@ 2013

CHILDRENS' ADVOCACY:

WHERE WE'VE BEEN...WHERE WE'RE GOING

INTRODUCTION:

- "Political couch-potatoism"
- Poor Advocacy ⇔ Hypocritical
- Chronic Illness of children has become a global concern

"STATE OF THE UNION": The FACTS and **POINTS TO PONDER**

- WE INVEST POORLY IN OUR CHILDREN! ➔ All infants are NOT created equal
- 30% of the population is < 19 years old
- Estimated that 12% of Noninstitutionalized children ages 0-17 have a chronic condition that results in elevated services or limitations in normal activity (Davidoff, 2004)
- We spend 1/10 of what we spend on beer/year on meeting the basic health care needs of kids
- Based on the world's military spending:
    - 1 Hour: stopped smallpox
    - 3 Hours: would support WHO's annual budget
    - 12 Hours: fully immunize all children
    - 6 months: eradicate hunger for the next 20 years
- Changing roles & composition of "The Family"
    - Married with children now the minority %
    - 1 in 12 children probably go to bed hungry
    - Increased use of day care
    - Greater than 29 million schoolage with both parents/only parent in the workforce; greater than 5 million children age 12-17 "work".
        - FBI statistics (2005): crime greatest in children between 2-8 PM.
        - Perhaps up to 15 million "latch key kids"
    - 15.7 million (21%) living in immigrant families.
    - About 1.6 million (1 in 45) American children experienced homelessness in 2010 (AAP, 2013).
- Increased indoor time and decreased extracurricular activities
    - Immune System changes/Allergies: dramatic increase since mid 1990's.
    - ~ 70% of children entering school FULLY immunized
    - About 14% of children with DX of asthma for ages under 18 years
- 8.5 million children without health insurance
- Decreased literacy and basic educational scores
    - @2011: estimated 8% ages 3-17 with learning disability, and estimated 9% with ADHD.
- Teenage pregnancy:
    - 1/3 children now born to unwed parents.
    - 15% of births to girls 15-19 years of age; 2% to girls UNDER 15 years
    - Increased premature births and less healthy infants
    - 2005: rates are slightly decreasing but #'s are the same.
- Child abuse:
    - US Dept of HHS: executive summary of child protective system.
        - Families in the "child welfare system: for families assessed after reports of abuse neglect: 19% less than 2 years old; 20% between 3-5 years old; 36% between ages 6-10; and 25% older than 11 years.
        - @2011: 1 in every 100 children in USA abused
            - `About 75% neglect cases ⇔ 25% abuse (65%physical, 25% sexual, 10% emotional/moral/legal)
            - An average on nearly 5 children die/day as result of abuse or neglect.
            - Children under 2 years old: most likely neglected rather than abused.

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        - Children over age of 5: high rates of violence in the home reported. (15% beaten by adult).
    - From Children's Defense Fund: child dies from neglect/abuse every 6 hours.
    - 2006: over 3 million allegations of child abuse & neglect (over 3.3 million children), with 40% substantiated. More than 88,000 confirmed victims of sexual abuse.
    - Once abused ➔ 50% greater chance of being abused again, and increased risk of being killed.
    - Over 875,000 determined to be victims of abuse of neglect in 2004 (Children's Bureau).
    - AAP, 2005: up to 19% of adolescents who are regular internet users have been solicited by strangers for sex through the internet.
- Foster Care: over 500,000 nationally, and about 2000 "age out" with no permanent family.
    - Within 4 years, about 84% of "foster care graduates" will have become parents, with about 50% having high school degree.
- Missing Children (www.missingkids.com) numbers from National Center for Missing & Exploited children
        - From 1984-March 2012: recovery of more than 175,000 children
        - Toll free hotline with greater than 3.5 million calls (1-800-THE-LOST)
        - US Dept of Justice:
            - Average of over 2100 children reported missing each day
        - AMBER ALERTS: 1997-March 2012 ➔ safe recovery of 572 children
- Substance abuse (ages 10-17): estimate that > 15 million children younger than 18 years being raised by substance-abusing parent/guardian (AAP, 2009).
        - > 5 million smokers, with >1 million "heavy" -> also smokeless
        - > 9 million drink, with > 2 million "heavy" (start 4-5th grade)
        - > 3 million marijuana users, with > 1/2 million regular users
        - > 1 million cocaine users, with 50% regular users
        - Increased trends of "inhalation"
- 2009: approximately 1.9 million persons under 18 years old were arrested, and juvenile offenders continue to account for about 15% of all violent crimes and 24% property crimes
- Ergogenic Aids: to enhance performance in competitive activities <-> ELEVATE health risks
        - Dietary supplements
        - Stimulants: caffeine, ephedra, methamphetamines (controlled substances)
        - Anabolic Steroids
        - Blood doping: use of erythropoietin (increasing RBC -> hyper viscosity)
- 2007 study (Finkelhor): about 20% of schoolage children been assaulted by another child past year
    - Preschoolagers suffered most physical injuries, most likely to be hit with objects or attached with weapons.
- Cigarette smoking: Responsible for 35% of all fatal fires & 15% of fires that kill children
- Obesity: > 17% of youth (greater than 95%).
- Unintentional injuries: @2011 data
        - Accidents kill over 12, 200 children/year
        - Poisonings: over 30,000 children die/year and greater than 2 million calls to poison control centers with majority of non-fatal poisonings younger than 5 years of age.
        - Suicide: > 5000/year
        - Drowning: > 2500/year, about 70% toddlers.
        - Homicides: Among teenagers (> 20,000/year): increased # with decreased socioeconomic. Child killed every 3 hours (Children's Defense Fund).
        - 13% of children with ED visit, and 6% with 2+ visits
- Sports: Increased activity, increased injury, increased "worshipping"
- School professionals have a (+) attitude about children's chronic health (Olsen, 2004)
- Child born into poverty every 36 seconds; 12.8 million children (18%) living below poverty line.

HISTORICAL PERSPECTIVE OF CHILD ADVOCACY:

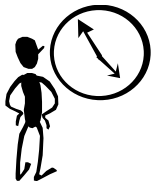
- What is this term? ➔ derived from Latin advocare which means **"to stand beside"**
- Children were often treated as "property"
- 17th & 18th Century: advocacy barely existed (property, chores, work, apprentice)
- 19th Century: improved but still poor (sweat shops, etc)
- Civil War: MAJOR impact -> improved conditions and increased "schooling"

IMPORTANT EVENTS IN DEVELOPING CHILD ADVOCACY:

1802: Jenner's smallpox vaccine tried on children in almshouse Sir Robert Peel: bill limiting Apprenticeship to 12 hours/day
1819: no children under 9 years of age to work, and 10-16 restricted to 12 hrs/day
1870's: Abraham Jacobs was one of first pediatricians to lead the way
1874: "Little Mary Ellen" foster case -> ASPCA first involved in advocacy
1889: American Pediatric Society
1890: increasing reform campaigns (education laws, new schools, vocational schools, restrictions in child labor).

Turn of the century => increasing "experiments" for "scientific" purposes -> raised issues of informed consent and "voluntary" involvement.

1904: National Child Labor Committee
1909: Teddy Roosevelt -> White House committee on Children (emotionally disturbed)
1912: Children's Bureau (birth registry, etc)
1915: "pediatrics" replaced "pediatry" and "pediology"
1919: Save the Children Fund started (Eglantyne Jebb)
1924: Declaration of the Rights of the Child
1935: Aid of Dependent Children (part of the Social Security Act)



End of WW II: Nuremberg Code
1950's: "Ozzie & Harriett" philosophy with baby boomers
1950's-1970's: Willowbrook State School (mentally retarded infected with hepatitis)
1965: Medicaid and Headstart
1960's: examination of "societal blemishes" => poverty, racism, inequality
Increasing: day care and child labor laws
1968: ACCH created -> first multi-disciplinary association for children
1969: Joint Commission on the Mental Health of Children
1970: American Association for protecting Children
1971: National Center for Child Advocacy (within Office of Child Development)
1970's:

- WIC
- Decreasing/failing family system -> increasing divorce, increasing of "non-traditional families, latch-key kids.

1974: Child Abuse Prevention & Treatment Act
National Committee for the Proetection of Human Subjects of Biomedical & Behavioral Research
1980: Mental Health Systems Act
1981: Pediatric Nutrition Surveillance System ➔ Select Panel for the Promotion of Child Health
1980's: Helpful trends included laws for: seat-belts, drinking age, childproofing caps, window guards, outlet plugs, etc.
1986: Children's Miracle Network
1988: Child Abuse provention; Adoption & Family Services Act
1989: in England => The CHILDREN'S ACT
1990: National Child Abuse & Neglect Data System
1990's helpful trends include: helmet, fingerprinting, ATV, "smoke" detectors, ? air bags
1992: Society of Pediatric Nurses
1993: Comprehensive Child Immunization Act proposal & Healthy People 2000 Initiative
2000: Healthy People 2010 Initiative
2006: Immunization rates update:
2006: traditional married couples household now minority statistics
2010: Healthy People 2020 Initiative

HOW DID WE GET INTO THIS MESS??

=> Not keeping up with societal changes: technology, feminist movement, civil rights
=> Downward expectations in school & society ➔ the rise of “entitlements” with no strings attached.
=> Media and bias of the “few” with the voice for the “many” ?
=> $$$ and the need for "profits"
=> Children are NOT small adults
=> "POLITICAL"
=> Factors that compromise the safety of children:

- Poverty, inconsistent pattern of employment; limited access to services;
- Inadequate: housing, transportation, places for children to play, leisure/sports facilities
- High crime rate

"POLITICAL POWER DOES NOT GO TO THE MAJORITY...BUT TO THE MINORITY THAT CARE THE MOST" -CONGRESSMAN PAUL MCCLOSKEY, 1992

ADVOCACY <--> ADVERSARY <--> "CHILDREN'S RIGHTS"

SOCIAL ISSUES:

- Child labor laws: traditional <-> new concept: "best interest of the child"
- Mandatory schooling
- Work laws
- Latch-key kids
- Day Care

LEGAL ISSUES: "GOOD MEDICINE" <--> "LEGAL" <--> ETHICAL

RESEARCH:

- Increasing interest in child welfare & desire to learn more about physical aspects
- Historical perspective:
  - Locations: asylum's and almhouses for poor or emotionally disturbed
  - Many unethical practices: procedures, vaccines, etc.
- ***Nuremberg Code***: 10 principles comprising the "basic" text of modern medical ethics! Perhaps the MOST important document in the history of the ethics of medical research.
  - Articulated in Nuremberg trials of 1947➔ was the start of numerous others such as Declaration of Helsinki (1964) and National Commission for the Protection of Human Subject of Biomedical and Behavioral research (1974) and finally the Belmont Report (1979)
    - #1: voluntary consent of the human subject is absolutely essential
    - #2: The experiment should yield fruitful results for the good of society, and unprocurable by other methods or means of study
    - #3: Experiment should be designed and based on results of animal experimentation and a knowledge of the natural history of the disease
    - #4: The experiment should avoid all unnecessary physical and mental suffering and injury
    - #8 and then #10: experiment should be conducted by scientifically qualified persons, and then, in #10, that person should be prepared to terminate study if negative outcomes may be likely.
    - #9: subject may withdraw from participation in experiment
- Issue: can parent REALLY decide best interest?
- Parents ability to take changes with child's health ⇔ risk
  - What is a child: person who has not attained the legal age for consent to treatments or procedures involved in the research under the laws of the jurisdiction in which the research is to be conducted.
    - No uniform definition under federal rules
    - FOCUS ON SAFEGUARDING THE WELFARE OF CHILDREN

CATAGORIES OF RESEARCH (From: US Dept of Health & Human Services, 1991)

1. No greater than minimal risk
2. Greater than minimal risk but presenting prospect of direct benefit
3. Greater than minimal risk and no prospect of direct benefit, but likely to yield generalizeable knowledge
4. Not otherwise approvable which presents opportunity to understand, prevent or alleviate a serious problem affecting the health or welfare of the child.

American Academy of Pediatrics: 1995

- AAP Committee of Bioethics: encourage MD's to obtain the "assent" of children
- AAP Committee on Drugs: placebo or untreated observational controls groups can be used in pediatrics IF THEIR USE DOES NOT PLACE CHILDREN AT INCREASED RISK.

WHAT IS INFORMED CONSENT??

- Is it really possible? => parents are especially vulnerable when child is ill
- Need to inform ⇔ developmentally appropriate. Does the child understand?
  - Minors presumed to lack the capacity to provide consent d/t immaturity, cognitive skills, past life experiences
- Protection of privacy & dignity
- Liability
- Risk ⇔ Benefit and therapeutic ⇔ non-therapeutic
- Often conflict of interest for nurses if child wishes ⇔parents!!

- Rationale for refusal for research (Gattuso, @2006):
  - Methods too involved or burdensome; not interested in topic; unsure why
  - Topic too sensitive; personal trait/characteristic
  - Perceive no benefit for self/child in participating

CHILD WITNESSES:

- Often seen with physical and sexual abuse cases
- May involve civil or criminal proceedings
- GOOD OR BAD IDEA ?
  - Since 2000 ➔ concerted efforts to "bridge the gap" between what is required of child witnesses and what their abilities enable them to achieve (Crawford & Bull, 2006)
    - "**Protection school approach**" with use of live television links
    - "**Empowerment tradition**" = more child focused and aims to strengthen children's ability to cope with demands of the trial.
    - Most studies show process is NOT traumatic overall; that child is an accurate and reliable historian, and younger child does BETTER than older.
  - Use of anatomically correct dolls, stuffed animals
  - **ISSUES:**
    - Child's ability to remember, quality of memories, suggestibility
    - Hearsay and competence
    - Confrontation clause of 6th amendment { for defendant to confront witness}
    - Some inherent problems:
      - Many interviews
      - Alleged perpetrator generally present during testimony
      - May need corroborating evidence of alleged act if child unavailable

ETHICAL CONSIDERATIONS: **ETHICAL ⇔ LEGAL**

- ***Declaration of Helsinki***: initially in 1964 and since undergone SIX revisions
  - Set of ethical principles regarding human experimentation developed for the medical community by the World Medical Association. Considered cornerstone document of human research ethics.
  - This MORE specifically addresses clinical research and is a reflection of changes in medical practice ⇔ term "human experimentation" (used in Nuremberg Code).
  - Question of the term "placebo" and its use in studies: believe was that these are necessary, are more scientifically efficient and are justifiable where the risk of harm is low especially where/when there are no "standards of care" in existence.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research
  - Formed in the aftermath of Tuskegee Experiment scandal (1974)
  - 4 major goals identified: perhaps most significant was determining appropriate guidelines for how human subjects can be chosen for participation in research
- The Belmont Report (April 1979): was a summary of the 1974 document, and is basically a statement of basic ethical principles and guidelines that should assist in resolving ethical problems that exist when performing research with human subjects.

- **ITEMS TO CONSIDER !!**

"Permission to do"	<--> "Refusing"
"Born"	<--> "Unborn"
Competency	<--> Decision making capacity
Ordinary	<--> Extraordinary
"Withdrawing"	<--> Withholding
"Best Interest"	
EGO's	
Genetic testing	
DNR	

THE LAW SHOULD BE VIEWED AS REPRESENTING THE MINIMUM REQUIREMENTS, AND NOT THE CEILING, FOR STANDARDS ABOUT MORAL DUTIES.

-BURNS & TRUOZ, 1997

A SOCIETY THAT IS BASED ON THE LETTER OF THE LAW AND NEVER REACHES ANY HIGHER IS TAKING SMALL ADVANTAGE OF THE HIGH LEVEL OF HUMAN POSSIBILITIES.
-ALEXANDER SOLZHENITSYN

- ASSENT (AAP, 1995):
  - Help patient achieve a developmentally appropriate awareness of condition
  - Providing information on what to expect with tests and treatments
  - Make a clinical assessment of the child's understanding of the situation
  - Obtaining patient willingness & acceptance of proposed care

"BABY DOE" regulations (1982):
- Landmark case => withholding & withdrawing life sustaining treatments from handicapped
- Parents refused surgery: child would never achieve a "minimally acceptable quality of life"
- 1984: Congress passed amendments to the Child Abuse Prevention & Treatment Act, whereby states are to investigate cases where medically indicated Rx is withheld.

DNR:
- 1970's: Critical Care Comm @ Mass General developed original guidelines in response to nursing requests for clarification of what should be done when CPR was unwanted. Written on assumption that cardiopulmonary arrest will be spontaneous event that is culmination of dying process (APP,2004)
- Focus of what will "not be done" rather than what will be done
- Is this against the Hippocratic Oath? => the concept of doing less than everything possible to preserve life is NOT new

DOCTRINE OF DOUBLE EFFECT:
==> When an action has 2 effects, one of which is inherently good and the other bad.
==> Can it be justified it certain conditions are met?
  - Action in itself must be good or at least morally indifferent
  - Agent must intend only the good effect and not the evil effect
  - Evil effect can not be a means to the good effect
  - Good intended must outweigh evil permitted
- In reality: largely irrelevant in everyday practice!

GENETIC TESTING:
- Is it in the child's best interest?
- Should we offer/disclose available tests?
- ? Medical and legal duty to advise about pre-symptomatic testing.
- Impact/stigma with positive results => F/U education and counseling
- Current status: newborn screening for PKU, CF, duchenne's MD, alpha-antitrypsin deficiency

For Pediatric Nurses: "THE CONCERN OVER ETHICAL ISSUES IS NOT A PROGESSIVE LUXURY, BUT AN INTEGRAL PART OF THEIR WORK". -BRYKZNSKA, 1989

CHILD NEGLECT & ABUSE:

Definition (from McDonald, 2006):
- Child Abuse Prevention & Treatment Act: recent act or failure to act that results in death, serious physical or emotional harm, sexual abuse or exploitation, ir imminent risk of serious harm: involves a child; and is carried out by a parent or caregiver who is responsible for the child's welfare.

NEGLECT:
- Most common form of abuse -> often not obvious and undectable for years
  - @2009: about 78% of reports to CPS involve neglect
- MANY types of neglect: emotional, physical, nutritional (TT ⇔ obesity), environmental (eg: second hand smoke; safety)

- "Acts of omission...the failure of a parent or other person legally responsible for a child's welfare to provide for the child's basic needs and proper level of care with respect to food, clothing, shelter, hygiene, medical attention & supervision".
  -first defined by National Center for Child Abuse & Neglect (1988)
  - 2011: USDHHS added "..or supervision to the degree that the child's health, safety and well being are threatened with harm".
    - Lack of supervision: child(ren) inadequately supervised for extended periods of time or allowed to remain away from the home overnight without the parent knowing the child's whereabouts.
    - Parenteral monitoring = identified in criminology literature as instrumental in the development of juvenile offending (Ryan, 2013).

ABUSE:

- Historical perspective:
  - 1st descriptions of injuries associated with child abuse from France in 1860's.
  - 1940's: USA and description of 6 infants with chronic subdural hematomas and classified as "obscure" traumatic origin
  - 1962: "**Battered Child Syndrome**" first used, with description of a constellation of findings from the trivial to the fatal (Greeley, 2012).
    - Kempe et al were 1st epidemiologic study and highlighted important aspects of the evaluation of suspected abuse (Leventhal & Krugman, 2012)
      - Discrepancy between stated HX ⇔ clinical findings
      - Questions that can be asked OF PARENTS when concerned about abuse
      - Some of the key physical exam and XRAY findings
      - Associated findings (eg: poor hygiene, FTT, etc)
      - Reasons why providers may have difficulty believing parents can hurt child
    - Term **CHILD MALTREAMENT** now used, to include all forms of abuse.
      - Research clearly shown that children who have experienced 1 type of maltreatment often experienced other types and often violence.
      - Consequences can be LIFE LONG
- Some statistics from 4th National Incidence Study of Child abuse and Neglect (2011)
  - Average time for CPS to initiate report of abuse = 71 hours
  - Unemployed parents with 2x rate of abuse and 3x rate of neglect
  - Married, biological parents at lowest risk ⇔ single parent with live-in 8x risk
- Signs of child abuse (from SafeHorizon.org)
  - Unexplained injuries
  - Changes in behavior
  - Returning to earlier behaviors: of the child
  - Fear of going home
  - Changes in eating and eating behaviors
  - Changes in school performance and/or attendance
  - Lack of personal care of hygiene
  - Risk taking behaviors
  - Inappropriate sexual behaviors
- "DAMAGE" done to child, including: physical, sexual, neglect, emotional
  - Signs:
    - Physical: bruise, burn, old scars, skeletal injuries
    - Emotional: withdrawn, overly compliant, poor social skills, decreased self esteem
    - FTT
- Parties involved: child <-> family <-> community
- Issues:
  - Legal { abandonment, liability }
  - Ethical { autonomy, child<-> family interests)

- ***Risk factors include***: these are the “negative” outcomes ☹
    - Child viewed as "different"
    - Frequent separation from parents
    - Clear evidence that abuse AND neglect are associated with an increased prevalence of mental health issues (eg: anxiety, PTSD, depression, suicide) as well as aggressive and violent behaviors (Leenarts et al, 2013).
    - Maltreatment is consistently identified as powerful predictors of juvenile and adult crime. (Ryan et al, 2013).
    -

SUBSTANCE ABUSE: grossly under recognized!

- ? parent role models <-> justifiable { " it's only a phase"}
- Treatment includes identifying risk factors

HOMELESSNESS:

- Some stats to consider: (AAP, 2013)
    - From 2007-2011: increase by 1.9%
    - Families with children = 35.8% of total sheltered population in 2011
- Risk factors: unemployment, substance abuse, mental illness, previous history of domestic violence or physical/sexual abuse.
- Health effects:
    - Homeless children = higher rates of acute and chronic health problems than low income; higher rates of multiple infections, respiratory, GI, derm, Otitis, diarrhea, lice and dental caries.
    - These children without a “stable home” more likely to skip meals/not eat ⇔ consume food with low nutritional value and higher fat content
    - Interruption of education and impact school performance.

FAMILY ISSUES:

PARENTING:

- 3 P's: provide, protect, procreate
- Roles: should provide stability, teach social rules & expectation
- FAMILIES:
    - Small social systems providing nurturance, security, love
    - What makes a family? => biology, social parameters, sharing responsibilities
    - Categories: biological, adoptive, foster, simple, nuclear, extended

- PARENT <-> CHILD RELATIONSHIP: many types
    - Ownership
    - Partnership
    - Club

WHAT CAN WE DO??

FAMILY CENTERED CARE: ACCH first coined phrase early 1970's

- What is it? => PARTNERSHIP
- Family resilience: “Ability to function well and to be competent when faced with stress".
- 1994 Revision: critical elements
    - Family is constant in child's life
    - Recognize/respect different methods of coping
    - Exchange complete & unbiased information
    - Encourage/facilitate family to have family support & peer networking
    - Ensure flexible, accessible, coordinated and comprehensive support systems
    - Recognize children as children and families as families
    - Honor cultural diversity
- Parent-led support groups for children with disabilities with POSITIVE results -> feelings "belonging" and empowerment. Sharing of ideas.
- Self esteem, school functioning & sports participation are among the most significant psychosocial issues that affect children with chronic illnesses-> special concerns often present

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- Giving children & parent a “voice” (Taylor, 2006):
  - Finding that voice & speaking out
  - Hearing the child and parent(s)/caregiver(s)
  - ADVOCACY
  - Responding to changing priorities & remaining sensitive to the NEEDS OF THE CHILD!

The child has the right to say what they think and be listened to by adults when they make decisions that affect the child. (UN Rights of the Child, Article 12).

"CHRONIC ILLNESS DOES NOT STRIKE INDIVIDUALS: IT STRIKES THE WHOLE LIVING UNIT OF THE FAMILY." -ROBERT MASSIE, 1976

ADVOCACY: Putting children first!!

- Children are NOT property
- Primary right of every child = ADEQUATE PARENTING!
- Ethical principles for adults usually insufficient for children
- Need family centered approach: "triad"
- Don't assume parents are always right!

"DEMOCRACY IS NOT A SPECTATOR SPORT."
Richard Celeste

LEARN:

Listen with understanding
Explain your perception of the problem
Acknowledge & discuss differences & similarities
Recommend treatments
Negotiate agreements

Provide a culture that “gives permission” to disagree ⇔ actually question!! Some questions to ponder

- How can I support this child and family today?
- What are they saying and feeling?
- What are they NOT saying?
- What do you find hardest? Easiest?

THE PRINICPLE OF FIRST CALL: Started with Eglantyne Jebb (Save the Children)

- Controversial -> the child must be the first to require relief in times of distress OR the family as a WHOLE should have priority

"RIGHTS":

"THE CHILD HAS A RIGHT TO EXPRESS AN OPINION AND TO HAVE THAT OPINION TAKEN INTO ACCOUNT, IN ANY MATTER OR PROCEDURE AFFECTING THE CHILD"
UNICEF, 1989

THERAPEUTIC BOUNDARIES: finding the correct level of involvement

- Reflects the philosophy & values of the health care institution, departments and individual staff members and RESPECTS patient/family values
- Do NOT make assumptions based upon the fact that no policy exists addressing a situation
- Both health care provided AND patients should be empowered
- Clear, concise therapeutic relationship with EMPOWERING behaviors

POWER OF THE PEN: Be involved; "write", utilize the internet. Remember, kids sell but they don't vote!

- Internet: good news ⇔ bad news due to availability of vast amount of “information”
  - Families and society at large using this medium
  - 2013 study (DiPietro et al) on neurodevelomental disorders found:
    - 1st: website of advocacy groups largely unexamined source of information
    - 2nd: the % of claims about treatment safety and efficacy were unsubstantiated ➔ lots of rhetorical strategies used to imply scientific support. Minimal peer reviewed studies and

- Many not evidence based. Up to 20% of citations failed to support relevant claims or were irrelevant to the context of the citation.
- Also found many erroneous references to scientific evidence and/or laden with emotional testimonials.
- Generally speaking: these sites serve as information "warehouses" rather than evaluation services and tend to provide information about a variety or readily available treatment products and services.
    - Much of the information was overwhelmingly encouraging, regardless of the type of product or services and regardless of its acceptance by healthcare community.

CURE ⇔ CARE:

- Requires compassionate responses -> NOT taking on pain that is not theirs
- Create standards, guidelines to address needs & diversity of family

Fiona Stanley (Daube, 2013): founding director of Telethon Institute for Child Health Research; epilemiologist and public health advocate in Australia

- Characteristics to consider that made Dr. Stanley a model researcher-advocate
    - Science: evidence based
    - Personal involvement: need to "open the door" and step in
    - Focus: on what WILL really make a difference
    - Policies and politics: need to get involved, READ all the information, and not just sound bites
    - Credibility:
    - Real passion
    - Courage: being a campaigner is not easy. LOTS of "marshmallow" advocates; ie, crisp coating but a soft center and run for cover when first shots are fired. STAND UP and advocate
    - Professionalism: availability, evidence based
    - Persistence: change is not easy
    - Reliability: be there when it is most needed

IN CHILDREN LIE SOCIETY'S HOPE FOR THE FUTURE. WHENEVER WE COME INTO CONTACT WITH THE YOUNG, TO SOME EXTENT WE CONTRIBUTER TO THE TYPE OF PERSONS THEY WILL BECOME. -CHADWICK & TODD, 1992

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GOOD LUCK…ADVOCATE FOR THE KIDS!!