

Swedish "God man"

– An unique supported decision making system – but does it work?

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Magnus Tideman Halmstad University Sweden

Support and services

- Shared responsibility: the state, the 21 county councils and the 290 municipalities (strong self-government)
- Social Service Act, Health and Medical Services Act
- The act concerning support and services for persons with certain functional impairments Applies to:
 - people with an intellectual disability, autism or a condition resembling autism
 - 2. people with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness
 - 3. people who have other major and permanent physical or mental impairments which are clearly not due to normal ageing and which cause considerable difficulties in daily life and consequently an extensive need of support and service.
 - Total: ~ 100 000 (group 1: 50 %, group 2: 6 % and group 3: 44 %)
 - 10 different measures available



Equal living conditions, a good life and full participation

- People with disability should live a normal life together with non-disabled people
- All humans are legal subjects
- Shall be treated the same, have the same rights and duties
- Not everone has the capabilities
- People with ID can have substantial difficulties accessing their welfare rights and making decision about their own life



"God man" - History

- Strengthening the possibilities for persons with ID to be legal actors by enabling their needs to addressed and vocies to be heard
- 1924 create safety and "taking care of"
- 1974 support self-determination
- 1988 no one legally incompetent
- Increasing number of "God man" due to more complicated society and emphasis on self-determination (e.g. UNCRPD)



"God man"

- Concept of an appointee = "God man" (~ administrator/trustee?)
- "God man" = be the benevolent bridge that a person with ID (or other cognitive disability) needs to claim his or her rights
- Facilitate self-determination
- If needed, power to represent a person
- Appointed by the court
- No legal consequences for the individual's legal capacity



"God man"

- A volunteer appointed by the court
- Should be someone free-standing
- Contact every week, meetings at least once a month
- No demands on special skills or training
- Remuneration ~ 1000 AUD/year



What do we know?

- Literature review 2014
- Some studies about different legal aspects of "God man"
- Only 3 studies which touched on how "God man" works in practice



In practice

- Problems to find free-standing "God man", often a relative or former staff
- Lack of competence to promote real selfdetermination
- Free-standing "God man" often trust on what staff or parents say is the will of the person
- Examples of how the "God man" decides on behalf on the person (act as a trustee/guardian) - practise paternalism



"God man" in practise

- Often most focus on economical issues
- Some individuals perceive the "God man" as an guardian who has the right to decide
- But also some good examples where the "God man" has facilitated the persons selfdetermination and offered good supported decision-making
- Jacob living on his own with support
- The lack of training and support to the "God man"



Conclusions

- Good ambitions behind "God man"
- We don't know much about how "God man" and supported decision-making works in practice
- Starting up a 4 year project re supported decision-making in practice for young adults with ID

