

# FAMILY PLANNING

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## FAMILY PLANNING

Sophie is 23 years old and has Down syndrome. She lives with her parents and works in a facility for people with disabilities. Her mother is the Betreuerin (appointed by court) in the matters of property and health care, as well as authority matters – or her mother is the assistant (appointed by the court). Sophie met 27-year-old Luis H. at her workplace. The two fell in love and have a relationship. Sophie's mother is very worried that **her daughter might get pregnant** and then **she would have to take care of the child**. She wants to **prevent pregnancy** at all costs and wonders if **sterilization** or another **contraceptive method** is possible as a precaution, or if she could **stop the contact** between her daughter and her boyfriend altogether.

Sophie and Luis H. say they want to **have sex**. They also want to **live together** and are considering **marriage**. Luis H. also has Down syndrome and lives in an assisted living facility. He has a professional Betreuer in the matters of property and health care, as well as authority issues – or he has an assistant.

**What questions arise?**

**How can Sophie and Luis H. be supported so that their wishes are fulfilled?**

**What role do both Betreuer/both assistants and their concerns play?**

## WHAT QUESTIONS ARISE?

### WISHES OF SOPHIE AND LUIS

- Is it possible for Luis and Sophie to live together and marry?
- How should Luis and Sophie be sexually educated?

### CONCERNS OF SOPHIE'S MOM/BETREUER

- Is it possible to prevent contact / pregnancy as a Betreuer?
- Under which circumstances is sterilization an option?
- Which contraceptive methods could be a less invasive alternative?
- What are the options of parenthood / childcare for Sophie and Luis?

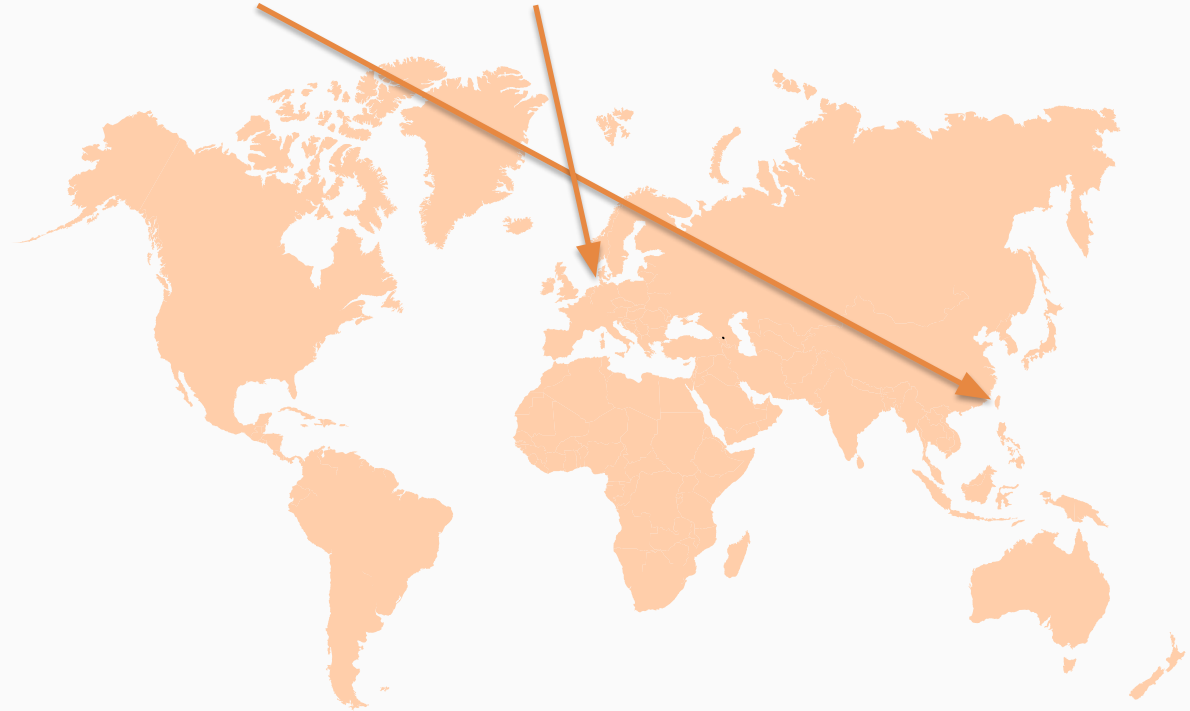
- What are the conditions of Down syndrome?
- How are the situations in Taiwan & Germany for people with Down syndrome?
- How can Sophie and Luis H. be supported so that their wishes are fulfilled?**
- What role do both Betreuer/assistants and their concerns play?**

- Down Syndrome
- Situation of people with Down Syndrome in Taiwan & Germany
- Living arrangements & marriage
- Communication & supported decision making
- Sterilisation
- Sex Education
- Parenthood & Childcare
- References

## DOWN SYNDROME

- Combination of mental retardation & physical malformations in varying degrees and severity
- People with Down Syndrome tend to be born with other diseases, such as:
  - heart defects
  - poor immune function
  - epilepsy
  - higher chance of dementia
- Fertility
  - Men with Down Syndrome: usually can't father children
  - Women with Down Syndrome: low fertility rate (30 - 50%)
  - If parents have Down Syndrome, their children have about 50% of having DS

# SITUATIONS IN TAIWAN & GERMANY





## TAIWAN

- ~ 30.000 people with Down syndrome
- primarily grow up & live with own families (instead of in institutions)
- majority of people with Down syndrome now in Taiwan are of middle or old age
  - Reason: they were born before the Amniocentesis became widely accepted
- primarily work in factories / shops for people with Down syndrome
- almost impossible to work in normal workplace

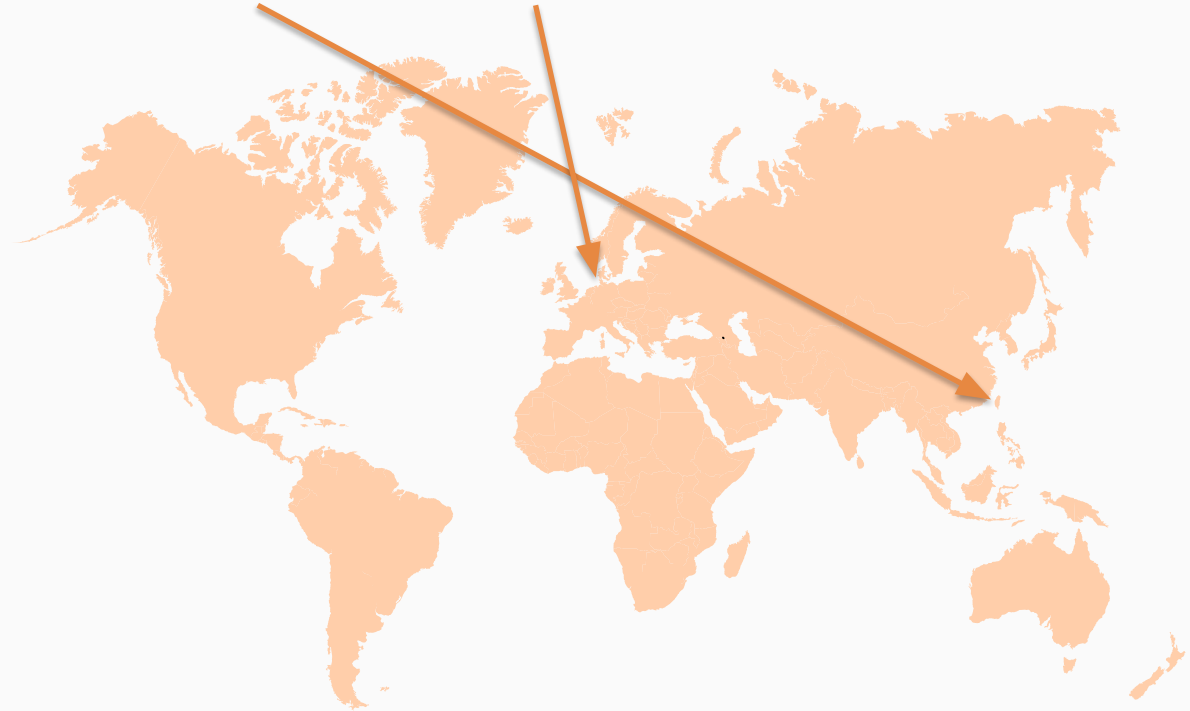


## GERMANY - 2014/2016

- 50.000 people with Down syndrome
- 60 % of people with intellectual disabilities live with parents or relatives
- alternative: residential institutions for the disabled
  - Only a few live on their own with personal assistance or independently
- about 700 workshops for people with disabilities
  - ~ 70 % employees have an intellectual disability
- Less than one percent of people with down syndrome work in the first labor market

(de Braganca 2021; BAGWFBM 2020)

# COMMUNICATION & SUPPORTED DECISION MAKING IN TAIWAN & GERMANY







## TAIWAN

### Guardianship

Civil Code

Art. 1112 When enforcing guardianship **relating to the ward's life, treatment, and financial management, the guardian shall respect the ward's intent.**

→ **lack of legal capacity**

### Assistance

Civil Code

Art. 15-2 A person under assistance **must obtain the consent of his/her assistant** if he/she intends to perform any of the following acts; provided, however, that, this shall **not apply** to any act relating to pure legal benefit or the necessity based on the **person's age, status, and daily life**

→ **person under assistance can ask for permission in court, when consent is not given by assistant**



## GERMANY

§ 1901 Civil Code

(2) The Betreuer shall attend to the affairs of the person being cared for **in such a way as is in his or her best interests**. The **welfare** of the person being cared for also includes the possibility of **shaping his or her life** according to his or her own wishes and ideas within the scope of his or her abilities.

(3) The Betreuer **shall comply with the wishes of the person in care insofar as this is not contrary to his or her best interests and is reasonable for the guardian**. This shall also apply to wishes expressed by the person under care prior to the appointment of the Betreuer, unless it is evident that he does not wish to adhere to these wishes. **Before the Betreuer deals with important matters, he/she shall discuss them with the person under guardianship, provided this does not run counter to his/her best interests.**

# CLARIFY THE REAL WISHES OF SOPHIE AND LUIS

## STEP 1: GETTING TO KNOW THEM

- understand their style of communication (e.g., their wording) from their surroundings

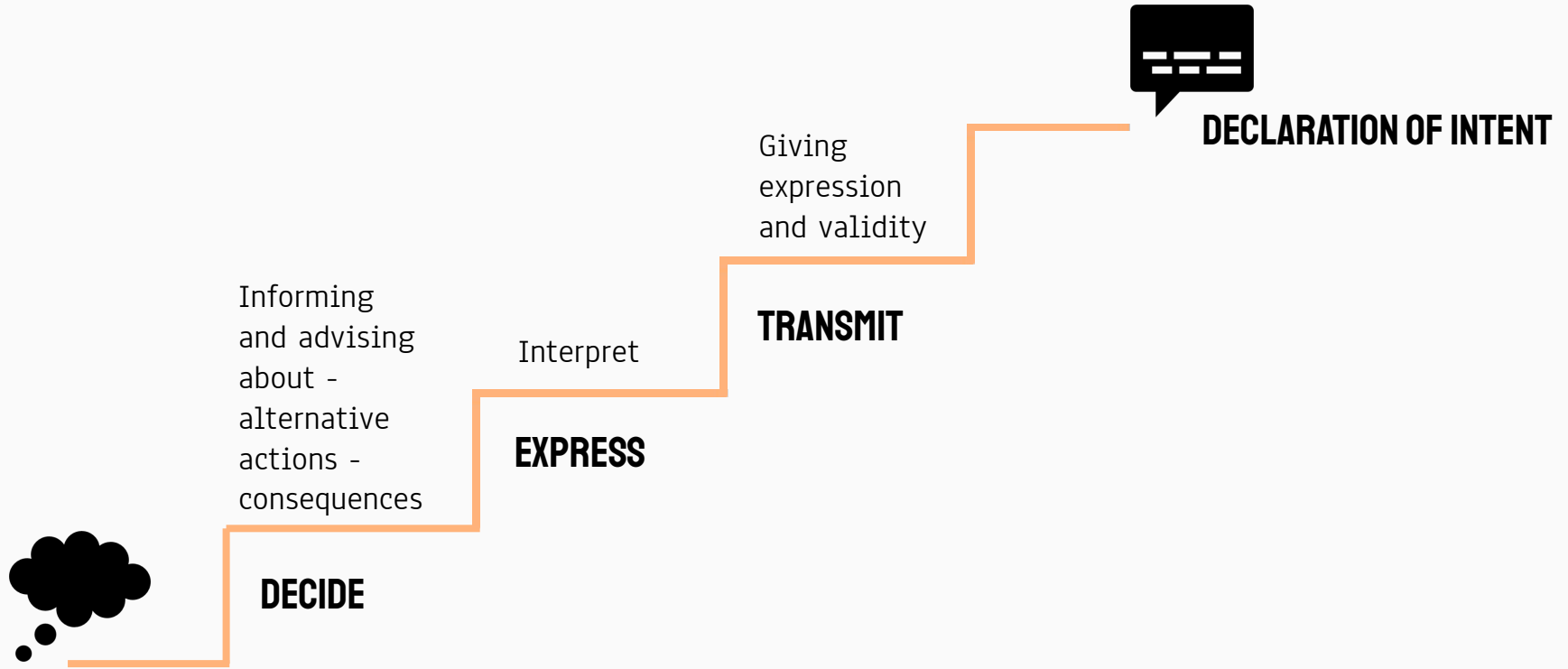
## STEP 2: BUILDING RAPPORT

- make sure to communicate without judgement / presumption
- be prepared to patiently listen to them

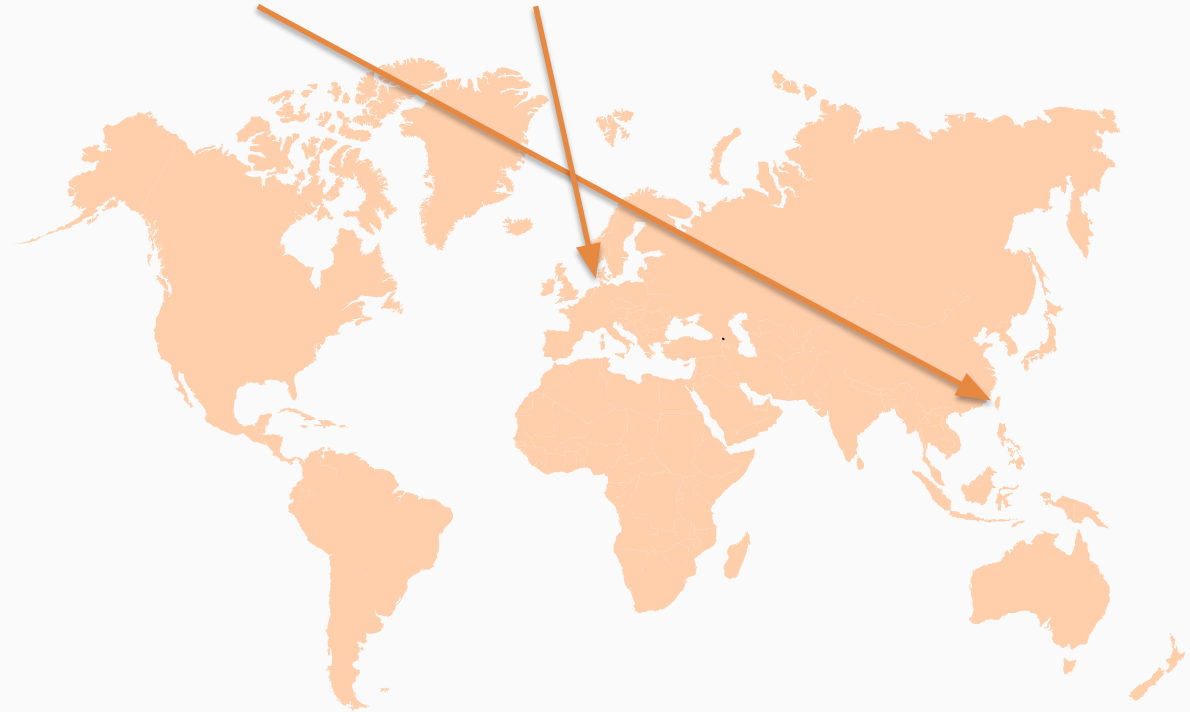
## STEP 3: LISTENING WHILE MAKING SURE THERE IS NO MISUNDERSTANDING

- formulate questions in their language
- listen, respond, and ask questions to confirm if you understand correctly

# STEPS TO SUPPORT THE EXERCISE OF LEGAL CAPACITY



# LIVING ARRANGEMENTS IN TAIWAN & GERMANY





## TAIWAN

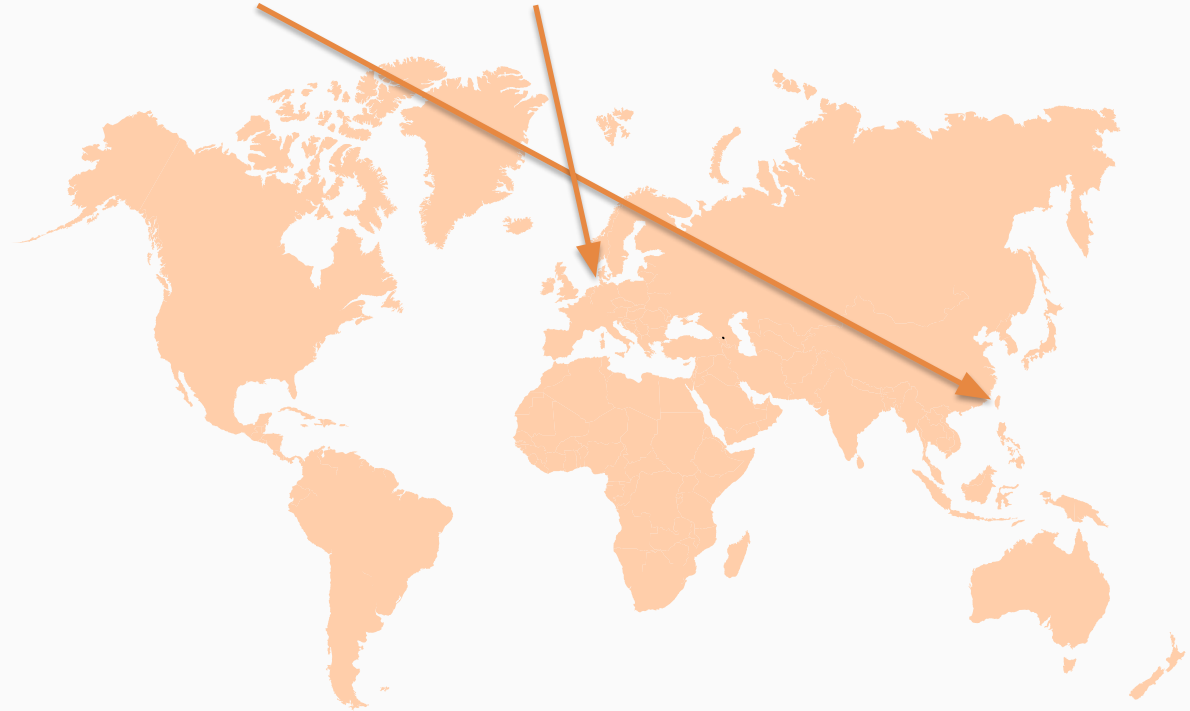
- living with family
- living in facilities (for people with mental disabilities):
  - private facilities with subsidy
  - private facilities without subsidy (Long-Fa Hall)
  - religious institutions



## GERMANY

- living with family
- living on their own
- inpatient facilities or outpatient support (Caritas Deutschland, 2021)
  - individual design of possible offers of assistance
  - Social welfare agency assumes living costs
  - clients are taken into account from a certain income level

# MARRIAGE IN TAIWAN & GERMANY





## TAIWAN

§ 982 Civil Code: A marriage shall be effected in writing, which requires the signatures of at least two witnesses, and by the registration at the Household Administration Bureau.

- Whether a person under guardianship or assistance is capable of entering a marriage legally is controversial under the current Civil Code.
  - Guardianship: subject lacks legal capacity
  - Assistance: requires assistant's consent for certain legal actions (does not include marriage, §15-2)
- The Civil Code's restriction on the subject's expression of intent and juridical acts should not extend to actions and decisions core to the dignity of a human being, such as marriage.



## GERMANY

§ 1304 Civil Code: a person who is legally incapable cannot enter into marriage

- Establishment of a Betreuer does not affect the legal capacity
- Person under guardianship is capable of entering into marriage depending on his or her natural legal capacity within the meaning of § 104 No. 2 of the Civil Code
- Marriage is a highly personal legal transaction in which the Betreuer cannot, in principle, represent the person under guardianship
- A reservation of consent cannot relate to marriage, § 1903(2) Civil Code

# STERILIZATION IN TAIWAN

## Genetic Health Act

A **married man or woman** may, **on his/her own accord** and **subject to his/her spouse's consent**, receive ligation, provided that ligation may be imposed **straight on his/her own accord** if anyone of the following conditions founded through diagnosis or certification:

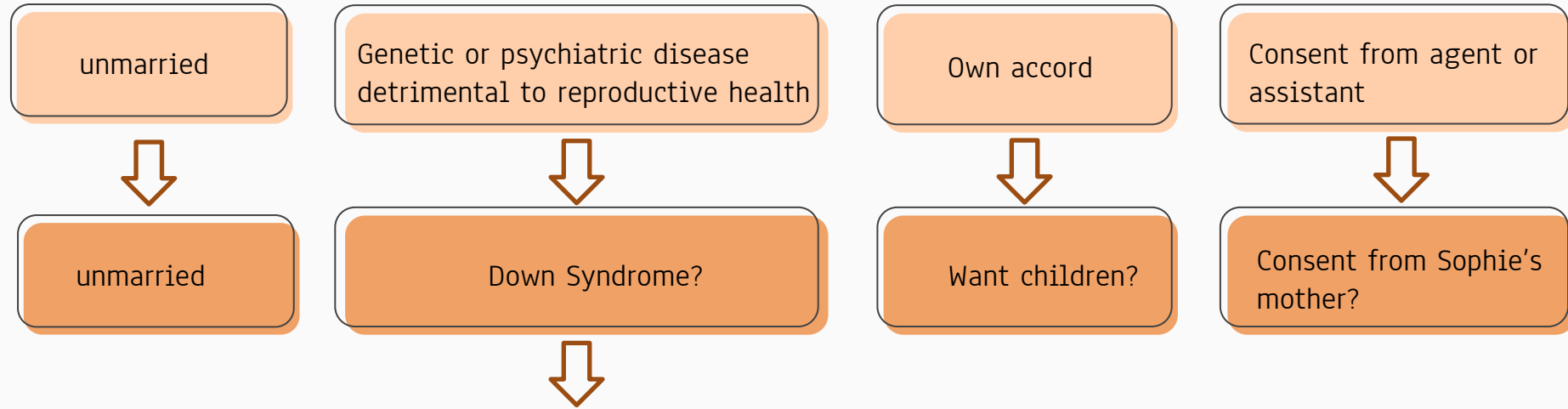
1. **She/he** or her/his spouse acquires **genetic, infectious or psychiatric disease detrimental to reproductive health.**
2. (omitted, unrelated)
3. Her or His wife's pregnancy or delivery is **endangering the mother's health.**

**An unmarried man and woman meeting any one under provision above** may receive sterilization **straight on his/her accord**; **an unmarried minor or a person under guardianship or assistance shall be subject to consent from his/her statutory agent or assistant** before receiving sterilization.



# GENETIC HEALTH ACT

However, in reality, the subject's wishes are often overridden by the guardian's consent.



The scope for persons suspected to have genetic defects , infectious diseases or mental illness referred to in this Act is as follows:

1. ...
2. Persons who are suffering from **severe mental retardation** or schizophrenia and are therefore **incapable of taking care of a baby**.
3. Persons who may **transmit abnormal chromosomes or genes** to future generations, such as patients suffering from **Down syndrome** or Huntington's disease.

# STERILIZATION IN GERMANY

§1905 BGB

(1) If the medical intervention consists of a sterilization of the person under care, to which the person under care cannot consent, the guardian may only consent if

1.the sterilization does not contradict the **will of the person under care**, ...

3.it can be assumed that a pregnancy would occur without the sterilization,

4.as a result of this **pregnancy a danger to life** or a danger of serious impairment of the physical or mental state of health of the pregnant woman would be to be expected, which could not be averted in a reasonable manner, and

5.the pregnancy cannot be prevented by other reasonable means. ...

(2) The consent shall require the **approval of the guardianship court**.

*"And that's part of the big problem to fix that, because I want to **have more social experience with dating**. Getting together with boys is okay as friends. But girls, getting to know them, I'd be happy to do it. ... But, I would like to keep my experience up by dating again and now I'm making decisions of what my values are and what kind of things and responsibilities for me to do in the future of marrying Tami. It's premature but it's okay ... after you have the experience to decide if you want to get married."*

## SEX EDUCATION AND CONTRACEPTION

*Count Us In: Growing Up with Down Syndrome.*

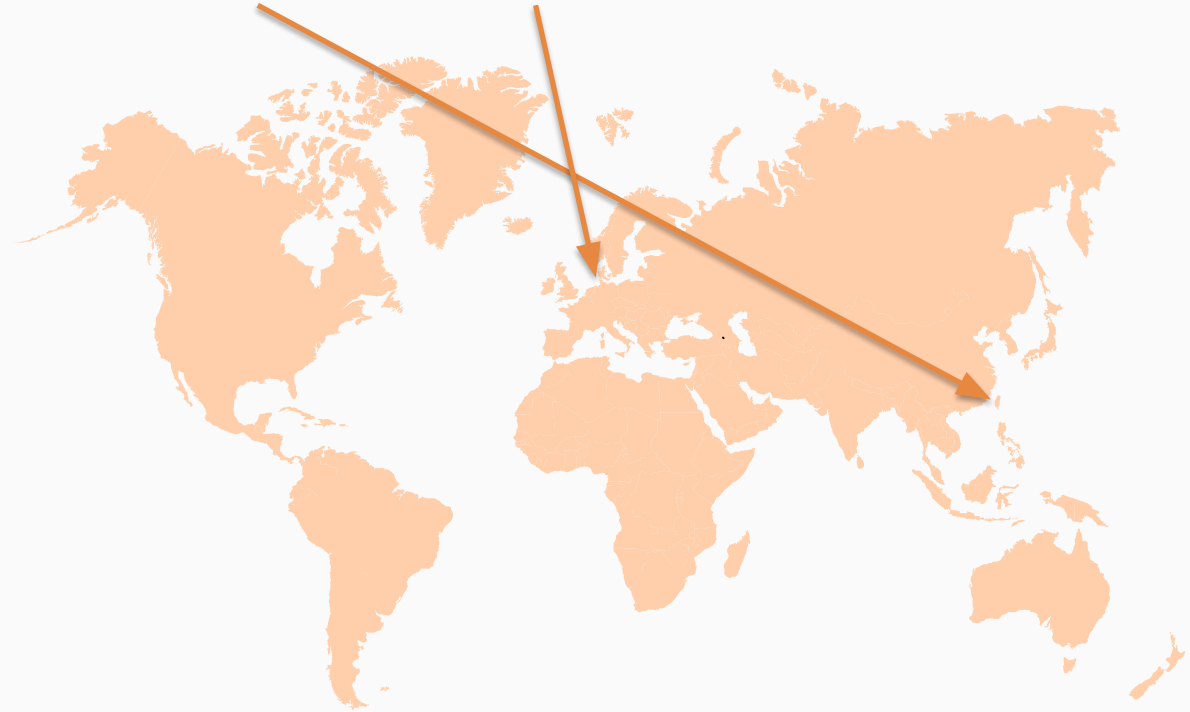
## PEOPLE WITH DISABILITIES RIGHTS PROTECTION ACT (TAIWAN)

Art. 8 To **prevent and reduce the occurrence of disability**, the competent authorities in charge of related services in all levels of governments hierarchy shall **systematically promote the prevention of disability, propagandize the knowledge of eugenics, health care education on disability-related heredity**, morbidity/disease, disaster, environmental pollution, etc. In addition, they also shall promote the related propaganda and social education.

# SEX EDUCATION AND CONTRACEPTION

- If the topic of sexuality has not been dealt with (sufficiently) sex education is always an issue in adulthood:
  - sex education, which prepares for sexual maturity in a positive way, can motivate young people and adults with intellectual disabilities to **take responsibility** for contraception
  - they should **learn the correct terms** for the sex organs and not any trivializing terms: it is easier to explain what exactly happened e.g. in cases of sexual assault
  - educators or parents should **discuss and practice** with young people "How do I show someone that I like them? Where can I touch someone?"- "Where can someone touch me?"
  - with regard to contraception, it is important to consider how much **personal responsibility** people with disabilities can take, if medications must be taken, which could possibly **impair** the effect of contraceptives and that contraception is always a matter for **both partners**  
(cf. pro familia 2007, p. 8-13)

# PARENTHOOD & CHILDCARE IN TAIWAN & GERMANY





## TAIWAN

childcare support for disabled parents

- Long-term home care: does not extend to childcare
- Long-term medical care: does not extend to children of the disabled
- Facility support for Disabled:
  - Inadequate for disabled parents
  - Focused on specific physical disabilities

(郭惠瑜, 她們不配當媽媽? ——被遺忘的身心障礙女性家庭照顧者, 2017/05/14, <https://www.twreporter.org/a/opinion-disabled-women-caregiver>)



## GERMANY

- special projects in Germany for outpatient or inpatient "accompanied parenthood", depending on the need for help

- But these are **exceptions**: the social framework conditions for intellectual disabled parents are not present to a sufficient extent

(cf. pro familia 2011, p.15)

- e.g. Pilot project in NRW, for parents with disabilities or those who want to become one: 'Assisted parenting' (<https://begleitet-e-elternschaft-nrw.de/>)

## CONCLUSION

**1.**

A prohibition of contact between Sophie and Luis is not an option.

**2.**

Options for living arrangements and family starting should be presented to Sophie, Luis and their parents for supported decision making.

**3.**

Sophie's wishes must be respected regarding marriage and sterilization.

**4.**

Sex education tailored to Sophie and Luis's needs should be given.



## Problems in the current framework

1

There is a lack of adequate living arrangement and parenthood support options for people with Down syndrome.

2

There is a lack of sexual education resources for people with Down syndrome.

3

Insufficient respect for and/or trust in the will of people with Down syndrome.

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# DISCUSSION

## QUESTION 1

Have you ever encountered / known anyone with Down syndrome forming a family?  
What kind of difficulties do you think they might encounter?

## QUESTION 2

Should the court play a role in deciding whether a person under guardianship could  
get sterilized?

## QUESTION 3

What questions do you have?