Aligning the SRCD Ethical Principles & Standards with Research Ethics Practices in a 21st Century World:

The 2021 SRCD Ethical Principles and Standards for Developmental Scientists

Participants: Celia B. Fisher & Lorah D. Dorn (Organizers)
Celia J. Gomez, Frosso Motti-Stefanidi & Carola Suárez-Orozco

Introducing the 2021 SRCD Ethical Principles and Standards for Developmental Scientists

Lorah D. Dorn, Ph.D., CPNP
Professor of Nursing and Pediatrics
KL2 Program Co-Director in the CTSI
The Pennsylvania State University
College of Nursing
dun@psu.edu

A New Ethics Code: Why Now?

In January 2020 Governing Council (GC) requested revision

- Code outdated (2007); Yet receives the highest "hit rate" on the SRCD website.
- The Revision Needed to:
  - Harmonize with updated federal regulations: "Common Rule"
  - Reflect contemporary national and international human rights and social justice orientations
  - Incorporate sensitivity to societal changes (e.g., populations, communities, advances in tech)

History of Our Work

Task Force expertise included federal and international research ethics guidelines, NIH policy, and a diversity of developmental science populations and contexts.

Celia B. Fisher, Chair	Cheryl Boyce
Lorah D. Dorn	Celia J. Gomez
Frosso Motti-Stefanidi	Carola Suarez-Orozco

Goal of the Task Force:

- To create a living document that reflects the highest ideals of scientific integrity and responsibility, that
- Merits the trust of the participants, communities and others with whom developmental scientists work.

Process

Meetings across 2020-2021

- Resources included:
  - <u>Historical documents</u>: (e.g., Belmont Report, Code of Federal Regs, European Commission on Ethics for Researchers, UN Declaration of Human Rights, SRCD Policy on Scientific Integrity, Transparency & Openness, etc.)
  - <u>Other professional organizations' ethics codes</u>: APA, APHA, AAA, ASA
  - Expertise of task force members

Key Terms Defined in Footnotes

- Children = infants, children & adolescents
- Families = broadly defined/inclusive of legal, formal/informal arrangement, biological & non-biologically related individuals, extended families & other family forms
- Communities = can reflect geographic region, culture, health condition, socially shared characteristics & other characteristics, contexts or affinity groups.
- Itemizes how "diverse" and "diversity" encompass multiple variations across constructs (see website)
- Parent/legal guardian = parent, legal guardian, extended family member, foster parents, and others responsible for welfare of child participants, legal or otherwise. In the case of refugee/homeless children this may be government agency

Final Approval

- Many iterative versions of the document as a team
  - Feedback provided by GC Nov. 2021

- Approved by GC Feb. 2021 with roll out for April 2021 biennial meeting

The Purpose and Format of the 2021 SRCD Ethics Code

Celia B. Fisher
Marie Ward Doty University Chair in Ethics
Professor of Psychology,
Director Center for Ethics Education
Director HIV and Drug Abuse Prevention Research Ethics Training Institute
Director, Human Development and Social Justice Lab

The Purpose of the Code

The SRCD Ethics Code was revised to facilitate the responsible conduct of research

- The Code reflects the decisions developmental scientists make everyday to protect the rights and welfare of those with whom they work.
- The Code is not intended to describe specific research designs, populations, or contexts.....
- Rather, it provides a set of values and broad general rules that developmental scientists can interpret and apply as a function of their own unique roles and the contexts in which they are embedded.

Specific Aims

- Maintain the viability of developmental science as field with a set of core values across a broad spectrum of research activities and populations
- Create a contract with society that merits public trust by demonstrating that developmental science is a field with high ethical standards
- Educate and socialize students and early career professionals in the values and practices they should expect of themselves and one another
- Serve as a resource for gaining approval of IRB proposals

The Format: Principles and Standards

Principles reflect “the highest ideals of developmental science”

A. Maximize Benefits and Minimize Harm
B. Respect for the Dignity of Persons and Peoples
C. Equity
D. Scientific Integrity

Standards describe “the more specific behaviors that guide developmental scientists to achieve these ideals”

1. Competence
2. Informed Consent
3. Equity
4. Scientific Integrity
5. Balancing Risks and Benefits

Example 1: Principles and Standards

Principle A. Maximizing Benefits and Minimizing Harms

Developmental Scientists aspire to….

- Maximize scientific, individual and societal benefits of research
- Avoid, minimize or remove harms to participants and communities…including consideration of how research will be applied to practice and policy
- Consider harms that may be associated with the sociopolitical context for persons with vulnerable legal status
- Create compassionate and safe research environments for participants, staff and 3rd parties.

Standard 5: Balancing Risks and Benefits

5.a. Ensuring appropriate balance of risks and benefits

- *When designing a study without direct benefits, developmental scientists take steps to ensure that risks never exceed the prospective scientific, educational or humanitarian value of the problem addressed*

5.b. Confidentiality and disclosures

- *Ensure adequate confidentiality protections*
- *Construct procedures in advance when it can be anticipated that disclosure may be necessary to protect participants or others from harm, and*
- *Clearly communicate disclosure procedures during informed consent*

5.c. Dynamic Assessment

- *Investigators are prepared to terminate research if there is probable*

Case Example: Prevention Program on Bullying in Middle School

Principle A. Maximizing Benefits and Minimizing Harm

- *To the extent possible, does the study maximize individual, scientific and/or societal benefits for improving developmental outcomes for victims and perpetrators of bullying?*
- *Do procedures create compassionate and safe environments for participants (victims and perpetrators) and community collaborators (e.g. teachers)?*
- *Do procedures protect the safety of children with vulnerable legal status (e.g. foster care; w/out documentation) if bullying needs to be reported?*

Case on Bullying
Standard 5. Balancing Risks and Benefits

5.a. Ensuring appropriate balance of risks and benefits:

- How can we reduce the possibility that participation in the study will endanger the safety or reputation of children or school personnel?

5.b. Confidentiality and disclosures

- Become familiar with district policies or local/state laws that require reporting of certain violent behaviors or threats in schools
- Consult with school personnel to develop adequate disclosure policies
- Obtain a Certificate of Confidentiality to protect data from subpoena

5.c. Dynamic Assessment

- Be prepared to assess whether it is necessary to terminate the study if the prevention program appears to be increasing victimization

Example 2: Principles & Standards

Principle B. Respect for the Dignity of Persons and Peoples

- *Regardless of developmental status*, all persons are entitled to appropriate protection of their privacy, confidentiality, and right to self-determination.

- Investigators take steps to ensure their study does not exploit individuals who may be *vulnerable to interpersonal and institutional authority.*

Standard 2: Informed Consent

2.a. Developmentally appropriate child assent procedures

- Assent is tailored to child's developmental level
- Longitudinal studies plan for developmentally modified re-consent procedures
- A minor's objection should be binding unless an intervention holds out a prospect of direct benefit essential to the child's wellbeing

2.b. Requirements of parent/guardian permission

- Familiar with relevant cultural and legal definitions of guardianship
- Recognize cultural contexts in which community or tribal permission is required

Waiver of parent/guardian permission

2c. Waiver is permitted if

- Studies are conducted in jurisdictions that grant adolescents independent access to related health services (e.g. sexual health research)
- If guardian permission risks child's safety

If waived, alternative protections are required

- Supported decision making
- Ascertaining youth consent capacity

Case Example: Ethnic Discrimination and Substance Use Among American Indian Youth

Principle B. Respect for the Dignity of Persons and Peoples

- Tribes have historically been exploited by research that has perpetuated stereotypes of alcohol use and related stigma
- Tribal communities are entitled to respect for their cultural values and the dignity of their tribal leaders
- This requires consultation with tribal leaders on the benefits and risks of the research for tribal members

Standard 2 B. Requirements of Parent/Guardian Permission

- Informed consent procedures need to reflect the cultural contexts in which permission of tribal leaders may be required

Case: Substance Use Among American Indian Youth
Protecting the Rights of Adolescent Participants

Principle B. Respect for the Dignity of Persons & Peoples

- Regardless of their developmental status, *adolescents are entitled* to protection of their privacy and self-determination rights regarding participation in substance use research

Standard 2.c. Waiver of parent/guardian permission

- Determine if substance use treatment is included in *mature minor laws* in the jurisdiction (including tribal land) the study will be conducted
- Consult with tribal leaders to ensure waiver procedures are culturally appropriate
- If waived, construct alternative protections; i.e., a tribal member who can serve as a participant advocate during adolescent consent

The Relationship Between Principles and Standards: Scientific Integrity

Lorah D. Dorn, Ph.D., CPNP
Professor of Nursing and Pediatrics
KL2 Program Co-Director in the CTSI
The Pennsylvania State University
College of Nursing
dun@psu.edu

Principle D. Scientific Integrity

Key to advance scientific knowledge of development of all children

- Improves current and future health and well-being
- Reflects core values of research: openness, objectivity, fairness, honesty, accountability and responsible stewardship
- Considers current and future implications for child and family welfare
- Recognizes implicit/explicit power relationships among students, junior colleagues and peers
  - Requires professional standards of collaboration in:
    - the conduct of research, administration, mentorship, authorship, and funding

Standard 4: Scientific Integrity

4.a. Scientific Standards

- Ensure work meets highest standards
  - Of scientific design, analysis, interpretation and dissemination
- Report all methods and procedures honestly
- Recognize potential social impact of findings on communities:
  - Seek community input and ensure community dissemination

4.b. Independent Ethics Review

- Protects participant rights and welfare of children
- Protects against investigator bias

Standard 4: Scientific Integrity continued

4.c. Data Security

- Confidentiality protections for data collection and storage particularly for:
  - Emerging technologies (geospatial profiling, data mining, big-data analytics, genomics)
  - As data breaches may pose higher social, financial, health, legal & political risks .

4.f. Transparency

*Funding agencies & journals requiring **greater transparency***

- Transparency is ensured through clear, accurate & complete reporting of all components

- Transparency also includes transformation in measures or observations that occurred, material & financial resources supporting research, conflicts of interests

Standard 4: Scientific Integrity continued

4.g. Data Sharing

- Scientific resources shared to further scientific advances
- Protecting participant confidentiality takes precedence over data sharing
- Considerations necessary for reasonable time:
  - for data analysis and dissemination
  - investigator financial or other burdens
- Does not preclude protection of scientists from requests that veer into attacks on integrity or limit scientific progress

Case Example: Increasing Consistency in Use & Reporting of Measures for Research on Puberty

Principle D. Scientific Integrity

- Scientific knowledge about puberty's role in psychosocial development is key for improving health and wellbeing in adolescence and beyond.

- Lack of detail in reporting of measures across studies jeopardizes:
  - replicability of findings,
  - validity of application to health promotion

- Responsible stewardship requires:
  - selection and reporting of appropriate methods,
  - measures that yield robust, reliable findings that enhance replicability.

Case Example: Research on Puberty

4.a. Scientific Standards

- Use of biological measures of puberty need to:
    - Reflect current standards for data collection, analysis and storage in behavioral endocrinology including:
        - specialized competency of investigators and staff

- With non-biological measures of puberty (self-report), investigators need to ensure the population validity of the measure

- Important to recognize potential social impact of puberty research on youth of all genders and race/ethnicity

- Seek community input on the aims, design, procedures and data interpretation

Case Example: Research on Puberty

4.c. Data Security

- Biological samples: need up-to-date confidentiality protections for collection and storage

4.f. Transparency

- Rationale for, and description of puberty measure, where and by whom, collected, how scored (if applicable), and how pubertal timing was computed
- Ensure replicability: Include all observations made and measure transformations (if any) e.g., was pubertal timing categorized by norms in past studies, distributions in current study, etc.
- Report financial resources for collecting, storing or analyzing biological material and statements regarding potential conflicts of interest, if relevant

Revising the SRCD Ethics Code with a Focus on Diversity & Equity

Carola Suárez-Orozco
Distinguished Professor
University of Massachusetts, Boston

Diversity & Equity: History

The revision reflects the sensitivity and enhanced attention to diversity and equity that has occurred since 2007

- Challenge of WEIRD psychology
- Under-recognition, under-representation, &/or over-pathologizing of minoritized populations
- Evident prior to the racial reckoning of 2020
- Keen awareness given my work with immigrant families, children, & youth

Principle A: Maximizing Benefits & Minimizing Harm

- Carefully consider the *sociopolitical context* in which research is conducted.
- May require *additional steps* to ensure the safety of persons with vulnerable legal status (e.g., children living in families who are undocumented, victims of interpersonal violence).

Principle B: Respect for the Dignity of Persons & Peoples

- Recognizes *the inherent worth of all human beings* regardless of differences in age, SES; race, ethnicity and nationality, etc.[4]

- Not simply individuals but are also *interdependent social beings with cultures, religions, and histories that connect them across generations*, and which are integral to the identity of its members and give meaning to their lives.

Principle C: Equity

Developmental Science:

- Designed to *promote fairness and justice for individuals' developmental outcomes* and equity in access to experiences and resources regardless of group characteristics

- *Does not exploit or exacerbate existing inequities* that may lead to further injustices or inequities in social, economic, educational, environmental and health outcomes.

- Promotes equity by providing opportunities for participating in research. . . Both *benefits and burdens of research should be equitably distributed* across individuals, families and communities.

Ethical Standard I: Competence

1.a. Scientific competence.

Develop *cultural and linguistic competencies* to ensure population-valid and appropriate research methods (e.g., recruitment plans, measure selection, dissemination procedures) across and within diverse populations.

1.b. Population competence.

Develop *population specific competencies* to minimize harm & best serve populations.

Ethical Standard 3: Equity

3.a. Consideration of individual, cultural and contextual differences.

Be aware of such differences so biases not perpetuated.

3.b. Reducing developmental inequities.

Understand current inequities in outcomes; engage in work that does not perpetuate inequities.

3.c. Equitable recruitment.

Neither privilege nor disadvantaging certain individuals or communities.

3.d.Fair compensation.

Avoid inadequate or excessive financial and other inducements.

Case Example: Families without Documentation

Ethical Principle A. Maximizing Benefits & Minimizing Harm

- Recognize current socio-political context in home country and the U.S.
- Take additional steps to protect legal safety of undocumented participants and citizen children and families living in mixed-status homes

Ethical Principle B. Respect for the Dignity of Persons & Peoples

- Recognize interdependence of cultural values and histories of oppression among family members with and without documentation

Ethical Principle C. Equity

- Research should not exacerbate existing inequities and vulnerabilities among children and families without documentation.

Case Example: Families without Documentation

Ethical Standard 1. Competence

- Developing PI and staff cultural, linguistic, population, legal and sociopolitical competencies required for adequate participant protections

Ethical Standard 3. Equity

- Recognize structural impediments/inequalities to not perpetuate biases against persons without documentation
- Search for levers of change in order to reduce developmental outcome inequities

Society for Research
in Child Development

Applying the SRCD Ethics Code in Community Engaged Research

Celia Gomez, Ed.D.

Policy Researcher and Co-Director of the Center for Qualitative and Mixed Methods

RAND Corporation

SRCD Ethics Code and Community Engaged Research

Community engaged research includes active partnerships between community members and research collaborators

- Community-based participatory research
- Community-embedded research
- Research-practice partnerships
- Practitioner research

There is a long tradition of community engaged research among developmental scientists across settings

- Universities
- Research and policy organizations
- Educational and service-based settings

How do the SRCD ethics principles and standards align with community-engaged research practices?

Community Engaged Research

Principle A: MAXIMIZING BENEFITS AND MINIMIZING HARM

"Maximizing benefits and minimizing harms may also extend to creating a compassionate and safe research or work environment for participants, community collaborators, students and colleagues and building community capacity and other benefits for communities."

Community-engaged research requires researchers to deeply engage with and understand the context of their research setting

Community Engaged Research

Principle B: RESPECT FOR THE DIGNITY OF PERSONS AND PEOPLES

- Respectful consideration of communities and institutions (e.g., schools, clinics, community centers)
- Individuals who work within the contexts in which research is conducted (e.g., teachers, healthcare providers, community members and others).

Standard 1.Competence

1.c. Inter-personal and inter-professional competence. Establish interpersonal & productive collaborative relationships across communities.

Community partnerships take place at multiple levels; ethical research requires respect for individuals, institutions and communities

Community Engaged Research

Principle D. Equity

- Developmental research does not exploit or exacerbate existing inequities between groups of differing social status or power based upon group characteristics,
- or lead to further injustices or inequities in social, economic, educational, environmental and health outcomes.

Standard 3.d. Fair Compensation

- When recruitment involves subordinates such as a researcher's students, patients recruited in health care settings, or persons otherwise vulnerable to exploitation or coercion,
- Developmental scientists take steps to avoid the influence of multiple relationships and to protect individuals from adverse consequences (real or perceived) of declining participation.

Community partnerships can encourage equity in research by dismantling unfair power dynamics and ensuring the research aligns with the values and needs of the focal community

Community Engaged Research

Principle D: SCIENTIFIC INTEGRITY

- The advancement of scientific knowledge regarding the development of the world's children rests on the formation of relationships of trust.
- The success of the scientific enterprise is dependent upon research participants' and other stakeholders' firm belief in the reliability, honesty, competence and trustworthiness of the investigator(s)

A history of mistreatment and imbalanced power dynamics has led some communities to mistrust research. Strong partnerships within community-engaged research is one way to build trust.

Competencies for Community Engaged Research

Standard 1.b. Population competence.

- Develop and maintain competence through involvement and consultation with members of the group under investigation, continued review of the literature, and by continual updating of designs and procedures.

Standard 1.c. Inter-personal and inter-professional competence

- Work to eliminate the harmful effect that personal and professional biases can have on participants and their communities, and they do not knowingly participate in or condone the activities of others based upon such prejudices.

Standard 1.d. Ensure staff competence.

- Utilize appropriate selection criteria and training tailored to the population of children under study and the staff member’s current skill level.
- Supervision includes training staff in appropriate anticipated and unanticipated ethical procedures and practices

Standard 4: Scientific Integrity and Community Engaged Research

4.a. Scientific standards

- Investigators recognize the potential social impact of their findings on communities
- make every effort to obtain community input on the aims, design and interpretation of data to ensure that their research is disseminated to participants and the communities they represent.

4.d Debriefing.

- Investigators are also sensitive to the personal and social impact of their findings and ensure as appropriate that debriefing includes information on the implications both risk and resilience of persons and communities.
- As soon as feasible, investigators provide an opportunity for participants to obtain additional information about the purpose, nature, results and dissemination of the research.

Reciprocity is a key tenet of community-engaged research. Researchers have a responsibility to ensure that communities benefits from the research outcomes

Case Example: Developmental Evaluation of an Early Care and Education Quality Rating and Improvement System

Principle B. Respect for the Dignity of All Peoples and Persons

- The developmental evaluation was conducted in the context of a research-practice partnership
- The project included a leadership team comprised of researchers and practitioners from two lead organizations, as well as an advisory council with representation from all partner organizations
- The partnership took place at many levels, and questions remained regarding how best to involve community members with different roles

Case Example: Developmental Evaluation of an Early Care and Education Quality Rating and Improvement System

Standard 4: Scientific Integrity

- Reviewed data elements with partners to ensure the correct use and interpretation of information
- Researchers maintained analytic independence within the collaborative partnership
- Held “sense-making meetings” with community partners to review and process findings
- Research-informed policy recommendations emerged from these meetings based on stakeholders needs

The New SRCD Ethics Code:
A Comparison with The European Perspective

Frosso Motti-Stefanidi, Ph.D
Professor of Psychology
National and Kapodistrian University of Athens
www.frossomotti.com

European Union (EU) Research Context

EU is a political and economic union of 27 member states.

- An expert panel appointed by the European Commission drafted the *Ethics in Social Science and Humanities* which does not specifically address developmental science.

- European researchers funded by the European Commission (such as ERC or Horizon 2020 funds) need to abide by these guidelines as well as by their own national ethics guidelines.

- US investigators conducting research in the EU need also to abide by these guidelines

Key Sources of EU's Ethical Principles for Researchers

The EU like the SRCD ethical principles are anchored in fundamental human rights and ethical principles of scientific research.

Human rights resources

- Charter of Fundamental Rights of the European Union
- European Convention on Human Rights
- UN Declaration of Human Rights and

Biomedical research ethics resources:

- Nuremberg Code
- Helsinki Declaration
- Belmont Report

Similarities between the SRCD Ethics Code and the European Perspective on Ethics in Social Sciences

EU guidelines do not differentiate, the way the SRCD code does, between ***general ethical principles reflecting the highest ideals of social science*** and the ***more specific behavioral standards*** that allow us to meet these ideals.

Common Principles

- EU: "respecting human dignity and integrity" and "minimizing harm and maximizing benefit "
- SRCD: Principle A. Maximizing Benefits and Minimizing Harm; Principle B. Respect for the Dignity of Person and Peoples

Similarities between the SRCD Ethics Code and the European Perspective on Ethics in Social Sciences

- EU principles: "ensuring honesty and transparency towards research subjects" and "respecting individual autonomy and obtaining free and informed consent (as well as assent whenever relevant)"

- SRCD Standard 5 includes 4 behavioral standards (2.a. – 2.e) on child assent procedures, requirements for and waiver of parent/guardian permission, voluntariness, and participants with informed consent vulnerabilities

Differences between the SRCD Ethics Code and the European Perspective

- Crises outside the EU coupled with migration, have given rise to new, socially important issues, requiring the involvement of vulnerable groups in research, but also calling for social science research in crisis areas.
- The EU guidelines drafted to address rapid technological development and political upheavals witnessed in recent years.
- The EU has separate ethics guidelines for research with refugees, asylum seekers and migrants.

Case Example: Covert Research

Both EU and SRCD

- Permit deception if disclosure of real purpose would lead participants to modify their behavior.
- SRCD recommends debriefing, unless participants would be negative affected; EU recommends post-study informed consent
- SRCD prohibits deception if it would cause physical pain or emotional distress

EU guidance

- Consult legal department and data protection officers at partner EU institution to ensue design does not risk breaking the law
- Keep in mind positive disclosure obligations in many EU states if you are intending to conduct research involving terrorism or other criminal activities

Internet Research and Social Media Data

EU Guidelines more specific than SRCD Ethics Code's more general principles and standards on privacy and confidentiality:

- Are data public and is it fair to use them in research?
- Does research meet conditions of free and voluntary informed consent?
- Is data anonymous? Can disparate threads be linked to uncover user identity?
- Is there uncertainty about vulnerability of users (e.g., minors) ?
- Might study cause harm to a group?

Research refugees, asylum seekers and migrants:

The SRCD Code integrates consideration of the sociopolitical context, safety, respect for, and fair treatment of vulnerable groups (including individuals without documentation) throughout the principles and standards

EU guidelines specifically address these groups:

- Treat refugees, asylum seekers & migrants with **care** and **sensitivity**
- Avoid **ethnocentricity**: show respect for their ethnicity, values, language, religion, gender and sexual orientation
- Rigorously safeguard the dignity, wellbeing, autonomy, safety and security of their **family & friends**
- Give special protection to participants with diminished autonomy, e.g., **unaccompanied minors** —e.g. involving NGOs to provide legal advice, psychological support, language interpreting and/or legally appointed supervision

Audience Q&A
Send Your Questions through the Chat Box

- How does the Code Apply to My Research
- How else might I use the Code?
- How Is the Code Related to Federal Regulations: Common Rule Changes and Regulations on Research Involving Children

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