

Family Carers Ireland

Life after care conference 2018

Address of Dr John Hillery

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June 18<sup>th</sup> 2018

### Introduction

I want to thank Family Carers Ireland for inviting me to address this conference. It is humbling and I must ask myself if I am I in a position to comment on the needs of carers when I am not a carer? It's easy to talk about my long experience of working with carers but this can seem platitudinous and patronising. Still my position in the College and my years of training and practice in psychiatry and in the services for people with intellectual disability give me some academic and practical knowledge that informs my perspective. On a purely personal level when my father was President of Ireland my mother was involved in the Caring for Carers organisation that one of my neighbours in west Clare, Judith Ironside, helped found. She insured

that I was aware of the carers' perspective from an early stage of my career.

In 2009 the College of Psychiatrists worked with the carers association and produced a Carers survey. We plan to repeat this in the coming year. Unfortunately one of my former nursing colleagues who is a carer recently in conversation while agreeing that this was a good idea told me that we would find that little had changed. However I will go over some of the findings of this survey in the course of this talk.

My experience and interactions such as that just fuel an anger that a modern democracy such as ours does not seem to cherish all the children of the nation equally, out founders' aspiration.

A good friend of mine and a devoted carer developed a depression when the child cared for finally got a residential place. Embarrassingly, I was surprised by this. Now I know that the total all absorbing commitment to caring can mean that when caring ends the gap is too large to fill and there has been no time to prepare to fill it.

Something similar to Yeat's too long a sacrifice making a stone of the heart. Thus the subject of this conference, 'Life after care' is of vital importance. The answers to how we ensure a good life for carers when the caring role ends seems to me to lie in there being appropriate support for caring and carers from the beginning of the caring process. This needs proactive support – respite, financial support, and training. This is really about how Ireland provides health services and other supports for vulnerable people, the cared for and the carers.

The fact that we are still discussing these issues as needs rather than as actual operating services is a disgrace. It is one of the reasons I resigned my clinical post earlier this year. The quote from the film 'Network' comes repeatedly to mind: "I'M AS MAD AS HELL, AND I'M NOT GOING TO TAKE THIS ANYMORE!" ”.

A major problem I see for carers is that though everyone admires those who care they have little political clout. Caring leaves little time for political action.

### The College

The College of Psychiatrists of Ireland, formed in 2009, is the professional body for psychiatrists in the Republic of Ireland. It is the sole body recognised for training of doctors to become specialists in psychiatry and for providing career long competence for specialists in psychiatry. The College is not a regulatory or disciplinary body. The College is a not for profit professional membership organisation and is a Registered Charity. The College has nearly 1000 members and over 300 trainees.

The Mission of the College is to promote excellence in the practice of psychiatry.

To fulfill our mission of promoting excellence in the practice of psychiatry the College focuses on the following objectives:

1. Supporting, representing and leading member psychiatrists nationally & internationally
2. Promoting excellence, best practice, recovery & collaboration in mental healthcare
3. Setting standards for trainee psychiatrists
4. Supporting the continuous professional development of our qualified members
5. Working with key stakeholders, government committees/agencies and other organisations
6. Promoting human rights & ethical conduct in psychiatry and mental health services.
7. Working with service users, carers and their organisations

The College undertakes collaborative work with other bodies and, as part of this activity, worked with the predecessor of this association, the Carers Association, to survey the experiences of carers in Ireland in 2009. This Carers' Health Survey (2009) had the following results:

- Vast majority of carers were female and married/cohabiting
- Over half of carers were between 45-64 years of age; One fifth were over 65 years.
- Most of the carers were retired and over one fifth were unemployed.
- Almost 40% of all Carers had at the time of the survey carried out the caring role for between 1 and 5 years; 57% for over 6 years. But an amazing 12.4% for over 20 years
- The vast majority (80%) of Carers spend more than 35 hours per week caring.
- The vast majority of those carers (20%) who do not live with person being cared for visit them daily

Carers Health

- Most Carers (71%) reported their health as “quite-good” or “very-good”, but well over 50% experienced being mentally & physically “drained” by their role.
- Regular carer tasks most reported to cause ill health reported as: - dealing with verbal/emotional abuse - coping with bizarre/inconsistent behaviour - getting up in the night - dealing with physical aggression
- Over half (>1,000) of Carers had a medical problem (most frequent being back injury)
- Physical medical problems most reported to be worsened by caring reported as: backache or bruising/cuts or peptic ulcer disease or high blood pressure
- Mental health problems - Over half of Carers reported having been diagnosed with a significant mental health problem.
- The most frequent mental health problem is anxiety disorder.
- Both anxiety and depressive disorder were reported to be the medical conditions most highly associated with their caring role.

- Most carers worried how the person being cared for would cope if they could not care any longer due to illness/death
- Most carers reported that they had no time for themselves due to caring.

## Supports

- Carers reported that the services which provided most ongoing support to them are:- - G.P., - Care workers, - Carer/charity organisations - Community PHNs/religious groups.
- Vast majority (74%) of respondents reported that services made available to them for their role as carer are inadequate.
- 12% of carers reported that they could not access services.
- Of the 31% who reported being diagnosed with an anxiety disorder 69% said it was caused or made worse by their caring role.



- Just over half (>1,000) of Carers knew whether the person cared-for has opportunities for respite care. The availability of respite was variable.
- Over one in five respondents reported that the person cared for refuses to go into respite care.
- At least half of Carers(1,000) reported not receiving any extra help with caring

What Carers said would help:

- At least 9.6 extra hours per-week to improve their own health
- Better and more flexible back-up support services, especially home-help & respite care, to allow them to have a break.
- More financial support
- More understanding and “joined-up thinking” between agencies relating to caring
- Psychological support
- Training to aid them in their caring role

- The vast majority of carers had never received training to help them carry out their role and would like training made available to them.
- Lack of Understanding about caring. Most carers believe that people do not understand what is involved in caring and that there should be more publicity about caring.

The College and Family Carers are now planning to repeat this survey. As I already mentioned I recently discussed this plan with a former nursing colleague who has been a carer for many years. Sadly he predicted that, both from professional and personal experience, the results will be little different.

Another part of the fabric of the College is the Refocus Committee. This committee whose name is an acronym of Experience Forum of Carers and Users of the Services is made up of equal numbers of service users, carers and psychiatrists. It has produced many papers for the College that inform our activities especially the training

activities. In 2013 the committee launched - Who cares? Listening to the needs and experiences of carers of people with mental illness.

This paper's recommendations are as follows:

1. Explicit Recognition of the Crucial Role of Carers
2. Need to Acknowledge the Unique Impact of Mental Health Difficulties of a Family Member on Carers
3. Need for Provision of Information, Knowledge and Prognoses to Carers
4. Recognition of the Possible Enduring Nature of Mental Health Problems
5. Use / Abuse of Patient Confidentiality to Justify Lack of Communication
6. Importance of Continuity of Care
7. Issues of Aftercare and Follow Up
8. The Role and Importance of Support Groups and Self Help Organisations
9. The Need for a Formal, Robust Complaints Mechanism and Information re same

## 10. Formal and Structured Recognition of Carers as Important Contributors in the Training of Psychiatrists

Refocus members are now involved in all our training activities and will be a key part of the teams we are establishing to inspect training sites around the country.

### Other activities

In the last few years the College has also co-presented a yearly conference with SHINE on Family friendly mental health services. In this we seek to disseminate good models of service and deal with issues that families and other carers feel may be adversely affecting them and their loved one with mental health problems in dealing with services.

Amongst these is the issue of Confidentiality which can be a frustration for carers. Though confidentiality is a vital part of the relationship between people with mental health problems and the

professionals who treat them it should not be a burden to carers. We are constantly seeking ways in which we can develop models of interaction between the triad of patient, carer and therapist that facilitate exchange of necessary information without damaging true confidentiality.

### Personal

I want to give a personal context for a few minutes. I resigned my clinical post in February after nearly 30 years in the mental health and intellectual disability services as a trainee and consultant. During that time I found change and response to the broader needs of individuals with mental illness and their carers to be constant but very slow. The inability for rapid change in systems and poor environments was always a frustration. The introduction of regulation of environments with HIQA provided great hope but seemed to me to become somewhat of a box ticking exercise. Regulation in the services I mostly worked in was not interactive from my point of view with reports written without a right to correction or other reply. It seemed to be

what is known in regulatory circles as ‘whack a mole regulation’, after the old fair ground game, where a hammer is applied to the figure whose head sticks up. Dictats from HIQA about individual service users in intellectual disability and old age support services put pressure on service providers to transfer ‘difficult’ service users even when from the point of view of clinicians they were in the most suitable places available. This has led to vulnerable people being transferred to hospital settings that do not suit them. At the same time service deficits led to pressure to decrease risk ratings as there were not resources available to meet the existing ones. I continued to spend too much time writing memos and making phone calls advocating for respite and other supports for individuals and carers that should be taken for granted. One example being the way young people with intellectual disability and challenging behaviour lose their respite and sometimes other services once they leave school. It continues to amaze me that this was an issue when I was first a consultant and is still an issue today. To my naïve mind this is

predictable and solvable but my naiveté has been unfortunately demonstrated year after year. Time to step aside.

### Other issues in providing appropriate supports

What are the other problems in ensuring a supportive environment for carers and people who need care?

Our health service has major staffing problems. No one seems to have connected the difficulties in recruitment and retention to the culture and environment of the main employer, the HSE. Recent developments in the Wexford Child and Adolescent Mental Health Services are a worrying illustration of this. The Consultant Psychiatrists have resigned following unsuccessful efforts on their part to lobby for the services to be fit for purpose. Reports of snails on the walls of the clinic and no hope of improvement until a successful business case was made for environmental improvements seems to be bureaucracy gone mad. The HSE is advertising for temporary consultants to replace the ones who are leaving. It is unlikely that high quality candidates will apply having heard the lead consultant's reasons for leaving. The recruitment and retention

problems are across the health professions but I will address the medical issues briefly. Unfortunately despite opening more medical schools we continue to have problems retaining our graduates. Some of this is to do with pay and the changes introduced at the time of the financial crisis. However the issues of quality of life outweigh these.

Surveys of trainees in psychiatry reveal that for young doctors today it's not just about income. Though the reduction in salary brought in by a previous Minister is an issue trainees want to work in multi-disciplinary teams that have appropriate administrative support and environments that are therapeutic for the patients they see. Experiences during training and stories such as those from Wexford, allied to reports of how systems work in countries such as Australia and Canada are strong push and pull factors that take young doctors out of our system. Recent reports that advertisements for consultant posts in our mental health services are receiving only one or no suitable applicants are a manifestation of these effects.



I have already spoken about the punitive and scatter gun approach to regulation, the Whack a Mole regulation that seems to target frontline professionals and use only punitive methods to bring change.

The phenomenon of Moral Distress, where professionals know what they want to do for patients but cannot supply it is another stressor that encourages young health professionals to leave our system. My experience of knowing that respite would relieve the pressure on young men with autism and their families but finding this unattainable and having to prescribe medications to try and ameliorate the stress in the young person and thus relief pressure on their families is an example of this. Many of my colleagues are finding themselves in such ethically compromising situations on a regular basis.

### Politicians

Though government ministers regularly communicate their intention for reform in the mental health services the current situation leads

me to question the intent. Our structures lack governance. The HSE has no board and an acting CEO. The main policy on mental health services A Vision for Change recommended a leader in this area but recently the last CEO of the HSE in one of his last acts absorbed the Mental Health Division into a bigger grouping thus removing the focus at the necessary high administrative level from mental health. This allied to the fact that the national budget for mental health services remains at 6% when a Vision for Change recommended a higher figure 10 years ago and when that of equivalent countries is around 12% gives the lie to stated commitments to services for people with mental health problems. The Minister for Mental Health has been quoted as saying that the current budget is sufficient despite these comparators and issues such as lack of appropriate teams and environments for mental health service delivery.

The lack of implementation of reports and legislation such as the Carers Strategy and the Capacity Act which would make life easier for patients, carers and those working to support them is another sign of a lack of true commitment to change.

We continually hear of how Slainte Care, the cross party policy for the future of the health services, will revolutionise our health services. Yet the fact that the proposed lead has not yet been advertised after nearly a year and that that leader will not now be based in the Taoiseach's department as proposed in the plan again suggests a lack of commitment to change at the highest level in our country.

It may be that there is no money for these issues. However if that is so why is there money for less important issues such as Metro link.

We also will soon see a large investment in services that will follow from abortion legislation. It will be ironic if moneys go in that direction at the expense of people who need support to live the lives they would like to live despite chronic illness or disability.

There are also areas in which improvement would seem to me to be resource neutral. Dr Muiris Hueston recently wrote in the Irish Times about the disparities and differences in processes for accessing supports in different areas of the country. In some cases these seem set up to thwart rather than support people. Why cannot there be consistency in how these are run across the country.

In Ireland there is a tendency to respond to high profile campaigns for the provision of certain treatments. With developments in high tech medicines for previously untreatable conditions the emotional pressure on government can be huge and irresistible. The costs are huge also with individual treatments running into six to seven figure costs. What is rarely mentioned in the celebrations that ensue is that we have finite resources and the monies that support these treatments are lost to other, less glamorous, less emotive and less noisy areas.

### Solutions?

We need transparent, simple governance of our health service as regards financing, planning and delivery. The multiple layers and cross responsibilities, a diagram of which resembles a Jackson Pollock painting, have to be reduced into a simple effective model with allocated decision making and accountability.

We must be honest about what funds are really available and then use those funds where they will have the most impact. Funds used in

one area must be shown to have a more general effect on the efficient delivery of health services. I think that appropriate funding of carers would be a prime example of such an effect.

We should not rob Peter to pay Paul. This once again requires honesty about resources and fair and accountable decision making based on where best to intervene in order to help individuals and bring more general improvement.

In the same vein if we have strategies and legislation we should honestly face the resource implications and implement what is implementable and be honest about what is not.

Regulation is vital but must be done in a way that deals with poor practice but is interactive and formative in nature, supporting good practice and helping service providers who want to improve, and I think most do, rather than having blaming and shaming as the only way to force change.

We need to get the simple stuff right such as working conditions for staff and treatment settings for patients before we do anything else.

Simplification and honesty is the only way to deal with complex systems that should be improving our lives, not running them.

Thank you.