



Interdisciplinary Seminar on Decision-Making in Persons with Disabilities

GROUP 6

Marvin Büsselmann, Michaela Friedrich
Chi-Jean Tang, Shao-Chia Li, Yi-Sheng Tseng



Dementia and refusing care

Tina W. with dementia is fiercely independent. Above all, she insisted upon remaining in her own home. She believed that she could cope without assistance, and refused to admit carers. In fact, only with such care could she be sustained in her own home. Her son sought a court order. Tina W. declared that she much loved her son, but did not need a representative and did not wish him to be appointed. The son was appointed as a Betreuer with powers to ensure that carers would be admitted and could properly perform their functions – or the son is appointed as an assistant, because otherwise her overriding desire to remain in her own home would not be sustainable.

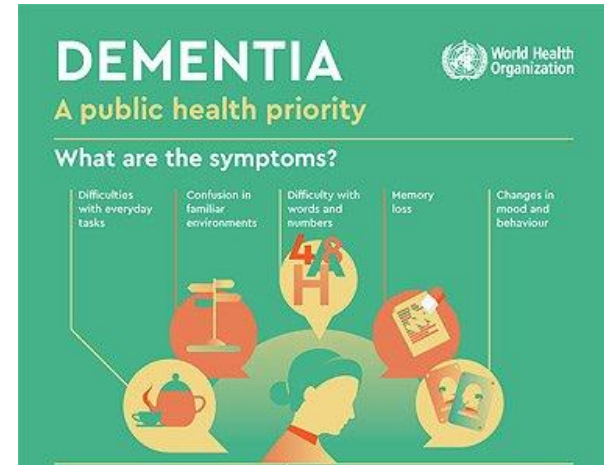
The Betreuer or the assistant asks himself what is obliged to do.

Structure

- Introduction of dementia
- Legal background in Taiwan and Germany
- Care services and situations of people in need of care in Taiwan and Germany
- Taiwanese and German solutions for the case

Introduction to Dementia

- Common symptoms
 - Attention deficiency
 - Can't remember things clearly
 - Unhygienic behaviour
 - Resist other's care



resource: https://www.who.int/mental_health/neurology/dementia/infographic_dementia/en/

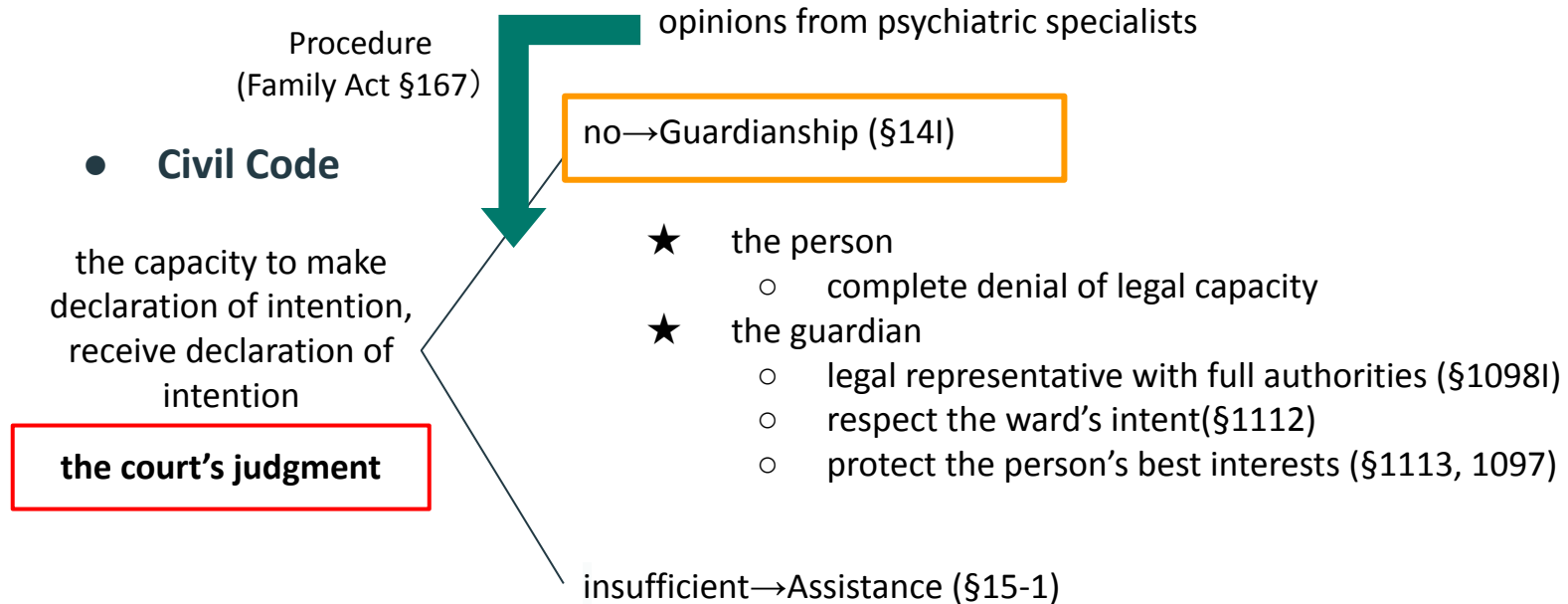
CLINICAL DEMENTIA RATING (CDR)

CLINICAL DEMENTIA RATING (CDR):	0	0.5	1	2	3
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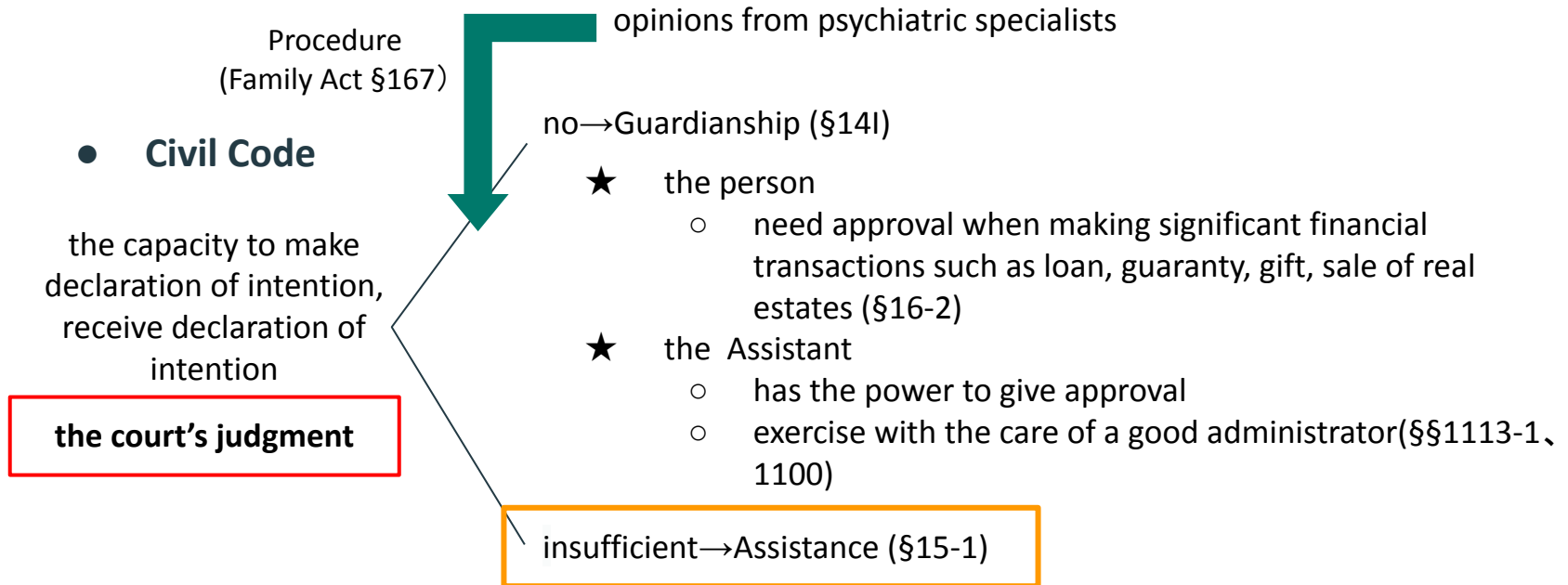
	Impairment				
	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Memory	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Fully oriented	Fully oriented except for slight disorientation with respect to time (when events happened in relation to each other)	Moderate disorientation with respect to time (when events happened in relation to each other); oriented for place at examination; may have geographic disorientation outside the place of examination	Severe disorientation with respect to time (when events happened in relation to each other); usually disoriented to time, often to place	Orientated to person only
Judgment & Problem Solving	Solves everyday problems & handles business & financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
Community Affairs	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal to the casual observer	No possibility of independent function outside home Appears well enough to be taken to functions outside a family home	
Home and Hobbies	Life at home, hobbies, and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult tasks abandoned; more complicated hobbies and interests abandoned	Only simple tasks preserved; very restricted interests, poorly maintained	No significant function in home
Personal Care	Fully capable of self-care		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal belongings	Requires much help with personal care; frequent incontinence

Score only as decline from previous usual level due to cognitive loss, not impairment due to other factors.

Legal background in Taiwan



Legal background in Taiwan

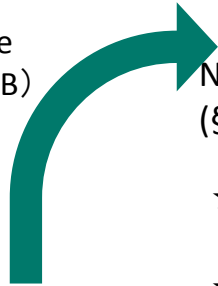


Legal background in Germany

Procedure
(§ 1896 BGB)

- **Civil Code**

Cannot take care of his affairs, by reason of a mental illness or a physical, mental or psychological handicap



Judgment of the supervisory court :

No free will of the adult or approval → Betreuung (§1896 Ia BGB) for **required** areas of responsibility

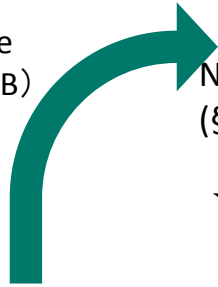
- ★ the person
 - needs support for all or some of his affairs
- ★ the Betreuer
 - has to protect the welfare of the supervised, but should consider his own wishes and ideas (§ 1901 II BGB)
 - must comply with wishes to the extent that this is not inconsistent with the person's welfare and is reasonable for the Betreuer (§ 1901 III BGB)
 - must inform the court of any changes in the need for Betreuung (§ 1901 V BGB)

Law background in Germany

- **Civil Code**

Cannot take care of his affairs, by reason of a mental illness or a physical, mental or psychological handicap

Procedure
(§ 1896 BGB)



Judgment of the supervisory court

No free will of the adult or approval → Betreuung (§1896 Ia BGB) for **required** areas of responsibility



the court

- must appoint a suitable person (§ 1897 I BGB)
- appointment should consider suggestion of supervised (§ 1897 VI BGB)
- if there is substantial risk or danger to the person or the property ► **reservation of consent** (§ 1903 I BGB)

Care services in Taiwan

- Percentage of population over 65: 14.6% (2018), 20.1%(2025)
- Care Services - the gloomy fact
 - overloaded environment in nursing home; few spots left in ones with good quality care
- Long-term Care Plan 2.0 (2017-2026)

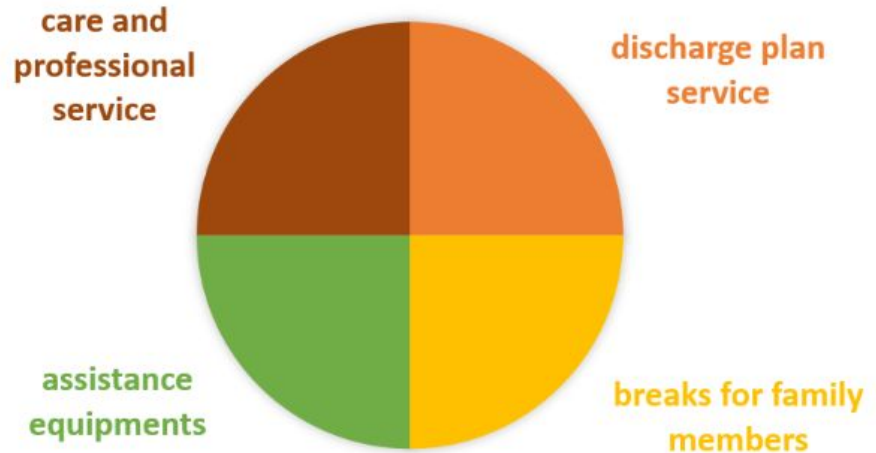
Long-term Care Plan 2.0 in Taiwan -1

Who can benefit?

	% of total population
people with dementia and aged over 50	≈0.53
people with frailty and aged over 65	≈2
people with disability	≈0.46
people with functional limitations and aged over 65	≈0.07
indigenous people with functional limitations and aged over 55	≈0.03

Long-term Care Plan 2.0 in Taiwan -2

- What are provided?
- Criticism






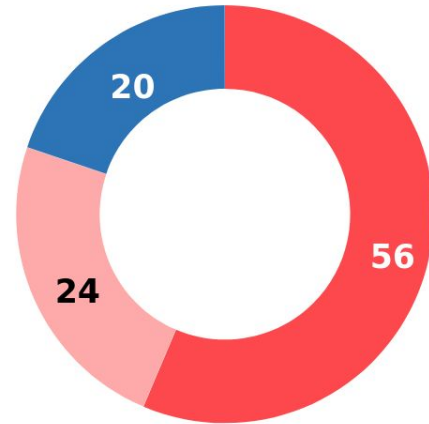
Care Services in Germany

- Task of the care services
 - support concerning personal hygiene, organisation of the daily life, medication administration, housekeeping
 - visit the persons in need of care at home

Persons in need of care by type of care (Germany)

4.1 million persons in need of care (2019)

-  provided at home (mainly by relatives)
-  provided at home (nursing/care services)
-  living in residential homes



Taiwanese solution

CDR®
Clinical Dementia Rating Assessment Protocol

CLINICAL DEMENTIA RATING (CDR)

Patient's Initials _____

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Home and Hobbies	Life at home, hobbies, and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult tasks abandoned; more complicated hobbies and interests abandoned	Only simple tasks preserved; very restricted interests, poorly maintained	No significant function in home
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Score only as decline from previous usual level due to cognitive loss, not impairment due to other factors.

Can Tina make her decision? from the aspect of law

- Tina's condition
 - Score 2 in CDR
 - Severe memory loss
 - Social participation is impaired
- Court's judgement
 - Appoint a guardian for Tina though she doesn't want one
- Result
 - Respect Tina's wish only if it doesn't contradict with her best interests
 - Her guardian can allow carers entering her home on her behalf
 - disregard Tina's individual autonomy (CRPD12 IV)

Discussion with Tina -Taiwanese solution

- Cultural aspect: nursing homes in Taiwan
- Three probable reasons why she might insist on staying at home
 - collective society: “Your sons/daughters are unfilial. ”
 - social support : unwillingness to live in a new environment

e.g. “My friends are not there”, “There is no park where I am used to go to every morning.”

- financial burdens: “It costs too much.”

Discussion with Tina -Taiwanese solution

1. She could remain in her own home with some extra care:
 - Long-Term Care 2.0 in Taiwan
 - Supportive Decision Making: accompany her to make her home safe and meaningful

1. She couldn't remain in her own home even if there were extra cares:
 - How to guide her to adapt into a new environment

Discussion with Tina -Taiwanese solution (the option of remaining at home)

- Be patient
 - Give her adequate time to adapt to new people
- Provide mental support
 - Let Tina know her family is aware of her feelings instead of making demands of her
- Give respect
 - Treat Tina as a mature adult ,not a child beacuse she has dementia

Discussion with Tina -Taiwanese solution (the option of moving to a nurshing home)

- Culture
 - Show empathy and express children's concerns
- Social support
 - Provide examples that there are other friends who are happy in the home
- Economic
 - Tell Tina that the government will provide financial subsidy, so she can be less concerned

Discussion with Tina -Taiwanese solution (moving to a nursing home)

- More visits
 - At the beginning, visit her more to reduce her anxiety
- Familiarity
 - Bring some familiar items in Tina's original home to the nursing home.
 - E.g.: Family photos
- Friends
 - Try to choose a nursing home where there are already Tina's friends if possible.

Discussion with Tina - German Solution

- son wouldn't be a betreuer according to Tina 's wish § 1897 para 4 BGI
- betreuer **should get to know** Tina
- betreuer has to **give information** about his task as betreuer
 - betreuung is only about to make sure that nursing service gets acces (§1897 para 2 BGB)



Discussion with Tina - German solution

- betreuer has to **explain** the task of the care service
- there are **not just negative** but also positive **consequences to be supported** by a care service
- betreuer should give Tina the **opportunity to choose** the care service (1901 para 3 BGB)

Conclusion



- in both solutions:
 - it's **up to Tina** and also up **to the applied SDM** of the betreuer or guardian **if she can stay** at home and accept the care service **or if she has to move** into a care facility

References

https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Pflege/_inhalt.html;jsessionid=DAB5FC04D13C6806F20E2111A308C5A2.live722#sprg235892 (access 02.06.2021)

https://www.pflege-durch-angehoerige.de/haeusliche-pflege/ambulanter-pflegedienst/#Welche_Aufgaben_uebernehmen_mobile_Pflegedienste (access 10.06.2021)

Picture Sources

<https://de.dreamstime.com/stockbild-geben-von-informationen-image4374931> (access on 10.6.2021)

https://www.google.com/search?q=supported+decision+making&tbm=isch&ved=2ahUKEwi0md3S4YzxAhXYqgQKHTToAwgQ2-cCeqQIABAA&og=s_supported+decision+making&gs_lcp=CgNpbWcQAziECAAQEzoECAAQZoFCAAQsQM6AggAOqglABCxAxCDAToECAAOHlD1KVj6Z2C6bWgAcAB4BYAB8Q-Ia9rkqETMC42LjUuMS4yLjMuMy4yLjEuMzgB AKABAaoBC2d3cy13aXotaW1nsAEAwAEB&scient=img&ei=u9zBYPTPC9iFkgW00I9A&bih=759&biw=1528&client=ubuntu&hs=tlf#imgsrc=aH6jhQYemhVW8M (access on 10.6.2021)