

# **Enduring Lessons of Principles of Treatment of Disabled Infants (1985)**

**(copies of written essay available to audience)**

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# Key Topics

**Quality of Life – of person and family (3 & 4)**

**Presumptions and Assumptions (5-8)**

**Support (9 and 10)**

**Principle of Deference to Professional  
Decision-Making (11-13)**

**Supreme Court (14-16)**

**Outcomes and Education (17-24)**

# Background – Withholding and Withdrawing

- Principles of Treatment
  - Coalition of medical and disability advocacy associations
  - Response to movie at Johns Hopkins Hospital
  - Response to articles in medical journals

# Presumptions and Assumptions

- Formula – Presumptions
  - $QOL = NE + (H+S)$
  - Quality of life
  - Natural endowment
  - Sum of home and societal contributions
- Caution – mathematicalization
  - Nature of decision
  - Purely medical (scientific)?
  - Purely ethical?
  - Quasi-medical/ethical?

# Policy-Making Body: Who “Did” the Principles?

- Passionate insider – Asst. Sec. Ed. Madeleine Will, mother of Jonathan
- Medical associations
- Disability advocacy associations
- Totally ad hoc
- Effect: Sec. 504 and Child Abuse Prevention and Treatment Act – mandatory notices and state child protection laws apply

# Principles: Nature of Discrimination

- Intolerable at birth
  - If tolerable then, tolerable thereafter
  - Lifetime claim to negative right
- Irrelevant factors
  - Nature of disability
  - Severity of disability
  - Discriminatory “home” factors
  - Discriminatory “community” factors

# General Legal Claim: Presumptions

- Principles Presume in Favor of Treatment
  - Rebuttable – medical reasons only
  - Standard of proof not stated but commensurate with gravity of interest (life)
  - Burden of proof – not stated but default rule is burden is on those seeking to rebut
  - Nature of facts – scientifically sound body of knowledge – presumed about QOL
  - Body of knowledge – belongs to particular profession – presumed primacy

# Impermissible Presumptions

- Anticipated or actual limited potential of child
  - Present or future lack of community resources
- Sole factor – child's medical condition



# General Ethical Claim: Inherent Worth and Support

- Worth and dignity at birth
  - Inherent worth
  - (Duck issue of abortion)
- Profession as steward of national culture
  - Recognize inherent worth, dignity
  - Create a norm, shape a culture

# Claim to Support

- Compel a life, support the life
- Nature of support
  - Medical
  - Home/family support
  - Community/public support
- Positive right complements negative right
  - Negative right against discrimination
  - Positive right to support

# Challenged Assumptions: Issues in Deference Doctrine

- Decision-making process
  - Whose decision
  - Professional
  - Family
  - Joint
  - What influence of physician

# More Issues in Deference

- Time and circumstance of decision
  - Recently born
  - Immediacy to decide
  - Usually unexpected
  - Edges of life
  - Deference gathers power in these circumstances
  - Consider parents' situation

# Defensible Deference ?

- Predictability of QOL doubtful
  - Home contributions
  - Societal contributions
  - Changing conditions H and S
  - New laws
  - New supports
  - Power of technology
  - New cultural norms

# ***Bowen, Supreme Court and a False Predicate***

- Issue: Is there a factual basis for Sec. 504 regs that make withholding/withdrawal discrimination?
- Held: No – “family decides” = false factual predicate
- Justification: No proof otherwise, customary rule of parental consent
- Response: Codify Principles

# *Bowen* (cont'd)

- *Bowen* as anti-statist stance
  - Federal intrusion into profession
  - Medical profession off hook
- *Bowen* and separation of powers
  - Executive agency lacks factual basis for regs
  - U.S. Solicitor General “throws” case
  - Court refuses to grapple with issue

# *Bowen* (cont'd.)

- *Bowen* and Federalism
  - State laws against abuse, neglect
  - Sufficiency of state protection not addressed
- The “thicket” the Court learned to avoid
  - *Brown* and school desegregation
  - *Roe* and women’s rights



# Special Education and Lessons from Baby Doe: Non-rebuttable Presumptions

- Survivability, educability, zero reject
- Access – ZR – discipline, contagious disease
- Nondiscriminatory evaluation
- Use of research-based interventions in IEP
- *Endrew* doctrine of progress, appropriately ambitious, challenging objectives

# Lessons (cont'd.) – Not rebuttable

- Accountability – dispute resolution
- Parent participation
- Four policy goals – equal opportunity, full participation, independent living, economic self-sufficiency
- Statement of dignity and worth – the ethical claim – natural part of human experience ... not justify discrimination

# Lessons – Rebuttable

- Quality of outcome projections : QE = ? + ?  
(meaning of ?)
- Who, what, when, how determine QE ?
- Program – elements of IEP
- Placement – least restrictive environment
- Burden of proof (*Shaffer v. Weast*) – state may change “default” rule
- Standard of proof – state may change amount of proof (arguable)
- Qualifications of personnel – state licensure, “emergency” hires

# SCOTUS and Deference

- *Rowley* (1985) – benefit – unanimous
- *Endrew F.* (2017) – progress – unanimous
- Mere “preference” for LRE
- Tokenism for parent participation – expertise vs. input, officials’ expertise and experience as critically important (but not parents’ also?)
- Continued deference to professionals
- Federal, state district and appellate courts: same as before, or “heftier”?
- SEA, LEA defenses: doing *Endrew* already, always did

# SCOTUS (cont'd.)

- Remission doctrine (see Mueller report)
  - Remit issue to Congress, state legislatures (burden of proof, e.g.)
  - Majoritarian decision-making
- Contemporary thicket cases
  - Women's rights
  - Second amendment and gun control
  - Federal and state gerrymandering

# Enduring Lessons: Goals

- Purpose of support– ADA , IDEA
  - Equal opportunity
  - Full participation
  - Independent living
  - Economic self-sufficiency
- Nature of support
  - Individualized
  - Based on bias-free evaluation of need
  - Support of person: What about family?

# Issues About Support

- Where supported – general ed – three dimensions – academic, extracurricular, other school activities
- Where supported outside school
- When supported – transitions
- Who supports whom – role of educators, families, other public agencies and private entities
- The greatest social security is the “informal support” network

# Candid Fears – Support, Inclusion, Education – Effect on QOL?

- Tightening of eligibility benefits of Social Security programs
- Failure to support families
- Families as providers of last resort
- Department of Education proposal to reauthorize IDEA
- Advocacy—“If not you, who; if not now, when?”