

Viewing Time

The program will take up to one hour to complete.

Target Audience

This program is designed for primary care physicians.

Other health care professionals working with patients and their families may also find this program of interest.

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Faculty Disclosure

Donald Brunquell, PhD, MA and Melissa Winger have disclosed no actual or potential conflict of interest in relation to this educational activity.

During this educational activity **Dr. Brunquell and Melissa Winger** will not be discussing the use of any commercial or investigational product not approved for any purpose by the FDA.

Analyzing Ashley X: Should Parents Control Their Child's Body?

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Analyzing Ashley X: Should Parents Control Their Child's Body?

A lecture about the ethics on and obligations and objections to a parental decision to alter a child's growth trajectory and body shape.

Program Objectives

Upon completion of this program, participants should be able to:

- Understand the obligations and limits on parental decision-making for their children with medical problems.
- Analyze the potential objections to a parental decision to alter a child's growth trajectory and body shape.

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Receiving CME Credit

To receive CME credit you must view the entire program and complete the evaluation form at the end.

Analyzing Ashley X: Parental Control of their Child's Body

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The views expressed in today's rounds do not represent official positions of Children's Hospitals and Clinics of Minnesota, its Ethics Committee or its Family Advisory Committee. Melissa Winger also states that she does not claim to represent the views of all parents of children with disabilities.

Analyzing Ashley X: Parental Control of their Child's Body



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Analyzing Ashley X: Parental Control of their Child's Body

- Ashley's case raises many questions
- the meaning of size and growth to being a person
 - the significance of cognitive ability to personhood
 - the meaning of reproductive capacity and sexual characteristics to personhood
 - the nature of parent-child relationships
 - the degree of parents' control of their child's body
 - how do we judge parents' intentions toward their child
 - when should we disallow or override parental decisions

Analyzing Ashley X: Parental Control of their Child's Body

- Many other procedures raise similar questions:
- Craniofacial surgeries for appearance
 - Limb lengthening surgeries
 - Many surgeries for disorders of sexual differentiation
 - Use of LHRH analogs to stop precocious puberty
 - Cleft lip repair
 - Breast reduction surgery during adolescence
 - Growth hormone for short stature
 - Removal of lymphangioma that does not impair function
 - Moderation of GT feedings to reduce growth
 - Not using growth hormone for short children with profound developmental disabilities

Analyzing Ashley X: Parental Control of their Child's Body

These decisions need to be put in the context of other procedures that lie on the continuum of treatment to enhancement:

- gait normalization
- stimulant for ADHD for mild behavior problems
- SRIs for dysphoria (not major depression)
- laser or surgical procedures for birthmarks
- anxiolytics for performance anxiety

Analyzing Ashley X: Parental Control of their Child's Body

Melissa would like to describe her situation and issues she has faced, and reflect on the procedures described here.

Problem List:

Chromosome Abnormality 46XY,der(4)t(4;6)(q33;p25)
Cleft Palate – Repaired
Pierre Robin Syndrome
Atrial Septal Defect – Repaired
Hemangiomas – *face, ears, head, esophagus,vocal chords–*1x Laser treatment
Malrotated Bowel – Repaired – G-Tube placed
Carotid Artery Aneurysm – Repaired
Bilateral Ureter Reflux – Repaired
Undescended Testicles - Repaired
Duplicating Collecting System, Left Kidney
Arnold Chiari Type 1

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Planovalgus foot deformity with midfoot abduction - Orthotics
Significant Bilateral gastrocnemius contractures - Orthotics
Ehlers Danlos syndrome – as needed meds surgery/trauma
Immunodeficiency decreased IgM
Leukopenia
Thrombocytopenia
Hearing Loss – Left Ear Hearing Aide (12 sets of PE tubes)
Silent Aspiration – Feeding Tube
Reactive Airway Disease -Nebulizer
Obstructive Sleep Apnea – History of Bi-Pap w/ O2
GERD - Medication
Pervasive Developmental Disorder – Autism Spectrum
Severe to Profound Developmental Disabilities
Incontinence - Diapers
Ptosis both eyes – Repaired and Glasses – Nystagmus, Astigmatism, Myopia
Chronic Nasal Drainage – Suction Machine

Analyzing Ashley X: Parental Control of their Child's Body

Plan for this talk

1. Review briefly the Ashley case
2. Discuss the context of medical/surgical decisions for children and changing their body
3. Briefly discuss best interest standard, the harm standard, and inclusion of children in decisions
4. Discuss the context of decisions for children who will never be competent
5. Consider objections to Growth Attenuation Treatment
6. Questions and group discussion

Analyzing Ashley X: Parental Control of their Child's Body

The Ashley Case

- October 2006- Gunther and Diekema publish "Attenuating Growth in children with Profound Developmental Disability" in Arch Pediatr Adolesc Med, reporting the high dose hormones, hysterectomy, and breast bud removal done at parents request
- January 2007- parents go live with website <http://ashleytreatment.spaces.live.com/> describing Ashley as their "pillow angel" and describing their desire to make her life as good as possible, to facilitate touch and inclusion, and to be able to care for her as long as possible

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The Ashley Case

- Media storm begins
 - Exceptional Parent Magazine editorial "When the Slippery Slope Becomes a Mudslide" :
"The deafening silence now accompanying the not-so-subtle threats that people with disabilities face because of procedures like "Ashley's Treatment", mental illness based assisted suicide, and infant euthanasia is appalling"
 - Board of Directors of AAIDD:
"We view growth-attenuation as a totally unacceptable option"
 - Not Dead Yet:
"This is an issue of basically subjecting a child to drastic physical alterations to fit the convenience of her caregivers."

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The Ashley Case

- TASH:
"This is the denial of a child's basic right as a human being to be free from the unwarranted and unnecessary manipulation of their basic biological functions merely to satisfy the needs of a third party...Children with severe developmental disabilities are, first and foremost, human beings. The manipulation of a child's physical development relegates those receiving such treatment to a less than human category."
- Dr. Joel Frader:
" I find it difficult to argue that this child and similar patients benefit merely from reaching their genetic growth potential... the measures taken to limit the Seattle patient's growth seem reasonable and well within the scope of caring parents' authority to undertake."

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The Ashley Case

- Dr. Norm Fost:
"There are compelling arguments that limiting Ashley's growth is likely to be in her interests, as well as the parent's interests, with low risks...the father makes a compelling argument that her interests will be better served by limiting her size, regardless of whether devices or supportive services are available.. She will be easier to hold and move... she is more likely to be brought on trips and have more pleasurable experiences, she is less likely to have complications such as bedsores."

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The Ashley Case

- May 2007 The Washington Protection and Advocacy system releases an investigative report
 - A court order is required for sterilization in Washington
 - The other aspects of the treatment should also have been take to court
 - This is discrimination because the treatments would not have been done if Ashley was not developmentally disabled
- May 2007 Seattle Children's acknowledges that a court order was required in Washington State to perform the hysterectomy

Analyzing Ashley X: Parental Control of their Child's Body

Look again at the list of other procedures that have profound effects on the child's body, appearance, and function:

- Craniofacial surgeries
- Limb lengthening surgeries
- Many surgeries for disorders of sexual differentiation
- Use of LHRH analogs to stop precocious puberty
- Cleft lip repair
- Breast reduction surgery during adolescence
- Growth hormone for short stature
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The Context of Decisions for Children

1. We are discussing the child's rights and interests
2. Because of lack of legal competence and lack of capacity to understand, a proxy decision-maker is needed for young or permanently cognitive disabled children
3. The parents are the presumed best decision-makers for the child (the other possibilities being the state or court or health professionals)
4. It is a parental duty (not a parental right) to act on the interests of the child

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The Context of Decisions for Children

5. The full range of medical treatment options open to competent adults are open to the child with the parents as their substitute decision-makers, including risky surgeries, withholding/withdrawing life-sustaining treatment.
6. The health care providers have the role of oversight to be sure choices of parents are not harming the child, and to involve legal authorities if the choices are harming the child.

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Parental Control of the Child's Body

- Are children "possessions" or "objects" (Bestand) to be used by the parents in any way they see fit?
 - Is a choice to do a body transforming surgery always a choice that treats the child as an object (of the parents desires/convenience)?
 - Or can it be a loving choice to enhance the child's life?
 - The goals of the procedure are essential in analyzing this.

Analyzing Ashley X: Parental Control of their Child's Body

Parental Control of the Child's Body

- Given the natural inequality of power between parent and child, is the decision to alter a child's body a violation of the child's interest?
 - Yes, if it does not comply with a good faith understanding of the child's interest
 - Yes, if it overrides the express desire of a child who can have a meaningful preference
 - No, if it can be demonstrated how it serves clear interests of the child
 - Maybe, if the balance of the child's interests are unclear

Analyzing Ashley X: Parental Control of their Child's Body

Parental Control of the Child's Body

- Does the choice reflect a physical "functional" benefit or a social benefit
 - Physical functional benefits are somewhat more clear
 - (although, for example, is walking a clear functional benefit worth multiple years of surgery for someone who is at best a marginal walker)
 - Social benefits can be real, but are harder to predict and measure; social benefits may be sufficient, but must be questioned carefully
 - Social benefit to the child can be argued for; social benefits primarily to the parents, especially appearance or social desirability, are not sufficient

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Parental Control of the Child's Body

- Some body altering surgeries are based on habits of action and perception when in fact society can be adapted to the individual
 - Ellen Feder argues that in intersex genital "normalizing" surgeries parents and physicians give in to appearance over function to meet society's standard
 - This, she says, represents a failure of identification with the child;
 - She holds that often what is called a desire to protect the child is the parents desire to protect themselves

Feder, E. 2006 "In Their Best Interest" in E. Parens, ed. Surgically Shaping Children

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Parental Control of the Child's Body

- This can also be thought of as the "master narrative" that the parent uses to decide for the child
 - Hilde Lindeman describes two master narratives common in medicine
 - "Science and medicine can fix all discomforts"
 - "Difference in appearance means unhappiness"
 - "The world is divided into boys and girls"
 - It is useful to ask, "What is the "master narrative" at work subconsciously for the parent decision-makers, and does it reflect the child's interests?"

Lindeman, H 2006 The Power of Parents and the Agency of Children in E. Parens, ed. Surgically Shaping Children

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Parental Control of the Child's Body

- Is achieving "normalcy" a legitimate goal? Many people with disabilities and advocates for people with disabilities argue that procedures to attempt to achieve "normalcy" are a violation of the unique individuality of the child.
 - Can we distinguish "normalcy" for the sake of appearance vs. to achieve adaptive functioning?
 - Consider the differences between the terms "normal", "typical", and "functional."

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Parental Control of the Child's Body

- Is a body altering surgery a failure to love the child as they are; does it subconsciously say to the child "I love you as you are, now I will change you."
 - Must it be interpreted that way?
 - Can it be an act of love for the child and endorsement of their future rather than rejection of their past and present?

Analyzing Ashley X: Parental Control of their Child's Body

Parental Decisions for the Child

Typically we talk of making decisions "in the best interest of the child."

This has been challenged because we do not generally require the "best", but "basic interests be served."

Douglas Diekema has suggested that the standard should not be if it is the child's best interest, but if the parents decision will bring clear and demonstrable harm to the child, what he calls the "harm standard".

Diekema DS. *Theoretical Medicine and Bioethics* 2004; 25(4): 243-264.

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Including a Child in a Medical Decision

The decision-makers for a child are acting on the child's interests and rights, so to the extent a child can be included in a meaningful way in the decision, they should be.

This does not imply that a child should be allowed to make decisions that harm the child when the parents and health care team are in agreement it is a harmful choice.

Analyzing Ashley X: Parental Control of their Child's Body

Decision-making for those who will never be competent

- To fully respect personhood, the full range of decisions should be allowed for these persons as for autonomous persons, since their situations are just as varied
- Who is best situated to decide for the never competent person? Generally we would answer someone with an attachment to the person and a current understanding of the person's life and well-being
 1. Their parent or family members
 2. Professionals
 3. The court or court appointed advocates
 4. Third party advocates from advocacy organizations
 1. Who share their life experience
 2. Who share other experiences of disability
- Retain the presumption of parents as decision-makers

Analyzing Ashley X: Parental Control of their Child's Body

Should parental decisions that affect bodily integrity be restricted? Possible rules:

1. Only allow decisions for life-threatening conditions
 1. Clearly many decisions beyond the immediately life-threatening are required for the child's wellbeing
2. Only allow non-life-threatening decisions if there is agreement with treatment team that it is in the child's basic interest
 1. This is similar to our current practice- if disagreement outside permission is sought
3. Only allow non-life-threatening decisions if there is consensus within society that the decision is acceptable
 1. Whose voice counts? Whose voice counts the most?
 2. Does consensus mean 100%?
 3. This holds the interests of the individual child hostage to the view of the majority (or perhaps the entire population)

Analyzing Ashley X: Parental Control of their Child's Body

Should parental decisions that affect bodily integrity be restricted? Possible rules:

4. Apply the "precautionary principle"- potential or unknown risks should carry more weight than potential or uncertain benefits, so don't act unless there is certainty that benefits outweigh harms
 1. This would prevent many generally accepted medical choices
5. Parents make many decisions with potentially equal or far greater implications for the child well being (e.g. education, religion, place of residence)
6. No decision should be allowed outside the current standard of care
 1. Many cases do not fit neatly in the standard of care
 2. This would restrict new variants that might benefit a child
7. No decision outside the current standard of care should be allowed without outside review
 1. If standards for seriousness of decision could be worked out this might be reasonable
 2. Outside review should presumptively be broad and informed teams but within health care framework

Analyzing Ashley X: Parental Control of their Child's Body

Should parental decisions that affect bodily integrity be restricted?

Once the tests for harm and inclusion of the child have been answered, parental decision making should be allowed within the range of the medical standard of care.

Analyzing Ashley X: Parental Control of their Child's Body

Given all these considerations, let's turn to specific analysis of the decision for Growth Attenuation Treatment (GAT)

(separating this from the "Ashley Treatment" that includes hysterectomy and breast bud removal)

GAT: Categorical Objections and Responses

1. Past abuses, especially of hysterectomy

- history of misuse of an object or treatment does not mean current use is wrong
- this limits available beneficial options
- history of misuse of medication and institutionalization does not rule out medication or institutional placement
- request from parents of boys

GAT: Categorical Objections and Responses

2. If it is permissible in individual cases, will it someday be required by the state

- similar concern exists for many treatments
- history of strong individual rights in medical decisions in U.S.
- the proper response to future potential abuses is to guard against them, not rule out a current potentially beneficial action

GAT: Categorical Objections and Responses

3. Lack of societal consensus

- lack of consensus in many areas does make something impermissible, rather a matter of individual choice (DNR orders, use of dialysis, medical nutrition/hydration, transplant)
- holding the individual patient hostage to the views of some individuals

GAT: Categorical Objections and Responses

4. Against nature (natural course)

- most of medicine is interference with natural course (e.g. antibiotics, psychotropic medications, heart surgery, joint replacement)
- most children with profound delay have already experienced many actions that interfere with the natural course, especially often feeding tubes

GAT: Categorical Objections and Responses

5. Against "human nature"

- what constitutes the essence of human nature
- is physical size the determination of the human being (personhood)

GAT: Categorical Objections and Responses

6. An interference with normal development
- for children with profound developmental delay, what is "normal"

- we often fight to abandon the expectation of "normal" for children with special needs

GAT: Categorical Objections and Responses

7. Against "the will of God"

- a private, secular institution works with all religions or with families who profess no religion
- medicine is generally independent of a specific religion
- definition of religious belief is generally left to the family
- families are free to choose to hold this view and apply it to their child

GAT: Categorical Objections and Responses

8. We do not know what the child wants

- we similarly did not know when we previously intervened in very aggressive ways, but we still intervened
- the child can not develop or state a preference for or against the treatment; must we conclude the child would always be against treatment?

GAT: Categorical Objections and Responses

9. It is a harm based on gender

- not if it is also available to boys
- is it possible that related treatments make it unavailable to girls?
- continued vigilance around use and "disparate impact" is warranted

GAT: Categorical Objections and Responses

10. It is a harm to the disabled as a class

- they have already experienced an injury, this adds to the injury
- "the disabled" is not a single, unified class that must all be treated the same, in fact they must be **treated as individuals**
- if there are on balance benefits to the individual, to withhold a potentially beneficial treatment for the aggregate good of others in that class treats the individual as an object, not a person,

GAT: Categorical Objections and Responses

11. It is a dignitary harm to persons with disability
- what view of dignity is actually harmed?
 - physical size; is it undignified to remain small?
 - match of age and size; is it undignified for a chronological adult to be small?
 - match of pubertal stage and size; is it undignified for someone with secondary sexual characteristics to be small?
 - whose view of dignity is offended?
 - the affected child? the family? a third party advocate? some abstract view?

GAT: Categorical Objections and Responses

12. This is not done to "typical" children, so should not be done to the profoundly developmentally disabled
- many medical procedures are not done to typical children, because the balance of benefits to harms is not correct
 - generally treatments and actions should be based on the individual, not the class
 - individuals similarly situated should be treated similarly
 - comparison to moving away from home

GAT: Categorical Objections and Responses

13. Other accommodations are possible which make this unnecessary
- are complete, optimal accommodations (lifts, help at home, out-of-home placement) necessarily (on balance) better than GAT
 - the best other accommodations are often not truly available

GAT: Categorical Objections and Responses

14. We can not be sure the parents will maintain their intent to care for the child at home
- we can attempt explicit agreement , which we generally do not do
 - there is less reason to doubt parents with a history of loving care-giving than any other alternative

GAT: Categorical Objections and Responses

15. Parents should not be allowed to decide about GAT because of the inherent conflict of interest between parent and child, and other persons with should determine if the treatment should be permitted
- overrides the assumption that parents are best situated and bonded to interests of child that holds for all other decisions, including life and death decisions
 - two variants are suggested
 - court should make the decision; this removes authority from those most attached to child and who will be affected by decision
 - a disability advocate should make the decision; it is not clear that someone with their own capacity is similarly situated to someone without cognitive capacity and it is a better decision

GAT: Categorical Objections and Responses

16. It allows society to avoid its obligations to the developmentally disabled
- the real question is whether the child's life is likely improved by the treatment
 - not performing a likely beneficial treatment to change the society treats the child as an object not a person
 - holding the ideal out as possible when it does not exist harms the child

GAT: Categorical Objections and Responses

17. There is a possibility of future advances in treatment

- this must be carefully examined as time and treatment progress
- as in other decisions, we should not wait for an unrealistic but imaginable future
- a calculation regarding best estimate of likelihood and best estimate of balance of current and future harms/benefits should be done

GAT: Categorical Objections and Responses

18. Is this an "Experimental Treatment" Requiring Research Review?

- It is clearly a novel treatment
- It is not experimental according to the definition of the U.S. "Common Rule" either as a research project to create generalizable knowledge or in using a non-approved medication

GAT: Categorical Objections and Responses

19. If permitted there will be borderline cases

- The existence of a slippery slope can not prevent decision-making
- Holding an individual who would benefit (person A) hostage to the interests of those for whom it is questionable (person B) harms the first individual (person A)

GAT: Categorical Objections and Responses

20. Is this an attempt to permanently infantilize a child because of parental discomfort with an adult with profound disabilities?

- the Ashley case "pillow angel" language suggests this
- it is not a necessary component to the parent master narrative
- if this is part of the parents motivation, does it make other motivations invalid?
- how certain can one be of this motivation if denied?

Analyzing Ashley X: Parental Control of their Child's Body

21. Is this an attempt to deny the sexuality of a person with profound developmental disability?

- this can be explored and overcome
- if this is part of the parents motivation, does it make other motivations invalid?
- how certain can one be of this motivation if denied by the parents?

Analyzing Ashley X: Parental Control of their Child's Body

After considerable analysis, I find that the categorical objections are not sufficient to override parental decision making, and in this case, in which there is permanent incapacity for the child, the decision, with advice and oversight from the health care system should be permissible.

What do you think?

Donald Brunquell, PhD, MA
Melissa Winger, Parent Member
"Analyzing Ashley X"

**Comments
and
Questions**

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this presentation!*



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