to caregivers accused of sexual abuse. We analyze the sources of these troubling developments, explore their ethical implications, and offer recommendations for addressing the spread of FC and other fad interventions.

Keywords: *Fads; Autism; Autism spectrum disorder; Developmental disabilities; Facilitated communication; Treatment; Science-practice gap.*

INTRODUCTION

The past is never dead. In fact, it's not even past (Faulkner, 1950).

As Santayana wrote, those who forget the past are doomed to repeat it (see Thomas, 2007). The legacies of pseudoscientific and otherwise unsupported practices in com-

a trend that has received scant attention—namely, the propensity of certain interventions to endure in the practice community well after researchers have discredited them (see also Kurzban, 2011, on “zombie psychology,” or erroneous ideas about the mind that will not disappear). In this article, we examine a recent example of this phenomenon with an eye to better understanding its causes, the persistence and





<https://www.youtube.com/watch?v=OQgK4L9cWHQ>

Reflections

- Were participants and guardians fully informed about the procedure and limitations of FC?
- Did they make decisions after fully understanding the process and limitations of FC?
- Did researchers ensure the validity of the communication produced by the FC-supported communication? Did they validate whether the information or communication produced was from the individual with autism or if it was influenced by the FC facilitator's biases, beliefs, feelings or intentions?
- What are your thoughts on the potential emotional, physical, and psychological harm that could have been unintentionally caused by the use of FC or by the FC facilitator?
- What are the implications of psychological harm and trauma caused to the families of individuals using FC?
- Did practitioners and/or facilitators ensure accuracy and transparency during the dissemination of the FC results?
- What is the responsibility of researchers and/or innovators to the community of individuals with special needs?

March 31, 2020, BBC news, UP



March 31, 2020, BBC news, UP





In the same way that protesters have argued the lockdowns infringe their rights, much of the anti-mask rhetoric seems to come from the same well - American resistance to government mandates.

Discuss the Pandemic episode – Disinfectant Spray Through the Lens of Basic Ethical Principles

- Beneficence – participants' welfare
 - Respect for persons (autonomy) – freedom of choice
 - Justice – equality
-
- Focus:
 - Risk and benefits
 - Informed consents
 - Participants selection

<https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html#xjust>

Cozby and Bates (2012), chapter3 : Ethical Research



Discuss the Human Shield Case – Disinfectant Spray Through the Lens of Basic Ethical Principles

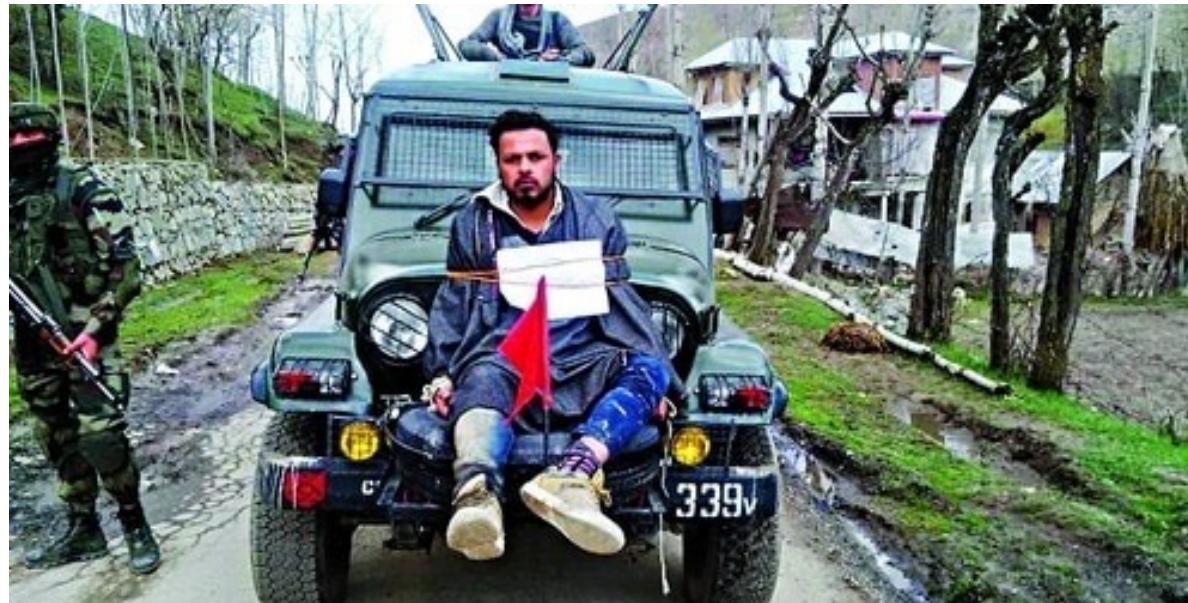
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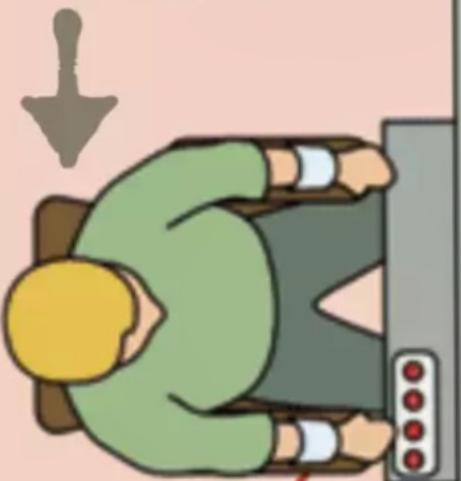
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Cozby and Bates (2012), chapter3 : Ethical Research

- How are these cases relevant to our Ethics Class?
- How are these cases relevant to the Stanford Prison Experiment and Milgram Study ?
- Why should we discuss these cases in relation to the SPE and Milgram's Study?

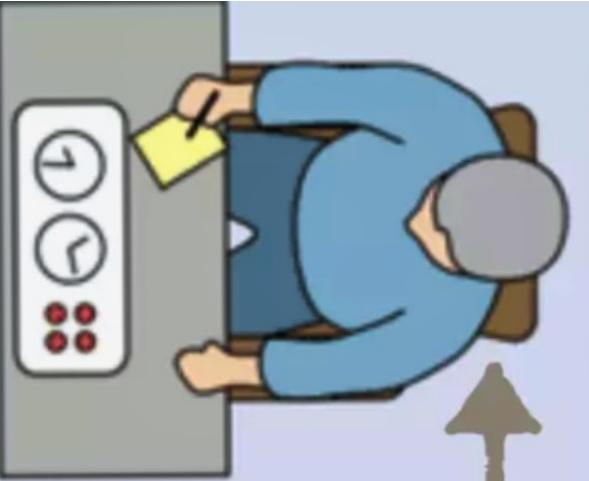


Fake Test Subject

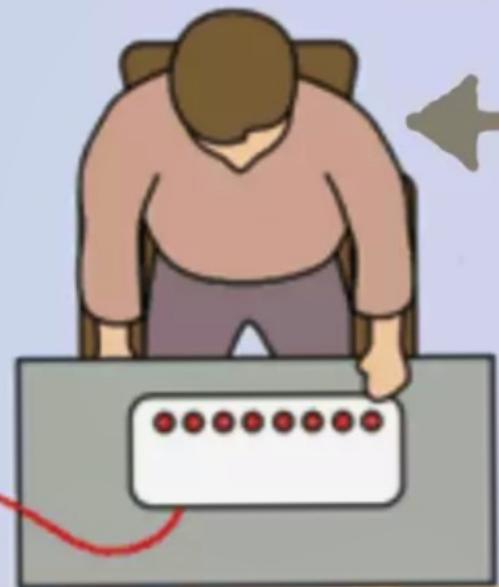


(Pretends to feel pain)

(Urges the participant to keep going)



Experimenter



Subject
(Administers shocks)



Milgram Experiment (1963)
Stanley Milgram (1933 - 1984)
American Psychologist, Yale University

purpose. In one of the most controversial studies in the history of psychology (see Chapter 13), Stanley Milgram (1963), then at Yale University, invited volunteers to participate in a study of the “effects of punishment on learning.” The experimenter deceived participants into believing they were administering painful electric shocks of increasing intensity to another participant, who made repeated errors on a learning task. In reality, the other “participant” was actually a *confederate* (a research assistant who plays the part of a participant) of the experimenter, and never received any shocks. Moreover, Milgram had no interest in the effects of punishment on learning; he was actually interested in the influence of authority figures on obedience. Many of the actual participants experienced considerable distress during the procedure, and some were understandably troubled by the fact that they delivered what they believed to be extremely painful—even potentially fatal—electric shocks to an innocent person.

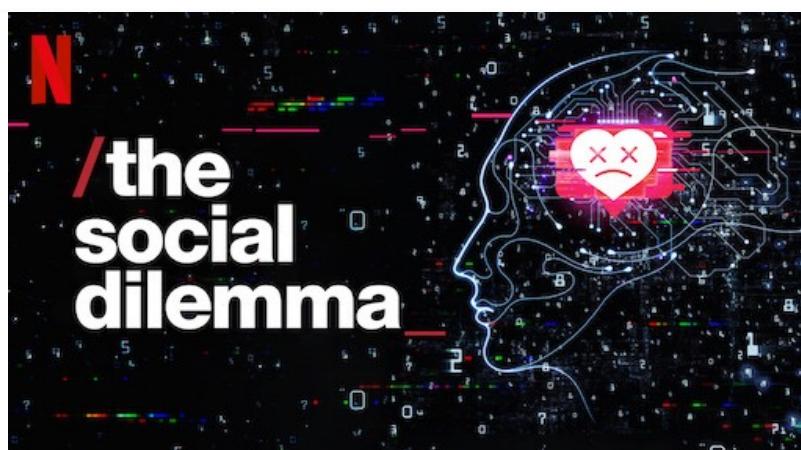
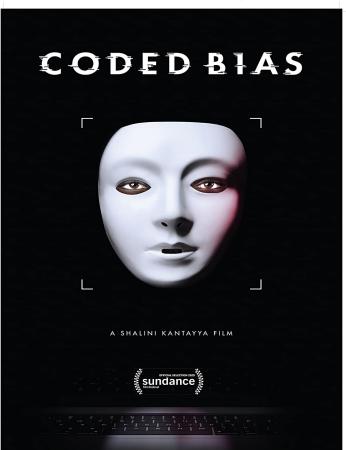
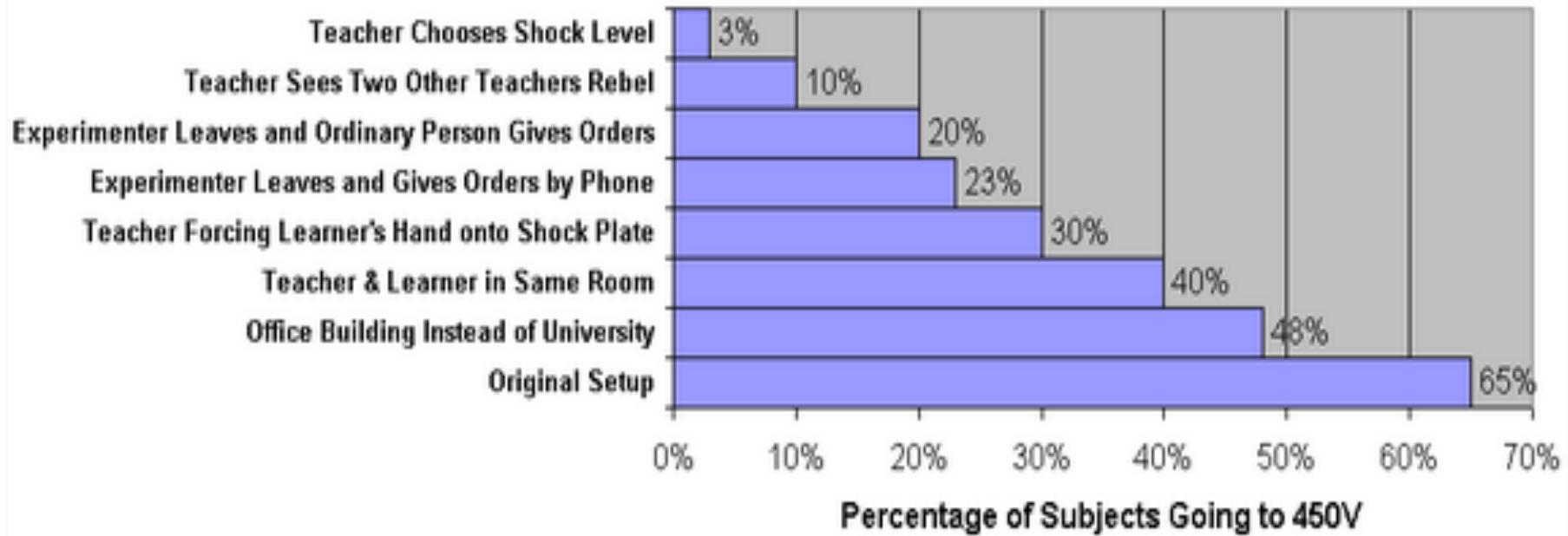
Milgram himself reported that participants were observed to sweat, tremble, stutter, bite their lips, groan, and dig their fingernails into their own flesh. Three of the participants were even described as experiencing full-blown, uncontrollable seizures. That level of psychological trauma would never be allowed today.⁷

Was Milgram’s elaborate deception justified? Milgram (1964) argued that the hoax was required to pull off the study, because informing subjects of its true purpose would have generated obvious demand characteristics. He further noted that he went out of his way to later explain the study’s true purpose to participants and assure them that their obedience wasn’t a sign of cruelty or psychological disturbance. In addition, he sent a questionnaire to all subjects after the studies were completed and found that only 1.3 percent reported any negative emotional aftereffects. In contrast, Diana Baumrind (1964) argued that Milgram’s study wasn’t worth the knowledge or psychological distress it generated. Milgram’s failure to provide subjects with full informed consent, she maintained, was ethically indefensible. Simply put, Milgram’s subjects didn’t know what they were getting into when they volunteered.

The results were sobering. Out of 40 men who participated in the experiment as teachers, 26 of them—65%!—continued to obey the experimenter’s instructions and never stopped administering the shocks.

The debate concerning the ethics of Milgram's study continues to this day (Blass, 2004). Although we won't try to resolve this controversy here, we'll say only that the ethical standards of the American Psychological Association (2002) affirm that deception is justified only when (a) researchers couldn't have performed the study without the deception and (b) the scientific knowledge to be gained from the study outweighs its costs (see **TABLE 2.3**). Needless to say, evaluating (b) isn't easy, and it's up to researchers—and ultimately, the IRB—to decide whether the potential scientific benefits of a study are sufficient to justify deception. Over the years, IRBs—which didn't exist in Milgram's day—have become more stringent about the need for informed consent.  **Simulate**

Variations on Milgram's Experiment



Psychological harm
& Well-being

Physical harms

Protecting Human Rights

Beneficence

Stress

Risks and Benefits

Privacy and Confidentiality

Deception
&
Debriefing

Information
Withholding
Issues

Respect for

Autonomy

Individual

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Justice

Selection of
Subject

Justice and Equality

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Basic Ethical Principles

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 - Participants selection

<https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html#xjust>

Cozby and Bates (2012), chapter3 : Ethical Research



Stanford Prison Experiment (1971)
Philip Zimbardo(1933-2024)
American Psychologist,
Stanford University

Quiet Rage: The Stanford Prison Experiment (1992)



Basic Ethical Principles

- Beneficence – participants' welfare
- Respect for persons (autonomy) – freedom of choice
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Cozby and Bates (2012), chapter3 : Ethical Research

Debunking the Stanford Prison Experiment

Thibault Le Texier
Université de Nice Sophia Antipolis

The Stanford Prison Experiment (SPE) is one of psychology's most famous studies. It has been criticized on many grounds, and yet a majority of textbook authors have ignored these criticisms in their discussions of the SPE, thereby misleading both students and the general public about the study's questionable scientific validity. Data collected from a thorough investigation of the SPE archives and interviews with 15 of the participants in the experiment further question the study's scientific merit. These data are not only supportive of previous criticisms of the SPE, such as the presence of demand characteristics, but provide new criticisms of the SPE based on heretofore unknown information. These new criticisms include the biased and incomplete collection of data, the extent to which the SPE drew on a prison experiment devised and conducted by students in one of Zimbardo's classes 3 months earlier, the fact that the guards received precise instructions regarding the treatment of the prisoners, the fact that the guards were not told they were subjects, and the fact that participants were almost never completely immersed by the situation. Possible explanations of the inaccurate textbook portrayal and general misperception of the SPE's scientific validity over the past 5 decades, in spite of its flaws and shortcomings, are discussed.

Keywords: Stanford Prison Experiment, Zimbardo, epistemology

Supplemental materials: <http://dx.doi.org/10.1037/amp0000401.supp>

Individual user and is not to be disseminated broadly.

Article



The Stanford prison experiment in introductory psychology textbooks: A content analysis

Jared M. Bartels
Missouri Valley College, USA

Abstract

The present content analysis examines the coverage of theoretical and methodological problems with the Stanford prison experiment (SPE) in a sample of introductory psychology textbooks. Categories included the interpretation and replication of the study, variance in guard behavior, participant selection bias, the presence of demand characteristics including the contribution of the guard orientation, and the ecological validity of the prison. In general, results revealed minimal coverage of problems with the study, with only two of the 14 textbooks citing any critical articles. The majority of textbooks presented the study in a fashion consistent with a "power of the situation" interpretation with no account

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DOI: 10.1177/1475725714568007
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Results

The description and discussion of the archival content analysis will be structured around seven main findings: (1) in designing the SPE, Zimbardo borrowed several key elements from a student experiment conducted 3 months before; (2) the guards knew what results Zimbardo wanted to achieve and how to achieve them; (3) the guards were asked to play a specific part but were not informed that they were subjects; (4) the prisoners could not leave of their own will and were subjected to harsh conditions designed by the experimenters; (5) the participants were almost never completely immersed in the unrealistic prison situation; (6) the

collection and the reporting of the data were incomplete and biased; and (7) the conclusions of the SPE had been written in advance according to nonacademic aims.

1. Participants were not informed about the tests/ procedure/ experiments
2. Participants weren't informed about the risks/ benefits would be expected from the experiments
3. No consideration of their consent
4. No risks have been evaluated
5. Autonomy was at risk
6. Privacy / confidentiality issues

Ethical focus

- 1. Risk and Benefits** – protecting participants from physical and psychological, and social harms
- 2. Informed Consent** – Providing freedom of choice about participating in research , describing the nature and use of the research to the participants
- 3. Selection of Subjects** – equal chances of selection

The Belmont Report

- The Belmont Report: *Ethical Principles and Guidelines for the Protection of Human Subjects for Research* (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research , 1979)

Cozby and Bates (2012), chapter3 : Ethical Research

- Clinical versus Research Practices

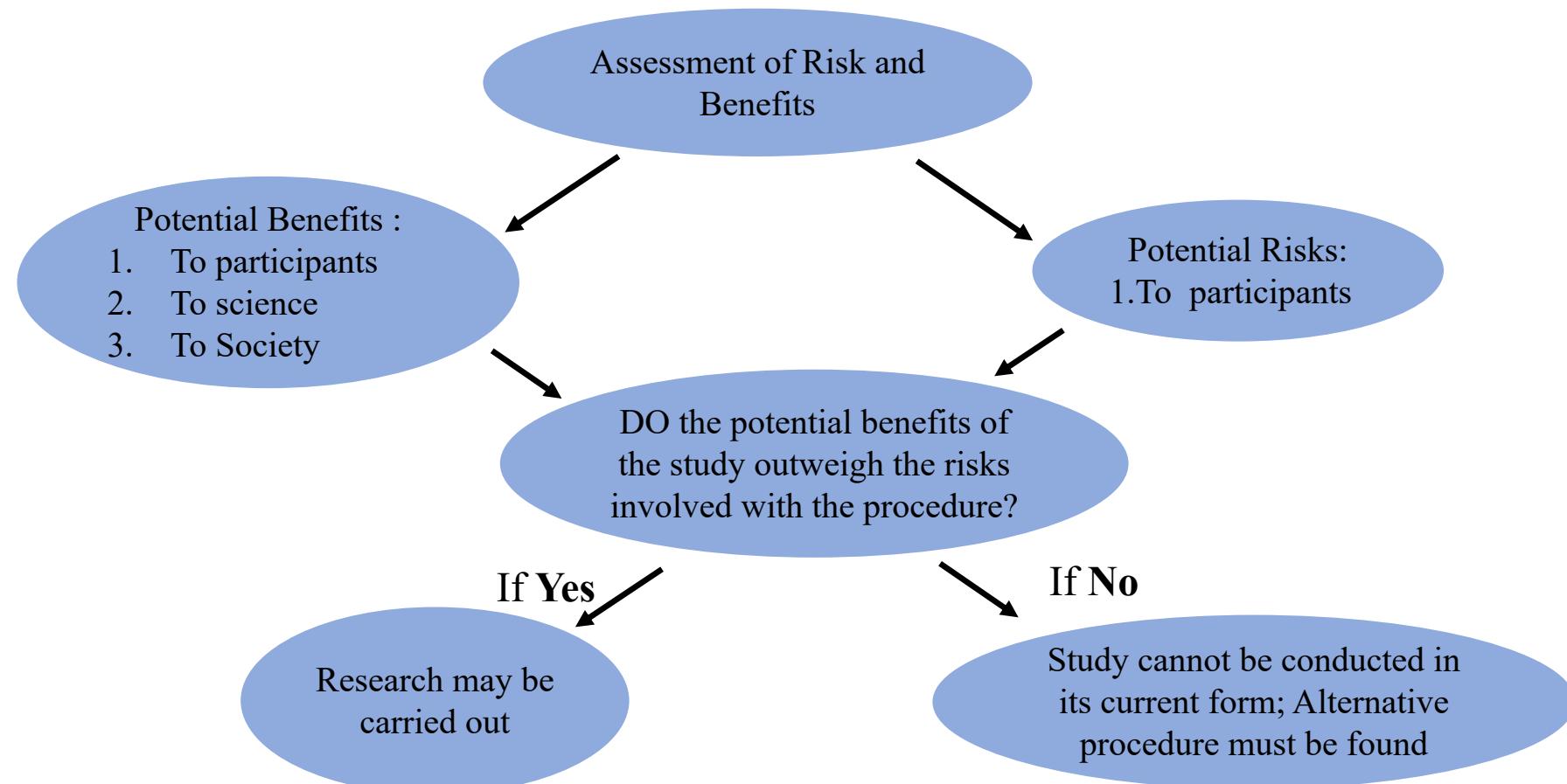
“It is better to risk denying treatment for a while until there is enough confidence in treatment than risk harming innocent people.”

Cozby and Bates (2012), chapter3 : Ethical Research

Basic Ethical Principles – Risk and Benefit Analysis

- Levels of Risk
 - No Risk Research
 - Minimal Risk Research
 - Greater than Minimal Risk
 - Physical stress
 - Psychological stress
 - Social / reputation risk
 - Invasion of privacy
 - Confidentiality
- IRB – Institutional Research Board Committee
- Risk-benefit analysis

Basic Ethical Principles – Risk and Benefit Analysis



Basic Ethical Principles – Informed Consent Form

- Consent form
 - Purpose of the study
 - Procedure / methods will be used in experiment
 - Stimuli / materials
 - Method of observations
 - Their responses
 - Total time
 - Risks and benefits
 - Any compensation
 - Confidentiality
 - Assurance of voluntary participations and permission to withdraw
 - Contact information for questions
- Importance increases with increasing risks to participants

Cozby and Bates (2012), chapter3 : Ethical Research

Basic Ethical Principles – Informed Consent Form

- Autonomy issues
- Information issues: withholding information and deception
- Debriefing
- Increased importance in case of special population
 - Children / young under 18
 - Patients
 - Incarcerated

Cozby and Bates (2012), chapter3 : Ethical Research

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