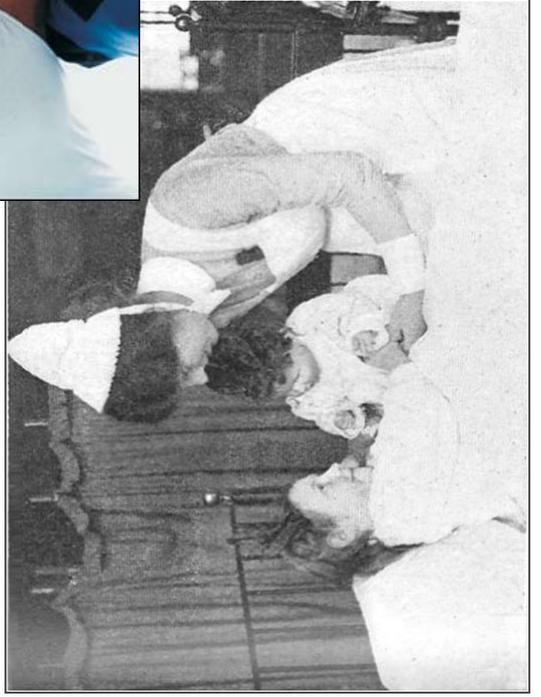
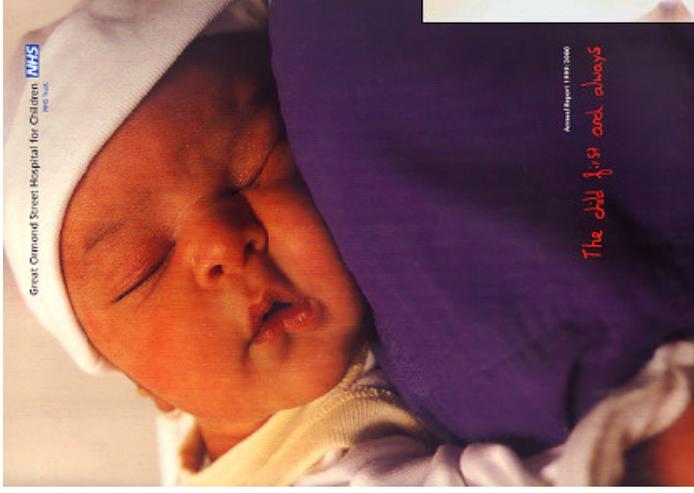
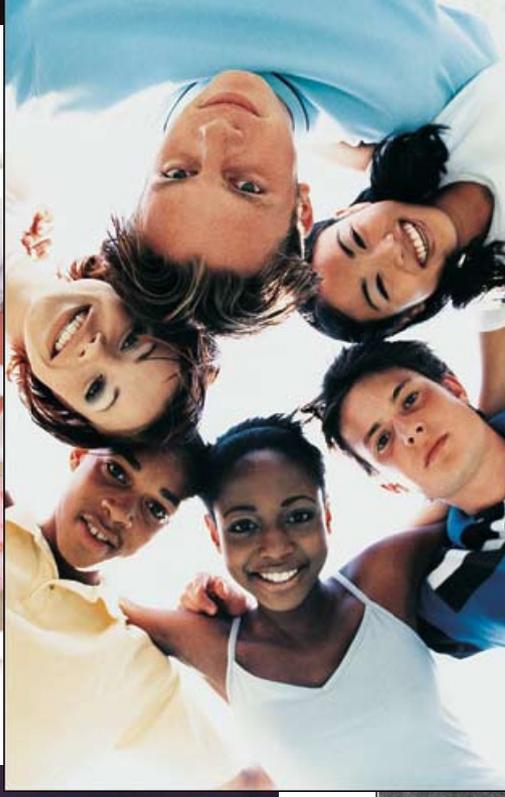
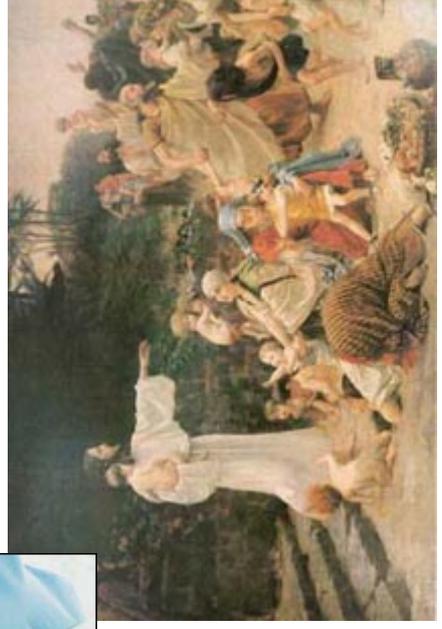


Ethics in Action: How much should children count?

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How much do Children count in the UK?

- Legal status depends on capacity.
- Limited recognition as valuable in themselves.
- Property of parents.
- Limited contribution to policy making.
- Significant identified failures to meet needs.
- Inconsistency/variability of treatment.

Are these purely historical concerns?

What should we do about them?

What is Ethics?

- A set of rules or principles that distinguish between right and wrong.
But there is not often one single “*right*” way to do something.....
- So.....
Ethics provides a means of evaluating and choosing between different, often competing options.
- Ethics also describes a field of study in which people examine the standards of right and wrong.
- Ethics is about analysing values rather than facts.

Ethics and the Law

- Law has been conceived as a minimalist ethical standard; i.e., respecting law is a necessary but not sufficient condition for respecting ethics.
- Being ethical is not the same as following the law; tensions can and do arise.
- The law often incorporates ethical standards to which most citizens subscribe. But laws can deviate from what is ethical. For example laws on slavery and apartheid.

How do we make Ethical Decisions?

- Applying moral theory.
- Conforming to ethical values e.g. virtues.
- Accepting laws, that are formulated and implemented by appropriate democratic process.
- Using “ethical memory” or precedents.

Ethical Theories

- Consequentialist - outcome based.
- Deontological - duty based (incl. 4 principles).
- Rights.

And more.....

Moral Theories 1

Consequentialism; Utility

- Concerned with outcomes of actions.
- An action is morally right if it is useful in maximising happiness/preferences/welfare and minimising pain for those involved.
- Everyone counts, no-one counts more than one.
- “The greatest good for the greatest number.”

Some utilitarians excluded children.

Is there room for emotional/psychological factors?

Moral Theories 2

Deontological

- Doctrine of moral obligation or duty.
- To be moral is to obey moral rules.
- Rules may be derived rationally or “discovered.”
- Rules are universal (apply to all), unconditional (no exceptions) and imperative.
- Moral individuals are rational (can discern rules) and able and free to act on them (autonomous).
- Rational, autonomous beings have their own intrinsic value and are worthy of respect.

How much do children count?

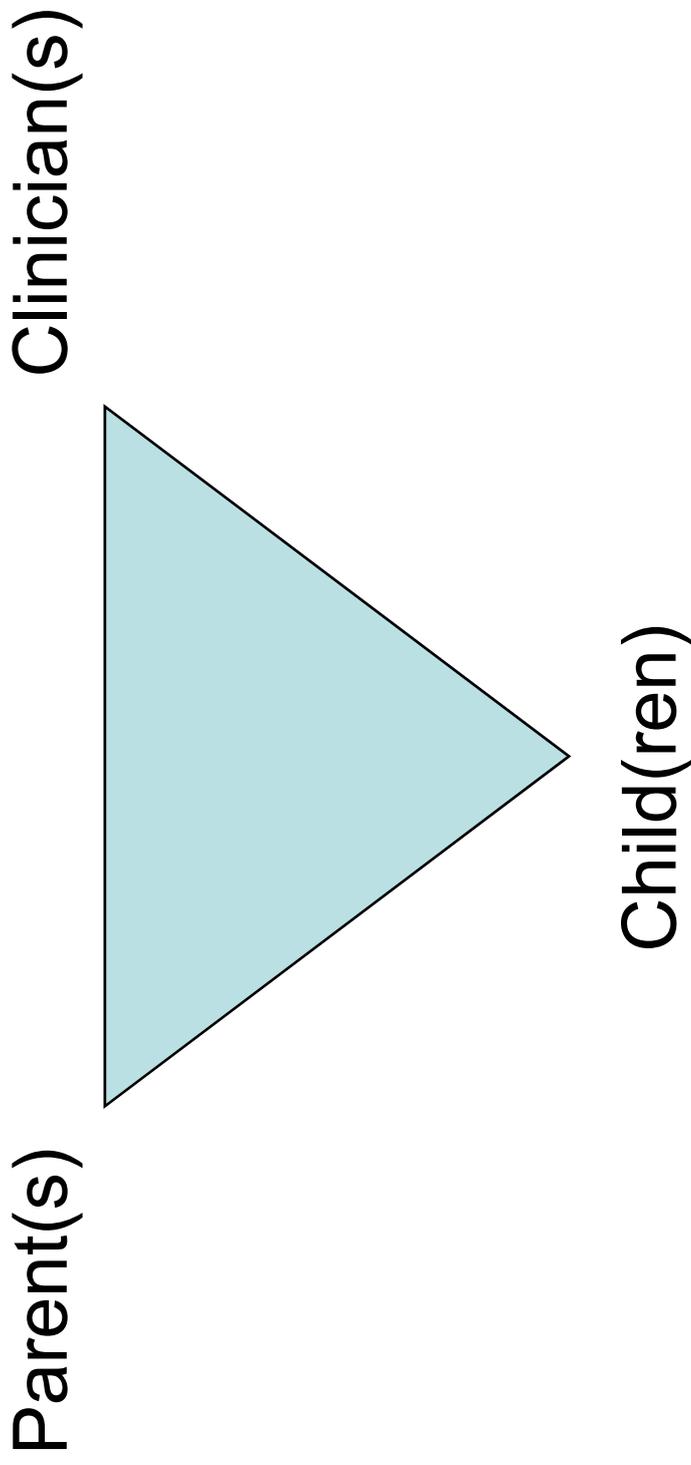
Moral Theories 3 Rights

- Justifiable moral claims made by others.
- Entail obligations on others.
- Negative rights have greater moral force.
- Derived from natural law or social contract.
- Special rights exist e.g. between parents & children.
- Conflicting obligations lead to practical tensions.

But Rights claims may not trump other moral claims
Whose right, who's right?

Child Health

A triangular dynamic relationship



How should we regard Children?

Competent sentient individuals with capacity for self determination i.e. autonomous agents.

Individuals in transition with variable capacities.

Vulnerable individuals who need protection from unwise decisions, in whom paternalistic interventions are justified.



Does Moral Status Matter?

- Traditional moral theory relates to persons whose interests we ought to regard as important.
- We attach great importance to respecting the free self determined (autonomous) choices of persons.
- Some children lack- and will never the develop- the characteristics we attribute to personhood.
- A rights based approach may help safeguard the interests of such children- but *competing* rights.
- If status questionable the law uses a “best interests” approach- what does this mean ethically?

Making Decisions *with* Children

Ethical & Legal Principles

Ethics

- Best interests
- Informed consent
- Rights

Law

- Best interests
- Valid consent
- Rights

*UN Convention on the
Rights of the Child*

Statute: Children Act

UK Human Rights Act

*Act of Legal Capacity
(Scotland) 1991*

Common: Gillick (E&W)

Children's Rights

UN Convention Rights of Child

Sets out, and creates obligations to provide

- Survival rights: Life, food, shelter, health.
- Development rights: Education, play.
- Protection rights: Abuse, exploitation, neglect.
- Participation rights: Free expression, respect for views.

Relevant Human Rights (UK Human Rights Act 1998)

Art 2—Right to life.

Art 3—Prohibition of torture & inhuman & degrading treatment.

Art 5—Right to liberty.

Art 8—Right to respect for privacy and family life, home, and correspondence.

Art 9—Freedom of thought, conscience, and religion

Art 10—Freedom of expression and right to information.

Art 12—Right to marry and found a family.

Art 14—Right not to be discriminated against on grounds of race, sex, etc, in enjoyment of other convention rights.

NB No specific provision for children or adolescents.

The background of all treatments, now and in the future, must be that they should be “***in the child’s best interests.***”

Withholding/withdrawing life sustaining treatment: a framework for practice **RCPCH** 2004

What are Best Interests (BI)?

Ethical theories of best interests

- Mental state e.g. pleasure/happiness.
- Desire-fulfilment: BI is a person getting what they want-irrespective of pleasure/happiness e.g. wealth.
- Objective list: certain things are good or bad and contribute to BI whether or not they are desired or lead to pleasurable mental state.

Children often regarded as not having objective view of BI; is this *really* so?

Best Interests: a more clinical view

An action or intervention is in someone's best interests if:-

- Benefits outweigh burdens.
- There is acceptable minimisation of harm.
- There is respect for as much autonomy (capacity for self directed, informed choice) as the individual is capable of exercising.
- [An individual is treated fairly and justly.]

Best Interests: Who Decides?

Adults can determine their own best interests; who decides for those who cannot?

Consultant

Health Care Team

Parents

[Relatives and friends]

[Divine Being]

[Courts]

Unequal partners?

Assessing Best Interests in Law

- Balance of legal principles and presumptions.
- Child's welfare is paramount.
- Welfare Check List (Children Act).
- UK Human Rights Act.

Legal considerations Of BI

Welfare checklist: the Children Act

- The ascertainable wishes and feelings of the young person concerned in the light of age & understanding.
- Physical, emotional, and educational needs.
- Likely effect of change of circumstances.
- Age, sex, cultural, religious, and ethnic background.
- Harm or risk of harm.
- Capability of parents or others to meet the young person's needs.

Used to consider impact of proposed intervention on child's welfare or best interests.

Liberty & Consent

“ ...the only purpose for which power can be rightfully exercised over any member of a civilised community, against their will, is to prevent harm to others. His own good, either physical or moral, is not sufficient Over himself, over his own body and mind, the individual is sovereign.”

John Stuart Mill , *On Liberty* : 1859

Valid consent to treatment is central to all forms of health care

DoH Good Practice in consent implementation guide 2001

Ethical & Legal Requirements for Valid Consent

All medical treatment requires valid consent. Consent is ethically and legally valid if it is:-

- Sufficiently informed.
- Given by a competent person.
- Obtained without coercion or duress.

Medical Treatment: The Legal Age of Consent

- Adults (>18yrs) are presumed competent to consent and to refuse any medical treatment. In E&W over 16's can consent.
- Age at which a child's refusal constitutes a veto appears to differ between England & Wales and Scotland.
- Capacity of <16yr-old children to consent is determined by assessment.

Consent-Information

- Benefits & risks of proposed treatment.
 - What the treatment involves.
 - The implications of having the treatment.
 - Alternative treatments; risks benefits etc.
 - No treatment & its implications.
 - Effects of treatment (or not) on future life.
- Even if child is not competent they have right to receive information given in a form and at a pace they can comprehend.

Competence/Capacity

The ability to perform the task in question

In consent to treatment it involves the ability to:-

- Comprehend information about a procedure, its alternatives & consequences.
- Believe the information applies to oneself.
- Retain the information.
- Use the information to make a decision.

Competence is context-dependent & variable.

Theoretical Basis for Development of Competence to Consent (1)

- Understanding of illness as malfunctioning organ system..... 11yr
- Abstract reasoning.... what if ? 12yr
- Ability to make a free choice.... 14yr
- Understanding of moral significance of death in relation to self-existence..... 14yr

Are these a reflection of actual competency?

Theoretical Basis for Development of Competence to Consent (2)

- Focus on negative aspects outdated?
- “Able instruction” and enhancing competence.
- Brain development research.
- Response to hypothetical situations.
- Experiential considerations.

Assessment of Competence

- General considerations.
 - Context, evolving relationships, background, time
- Developmentally appropriate assessment.
- Exploration of systemic influences.
- Assessment of emotional state.
- Cognitive development.
- Ability to balance risks and benefits.

Coercion

- Subtle forms of coercion are common.
- Failure to provide adequate time or facilities to receive and reflect on information may be coercive, even if unintentional.
- Adolescents may feel that unquestioned agreement with authority figures-doctors, parents etc, is required
- Pressurising adolescents to make decisions when they feel neither happy nor confident to do so may be coercive.

Encouraging Children's involvement



Participation potential

Imagine that a child's participation in decision making is analogous to the potential required by a battery to fulfil certain functions e.g. start engine, run lights, radio.....



How may we enhance it ?

Enhancing participation potential

- “Charging”
 - giving information, education, support, practice.
- “Selecting/conserving”
 - one task at a time.
- “Support in parallel”
 - working with child to decide.
- “Support in series”
 - doing for child what they cannot.

It's all very well but.....

- What happens when disputes occur?
- Disputes may arise between any combination of parties involved.
- Sources of Conflict:-

Changing goals of care

Best interests

Communication styles

Interpersonal interactions

An Approach to Conflict Resolution

Communication

Negotiation

Consensus building

Education, information

Deferring to requests for benign treatments

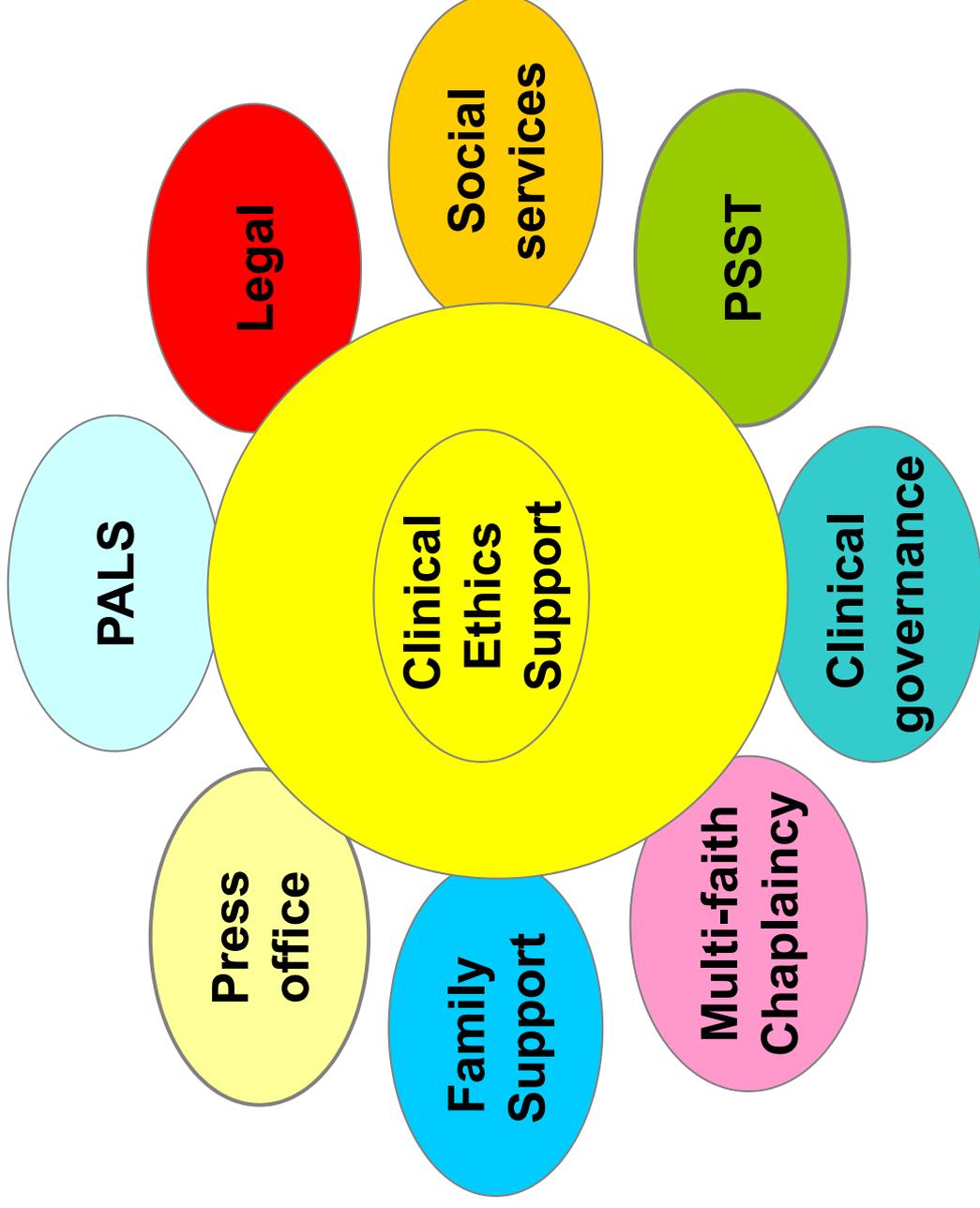
Referral/ Second opinion

Ethical review

Courts

Ethics reviews

Interactions with other services



Ethical Values in Decision Making

- Good decision making processes are:
 - Inclusive
 - Open
 - Reasonable
 - Responsive
 - Responsible

A Note of Caution

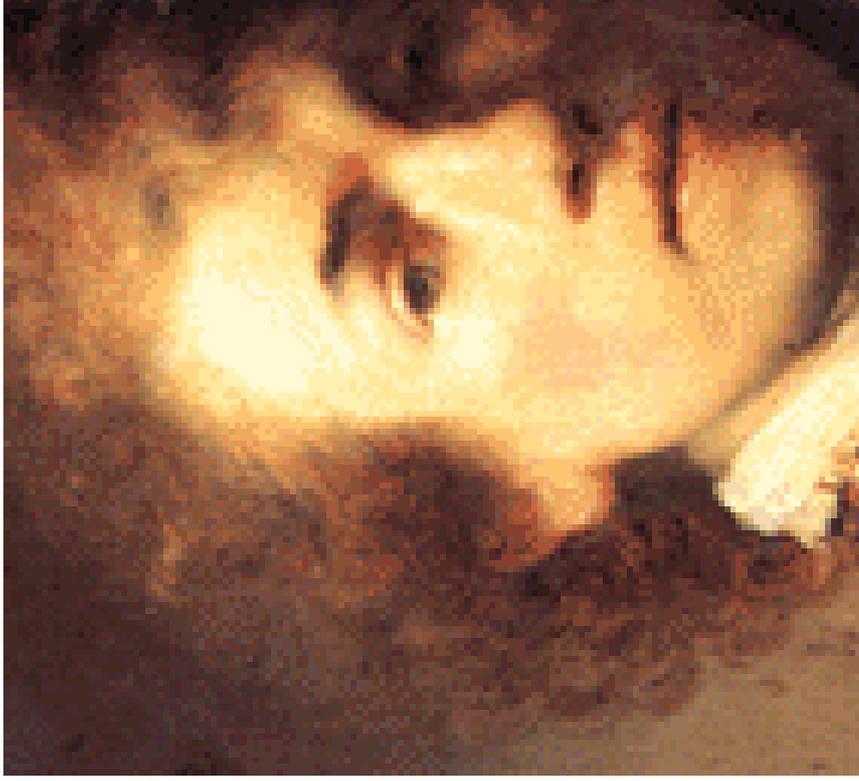


It is important to involve as many of those whose views are relevant as is possible.

However, not all will feel that their views have been accorded the weight and respect that their status appears to demand.....

Ethical debriefing after events is important for all

And Finally.....



**Neither youth nor childhood
is folly or incapacity.**

**Some children are fools and
so are some old men.**

William Blake