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“DO FAMILY LAWS REFLECT THE REALITIES OF FAMILIES WITH ELDERLY AND/OR DISABLED FAMILY MEMBERS?”

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by

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“Do family laws reflect the realities of families with elderly and/or disabled family members?” Every element of that question raises further questions. They must be answered in the context of the fundamental reorientation of legal systems that I believe must lie ahead. Each element implies categories. But such categorisation conflicts with the principle that human rights are universal. We must seek not rigid precision, but centres of meaning. And, while we are all together here, I would like to explore whether we can agree three basic points of English-language terminology.

We can take the elements of that starting question in three batches.

Firstly, what do we mean by “elderly and/or disabled”? “Elderly” tells us that we are dealing with adults. “Disabled” can mean people with disabilities of any age. Adulthood may begin at anything from 16 to 21 or more, sometimes different ages for different purposes, or for different categories of people.

When did I become elderly? There are of course various important human rights instruments for the elderly, but the answers in laws seem to be even more variable than for adulthood. I have various entitlements which began at different ages, starting with a free bus pass in 2004.

As to children, “disabled” only engages characteristics attaching to some children because they have disabilities. So, “elderly **or** disabled” covers people who are elderly and not disabled; and adults and children with disabilities; while “elderly **and** disabled” can mean two distinct groups – those with lifelong disabilities, and those whose disabilities have developed during adulthood.

And we have to be aware of the vast diversity of disabilities, and which of those disabilities may have relevance in law.

For this short presentation, I shall select just one category: adults with disabilities affecting their capability to act or decide with legal effect, which have arisen or developed while they were adults. Worldwide, that is a vast and growing number of people, and a growing proportion of most populations. Quite apart from the private law issues upon which this conference concentrates, they present massive challenges to services and economies. I mention economies for two reasons: not only the cost of services, but also this point. If people in this group do not remain economically active, a growing proportion of total national wealth becomes economically inactive. Use of measures to allow that inactive wealth to be released boosts national economies.

My first issue about terminology is this. What should be the generic term for disabilities, however caused, which impair or may impair an adult's ability to act or decide with legal effectiveness, except with special support or special measures? We have language for many of the potential causes: learning disabilities, head injury, mental illness, incapacitating physical illness, ageing conditions, and so forth. Each of these may, or may not, be a causative factor for such a disability, at some time, for some purposes, in some circumstances. Article 1 of the UN Convention on the Rights of Persons with Disabilities (which I shall call the UN Convention, or simply the Convention) defines persons with disabilities as including "those who have long-term ... intellectual ... impairments". So, should our term be "intellectual disability"? Unfortunately, in the United States that is synonymous with learning disability. "*Cognitive impairment*" is emerging as the generic term which could helpfully be standardised. If anyone disputes that, let's hear in the discussion at the end of this session.¹

For today, I shall call people within these parameters "disabled adults".

My second batch of questions picks out the terms "families", "family members" and "family laws". What is my family? If I become a disabled adult, who is within the circle of my family membership – and who is not? We have heard about traditional and non-traditional families, intact and fractured family relationships, the right to family life; concepts of family autonomy, coupledom, genetic entitlement, step-parent families, the boundary of the acceptance of diversity, and the other factors reviewed by Prof Khazova this morning in relation to children². Do we need to pick our way through all such complexities, or in relation to disabled *adults* do we need concepts of "family" and "family members" at all?

Thirdly, that one word "realities". If I am a disabled adult, what are my "realities"? I was born into an entirely traditional family: four children, married parents, no step-siblings. Was my family the six of us, or did it extend further? Here in the Netherlands we have the distinction between "gezin", the immediate family unit, and "familie", the whole extended family; but even these do not have precise definitions for all circumstances. What is my reality now that I have no surviving ancestors? My nieces and nephews and their offspring are in all 22 lovely people, but not one of them has ever lived in the same country as me! Of people in my life, while I am alive, should any within any categorisation of family have automatic priority over anyone not within such categorisation? For me, and I believe for most people – the answer has to be no. Presentations here tell us about various realities that are likely to matter to disabled adults: friendship, caring, relationships of trust and support, joint ownership, dependency, and so on. As a centre of meaning, I would suggest that what one might call "*the area of personal linkages*" is – in the case of disabled *adults* – what relevant law should address.

"Family" is significant in Article 8 of the European Convention on Human Rights and elsewhere, but I would suggest that the combined concept of "private and family life" in Article 8 may include my "area of personal linkages". Assertions about "family" alone risk unhelpful outcomes, such as an adult with disabilities trapped in a parental home lifestyle, at an age when others would normally have moved on to greater independence.

For disabled adults and their areas of personal linkages, are laws fit for purpose? What is that purpose? There is reasonable international agreement upon the nature of universal human rights. The purpose of laws is to give us ways to protect and exercise those rights. Could legal systems do that job better for disabled adults? I shall not review the whole range of potential measures,

¹ There was no dispute in the ensuing discussion.

² Prof. Dr. Olga Khazova, Institute of State and Law, member of the UN Committee on the Rights of the Child, speaking on "Child and the Family".

voluntary and involuntary, that may be offered by legal systems. I have two reasons for concentrating upon voluntary measures.

First is my current task as consultant to Council of Europe, reviewing implementation of Recommendation CM/Rec(2009)11 on principles concerning powers of attorney and advance directives for incapacity. In that Recommendation, a continuing power of attorney "is a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force, in the event of the granter's incapacity". Advance directives "are instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity". I shall come back to those particular measures.

Before this fully international audience, I require a second reason, and that is provided by the UN Convention. On at least one reading of the Convention, all measures applicable to disabled adults should be either voluntary, or at least constructed to achieve the best interpretation of that adult's autonomy and voluntariness, subject to the requirements and protections of the Convention.

There is a contradiction embedded in many relevant laws and in the Convention itself. At heart, it is a contradiction between the concept of the universality of human rights, attached to every human being on this planet; and the creation of categories to whom special rights are allocated.

Back in the 1970s I promoted the principles that for disabled adults we should seek the minimum necessary special provision, accurately related to need; and that there should be no unnecessary imposition of special provision. I pointed out that any special provision amounts to discrimination, and that any special protection results in disqualification. How can we justify measures which discriminate and disqualify when we seek to avoid discrimination and to respect the universality of human rights?

The same contradiction appears within the Convention:

- Article 5: prohibits discrimination against persons with disabilities
- Article 12: requires recognition of legal capacity in all matters on an equal basis
- Article 16: requires protection against exploitation and abuse

I am not the first to point out that meeting any two of these requirements will violate the third: protection against the vulnerabilities resulting from cognitive impairments requires discrimination, for example.

My solution is to remove the need for special provision in the first place, by a process which I have called "reversed jurisprudence". Back in 1993 I wrote that:

"Laws everywhere are based on assumptions – a norm – which do not fit everyone, in every situation. So special rules of law are needed for some people, in some situations. The category of 'the norm' forces the creation of other categories, outwith the norm. The difficulty is caused by the boundary put round the category described as the norm. ...In society, there is no need for such a boundary."³

³ Extract from "Postscript: A Contradiction and a Vision", p198 English-language version, of Ward, "A New View", ILSMH 1993, also published in Russian (p225), Czech (p169), Polish (p189), Estonian (p194) and Lithuanian (p225).

20 years later, in an overview of laws applicable to children and to disabled adults, I wrote that:

"The factors now drawing [these two areas of law] closer together lead to fundamental questions. Why do we have these areas of special law at all? Why does our law treat healthy adults as the norm – indeed, historically, healthy adult males as the norm – and then deal specially with others? Why should the norm be those least in need of the law's protections and safeguards? Should we not reverse that whole structure and start, generically, with an assumption that we should apply all protections and safeguards such as have been developed in both child law and adult incapacity law, to everyone, and then relax them by way of exception to the extent that individuals clearly do not need them?"⁴

Reversed jurisprudence can be seen as reducing, and ideally eliminating, the need for special provision in the form of imposition of involuntary measures.

"Voluntary measures" and "involuntary measures" are the two further terms on which I would welcome your comments.⁵ For a long time we had "anticipatory measures" and "responsive measures". People themselves create anticipatory measures to apply in the event of their subsequent incapacity. In the absence of an anticipatory measure, a responsive measure might be initiated, generally by judicial or other public intervention. But in reality there is no neat dividing line between capability and incapability. Encouraged by the requirements for support in the UN Convention, people with cognitive impairments increasingly use so-called "anticipatory measures", so we changed that to "autonomous measures". But that was ambiguous. It could mean measures that spring into effect automatically, such as those measures for *ex lege* representation which in Europe cause worries about compliance with Article 6 of the European Convention. So for greater clarity, and to emphasise the distinction, we have arrived at "voluntary measures" and "involuntary measures".

Two important examples of voluntary measures are powers of attorney and advance directives. They both help to operationalise the principles of autonomy and self-determination. I can structure them to operate in the context of my area of personal linkages. The safeguards required by Article 12.4 of the UN Convention, such as the safeguard against undue influence, are needed at the time when such instruments are issued, regardless of existence or perception of any disabilities. Safeguards are required against misuse of powers conferred. There are all the difficulties that people's views, so far as they can be ascertained or deduced, when in a situation may differ from past views when they considered such a situation hypothetically.

For the findings and recommendations in my report for Council of Europe, you will have to await publication, which should be before the end of this year. It is however uncontroversial to say that the current picture which emerges is one of great diversity; diversity internationally in the availability and use of such instruments, and in the solutions adopted to the issues which they raise. This diversity compounds the regrettable difficulties that arise in cross-border situations.

One consistent trend is that where such voluntary measures are available, and their availability is publicised, people use them, increasingly. They are generally preferred to involuntary measures. At present that is true of powers of attorney rather than advance directives, which are as yet under-developed. The advance directive in its broadest sense is a unilateral measure which, alongside

⁴ Reversed jurisprudence (excerpt from chapter on Great Britain, pp249 et. seq., by Ward, of *Kindesrecht und Elternkonflikt*, Giesecking (2013)).

⁵ There was no disagreement about this terminology in the ensuing discussion. These terms were used by some speakers, with the meanings proposed here, in subsequent presentations.

powers of attorney as bilateral measures, can be used by each individual to maximise autonomy and self-determination.

But how can such measures truly achieve universality and inclusiveness, and get away from artificial creation of distinct categories, including those of capability and incapability? Part of the answer is to be found in requirements for provision of support, regardless of any categorisation such as incapability or disability. The existence of legal professions demonstrates everyone's need, in some circumstances, for the support of a lawyer. Provisions for supported decision-making and co-decision-making should be incorporated in most, if not all, power of attorney documents. Under co-decision-making, the joint acts and decisions of the supported person and the supporter will always be valid, because – in legal analysis – they will be the decisions of the supported person insofar as deemed capable and those of the authorised supporter insofar as the adult might be deemed incapable.

In practice, the dividing line between capability and incapability is erased. Erasure of that dividing line lies at the heart of the concept of reversed jurisprudence, a concept which from now on must shape all laws and law-making towards achieving full inclusivity, and respect for the universality of all human rights.

In conclusion, I offer two responses to that starting question.

(One) Existing laws perform poorly in providing ways to protect and exercise human rights for the universality of mankind.

(Two) Laws will perform better if we progressively eliminate the many artificial categorisations implied in that starting question, and apply the one word that requires their elimination – the word “realities”.

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