

HSE National Conference February 22nd 2016 - Sarah Lennon – Inclusion Ireland.

Slide 2: When I was employed by Inclusion Ireland a decade ago it was under a project called 'Who Decides & How'? The project aimed to raise awareness about 'mental' capacity and address the many concerns being raised on the issue.

It quickly became clear that 'Who Decides & How' really was the question on people's lips.

The focus from families at that point was when their son, daughter or sibling had questions over their decision-making ability then who could make decisions for them, who could become a substitute decision maker, what form of guardianship was there.

Often a phonecall would start with 'I'm calling about my daughter. She lacks capacity'. When I replied 'To do what?' I was routinely met with confused silence.

Slide 3: Over the decade or so that has passed since the thinking has shifted quite dramatically. Reports such as the Law Reform Commissions Reports on the Elderly and Vulnerable Adults and projects like 'Who Decides & How' began a conversation away from Status Approaches and Guardianship to where we are today.

Slide 4: In 2007 Ireland signed the United Nations Convention on the Rights of Persons with Disabilities calling it a blueprint for significant improvement in the lives of people with disabilities. It remains to be ratified.

A 2008 Bill was introduced by Government called Mental Capacity & Guardianship Bill. Although Inclusion Ireland welcomed it as making 'some strides towards addressing the complex issue of legal capacity' we were concerned that it seemed to place an emphasis on replacing the existing Wardship procedure. While in the end we were glad that the 2008 Bill did not become an Act, we do need to acknowledge that in the 8 years that have passed there have been between 2-3,000 people through the Wardship system and for many that has been extremely detrimental.

Slide 5: To be clear, Inclusion Ireland's position on Ward of Court has been consistent. We have always maintained that the Lunacy Act must be repealed with absolute urgency. We have seen, through our advocacy work the misery and distress it can cause.

- Individuals forced into homeless services
- Individuals prevented from seeing family members who they express a wish to see
- Individuals denied the right to travel to visit family
- Individuals denied the right to use their money to buy a home
- Individuals told they cannot purchase a winter coat because they bought one last year
- Individuals told they can never marry their partner
- Individuals losing money from their fund and not knowing how much is left (recent Public Accounts Committee findings confirmed this)
- Individuals angry and upset at being legally labelled a Lunatic
- Adults becoming embroiled in custody arrangements when there is a marriage separation
- Secrecy, expense, redtape and lack of control

Slide 6: Most people never become a Ward of Court. Most people with intellectual disabilities or support needs don't have the assets to become Ward of Court and they are in a legal limbo. Not legally entitled to support, but wanting it or needing it and instead a swathe of informal systems have cropped up. Informal supports are necessary but informal decision-making can be dangerous and inconsistent.

Through our advocacy work we have seen;

- Financial Institutions requiring co-signatories or joint accounts
- Financial Institutions requiring services to sign an indemnity
- Contracts or leases signed or co-signed by family
- Medical Professionals asking family members to sign consent forms
- Medical Professionals refusing to act because of a perceived incapacity leaving a person in pain.
- Families confused as to whether their son or daughter can inherit and the consequences of that
- Individuals who want support to make decisions finding that there is no support or no choice of support
- Confusion around a person's right to a sexual relationship or marriage and founding a family.

Slide 7: It's fair to say that people are excited and encouraged by the new law. For many people, it offers an opportunity for greater autonomy. For others the power to choose their support rather than have it foisted upon them. For some people who are Ward of Court and their families it means they will regain control.

On an international stage the biggest barrier to ratification of the UNCRPD is removed, paving the way for ratification. We can join the 93% of countries worldwide to sign & ratify.

Slide 8: There is fear too around this new law, and confusion. People are worried that individuals will be left more vulnerable. There is always a risk, we all face risk every day but there is a dignity in risk and living a safe life is not a rich life. I think we owe it to the law, to individuals with support needs to embrace the new law and make it work. A recent review of the Mental Capacity Act in the UK said that their system was failing because **“Social workers, healthcare professionals and others involved in the care of vulnerable adults are not aware of the Mental Capacity Act, and are failing to implement it”** We have an opportunity and an onus to not let that happen here. People providing frontline services – be it social or health services, financial institutions, citizens information or even retail services for example, need to be signposting people towards the support structures. The only way this new system works is if it is used and we embrace assisted decision-making making it commonplace.

In the video that follows, we asked several people to say – in one sentence – how they felt about the Act. The video features people with support needs, intellectual disabilities, families and staff all saying what the Act means to them.

Slide 9: Video