Ethics in Pediatric Medicine: Current Considerations, Emerging Concerns

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1345 - 1445

"Medically Ready Force…Ready Medical Force"

Presenter

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- James Giordano, Ph.D., M.Phil., is a Bioethicist with the Department of Defense Medical Ethics Center (DMEC), Chief of the Neuroethics Studies Program, Scholar-in-Residence, leads the Sub-Program in Military Medical Ethics, and Co-director of the O'Neill-Pellegrino Program in Brain Science and Global Health Law and Policy in the Pellegrino Center for Clinical Bioethics.
- Dr. Giordano is also a Professor in the Departments of Neurology and Biochemistry at Georgetown University Medical Center, Washington, DC, USA. He is a Distinguished Visiting Professor of Brain Science, Health Promotions and Ethics at the Coburg University of Applied Sciences, Coburg, Germany, and was formerly the 2011-2012 JW Fulbright Foundation Visiting Professor of Neurosciences and Neuroethics at the Ludwig-Maximilians University, Munich, Germany.
- Dr. Giordano currently serves as Chair of the Neuroethics Program of the Institute of Electrical Electronic Engineers (IEEE) Brain Project, and an appointed member of the Neuroethics, Legal and Social Issues (NELSI) Advisory Panel of the Defense Advanced Research Projects' Agency (DARPA). He has previously served as Research Fellow and Task Leader of the EU Human Brain Project Sub-Project on Dual-Use Brain Science; an appointed member of United States Department of Health and Human Services Secretary's Advisory Council on Human Research Protections (SACHRP); and as Senior Science Advisory Fellow of the Strategic Multilayer Assessment Branch of the Joint Staff of the Pentagon.
- The author of over 290 publications in neuroscience and neuroethics, seven books, and 15 government whitepapers on neurotechnology, ethics and biosecurity, he is an Editor-in-Chief of the international journal Philosophy, Ethics and Humanities in Medicine; Associate Editor of the Cambridge Quarterly of Health Care Ethics; and Contributing Editor of Frontiers in Human Neuroscience.
- His ongoing research addresses the neurobiological bases of neuropsychiatric spectrum disorders; and neuroethical issues arising in and from the development, use and misuse of neuroscientific techniques and neurotechnologies in medicine, public life, global health, and military applications.

Disclosures

- Dr. Giordano has no relevant financial or non-financial relationships to disclose relating to the content of this activity.
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Learning Objectives

At the conclusion of this activity, participants will be able to:

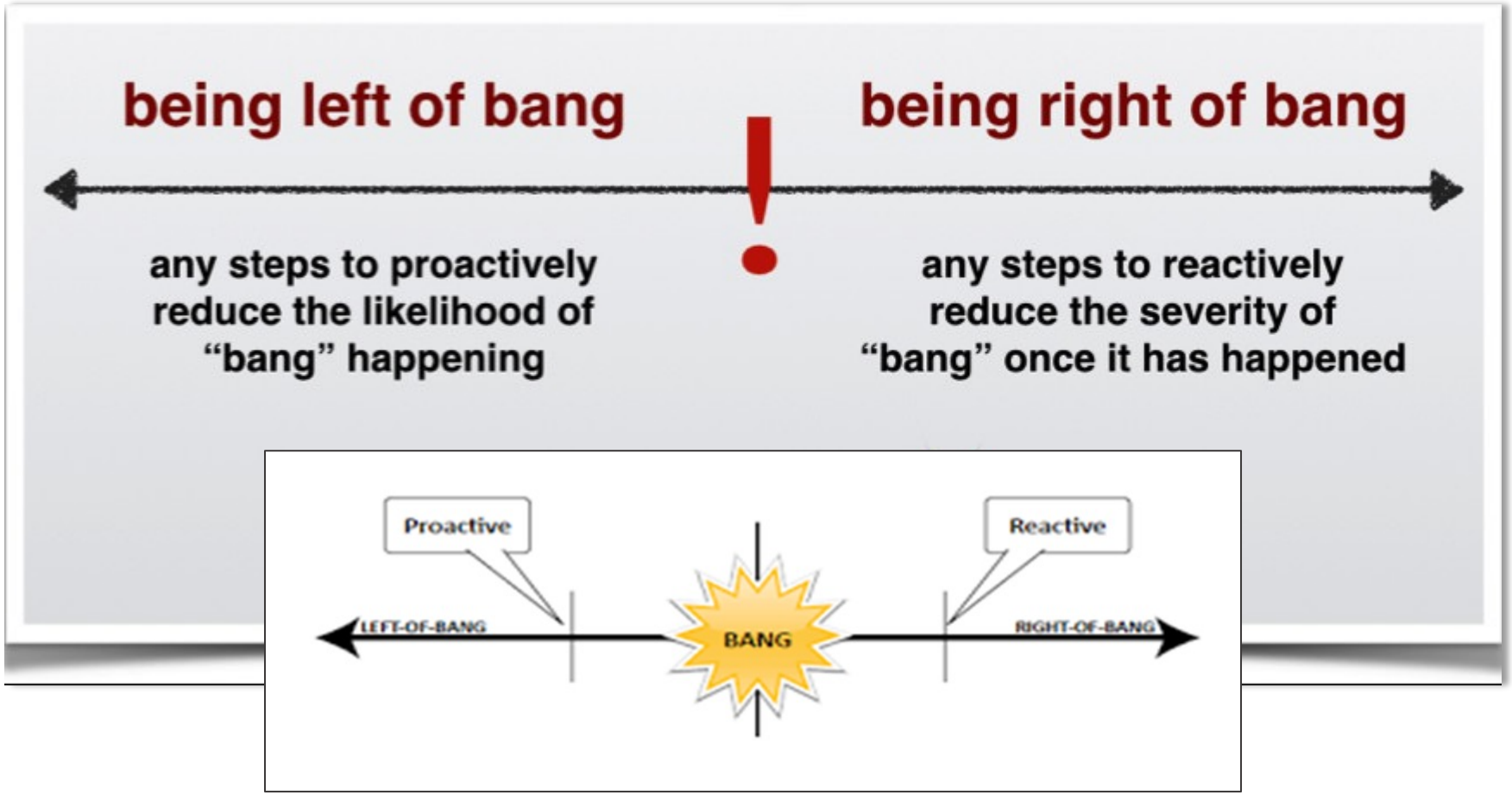
1. Define primary ethical issues common to both civilian and military pediatric medical care
2. Describe key considerations of current and near-term pediatric preventive care
3. Distinguish treatment, enablement, and enhancement
4. State a general approach to addressing and mitigating risk(s) of new and emerging tools and methods applicable in pediatric biomedicine

Ethical Issues in Pediatric Medicine

- **Vulnerable population**
  - **Concern for autonomy**
  - **Chronological age; cognitive age; social considerations**
- **Assent vs. Consent**
  - **Extent and nature of information provided**
- **Parentally-driven**
  - **Clinician (often) serves in *Loco co-/quasi parentis***
- **Questions of (Real) Equipoise**

Most = Equivalent, if not Identical in Military & Civilian Medical Practice

The Continuum of Care



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Pediatric Preventive Medicine

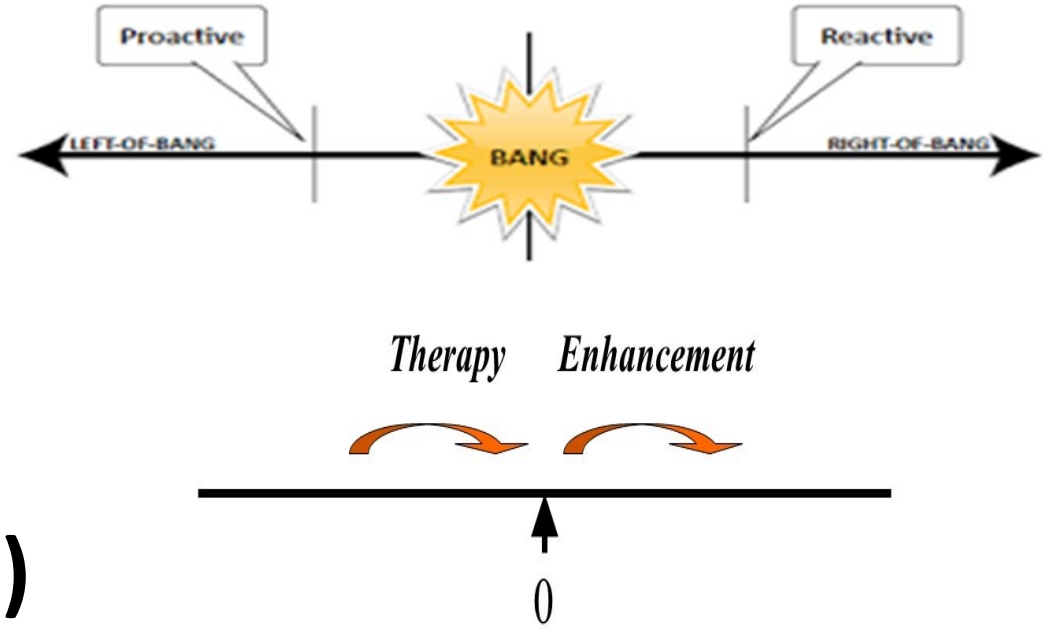
Providing *HOPE* to Pediatric Patients:

Health

Occupational

Protection

Enablement (Enhancement)



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Types of Alteration(s)

"Treatment": aims at relief of impairment, perhaps regeneration, and possibly restoration of structure or function.

If reliably effective, a treatment is "*therapy*."

With supportive tools/training, a therapy contributes to "*rehabilitation*".

In the context of appropriate social accommodation, rehabilitation is also "*generic enablement*."

"Supplement": aims at exceeding population norms.

If reliably attained without deleterious side-effects, it is "*enhancement.*"

Enhancement dramatically exceeding norms is "*extraordinary augmentation*."

"Modification": adds non-standard capacity to individuals' structure/function to transcend human capacities.

If reliably practical, it provides "*radical augmentation*."

Issues (from synaptic to social)

- **Alteration to single system: system's capacity for sensitivity and signaling may get degraded from over-excitation, so improvement can be impeded.**

- **Alteration affecting network of systems: one system's deviation from regular functioning may cascade across network and obstruct that or other system's ability to effect desired improvement.**

- **Alteration to networked systems: other related performance capacities aren't appropriately adjusted, and hoped-for performance rewards can't fully materialize.**

- **Alteration effecting improved performances: heightened performance by one person inspires others to reactively compensate with conflict or matching enhancements.**

(Shook & Giordano, 2016)

Constraints upon Improvement

Asymmetric improvement -- further 'improvement' is futile because additional alteration causes obvious divergence from the optimal level. E.g.- skills for photographing ordinary objects for a realistic effect.

Asymptotic improvement – further improvement produces lessening results while optimal level is approached. E.g- making finer adjustments toward some ideal of physical beauty; adjusting how to play poker -eventually reaching maximal performance level constrained by uncontrollable chance.

Asymptomatic improvement – further improvement produces undetectable measurements of real enhancement. E.g.- improving ability to play chess may reach point of winning every game , but after winning constantly, how can further enhancement of chess playing be detected?

Asynoptic improvement – further 'improvement' confusingly produces different results from different perspectives; it becomes difficult to recognize enhancement. E.g.- additional improvements for surpassing artistic beauty, observers cease agreeing about what sort of beauty can result.

Asynchronic improvement – further 'improvement' causes more delayed result, obviating point of the activity. E.g.- Skill at making witty remarks –wittier remarks may require longer time for comprehension by a general audience, so what's the point?

Asymphonic improvement – past certain degree of 'improvement', causes discord to the point of destroying the context in which the improvement made sense. E.g. -playing instrument in an orchestra could be excessively enhanced such that orchestral performance is disrupted.

(Shook & Giordano, 2016)

Addressing Alteration(s)

4 domains/dimensions of address/analysis needed:

- **Physiological results: diligence in laboratory and clinical research into experimental improvements**
- **Individual capacities: assessing personal performances under real-world conditions**
- **Group achievements: surveyance of social networks regulating incentives/rewards for performance**
- **Civic harmonies: cognizance of disruptions to central moral values, social ideals, and legal principles**

(Shook & Giordano, 2016)

For the Patient's' Good…

Patient: from the Latin, *patior* – "the one who suffers"

Whence suffering?

<u>What Good(s)?</u>

Biomedical

For the Patient's Choice(s)

For the Patient as Person

For Humanity

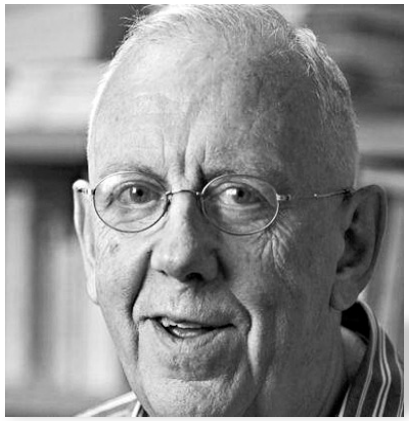
To What Extent?

Consider, Frankena's Conceptualization…

Obligate…
Responsible…
Exceptional…
Supererogatory

(Wikipedia.com, n.d.)

…and (a reversal of) MacIntyre's Query
"Which Rationality? Whose Justice?"



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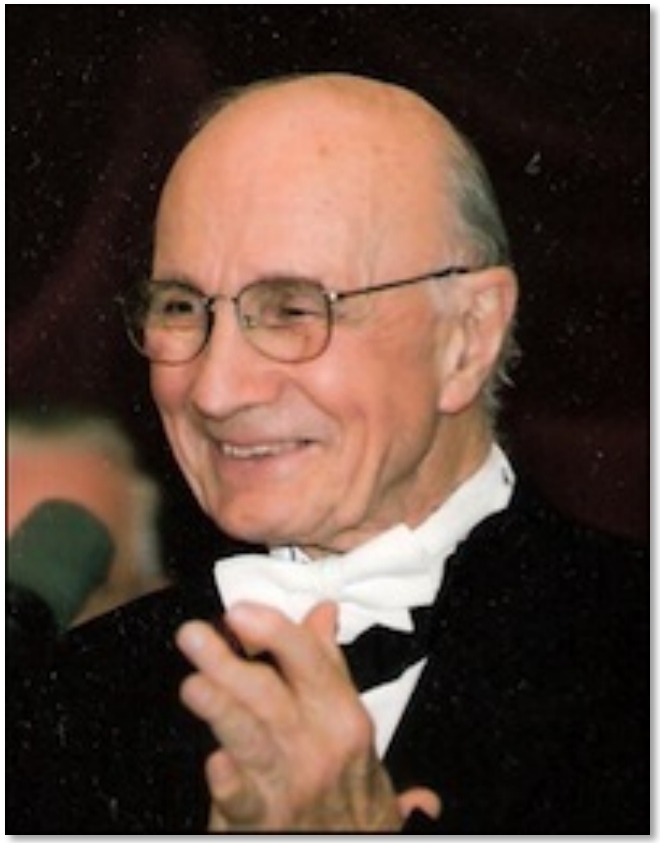
In an Era of "Patient-Centered Care"…Who Decides?

Define the Issues…



(Pellegrino, n.d.)

"…the issues and questions are of the most fundamental kind…they arise from a practical question - shall we or shall we not use a certain biotechnology…"

"…specific questions or issues are … centered on…what do we do to improve improve the human being, and human condition, with the biotechnology that we have, and that we might create."

Prof. Edmund D. Pellegrino

Current Neuromodulatory Science and Technology (S/T)

- Technopharmaceutics
- Neuro(psycho)genetics
- Tissue implants
- Transcranial Modulation
- Deep Brain Stimulation
- Brain-computer Interfaces
- Neuroprosthetics

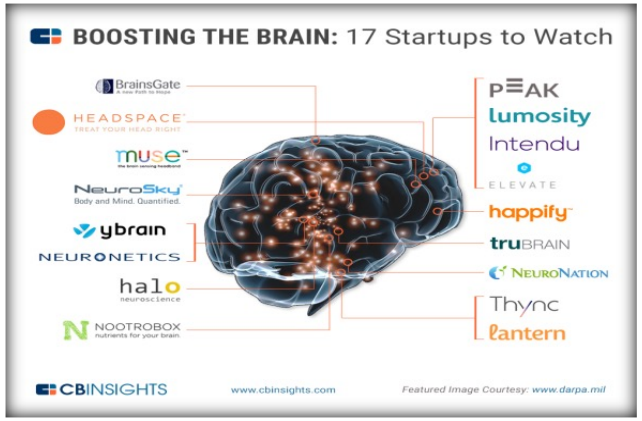
…and more

(Getty Image, n.d.)

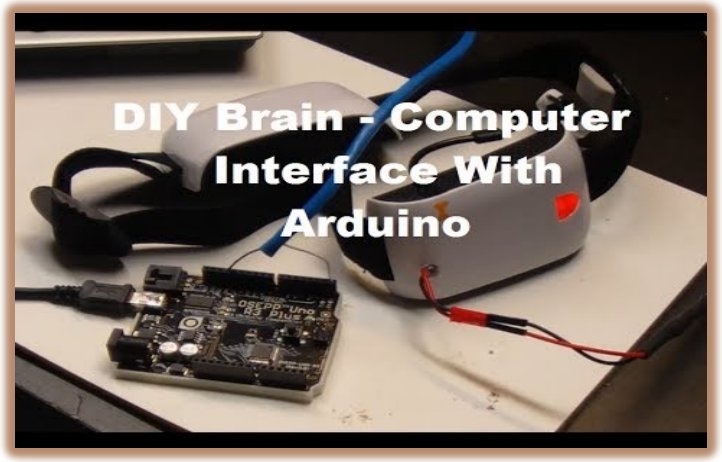
Public Use

- **Direct-to-Consumer Brain Tech**

(darpa.mil, n.d.)



- **Do-it-Yourself Neuroscience and Technology**



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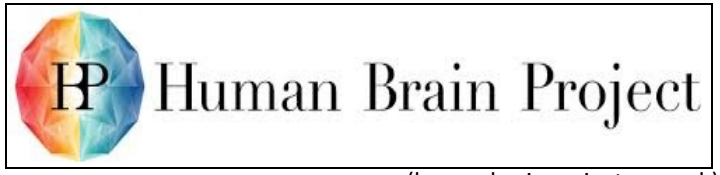
International Enterprise in NeuroS/T

- **EU Human Brain Project**



(humanbrainproject.eu, n.d.)

- **China Brain Project**

(xinhuanet.com, n.d.)

- **Japan BrainMind**

(brainminds.jp, n.d.)

- **Korea Brain Project**

NeuroS/T on the Global Stage

“Cultural variations in history, philosophies and ethics can create ambiguities in definitions of right and good use…”

Organisation for Economic Cooperation and Development 2018 Reports

<u>Opens the Bag for</u>…

“Research Tourism”

The Dilemma of “Ethics Dumping”

“Medical Tourism”

“Conformity via Burden”

Preparatory Neuroethical Stance

- **Realistically appraises actual capabilities and limitations of technology and techniques**
- **Defines domains and dimensions new techniques and technologies will influence;**
- **Addresses what can and should be done to mitigate burdens, risks and harms while maximizing benefits**
- **But must:**

  (1) Define ‘benefits’ and ‘burdens’ in context and scale; and

  (2) Engage discourse/dialectic toward guidelines and policies

Preparatory Neuroethics Paradigm

Informed by...

6-W Questions:

- ***What*** **neuroS/T are available for current use?**
- ***Why*** **is neuroS/T considered or advocated for use?**
- ***Who*** **will receive neuroS/T?**
- ***When*** **will neuroS/T be considered (algorithm/protocol)?**
- ***Where*** **will neuroS/T be administered (e.g.-hospital; clinic, school; worksite; home)?**
- ***Which*** **mechanisms will be in place for ongoing provision of services/resources?**

(Giordano, 2015)

Preparatory Neuroethics Paradigm

Framed by...

6-C Considerations:

- ***Capacities*** **and limitations of the neuroS/T**
- ***Consequences*** **incurred by neuroS/T on recipients, families, and society in the short, intermediate, and long-term**
- ***Character*** **of the research and recipient (e. g, patterns of cognition, emotion, and behavior) affected by neuroS/T**
- ***Contexts*** **of need and value that influence use of neuroS/T**
- ***Continuity*** **of research and clinical care**
- ***Consent*** **through provision most information possible**

(Giordano, 2015)

Principled and Globally Relevant

Shook and Giordano *Philosophy, Ethics, and Humanities in Medicine* 2014, **9**:1
http://www.peh-med.com/content/9/1/1

PEHM PHILOSOPHY, ETHICS, AND HUMANITIES IN MEDICINE

EDITORIAL Open Access

A principled and cosmopolitan neuroethics: considerations for international relevance

John R Shook[1] and James Giordano[2,3*]

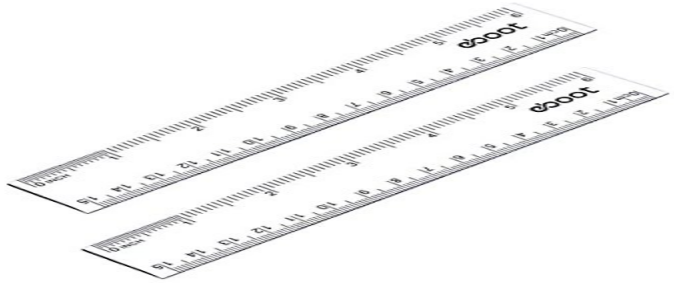
1. **Self-creativity: The right of persons to re-create themselves for enriching their lives.**
2. **Non-obsolescence: The duty to avoid the creation of obsolete people.**
3. **Empowerment: The duty to increase the capabilities of people to live autonomous and fulfilling lives.**
4. **Citizenship: The duty to promote free, equal, law-abiding, and participatory citizenship.**

(Shook & Giordano, 2014, 2016)

Take Home Messages

Reflection, insight and prudence must be the stepping stone for all future acts of inquiry, invention and intervention…

“ *Measure twice, cut once*”, for all too often, there is no turning back.



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Key Takeaways

At the conclusion of this activity, participants will be able to:

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