



Disclosure and Reporting Challenges in Aggression Research Involving Children and Adolescents

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Advancing the Science of Aggression Across Species and Disciplines

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The Take Away

- Aggression science is critical to understanding and promoting individual and public welfare
- Concerns regarding stigma and reporting laws *can be starting points, not* barriers to conducting research on aggression
- Developing evidence-based disclosure and reporting policies can increase IRB approval and enhance participant and public trust.

Range of Study Results Involving Clinical and Asymptomatic Participants

Clinical Characteristics

- Oppositional defiant
- Disruptive conduct disorder
- Anti-social behavior
- Sociopathy
- Callous-unemotional traits
- Impulsive aggression
- Delinquency

Associated Characteristics

- Attention-deficit- hyperactivity
- Cognitive deficits (e.g. executive functioning, reward/punishment sensitivity)
- Depression
- Substance use disorder
- Self-reported harm (NSSI, suicidality)
- Intent to harm others
- Self-reported physical, sexual, emotional abuse

Value of Confidentiality

Protects

Participant privacy

Individual social, economic, and criminal harms

Encourages

Future participation

Truthful and accurate data

Avoids

Feelings of betrayal

Inconsistent disclosure/reporting policies



When Do We Need to Consider Disclosure to Parents?

When Psychological Test Batteries or fMRI Assessments Indicate

- Serious cognitive, neurological, or mental health problems, *or*
- Child/adolescent health compromising behaviors, *and*
- Which would benefit from services, *and*
- Of which the guardian is unaware

When Do We Need to Consider Reporting to Authorities?

When Child/Adolescent Self Report

- Victim of unreported child abuse
- Access to a gun with violent or suicidal intent
- Sexually aggressive behavior toward another minor

Failing to Disclose or Report....

- May delay parents and participants from seeking needed services
- May place child/adolescent or others in continued harms way
- *May communicate to children or adolescents that their problems are: unimportant, unsolvable, or that adults cannot be trusted to help*

Fisher, 2003a, 2003b; Fisher, Higgins-D'Allesandro, Rau, Kuther & Belanger (1996)

The Scientist-Citizen Dilemma

- Do scientists have a citizen's obligation to help those they know are in jeopardy?
- Does the investigator role supersede such citizen obligations?
- Do scientists with special expertise in aggressive disorders have a special obligation to help those their research indicates are in jeopardy?



Steps for Determining Disclosure & Reporting Policies



Problem Identification

Do the assessment instruments have...

- Clinical utility for the child?
- Validated cut-off points for determining diagnosis or level of risk to guide a disclosure decision?

Will research methods potentially uncover...

- A serious clinical disorder unknown to parents?
- Immediate threats to participant or harm to others?

Legal Reasons to Disclose

- Mandatory Child Abuse Reporting Laws - *in some states they apply to all “citizens”*
- *The Certificate of Confidentiality does not apply to child abuse*
- Tarasoff laws – have not been tested but criteria may apply:
 - Special relationship,
 - Identifiable victim,
 - Ability to predict violence

Policy Development

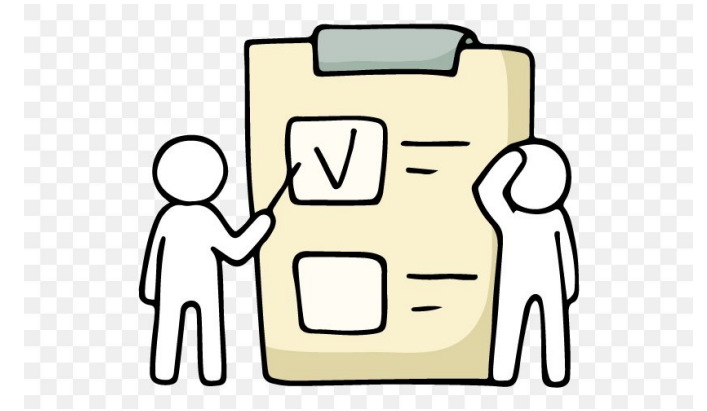
If Prior Steps Indicate Disclosure or Reporting May be Required:

- Identify test scores or participant behaviors that will require disclosure/reporting
- Consult with prospective participant families to develop procedures that reflect their values and merit their trust
- Decide how and to whom information will be disclosed/reported
- Establish relationships with referral or reporting sources
- Train research staff in implementation

Fisher & Goodman (2009)

Informed Consent Should Include:

- Specific types of information that will and will not be disclosed or reported
- The rationale for the policy
- To whom information will be disclosed/reported
- Whether and how guardians and participants will be informed if a disclosure or report is made.



Frontline Research Staff

May experience vicarious trauma or moral distress



Burnout or modify procedures to help participants



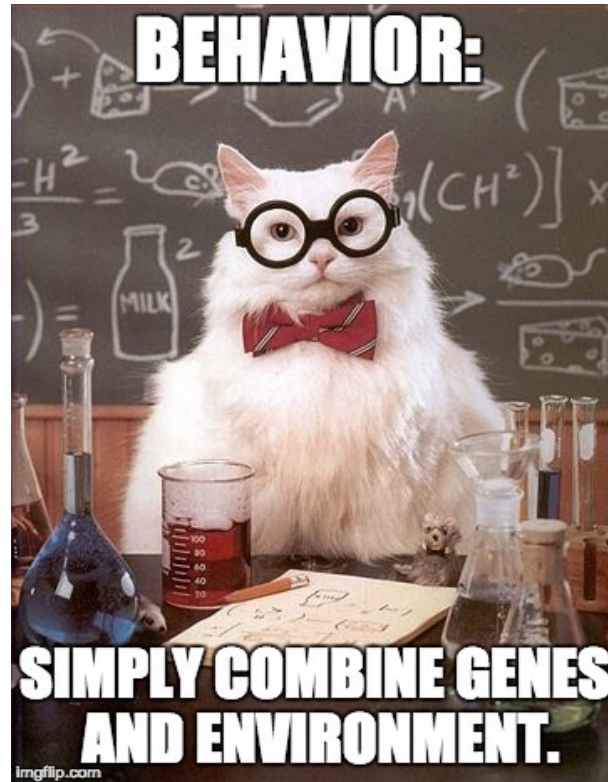
Threaten scientific validity

At weekly staff meetings encourage open discussion of staff experiences with disclosure and reporting challenges, discuss solutions, and offer assistance when needed.

Fisher, True, Alexander & Fried (2013); Fried & Fisher, (2016) True, Alexander, & Fisher, (2017)



Genetic Research on Child and Adolescent Aggression



Should Genetic Data be Shared with Parents?

Difficult to conclude from study results whether a specific genotype can explain an individual child's current or future aggressive disorders:

- Aggressive disorders derive from multiple genetic and non-genetic factors
- May be the result of different genes that influence the same behaviors
- Heritability estimates differ across different genotypes, populations and contexts
- Gene X Environment effects are highly probabilistic

Fisher & Layman (2018).

The “Child’s Right to an Open Future”

Sharing genetic information related to aggression may violate the child’s right to withhold information from others that may be detrimental to their self-interests

- Risk to child’s self-concept
- Parental over-or under-estimation of risk influencing opportunities for prevention or treatment
- Future genetic discrimination in health care, educational placement, and criminal justice decisions



Sharing Results: Who Decides?

The science establishment has traditionally determined appropriate human subjects protections

- Societal trends toward transparency, self-determination and parental rights in research, healthcare and consumerism
- Parents are increasingly requesting access to their child's raw genomic data, to pursue their own analyses or for onward sharing with health professionals and researchers.
- As research is disseminated through publications, there is less control over parental misconceptions
- Parents have access to commercially available genetic testing services

Steps for Determining Sharing Genetic Results with Parents or Participants



Should Genetic Data be Shared?

- What is the probability that specific genetic data analyzed can explain an individual child's current or future aggressive disorders?
- Has whole gene sequencing been collected that may be useful to parents and children across a wide range of health factors currently or in the future?
- Are there risks to the participant if genetic information is disclosed, and can these risks be reduced?

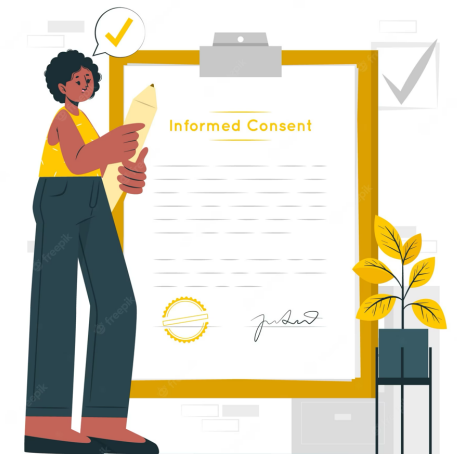
Fisher & Layman (2018)

How Should Genetic Data be Shared?

- Under what circumstances should genetic information be shared with only parents or with only older adolescents?
- Have qualified staff (e.g. genetic counselors) been identified to conduct disclosure of genetic information
- Have adequate steps been taken minimize family misconceptions

Informed Consent

- Create materials to enhance the genetic literacy required for an informed consent decision
- Provide a rationale for why genetic data *will or will not* be shared
- Describe disclosure procedures if it will be shared.
- Describe extent and limits of confidentiality protections & participant rights related to NIH Genomic Data Sharing Policies
- For longitudinal studies consider adolescent re-consent for use and storage of their genetic information



Aggression Research: Responsibilities to Racial/Ethnic Children & Adolescents



Research Dissemination and Community Harms

- Aggression science is not conducted in a socio-political vacuum.
- Use of research results may produce policies disadvantageous to marginalized populations
- Algorithms for de-identification may result in community or population harms
- Data may unintentionally nurture the public tendency toward group stigmatization or “genetic essentialism”

Fisher, Busch-Rossnagel, Jopp & Brown (2012)

Listening to Community Voices

"The key is Dr. Fisher, that when you...talk to your counterparts...ask yourselves what will others do with this research?"

No matter what role that you have played to make this happen, you could have the purist intention, but if it gets into the wrong hands then it becomes a weapon"

Fisher, C. B., & Wallace, S. A. (2000).

Steps for Avoiding Participant and Community Harms:



Avoiding Participant and Community Harms

Research Design

- Establish whether assessment instruments were sufficiently validated on the racial/ethnic composition of your research sample
- Avoid analyzing racial factors as implied biological markers for genotypes associated with aggression

Avoiding Participant and Community Harms

Disclosure and Reporting

- Avoid over-estimating individual factors, by evaluating disclosure and reporting decisions within the context of cultural and systemic influences on aggressive disorders and behaviors
- When deciding to disclose, identify referral sources sensitive to the needs of racial/ethnic families
- When deciding on reporting options, consider the impact of potential racial biases within social services and gov't agencies

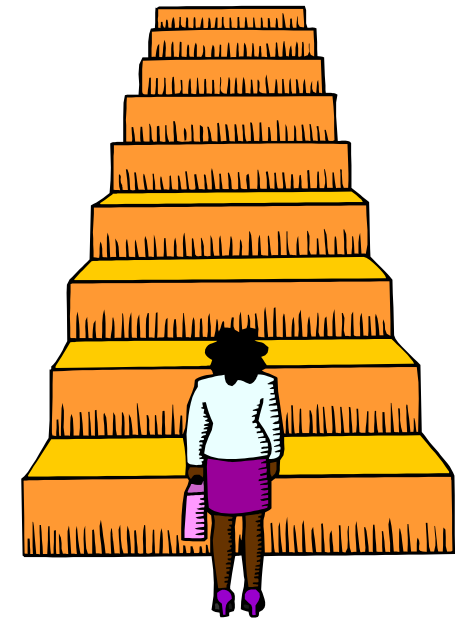
Avoiding Participant and Community Harms

Dissemination

- When racial groups are over or under sampled... discuss the scientific justification, implications, and limitations of racial stereotyping in all sections of the article—and not just the limitations section

Aggression Research: Doing Good Well

- Aggression science is critical to understanding and promoting individual and public health
- Concerns regarding stigma and reporting laws *are starting points not barriers* for conducting good science and good ethics
- Evidence-based, population sensitive disclosure and reporting policies will enhance scientific validity and increase participant protections and public trust



Thank You



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