**Disability Studies Association of Ireland**

**UCD, 9 October, 2015**

**‘All Power to the People – why change on disability policy is so slow in Ireland**

**Lessons for the next generation of researchers’**

**DRAFT**

**Professor Gerard Quinn.**

**Director, Centre for Disability Law & Policy**

**Lifecourse Institute,**

**NUI Galway.**

[**www.nuigalway.ie/cdlp**](http://www.nuigalway.ie/cdlp)

[**gerard.quinn@nuigalway.ie**](mailto:gerard.quinn@nuigalway.ie)

1. ‘Facts are Stubborn things’: Evidence-Based Policy Making or Policy-Based Evidence Making.

2. The Brakes on change - the Centrality of Old Policy Narratives.

3. Changing the Policy Narrative – the complex role of Ideas, Knowledge and Research in nudging change.

4. International Law – socializing States to a new narrative and right behaviour.

4. Case Study - Independent Living, Supported decision-Making and Personalised support in Ireland – a change in the ‘myth system’ of policy but not yet the ‘operation system’.

5. Lessons for you as the future generation of researchers.

Good morning. This is a talk about research. More specifically it is a talk about the relationship between research and change. It affects you as you think about your future lives as researchers and the relationship of your work to change. But first a little story.

I – along with people here like Patricia Noonan-Walsh, Martin Naughton and Eithne Fitzgerald – was involved in the Commission on the Status of Persons with disabilities in the mid 1990s. After elaborate listening exercises throughout the country and after extensive cost/benefit analysis we produced a Report that basically contained a blueprint for change. We congratulated ourselves on a job well done. We set a high benchmark for similar exercises throughout the world. The European Commissioner for Social Policy himself launched the Report which was strongly attended by the highest possible level delegation from the US Government. “Thats it” – I said to myself in my mind. Now Ireland is on an entirely different course.

Well, I remember sitting in my office about 5 years later wondering what happened. Very little as it turns out. True, Ireland had enacted wide-ranging anti-discrimination law – with a very odd detour to the Supreme Court whose 1997 judgment stills hangs over us. But this anti-discrimination legislation was planned anyway – and much of it actually went against the advice of the Commission on the Status of People with Disabilities (especially on the issue of the definition of disability but also on the issue of medical testing which was left unregulated). So I began to think ‘ hymmm...how naive to think that elegant, and even incontrovertible ideas, can actually bring about change.’ This is not a criticism of Ireland or Irish policy-makers. In other words, it is not at all peculiarly Irish. But it did prompt some deep questions about the nature of research and its complex relationship to change – no mater what country you live in.

I have a lot of questions to share with you about this topic – about the relationship between ideas, knowledge and research with the process of change. Even after about 25 years in the field I have few answers. I suspect it is a question that hangs over your own minds – or should hang over your own minds – as you launch your own research careers. I assume – hopefully correctly – that you are not merely fascinated by what you find in your own research field but how you intend that research to have impact, to inform a process of change or maybe even start a process of change where none currently exists. After all, what is the point of explicating the obvious unless it has traction in helping to change the policy landscape, and, in turn helping to transform lives.

Thankfully most universities these days measure (in so far as this can be measured) the ‘impact’ of research. It wasn’t always so. That's one good reason to be thinking not just about the intrinsic attractiveness of your chosen subject but of its overall place in the firmament of change. Yet I hope and trust you are not thinking about impact solely to advance your career – but more importantly because at the end of the day it is the only thing that counts – the only trace we leave behind in the sand when our own research career is over.

I want to ground my reflections on the progress so far (???) in implementing the right to live in the community (and not in institutions), the personalisation of support serves to enable that to happen, and restoring full voice to people through supported decision-making. I am choosing this policy mix because it goes much deeper than the rather shallow equal opportunities philosophy of the 1990s and because I think it reveals much about the relationship between research and change – or the lack of change.

But first I can’t resist a few preliminaries. I am sure you have heard much about ‘evidence-based’ policy making. And of course research is the main tool for revealing the evidence. Evidence-based policy making is one of those verities that if repeated enough becomes a talisman. If you want to put fancy words on it then ‘reification’ comes to mind. What does the emphasis on ‘evidence-based’ change mean? Let me deconstruct it before we proceed.

First of all, since facts rarely, if ever, speak for themselves, it cannot mean that facts (or new facts) can, in and of themselves, trigger a causal chain that brings about change. Facts always have to be interpreted, applied and drawn out. The framework or narrative you bring to the facts are almost always as important, if not more important, than the facts themselves. These frameworks pre-dispose us to ‘see’ different facts or to see the facts differently. It can even pre-dispose us to ignore certain facts since they might inconveniently challenge preconceived narratives. Nothing new here. This is what the Legal Realists of the 1930s called ‘fact skepticism.’

We all have our on mental reservations – and policy-makers are no different. It may be true, as John Adams once said, that ‘facts are stubborn things’ that force themselves on us. Yet it is perhaps unsurprising that we often resist facts – or their entailments – even in our own lives. Something else has to happen besides a clear exposition of the facts before the jump spark for change kicks in.

Secondly, probe a little closer and you will see that facts do not necessarily point to change or the need for change. Enter on stage left the so-called ‘naturalistic fallacy.’ Stripped bare what this really means is that we too often make (even in our own lives) the mistake of assuming that the ‘ways things are’ is in fact the ‘way things ought to be.’ So, rather than trigger change much empirical work may (entirely unwittingly) reinforce the *status quo*. A static picture of the way things are tends to bury within itself a constellation of forces which, through time, have produced the evidence that currently presents to us. Rather than excavate and expose these forces – these implicit choices of the past – the facts tend to remain at the level of epiphenomenon – and the subliminal undertow is always toward outdated models. This is why some in the field of social change have labeled fact-finding as an interestingly conservative project that may end up patronising people instead of liberating them. Conservative in that they may very subtly point backwards and not necessarily forwards.

Thirdly, the policy-making world in inherently messy and especially in responsive democracies. Again this is certainly not a criticism – merely an observation. It may shock you to learn that it is estimated that senior policy-makers will innovative, on average, only once over a long career. That shouldn’t be so surprising. The usual career-ladder does not exactly reward risk-takers – people who want to self-consciously break the mould. Most of the time senior policy-makers focus on containing, narrowing and mitigating risks. Out in their shows, and given the parameters of their job, you would likely do the same. This applies as much to the framing of new policy as it does to the implementation of long-standing policy.

Of course, politicians are drawn in the opposite direction. Civil society may (but not necessarily) have an entirely different vision of the future with no toeholds in the past. Sometimes politicians will share this new vision. Often they will go along with it (even without really fully understanding it) if, by so doing, this portrays them in a good light or even captures some extra support - and votes. Rarely will you find mould-breaking politicians and mould-breaking policy-makers (senior civil servants) working together. Sometimes it happens – but you can’t count on it. Sometimes it is the politician Minister who is ahead but can’t count on 100% back-up from the policy makers. Sometimes the policy-maker is ahead but lacks political cover. Rarely do the two generate a mutually reinforcing chemistry for change. When a duet for change happens between the two it is beautiful to behold.

Generally, at least in my experience, the opposite reflex seems to kick in. One acts as a break on the other. So the first reflex of the policy-maker is how to manage an ambitious Minister – how to make steps in the direction of his/her vision without creating unmanageable risks (or at least risks that are perceived as unmanageable). This may postpone difficult choices – that stretch beyond the electoral cycle and so maximizes the political advantage without actually bringing about deep change. Again, nothing new here. Everyone know that political cycles affect change.

Fourth, one might be tempted to think that money makes a big difference. That is to say, one might have thought that switching resources to a better (and somewhat cost effective) model that delivers better outcomes for people as well as the taxpayer is what clinches the case for change. Well, sometimes.

Let me voice some skepticism about this. The disability field has never lacked money. True, this money has been spread unevenly across different cohorts and policy domains. There is nothing surprising in this – usually these domains exist and are funding due to the variable political pressures brought to bear by different groups in the past –whether parents, service providers or the people themselves. This money generates an apparatus –normally one funded by Government but run by semi-autonomous entities (service providers). Soon, these entities attract a momentum of their own – a set of rationales that converge on - but also diverge from - official Government policy. There is nothing inherently wrong with this – its just a ‘fact’ of policy life – something Max Weber observed over a century ago.

The real point I want to make is that policy change is not just about switching key premises and announcing a new policy. Responsible policy change means facing squarely the challenge of re-engineering deeply embedded systems to change how they function – and to change the regulatory and – most crucially – the funding environment to enable this change. Don’t underestimate the difficulty of doing this – in any policy domain.

OK – where are we. I’m not a cynic. I don’t subscribe to the view that evidence only becomes relevant when policy-makers engage in or commission ‘policy-based evidence making.’ This sometimes happens but only when policy-makes are intent on real change and need an evidence base to neutralize predictable opposition. Of course this creates ethical dilemmas for you - the researcher. You instinctively ‘know’ your research is being used – is being commissioned - for a highly instrumental purpose. And yet you worry that this fact in itself detracts from the much vaunted ‘objectivity’ of your research. This is a delicate dance and I have no easy answers – except to say you have to be fully conscious of this when you accept the King’s schilling. You have a conscience and you are expected not to abandon it as a researcher.

So, facts seldom speak for themselves. Facts may contain an inherent bias toward the past – they don’t necessarily in and of themselves point to a radically different future. You want an example? Well consider how the vast majority of people reacted to the ‘facts’ of the recent scandal dealing with violence and harassment within institutions. Most people reacted by saying ‘we can regulate the conditions in these places better.’ They didn’t say, ‘wait a minute, isn’t it long-standing Government policy to close down these places and create genuine living conditions in the community – why do such places continue to exist”? I think part of the reason is that a realization of the ‘facts’ – violence behind closed doors – is suffused with an acceptance of the past whereby institutionalization was the ‘normal’ default for certain categories of persons with disabilities. The ‘facts’ were judged against an old model that could be improved – not against an entirely new model which Government actually agreed to several years ago.

Change is messy anyhow in the policy making world and a full unity of purpose between high level political goals (with many different motivations) and policy-making exigencies is often a rare thing. Money, in itself, is not necessarily the key driver of change. I’m not saying it should. But it is interesting to note that even where cost/benefit analysis clearly makes the case for change it is not followed through on.

**2. The Brakes on change - the Centrality of Framing and Old Policy Narratives.**

So something else is going on.

Clearly, framing is crucial. Your frame of reference even determines whether some facts are even ‘seen’ as facts. It affects the salience of these ‘facts.’ After all, the institutional mindset managed to persuade most people in Ireland that the most salient ‘fact’ of institutional abuse argued for better regulation of conditions in closed environments – it did not advert the gaze of the public to the most salient fact which is that these places still exist and shouldn’t. In turn, the wrong questions are asked – nobody was asking why progress has not been made in closing down these intrinsically dark places. Framing also influences how we ‘judge’ the facts. And it can point to how we bring about change.

A few years ago the research arm of the British overseas development agency withdrew from a certain country. It assessed its historic impact in that country. It came to the conclusion it had virtually no impact despite the massive investment. Why? The reason was revealing. The investment did not attach itself to any process of change. Why? The senior policy-makers in the relevant country had a very narrow ‘policy narrative’ – one that pointed to the past and precluded change. So no bedrock process of change was embedded. Further, this old ‘policy narrative’ hung in the air and was resistant to any evidence to the contrary. That the interesting thing about ‘policy narratives’ – they don't change much or often and they lock in a certain way of framing the world – a certain way of explaining away facts and evidence.

Whats my point? My point is that the ‘normal’ policy narrative on disability is simple – it is that ‘disability costs.’ This is the frame through which disability is framed, narrowed, measured and judged. It is also the default against change – in all countries. It doesn’t matter so much that the ‘evidence’ is to the contrary - or even clearly to the contrary. The policy narrative exerts a controlling influence over debate about policy options. Given the predominance of this policy narrative it is easy to see why and how certain facts are not acknowledged as facts (e.g., the fact of the failure to close institutions), and why existing systems (no matter their actual cost) are relatively immune to change, why policy-makers have reduced appetite for real systemic change.

**3. Changing the Policy Narrative – the complex role of Ideas, Knowledge and Research.**

Now of course framing can change.

The entire field of disability studies came into being about 30 years ago precisely to change the policy narrative. To put it simply, its key premise was that people with disabilities are not problems – the problems exist in how systems react to people with disabilities. This is the essence of the migration away from the medical model to the social model. In a roundabout way this is asserting that people with disabilities were treated in the past as problems to be managed or cared for or even pitied. Well of course, that's the whole point of the traditional policy narrative – people with disabilities are ‘costs’ that fall on the public purse and to be managed.

So the key messages from the social model are very subversive of the traditional narrative – and intentionally so. Now, the academic insights founded on the social model can remain just that – academic insights. They don’t necessary connect with any process of change. Recall, these ideas generated change in the US and the EU because authoritative and authentic voices championed them. In the US it was the US National Council on Disability that adopted and drove them (‘Toward Independence’ and ‘On the Threshold of Independence’). In the EU it was the European Disability Forum’s ‘Invisible Citizens’ Report that drove change. It wasn’t the academics sitting in ivory towers.

And so the new academic industry of publications is harder to keep up with and more and more detached from reality. But, on occasion some of the insights reach into and animate social action movements. And so the otherwise harmless insights from academia became the fighting words of civil society throughout the world from the 1980s onwards. Academic drift is quite normal – all new industries tend to reproduce themselves for no other reason than to reproduce themselves. But at a certain point in time the fusion of academic insight with social action movements can be electric – this is true across all domains and no less true of disability especially from the late 1980s and early 1990s. And over time – mainly because people like you eventually occupy policy positions within systems of governance – the policy narrative can change.

If I have a reservation it is this. It is much easier to change the ‘myth system’ of a policy narrative than it is to change the ‘operation system.’ Maybe a lag between the two is to be expected – part of the normal pathology of change. The lag is probably bigger if the policy source for the change (e.g., a Ministry of Justice) is different to the policy body that actually funds or implements the change (a spending Department like Social Affairs). Again, this is probably a normal part of the process of change. In the disability context (and I suspect in all countries) we have no lacking of high-sounding policy announcements, reports and plans. But because of the gap between the new myth system and the old operation system we have yet to see the deep systems-re-engineering that would have to take place to actually give breathing space to convert the myth system into reality. Always be aware of this gap in your research – do not be seduced by the new myth system and don’t ingest the Lethean draught of forgetfulness. Collectively as researchers we have to ‘mind the gap’ - and as citizens we have to ‘close the gap.’

**4. International Law – socializing States to a new narrative and right behaviour.**

But surely you might say we now have clear international legal obligations not just to bow to change but to bring it about and faster than the normal lag between a change of myth system and a change in operation system. We can, of course, call in aid the big guns of international law – specifically the UN disability treaty – to highlight deficiencies (which might not even occur to most people and policy makers as deficiencies) and to prod change. In other word, the shift to a totally different policy narrative isn’t just down to the persuasiveness of those who advocate the social model of disability – it is now an international legal obligation. This is my world – the world of international legal obligations. I am naturally attracted to its own ‘myth system’ which is beguiling and seductive. But allow me to make a few observations from experience.

The relationship between international law and domestic change is not a one-to-one relationship especially in a country like ours that adopts a dualist approach to international law whereby it is intentionally kept at arms length. Certainly, if one were to fall back on the imperative and compulsory nature of international legal obligations one might score the odd episodic victory. This is the way lawyers are predisposed to see the treaty – indeed any treaty. Yes, you want to see domestic law and policy ‘comply’ with the convention. Yet I’m not sure if this is the path to systems’ change – to moving faster from a new myth system to a new operation system. If one wants to see the treaty values embed themselves deeply in domestic process of change then they have to be internalized – we have to get beyond formal conceptions of compliance and to internalize the externality of the treaty (again any treaty).

One of the problematics here is that in the process of ‘compliance’ it is possible to allow the new narrative to continue to sit alongside the old narrative. In other words, the new narrative does not serve to oust the old narrative – it is actually controlled and bounded by the old narrative. So lets, by all means move to a regime of supported decision making – whilst clinging to remnants of guardianship as it was understood in the past. Contradiction – what contradiction? None is experienced. So, in compliance mode, the new narrative only chips away at the edge of the old narrative – it does not displace it. That would create too many policy risks.

Ryan Goodman and others have spoken about the need to re-frame and re-value international law as a way of socializing States to right behavior. Translated to the disability context this means genuinely internalizing the externality of the treaty so that its values become a reflex in the policy apparatus. Now and then we come across public servants who understand this and who naturally embed the values of such instruments as the cornerstone of change. I’ve had the privilege of working with some of them.

Of course, they can’t really influence others who control the operation system. Until they too are socialized then no real change will happen. Sometimes, we find senior policy-makers struggle hard to embed new values out of a sense of enhancing reputation and not losing face with their international peers. There is nothing inherently wrong with this. But this depends on where your peers are at. If everybody is afraid to jump (e.g., on abolishing guardianship) then all ships in the convoy will be slow and defer to each other.

And, just to muddy the waters a bit further, it is not necessarily true that the relevant international norm has the one right and clear answer to every policy dilemma. Scratch the surface of any treaty and you will find multiples rationales – multiple stabs at a new myth system. What treaties tend to do – apart from some very clear areas like the prohibition against torture – is to give States a new framework within which to work out solutions for themselves. What is new is that the treaty provides parameters – States are not left completely to their own devices.

Enough meandering – whats my point? Don’t fall for the trap of considering the treaty a magic bullet. It plays a role in the process of change – it doesn’t dictate it. Don’t fall for the trap of thinking that all questions have one right answer. For one thing you will only feed the perception (prejudice) that such instruments are so utopian as to be of little use in the messy process of change. Instead, try to find ways of making the treaty useful and relevant to the process of change. The best process of change is not one that is handed down on high from the UN – it is one that commands native support – not one that is imposed because of an external instrument but one that reinforces sound principles that make sense locally. What you really need is marriage between the domestic process of change and the treaty. Indeed, we should aspire to innovate to supply ideas for others on how to implement the treaty. The two-way nature of international and domestic law seldom gets the attention it deserves. Incidentally, this is what I consider Article 33 of the treaty to be among its most important provisions. It's the one that demands the existence of a domestic process of change between Government, independent monitoring mechanisms and civil society. At long last our Law Reform Commission is working on the relationship between in international and domestic law. I’m sure this will be a landmark publication in Ireland.

**4. Case Study - Independent Living, Supported decision-Making and Personalised support in Ireland – a change in the ‘myth system’ of policy but not yet the ‘operation system’.**

OK – let me ground the above in something a bit more concrete – something that hits home. And I want to ground it in the policy mix of independent living, personalized supports –without which independent living is well nigh impossible – and restoring voice to people with disabilities.

You are no doubt well aware that this policy mix goes to the heart of the new UN treaty – indeed they are often said to be emblematic of the paradigm shift of the treaty. In a way this policy mix goes deeper than the traditional equality agenda. The traditional agenda had more to do with breaking down arbitrary barriers into the life world – the world of education, employment and social interaction. The new policy mix goes deeper because it is all about the ingredients of human flourishing – having a home of one’e own, having control over supports and not the other way around and having a voice – the predominant voice in all matters that affect you, in all entities like service providers that touch your life and in the collective political process to maintain the momentum of change. I could give you the banal jural explanation of all this. But what lies at its heart is a fruitful mix of individualism (“my way or the highway”) and social inclusion – the insight that we become individuals through free social interaction and that the better the environment that allows for this the better the human flourishing. Interestingly, there is a big revival now in philosophies of ‘home.’ I can’t resist quoting this:

It’s not only other people who hold us in our identities. Familiar places and things, beloved object, pets, cherished rituals, one’s own bed or favourite shirt, can and do help us maintain our sense of self. And it is no accident that much of this kind of holding goes on in the place where our families are: at home. The home...is an extension and mirror of the living body in its everyday activity and is thus a *materialization* of identity...our homes manifest who we are at the same time as they provide the physical scaffolding that *supports* who we are.

Where are we on this policy mix in Ireland? Well, the ‘myth system’ has indeed moved on. But has the ‘operation system’ moved on and, if not, why not?

The myth system began to change with the 1996 Report of the Commission on the Status of People with Disabilities– a report that will be 20 years old next year!!! I looked back at it recently and was most impressed. It said:

Independent living is the ability to decide and to choose what a person wants, where to live and how, what to do and how to set about doing it. It also involves establishing and taking control of the total management of a person’s everyday life and affairs. The philosophy behind it is generally defined as living like everybody else, having a right to self determination, to exert control over one’s own life, to have opportunities to make decisions, to take responsibility, and to pursue activities of one’s own choosing regardless of disability.

I’m really sorry to repeat myself but I think it is important to state that this was written 20 years ago!!!!! It is still fresh and inspiring – and not implemented. It combines the question of choice of where and with whom to live, supports that one controls and not the other way around and respect for one’s own decision making. 20 years on how fares the operation system?

Well, anyone who watches RTE will know, we still have institutions! Again, let me repeat we still have institutions! And that despite an excellent HSE report in 2011 on ‘ending congregated settings.’ By the way, this report has inspired other countries around the world. So we earned lot of political capital from it. But we still have institutions! While the ‘myth system’ changed the operation system did not. And research seems to have made little difference. Professor Jim Mansell did the maths showing the cost/benefit results of moving from one system to another. Professor Noonan-Walsh and Professor Meindert Havemen proved in the Pamona Study what the benefits were for the people directly affected. The fact that there has been little change has nothing to do with the research or the lack of research or its quality. In a way the general culture itself did not change – making it harder for the operation system to change. Reflect again – most ordinary people out there did not react to the scandals in our institutions with a renewed commitment to accelerate their closure – they reacted with a seemingly well-intentioned commitment to tighten up further on the living conditions within the institutions (leading, paradoxically to over-regulated selves- something we could not accept for ourselves).

Why has the ‘myth system’ of the 1996 Report and the 2011 HSE Report not translated into changes in the ‘operation system’? It can’t just be about the financial crisis. In point of fact, it is exactly in such moments of crisis that changes in the operation system become not just easier but also more urgent.

I think a more telling explanation lies in the inherent difficulty of supplanting one social mechanism (with its own funding stream) with another with clear timelines for change. Normally, this brings you over at least two political cycles – which may explain the evident hesitance at a political level to drive hard at this change. And maybe an even more telling explanation has to do with the way we conceive, design and deliver supports because they are needed to enable a person get a life in the community.

Ireland is not the only country locked into a mid-20th century welfare system that is no longer fit for purpose. Elegant reports like the 2005 ‘Developmental Welfare State’ of the NESC have repeatedly rammed home this point. The mid-20th century model was premised on certain categories of need (disability = need), on providing public funds to meet those ‘needs,’ on using labels (like disability) as a proxy for need, and on delivering services to meet those needs via intermediaries like service providers. It doesn’t make a whit of difference to me that those services are private, semi-private or so-called voluntary. Functionally, they perform the same role. And, whether this is an accident of history or otherwise, these bodies seemed not to have been accountable in the past either to Government or to their ‘clients.’ Of course, the blame – if blame is the right word – attaches to a succession of Governments. In the US Air Force they talk about ‘set-and-forget’ technologies that allow for target acquisition and destruction. Well, it looks like something akin to ‘set-and-forget’ was applied in the disability service sector over the decades. The proof of the pudding was (and still is) in the allocation of block grants to service providers on account of their clients – but the clients were not allocated monies which they could individually control. Again, there is nothing peculiarly Irish here – most countries have gone through this phase and some have managed to get beyond it.

An impressive wave of studies and reports have demonstrated the need (as well as the practicality) of moving to a different operation system. I personally found the report of the Competition Authority (on the lack of competition) very telling. Since then there have been Value for Money reports and others commending the move to a more personalized funding model. Some change has happened. Some service providers have managed to unbundle their allocation to allow for more individual control. And much innovation has been stimulated especially in the domain of intellectual disability – which actually comes nowhere near the full spread of disability. What do I mean by this? Well, unbundling a lot of money tied up in institutions will help people with intellectual disabilities live in the community. That's only right and fair – almost as a form of reparation for wrongs done. But what about the others with physical or sensory disabilities still living at home. Independent living apples for all people with disabilities - not just a few. Its strange how we forget this.

I believe it is fair to say that successive Governments have not driven change in a hard way setting timelines and clear goals and outcomes. You can’t wait for the slowest ship in the convoy. You can’t outsource the ‘public interest’ to private actors. Yes, change is risky – but at some stage the operation system has to match the myth system. At some stag there will be a political backlash of people realising that things can be different but are not changing and for no obvious reason. Fewer and fewer families will tolerate bundled resources into day services in lieu of control over supports to enable their offspring to get a life. And rightly so. Again, Ireland is not alone here. But what makes the slowness of change so galling in Ireland is that we were among the first to see the need for change and to commit to a new funding and accounting model – without doing much to implement it. Somethings gotta give!

And of course, we all knew that over-restrictive guardianship laws in Ireland had to change. We have come a long way. There was a mooted change from an old myth system (wardship) to a new one – controlled, regulated and restrictive guardianship as represented in the recommendations of the Law Reform Commission in the mid-2000s. To the great credit of this Government, official policy has since moved on to prioritize the move to supported decision-making. We still don't have the legislation and indeed the draft legislation represents a compromise between a thoroughly new model (supported decision-making) and a toned down version of guardianship. So the new myth system had made inroads into the old operation system – but will not entirely displace it. Here is not the place to dwell on that seeming contradiction. I am sure Liz Brosnan (up next) will have a lot to say on that! Suffice it for me to say that if the move to supported decision-making is given breathing space it will of course increase the pressure to move toward genuinely personalized. The underlying logic of personalized supports with respect for personal preferences sing the same tune.

**5. Lessons for you as the future generation of researchers.**

OK – so the world isn’t perfect and the policy world abounds with contradictions. I think we all intuit this – but it is a useful exercise to put words on it. What are the lessons for you as the next generation of researchers and maybe even citizen-researchers interested in change – at least as I see them?

I think the first lesson is that if, and only if, you want your work to have impact and traction you need to get beyond your subject – whether it be employment, housing, etc. You need to over-layer your subject with a theory of change in your own chosen domain. This entails looking at why exactly the operation system is not budging despite several iterations at a new myth system of change. Where is the resistance – has it to do with the inevitably backward glance of much ‘fact finding,’ does it have something to do with risks and a feeling of exposure to too many risks, does it have something to do with the political cycle which is often too short to incentivize Ministers, does it have something to do with the genuine difficulty of re-engineering how services are conceived, delivered and monitored, does it have something to do with the relatively short tenure of senior policy makers in a position to do something long term and be around to shepherd it though? Maybe a combination of the above – maybe something else entirely? And, by direct implication, ask yourself what kind of ideas or research inserted in what kind of environment will help nudge change forward?

I’m not saying that you have to grasp the theory of change – where openings for change lie – and then always tailor your research product to advance change. You do have an obligation to be true to yourselves. You should not enslave your research agenda to speak to and only to speak to how you can contribute to change. But I think you have to be conscious of the theory of change within your field and at the very least avoid doing anything that inhibits change or provides a pretext for delay. You do have an obligation to speak the truth as you see it and let the chips fall where they may.

Secondly, develop and constantly update your theory of change through direct experience. There is no substitute for this. You have to be ‘out there’ and directly engaged. Indeed, ideally, you should follow a career that sees you circulate between academia, Government, service providers and others. You will quickly learn that there is no instant or hard and fast ‘good guy’/bad guy’ distinction. Everyone operates within pre-determined parameters. Change is all about recognizing these parameters and helping to change them.

Thirdly, work with all forces for change. Primarily this will engaging with civil society. Jean Jacques Rousseau once said that no one – no one – can speak for another. By all means add you distinctive voice but don’t think you speak for others. At the end of the day its their voice that counts – not yours.

Personally, I have spent most of my whole career in the ‘no-mans-land’ between knowledge work in the university and policy work in international organizations and Government. I suspect (indeed I hope) many of you will do the same. I have found that engagement in the policy world has given my own research and edge which it would otherwise lack – and has, betimes, given it some traction in the policy world. Indeed, sometimes, to have impact, you have to father an idea but then allow others to adopt it publicly without acknowledgement of paternity. The bigger picture demands this. Always have the courage to do it.

In a sense you are doomed to be political if you want your ideas to go anywhere – i.e., beyond the pages of the social science journals. I don’t mean political in a party political sense. In Ireland, for example, the pressing priority is to press home the continuing gap between the ‘myth system of public policy and the ‘operation system’ of our public services. You can do this best with civil society groups. Indeed, we, in the academic community, have a big job in hand to grow participatory research models – which is another day’s story.

With the 100th anniversary of 1916 looming next year – which happens also to be the 20th anniversary of the publication of the Report on the Status of Persons with disabilities, hard, raw questions have to be asked of all the political parties about why institutions still exist in Ireland, why people are still obliged to utilize a service model that is far beyond its sell-by date and why we have to live with compromises on supported decision making? To my mind, these are election issues – to be faced by all the parties.

Hopefully I don’t need to remind you that one of the ‘objects’ of independence was to rid ourselves of the odious Poor Law. I will say that our citizens with disabilities are still waiting for the promises of 1916 to be kept. It is at least partly your job as a future researcher not to lose sight of this and to remind others. Otherwise our founding moment of 1916 itself remains just part of our collective ‘myth system.’