

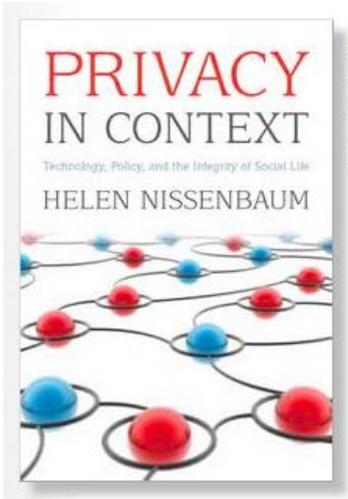
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Comments before the
Presidential Bioethics Commission
Atlanta • June 9, 2014

Privacy as Contextual Integrity

Appropriate Flow
(not control or secrecy)

Context specific
informational norms



Informational norms model Appropriate Flow

In a job interview, the interviewer asks about a candidate's past work experience but not about religious observance

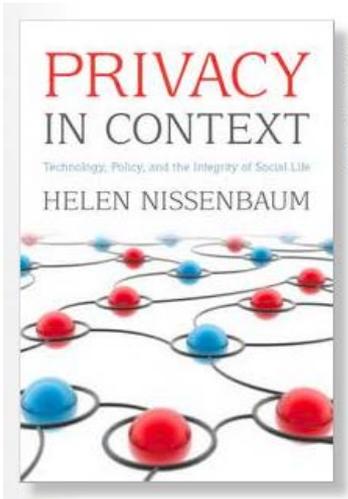
A priest never shares congregants' confessions with others

A citizen of the U.S. reveals gross income to the IRS, under strict conditions of confidentiality except as required by law

You do not share a friend's secrets with others, except, perhaps, with your spouse, unless your friend expressly requests otherwise

Parents closely monitor their children's academic performance

Context specific informational norms



<Information Type/Attributes> about <Data Subject> is transmitted from <Sender> to <Recipient> under <conditions defined by Transmission Principle>

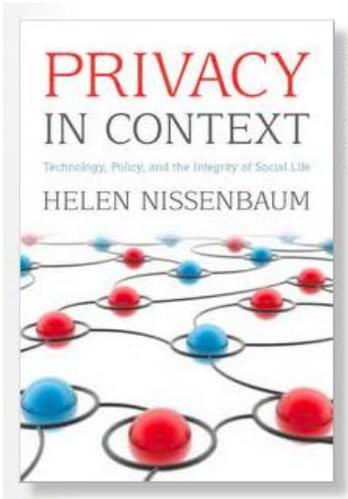
Actors [sender, recipient, subject]

Attributes [type of information]

Transmission Principles [constraints on flow]

Disruptive flows
Threaten privacy

Context specific informational norms



<Information Type/Attributes> about <Data Subject> is transmitted from <Sender> to <Recipient> under <conditions defined by Transmission Principle>

Actors [sender, recipient, subject]

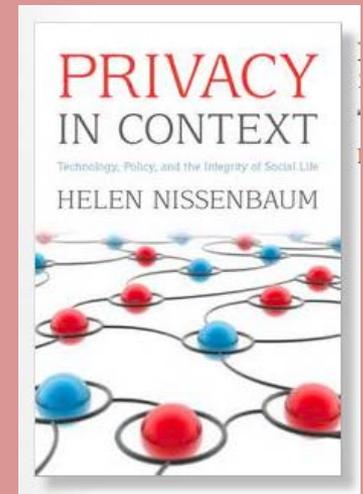
Attributes [type of information]

Transmission Principles [constraints on flow]

Evaluating disruption

Ideal informational norms

- 1) Interests, preferences, desires
- 2) Ethical & political values
- 3) Context-specific ends & values



Neuroscience & Privacy?

Privacy and intrusion

Access to data

Go to solution: Anonymity & Informed Consent?

- ` How to anonymize
- ` Effective operationalization of Notice & Consent

Big Data: Anonymity & Consent

- ` Nameless preserved: not the underlying value
- ` Informed consent achieved but irrelevant

Clinical

Research

Identify Patters of Disruptive Flows

Actors

Information Types

Transmission Principles

Evaluate informational norms

- Interests, preferences, desires
- Ethical & political values
- Context-specific ends & values

A Contextual Approach: 3 Proposals

Follow separate tracks for clinical and research contexts
Ontologies of actors and information types are different
Purposes and values are different

Accountable (open) access
Open access can be implemented in many different ways
Devil is in the details

Establish and guard contextual barriers, particularly
Against commercial and governmental actors

PRESIDENTIAL COMMISSION
for the
STUDY OF BIOETHICAL ISSUES



Seventeenth Meeting
June 9-10, 2014
Atlanta, GA

www.bioethics.gov