Ethics in Sterilization of Mentally Challenged Females

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• I have *no conflicts of interest* to disclose
  
  – No relevant financial relationships
  
  – No commercial support from commercial interests related to this activity
Objectives

At the conclusion of this presentation attendees will be able to:

– Discuss the history of involuntary sterilization in the US.

– Evaluate ethical arguments that are relevant to permanent involuntary sterilization in the mentally challenged person.

– Discuss pertinent cases, using the framework of ethical analysis to evaluate what actions one can take in difficult cases, comparing ethically viable options to legal constraints.

Overview

• Ethical Issues regarding sterilization of developmentally disabled

• History of Abuse/Misuse of Sterilization of unprotected individuals in United States

• Describe and define:
  – decision-making capacity regarding reproductive rights
  – Voluntary or Involuntary Sterilization
  – Legal Requirements/Constraints

• Describe Practical Approach for Patients Today
History of Sterilization / Eugenics Movement in U.S.

During the late nineteenth and early twentieth century, the eugenics movement strongly influenced policy regarding sterilization. Involuntary sterilization was inspired by the false belief that most social ills resulted from characteristics transmitted across generations by those who were genetically “unfit,” a group that included the mentally retarded, the poor, and those who had committed crimes.

Eugenics - Origins

- Sir Francis Galton (1822-1911)
  - ½ cousin of Charles Darwin
  - Origin of the Species -1859

  - 1883- defined Eugenics as "the study of all agencies under human control which can improve or impair the racial quality of future generations"

  - 1904 -clarified definition of eugenics as "the science which deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost advantage"
Eugenics – two sides

- **Positive Eugenics** – increase reproduction of advantageous hereditary traits

- **Negative Eugenics** – decrease reproduction of undesirable or ‘poor’ hereditary traits

Forces in Play – turn of the century

- **Charles Davenport** –
  - 1904 - funds from the Carnegie Institution founded the Station for Experimental Evolution at Cold Spring Harbor
  - 1910 – Eugenics Record Office opened

- **Immigration Restriction League** - 1894
  - sought to bar what it considered dysgenic members of certain races from entering America and diluting what it saw as the superior American racial stock through procreation.

- **Harry Laughlin** - 1914
  - wrote a Model Sterilization Law that was circulated widely in the United States and Europe
Forces in Play – turn of the century

• **American Breeder’s Association** - 1903
  – worked with breeding the best in livestock. Chief biologist David Jordan Starr had a Committee on Eugenics. The committee unequivocally extended the principle to man

• **Stanford – Binet IQ test** – 1905
  – On the basis of IQ tests given to immigrants arriving at Ellis Island, eugenicist Henry H. Goddard "discovered" that more than 80 percent of the Jewish, Hungarian, Polish, Italian, and Russian immigrants were mentally defective, or feebleminded.

Eugenics – methods

• **Institutionalize ‘feeble’,**
  – laws to restrict marriage

• **Fairs/contests**
  – to promote “fitter families”

• **Restrict immigration** –
  – used to keep non-northern European immigrant flow restricted

• **Sterilization**

• **Extermination**
History of Eugenics in U.S.

• Sterilization must be examined in light of the eugenics movement in the U.S.

“The state of California was at the vanguard of the American eugenics movement, performing about 20,000 sterilizations or one third of the 60,000 nationwide from 1909 up until the 1960s”

http://en.wikipedia.org/wiki/Eugenics

Courts weigh in on Sterilization

• 1907 - Indiana became the first state to pass a law permitting involuntary sterilizations on eugenic grounds;

• At least 30 states would follow suit, many simply adopting a model "eugenics sterilization law," crafted by the Harry Laughlin, head of Eugenics Record Office (ERO) at Coldspings Harbor

• By the mid-1920s, more than 3,000 people had been sterilized against their wills. These included the homeless, orphans, epileptics, the blind and deaf. Also sterilized were those who scored poorly on IQ tests, who were diagnosed as being "feebleminded."
Courts – Buck v Bell

• 1924-, a teenager Carrie Buck, was chosen as the first person to be sterilized under the state of Virginia’s newly adopted eugenics law.
  – Ms. Buck’s mother resided in an asylum for the epileptic and feebleminded
  – She was accused of having a child out of wedlock.
  – She was diagnosed as promiscuous and the probable parent of "socially inadequate offspring."

Courts – Buck v Bell

• A lawsuit challenging the sterilization was filed on Ms. Buck’s behalf.
  – Scientists from the ERO attended the trial to testify to Vivian’s "backwardness."
  – In the end, the judge ruled in the state’s favor.

• 1927 – Appealed to the U.S. Supreme Court in the landmark case Buck v. Bell (1927),
  – ruled 8-1 to uphold the sterilization of Ms. Buck on the grounds she was a "deficient" mother.
Buck v Bell – cont’d

Chief Justice
Oliver Wendell Holmes Jr, declared

“The judgment finds... that Carrie Buck
‘is the probable potential parent of socially
inadequate offspring, likewise afflicted,
that she may be sexually sterilized
without detriment to her general health and that her welfare and that of
society will be promoted by her sterilization...’ It is better for all the
world, if instead of waiting to execute degenerate offspring for crime,
or to let them starve for their imbecility, society can prevent those who
are manifestly unfit from continuing their kind. The principle that
sustains compulsory vaccination is broad enough to cover cutting the
Fallopian tubes. Three generations of imbeciles are enough [“Buck v
Bell, 1927”]

Buck v Bell – cont’d

• On October 19, 1927, Carrie Buck was the
  first person in Virginia sterilized under the new
  law.

• Evidence later revealed that supports the claim
  that Carrie Buck’s child was not the result of
  promiscuity;
  – Ms. Buck had been raped by the nephew of her foster parents.
  – School records also indicate her daughter Vivian was a solid student and
    had made the honor roll at age 7. A year later, Vivian died of an intestinal
    illness

• Formal apology by Virginia Governor Mark R.
  Warner - issued 75 years after the Supreme Court’s
  – he denounced the eugenics movement as “a shameful effort in which
    state government never should have been involved”
Leaders of early 20th Century

• Theodore Roosevelt – 1910

"Some day we will realize that the prime duty, the inescapable duty, of the good citizen of the right type is to leave his or her blood behind him in the world."


• Margaret Sanger - 1920

In her book, Woman and the New Race, Sanger explicitly called her work "nothing more or less than the facilitation of the process of weeding out the unfit, of preventing the birth of defectives or those who will become defectives."

As she wrote in The Birth Control Review, "the most urgent problem today is how to limit and discourage the over fertility of the mentally and physically defective."


After WW II - North Carolina stands apart from other states

A state apart

The number of eugenic sterilizations performed in the United States may never be known. Records kept varied from state to state and were often incomplete or inadequate. Most researchers estimate about 65,000 people were sterilized. Most states sharply curtailed their sterilization programs after World War II and the atrocities of the Nazis became known. North Carolina didn’t. It went in the other direction, and nearly four-fifths of its procedures were done after 1945.

http://extras.journalnow.com/againsttheirwill/graphics/partone_astateapart.html

Reasons for sterilizations 1929-1968

Mental disease 23.6%
Epilepsy 5%
Feeble-minded 71.4%

Source: Eugenics Board of North Carolina, Human Betterment Foundation

http://extras.journalnow.com/againsttheirwill/graphics/partone_reasons.html
North Carolina

Was NC different?

• NC radically EXPANDED its program after 1945

• More than 2000 people, ages 18 and younger were sterilized - A 10 year old was castrated

• By the 1960’s – the program was not racially balanced – 60% black, 99% female
  
  – It was supported economically by the elite through The Human Betterment League – established 1947
  
  – Government sanctioned through an Eugenics Board – 90% of cases brought to the board, were approved, some retroactively

  – We have the records to see the biased thinking that occurred, couched as done for the ‘social good’
News – as of Jan 2012

• NC Justice for Sterilization Victims
  – At the request of Governor Beverly Perdue, a task force was formed. Its members -- a judge, a doctor, a former journalist, a historian and a lawyer.
  – Fewer than 2,000 of the nearly 7,600 residents forcibly sterilized from 1929 to 1974 who are believed to be still alive.
  – The task force acknowledged that "no amount of money can replace or give value to what has been done to nearly 7,600 people -- men, women, boys, girls, African Americans, whites, American Indians, the poor, undereducated, and disabled -- who our state and its citizens judged, targeted, and labeled 'morons,' 'unfit,' and 'feebleminded.'"
  – The task force determined that of the state's victims, those people still living should receive $50,000 each. In addition, the task force recommended that the state provide mental health services for those victims who still may suffer from feelings of loss, anxiety or depression. Compensation will not be paid to victims' family members or descendants.

Ethical principles within these Sterilization programs

• Justice – unequal Distribution of Health Care Services
  – Standard applied was “social worth standard.”
  – This is never deemed appropriate, but still is raised by others in many situations (e.g. distribution of available organs for transplant).
  – The video on CNN – had subtle implications of the belief this is still a valid standard.

• Autonomy - Informed Consent –
  – The records show over and over that sterilization occurred without proper consent, and even with opposition.
  – Coercion was used, people were not allowed out of institutions, or welfare checks were withheld if they were not sterilized.
What are our Reproductive RIGHTS?

• The World Health Organization defines reproductive rights:
  – Reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. They also include the right of all to make decisions concerning reproduction free of discrimination, coercion and violence.

Historical proclamations re: reproductive rights

• 1945 – UN Charter for Human Rights - Reproductive rights as a subset of Human Rights
  – "to promote... universal respect for, and observance of, human rights and fundamental freedoms for all without discrimination as to race, sex, language, or religion"

• 1968 - Proclamation of Teheran
  – "Parents have a basic right to decide freely and responsibly on the number and spacing of their children and a right to adequate education and information in this respect".

• 1994 - "Cairo Program of Action" - International Conference on Population and Development (ICPD) First international policy to define reproductive health:
  – “Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and its functions and processes... therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. ... the right of men and women to be informed [about] and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, ... and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant"
Most Recent International statement

- 1995 - Beijing Platform - Fourth World Conference on Women in Beijing, but established a broader context of reproductive rights:
  - *The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behavior and its consequences.*

- These are non binding, and not adopted by all countries/states.

United States - 1970’s-1980’s

- Compulsory State Sterilizations end

- Coercive patterns still exist
  - Inadequate funding of alt. methods of birth control, no fed'l funding for abortions, full insurance for sterilization – led to higher sterilizations in poor and minority women

- Stump vs. Starkman – went to Supreme Court - 1978
  - In 1971 -Indiana state court authorizes sterilization of minimally retarded 15 y/o girl w/o her consent, on petition of her mother. She later marries and files a suit against judge who authorized this w/o hearing or lawyer to support girl's interest

*Sterilization Abuse: Current State of the Law and Remedies for Abuse; Dick Grosboll. 10 Golden Gate U. L. Rev. 1147 (1980)*
### Federal Regulations - 1979

- **1st state Regulations – NY – 1974**
  - Later enacted by HEW, and California

- **Federal Regulations – passed 1978, effective Feb 1979**
  - Federal funding PROHIBITED if under 21, mentally incompetent, or institutionalized
  - Consent that it is voluntary
  - 30 day waiting period after consent, unless premature birth, emergency abdominal surgery – then 72 hour waiting period
  - Cannot consent during childbirth, or when seeking an abortion
  - Cannot be under influence of Etoh or other mind altering drugs
  - **Hysterectomy cannot be authorized as a form of Birth Control**
  - Patient may have a witness present
  - Informed consent per rules

### Informed Consent - Federal

- Decision to have /not have sterilization will not impact any other welfare or medical benefits
- Full description of available forms of Birth Control
- Advise that sterilization is irreversible
- Thorough explanation of specific sterilization procedure to be performed
- Interpreter provided if pt does not understand language of the consent form
- Effective communication to the blind, deaf or otherwise handicapped

[http://digitalcommons.law.ggu.edu/cgi/viewcontent.cgi?article=1205&context=ggulrev&seiredir=1#search=%221978%20guidelines%22 sterile%20federally%20funded%20sterilization%22]
Has the Pendulum Swung the other way?

• Parents or legal guardians of persons with mental retardation may have legitimate and important reasons for seeking sterilization on behalf of their children and wards….
  – Various surveys suggest that approximately half of all parents of mentally retarded children had considered or would consider sterilization for their child …

• Parents of children with mental retardation cite
  – the fear of pregnancy
  – fear of sexual abuse
  – uncertainty about the efficacy of other birth control methods
  – belief that the child or young adult would never be able to sustain a marriage or care for a child

Ethical Issues

• Who Decides for the Patient?
  – Must determine if the patient has any decision-making capacity specific to their reproduction

  – If patient cannot decide, who is the legal decision-maker – parent, family member, state guardian

  – If the patient cannot decide for him/herself, can sterilization be involuntary – or against the patient’s wishes
Ethical Issues (cont’d)

• What Constitutes “Best Interest” for the patient?

  – Very important to determine that the decision is made for Best Interest of the patient, not for the Best Interest of the caretaker
  – Not offered as treatment for sexual abuse or hygiene reasons
  – Sterilization is the Least Restrictive Contraception available

Ethical Issues – cont’d

• What are Legal Constraints/Regulations?

  – Know when court order is required versus recommended
  – Know different laws/regulations if the developmentally delayed patient is a minor versus an adult
Basic Concepts – ethically and legally

- **Decision-Making Capacity**
  - Must be specific to Decision at hand

- **Voluntary Agreement/cooperation for procedure**
  - Those who cannot provide consent, can assent to procedure

- **Best Interest of Patient**
  - Protection of Minors and Vulnerable Adults
  - Disability Rights Advocates – laws protect the rights of those with disabilities

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Capacity – re: Reproductive Decision

- **full decision-making capacity**
  - To have full decision-making capacity relative to reproductive choices, the individual would need to understand sterilization, contraception, pregnancy, child-birth and parenting
Determining Decision-Making Capacity – re: reproductive decisions

• **LIMITED decision-making capacity**
  
  – If a patient meets any of the following three capacities, but not all of the following three capacities, they have limited decision-making capacity for reproductive decision-making

  • Patient has the capacity to understand decisions regarding their reproductive choices
  • Patient has the capacity to raise a child.
  • Patient has the capacity to consent to marriage.

  The last criterion is the most stringent, but if a patient has the capacity to consent to a meaningful adult relationship, that person should not be held to higher standards than other adults who are not mentally retarded.

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Capacity - re: reproductive decisions

• **PERMANENTLY lacks decision-making capacity**
  
  – This individual fully lacks competence in any area of reproduction including choices of

  • reproductive options
  • child-rearing and
  • consent for meaningful consensual relationship.

(This group would include persons who are fully dependent on others throughout their lifetime, likely have severe mental retardation with IQ below 50, or who's retardation is complicated by severe emotional or physical handicaps)
Is Sterilization Voluntary?

- **Voluntary sterilization**
  - free and un-coerced choice of a competent individual to limit his or her ability to have children in the future

- **Involuntary sterilization**
  - individual who is incapable of providing consent is subjected to a sterilization procedure.

- **Compulsory sterilization**
  - legislation requires the sterilization of certain individuals to accomplish societal purposes

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Provisions of American with Disability Act – California

- **ADA Title II: State and Local Government Activities**
  - Title II covers all activities of State and local governments regardless of the government entity’s size or receipt of Federal funding. *Title II requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services and activities* (e.g. public educations, employment, transportation, recreation, **health care**, social services, courts, voting, and town meetings)
Definition of “Disability”

- **Federal definition of Disability**-
  - Has a physical or mental impairment that substantially limits one or more major life activities;
  - Has a record of such an impairment; or
  - Is regarded as having such an impairment.

- **California definition exceeds the federal definition**
  - age (40 and over), ancestry, color, creed, denial of family and medical care leave, disability (mental and physical) including HIV and AIDS, marital status, medical condition (cancer and genetic characteristics), national origin, race, religion, sex, and sexual orientation.

http://www.disabilityaccessinfo.ca.gov/lawsregs.htm

Legal Protections

- **1942 - U.S. Supreme Court in Skinner v. Oklahoma**
  - argued that the right to procreate was fundamental, requiring a compelling state interest to justify interfering with it - protecting an individual’s fundamental right to make reproductive decisions without the interference of others

- Procreative choice includes both the right to *refuse* sterilization and the right to *choose* it.
  - Although “irreversibility sets [sterilization] apart from [temporary] birth control measures . . . [it] . . . does not affect the status of the right to choose sterilization as a fundamental right.”
  - Blanket prohibitions against sterilization of the mentally incompetent may violate this right
  - The irreversibility of sterilization, however, does obligate us to more rigorously ensure that it is in a patient's best interests.
California Probate Code Section 1958

The court may authorize the conservator of a person proposed to be sterilized to consent to the sterilization of that person only if:

• (a) The person named in the petition is incapable of giving consent to sterilization, and the incapacity is in all likelihood permanent.

• (b) Based on reasonable medical evidence, the individual is fertile and capable of procreation.

• (c) The individual is capable of engaging in, and is likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy.

• (d) Either of the following:
  – (1) The nature and extent of the individual's disability as determined by empirical evidence and not solely on the basis of any standardized test, renders him or her permanently incapable of caring for a child, even with appropriate training and reasonable assistance.
  – (2) Due to a medical condition, pregnancy or childbirth would pose a substantially elevated risk to the life of the individual to such a degree that, in the absence of other appropriate methods of contraception, sterilization would be deemed medically necessary for an otherwise nondisabled woman under similar circumstances.

• (e) All less invasive contraceptive methods including supervision are unworkable even with training and assistance, inapplicable, or medically contraindicated. Isolation and segregation shall not be considered as less invasive means of contraception.

• (f) The proposed method of sterilization entails the least invasion of the body of the individual.
California Probate Code Section 1958

(g) The current state of scientific and medical knowledge does not suggest either
   (1) that a reversible sterilization procedure or other less drastic contraceptive method will shortly be available, or
   (2) that science is on the threshold of an advance in the treatment of the individual's disability.

(h) The person named in the petition has not made a knowing objection to his or her sterilization. …
   the court shall ensure that adequate effort has been made to elicit the actual views of the individual by the facilitator appointed pursuant to Section 1954.5, or by any other person with experience in communicating with developmentally disabled persons who communicate using similar means.

Kaiser Permanente
Medical Legal Manual – Ch. 6

Informed Consent Age Requirements Private Pay or Non-Medi-Cal Patients - Elective Sterilization
- 18 years old, or
- Under 18 married or previously married, or
- 15 years or over - emancipated minor, or
- 14 years or over - DMV card stating emancipated, or
- Under 18 on active duty with U.S. Armed Forces.

Medi-Cal Patient - Elective Sterilization
- 21 years old
• *Private Pay or Non-Medi-Cal and Medi-Cal Patient - Medically Indicated Hysterectomy*
  
  – 18 years old, or
  – Under 18 married or previously married, or
  – 15 years or over - emancipated minor, or
  – 14 years or over - DMV card stating emancipated, or
  – Under 18 on active duty with U.S. Armed Forces, or
  – Under 18 - consent of parent or legal guardian

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**Informed Consent- KP MLM**

• An elective sterilization may not be performed without the patient’s informed consent. *The consent of a parent, guardian or conservator is not sufficient.*

  – California statutes provide that a conservator cannot authorize sterilization. However in *Conservatorship of the Person of Valerie N.* [40Cal.3d.143 (1985)], the California Supreme Court made it possible for a guardian or conservator to obtain a court order authorizing the guardian or conservator to consent to sterilization on behalf of a developmentally disabled woman conservatee or ward. The physician may be called upon to provide a medical affidavit or letter to justify the granting of the court order.
Informed Consent- KP MLM

• Informed consent may be given by the patient only as indicated below:
  – The patient is able to understand the content and nature of the informed consent process. (In cases that do not involve Medi-Cal or other federally funded patients, the regulations provide that no patient shall by reason of mental retardation alone be prevented from giving informed consent for sterilization.)

• The regulations applicable to Medi-Cal patients specifically provide that a “mentally incompetent individual” and an “institutionalized individual” may not give informed consent for the performance of a sterilization which is reimbursed by Medi-Cal or other federally funded programs.

• Informed consent for elective sterilization must be obtained at two separate times.

• Advised that the sterilization will not be performed for at least 30 days, except under specified circumstances. (See “Waiting Period” page 6-7.)

Wrapping UP

• American College of Obstetrics and Gynecology
  – “The initial premise should be that non-voluntary sterilization generally is not ethically acceptable because of the violation of privacy, bodily integrity, and reproductive rights that it may represent

• American Academy of Pediatrics
  – “Consideration of sterilization should focus on whether there is a need for permanent prevention of reproduction.” The focus ought to be on “interventions substantially less radical than sterilization.”
When to Consider Sterilization of Developmentally Delayed Patient

• The patient is permanently incompetent and a court-appointed guardian represents her in full judicial hearings

• The patient undergoes medical, psychological and social evaluations

• The patient can reproduce but cannot care for offspring

• Sterilization is in the patient's best interest and she is allowed to express her understanding and opinion of the procedure.

• Sterilization is the most practical, least restrictive contraception available

• Motivations for requesting sterilization are examined.

Case #1

• 22 year old G0P0000 female, with a history of mild mental retardation, who has a history of Parathyroid Cancer, Polycystic Kidney Disease, and Stage 3 Chronic Renal Failure and Anemia. She was brought to clinic by her mother to discuss sterilization.

  – In Doctors opinion pt is not competent to consent to surgery or permanent sterilization.
  – The patient expresses the wish that she would like to have a baby sometime in the future, but she does not want one now.
  – She has limited understanding of how babies are made.
  – Patient lives with her mother.
  – The patient works as an office assistant in a transitional school.
  – She remains alert, oriented and appropriately interactive during office encounters.
  – The patient also has medical issues that could make any pregnancy a high –risk pregnancy, risky both for the patient and the fetus.
    • Her parathyroid cancer is in remission.
    • Renal disease is stage 3, on Lisinopril.
    • Her kidney disease could worsen with a pregnancy.
Case #2

- 17 year old female, turning 18 in one month. She has moderate developmental delay,
  - ADL’s
    - reports of functioning at the level of a 7 year old.
    - She needs help with some personal hygiene.
    - The patient is at school and in a work program learning skills, which can be performed with supervision.
    - She cannot read, she cannot count over 10 and has difficulty writing her last name.
    - She is not capable of independent self-care.
  - Personal Relationship Desires:
    - Per observation, it appears she does not really comprehend sexual relationships or pregnancy.
    - She is unable to care for a child on her own.
    - At this point, she indicates she would not want to have an adult intimate relationship.
  - Caretakers:
    - The patient lives with her mother, who also had had developmental delays
    - Aunt, uncle cousins live in same building, help with some care issues
    - The patients aunt works and has her own family to care for, and at times is overwhelmed with extra care of the patient and her mother
    - Mother and aunt prefer to speak Spanish, the patient prefers English

Case #2 – cont’d

- Medical/Psychological
  - The patient is a product of a normal pregnancy,
  - She had gastrointestinal problems with vomiting in her first 2 months of life, with G-tube placement and surgery to correct an undefined anomaly (surgery not in US)
  - She has short stature, hearing problems (just being evaluated), and vision problems (often not wearing her glasses)
  - She has had a genetic work up showing normal 46XX karyotype and negative screening for fragile X syndrome
  - She had normal milestones until age 1.5 years, and was reported as essentially "normal" by her family until age 3 to 4.
  - She had delay in toilet training to age 7 or 8.
  - She has been in developmentally delayed schools programs. She qualifies for education services until she is 22 years old.
  - She is being treated for a recent PPD conversion with Isoniazid.