

# Supporting and promoting ethical discernment and decision making during life course transitions:

An integral part of care of  
people with intellectual and developmental disabilities (IDD)

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# Transformations in health care

**Systems Approach** considers the impact on health of the **organization of health care**

**Life Course Approach** considers the impact on health of **life stages and transitions**

**Multiple relationships**

**Changing relationships**

# Life course transitions as a developmental issue

- changes in biological, cognitive, and psychological functions and skills
- changes in social roles and expectations
- may experience loss, uncertainty, diminished self-worth, stress, and other distresses
- need to cope and adapt to new life phase for successful transition
- may require supports to do so

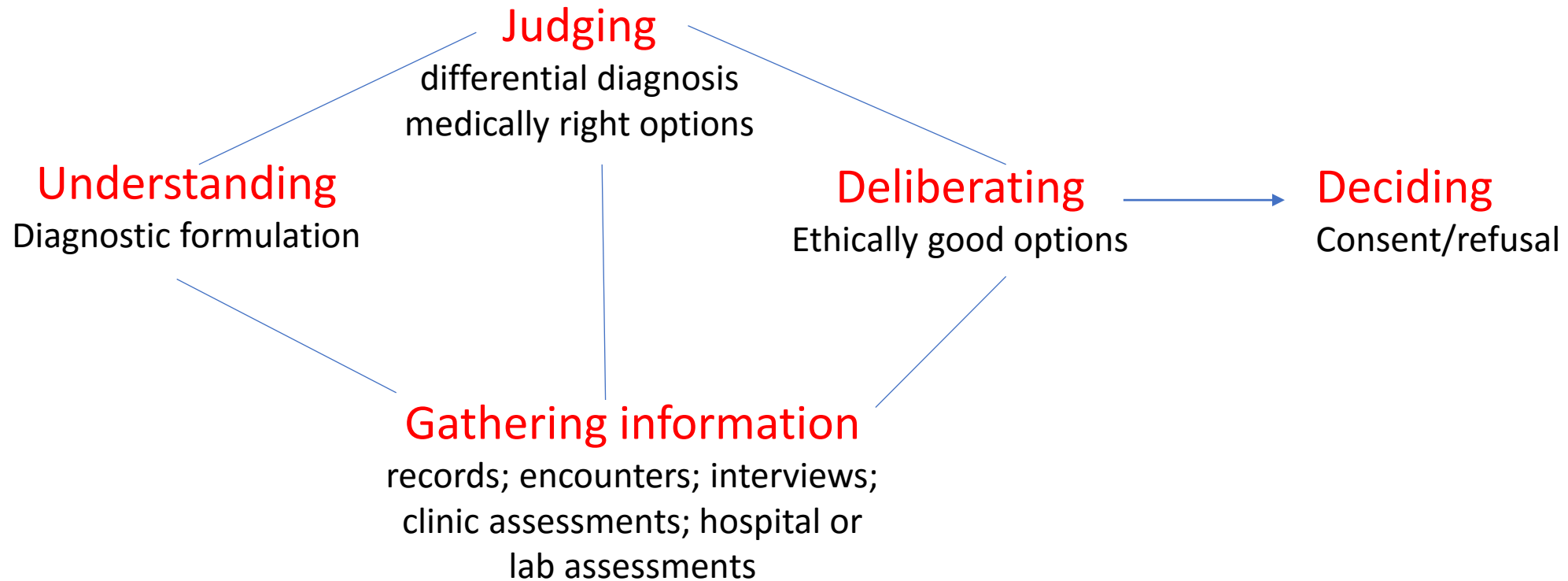
# Life course transitions as a systems issue

- Often there are discontinuities in various health care services as people transition to a new life phase
- E.g. 1, from pediatric to adult health care services
- E.g. 2, from adult or geriatric to palliative health care services
- Typically health care services are oriented to the needs of people in the general population rather than people with IDD

# Life course transitions and people with IDD

- discrepancies between chronological age and biological, cognitive or psychological changes that typically mark transitions (possibly advanced, delayed or absence of development)
- often experience changes in environments, social roles and expectations that are out of step with experience and abilities
- often experience disorientation, loss, diminished self-worth, stress and other distresses
- may be unable to communicate their distress or to do so in appropriate or safe ways
- experience significant physical and mental health problems during life phase and service transitions

# decision making



# decision making and people with IDD

- variable (cognitive and adaptive skills, experience, context, life phase)
- different capacities
- adaptation to mode(s) of communication
- assistance of family and other caregivers
- learned helplessness
- history, commitment to values
- spiritual goods

# case: Sarah

- Sarah is a 18 year-old single female with an IDD in the mild range (Age Equivalence 9-12 years old) who has a seizure disorder, lives with her parents and 1 of 3 siblings, and is completing school.
- She and her parents come to you, her new family physician, who have accepted her care from her pediatrician.
- A male friend from school, who does not have an IDD, has asked her to move in with him. He also found her work in the catering industry.
- Her neurologist has raised safety concerns regarding her plans, and her parents and siblings are divided on them.
- Sarah's case illustrates how issues related to a systems approach (pediatric vs adult generalists, adult medical vs IDD specialists, and related education, housing and employment systems) and a life-course approach (adult life phase for someone with IDD) provide contexts within which supported ethical discernment and decision-making are possible.



**Supporting decision making involves elucidating, discussing and weighing values and goes beyond assessing for legal capacity to consent.**

- ☐ **Medically right** decision(s)? [What is appropriate to do?]
- ☐ **Ethically good** decision(s)? [What ought to be done?]

Values

capable of consent

Legal standard of capacity for consent

incapable of consent

- ☐ understand information?
- ☐ appreciate consequences?

# Models of the physician-patient relationship

(Emanuel and Emanuel, JAMA Apr 22, 1992;267(16):2221-7)

- **Paternalistic Model**



- Which are medically right decisions?
- Are these also ethically good decisions? (Ought it be done?)

“FACTS”

# Models of the physician-patient relationship

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## Informative or Consumer Model



Which decisions are medically right?  
ethically good?

“FACTS”



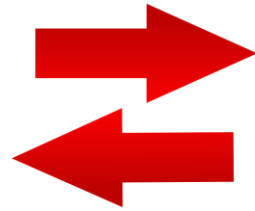
Is Which decisions are also

PATIENT  
VALUES

# Models of the physician-patient relationship

(Emanuel and Emanuel, JAMA Apr 22, 1992;267(16):2221-7)

## Interpretative and Deliberative Models



-elucidation of patient's values  
-discussion of physician's health-related values



Which decisions are medically right?

↪ Which decisions are also ethically good?

# case: Mario

- Mario is a 70 year-old single male with an IDD in the mild-moderate range (Age Equivalence of 6 to 12 years old)
- Following investigations of abdominal symptoms, he is diagnosed with pancreatic carcinoma and is likely to live 6 to 12 months with treatment
- His cancer specialist indicates that the medical evidence best supports palliative chemotherapy.
- Mario's cousin, his legal decision maker, thinks Mario should do all that is possible and is concerned that, due to his disability, this will not be offered
- Mario, however, is deeply committed to his being with his community and sticking to their daily routines, which includes communal prayer.
- Mario's case illustrates how issues related to a systems approach (generalist, specialist and palliative care systems) and a life-course approach (end-of-life phase issues for someone with IDD) provide contexts within which it is possible to support Mario's ethical discernment and decision making.