

Good afternoon everyone.

Thank you for coming back.

Hello to everyone watching online.

In this session we are going to talk about something that is a complicated subject.

I'd like to simplify it.

At the core it is a simple issue.

About treating people with respect and autonomy.

It gets slightly complicated in the application.

As we'll explore, but also in the workshops at 4 o'clock.

Just to tell you who I am.

I am a lawyer.

I'm at the university of Leeds in the UK.

Mainly I direct an international charity, the mental disability center.

We use the law to secure the law for people with intellectual disabilities.

And people with psychosocial disabilities worldwide.

By psychosocial disabilities I mean people labelled with mental illness.

This is the term used in the global community.

Check us out on mdac.org for more information.

Today we are going to zone into this intriguing phrase, legal capacity.

You may have come across it.

And in the literature, before the CRPD it meant what we do now.

Training lawyers, building legal capacity. That's not the meaning for us today.

We are going to find out what is the meaning.

What is guardianship. I have been asked to talk about that.

And contrast that with supported decision making.

What was the relationship between guardianship and human rights law.

The UN convention, the CRPD from now on.

And what can you as lawyers do to support civil society in your countries.

And in Europe and indeed around the world.

Trying to change the system for the better.

Before answering those questions, to illustrate, I want to introduce you to this man.

Some of you may know him. Some of you may know his story.

He is Rusi Stalev. He lives in Bulgaria.

In 2002, when he was in his mid 40' s, he was living alone.

In a town in Bulgaria.

He was picked up by an ambulance.

And not told why. But he was put into that vehicle.

And they drove him 400 kilometers to the site of, all being beautiful mountain.

That' s the road.

He was deposited in this charming building for men with mental disorders.

Where he spent the next 8 years in conditions in which the European Committee for the prevention of torture visited.

And said, it is unfit for humans.

Several people he had to share a bedroom with, died in the winters.

Because of hypothermia and malnutrition.

He managed to meet representatives of an NGO who did monitoring of this institution.

And said: Please can you help me get out?

I don' t want to be in here.

And he found out that he was in there because he had a year before being sent there, being placed under guardianship.

By some family members.

And the guardianship was transferred to the director of this institution.

So he was detained in there. He was deprived of his liberty.

On the authority of the guardian.

In civil law, he wasn't detained under the mental health act.

He committed no crime. He was just treated as an object. That his guardian said, I want you, the director of the social care institution to look after him. Don't let him leave. He escaped several times. But the police brought him back. And he, with his lawyers went to a local court in Bulgaria. The judge essentially said: what are you doing in my courtroom? Get out. You are a person under guardianship. You lack legal capacity. You don't have the legal standing, authority to bring a case in law. So the law treats people under guardianship as if they were silly children. They are not proper rightsholders. We exhausted domestic remedies. We went through the Bulgarian system quickly. And applied to the human court in Strasbourg in 2006. In 2012 the European Court issued a judgement which is one of the most important judgements in the disability field ever. In Europe. And the Strasbourg court, not the Luxembourg court under the EU. The Strasbourg court. Completely different system. Found a violation to the right of liberty. Article 5. First time ever in social care. And violation of article 3, the right to be free from torture and inhuman treatment or punishment. First ever in a disability case. What has this story got to do with legal capacity? It is obvious, isn't it. It illustrates how easily one's legal capacity can be taken away. In this case a EU country. Not at the time. It exceeded in 2007. And it illustrates the human rights implications. The consequences of having your legal capacity removed. In Mr. Stanov's case being placed in this institution for a long time in terrible conditions. So, you might ask yourself: what is this illusive thing called legal capacity? Unfortunately, if you look in the CRPD, you'll not find an answer. There is no definition. I use this definition. A legal construct, which comes from Roman law that enables law to recognise and validate the decisions and transactions that a person makes. It was developed by the Romans to keep wealth of a family in the family, if t-

he family wanted to bypass a man who they thought was either too crazy or too incompetent to properly look after the family's wealth. So, whilst nowadays we look back on the Roman times and think: they were quite good at putting in heating in buildings and creating a civilisation. We also have to say that some of their legal ideas were dubious. Slavery. Guardianship, not such a good idea. They may have been okay back then. But nowadays, neither of those 2 systems of law are fit for purpose. Slavery, everyone in this room will agree of course, why is he making the connection with slavery? - Because I think legal capacity, disability, is the next big and is already the next big civil rights issue. And it is discussion like this that are exposing some of the injustices.

So, in domestic law, in your countries, across Europe, there are a variety of systems in place. Most people with disabilities, even most people with mental health issues. Or intellectual disabilities, are not under any special legal category. In the same way you decided to come to Trier, in autonomous way. None forced you or prohibited you. Most people with disabilities make decisions autonomously. For some people they choose to have informal supports. Without any legal help. And in some countries, most European countries, there are systems of guardianship or substituted decision making. Or - proxy is another way. Proxy decision making. One person's decision is made by another person. And the person with disability classically like Mr. Stanev doesn't get to decide. If they are under substitution decision making, the guardian, - the other person decides.

Some systems say that the guardian has to pay or listen to the person with disability in many jurisdictions. There is - no obligation for the guardian to take into account the wishes of the person with disability.

Again, that system equates adults with disabilities as if they were children. I'm critical about the way the legal system treats children. And some jurisdictions, countries, but not very many have a form of supported decision making. And - further on we will look at what supported decision making actually means. Before doing that, just to say that, one other point about domestic law. These are the various provisions that one can have. And in many countries these type of laws - are dotted around all sorts of sources of law. So, in some countries there is like in England and Wales the Mental Capacity Act. In most civil jurisdictions there isn't something like that. It may be in civil codes, family codes and so on -

. You have to look in different places in many countries to find what happens to people with disabilities in terms of decision making.

So, that's a very superficial account of domestic law across Europe.. What does international law demand? And here in particular we are talking about the CRPD. You have already heard, I'm sure in the morning, while I was flying in, how - the CRPD tries to shift legal systems and people's attitudes from a place where we treat people with disabilities as objects. We objectify them like Mr. Stanev and we shuffle them around according to other people's management. We treat people as if they are objects of pity, of fear. Of management. Of treatment. And we are trying to get away from that worldview. And move towards a bit more humane system where we treat people of subjects of freedoms. What does the CRPD say about legal capacity? I just want to draw your attention to 4 important bits of the CRPD. You have the text in front of you. Feel free to open your folders. Scroll, draw, make faces. Become familiar with the text. It is not a novel where you should read from beginning to end. You have to learn to tear it apart. Look at different bits of it through other bits.-

Get to live it. So, first important part is in my view the executive summary of the whole convention. And that's in paragraph 12.2. The convention saying, for centuries people with disabilities have been treated as if they were sub humans-

. Let's stop doing that. Let's have laws treating people with labels with disabilities. Let's treat them as human beings with rights. Right? Everyone with disabilities has legal capacity in all areas of life. At all times. But, they are - talking about legal capacity. The convention and the draft are not naive. And in the UK right now, it is Freshers week. - It is the first week where students appear at university. And I can tell you for a fact that many many students have less decision making capabilities on a Friday and Saturday night than they do at 10.30 in the lectureroom. That's normal, - that's natural. And we all fluctuate in our capacities whether that is due to external influences. The second most important part of the convention is the next sentence, where it says that if someone requires assistance to make decisions and be the author of their own lives, then it flips over to place a duty on states to provide access to such supports. To-

So this is I would say a new obligation. Of course, one is not allowed to say the CRPD creates anything new. It might scare governments off. If one can say there is something new. Obligation to provide access to support, might be a candidate. Third bit is around safeguards. If we are freeing people from the chains of guardianship, it does not mean, it shoul-

do not follow that people are exposed to all sorts of harms. In fact, on the contrary. We know now beyond reasonable doubt that guardianship systems don't prevent abuse, they facilitate abuse. In 12.4 a lot of safeguards are in place. The director of the residential institution becoming the guardian. The CRPD says, please, don't do that.

And one of the longest provisions in the convention is article 16. That's obliging states to take all sorts of measures to prevent, investigate, remedy all sorts of exploitation, violence and abuse against people with disabilities. Domestic violence, gender based violence, financial exploitation. Everything. Those are in the convention and must be in place in domestic, legal structures.

And 4th, there is an obligation on states to ensure that not just the states, but all sorts of private bodies. You just had a huge workshop on this. Provide reasonable accommodations. And the rights to non discrimination is in article 5 of the convention. And you know already that the right to non discrimination includes in a sense the right to have reasonable accommodations. The failure to provide accommodations constitutes discrimination. And the definitions of disability based discrimination and reasonable accommodations are in article 2. I won't go into detail. There are 4 really important provisions. And article 12 is a bit curious. A bit of a hodge podge. And it may come as a shock to you that international treaties, much the same as domestic laws are not entirely always coherent or beautifully written. Because law is applied politics. And politics is all about compromise. So, at the final, well, throughout the negotiations of the crpd, - it was all negotiated. And it was adopted by consensus eventually, by the general assembly of the UN. That necessitated compromises, to be made.

You can see in article 12, that you might detect trace elements of substituted decision making. You might think it is strange that legal capacity is not defined. It is strange that guardianship, so evil, is not explicitly prohibited.

Well, article 12 is a political compromise. And so, it was then for the CRPD committee, the treaty body, which again you have heard about in the morning, to explain in a bit more detail what article 12 means.

It has done that in 2 ways. One is that it has issued many concluding observations of states. Country based reviews by-

the committee. And the other thing is, a couple of years ago, produced a general comment. The first general comment on - legal capacity. It shows one of the most difficult subjects to comment on first. It is a great idea. The most need to tell, to provide states with guidance, I would say they should have waited a few more years. For states and civil society - and lawyers and everyone to get their heads around what article 12 means. There you have it, a general comment.

It tells us what substitute decision making is. In here I use the word P for Person. Just to save letters.

Substituted decision making. Legal capacity is removed from a person. Can be appointed by someone other than a person, - and this can be done against his or her will. And any decision made by a substitute is based on what is believed to be - in the best interest of a person, as opposed to be based on the person's own will and preferences. That's the committee's definition of substitute decision making. What do you think they said about it? Is it always allowed? Sometimes allowed? Or never allowed?

3 choices. I wish we had an electronic voting. Including for the thousands people looking online. Sometimes.

Okay. 2 people said sometimes. There is a general grown in the room. Never.

Not always, certainly, clearly.

Nobody is shouting anything further.

Well, it was very very clear in the general comments, that substitute decision making is never allowed.

That's what the committee said. Many people agree with this interpretation of the convention. But, many people don't agree with this interpretation. What is the critique of this. The most is, what to do to protect against exploitation or violence or abuse of someone whose will or preferences are not known or knowable. With the best communicative technologies, with the best intention, it said for some people it is simply not known what their will and preferences are. For many people with profound communication difficulties. Intellectual disabilities. You may have examples from your own practice, families, countries.

Secondly I think, is it always morally. Forget about the law. Is it always morally unjustifiable to ban or not to go a-

head with substitute decision making? I have written these scenarios to tease this out a little bit in the workshop. There are genuine arguments to be had. Rather than be dogmatic about it. Another critic is the general comment contains very little guidance for states. Which states find feasible. And that's probably because the process the CRPD committee adopted, was so quick that it didn't allow to read and reflect. From the human rights institutions and governments. Such as Germany, France. And others. Which essentially said, look, we think there is room for substituted decision making. - If you don't have that you are shifting harm rather than removing harm. There it is. We have the general comment.

But, we are in Europe. And as I mentioned at the start. There has been some case law from the European court of human rights in different elements of legal capacity. So, I will not go through these cases. But just to say that for the past 8 years there has been a battery of cases. Many of which our organisation has taken. Which have challenged the brutal effects of guardianship and suggested another humane system needs to be put in place. The pressure points have been on psychiatric detention. What happens in long stay social care institutions. On automatic deprivation of the right to marry. - Automatic removal of children. If you want to read one case out of those. The most moving is Shtukaturov versus Russia. - If you Google Sky News. You'll see a 4 minutes film. The family being reunited after the child had been taken away of parents who had disabilities. Without any assessment of the child's safety. A load of access to justice cases. Which similarly to Mr. Stanov, many people are blocked in law from accessing courts. Even to argue human rights points. Bizarrely.

Bizarrely.

There is case law from Strasbourg. But, despite the critic and let's leave the case law to one side. I do a bit of drilling. Let's drill down into what article 12 is really trying to do.

To affect changes in people's lives. So, what article 12 is brilliant at doing is saying there is a difference between legal and mental capacity. Many or most lawyers and judges around Europe don't get this. They conflate. They think it is the same as legal capacity.

Legal capacity is the right that we have throughout our lives to have decisions that we make to be recognized by other people. To be legally valid.

To have us being the legal authors of our own lives.

Whereas mental capacity, that's not really a legal term. It is thought of as a person's ability or talent at any one-time to make a particular decision. And of course, it fluctuates throughout our lives. And is decision specific. I may - have the capacity to decide whether to have a filling in my tooth, but not whether to have a pacemaker in my heart. I may have the capacity to decide how to spend 1 euro, but not 1 million euro. And so it goes on.

We all, whether we have labels of disabilities or not, have all sorts of different ways of expressing our will and preference. And will here just means wishes, desires. Will and preferences to others. Essentially boils down to what you want to do, what you don't want to do. And there are numerous examples all over the world, in every country of people with labels of this and that severe whatever disability. Formally label is incurable, destitute, whatever. Hopeless is another word that people have used. People with disabilities expressing their will and preference through dance. Through movement. Through painting. Whether that is holding a brush between people's teeth. Whether it is writing a book through the flicker of an eyelid. We all have all sorts of different ways of communicating. For people with ways of communicating with a different voice and signing, it is usually a small amount of people around that person who can understand. So, if I hear someone they may be making noises, which I can't interpret. I don't know them. Whereas their loved ones may well be able to differentiate between I like this or I don't like this. I want to wear a red or blue T-shirt. I want to - have a coffee or a tea.

So, that's why lawyers when they come in and assess people, or judges, are so useless at doing this. We are not generally speaking in that person's sphere of who that person trusts and receives care from and can communicate to. And whose life is, whose decisions are affected by other people around them.

And so what many people around the world are trying to suggest is that this notion of disability equalling a lack of mental capacity, equalling legal capacity, let's put it in the dustbin and we need a new formula. Will and preferences. - How they uniquely make decisions. How they have their supports around them. How others provide the accommodations. Whether that's a bank, mobile company, dentist. Whatever.

And how there is equal legal recognition, in the CRPD. And all of that together. To make decisions. Difference between- this and forms of guardianship. Legal capacity is not the same as mental capacity. What the person wants should be at the center. Not what the guardian or the state wants. Or the commissioners want. The focus is on the supports that need to be put in place. So that people can exercise their legal capacity. And the accommodations which others need to provide. And instead of all this assuming that the proxy, the guardian knows best. I know what is best for you, they say. That - the duty of the supporters becomes to figure out what is the best interpretation of the person's will and preference.

So, a bit more Sherlock Holmes. To investigate things about that person's life. What is their history? What sort of life have they lead? Do they want to leave? The kind of questions which someone might ask of the person in the center. And this is an older woman. But age and gender doesn't really matter. So who am I? What's my story? What's important to me? Who is important to me? What places matter? Where I like to be. And in the future, what are my dreams, my hopes? What do I want my lifeplan to be? Instead of having 1 person to assume what that person wants, the new suggestion is that - there could be a network of people who can help the person with disabilities through their life. So, the group of trusted people can help in expressing, interpreting that person's will and preferences. And making decisions. Helping the person weigh up what is on stake. If the person can't go into the bank and ask for their money. There should be a legal framework which enables the supporters to do that. Without the risk of exploitation.

Instead of a guardian being appointed by the state or court. The supporters are appointed by a person. If a person is not able to do that, then others in some legal system can apply based on a minimum level of trust. Somehow a court or authority have to adjudicate. And evidence. I have been that person's carer for 5 years. Here is the evidence. And that this person trusts me.

There is all sorts of types of support. Decision making is not a model. It is a cluster of innovative ideas and has to be individualised. Could be a circle of support. Could be peer support. That's good for the people with psychosocial support. For interpretation. If these booths were being used, some people if we didn't understand the other person's language, they would be assisting with our interpretation. Signers assist too. And in the same way supporters can assist. -

It can be in plain language, easy read, alternative formats. Lots of innovative picture books. It could be independent advocates. That's important where you get people in settings where they might be at risk of having their decisions overruled such as psychiatric or social care settings.

You covered what types of accommodations others should provide.

Some of the practical safeguards are around having a body which has the power to investigate alleged instances of abuse. A monitoring system. Advisors in the mental health system. Maybe some decisions which are of a permanent nature or high financial. Have to be reviewed by a tribunal. Maybe the same body can mediate conflicts between supporters. It may be, - if you have 5 people and a person with a disability says, actually, I want to buy a Ferrari. And 3 of the supporters say, that's a great idea and 2 say: No, it is our duty to advise you as a very good friend would, not to spend that much money. Or go into this relationship with this horrible man or woman. So there might be a duticative functions which would be necessary.

And legal representation at the tribunal as well.

Some ideas about, if there is to be an agency or community body to help people get into supported decision making, and also get out of, if they want. And to help people and supporters, there are some pretty good examples from jurisdictions in Canada. Where this has been going on for some time.

So in summary.

In the field of legal capacity. What civil society organisations are trying to shift away from are people presumed to have capacity which can then very easily be taken away. To a presumption that people can act independently. From an assessment which is focused on what can you do without any supports and what are the things you cannot do without any supports. To an assessment, what sorts of supports are necessary for you to be able to do what you want. Assessment should be on the nature of the supports rather than your own deficits.

From detention, especially in the mental health field to exploration of alternatives. This is where a clear connection between article 12 and 19, the right to live in the community in the convention. And instead of judicial finding of incapacity, you might get an authority to find. This person needs support and that would trigger 12.3 obligation to provide-

access to support. Instead of substituted decision making which is a big no no, shifts towards supported decision making and authorising the person with disabilities with the power to appoint people. We covered this. Instead of assuming A - knows better for B, let's try and figure out what the person's with disabilities will and preferences are. I always say, would you want your parents, if they are still alive, to make decisions about your life now? It was very well when we were children. But would you want your parents or the parents of people you are close to, to make decisions about your life? Some people look at me in horror. Some people avoid eye contact all together. The answer is no. We would want, I would want to figure out who I am. And give effect to that.

Finally, how can you as lawyers predominantly help to support what civil society is calling for? These are the things - around the world that many NGO's, people with psychosocial disabilities, with intellectual disabilities and some of their family members are calling for. Legislation. To put in place the right in domestic law to support in decision making.- And put in place legislation which you know does what article 12 says on the tin. Provides access to supports.

Prohibits finding of incapacity. Unjustly. Prohibit substitute decision making and detention where alternatives exist.- Obligation to explore alternatives, instead of saying, psychiatric hospitals are all we got. We don't invest anything.- You have to give up some of your civil liberties and spend time in a psychiatric hospital. Which is a disaster.

Calling for a duty to be placed on third parties for accommodations. Rights advisors in mental health systems. And to - ask, to engage people with disabilities and representative organisations in policy law reform and implementing and monitoring as well.

As lawyers, the law reform needs to happen. It is so obvious. In most countries in Europe and the world. The legal system needs to radically change. So, in many countries in Europe NGO's are building coalitions together with other disability groups and beyond as well. They are being clear about what their demands are. Being prepared to compromise. Being clear about the bottom lines. Proposals to governments. Don't leave it to governments to come up with the innovative ideas. Probably they won't. Strategic litigation. To shake up the system. To leverage power. And to spark law reform. In some countries, NGO's are running pilot projects. Demonstrates that an alternative to guardianship can work. And can be -

effective. And can have positive results. They are working with the media. To provide positive stories. And activating the public through social media. Goes back to media.

Just to finish. You started by saying this complicated subject. If you drill down it is complicated. It will get more - complicated when you work in your groups in the next 20 minutes. Sorry about that. At the core, what we talk about is a - really simple idea. When Stanev flew to Strasbourg from Bulgaria twice in fact, to attend oral hearings at the European - court of human rights, he was talking about his case with his lawyer and this is a picture of him outside the court.

And in Bulgarian said this. I am not an object. I am a person. I need my freedom.

And so for him, his story is about the paradigm shift from object to subject. For him is also more than that. It is about a deep sense of personhood. What it means to be a human rather than being treated as subhuman. For him he was detained for 8 years it is about his freedom. On that note, I will end this part of the presentation. And what we can do, is take, it is fine to take 2-3 minutes for questions. Before we go into groups. If that's all right.

(applause)

-Thank you for this presentation. I'm sorry for being a lousy timekeeper.

But I couldn't interrupt. It was too much interesting and important what you were saying.

I think we are running out of time already. So, I will take just 1 or 2 very pressing questions. And we'll leave the - other questions for the final time of debate that we have.

- Thank you very much for that.

In a case on voting rights in Hungary, the Harvard law school of disability project put a submission of article 12, in the context of article 29, participation of public life. I was interested in your approach of capacity. That case was all about voting capacity. Somebody under partial guardianship. The debate which was started this morning, about whether - the convention adds rights or articulates rights is very sharply brought into focus. The Strasbourg court looked at the - issue of article 3 or 1. And didn't say, because this involves question of capacity and article 12 requires equal acces-

s. Therefore we don't analyse it any further. They said, looking at it through the prism of the Strasbourg convention, - we are dealing with voting rights. Qualified rights. We therefore look at whether the UNCRPD has an effect on that in terms of interpretation. What they said was, you have to have very weighty reasons which has the implication of course that in certain circumstances you can't justify. If one takes the view that it is articulating, preexisting rights. Isn't that always going to be a problem for trying to push the no guardianship at all approach forward. At least slow it down.

- thank you for the question. We are involved in that case. And the court left ajar, left it open for states to have not a blanket ban on people voting, but judicial determination to take away people's voting rights. Which need to be clarified in future cases. This or next week submitting a case against Bulgaria on similar issue. Other cases pending. Even if we didn't have the CRPD. It is obvious. If a person wants to vote and prohibited from voting. And fulfill age and citizenship criteria. What would the weighty reasons be? There are none.

So, I personally don't think the Strasbourg court is going to be persuaded by CRPD arguments. Looking at how the Strasbourg court has interpreted the CRPD. My conclusion is the CRPD has had little relevance to the case law. We don't need to be too upset. These are 2 different judicial systems. The only duty is to interpret the European convention on the human rights and the protocols.

This is a fundamental issue of equality.. I think you can use very many council of Europe arguments. From the committee of ministers recommendations 2012. What the council of Europe's commission of human rights has said. And the parliamentary assembly. They have issued strong statements. Everyone, every adult, citizen who wants to vote, and would normally be entitled to vote, should. And actually, all the discussion and investment shouldn't be on the gate opening the gate to allow people to vote. It should be all on accessibility.

And increasing the participation of people with disabilities, and making it easier for every person with whatever disability it is to participate in the democratic sphere.

- Okay. There is another question.

- Hi. I'm Felicity. I'm from a Mental health charity in England and Wales. I find your elaboration of article 12 com-

elling. In one of the latest slides you talk about how we want to get rid of detention and explore alternatives. I have an interest in substitute decision making. I'd like to know, we have a lot of beneficiaries. Probably less than 50%. Still a high proportion. Who say involuntary treatment, legal capacity has been taken away and the doctor has made a substitute decision. That has saved their life. Equally, we have a high proportion of people who say, it is one of the most dramatic things that happened to them. But given there is such a high number of people with positive experience. What steps can we take to acknowledge their experience as well?

- Yes, really great question.

I think, the key is to what you said is acknowledge people's experiences.

And so, globally, in many disability meetings, what you just said would be taboo.. So there isn't the space for people to say, well, actually I personally, represent an organisation who has members who didn't like at the time what they went through. But retrospectively say, it did save my life and I'm grateful it happened. Acknowledge these narratives exist and heart felt. And they are equally valid. They are people's experiences, is the first step. That's why there is being critic of the general comment. The general comment says, no substituted decision making. That includes in mental health. It is called for an abolition for all forms in the mental health system. The mental health system should become voluntary for everyone. Mental health should be on a par with physical health. But it is incredibly complicated. And I think the world is more nuanced and people's views are pulled in different directions. It is a great segway. Thank you for the workshop. They pull out some of the tensions.