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**TX: 19.02.03 NEW LAWS NEEDED TO PROTECT THE INTERESTS OF PEOPLE WITH MENTAL INCAPACITY, SAY DISABILITY CAMPAIGNERS**

**PRESENTER: WINIFRED ROBINSON**

**ROBINSON**
New laws are needed to protect the interest of adults who are incapable of making important decisions for themselves. More than a million people are affected - that's about one in fifty of the population - and the numbers will rise as dementia becomes more common. But the Government has so far failed to find parliamentary time for new legislation. Today an alliance of charities is launching a campaign to draw attention to the gaps in the current laws. These mean, for example, that people like Sarah Newman, whose sister Ali has severe learning disabilities and autism, have no legal authority to make decisions on her behalf. Ali's family discovered that the law gave them no say over the way her care home treated her.

**SARAH NEWMAN**
When Ali turned 18 she was moved into an adult residential care home. Within four days of her new placement in this home my sister was drugged forcibly against my parents wishes. Within days of being given this medication my sister became very withdrawn and uncommunicative, desperately upset but physically powerless to tell us what was wrong. My sister was a very outgoing bubbly, cheerful, individual who loves talking, chattering and loved having a good old natter and gossip. So the symptoms of her becoming uncommunicative and unable to get out what she was saying was very distressing, not just for her but for her family, who knew her in a good and normal state.

We were told by the care home manager that my sister had to be drugged, they told us that they had been given advice by a GP, they hadn't consulted a specialist team of experts, they hadn't consulted the adult services within social services and they hadn't consulted us. My mother stopped the medication to my sister, Ali, on a home visit one weekend. However, the care home manager reacted to this by telling us that they would turf my sister out of the home if we didn't comply with their decision to drug her. We didn't have any choice, we had to comply with the home, we had to comply with what we felt was a wrong decision taken by the GP and we had to see my sister suffer mentally, physically, gain weight and be unable to communicate.

**ROBINSON**
Sarah Newman. Well to talk about legal reform are Richard Crarmer who's from the Making Decisions Alliance and Rosie Winterton, the minister for family policy at the Lord Chancellor's department. Richard Crarmer how badly are these changes to the law needed?

**CRARMER**
Well we can see from the film that there are a number of gaps in the law and the main concern is that no one - not a family carer, not a close relative, not even a spouse or next of kin - has a right to be consulted on decisions where someone can't make a decision for themselves. So urgent reform is needed.

**ROBINSON**
How does the law stand now in providing for people with mental incapacity, because it is possible, isn't it, to get, for example, powers of attorney?

**CRARMER**
It is - it is possible to plan for the future but only on financial matters not medical matters and the real concern is that carers don't have that legal right to be consulted so they feel very vulnerable about what decisions they can or cannot make. But health professionals also would benefit from the law because they're uncertain about how to get the consent of someone who may have difficulty making decisions.

**ROBINSON**
So what changes is it that you want to see?

**CRARMER**
The first thing, we want a legal right for people to make their own decisions, where they can do so - a presumption of capacity. Secondly, we want the law to clarify on what basis carers can make decisions without having to go to court. We also want carers to have a legal right to be consulted on big matters, such as medical treatment. And finally we want people to be able to plan for the future by being able to appoint attorney to deal with not only financial but also medial and social welfare matters.

**ROBINSON**
So, for example, if you knew that you were in the early stages of dementia you could make plans for your future?

**CRARMER**
Yes that's right by appointing attorney - that would have to be registered as well and there would have be safeguards in place, but it would allow someone to plan for the future.

**ROBINSON**
Rosie Winterton, as I understand it, the law's been under review for over a decade, there have been so far four reports and a draft bill, the Scottish Parliament has already introduced a new system - when can we expect the Government to find parliamentary time for all this?

**WINTERTON**
Well Winifred can I just first of all say that I'm very aware of the difficulties that many carers face, as was so eloquently set out by Sarah. And that's why I set up, last year, a mental incapacity consultative forum, so that we could actually get going with doing some of the preparatory work that we need to do for the bill. I then, eight weeks ago, announced that officials, within the Lord Chancellor's department, were now starting work on a draft bill and I regard that as a great step forward and I agree that it will help to people who are in these very difficult situations.

**ROBINSON**
So what is the timescale?

**WINTERTON**
Well as you know it is - it's not possible for me to comment on the publication of parliamentary bills but I can re-emphasise that we are starting work on the draft bill. I'm also anxious that we take forward other aspects, for example, I was in Scotland and you referred to the Scottish legislation, I was in Scotland on Monday looking at what had happened when they passed their mental incapacity legislation and it was very clear that one of the things that needed to be worked out in advance were the codes of practice that accompany any legislation. Now I believe that we need to take a twin track

approach - not only do we need to be getting on with the work of actually preparing the draft bill but we also need to be working with organisations, like the Making Decisions Alliance and others, who I have got on my consultative forum, to make sure that we're all clear about the implications of the codes of practice and that, in a sense, we're all signed up to them as well.

**ROBINSON**
So what are you suggesting then - that you mustn't rush this and that the Scot's have had problems?

**WINTERTON**
I'm not suggesting that the Scot's have had problems but there's a lot that we can do to make sure that we learn from what happened there and certainly in terms of the timing - they were very clear that the code of practice was something that they felt it would have been more useful, put it that way, to have out a little bit earlier. Now we can learn from that and I think that what is important is that when we get the legislation itself we're able to get it up and running very quickly with the minimum of problems because that's what people want to see - they want to see legislation that does do something to help people quickly and with the minimum of difficulties.

**ROBINSON**
Okay, Richard Crarmer, it sounds very much as though you're pushing at an open door here?

**CRARMER**
We are and we're very pleased that the Government is working on a draft bill but we've been here before. We've been waiting for 14 years for this legislation. The Law Commission published their own bill in 1995 and that's a good basis to start from. I should also say there's a real consensus for reform, there's 20 organisations, including Turning Point and MENCAP and Age Concern, that are members of this Making Decisions Alliance. But we go further than that - the campaign for new legislation is supported by the BMA, the Royal College of Psychiatrists, the Law Society - so we've got health professionals - lawyers, psychiatrists - and the voluntary sector saying it's time for reform and it's time for legislation now, not further delay and consultation.

**ROBINSON**
Richard Crarmer, Rosie Winterton thank you both.