



## **Case Scenarios for Webinar 5: 1<sup>st</sup> June 2022**

### **Respecting the rights of the person and the role of families under the 2015 Act**

*This webinar is structured around a panel discussion of the scenarios below, which relate to the balancing of rights and responsibilities between the person and their family.*

*These scenarios were written by staff and received by the HSE National Office for Human Rights and Equality Policy in response to a survey of learning needs in November/December 2021.*

*A recording of the panel discussion will be available on [www.assisteddecisionmaking.ie](http://www.assisteddecisionmaking.ie) following the webinar.*

- 1. Kathleen cares fulltime for her sister Joan who has Down Syndrome. Kathleen and Joan have managed well so far and are considering leaving things as they are even after the Act is commenced. If Kathleen decides not to apply to be a decision supporter for Joan, will her GP and hospital staff exclude her from decisions relating to Joan?*
- 2. Denise is 42 and has a profound intellectual disability and is non-verbal. She is cared for by her parents who are both in their 80's. They have decided not to apply to be a Decision-Making Representative (DMR). Denise was admitted to hospital with an infection however is due to be discharged. Can she be discharged back to the care of her parents if neither are her DMR?*
- 3. Geraldine had attended for medical tests for another issue, her sister Pauline attended with her. This test came back requiring further tests. Pauline, having been present at the first test and recognising the distress caused to Geraldine felt that any future tests would not be in her best interest and declined to bring Geraldine for follow up tests. Shortly after this event their brother Frank, who lives abroad, contacted our service and said that Geraldine was being discriminated against by not proceeding with the tests and demanded that we perform the tests. Frank had not been involved with Geraldine's care up until this point and was in conflict with his other sister, Pauline's decision. Geraldine was unable to give consent on her own behalf. The Health Care Professional, having taken the time to explain all processes, felt that Geraldine did not understand the reason for the tests or what they involved, and therefore could not consent on her own behalf. How should the HCP proceed in this circumstance under the new Act?*

4. *Gary lives in full time residential services, whereby funds are managed by his father. In recent years, staff have introduced the notion of a 'float' to be given weekly or monthly, thus allowing Gary to access to some of his money, but this does not constitute access to the full Disability Allowance. There has been some disagreement around the use of Gary's funds. Gary has indicated he would like to save for a holiday, or pay for leisure and wellbeing activities for example concert tickets (ticket for Gary + staff ticket) or aromatherapy sessions or to buy better quality clothing rather than cheaper options. Gary's father Andrew considers these to be 'luxuries' and too expensive. How can Gary be supported to gain further financial independence?*
  
5. *John cares for his brother Michael who has a severe intellectual disability. Both men are in the 50's and live together. John takes care of all the household bills, shopping, house repairs etc. however his only income is Carers Allowance of €219 per week, so he is under financial strain. Michael receives Disability Allowance however does not want to contribute to the running of the household, bills etc. What rights does John have to ensure Michael makes a contribution?*
  
6. *Ian has an ID and is supported by a service to live independently, with supports. Over the years Ian's mother Cristina has made all decisions for him. Cristina considers herself to be Ian's decision-supporter, but staff are concerned that she makes decisions **for** him, not **with** him, as she believes Ian has no capacity. Cristina's care and devotion to Ian are evident, but Ian's rights are infringed. What recourse does the Act give us?*
  - a. *Ian would like to choose who to live with (within the service), however Cristina insists he should stay in single accommodation within the service*
  - b. *Cristina does not permit Ian to have a job or do volunteering work, as she says she objects to the low rates of pay.*
  - c. *Cristina does not permit Ian to be photographed for any newsletter articles of internal publicity, even though Ian has said he would be happy to be seen publicly in this way, especially in relation to projects he has been involved in.*
  - d. *When Cristina feels very strongly about something she feels she has a responsibility to persuade Ian of her point of view. Staff have seen that Ian can be strongly influenced by Cristina, and can end up agreeing to decisions which deny him his rights, and contradict what Ian has expressed as his own will and preferences.*
  
7. *Freya is an adult with an intellectual disability. Her father Jacob exercises control of Freya's personal appearance (tattoos, piercings, hair colour etc.) and has refused the requests of staff when they have advocated to support Freya to express her will and preference in this regard.*

*Will ADM offer anything to support Freya in this scenario?*