

## Knowledge Product

### Towards a Supported Decision-Making Model in Indonesia

#### Background

Indonesia has ratified the Convention on the Rights of Persons with Disabilities (CRPD) and harmonized the principles into the Law Number 8 Year 2016 Regarding Persons with Disabilities. The law is considered as a progressive step to protect persons with disabilities, including persons with psychosocial disabilities (PPD).

#### Who are PPD?

PPD are those who experience restrictions of rights and participation due to actual or perceived mental impairments, regardless the self-identification or diagnoses of having mental health problem (Human Rights Council, 2017).

#### What is legal capacity?

One of the rights that are mentioned in the CRPD is the right to legal capacity. Persons with disability have the rights to be acknowledged as persons before the law and, due to this status, are capable of receiving legal rights and conduct legal obligations. The article is important for PPD remembering that there are numerous stigmas directed to those who have mental health problems, such as schizophrenia and major depression (Thorncroft *et al.*, 2009; Lasalvia *et al.*, 2013). These malicious stigmas lead many people to believe that PPD do not have competence to think rationally while making any decision.

#### Violation of PPD Rights in Indonesia

In Indonesia, there are several legal products that violate PPD's rights to legal capacity. The Article 433 of the Civil Code allows PPD to be put under guardianship. Guardianship, which is a mechanism that replaces the mandate of making decision from someone to another individual (Dinerstein, 2012, p. 2), is a blatant violation to one's legal capacity. Besides the guardianship system, another discriminatory provision toward PPD is also manifested in the Article 21 Number 3 Law Number 18 Year 2014 Regarding Mental Health which allows the families to make decisions for their family members who have mental illness to undergo rehabilitation.

These legal provisions adhere to the principle of Substitute Decision-Making, a paradigm which denies the rights of persons with disabilities to full and equal legal capacity same with non-disable people. The CRPD rejects the Substitute Decision-Making because of the negative impacts toward individual liberty.

#### The number of PPD affected

LBHM's research on guardianship decisions in Indonesia published within 2015-2018 showed that 93.8% guardianship applications were granted without time limitation. The Human Rights

Watch Report (2016) revealed how PPD were restrained in private rehabilitation centres and mental health hospitals without considering their consents.

### Supported Decision-Making, what is it?

Supported Decision-Making is often defined as an alternative mechanism that can better accommodate the liberty of those who have impairments to make decisions, express their preferences, and live their lives without the help of guardians (American Civil Liberties Union, 2012, p. 4). SDM places people with disabilities still as the prime decision-maker for decisions related to themselves although, in making these decisions, they received support from others (Committee on the Rights of Persons with Disabilities, 2014, p. 5). Therefore, it replaces the principle of 'best interest' in decision-making into the 'best interpretation of will and preferences' (Committee on the Rights of Persons with Disabilities, 2014, p. 5; Barton-Hanson, 2018, p. 281)..

In the operationalisation of SDM, there are two important things to be considered, which are (a) the assessment of one's ability to make decision, (b) the support plan which is suitable with the ability, needs and surroundings of persons with disability (Shogren and Wehmeyer, 2015, p. 18). In other words, there should be an identification method to determine whether someone need SDM, and if they need, what support they could receive.

The general support which is typically included in the SDM is assistance. In providing assistance, there are two important things need to be determined, which are parties who will give assistances and types of assistances. The parties could be various, including (a) relatives, (b) court representatives, (c) community members, and (d) formal organizations. While types of support could include: (a) clarifying one's purposes and what options available for them, (b) facilitating communication with others, (c) helping persons with disabilities to fulfil the obligations or face circumstances rising from their decisions (Dinerstein, 2012, p. 10; Jeste *et al.*, 2018, p. 5).

### SDM Models

In principles, SDM can be implemented into various types of models. Implementations of SDM in many countries have helped people with disabilities in making decisions regarding health, finance, social life, and other such as decision to have sexual intercourse or decisions about sites to live (Jeste *et al.*, 2018, p. 9). Glen (2015, p. 8) differentiates six areas where SDM can be applied to people with intellectual disabilities, such as:

1. Life planning, including daily life decisions regarding where one should live, how to receive medications, and others;
2. Independent advocacy, including how to express will and rights to other people;
3. Communication and interpretation, including helps to create alternative strategies to communicate which can be utilised by persons with disabilities;
4. Representative help, including the help to make decisions under the name of persons with disabilities at emergency situations;
5. Support for interpersonal relationship, including help for someone to make meaningful interpersonal relationship with others;
6. Administrative helps, which cover other necessary helps, such as filing rent applications and opening bank accounts.

## Why do we need SDM?

We need SDM in order to guarantee the participation of persons with disabilities. Compromising with the particular situation in each state party, the CRPD does not dictate a rigid form of SDM. This enables many countries to design their own SDM, ranging from the family support, networks of supporters, private ombudsman's, advance directives, and other. These variations make it more difficult to draw a clear line of what constitutes Substitute Decision-Making and what constitutes Supported Decision-Making (Gooding, 2013, p. 434; Carney, 2014, p. 48). However, there are principles that can be guidance for a country to design SDM.

Aside from the purpose of respecting human rights, SDM also has positive impacts toward PPD's health. Through SDM, persons with disabilities are able to live independently, obtain jobs, and become productive in their daily lives (Wehmeyer and Palmer, 2003). The SDM mechanisms can also help the rehabilitation of one's mental health condition because it can reduce the one's self-stigma (Arstein-Kerslake *et al.*, 2017).

## In which countries SDM is used?

Canada was the first country to introduce SDM. They defined it as a process where a vulnerable individual is allowed to make and communicate their decisions regarding the health treatment or their property, prior of which this vulnerable person obtains advices, support and assistances from their support networks (Gooding, 2013, p. 433).

Peru has recently adopted a reform of its Civil Code to remove all restrictions on legal capacity based on disability. One element of these reforms is the obligation that notaries, courts, health care providers, financial services and other actors involved in the exercise of legal capacity ensure that their processes are accessible, offer and provide accommodations, and cooperate with individuals' chosen support arrangements (Martinez-Pujalte, 2019).

Sweden has a Personal Ombudsman program (PO PO Skane) which provides a legal mentor who help PPD to make decision. The support person usually comes from social workers, lawyers, or other professionals who are able to fight for the rights of their client (Gooding, 2013, 443).

[INSERT SOME EXAMPLES e.g. Peru, Australia see: the NDIS and [https://mhaustralia.org/sites/default/files/docs/supported\\_decision\\_making\\_fact\\_sheet.pdf](https://mhaustralia.org/sites/default/files/docs/supported_decision_making_fact_sheet.pdf)]

## Where to from here? LBHM's Research

In 2020, AIPJ2 and LBHM's will undertake a research project to look at Supported Decision-Making in order to:

1. Assess the key principles and application of SDM and the resources necessary for PPD to effectively engage in a SDM approach
2. Compare those SDM options established in other countries.
3. Discuss possible SDM approaches and resource requirements with the MARI Research Team working on Inclusive Courts for People with a Disability (Lead by Pak Hasbi Hassan)

4. Develop an action plan as the first step to reform the protection of PPD's rights in Indonesia, so that they become more equipped to make their own decisions.
5. Develop an advocacy tool for the public, government and civil society organisations in the efforts to remove stigma and discrimination for PPD.

The research will compare the law and the implementation of SDM from six countries which represents different regions in the world (North America, South America, Europe, Australia, Asia, and Africa).

## Closing

All persons with disabilities, especially psychosocial and intellectual disabilities, have legal capacity that must be respected by the state, private parties, and the general public. Recognition of legal capacity is important to ensure their participation in economy, education, legal activities, and health decisions.

## References

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