

 **19th Annual HIV CONFERENCE**
May 14-15, 2010 • Orlando, FL

Decisional Capacity in HIV Infected Children and Adolescents

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Objectives

- Describe ethical and legal issues associated with decisional capacity (DC) among youth with HIV
- Provide framework for assessing DC of youth with HIV and present model for using data to guide action along protection-autonomy continuum
- Present research data about DC of youth with HIV to participate in healthcare



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Decisional Capacity (DC)

- **Understanding**
- **Appreciation**
- **Reasoning**
- **Ability to express a choice**



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Decisional Capacity (DC)

- **Assumptions**
 - Task specific
 - Situational
 - Variable



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Relevant Ethical and Legal Issues

- Convention on the Rights of the Child
- Medical Treatment
- Research
- Considerations for minors with HIV



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Assessing Decisional Capacity

- **Understanding Disease**
 - Diagnosis
 - Features of Disease
 - Course of Disease
- **Understanding Treatment**
 - Name/Type of Treatment
 - Features of Treatment
- **Understanding the Benefits/Risks of Treatment**



Assessing Decisional Capacity

- Appreciation of Disease
- Appreciation of Treatment
- Important Considerations



Assessing Decisional Capacity

- Reasoning
- Ability to Express a Choice



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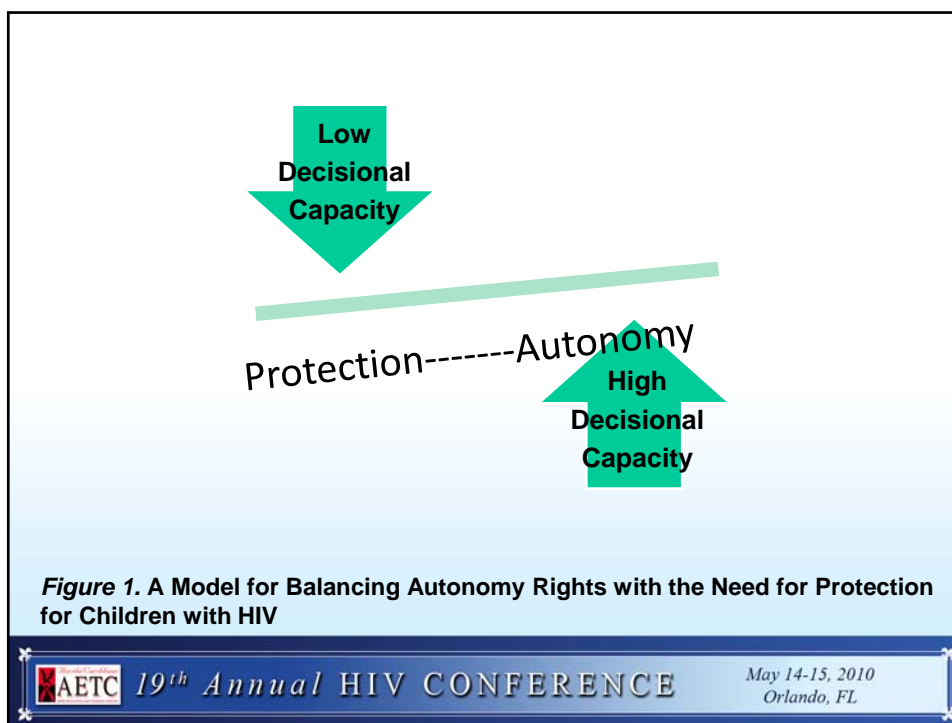
Protection-Autonomy Decision Model

- **Are minors a vulnerable group in need of protections?**
 - And should adults be responsible for protecting them?
- **OR**
- **Are minors capable of making decisions for themselves?**
 - Should they be afforded the opportunity to meaningfully participate in medical decisions that affect their lives?



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Research about DC among Youth with HIV

- **Participants (n=50)**
 - HIV Group
 - Healthy Child Comparison
 - 7-17 years
 - Matched on age and gender
- **Data Collection Measures**
 - Emotional functioning
 - Intellectual functioning
 - Decisional capacity

Chenneville, T., Sibille, K., Lujan-Zilberman, J., Rodriguez, C., Brown, M., & Emmanuel, P. (in press). Medical decisional capacity among children with HIV: Results from a pilot study. *AIDS Care*.

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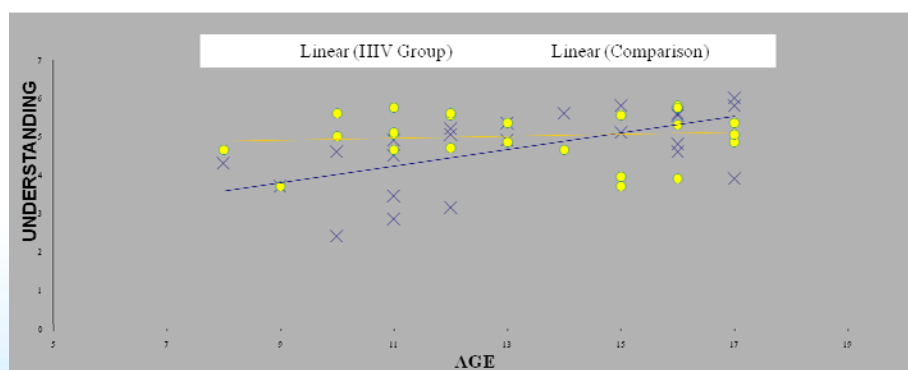
Research about DC among Youth with HIV

Understanding	Appreciation	Reasoning	Choice
81% correct	94% correct	84% correct	98% correct

DC adequate among both groups

Scores on understanding and reasoning somewhat lower than scores on appreciation and ability to express a choice

Research about DC among Youth with HIV



Significant relationship between age and understanding for HIV group but not comparison group

Research about DC among Youth with HIV

- Significant relationship between IQ and understanding for comparison group but not HIV group
- No significant relationship between DC and internalizing or externalizing behavior problems
- Qualitative data



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