What makes paediatric ethics different?

Health Law Ethics Network Seminar

Dr Georgina Hall & Dr Jenny O'Neill, The Royal Children's Hospital, Melbourne

9th September, 2025

We would like to begin by acknowledging the traditional owners of the land on which we are meeting today,
the Wurundjeri people of the Kulin Nation, and pay
our respects to their Elders past, present and emerging. This session is about storytelling and sharing knowledge for today and the future.

The Children's Bioethics Centre provides

Education and training

Specialised training to help clinicians talk with parents about their child's life-threatening illness.

We provide clinical ethics education to doctors, nurses and allied health workers.

Research

An evidence base about respectful decision making, best clinical practice, how children and families react in difficult situations, the best ways to help families, children and the medical team, and what children want to know about their health care.

Clinical Ethics Service

Timely advice to clinicians faced with difficult decisions.

Quality

Expert advice, ethical opinions, position statements, recommendations, procedures and guidelines involving clinical ethical issues.

Leadership

Leadership in clinical ethics issues involving children – locally, nationally and internationally.

Clinical Ethics Service

One-on-one advice

Ethics advice in Multidisciplinary meetings

Clinical Ethics Response Group (CERG)

Family ethics consultation

Ethics debrief with staff

Policy and leadership

Policy advice to RCH Executive

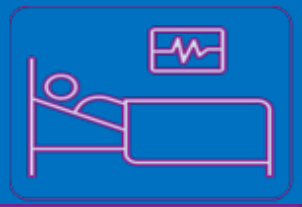
Advice to clinical departments and teams on processes and procedures

Policy briefing papers

Membership of RCH Committees

Development of RCH Nurse-ethicist leadership group

Hosting Senior Medical Staff sabbatical leave



Capacity Building through Ethics education

Ethics education sessions for clinical teams and departments

Attendance at ward meetings

Annual Paediatric Bioethics Conference

Workshops

Ethics in Clinical Practice Courses

Grand Rounds

JRMO Teaching

Podcasts

eLearning

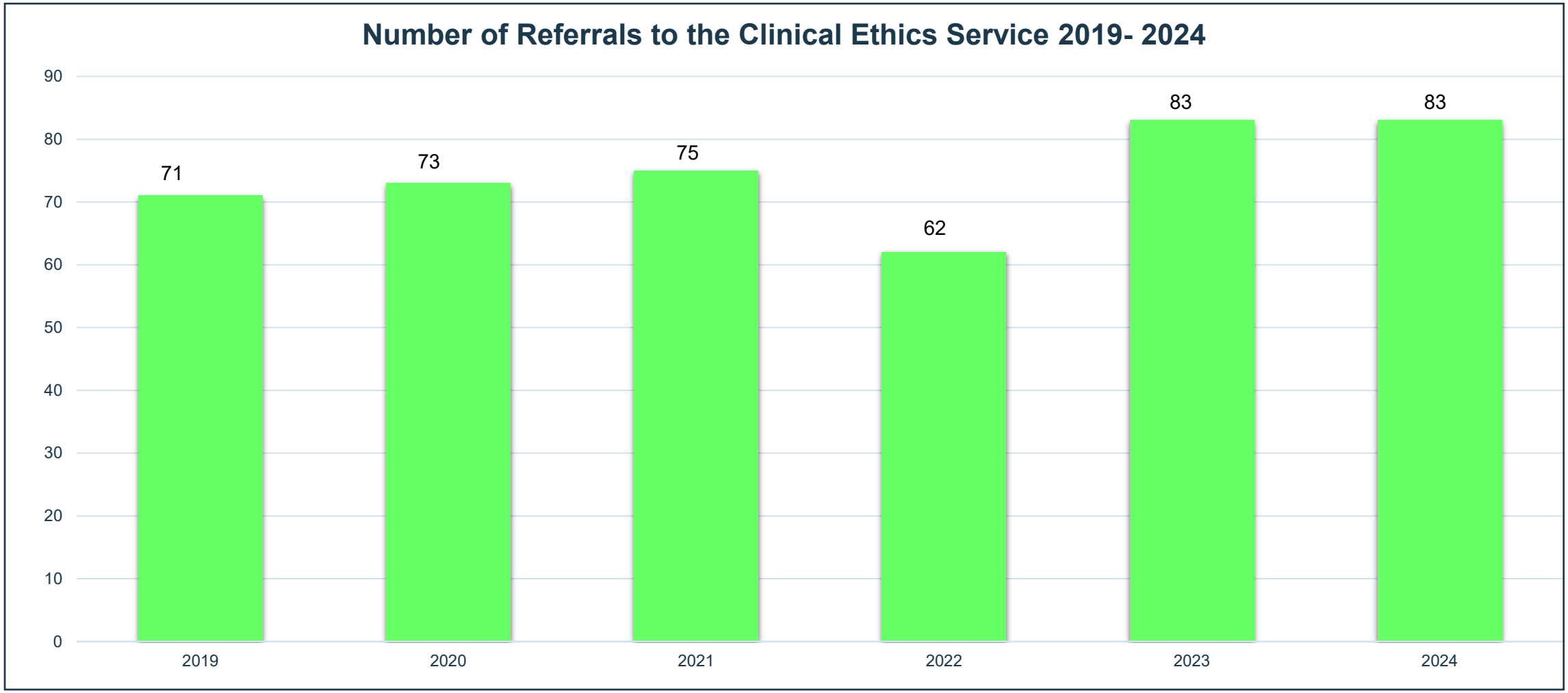
Research and publication

Academic Research

Supervision of research students:
-PhD
- Masters of Bioethics
- MD Research Projects

Peer-reviewed publications

Referrals for ethics consultation & support services



Referring teams & departments

SOURCE OF REFERRALS IN 2024			
1 referral	**2 referrals**	**3 referrals**	**4+ referrals**
Banksia (Mental Health) Creative services Disability liaison Endocrinology Oncology Gender Service Liver transplant team Medical Scoliosis Clinic Nephrology NICU (Neonatal Intensive Care Unit)) Operating Theatres Palliative Care Plastics Rehabilitation Rheumatology Social work Wombat ward Sugarglider ward	BMT Burns Corporate communications Critical Care SW DSD (Differences of Sex Development) Gastroenterology Psychology Haematology Koala ward Mental Health Neurology Orthopaedic Surgery Policy PICU (Paediatric Intensive Care Unit)	CCC (Children's Cancer Centre) Fertility Preservation General Medicine Respiratory	Adolescent Medicine NDD (Neurodevelopment Disability) Neurology

Typology of ethical issues referred to CBC

1. Medical disagreement or uncertainty about best treatment for child

2. Parents disagreeing with medically recommended management for child
   - Refusing recommended management
   - Wanting non-recommended management

3. Parents disagreeing with each other

4. Child resisting or refusing medical treatment to which parents have consented

5. Degree of involvement of child/adolescent – truth-telling, ethical weight of their views in decision-making re treatment

6. Concern about who should have access to what information – about patient or family (privacy issues)

7. Concern about cost of treatment or use of resources

McDougall, R., and Notini, L. "What kinds of cases do paediatricians refer to clinical ethics? Insights from 184 case referrals at an Australian paediatric hospital." Journal of Medical Ethics 42.9 (2016): 586-591.

Three key areas of ethical challenge

- Parents and doctors disagree
- Dealing with adolescent consent and refusal recommended treatment
- Younger child resisting treatment

First approaches to an ethical concern

- What are we worried about – ie what is at stake ethically?
- Are there competing / differing views of degree of benefit/burden or likelihood of various outcomes taking place?
- How much weight should be given to whose views?
- What are the goals of care? Where is this going in the long-term? Are there different ideas, or no clear idea?

Ethical Principles

- A standard way of thinking about ethics in health care (not discipline-specific).
- Principles put values (things that matter) into action
- Principles are not rules

Ethical principles in health care

- **Beneficence**

(benefiting, helping, doing good for someone)

- **Non-maleficence**

(not causing harm to someone, protecting from harm)

- **Autonomy**

(self-determination, making own choices about own life)

- **Justice**

(fairness, non-discrimination, fair allocation of resources)

Beauchamp, T. L., & Childress, J. F. (2019). Principles of biomedical ethics (8th ed.). Oxford University Press.

Basic ethical principles in child and adolescent health

- Promote well-being of the child
- Respect parents as decision-makers and care-givers for their child
- Respect the child as a person with developing and future autonomy
  - Respect the privacy of the child
- Treat everyone equally – do not discriminate
- Allocate fairly the resources at your disposal

Beneficence & non –maleficence

Autonomy (parental autonomy/ authority)

Respect for persons, autonomy (developing autonomy of the child)

Distributive justice

Why ethics gets complicated

INTERPRETING THE PRINCIPLES

- WHAT DO THEY MEAN?
- WHAT DO THEY MEAN *IN THIS SITUATION*?

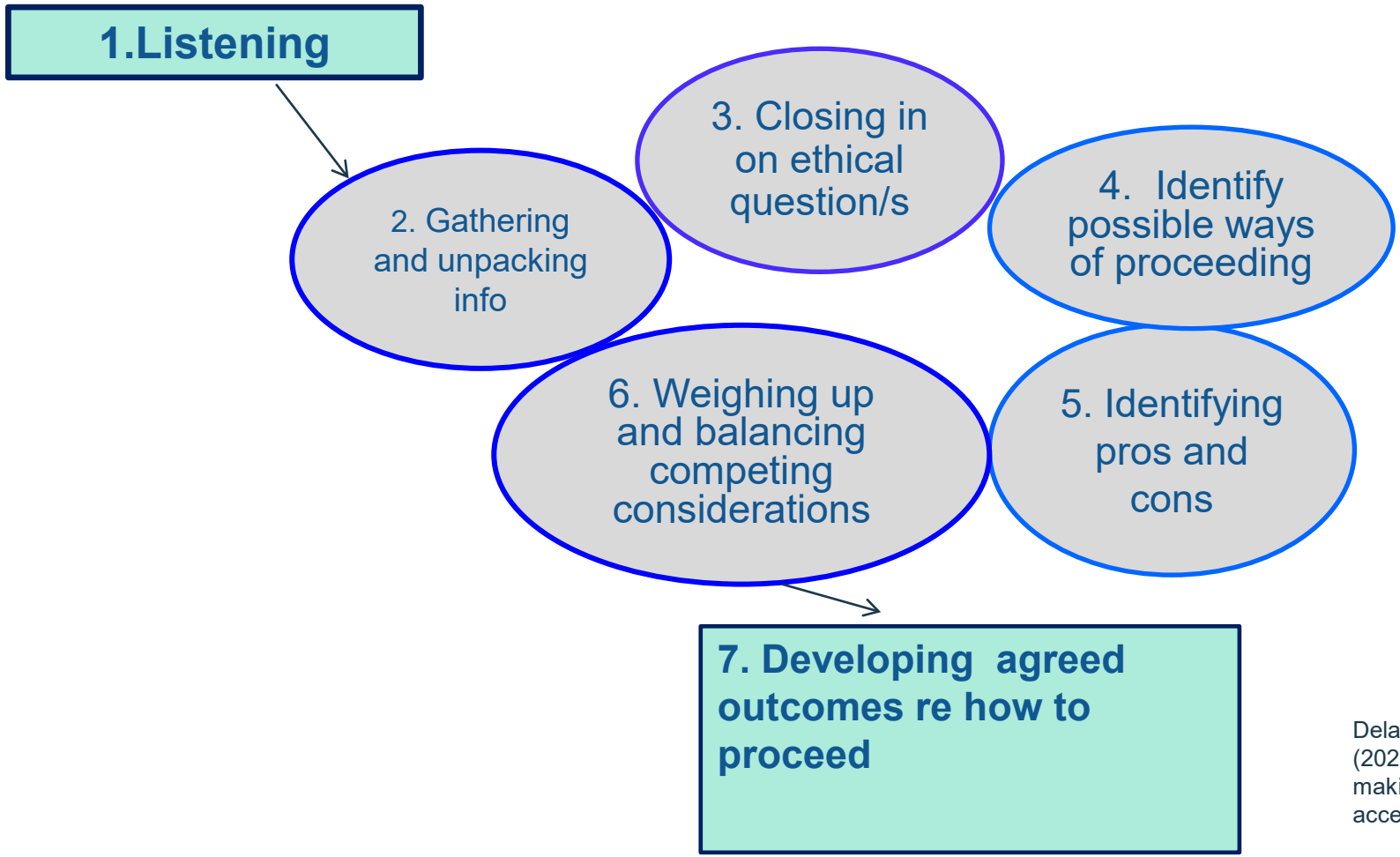
CLASHES

- DIFFERENT PRINCIPLES CAN (SEEM TO) REQUIRE DIFFERENT THINGS

LIMITATIONS AND BARRIERS TO DOING WHAT IS ETHICALLY BEST

- THIS CAN LEAD TO MORAL DISTRESS FOR THE CLINICIAN

The RCH method for clinical ethics consultation



Delany, C., Feldman, S., Kameniar, B., & Gillam, L. (2025). Critical dialogue method of ethics consultation: making clinical ethics facilitation visible and accessible. *Journal of Medical Ethics*, *51*(1), 10-16.

Scenario 1: When doctors and parents disagree

Meet Tahir

Tahir is 10 y.o. boy, born in Sudan to Sudanese parents and came here in the first year of life as a refugee with his mother Samah and 4 older siblings. Tahir's father's whereabouts is unknown.

Tahir has severe cerebral palsy, requiring full care - wheelchair dependent with quadriplegia, unable to hold up trunk and head. He is medically very fragile, in respiratory failure requiring night-time respiratory support, seizures, tube feeds, unable to control his own secretions.

His clinical condition has deteriorated over the past 12-18 months, partially due to rapidly progressing scoliosis and also multiple aspiration events. Tahir cries or grunts when distressed but otherwise has no communication method.

Tahir continued

In the last 4 months Tahir has had admissions to Paediatric Intensive Care (on average) every 4 weeks for increased respiratory support in the setting of aspiration pneumonia.

Tahir is currently in Intensive Care receiving maximum non-invasive ventilatory support (mask providing positive pressure to assist breathing), and is tiring.

The next step would be to intubate and ventilate Tahir with a tube down his throat and it is possible his lungs would never be strong enough to remove this.

- **What do you think should happen if Tahir deteriorates?**
- **What additional information would you want at this point?**
- **What ethical principles are at stake?**

Promote well-being of the child

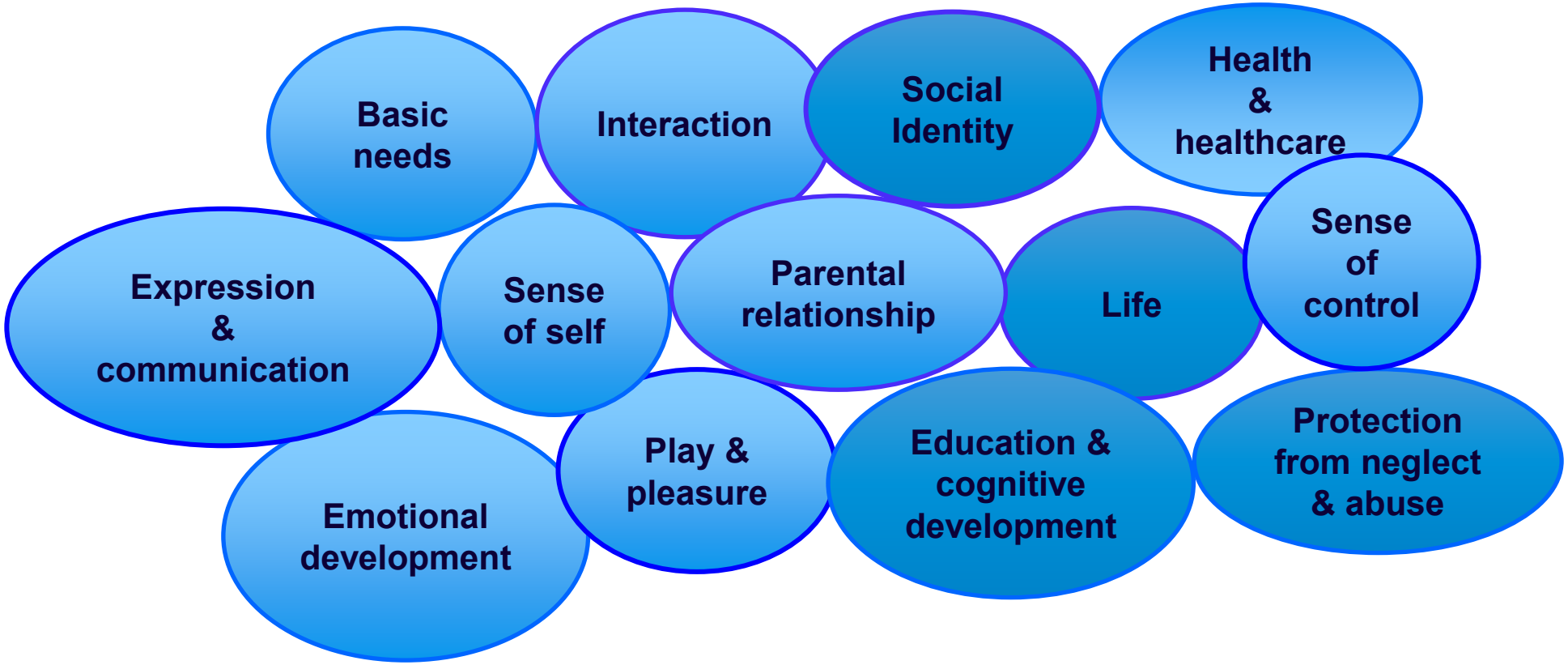
- Minimise harms, risks and burdens
- Maximise benefits

- Attend to all different aspects of child's well-being

- Consider the full range of the child's interests

Best interest of child may differ from best interests of family, but child's well-being deeply connected to family

A child's interests



CLUSTER OF INTERESTS

Gillam, L., Spriggs, M., McCarthy, M., & Delany, C. (2022). Telling the truth to seriously ill children: Considering children's interests when parents veto telling the truth. *Bioethics*, *36*(7), 765-773.

Basic benefits/burdens test:

Bottom line:

Any intervention should be reasonably expected to produce **more benefits than burdens** to the patient overall

Checks

- 1. Could the **same benefits** be obtained by a **less burdensome** method?

- 2. Could the **burdens be further reduced** while **maintaining the benefits?**

Tahir continued

There have been repeated efforts to discuss limitations of treatment (specifically no escalation to intubation and ventilation) with Samah who will no longer engage in these discussions except to say she wants ‘everything done’ and that Tahir will recover as he always has.

Attempts to increase pain medications to increase Tahir’s comfort has also been met with resistance by Samah. Samah has expressed that suffering is part of life in accordance with her faith.

- **What ethical principles are at stake now?**
- **What decisions need to be made? Who should be making these decisions?**
- **What options are there for the decisions to be made? What are the pros and cons of each option?**

Autonomy

- **Personal autonomy**
  - competent adult
  - **i**nformed decision about own health care
- **Parental autonomy**
  - parents are deciding for the child
  - i.e. proxy decision-maker **not** the same as personal autonomy

  ethical limits to decisions that proxies may make

Preferable expression – ‘respect for parents as decision-makers for the child’ or ‘parental authority’

Respect parents as decision-makers for child

Standard practice

- Engage parents in ***shared decision-making***
  - Information in understandable form
  - Express and think through their values – what matters most for them
- Seek parents' informed consent

The challenging situation

When parents

- do not agree to treatment that clinicians recommend as
- beneficial
- Seek treatment that clinicians think useless or harmful

Competing principles

Ways in which parents may appear not to be acting in their child's best interests

- Deciding against recommended medical treatment
- Not allowing child to take part in activities which staff believe will be beneficial to child
- removing the child from hospital earlier than recommended
- not bringing child for medical appointments
- not following advice on medication, rehabilitation, healthy environment for child at home
- using alternative therapies instead of prescribed medication

Zone of Parental Discretion

Ethically and legally protected space where parents may make decisions for their children

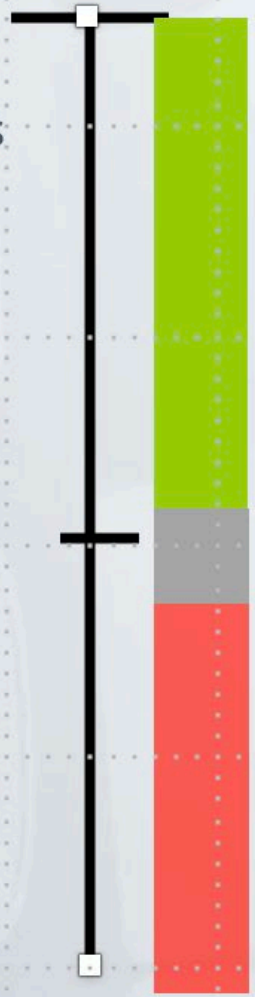
- Even if the decisions are sub-optimal for those children (ie not best for them)

- Provided that these decisions do not;
  - cause significant harm (***the "harm principle")***
  - Restrict the child's ***right to an open future***

Gillam L. The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*. 2015;11(1):1-8.

Best interests of child

Intervention will
produce ***maximum*** benefits



Zone of parental discretion

"good enough" interests

Grey Zone

No parental discretion

where their decision contrary
to child's interests (ie harmful)

Using ZPD – some questions to ask

- What will be the effect on the child of doing what the parents want?
- How bad is the effect, in comparison to what would otherwise happen?
- How likely is the bad effect?
- Is the bad effect so bad and so likely that it counts as causing significant harm to the child?

If yes, then that is a strong ethical reason to go against parents' wishes

- Keep in mind going against the parents wishes often also harms the child and this must be factored in

Back to Tahir

Tahir slowly improves over the next week and with further discussions Samah agrees to palliative care input to manage pain and distress.

He is eventually discharged to the ward with no clear plan about limiting future invasive interventions.

What do you think of this outcome?

Scenario 2: Dealing with adolescent consent and refusal recommended treatment

Meet Ava

Ava is 15 years old, the youngest of three siblings and lives with her parents in the outer northern suburbs of Melbourne.

She was diagnosed with high risk acute lymphoblastic leukaemia (ALL) 2 years ago. She was treated intensively, and during this time had a number of infectious toxicities.

She had almost finished her active treatment when she developed therapy-related acute myeloid leukemia (this is a rare complication of therapy).

While there was expected anger and some initial resistance from Ava, she accepted chemo and a long hospital stay. At that time Ava and her parents were counselled that the complication of AML on top of ALL is not curable without a bone marrow transplant (BMT).

Ava continued

At discharge, the recommendation is that when she relapses she will need a BMT.

Ava returned to school for some months and appeared to be relatively well. However, her last blood test showed that her cancer count is climbing and the medical team bring her into hospital to start high dose chemo to prepare her for the bone marrow transplant.

Her parent agree to this plan and her 17-year-old brother is a donor match, and he has consented to this.

However, Ava is adamant that she does not want any more chemotherapy and does not want a BMT.

What should the medical team do? Should they go ahead with chemo and BMT with parents' consent (against Ava's wishes)?

Gillick competence/'mature minor'

Legal term derived from a landmark UK case;

Gillick v West Norfolk Area Health Authority

House of Lords ruled that in certain circumstances, children under the age on 16 ('minors') could consent to medical treatment without the involvement of their parents and parents could not veto the treatment.

Competent minors could seek contraceptive advice and treatment such as the prescription of contraceptives.

Gillick competence/'mature minor'

Lord Scarman held that a competent minor will have '**sufficient understanding and intelligence to enable him or her to understand fully what is proposed'.**

(*Gillick v West Norfolk Area Health Authority* [1986] AC 112)

The ruling promised to make competent minors 'small scale sovereigns'

Gave them authority to make certain decisions

Gillick competence/’mature minor’

There is no set age at which a young person becomes a ‘mature minor’.

The assessment is situation-specific and in relation to a particular decision.

The higher the decision-related consequences and the more complex the information, the higher the level of understanding that is required for competence.

Factors relevant when assessing Gillick competence

- Willingness and capacity of the patient to engage in the decision-making process
- Young person's ability to understand information, understand implications of deciding one way or another, and give reasons for their decisions
- Young person's level of emotional & psychological development
- Previous experience of making independent or semi-independent decisions
- Lived experience of chronic illness or disability

The asymmetry of Gillick

Legally, Gillick applies to consent and refusal of treatment, but it has never been upheld in relation to a refusal.

In cases of adolescent refusal that have gone to court, the outcome has been treatment against adolescent's wishes (but note these are situations with high risk of death)

Ethically, for adolescent refusal, consider

- Level of risk/harm to patient
- Effects on patient of enforcing treatment
- Possible "good enough" compromises

Consent in u/18s in Victora

Rule of thumb (in Victoria, no law stating age, other states do have laws)

- < 14, assume not a mature minor, unless evidence to contrary
- > 16, assume young person is a mature minor, unless evidence to contrary
- 14-16 assess on case-by-case basis

Mature minors should be asked for their consent, and can give legally valid consent without need for parental consent as well.

- Though it is usual to involve parents unless there is a good reason not to.

What about non-competent children

- *A child's voice and a child's assent* still matters, even if doesn't carry determinative ethical weight
- Children of all ages can have varying levels of capacity to understand and participate in various medical decisions that affect their own bodies.
- Deciding *with* children seeks a child's participation in their own medical decision-making as a form of shared decision-making in paediatrics.
- The *process* of deciding and the child's participation is the important element, not the decision itself

Ethical weight of child's wishes

No capacity to understand.

Some capacity to understand. Agreement (assent) preferable. Dissent not definitive. Parents decide.

"Mature minor" Capacity to understand info, and some insight into own interests. Can consent independently to recommended Treatment depending on the complexity of weighing the risk. Parental consent can be omitted if good reason.

Adult-level capacity to understand information and own interests. Capacity to consent and refuse. Parental consent irrelevant.

Ava - some more information

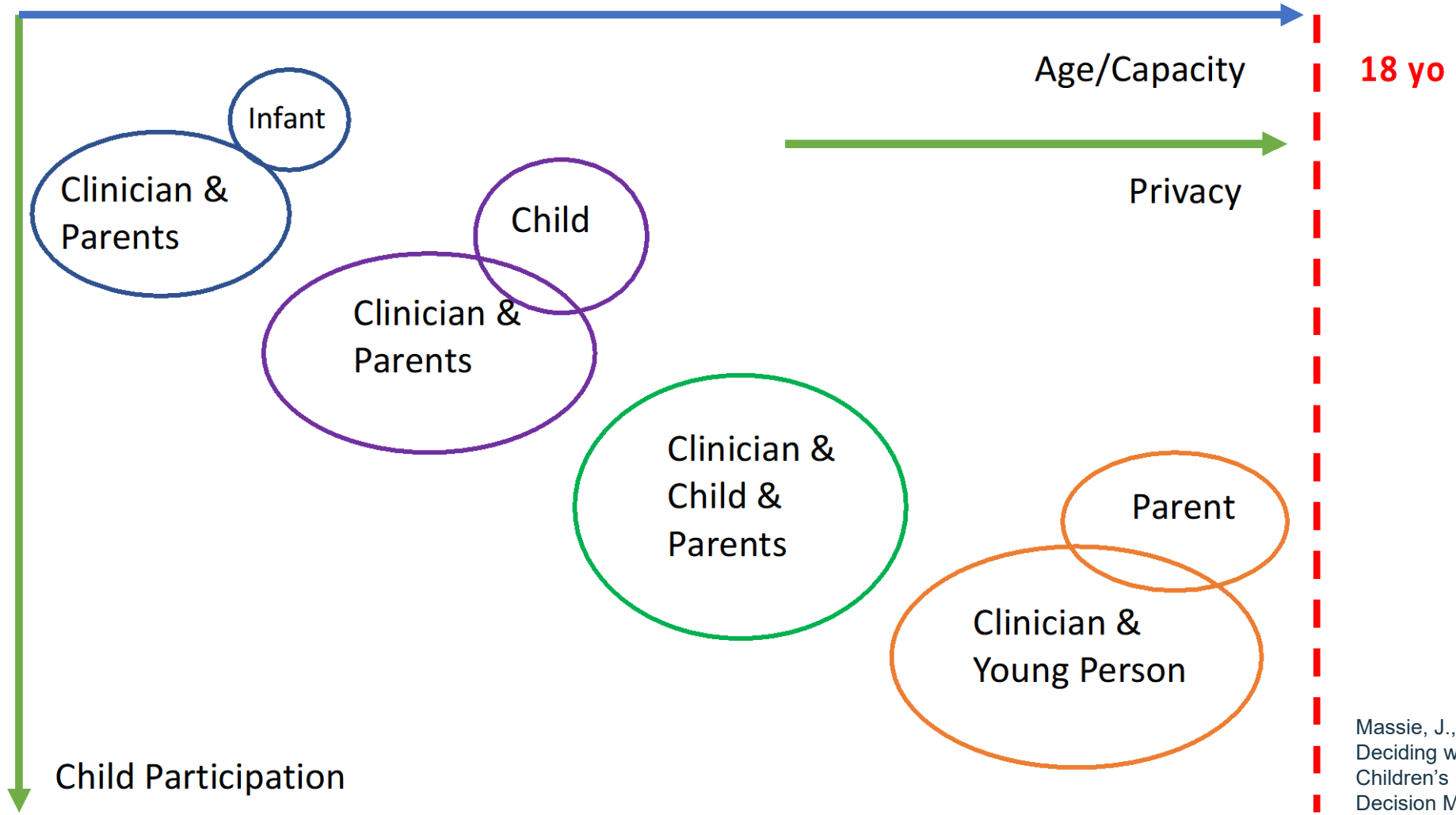
If Ava does not have the BMT, she could receive chemotherapy to try and keep the cancer at bay, but she will die of the cancer probably in months to a year.

The success rate of the BMT if Ava has a transplant is difficult to prognosticate but the best estimate is 60% chance of cure.

This is balanced with an estimated risk of death of 10-20% of the BMT period, and significant ongoing complications of the BMT (e.g. graft vs host, toxicity) of about 20-30%.

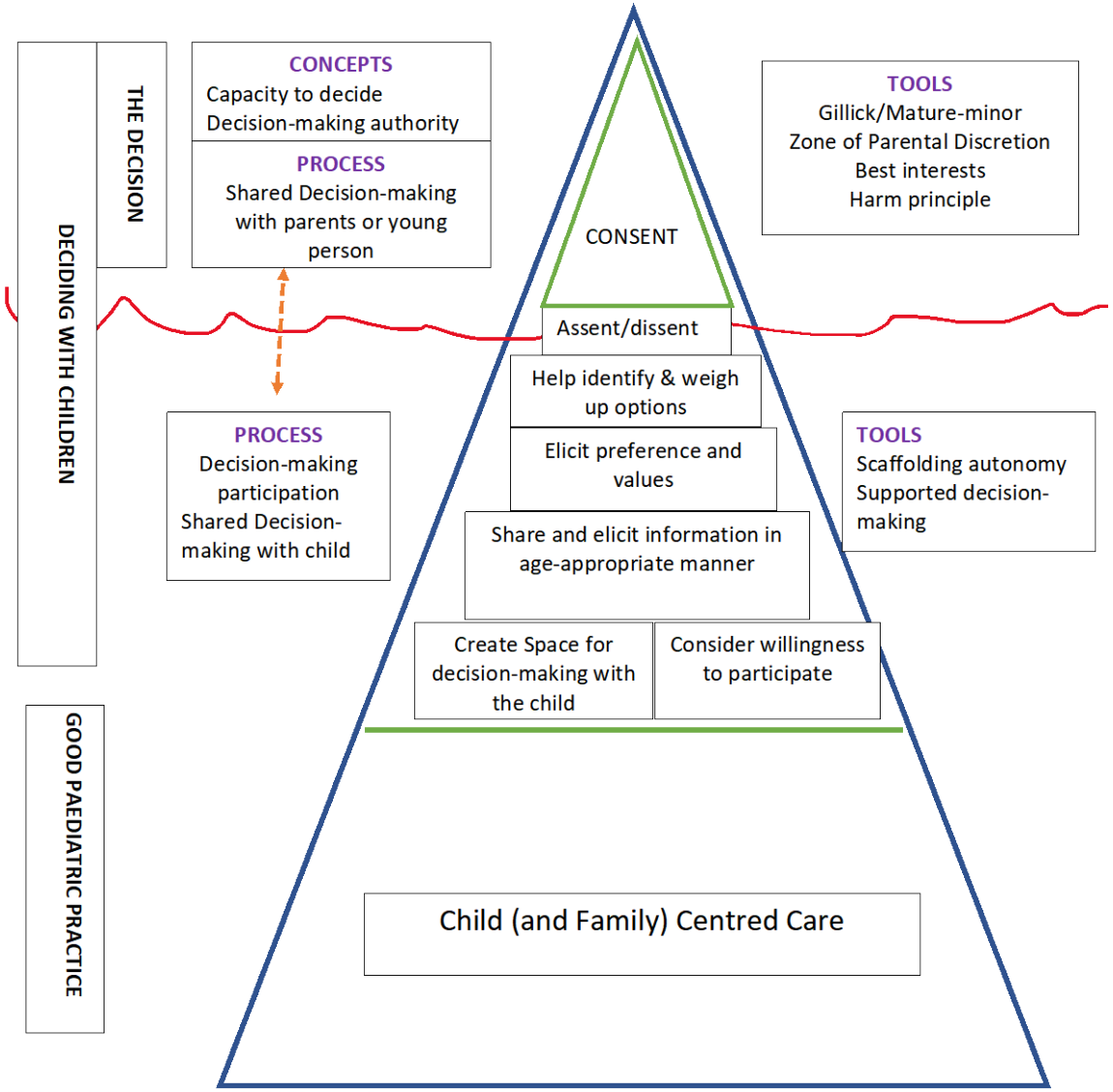
There is some urgency to make this decision - with each relapse the risk of complications/death increases and the team think that leaving her to relapse again may make BMT an unviable option. It should be undertaken in the next 1-2 months.

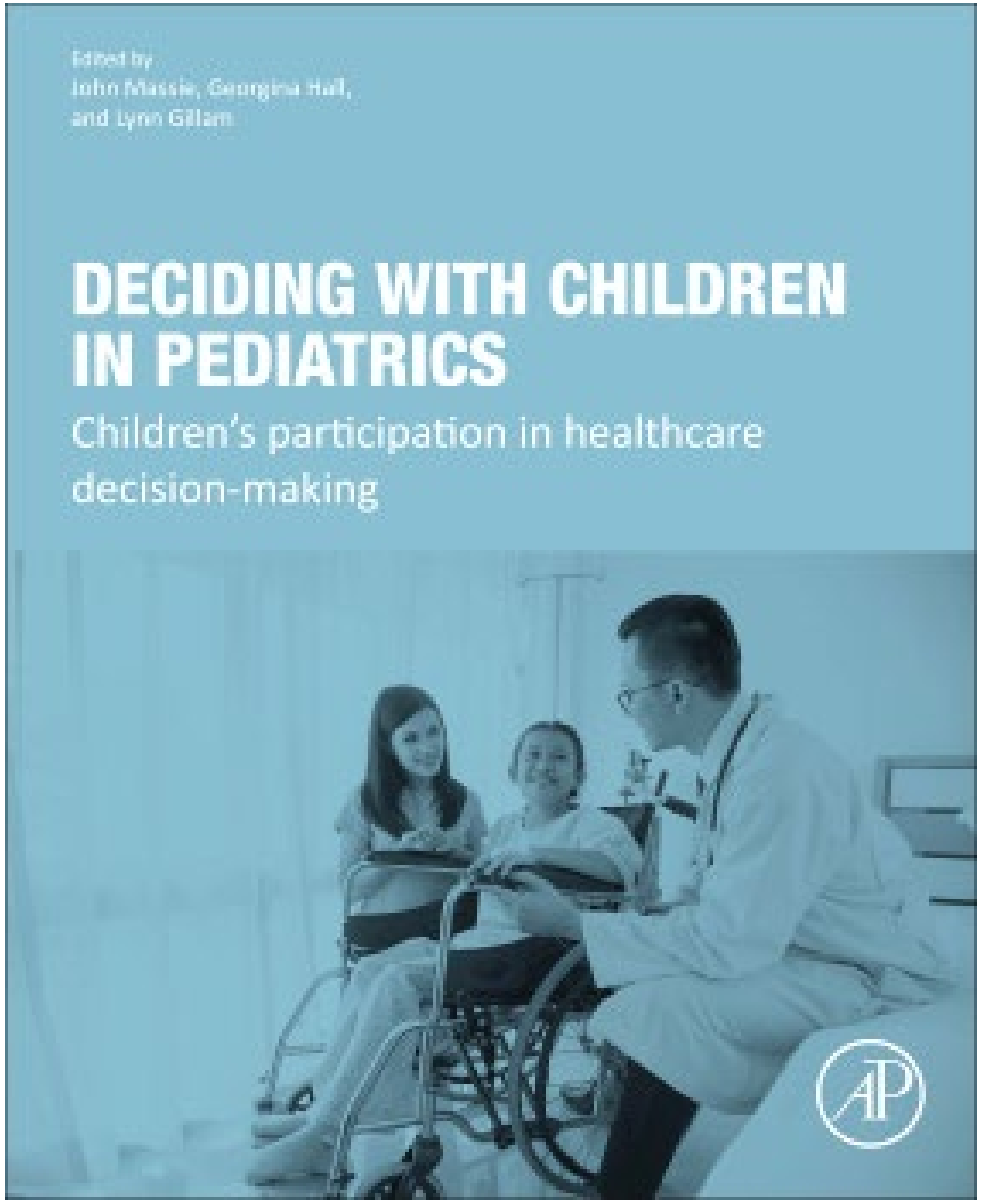
Deciding with children



Massie, J., Hall, G., & Gillam, L. (2024). Deciding with Children in Pediatrics; Children's Participation in Healthcare Decision Making. Elsevier.

SHARED DECISION-MAKING WITH CHILD = DECIDING WITH CHILDREN





https://www.courtsofnz.govt.nz/assets/cases/2025/2025-NZHC-2148.pdf

A guide to ethical decision-making – key questions to ask

1. What are the treatment/management options for this child at this stage?
2. What are expected benefits and burdens/risks of each option
3. Which option best promotes the well-being of the child? (How clear-cut an answer can be given?)
4. What do the parents want?
5. How much weight should be give to parents' wishes?
6. Does their decision fall within the zone of parental discretion?
7. What does the child/young person want?
8. How much weight should be given the child's view, on basis of child's level of maturity & understanding?

Thank you

The Royal Children's Hospital Melbourne