

International Interdisciplinary Seminar on Decision-making in Persons with Disabilities

Presentation Group 4 “Health care”

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CASE

- Paul J. has a **severe intellectual disability** and **no verbal communication**.

Care staff who knew him well noticed a deterioration in his behavior. In particular they noticed that he was extremely protective of his face. They suspected a toothache. However, he absolutely resisted letting anyone even come near his mouth. In attempts to find out what is wrong with him, it becomes clear that he completely resists any interference with his mouth. Later it turned out that he was indeed suffering from toothache.

The Betreuer/the guardian and the care staff ask themselves what is obliged to do.

ISSUES



Interaction



ISSUES



□

Serious health problem?

Severity?

Easiest way of examination / treatment for Paul?

Degree of mental health impact by forced treatment?

ISSUES



Do we need to act now?

When is it crucial to act?

Supported vs. substitute decision making?

Impact of PRAA ?

How to find out his (presumed) will?

Was he at any time capable of giving consent?

When is substitute decision making justified?

ISSUES



How can we communicate with him
so that he understands the situation?

How can we understand Paul?

How to overcome the barriers of communication?

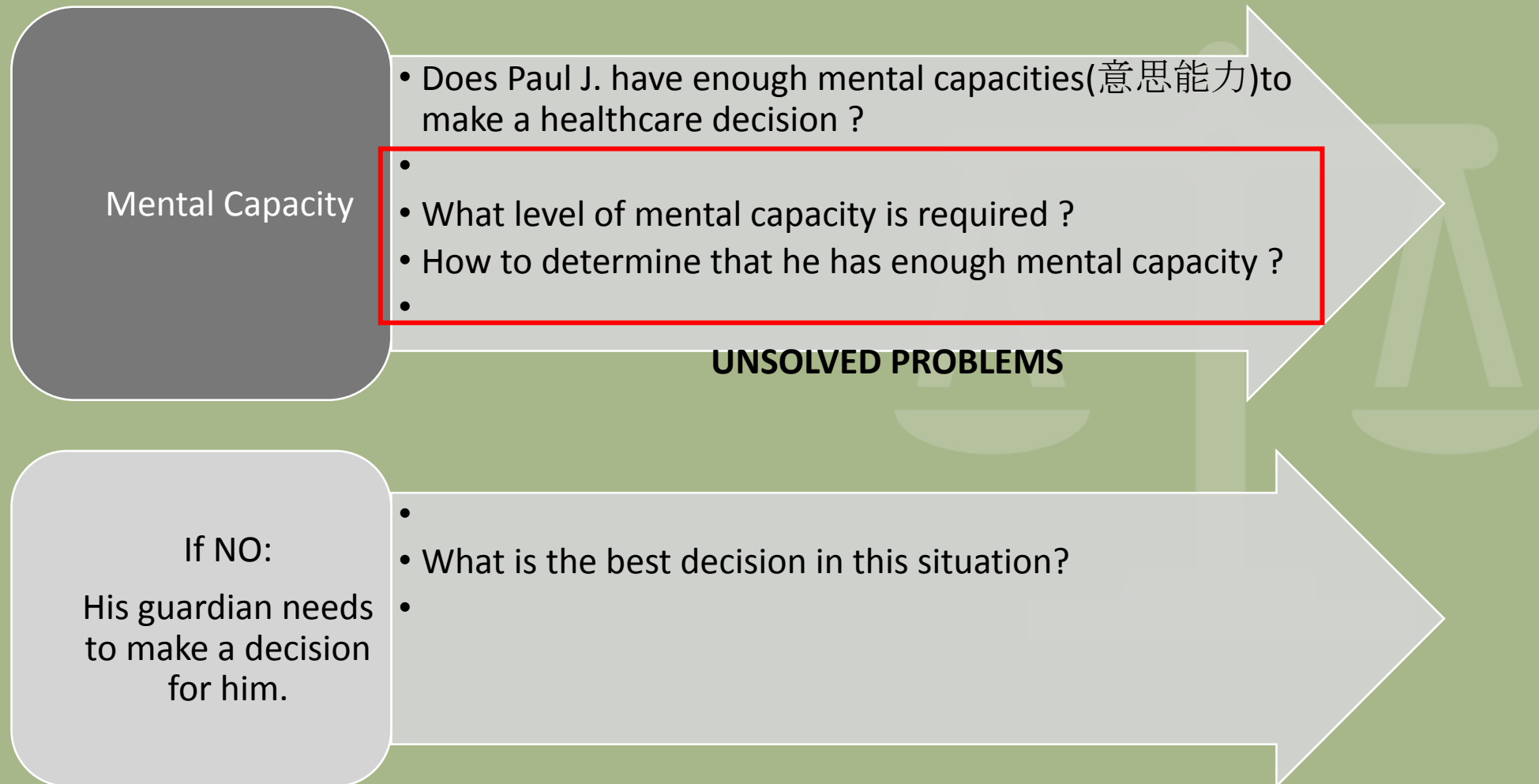
Communication of complex health informations?

Who is the best person to communicate with?

Taiwanese Law of Guardianship

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- ATTENTION !
- 1. Legal capacity \neq mental capacity
- 2. Affairs related to one's status cannot be represented by the guardian or assistant
- E.g. people without any legal capacity, as long as he/she has sufficient mental capacity, can still get married

Difficulty of a person-centered approach in Taiwan



Difficulty of a person-centered approach in Taiwan

Mental Capacity

- Does Paul J. have enough mental capacities(意思能力)to make a healthcare decision ?
- What level of mental capacity is required ?
- How to determine that he has enough mental capacity ?

If YES:

Paul J. can make a decision by himself

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- How to understand his will? → COMMUNICATION
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PRAA

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Does not change
the situation for
Paul

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Conclusion

No matter how the legal situation in Taiwan is, one should always follow a person-centered approach and implement supported decision-making

Person-centered solutions from a medical perspective

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- Specially trained dentist
- Trusting relationship with the dentist
- Organize a home visit for a basic examination
- Trusted person for company
- Avoid rushing the process
- Regular dental checks and prophylaxis
- General anesthesia?

Person-centered solutions from a legal perspective

- Supported decision making should always be implemented if possible.
- Principle of necessity
- Respect and integrate the will and wishes of Paul
- Help him understand the situation
- If it is not possible to remove the barriers of understanding, find out Paul's presumed will
- Broaden perspectives through ethical reflection
- Key-Question: **How to avoid forced-treatment**
- **Forced treatment only as a last resort!**

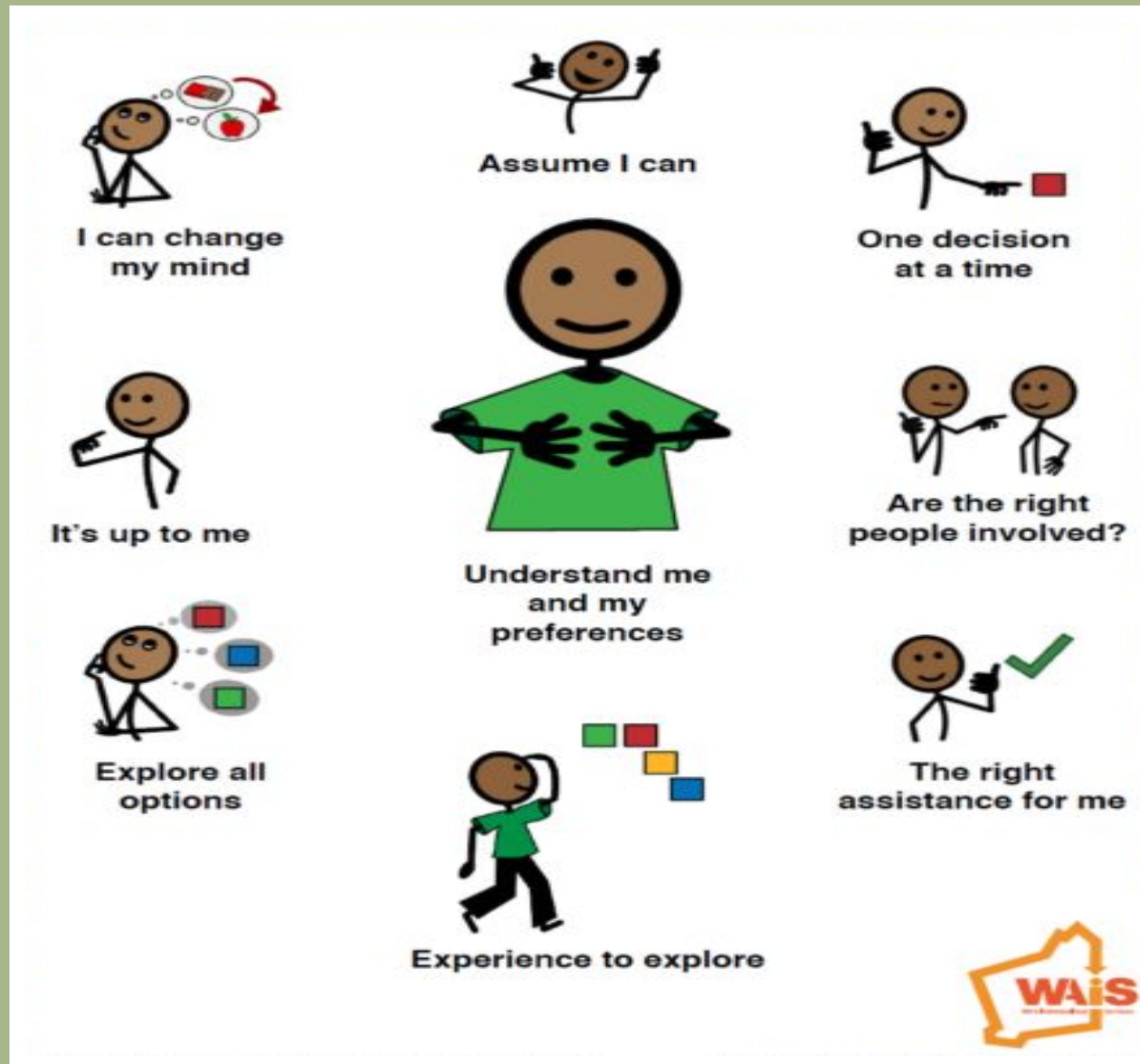
Person-centered solutions from a communication perspective

- Use AAC
- Who: People he trusts and know him well
- Build a trusting relationship
- Be careful about the setting
- Use a receptive Language
- Speak in full but easy sentences
- Try to figure out: Who the person Paul is and what he likes
- Get multiple sources of informations
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Person-centered solutions from a communication perspective

- Key Communication Criterias: Patience, Coherence, Sensitivity, Flexibility, Kindness, Objectivity
- Reflect!
- Be aware of interactional biases
- Practice “mindful attention“
- Listen to body expressions
- Make sure you have understood correctly
- **Conclusion: Less talking, more asking and “listening” (to the nonverbal)**

Principles of Supported Decision Making





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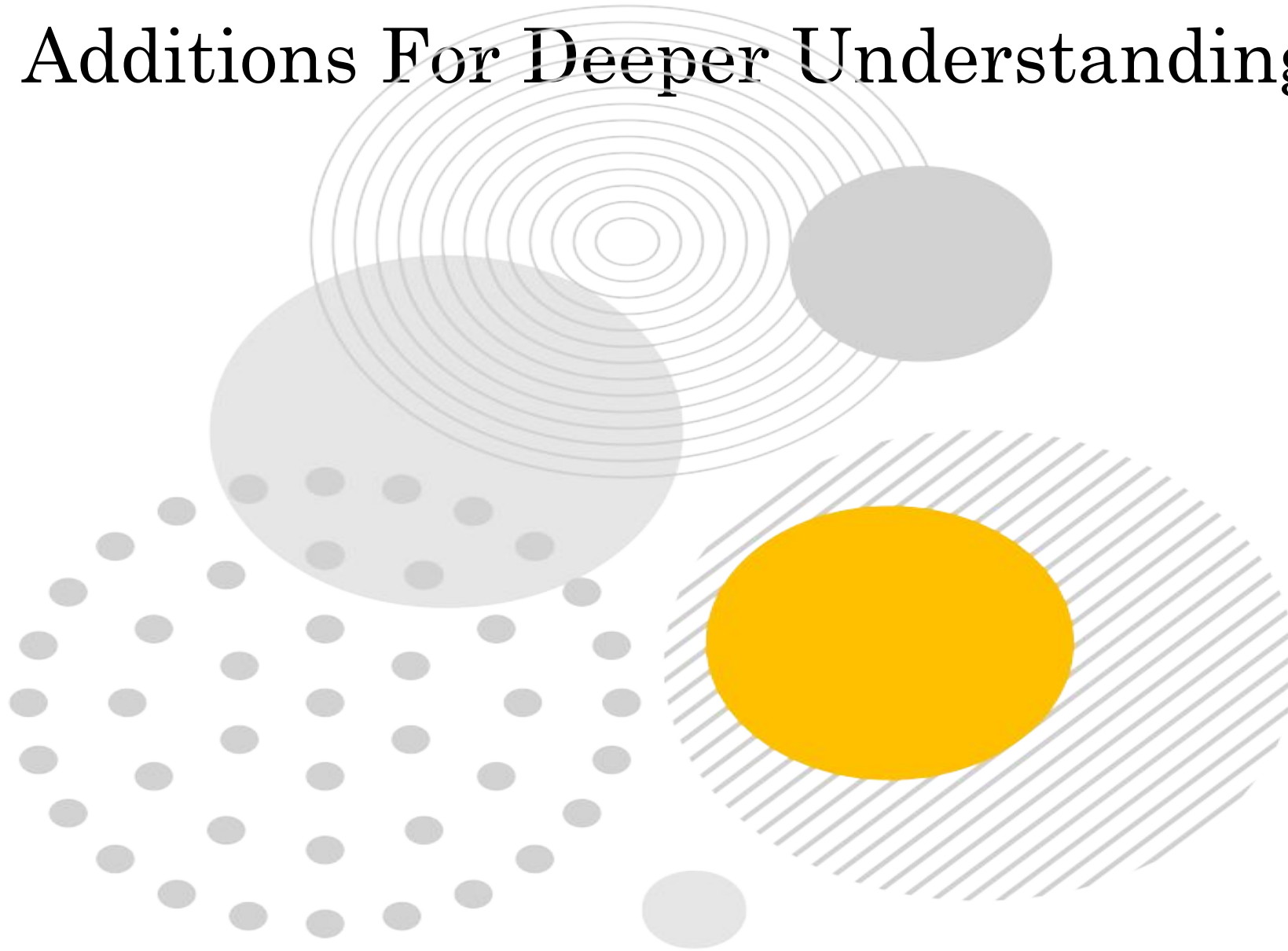
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Additions For Deeper Understanding



Basics on German Law of Betreuung

- The appointment of a Betreuer is made by a special court under participation of a medical expert and local authorities and the concerned person (if needed with special support or lawyer)

Attention ! The appointment has NO influence on the persons legal capacity!

- The Appointment is only legal when necessary
- Power of attorney & Social services gave priority over the appointment of an Betreuer
- The Betreuer has a **legal set of duties and powers** (court decision). E.g: Determination of residence, health care, Finances etc.

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Basics on German Law of Betreuung

The Person with Disabilities has the right...

- **to get support**

Persons with disabilities must be provided with access to the assistance they may need in exercising their legal capacity and ability to act.

- **of selfdetermination**

The concerned person can reject the Betreuung

But on the other hand: The person has the right **to be safeguarded if necessary**

- Only under very **certain conditions** (§1906a civil code) is forced treatment possible

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Basics on Taiwanese Law of Guardianship

- Classified into 2 types: Guardianship and Assistance, both lead to different effects
- Guardianship: Complete denial of legal capacity WITHOUT ANY EXCEPTION (§15).
- Assistance: Person under assistance has own legal capacity on affairs relating to pure legal benefit or the necessity based on the person's age, status, and daily life.(§15-2)

→ AFFECTS LEGAL CAPACITY

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Basics on Taiwan Law of custody

Attention !

1. Legal capacity ≠ Mental capacity (意識能力)
2. Affairs related to one's status (身分行為) can't represent by guardian or assistant.

eg. People without any legal capacity, as long as he/she has sufficient mental capacity, can still get married.

Basics on Taiwan Law of custody

- Mental capacity is a factual problem, depends on one's mental state
- Is health care decision a financial affair (whether or not to enter into a contract or what's the content of the contract)

OR

an affair related to one's status (related to his/her own health)