Exceptions to the rule: When minors get to make their own medical decisions

PRESENTED BY: Robert Macauley, MD, FAAP, FAAHPM, HEC-C
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Objectives

- Background on pediatric decision-making
- Define “minor”
- Identify situations were minors are able to make their own medical decisions
- Explore timely applications
  - Adolescents and COVID vaccines
  - Unaccompanied minors

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Hierarchy of ethical decision-making

1. Pure autonomy
2. Substituted judgment
3. Best interests

Right of adults to decide

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body."

—*Schloendorff v. Society of New York Hospital* (NY Ct of App, 1914)

Hierarchy of ethical decision-making

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Hierarchy of ethical decision-making

1. Pure autonomy
2. Substituted judgment
3. Best interests
   - Only relevant standard for those who *never* had decision-making capacity

Minors and decisions

- Controlling U.S. Supreme Court case (*Parham v. J.R.*, 1979)
  - "The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions."
  - "Most children, even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment. Parents can and must make those judgments."

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Rationale for parental decision-making

- Child's lack of decision-making capacity
  - Compromise "present autonomy" to safeguard "future autonomy"
- Importance of family unit
- Parental responsibility for outcome of decisions

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Decision-making capacity (DMC)

- Communicate a choice
- Understand information
- Appreciate consequences of the choice
- Manipulate information rationally
- Act voluntarily (i.e., free of coercion)

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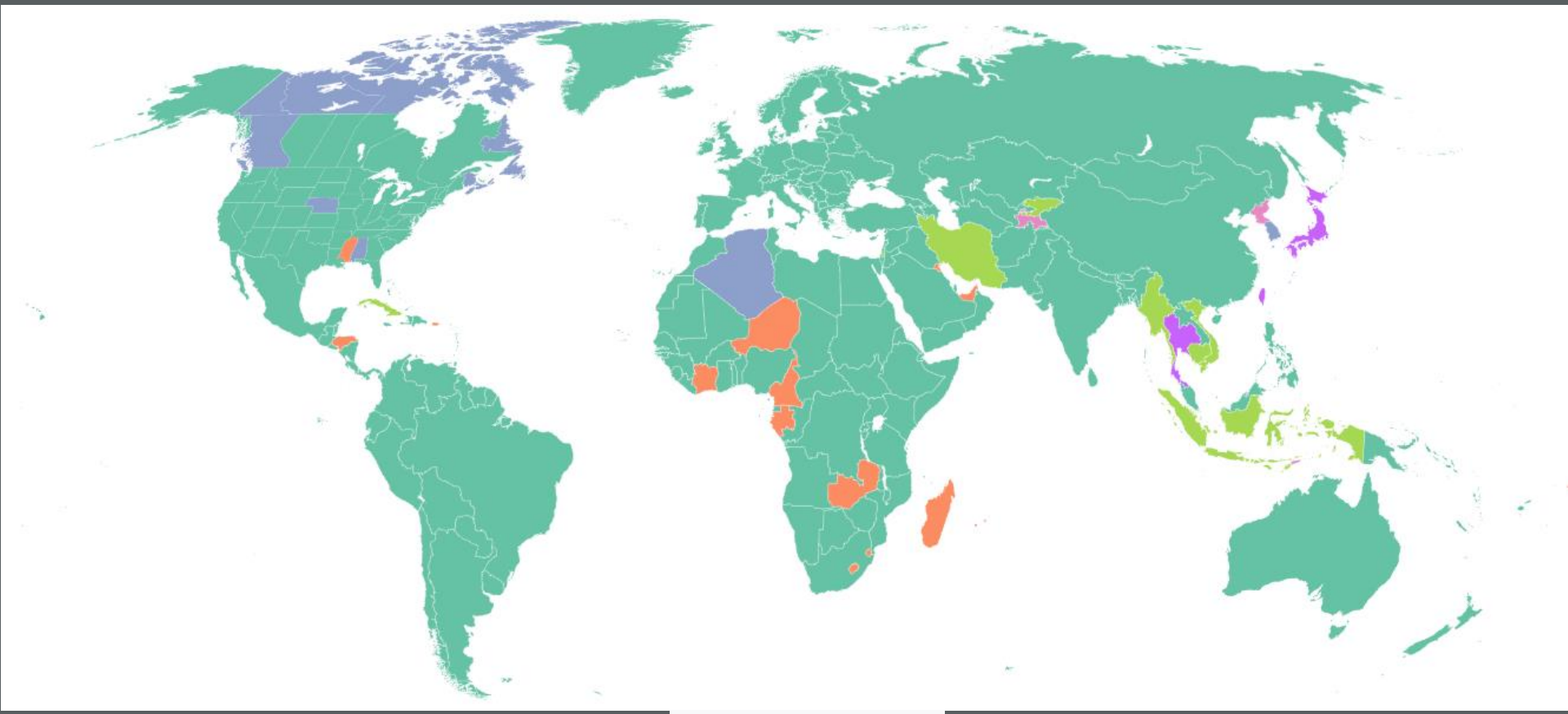
What is a “minor”?

Age of majority worldwide



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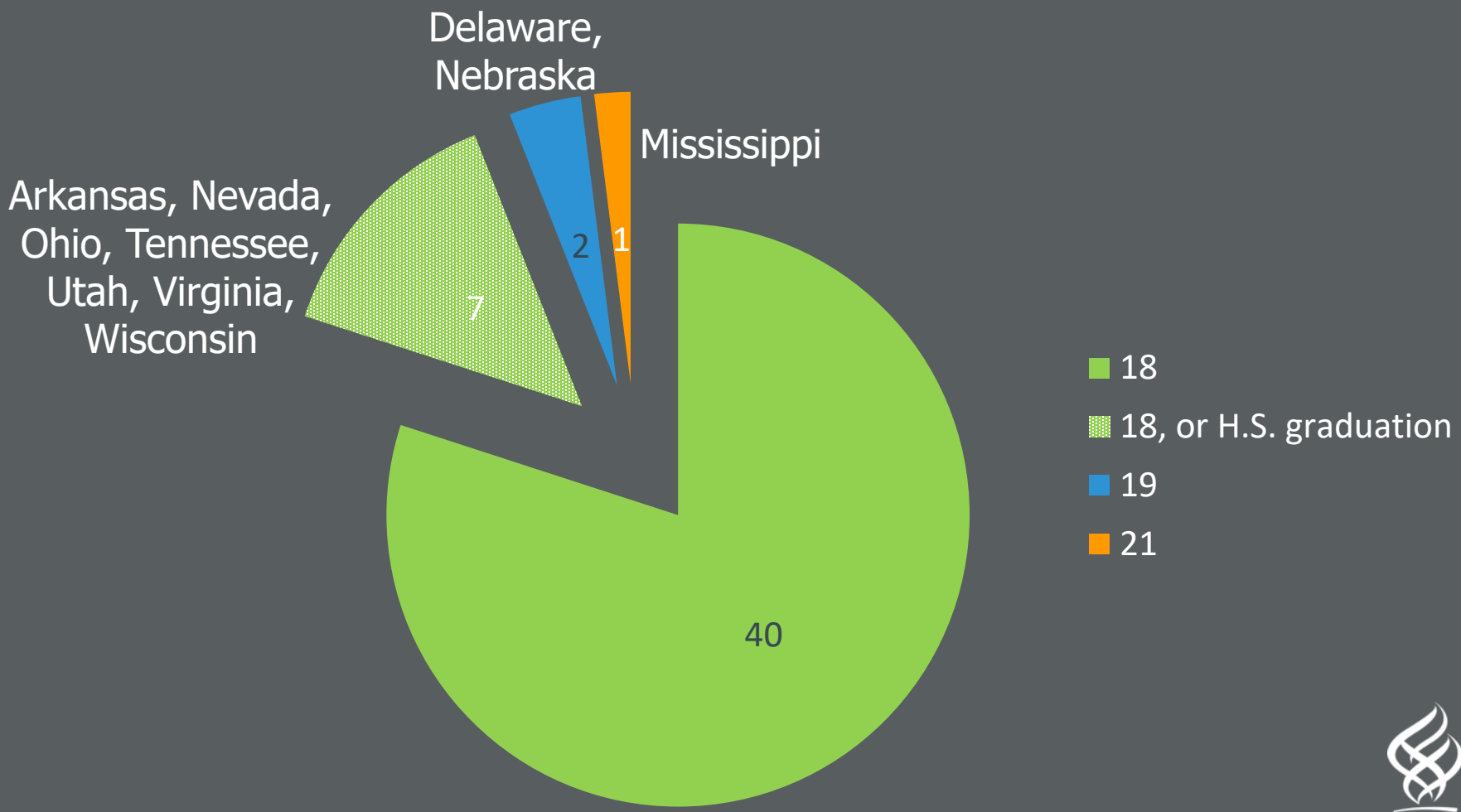
Age of majority by state



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When minors can decide

- Situations where minors can make their own medical decisions
  - Some decisions
    1. Minor treatment statutes
  - All decisions
    2. Emancipation
    3. Mature minor exception

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Minor Treatment Statutes (18 V.S.A. § 4226)

- A minor may consent to treatment and hospitalization if he is at least 12 years old and is
  - dependent upon regulated drugs; or
  - suffering from a venereal disease; or
  - is an alcoholic
- Note: if the condition requires immediate hospitalization, the parents or legal guardian must be notified.
- Also, patients at least 14 years old may consent to voluntary hospital admission for mental health care (18 V.S.A. § 7503)

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When minors can decide

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Emancipated Minors (12 V.S.A. § 7151)

- Married, or has been married
- On active duty in the military
- Declared to be emancipated by a court
  - Must be at least 16 years old
  - Must have lived on his/her own for at least 3 months
  - Must be self-supporting
  - Must have graduated from high school or be earning passing grades in some educational institution
  - Can't be in the custody of SRS or the corrections system
- **NOT** pregnancy or parenthood

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Mature minor doctrine

Historical evolution

Common law

Persons under the age of 21 incapable of consenting on their own behalf

Evolution of the “Mature Minor”

- Originally intended to prevent the requirement of parental consent from becoming a barrier to treatment
  - Especially concerned with abortion, STDs, addiction
  - Solely concerned with minor consenting to procedures in the absence of parental consent
- Became an “escape hatch” for high benefit/low risk cases that weren’t emergencies
- Limitation of life-sustaining medical treatment only invoked when both parents and the courts were in agreement

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20th century

Mature minor doctrine

1. Parent unavailable
2. Clearly beneficial treatment
3. Minor able to understand

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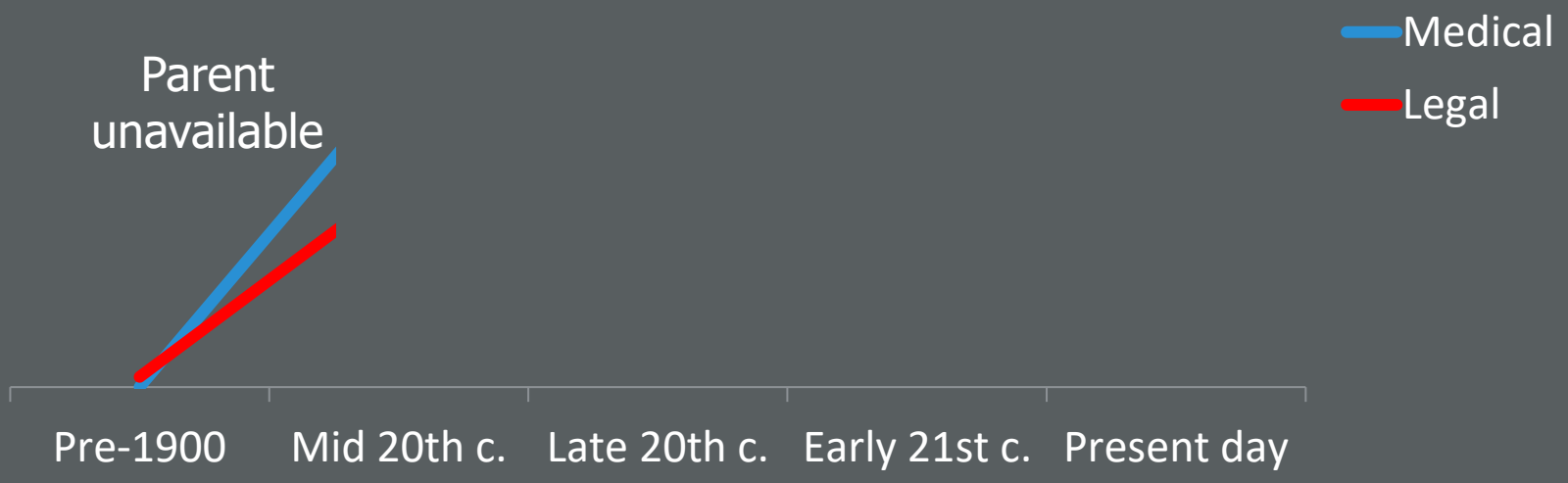
Trajectory of “mature minor doctrine”



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Mature minor doctrine

Legal

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A line in the sand?

18

Lacks DMC

Possesses DMC

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A line in the sand?

The age of majority "is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood."

– *In re: E.G.* (Illinois Supreme Court, 1989)

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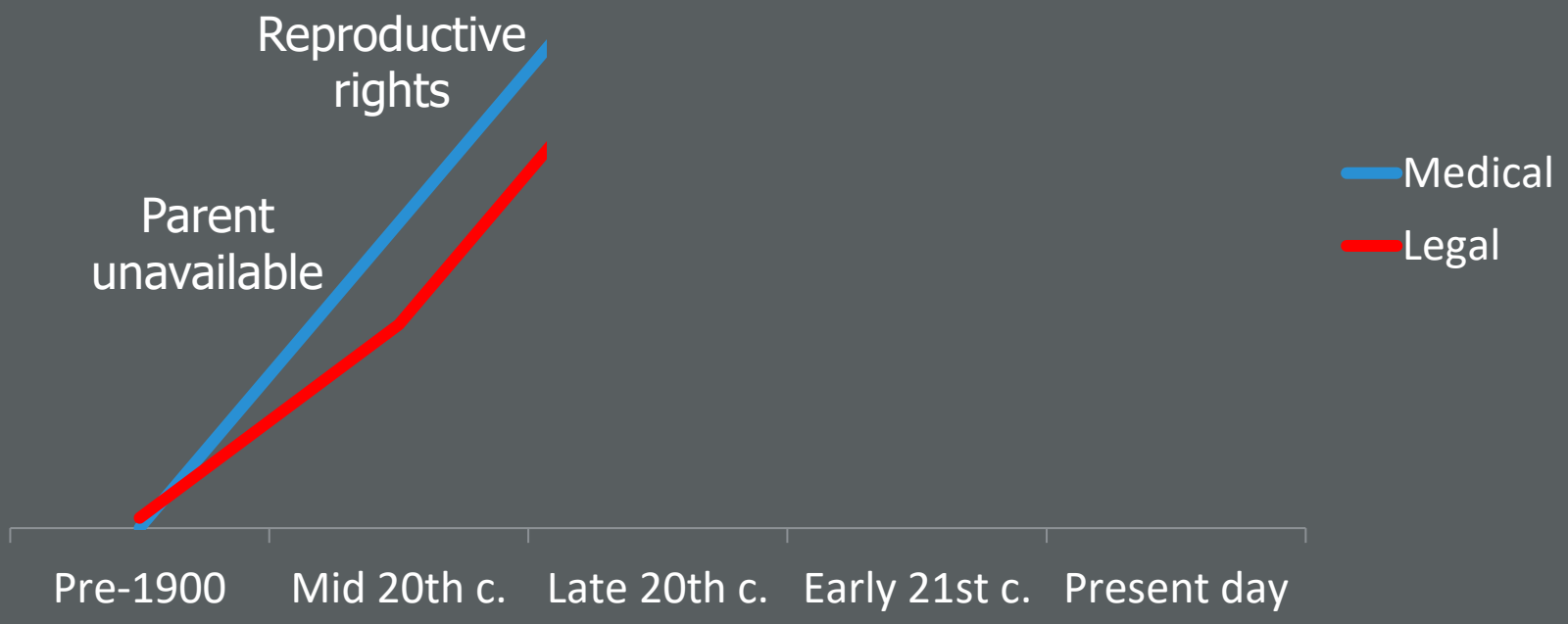

"The presumption on the part of physicians…should be that *all* adolescent patients between 14 and 17 have the capacity to make health care decisions, including EOL decisions, *except* when individual patients demonstrate that they do not have the necessary DMC." (Weir and Peters, *Hast Ctr Rep* 1997)

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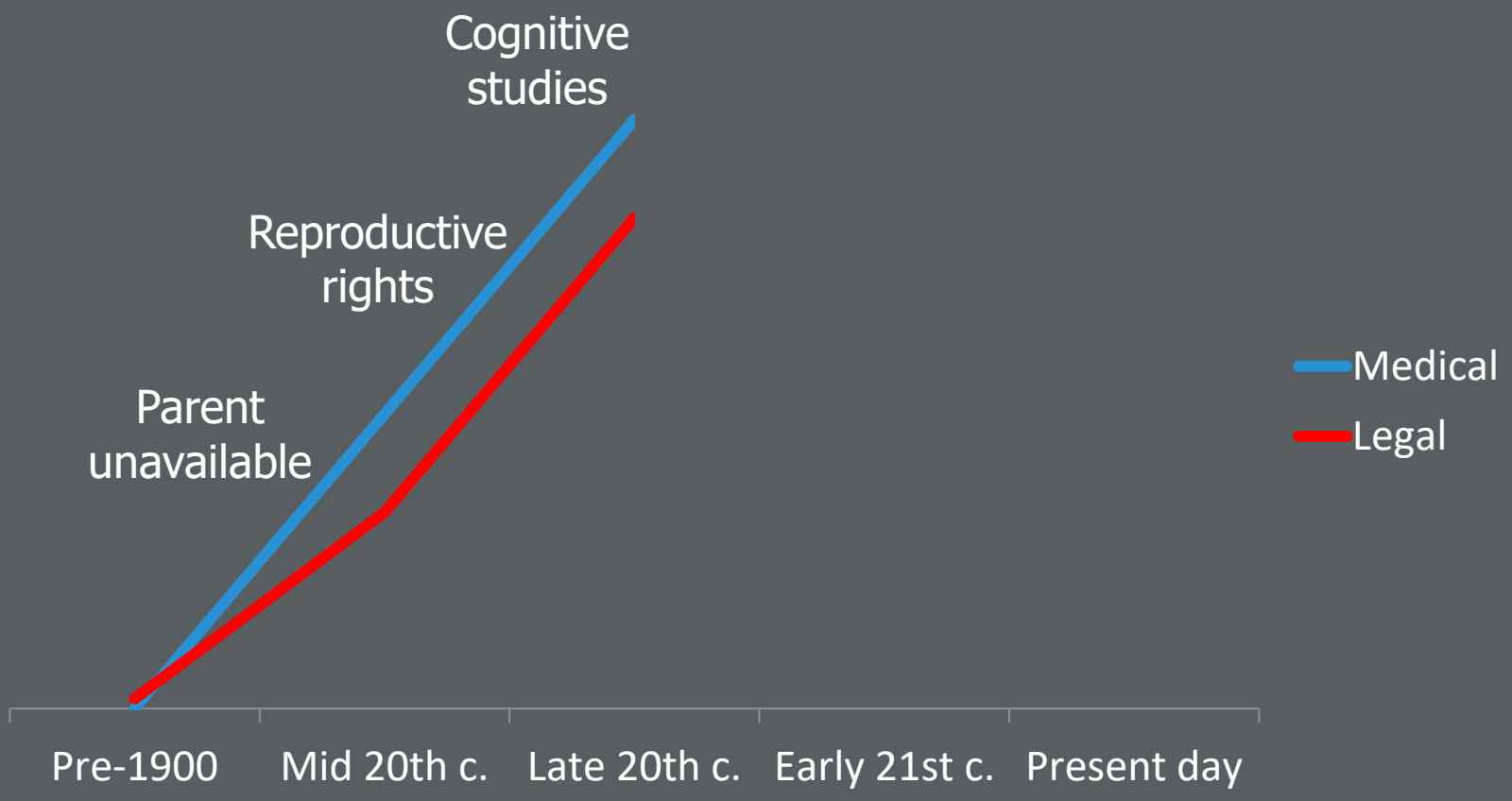

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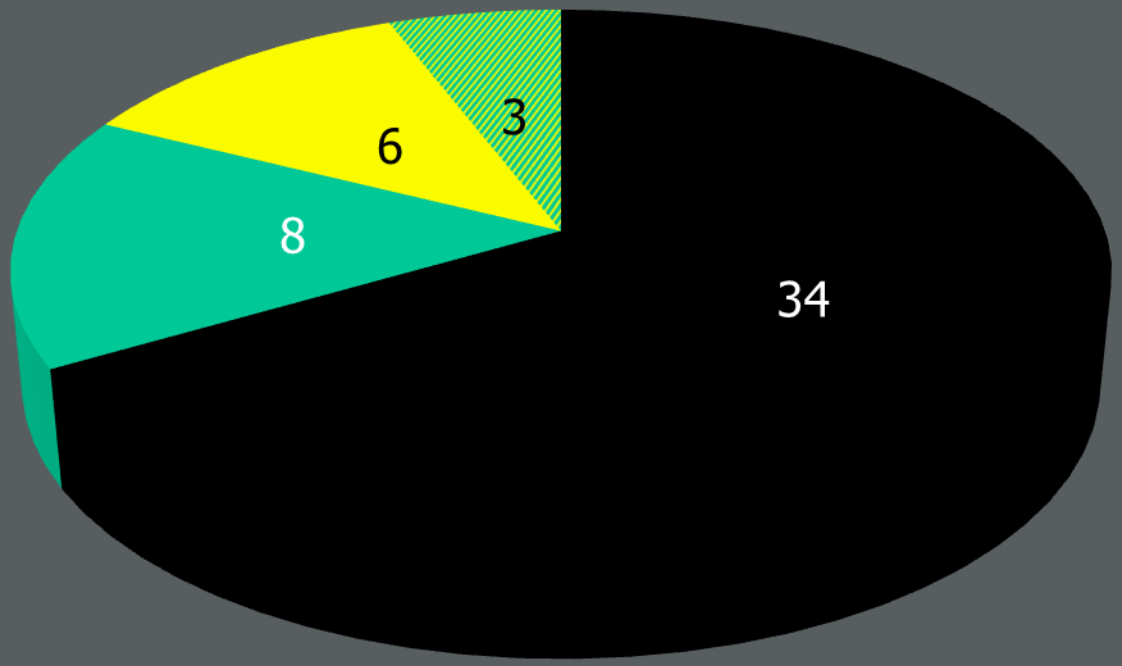
Mature minor exception in state laws



- No exception
- Broad exception
- Narrower exception
- Permit minors of any age to consent in some/all circumstances

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States with mature minor laws

Broad authority	Narrower authority	All minors of any age to consent to some or all treatment
Alabama, Tennessee (if ≥14)	**Kansas** (if ≥16, but only if parent is unavailable)	**Alaska** (if parent unavailable or unwilling)
Oregon (if ≥15)	**Maine** (pre-accident statements re: persistent vegetative states are binding)	**Delaware** (after reasonable efforts made to obtain parental consent)
South Carolina (if ≥16, except for "operations")	**Massachusetts** (if DMC, and best interests served by not notifying parents)	**Louisiana**
Arkansas, Idaho, Illinois, West Virginia (if possesses Decision Making Capacity [DMC])	**Nevada** (if DMC and not receiving treatment leads to a "serious health hazard")	
	Montana (if high school graduate)	
	Pennsylvania (if ≥18 and high school graduate)	

A two-edged sword

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- If minors are “mature” enough to make their own *medical* decisions, then they can be held responsible for their other decisions
  - Capital punishment
  - Life sentence without parole

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Mature minor doctrine

Neurodevelopmental

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Back-to-front brain development

- Recognition that brain development continues into the early/mid-20s
  - Early adolescence
    - Decrease in prefrontal gray matter, creating more efficient connections
    - Greatest dopaminergic activity in pathways connecting limbic system and prefrontal cortex
  - Adolescence → early adulthood
    - Myelination of prefrontal cortex
    - Improved efficiency in connections between limbic system and prefrontal cortex

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What this means

- Adolescents have the *ability* to understand the facts of a situation, but often decide for emotional reasons
- The greater the pressure, the greater likelihood of an emotional decision
  - "In emotionally salient situations, subcortical systems will win out (accelerator) over control systems (brakes) given their maturity relative to the prefrontal control systems." (Casey, Jones, Somerville)

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Decision-making in adolescence

- Characteristics of adolescence
  - Impulsivity
  - Sensation-seeking
  - Decreased future orientation
  - Susceptibility to peer pressure

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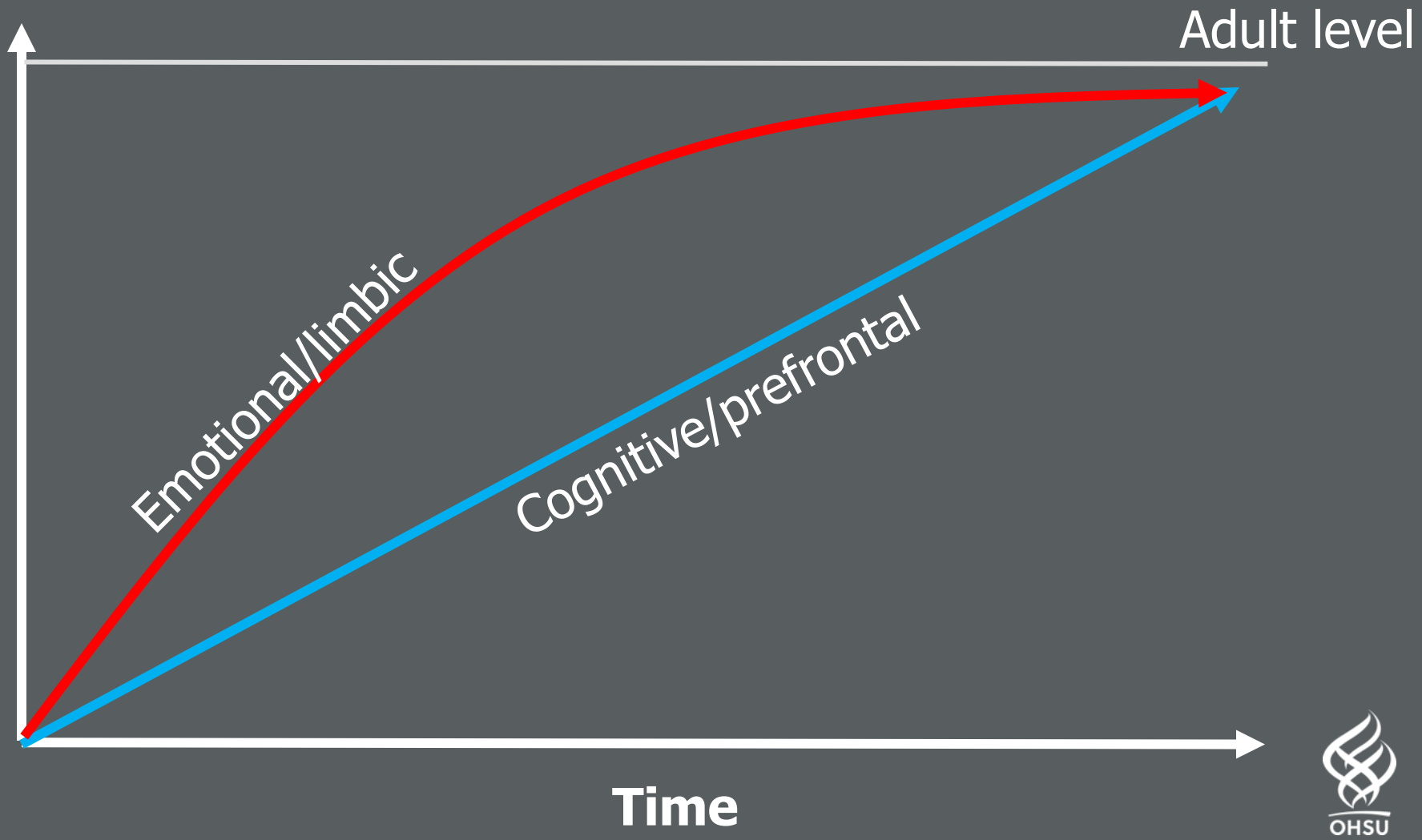
Dual-process model



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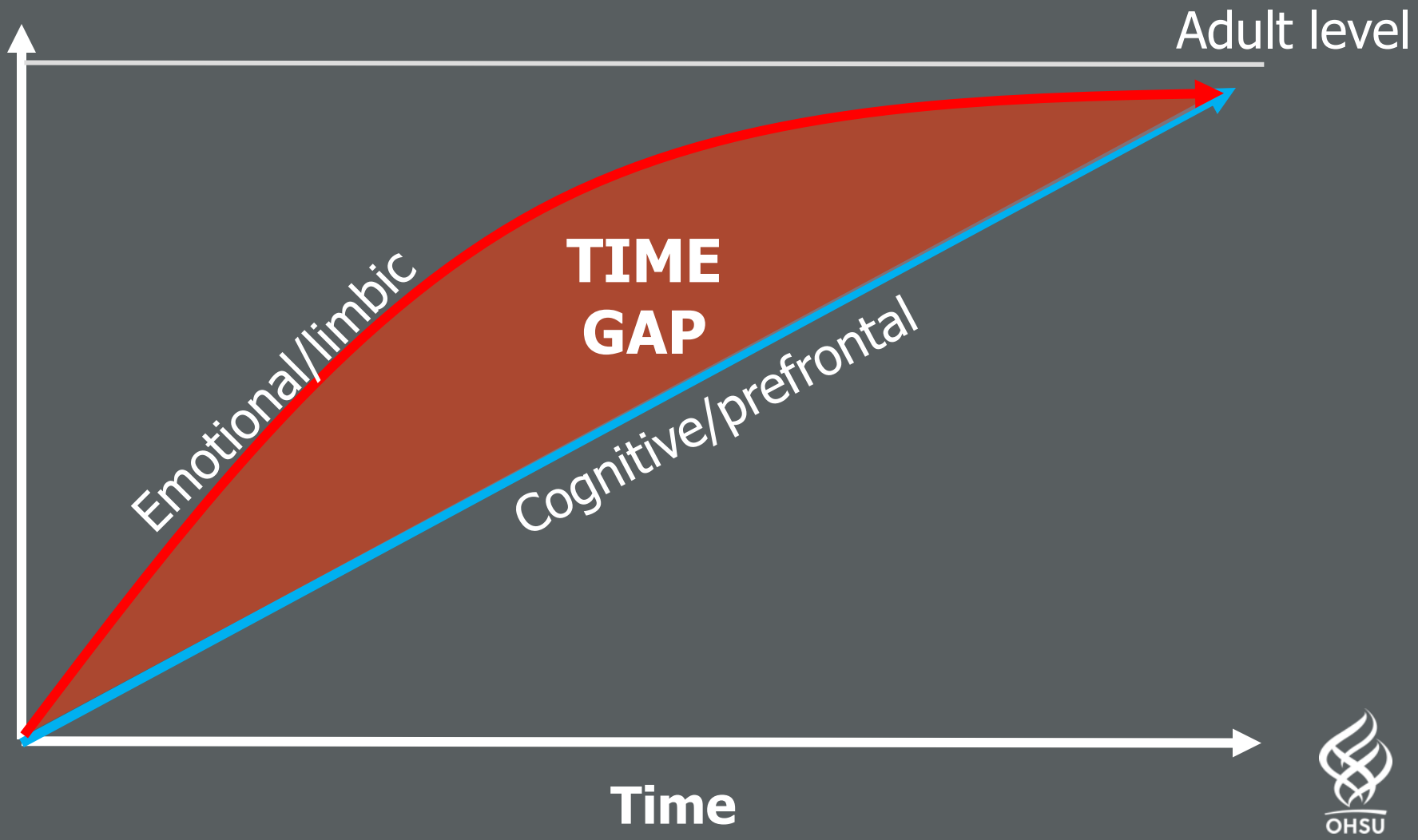

Growing up

When I was a boy of 14,
my father was so ignorant I could hardly stand to have the old man around.

— Mark Twain

Growing up

When I was a boy of 14,
my father was so ignorant I could hardly stand to have the old man around.

But when I got to be 21,
I was astonished at how much the old man had learned in seven years.

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Developmental Concerns: Voluntariness

- Younger children may not even realize they're making a decision (ages 6-9)
- Up to adolescence children view authority figures as legitimate and powerful
  - Conformity to adult role models peaks in early adolescence (~11-12 years old)
- Ages 15-16 reveal increased reliance on the opinions of peers, over those of adults
  - Voluntariness of dissent is called into question

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2000s

Legal restriction of "mature minor"

1. No capital punishment for crimes committed before age 18
2. No life without parole for crimes committed before age 18

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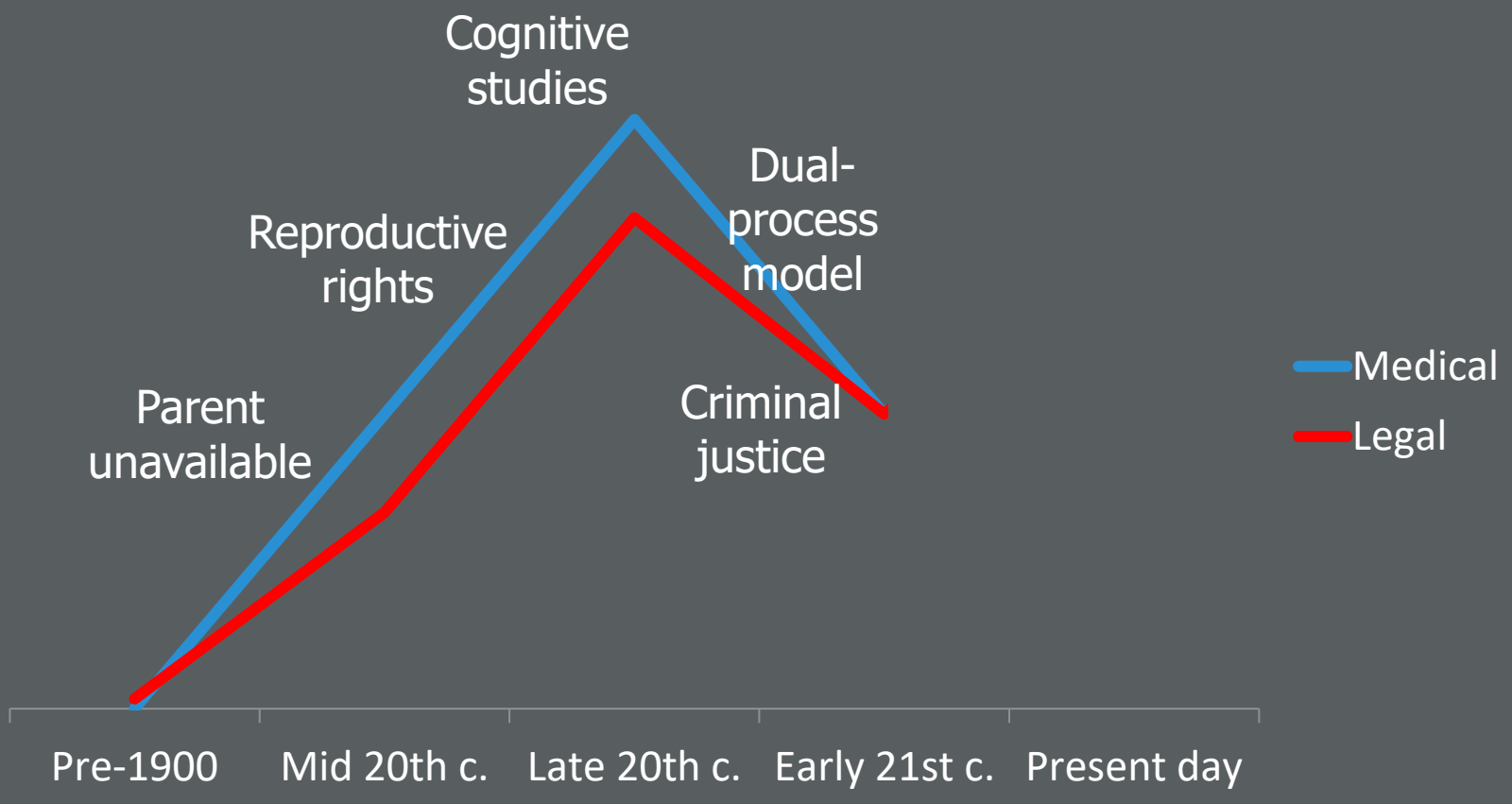

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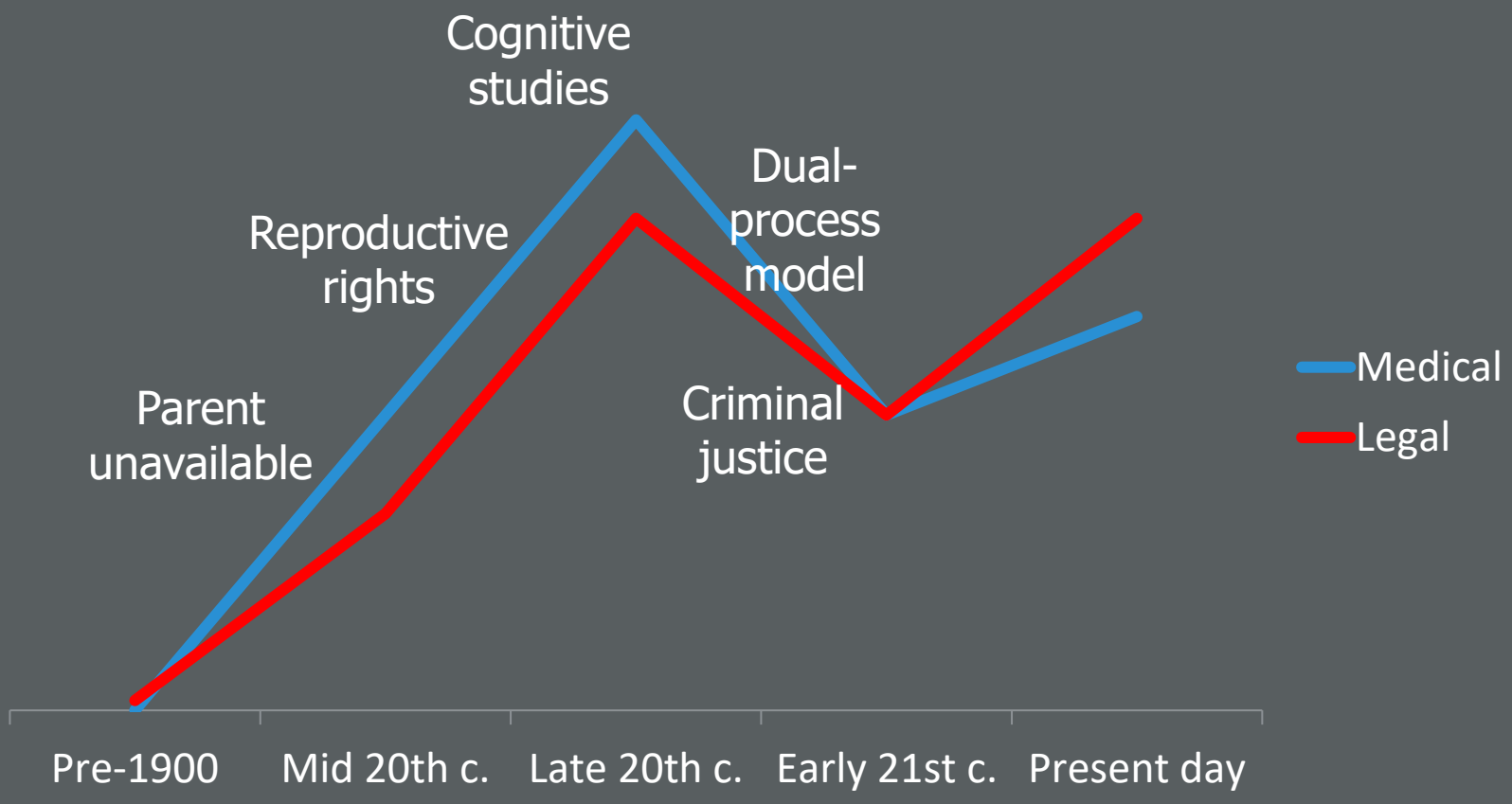

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Mature minor doctrine

Professional

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AAP (1995)

- Adolescents, especially those age 14 and older, may have as well developed decisional skills as adults for making informed health care decisions.
- In some cases in which the patient has no legal entitlement to authorize treatment, the physician may have a legal obligation in some jurisdictions to obtain **parental permission** or to notify parents in addition to obtaining the patient's consent.
- An adolescent’s refusal of consent in cases such as these may well be legally (and ethically) binding.
- If “conflict resolution” fails, formal, legal adjudication may be needed.

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AAP (2016)

- “In general, adolescents should not be allowed to refuse life-saving treatment even when parents agree with the child. “
- “In medical scenarios with a poor prognosis and burdensome or unproven interventions, more consideration should be given by the physician to advocating for the cognitively mature teenager who wants to refuse treatment and uphold an adolescent’s assent or refusal for further attempts at curative treatments.”

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So far, we've mostly been talking about minors when their parents aren't available/participating

But what happens when parents *disagree* with their child's decision?

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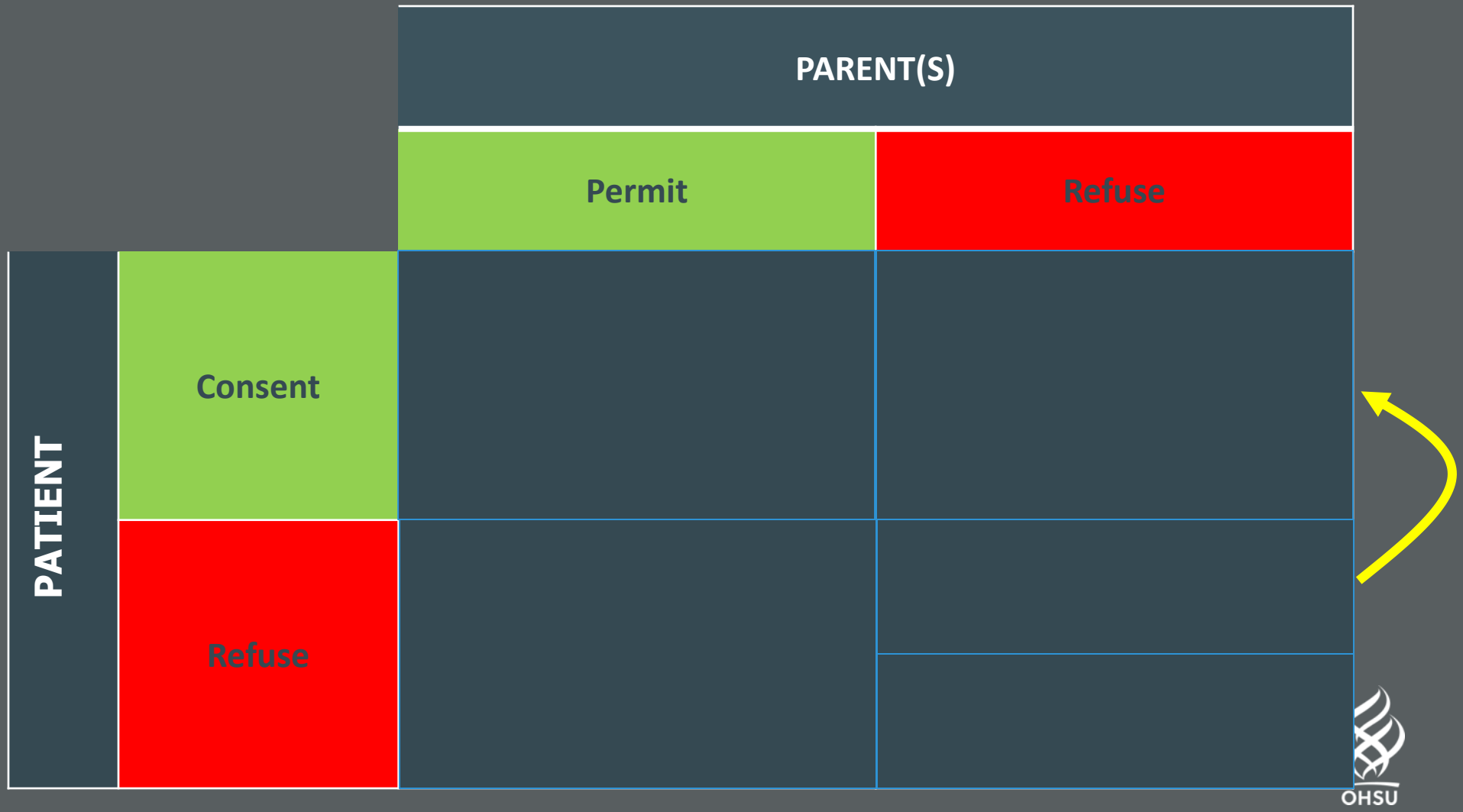
Paradigm for decision-making



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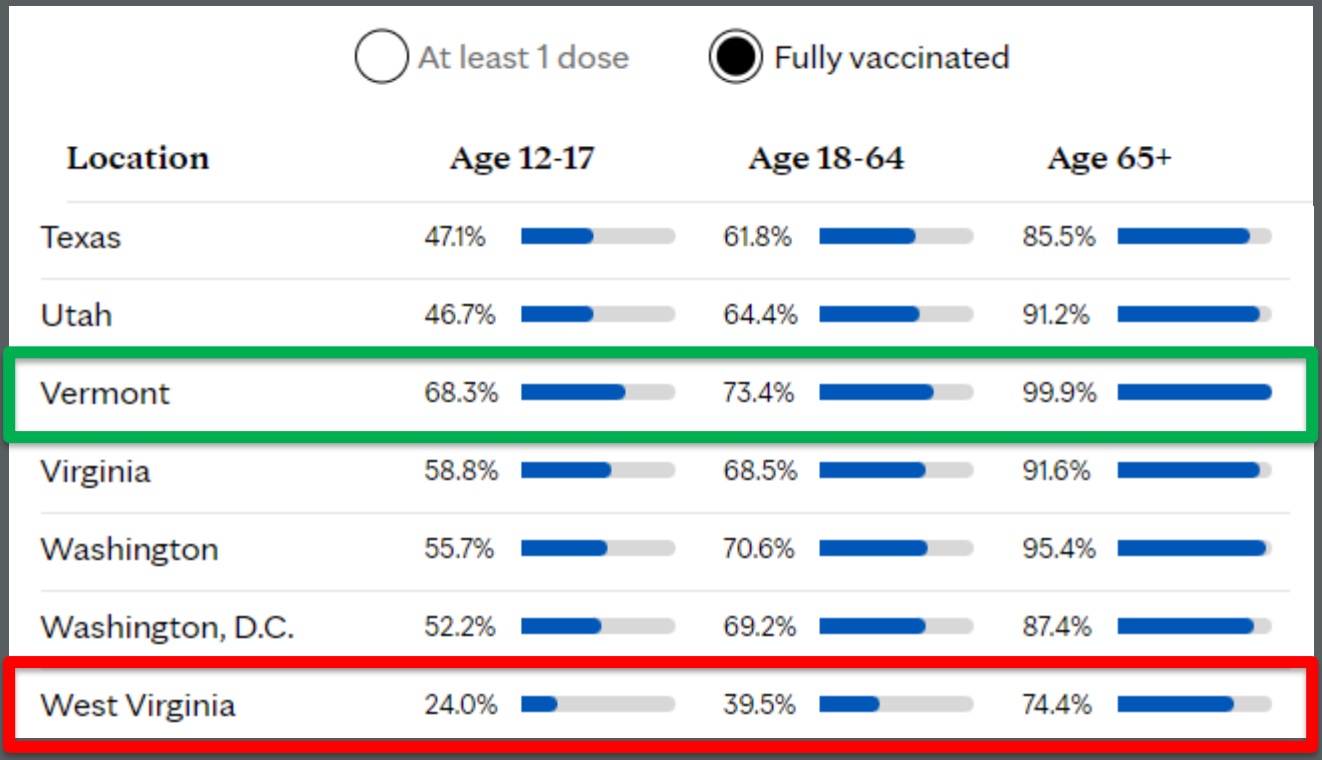
Vaccine hesitancy



Location	Age 12-17	Age 18-64	Age 65+
Texas	47.1%	61.8%	85.5%
Utah	46.7%	64.4%	91.2%
Vermont	68.3%	73.4%	99.9%
Virginia	58.8%	68.5%	91.6%
Washington	55.7%	70.6%	95.4%
Washington, D.C.	52.2%	69.2%	87.4%
West Virginia	24.0%	39.5%	74.4%

Source: Mayo Clinic (https://www.mayoclinic.org/coronavirus-covid-19/vaccine-tracker)

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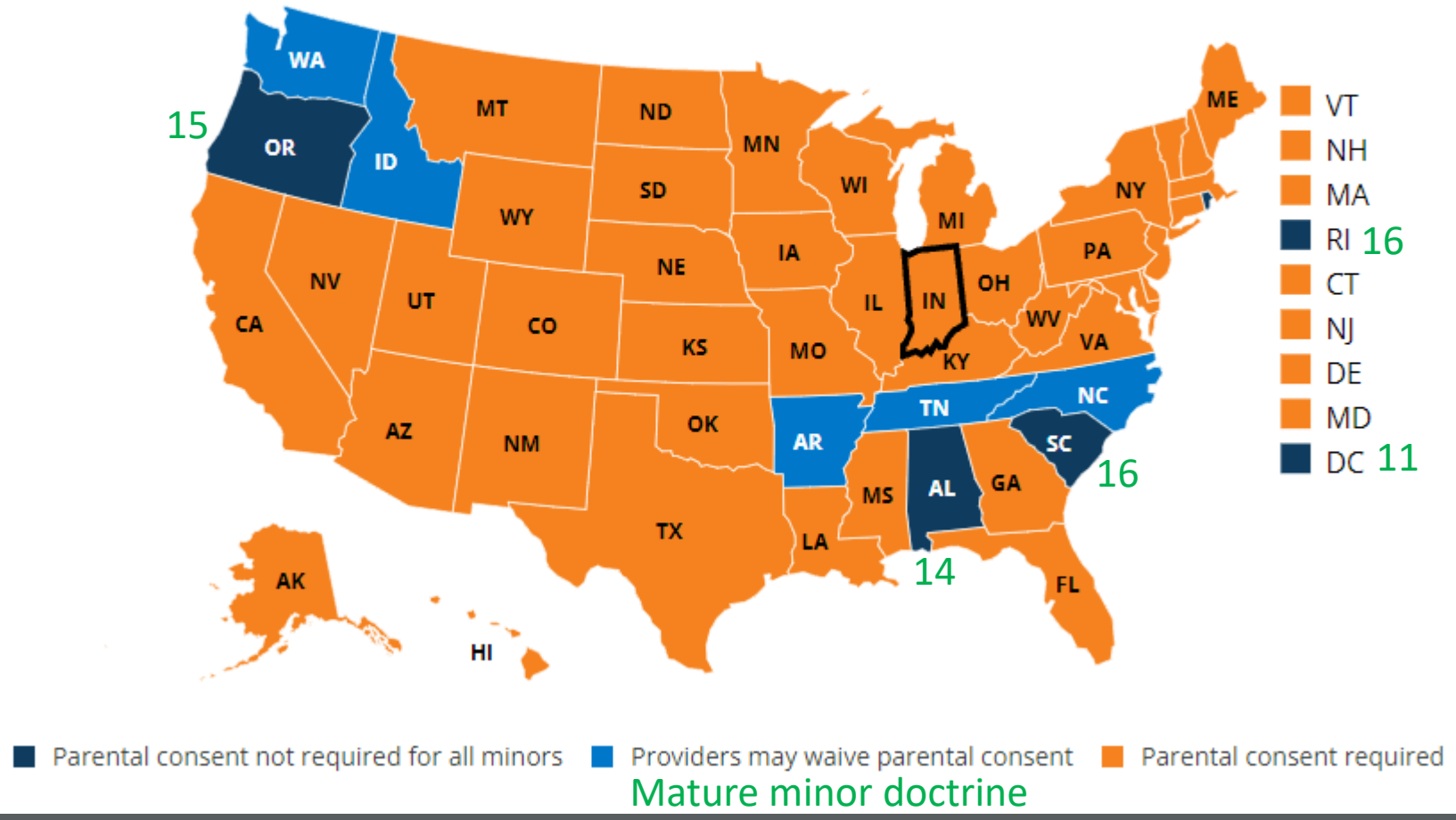
Parental Consent Requirements for COVID-19 Vaccine



Source: Kaiser Family Foundation (https://www.kff.org/policy-watch/covid-19-vaccination-and-parental-consent/)

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- < 12 years old
  - Require parental approval, unless
  - 9-12 year-olds with underlying medical condition and deemed to have capacity
- 12-14 years old
  - May consent
  - Parents should be notified, unless that poses a risk to the minor
- 15-17 years old
  - May consent
  - Remains confidential

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Unaccompanied immigrant children

- Deprived of treatment
  - Jane Doe, a pregnant teenager staying at a shelter for unaccompanied immigrant children in Texas, was initially prevented from obtaining an abortion (2017)
- Forced to receive treatment
  - Reports of Office of Refugee Resettlement shelters pressuring detained minors to accept medical treatments (up to 70% of minors in one facility were receiving psychotropic medications)
  - As reported by *ProPublica*, the "Department of Homeland Security instructed staff to file a 'significant incident report' every time a teen refused to take medication.... That report could then be used to justify delaying reunification with family."

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Who decides?

3.4.3 Requests for Health Care Services

Care providers have a responsibility to initiate health care services when they observe children in need of medical attention. As important as observing a child's need for medical care is creating an atmosphere that allows a child to request care. Therefore, care providers must have policies and procedures for UC to convey written and verbal requests for emergency and non-emergency health care services. Children who have language and literacy barriers also must have the opportunity to communicate their needs. All requests from a UC must be

Child Advocate — A Child Advocate is an independent third party who is appointed by ORR for select unaccompanied children to make recommendations to various stakeholders regarding the best interest of a child.

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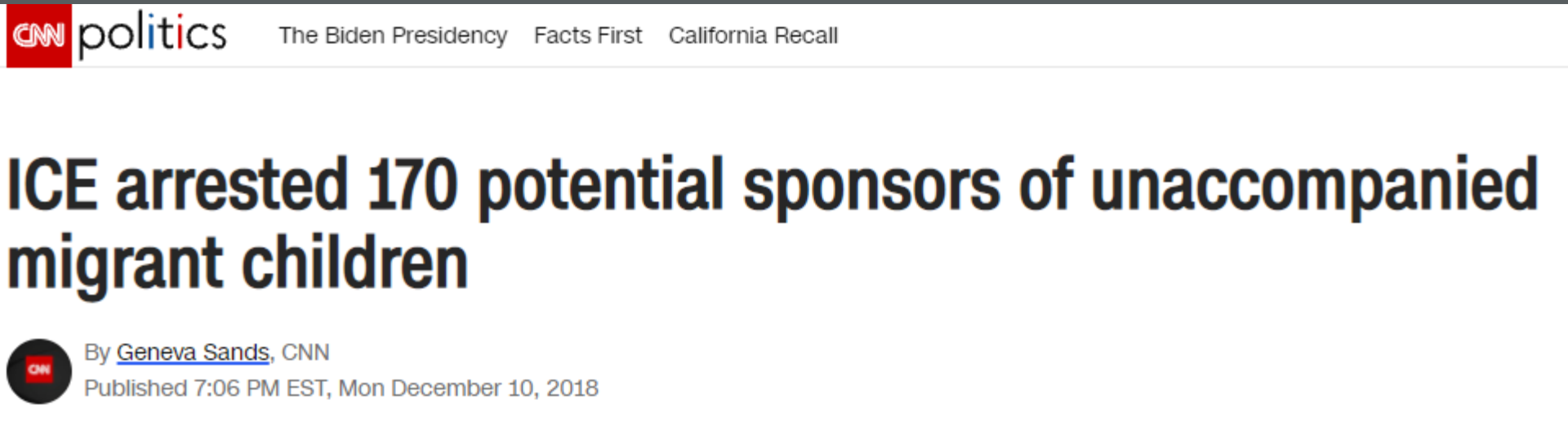
Who decides?

- In the absence of a parent, a local sponsor may be identified and authorized to make a decision
- However, government policies that took effect in May 2018 required fingerprinting of a sponsor's entire household and allowed for information sharing with the US Department of Homeland Security Immigration and Customs Enforcement



A proposed solution

- Child Advocate Program created under the Trafficking Victims Protection Reauthorization Act of 2008
  - But only served 321 children in 2015

One-Day Total of Child Migrants Crossing Border Hits Reported High Under Biden

The number of migrant children crossing the border alone hit its highest level since the Biden administration started releasing the figures earlier this year.

By Claire Hansen | Aug. 6, 2021, at 12:52 p.m.

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