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20 Minutes of Synthetic Remarks for Adrian[1]

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I am a philosopher both by training and by temperament. I have only been working in the area of Adult Capacity and Human Rights for fourteen years. So in the present company I am a new kid on the block. This is my very first World Congress.

One thing that I have noticed during our time together here in Edinburgh is that there is another philosopher whose work has loomed large in our proceedings, whether we know it or not.

Sixty years ago this year, Thomas Kuhn published a book called *The Structure of Scientific Revolutions*.[2] In it, he argued against the standard accounts of the methods of scientific research, the logic of scientific inquiry, and shape of scientific progress.

Kuhn's most famous and influential concept was of course the idea of a scientific paradigm – an exemplary scientific accomplishment that is used to train new practitioners in a science, to generate researchable scientific problems, and to predelineate the methods for solving them. According to Kuhn, a scientific paradigm provides a scientific community with a

[1] This document is a lightly edited version of oral remarks delivered in the final plenary session of the 2022 World Congress on Adult Capacity. I have corrected a few typos, added a few citations, and changed one or two paraphrased quotes into exact quotations. Otherwise, I have left the original text as it was originally presented. I am grateful to Adrian Ward for the opportunity to offer these concluding comments at the end of a remarkable Congress, and for inviting me to share them in this form.
[2] Thomas Kuhn, *The Structure of Scientific Revolutions*, first published in Neurath and Carnap (eds.) *International Encyclopaedia of Unified Science* Vol II (1962); reprint: Chicago, University of Chicago Press, 1962.

shared sense of what counts as a problem worth addressing, what counts as evidence, and what counts as a solution.

So whenever we talk here of a New Paradigm for Adult Capacity, our discussions are animated by the ghost of Thomas Kuhn.

I bring up Kuhn here and now not so much because of his fertile notion of a scientific paradigm, but rather because of a more fundamental notion in his account of the history of science. In recounting the history of any mature science – whether physics or cosmology or chemistry or biology – Kuhn distinguishes between two phases. He dubs them: "normal science" and "crisis science."

In periods of normal science, practitioners have a largely implicit shared understanding of the parameters of their shared enterprise. There is broad consensus about what are the important problems to research, who are the leading practitioners of the discipline, what are the appropriate methods for generating evidence-based answers to open questions —— also about what counts as a decisive demonstration of a result and what counts as a conclusive refutation. In normal science, Kuhn claims, working scientists often know in advance the answers to the questions they are posing – at least in broad terms. The work of normal science comes in producing a clear demonstration of the exact answer.

Periods of crisis science are not like that, according to Kuhn. Typically, there is a growing awareness that something is wrong in the theories and approaches that had been dominant, but practitioners disagree about how even to formulate the problem, and some deny that there is any problem at all. Periods of crisis science are not characterised by consensus over methods or approaches or authorities; instead a motley array of competing approaches proliferate. Among them, some will eventually come to dominate; others will seem ridiculous in hindsight. Productive periods of crisis science culminate, according to Kuhn, in a scientific revolution, in which a striking and elegant solution is found – not to all the outstanding problems, but to one or two which, in retrospect, are understood to be the ones that were causing the trouble.

Any reader of Kuhn's book with a taste for intellectual adventure will likely have the same reaction that I did when reading it as a student: *I want to live through a period of crisis science*! Normal science may be all well and good. Problems are posed and solved; questions are answered; theoretical and practical accomplishments accumulate; careers are made. But normal science is Apollonian. The real adventure comes in those Dionysian periods when everything is up for grabs, when there is a growing sense that we cannot go on in the same way, and where there is both the possibility and the necessity to try out radically novel approaches that would be dismissed as a waste of time during periods of normal scientific productivity.

So …. We may or may not yet have a New Paradigm in the arena of Adult Capacity. Indeed if Kuhn is right, we will only know that we have one in historical retrospect! But this much we can definitely say on the basis of this World Congress: We are the lucky ones who have found ourselves working through an enormously fertile and far-reaching revolution.

It is fitting that our Congress began with a session that included a forceful statement from the Vice-Chair of the United Nations Committee on the Rights of Persons with Disabilities,[3] and that our first day of work culminated with the contribution from Anna Arstein-Kerslake.[4] History will record them as key players in the revolution, and Anna in particular as one of the authors of a key world-historical document of the revolutionary period. It was shocking to learn from Anna of the death of Gábor Gombos, who was one of the instigators who lit the fuse on the revolution and who never abandoned the barricades, even when confined to his bed. To have Gábor's image, vastly larger than life, looming over a plenary session of what is *no longer* the World Congress on Guardianship … there could be no clearer sign that Times Have Changed!

I did have the opportunity of getting to know Gábor quite well over the years. Indeed at one point Gábor lost his patience with me and denounced me quite publicly – an experience that many of us probably experienced. But even then, Gábor did not give up on me. In

[3] Jonas Ruškus, "Equal Recognition Before the Law as Obligated under the UN Convention on the Rights of Persons with Disabilities," WCAC 2022.
[4] Anna Arstein-Kerslake, "Autonomy and Protection," WCAC 2022.

fact I realised later that he took steps to make sure I was surrounded by people who would help to educate me in the errors of my ways. And in continuing to work with them, I know that I am also continuing to work with him.

But if it is clear from this Congress that we are living through an enormously fertile period of revolutionary science, it is also clear that the work is far from done. Indeed, if there is one thing that has struck me over the course of these past three days, it is that we are precisely in one of those periods that Kuhn described. In Kuhn's terms, we have been living through a period of crisis science where there has emerged an increasingly broad consensus about the nature of the problem, and also that we cannot simply go on as we had been going before. That itself, in Kuhn's accounting, is a form of scientific progress. But what we cannot yet see is what the enduring solution (or solutions!) to that problem will be. Rather, we are in that fertile but unsettled Kuhnian phase where there are many candidate approaches, each pointing the way forward, but not all pointing in the same direction. Even four years ago, many of those suggestions were at best directions-of-travel on a compass. Now, increasingly, they are well-formed and well-formulated programmes for action. Indeed in quite a number of jurisdictions they either are, or are about to become, hard law.

I was asked to use my time in this final session – perhaps *instructed* would be the more fitting term – to reflect on what we have learned during the Congress, and on what it indicates about the road ahead …

It is of course an impossible task. But allow me to make an attempt.

As I have already indicated, I think that we have reached a point where the many and varied contributions to this Congress reflect a <u>shared understanding of a common challenge</u>. I hope I won't spoil the consensus if I attempt to give the challenge an explicit formulation.

Here is how I would frame it.

Question: How shall we devise new regimes of legal capacity which are respectful of the rights of older persons and persons with disabilities, and which are maximally inclusive of populations that were previously excluded from full recognition in society?

I welcome objections to and refinements of that formulation, but I hope and believe that some close variant of that challenge reflects a shared sense of our common endeavour.

To resort to an analogy from Kuhn's history of physics: we are at the point where we all recognise the need to account for the weird phenomenon of the retrograde motion of the planets – even if we do not yet have an agreed understanding of what that explanation should look like.

Let me go one step further. In the opening plenary, Jonas Ruškus reminded us of one key framing of that challenge that has the force of international law.

Art 12, section 2 of the CRPD states clearly that *"states parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."*

Most of us here live and work in jurisdictions in which this commitment has been formally undertaken – signed and ratified as a solemn commitment – even if that commitment has not yet been fulfilled. (The regrettable exception, I am sorry to report, are my American compatriots.)

But already with this formulation, we are coming to the limits of the consensus, and the beginning of some of the outstanding work that remains.

In mapping that outstanding work, I want to draw attention in particular to one clause in that formulation from Art 12: *on an equal basis with others*.

That phrase occurs again and again in the Convention, and everywhere it appears it serves as a reminder of the commitment, and the challenge, to end discrimination on the basis of

disability. But that same phrase also serves as the marker for a vital further question: what is the basis for the recognition of full legal capacity – and what should it be?

Jonas offered us one answer to that question. With Jonas's permission, I am going to call it *Gábor's Answer*. It is reflected in General Comment 1.[5] It is articulated forcefully in a seminal article by Amita Dhanda,[6] and it was reiterated by Jonas in his powerful opening address.

Gábor's Answer is both simple and powerful: the basis for the recognition of legal capacity must be nothing more and nothing less that *humanity*.[7] It is our shared humanity that is and should be the basis of the recognition of full legal capacity, including full legal agency. The consequence is clear: *any provision or practice that serves to exclude any human beings from full legal agency must be abolished.*

Now at this point I think that it is safe to say that we have entered the area beyond consensus.

Gábor's Answer to our common challenge may or may not be the right one. I won't try to answer that question here. But there is a key outstanding question that it raises for me, and which I would like to pose to Jonas and others as clearly as possible for further research, discussion and debate.

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[5] UN Committee on the Rights of Persons with Disabilities, 2014: *General Comment No 1, Article 12: Equal Recognition before the Law*, CRPD/C/GC/1.

[6] Dhanda, A., 2007: "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future", *Syracuse Journal of International Law & Commerce*, 34, 429-462.

[7] Here is Dhanda's formulation: "Fundamentally, there are two choices before humankind. One recognizes that all persons have legal capacity and the other contends that legal capacity is not a universal human attribute" Dhanda 2007: 457. Here is the formulation from GC1: "The right to equal recognition before the law implies that legal capacity is *a universal attribute inherent in all persons by virtue of their humanity* and must be upheld for persons with disabilities on an equal basis with others" (GC1, para. 8, emphasis added). I do not have access to the text of Ruškus' presentation to the Congress, but in my notes I wrote: "Everyone has legal capacity and legal agency simply in virtue of being human."

If indeed our shared humanity is the sufficient basis for the recognition of legal capacity, if all human beings should be recognised as having full legal capacity, including full legal agency, then what does Gábor's Answer mean for children?

From a logical point of view, it seems to me that we here face a dilemma. I propose to call it the Ruškus Dilemma, in honour of Jonas's rich contribution to this Congress, and recalling the fertile discussion that he and I shared on this topic earlier this week.

The Dilemma takes the form of a classic either-or.

EITHER human infants should enjoy full legal capacity, including full legal agency OR the equal basis for the recognition of legal agency is not in fact humanity alone. It must be humanity PLUS something else.

Now I firmly believe that both horns of this dilemma merit further research and exploration.

To deal with the first horn, we would need to grapple with the question of what it would mean to recognise human children, including human infants, as having full legal agency.

To deal with the second horn, we would need to ask what is the further ingredient …. beyond humanity alone … that should form the "equal basis" for the recognition of full legal agency.

I know that there are people in this room, and in our broader community of colleagues, who are working hard on both of these questions. I would propose that when we meet again in Argentina we devote a session to report on progress in dealing with this crucial dilemma. In the absence of a resolution of the Ruškus Dilemma, I don't see how we can be satisfied with what I have referred to as Gábor's Answer. So there is work to be done.[8]

[8] Lurking behind the dilemma there is a trilemma. If a proponent of Gábor's Answer *denies* that children are to be recognised as having full legal capacity, despite their humanity, then the basis for *denying* recognition must be either (i) age alone; (ii) age in combination with some other factor; or (iii) some other factor alone. Each of these options has consequences for the position advanced in GC1.

For now, let me move on.

The second key question that lies on road ahead pertains to the concepts of *will and preferences*.

For me, one of the most exciting results of our Congress has been to hear from colleagues working in jurisdictions around the world about the different ways in which the CRPD principle of respect for rights, will and preference is being incorporated into new approaches to adult capacity.

I won't try here to summarise all of what we have learned about this over the past few days, but it is worthwhile picking out a few examples.

Let me start with South Korea.

Yesterday, Professor Park from Inha University provided us with a summary of developments in South Korea.[9] In South Korea, as I understood Professor Park, there has not been a move to abolish substitute decision-making, which is viewed by many in the South Korean policy and advocacy community as being 'inevitable.' But what was particularly fascinating for me was to hear the second part of Professor Park's presentation, in which he drew out a number of guidelines which, on his analysis, are implicit in the existing guardianship legislation in South Korean. Among those guidelines, two in particular are especially noteworthy. Here are Prof Park's formulations

> "If the guardian makes a decision in violation of the rule of respect for the person's will, the decision is ineffective due to abuse of the guardian's power."

[9] Inhwan Park, "Good Practices of Supported Decision-Making under the Korean Adult Guardianship System," WCAC 2022.

> "If the guardian violates the rule of respect for the person's will, the guardian is responsible for compensation for the person's damages."

Notice the way in which Prof Park's proposal is operating within a system of guardianship – so within what can aptly be described as an "Old Paradigm" – while nonetheless incorporating a version of the CRPD principle of respect for rights, will and preferences.

Having said that, however, Prof Park also emphasised the ways in which principles of protection inform the South Korean approach in quite a fundamental way.

For example, in the context of Korean family courts, Prof Park's guidelines include the principle that "[the] court shall not appoint a guardian against the person's natural will unless doing so is inevitable to protect the person."

Some version of this principle of exception came up again and again as we toured the many jurisdictions that have been represented in our Congress.

Volker Lipp briefed us with characteristic elegance and efficiency on the ground-breaking legal reforms that will soon come into force in Germany.[10] Those reforms are intended, among other things, to underline the German principle that the appointment of a *Betreuer* does not constitute any kind of limitation of the legal capacity of the person.

Having said that, however, Volker went on to make clear, if I understood him correctly, that *there are residual forms of substitute decision-making in Germany.* Here is what I wrote in my notes, Volker:

"coercive measures *can* be authorised by the courts as a last resort for protecting rights if the person is unable to make a decision and is likely to be harmed significantly."

[10] Volker Lipp, "Law Reform in Germany: Re-Balancing Freedom and Protection," WCAC 2022.

The Republic of Ireland was celebrated by Jonas as one of four jurisdictions which are moving towards compliance with the CRPD by abolishing substitute decision-making. But in her brief on the Irish legislation, Aine Flynn made clear that principles of exception remain in Ireland as well.[11]

For example, under the new Co-Decision Making arrangements in Ireland, the co-decision-maker has a *duty of acquiescence* to the will and preferences of the person. That duty holds (and here we come to the principle of exception!) … *unless there is reasonably foreseeable serious harm*.[12]

In Peru, which as far as I know was not represented here in Edinburgh, we find a different kind of exception. Peru was another of the four jurisdictions that Jonas mentioned as having shown us a way towards compliance with the CRPD. But the Peruvian legislation draws a distinction, deeply embedded in its Civil Code, between those who are able to express a will in a matter, and those who are unable to do so.[13]

The new legislation in Columbian allows for the judicial appointment of a representative in circumstances where "the holder of the act is absolutely unable to express his will and preference by any possible means, mode or format of communication."[14]

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[11] Aine Flynn, "Legislative Reform in Ireland: A New Framework for Support," WCAC 2022.

[12] "[A] co- decision-maker … shall acquiesce with the wishes of the appointer in respect of the relevant decision, … *unless it is reasonably foreseeable that such acquiescence or signature, as the case may be, will result in serious harm to the appointer or to another person*." Republic of Ireland, *Assisted Decision-Making (Capacity) Act 2015*; Article 19 (5); emphasis added.

[13] See for example Art 659-E of *Legislative Decree 1384* (adopted 4 Sept., 2018): "Exceptionally, the judge can determine the necessary support for persons with disabilities who cannot express their will … . This measure is justified after having made real, considerable and pertinent efforts to obtain an expression of will from the person, and having provided them with measures of accessibility and reasonable accommodations, and when the designation of supports is necessary for the exercise and protection of their rights." For a discussion of the foundational place of the concept of "expression of a will" in regimes of legal capacity, see Martin, W., "Respeto a la Voluntad de la Persona," [Respect for the Will of the Person] (in Spanish), forthcoming in Bach and Yaksic (eds.), *Capacidad Mental, Discapacidad y Derechos Humanos* [Mental Capacity, Disability and Human Rights] (Supreme Court of Mexico, Human Rights Division), 2022. [English version of this MS available upon request.]

[14] "[E]l titular del acto se encuentre absolutamente imposibilitado para manifestar su voluntad y preferencias por cualquier medio, modo y formato de comunicación posible." Colombia; *Ley 1996* (2019); Article 48.

Finally, what about Scotland? The world is watching, Scotland, to see what happens here. Indeed, the world came here to watch! Already, the Scott Review has made a distinctive contribution to this extraordinary period of fertile innovation. As with the other jurisdictions that I have mentioned, the Scots are determined to embed the principle of respect for the rights, will and preferences of a person at the heart of a new regime of legal capacity. And like other jurisdictions, the Scottish review foresees the need for a principle of exception, authorising … indeed *requiring* forms of substitute decision-making where coercive interventions are found to be the best available way of protecting the full range of a person's fundamental rights, and where the person is unable to make an *autonomous* decision for themselves.[15]

Looking forward, I think we can safely make two predictions. In Kuhnian terms, I believe that we are entering a transition period between crisis science and a new form of normal science. In this new period we can expect a continuation of the debate about the basis for the recognition of full legal capacity. That debate is not going away, and we will need, among other things, to grapple with the Ruškus Dilemma. But I think we can also expect that there will now be a series of new debates, which will take different forms in different jurisdictions, depending on how the principle of exception is formulated.

In South Korea, determined lawyers will be on the lookout for a test case to put Prof Park's hypothesis to the test. Can the action of a Korean guardian be nullified on the basis that the decision was contrary to the ascertainable will and preference of the person? We look forward to finding out.

In Ireland, among many other things, there will be the need to test the limits of the principle of acquiescence to the will and preferences of a person who is party to a co-decision-making arrangement.

[15] Scottish Mental Health Law Review, *Consultation* (March 2022); https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/05/Scottish-Mental-Health-Law-Review-Consultation.pdf.

In Peru, there will need to be research and activism and litigation that seeks to clarify when a person is and when a person is not able to express their will in a matter.

And here in Scotland, there has already commenced a new kind of debate, about how to put into practice the assessment of the overall impact of an intervention upon the full range of a person's fundamental rights.

These are all important, hard, and productive questions. They also sound to me like the questions of Kuhnian normal science, in that they are well-formulated, and in that there are well-established and widely recognised methods for addressing them with rigour.

I very much look forward to hearing the results of these new areas of inquiry.