



NATIONAL REGISTER
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CLINICAL WEBINARS

FOR HEALTH SERVICE PSYCHOLOGISTS

TRANSLATING RESEARCH TO PRACTICE

Involving Minors in Decisions About Medical and Mental Health Care

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1 CE Credit, Instructional Level: Intermediate

1 Contact Hour (New York Board of Psychology)

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Disclosures/Conflicts of Interest

I have no conflicts of interest to disclose

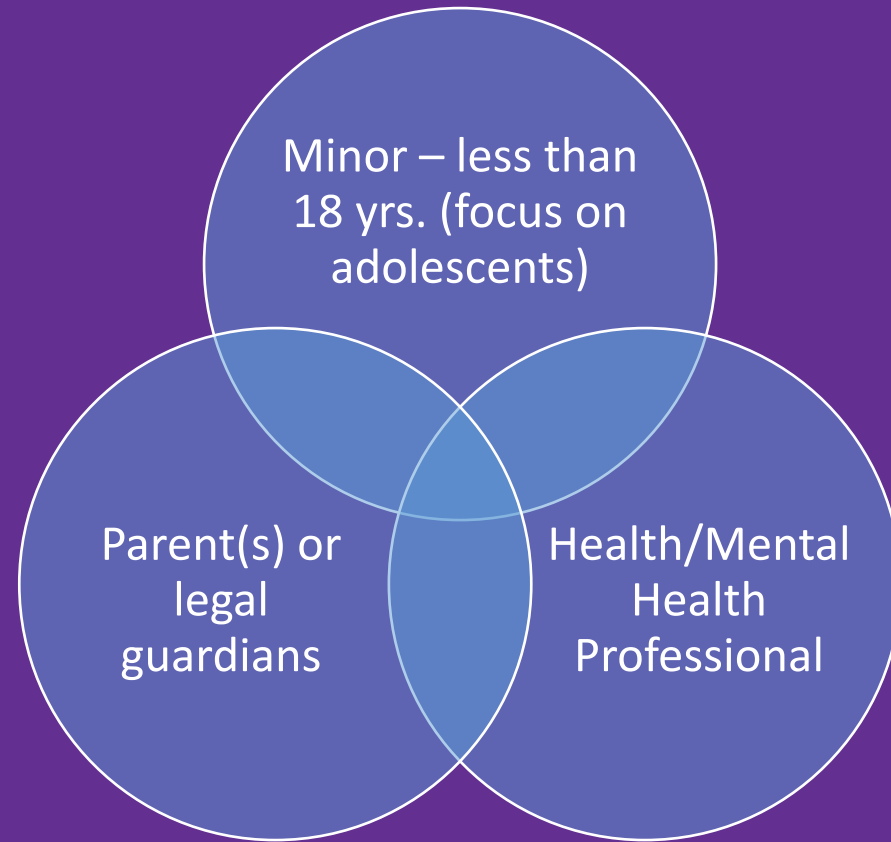
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Learning Objectives

1. List the competencies associated with the standard for informed consent.
2. Apply a framework for determination of minors' appropriate level of involvement in health care decisions.
3. Analyze the relative importance of ethical, developmental, and clinical considerations for involving minors in health care decisions.

Introduction

- There is an ethical imperative to include minors in health care decisions to the greatest extent that is appropriate.
- This becomes tricky in certain situations. For example, when:
 - Parents or professionals and minors do not agree on their level of involvement or the decision itself
 - Minors' risk-taking impacts decisions about care



Minor – less than
18 yrs. (focus on
adolescents)

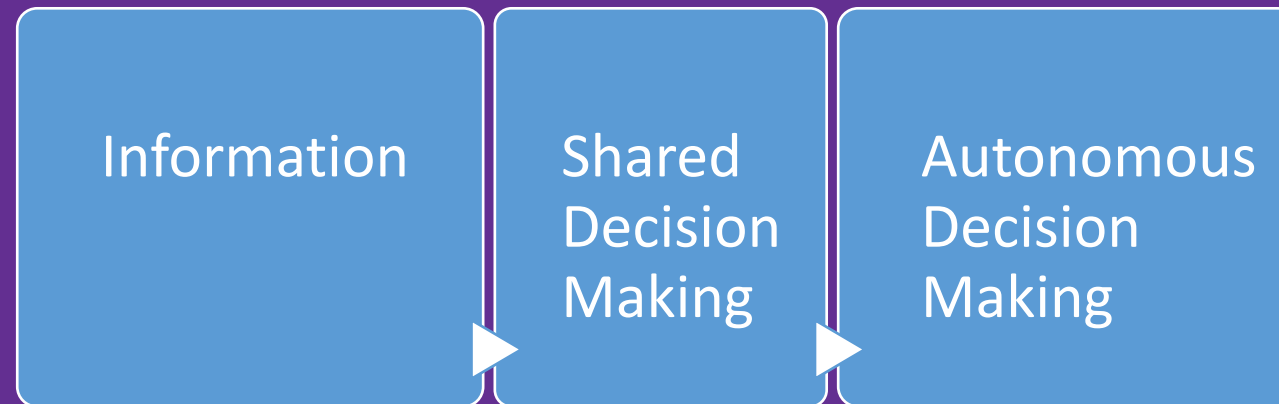
Parent(s) or
legal
guardians

Health/Mental
Health
Professional

Introduction

- Minors' competence for health care decision-making is situation-specific.
 - *Not all medical/mental health situations are alike*
- Decision-making should be viewed on a **continuum**, from sharing information/preparation for treatment to sharing in decision-making to autonomous decision-making.
- There are a variety of **legal, ethical, developmental and clinical considerations** that can be weighed in order to determine the best level of involvement for particular minors and their families in different health care decision situations. (McCabe, 1996)

Continuum of Decision-Making



Legal Considerations

Legal Requirements for Informed Consent

- Knowledgeable, informed choice; factual understanding
- Voluntary choice; free from coercion
- “Competent choice” (capacity assessment)
 1. Evidence of any choice
 2. Reasonable choice
 3. Reasonable decision-making process
 4. Appreciation of information, abstract understanding (highest standard of competence)

Legal Considerations

- **Competence** is a legal term and is determined by a judge in a court of law.
- **Capacity** refers to the mental capacities of understanding, appreciation, reasoning, and choice; capacity assessments are what psychologists (or other clinicians) are called upon to complete to provide information to a judge for a legal decision regarding competence.
 - Nonetheless, you will typically see “competence” used in the literature about minors and decision-making

Legal Considerations

- The **standard of parental consent** (substituted judgment) is based on the assumption that parents often have the same interests as their children, and/or will always act in the “best interests” of the child.
 - There are, of course, situations where parents clearly do not act in the child’s best interests (e.g., abuse, neglect) and parental rights are challenged.
 - There are other circumstances where there is a conflict of interests between parents and children. These lead to **exceptions** to the standard of parental consent.
- The **age of majority** (18 years) is a historical construct based on such considerations as military service.
 - In reality, family courts increasingly recognize that neither rights nor capacities appear on the 18th birthday.
 - As we will discuss soon, the science of adolescent development is removing some of the guesswork.

Legal Considerations

- All states have laws which define **Emancipated Minors**, which generally include those who:
 - financially support themselves
 - have married
 - are parents themselves
- **Mature Minor Doctrine:**

An *unemancipated* minor may legally consent to (or refuse) any surgical or medical treatment or procedure (and/or be afforded confidentiality) if that minor is determined to be of sufficient intelligence to understand and appreciate the consequences of the proposed treatment.
- Most **states** also have specific laws that grant rights to minors for decisions about certain medical (usually reproductive health) and mental health care without parental consent.

Ethical Considerations

- The ethical principle underlying Informed Consent, and minors' involvement in decision-making, is **Respect for Autonomy** or **Self-Determination**.
 - Autonomy has cognitive, emotional and social elements
 - The right to autonomy includes the right not to choose (or to appoint others to choose on one's behalf) and the right to change one's mind.

The best treatment decision for a given patient is based both on factual, technical information and the interpretation of this information within the context of purely subjective factors and values.

Ethical Considerations

- Recommendations to involve minors in health care decisions to the greatest extent appropriate have been made by :
 - American Academy of Pediatrics (1995, 2008)
 - Canadian Paediatric Society (2004)
 - World Health Organization (2010, 2014)
 - United Nations Committee on the Rights of the Child (2013)
- Grisso and Applebaum describe a “**competence-balance scale**” – with autonomy on one end and protection on the other.
 - Greater weight is initially given to autonomy
 - Then balancing is decided according to:
 - the patient’s abilities in light of the *specific decision demands* and
 - the *risks and benefits* of the decision

(Grisso & Applebaum, 1998)

Goals for Involving Minors

- Honor ethical principles of patient self-determination, autonomy
- Improve treatment alliance, cooperation with treatment
- Improve doctor-parent-child communication
- Increase realistic expectations of treatment
- Improve adherence
- Respect children's capacities, opportunities for development
- Provide opportunity to learn responsibility safely
 - Practice health care decision-making
- Increase sense of control, self-efficacy, self-respect

Developmental Considerations

Cognitive Development

- **Understanding** (e.g., bodily functioning, condition, psychological/behavioral constructs, treatment process)
- **Reasoning/Abstract thinking** (i.e., weigh more than one factor, weigh hypothetical possibilities, take future time perspective, inductive & deductive reasoning, prioritize and problem solve with abstract steps, flexible focus and concentration)

Developmental Considerations

Socioemotional Development

- Voluntariness (conformity/nonconformity)
- Developmental concerns
- Stability of values
- Influence of peers
- Experience within family
- Cultural and religious affiliations

Developmental Considerations

Decision-Making Literature

- Individuals make decisions by integrating the information they perceive with memories/experience and knowledge.
 - Adults tend to make “**gist-based**” decisions, integrating new information, summarizing what is essential, and weighing risks and benefits in relation to experience and values.
 - Adolescents engage in both gist-based and **verbatim processing** for decisions.
 - Often over-estimate risks AND benefits

(Reyna & Farley, 2006; Reyna, Wilhelms, McCormick & Weldon, 2015)

- Both spontaneous and cued **mentalization of the future** can enhance weighing actions, reflecting on long-term goals, and thoughtful decision-making (Rosenbaum & Hartley, 2018)

Developmental Considerations

Developmental Science/Neuroscience Literature

- Adolescent behavior is noted for:
 - Increased risk taking
 - Increased sensation seeking
 - Increased emotional reactivity
 - Immature impulse control
 - More conflict with parents
 - More emphasis on peers
 - Peers affect behavior and decisions (Albert, Chein & Steinberg, 2013).

The Developing Brain

- The increase in impulse control is linear from childhood to adulthood, but the increase in reward sensitivity is inverted U-shaped, peaking in mid-adolescence.
 - Adolescents make different decisions in the heat of the moment than they might make about the future.
- Different developmental trajectories for two brain systems from childhood to adulthood.
 - Earlier maturation of limbic regions (ventral striatum - reward sensitivity & amygdala - emotion processing) than the prefrontal cortex, anterior cingulate cortex (control system)
 - “**Maturation Imbalance**” (Duckworth & Steinberg, 2015)

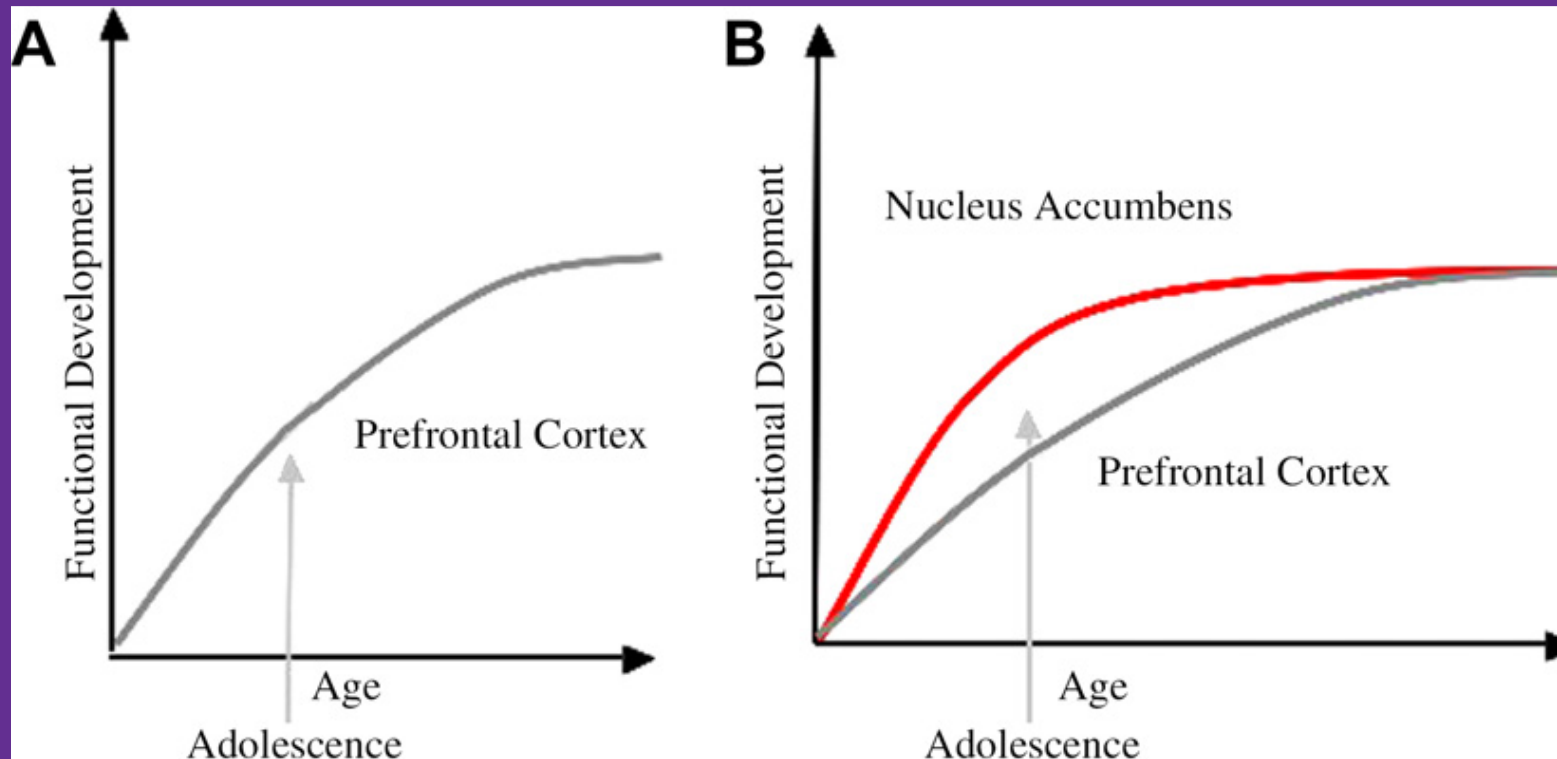


Fig. 1. The traditional explanation of adolescent behavior... due to the protracted development of the prefrontal cortex (A). Our model...the development of the prefrontal cortex together with subcortical limbic regions...that have been implicated in risky choices and actions (B).

Reprinted from Casey, et al. (2008). The Adolescent Brain. *Developmental Review*, 28, p. 62-77. Copyright © 2008. **Reproduced with permission from Elsevier.**

The Developing Brain

- There are **individual differences** in risk-taking due to differences in brain development (Casey, Jones and Hare, 2008)
- There are also **gender differences** in risk-taking (Shulman et al., 2014)
 - Heightened vulnerability for risk-taking (10-25y) may be both *greater and more protracted* for male adolescents
- The likely age range where “adult levels of neurobiological maturity” is reached is **15-22**. (Steinberg, 2012, p. 76)

Clinical Considerations

Child Factors

- disposition
 - health beliefs
 - style of coping with information
 - temperament
- history of adherence to treatment regimen
- preferences for level of involvement
- children's experience with decision-making
- physical state (e.g., pain, attention span)
- mental status (e.g., level of anxiety, depression)

Clinical Considerations

Family Factors

- views on the role of minors in decision-making
 - cultural background
 - religious affiliation
 - family structure, roles
- parents' experience with medical and mental health decisions
- parents' preferences regarding children's level of involvement
 - Difference of opinion within family

Clinical Considerations

Situation Factors

- complexity of choice
 - degree of difficulty in decision
 - immediate versus long-term consequences
 - degree of uncertainty
- level of stress
 - time constraints for decision
 - financial issues
 - differences of opinion
- nature of decision
 - benefits/risks for health

Clinical Considerations

Provider Factors

- Health Professional's values
- Roles for psychologists
 - Provide knowledge regarding development and other issues
 - Assess developmental and clinical factors
 - Make specific recommendations for minor's level of involvement
 - Facilitate provider-parent-child communication

Recommendations

- Be aware of own values regarding minors' rights and capacities, and the decisions themselves.
 - Don't assume impaired capacity for decisions if a minor (or parent) makes a socially undesirable choice based on values.
- Assess capacities and preferences for involvement in decisions repeatedly at treatment junctures.
- Be sensitive to the language of non-responsibility, or "I don't want to..."
- Be active in soliciting minors' preferences, including through their parents, when appropriate.
- Work with parents to address concerns about minors' level of involvement.

Recommendations

- Do not require minors to take a greater level of involvement in decision-making than that with which they are comfortable.
- Protect minors from attributions of responsibility for decision situations that are difficult for the adults involved.
- In situations where there are **differences of opinion**:
 - *Respect both the adolescent patient's right to self-determination and the integrity of the family.*
 - *Work toward reconciliation among patient, parent, and professional opinions.*
 - *Protect minors from serving a tie-breaker role among different opinions.*

Select References

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Q&A With Dr. McCabe



- Dr. Sammons will read select questions that were submitted via the Q&A feature throughout the presentation.
- Due to time constraints, we will not be able to address every question asked.