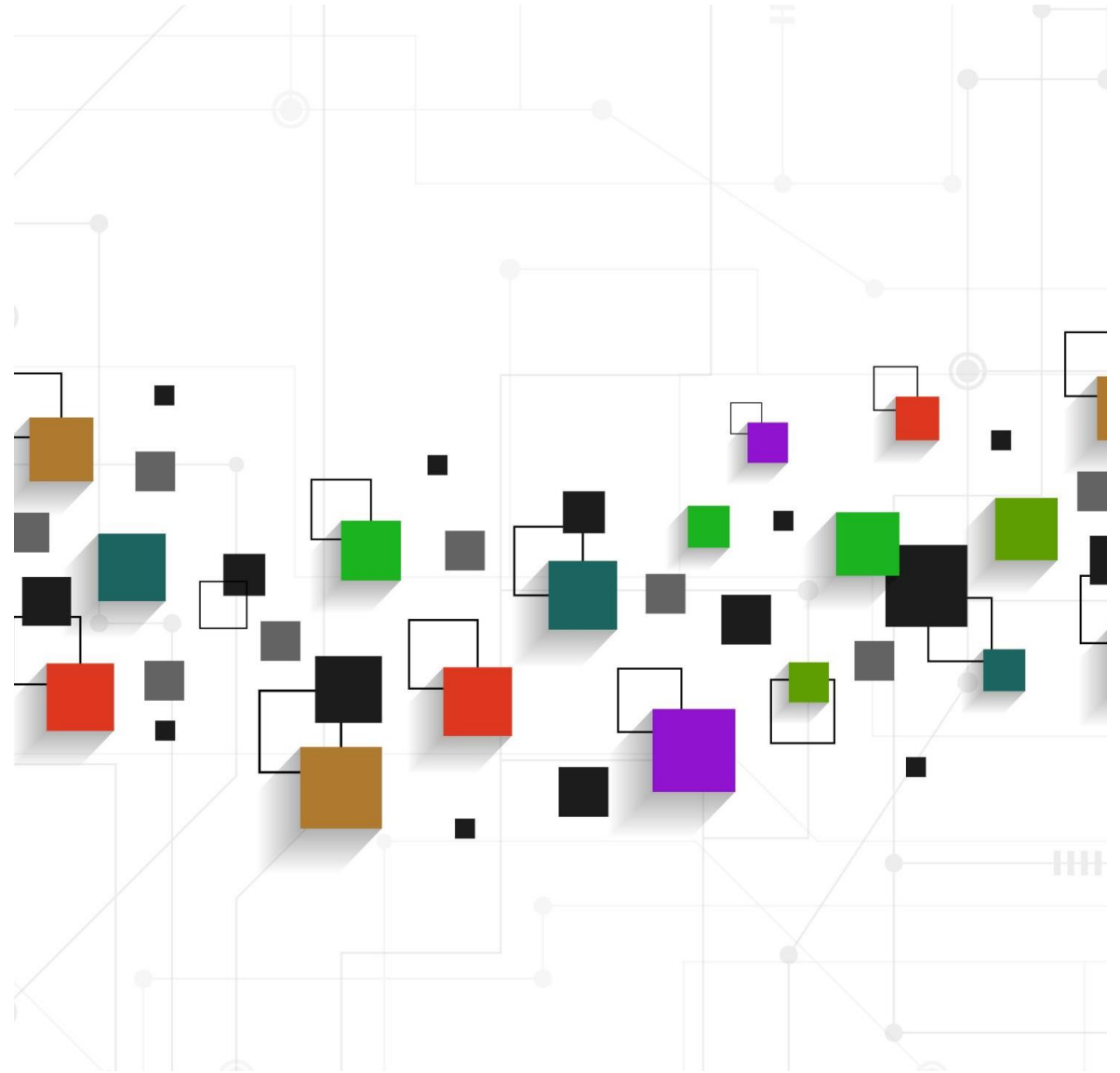




'Ethical principles: managing individual choice and the risk of harm when supporting people with PWS'

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Overview

- PWS: Challenges & opportunities
- Four principles of bioethics – and how they might apply
- Approaches to autonomy – not a fixed concept
- Legal frameworks – different ways of balancing the principles
- Human Rights – the UNCRPD & how it might apply to PWS



Challenges and Opportunities

- Hyperphagia
- Challenging behaviour
- Risk of psychosis
- (Intellectual disability)
- Persistence/determination
- Specialist support
- Medication (eg Growth Hormone)
- Potential

Ethical Principles: Beneficence

Beneficence:
We should help others if we can

Non-maleficence:
We should try to avoid harming others

Justice: We should treat people fairly in comparison to others

Respect autonomy:
People should have a say in what happens to them

- 'A duty to do good' can mean many things:
 - Saving someone's life
 - Protecting someone from harm
 - Improving someone's physical health
 - Improving someone's mental health
 - Making someone happy
 - Supporting someone to achieve their own goals
 - Enabling someone to lead a life like others
 - Helping someone to learn new skills
- Who decides what 'good' we should be aiming for?

Ethical Principles: Justice

Beneficence:
We should help others if we can

Non-maleficence:
We should try to avoid harming others

Justice: We should treat people fairly in comparison to others

Respect autonomy:
People should have a say in what happens to them

- ‘A right to be treated fairly’ can mean many things:
 - Being treated the same as everyone else
 - Receiving the same opportunities as others
 - Support to achieve the same outcomes as others
 - No one getting more than their ‘fair share’
- Who decides what is ‘fair’?

Ethical Principles: Respect autonomy

Beneficence:
We should help others if we can

Non-maleficence:
We should try to avoid harming others

Justice: We should treat people fairly in comparison to others

Respect autonomy:
People should have a say in what happens to them

- ‘A right to choose’ can mean many things:
 - Being free to do what you want
 - Choosing your goals & being supported to achieve them
 - Getting help to make your decision
 - Someone choosing what they believe you would want
- Who decides which choices we should respect?

Ethical Principles: Non-maleficence



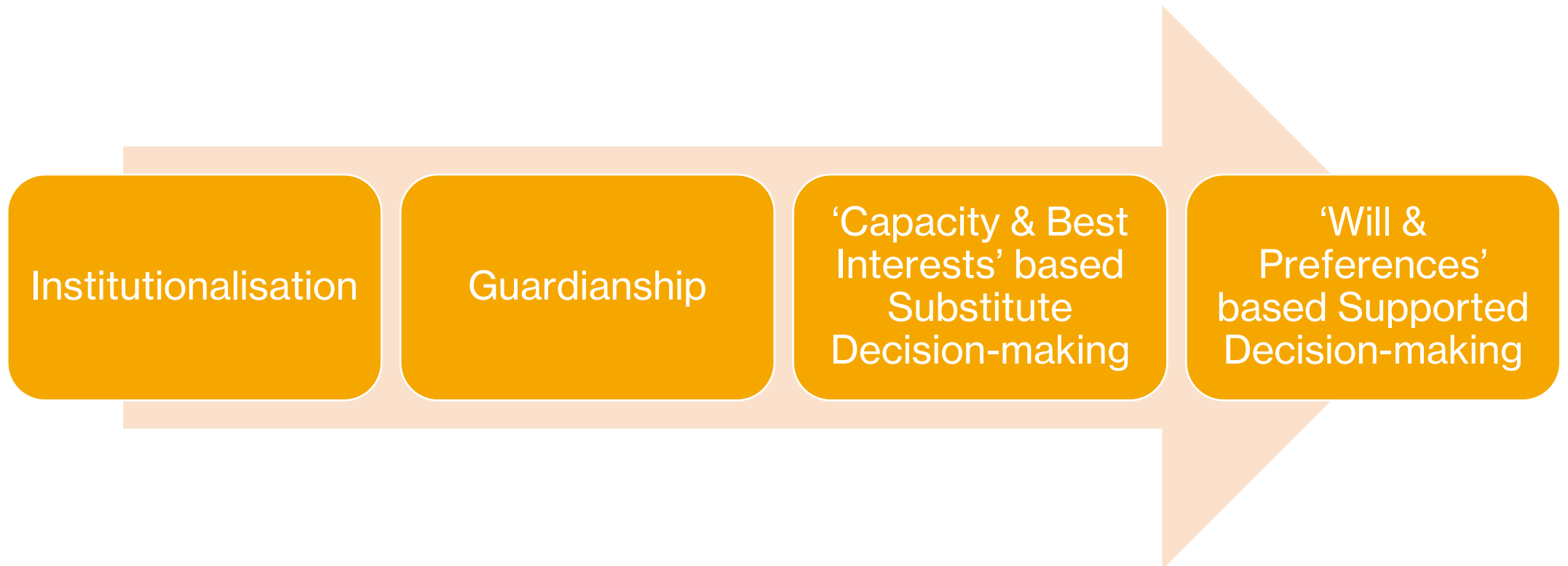
- ‘A duty to do no harm’ can mean many things:
 - With-holding something that could make someone ill
 - Not continuing treatment if burdens outweigh benefits
 - Not depriving someone of their liberty
 - Not taking away someone’s rights
 - Not making someone miserable
 - Not allowing someone opportunities to develop
 - Not preventing someone from socialising
- Who decides what ‘harm’ we should be avoiding?

Approaches to autonomy

- Varies over time – very young children have very limited capacity to exercise autonomy: the capacity develops as the child does.
- Varies across culture – some cultures treat autonomy as a property of individuals, others treat it as a property of families.



Legal frameworks: who decides what?



UN Convention on Rights of Persons with Disabilities

- Art. 10: States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.
- Art. 12: States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.