‘From the Tyranny of Patienthood to recovery and citizenship’

A personal view of mental health service change in a rural area and the application of a ‘Whole Life’ approach

It is a real pleasure to be back in Sardinia so soon after my last visit. In November I had the pleasure of working with colleagues from Trieste with a large number of mental health staff in Sassari and Nuoro. I have to say how impressed I was with the energy and enthusiasm that they showed and a hunger to make their services as good as they can be. Wherever I have worked in mental health over the past thirty three years I have been amazed at the determination, enthusiasm and passion of people wanting to continue to change and improve the way we work with people with mental health problems. There are also some people who will always want to resist change; ‘to maintain the status quo’. There are also always people who look at change and say, “Ah, but that could not happen here!” Later you will hear from my good friend Damien Murray how in his part of Ireland they made things work because they had people determined to succeed, often against ‘the odds’. Today I would like to talk a little about change; about harvesting the energy and enthusiasm of not only mental health staff but also those people who use services and indeed wider communities and citizens as a whole. I want to suggest that ‘change and citizenship go ‘hand in hand’ and that all things are possible when people have the courage and the determination to work together, to look around them and to do what works for their communities; not to try to copy Trieste, England, France or Ireland but to find their own way, the Sardinian way!

During the course of this talk I want to emphasize a number of key points:

- The importance of seeing people with mental health problems as people first
- The need to find ‘Whole Life’ solutions to ‘Whole Life’ problems
- The concept of Recovery and Social Inclusion
- The importance of leadership, courage, collaboration and optimism
- To rediscover the art of mental health work to complement the science
- To allow people to move from the ‘Tyranny of Patienthood to Recovery and Citizenship’

I hope to be able to illustrate some of these points from my own experiences, most recently as Chief Executive of The Cornwall Partnership Trust. I had hoped to have had Michaela Burt with me today who has been one of our most committed ‘champions for change’ and who still is leading the work on Cornwall’s Recovery and Social Inclusion Services whilst continuing to drive forward the ‘concepts of ‘Whole Life’.

I would like to briefly tell you a little bit about my background. I left school and deferred going to University in order to gain some experience of the ‘real world’ and spent two years working in various factories. It was a period when I was able to see the importance of community, the realities of family life and the impact of things such as racism, politics and oppression. But at the heart of this there were real people with ‘Whole Lives’, proud to be citizens. They were people full of optimism, courage and determination despite sometimes difficult circumstances. I probably learned more about what makes for good mental health here than I did from all my studies and experiences in the Health Service. We should all keep close to our hearts the fact that patients are people first, they do not want to be patients for the rest of their lives, they want to recover and regain their citizenship and it is the duty of mental health services to assist in that process.

I trained as a Psychiatric Social Worker and worked in various places both urban and rural, North and South. Having been a Senior Practitioner I began managing services and various roles in Service Development. I held jobs at different levels before taking on Director of Services in a Trust, which covered the

Bristol/Bath/Wiltshire Region of England. Finally, for five years I was the Chief Executive of the Trust in Cornwall.

In November it struck me just how many similarities there were between Sardinia and Cornwall. Whilst Cornwall is not an island it is surrounded by sea on three sides and a river on the fourth. It is very isolated being at the extreme South West of the country. It comprises mainly small towns and even smaller villages all of which are dispersed along a peninsular in which travel and communication is not easy.
Also, like Sardinia, Cornwall is a beautiful place where rich people come on holiday! The population more than doubles during the summer period. Wealthy people buy second houses in Cornwall, pushing the cost of housing up for local people. It comes as a surprise to many people that Cornwall is one of the poorest places in England and as such was eligible for Objective 1 support from the EU. Cornwall also has a very strong local identity with Cornish people being proud of their heritage as a culturally and ethnically different people to the English.

There is also a strong sense that decisions about services and approaches are taken a long way away. in London or Bristol or Birmingham and indeed England has suffered from a very centralized approach to developing services. Many times the solutions found in urban areas proved to be difficult to replicate in more dispersed rural areas.

If I think back to what psychiatric services were like in the 1970's, when I started in mental health work, I recall that there were still huge psychiatric hospitals in most areas often with literally thousands of people in them. Community services were almost non-existent and many people spent their whole lives incarcerated in institutions. We had given them a life of 'Patienthood' whilst ensuring that communities remained in ignorance about mental health issues which built up the fear, stigma and rejection that faced people with mental illness. What made matters worse was the paternalism of professionals where containment and treatment of symptoms was the priority. It would have been difficult to find any attention being paid to recovery, choice or citizenship. Many people were 'Out of sight, out of mind', forgotten and stripped of their citizenship.

Now in England there are few, if any, long stay hospitals and indeed there are far fewer in-patient beds but there are a wider range of local community services and increasingly more choices for people and more control over their own lives. There is a greater acceptance of the centrality of rights and citizenship and a belief in the efficacy of recovery and social inclusion programmes. Individuals are being placed at the centre of service planning and are less likely (although there is still much to do!) to be made to 'fit' into monolithic services. There is also a growing recognition of giving people what **they** want and not just what we, the professionals believe they should have. Thankfully, we are getting better at looking at the 'Whole' person and accepting that it is not enough just to tackle the 'problem' symptoms of their illness but to help them take their lives to where they want to be. Service users usually know very clearly what they want and are remarkably modest in their expectations. They do not want to be patronized by professionals telling them that they don't know what they want in their lives.

During the 1980's and 1990's the transition in England improved the general situation and certainly moved away from Institutional solutions to more community solutions. Services have improved, of that there is no doubt but it has been more difficult to change the thinking and change the culture to arrive at truly modern and citizen based approaches. It is perhaps this that is the greatest challenge to us all whether in Sardinia, England or wherever. Changing the thinking, changing the Culture and then changing the services. This has become one of the driving concepts of 'The Whole Life' approach of which Cornwall was a founder member and which became the driving ideal for service development in Cornwall.

I should say at this point that our association with our comrades from Trieste came through a recognition that they too had worked hard to develop the values, ideals and services that we hoped to develop. For many years they have demonstrated what can be done with a consistent philosophy, with determination and with leadership and a collective will. The International Mental Health Collaborative also seeks to ensure that across Europe, indeed the world there is support and collaboration to move mental health services forward in a holistic, democratic and socially inclusive way. I have much to be grateful to Trieste for.

'Whole Life' could be summarized by the words of my good friend Roberto Mezzina:

> **"The person and not the illness at the centre of the process of care, for recovery and emancipation, through users' active participation and through ensuring full citizenship….from hospital to hospitality…."**

It is certainly not a new concept but it is a value based approach which reaffirms patients as citizens with rights and that mental health services must help the person and not just treat their illness through understanding what is going on in the person's life and helping them overcome crises. This has to be done in the social context without the patient having to lose value as a citizen. Thus a major focus is on maintaining and creating social roles and networks. Underpinning all of this is of supporting people in their hopes and prospects for recovery. This involves us giving real choice and power to people; and a commitment to seeing change and ensuring community participation.

So, I have said a little about Cornwall as a place, a County with over half a million people but probably over a million in the summer. It has never been considered to be at the forefront of mental health work although when I arrived I was surprised just how much energy and innovation there was and how good local solutions were being developed. The Trust provided services which employed about 2500 people across 50 sites and 2.400 square kilometres. The Trust was responsible for providing a full range of services to the population although it still had two very old and centralized Hospitals. Good progress had been made in developing more dispersed services and, driven by a national initiative to improve services, had constructed new services to which I will refer to later. Some money had been made available by the government but the service models it expected were very prescriptive and difficult to fully develop in a rural area.

It seemed important to try to harness the whole organisation's energies and indeed to engage with the widest circle of community and public to bring about a change in thinking, a change in culture and ultimately to develop a more socially inclusive approach to mental health.

We began by improving communication throughout the organisation. We wanted to avoid being elitist by only working with senior clinical staff. Traditionally health care is hierarchical and ignored the collective wisdom of the widest circle of stakeholders choosing instead to leave decision making to a small, powerful group of professional staff. We began to hold meetings across the county to share thinking and involve not only staff at all levels but community groups, service user and carer groups and other agencies. We gave some very clear messages about what values and principles should underpin our services and tried to capture all the thinking that people had from their massive collective experience. The idea was very much to make it clear that change could only happen when:

- There were shared values
- There was commitment from Top to Bottom
- There was involvement and value from service Users
- We all worked collectively

By being part of the 'Whole Life Programme' we were able to expose staff at all levels to thinking from other places where change had happened. It was important to see that good services existed in places that perhaps we least expected them. Staff visited places like Trieste, Cavan and Monaghan and Lille and were inspired to believe that even in Cornwall, a place away from the 'so-called' centres of excellence, we could bring about change. Those staff returned, inspired and worked with their colleagues to implement some of the change in thinking and culture in their own localities and services. My colleague Michaela, whom I mentioned earlier, is an excellent example of somebody who brought enormous change within her service by applying 'Whole Life' and Socially Inclusive principles and using ideas brought from visits.

Just as I saw amongst the staff from Sardinia a few weeks ago, staff in Cornwall responded to the challenge of change in approach and it was important that I and fellow senior managers and clinicians gave full support for people to express themselves, for people to take risks and be bold to work towards change. People needed to see that their ideas and energy were not dismissed by senior managers or clinicians. I cannot overstate just how much energy and enthusiasm I saw once staff felt that the way forward was clear and that there were common goals and objectives. Of course, I have to also say that there were those who did not want change, those who perhaps had a heavy investment in the status quo. Some clinicians resisted the change in thinking and it was important to find 'Champions' in every profession, every area and every service. It was my job to support those champions of change whether they were doctors, nurses psychologists or manual workers. Where there was opposition we attempted to engage even more comprehensively and seek converts to the 'Whole Life' principles. Those struggles go on…there will always be people that will say:

> "It can't be done" or
>
> "That is OK for Manchester but it won't work here"

Throughout this time it was important to have allies, to have alliances and we worked hard both within and without the organisation to work openly and collaboratively and in this I am so grateful for the support given by services in Ireland, Italy, France and Sweden. It was important to be able to keep demonstrating to people that there were alternatives and that they were getting outcomes that service users wanted.

It remained important to make explicit and repeat concepts such as:

- Keeping Users at the heart of all that we did
- 'Whole Life' principles
- That everybody had the right to hope for recovery…and not just be symptom free
- Citizenship is what gives us social meaning….people need to retain it or be helped to recover it
- Waging war against stigma and discrimination
- That people want well-being as well as health.

The notion of Social Inclusion for groups often excluded from the benefits of citizenship has grown in importance nationally in the UK but there were difficulties finding practical expression at local community level. Indeed it remains a challenge but the "Whole Life' philosophy helped to give meaning to what Social Inclusion is all about and how it is foolish to expect simple clinical services to fully address the exclusion and discrimination experienced by people with mental health problems:

Thus, we began to think not only about how we could make our clinical services more 'holistic' but also how we might draw communities into mental health and how we could be more visible in communities. We embraced the idea that all citizens were empowered and valued when they:

- Had open access to help and also to full and helpful information
- Had a decent standard of living
- Had access to Employment, housing and leisure
- Spent as short a time as possible, if at all in hospital
- Did not have to 'negotiate' into or out of 'care'
- Could access help and advice when they wanted it and at an early stage of their problems
- Could access people (not necessarily skilled professionals) to give them time, advice and help with recovery, who could help with their social inclusion
- Were asked what they wanted and helped to achieve it (CUES)

This meant improving our links with schools and colleges and helping them to not exclude people who had experienced mental health problems. We made considerable efforts to meet with, support and encourage local employers and encourage them to be positive about employing people with mental health problems. In return we tried to say how they could get support for their workers who may experience mental health problems. It meant that we spent more time trying to use valued and ordinary settings in the community for our activities and taking every opportunity to network within those local communities. This often meant becoming partners in ventures not usually associated with a Specialist Mental Health service such as Catering, sustainability and local community development. We were amazed at the enthusiasm for new alliances amongst community groups. We also became increasingly involved in highlighting stigma and discrimination and finding ways to challenge and overcome them. Perhaps the most important message we repeated over and over to communities and anyone who would listen was 'This is about **us** not them' and highlighting that it was ourselves, our families, our friends and our fellow citizens …..not a race apart!

We knew that we had a long way to go and much to do but increasingly felt that we were working collectively to achieve our goals. We had to live up to our ideals and began to try to apply them, service-by-service, starting with those which were most receptive. Where we had our champions; Recovery. Early Intervention, Assertive Outreach.

Corporately, we maintained relentless top down pressure. Subjecting all staff to the philosophy and principles of 'Whole Life' from day one of their induction; through high profile contact with service areas, and through personal objectives. The role played by clinicians was central to success and it was important to challenge clinical practice; not in a disrespectful way but by asking what alternative approaches may be available and helping people to be bolder in their practice. England is a very risk adverse country and it was important to show real support for clinicians who had the courage to be bold and creative.

After dinner one evening Pepe suggested to me that I am ideologically opposed to doctors…but I assured him that nothing could be further from the truth. Good doctors who value social inclusion and who are driven by 'Whole Life' principles are worth their weight in gold. If only there were more such doctors, nurses, social workers, psychologists. Professionals who have the confidence and courage to break free of the clinical straightjackets that impede their creativity and skills in working with people.

During this period we took great care in who we appointed whether they were professionals or manual workers. Service users helped us to choose which staff we should appoint, recognizing that it is not enough just to be clinically sound it was important that people were culturally and philosophically sound.

We attempted to ensure that experienced staff had the opportunity to refresh their thinking and organised cohorts of key clinicians and managers to train together with 'Whole Life' and Social Inclusion featuring in all elements of the development work. In turn we then encouraged those people, at all levels of the organisation to 'lead' on different elements of the programme, ensuring that we gave support to those

'Champions of change'. In a wider sense we tried to give the message that we were interested not just in standards for better health but standards for the health and well being of whole communities.

The Trust worked hard on trying to make itself an organisation that not only spoke about these key concepts but behaved that way too. The Trust was seeking to become a 'Foundation Trust' which allowed for a better way of doing 'Whole Life' via a more locally accountable organisation based on mutuality and a Co-operative philosophy which demanded more democratic governance including recruiting 'members' from staff, service users and the public at large. This entailed a huge public consultation and debate, which brought mental health issues out into the open and reached out into all the communities of Cornwall. That particular piece of change is ongoing but hopefully will ensure more practitioner and service user engagement in running the services. It is part of a movement towards changing the nature of the organisation into one which is better equipped to deliver 'Whole Life' services and offer better opportunities to challenge and defeat the stigma and ignorance about mental health that exists in communities.

Whilst Mental Health obviously needs to make full use of the 'science' at its disposal we must not allow it to become a slave to that science. Working with people is also an art and we all need to strive to ensure that creativity and compassion and liberation have an equal importance. It is in this respect that service development, in addition to making use of ALL empirical evidence must also be a 'value driven' service. A service, which recognizes patients as citizens with rights and to strive to help the person and not just treat an illness. The importance of hope and the prospect of recovery demanded that we consider how to develop services that allowed people to maintain their social roles and social networks and where necessary to support people to change living conditions, lifestyle work. Increasingly we invested in trying to help people with mental health problems to be well physically as well as mentally and focused upon smoking cessation, exercise and healthy living.

In all this, it was also important to acknowledge that our staff are people first also and to try to create working environments that allowed people to flourish. Staff surveys told us that apart from the obvious frustrations of salary levels and accommodation the biggest frustration was people not feeling valued, not being taken notice of. The Trust attempted to greatly improve its two way communication through a wide range of communications media, always taking the opportunity to emphasise the total commitment to Social Inclusion and the 'Whole Life' approach and, most importantly stressing the importance of making full use of the extensive skills and experience the wider staff group possessed.

Many practitioners were wary of change and it was important to keep an active dialogue through regular meetings to assure people that it was not change just for changes sake. People had seen many previous 'false dawns'. Experienced clinicians needed to be assured that there was a clear goal. It was important to help to liberate practitioners from some of the bureaucratic, organizational and professional constraints that impeded their skill and creativity. We had a small but influential group of senior doctors who were real champions for change and who worked hard to support and encourage their colleagues to become involved and active in service development. I think one of the most important messages in all this was that we all had to feel better about what we do, to be optimistic and be positive. This could only be achieved when staff had real choices, real information and real involvement and the prize once the values, thinking and culture is understood and accepted is 'earned autonomy' to develop truly responsive local services in their areas of work.

Finally, I want to return to the issue of social inclusion and the 'Whole Life' approach. When I talk to some healthcare groups there is sometimes a question about whether social inclusion should have the urgency that I believe it merits. Some practitioners say that it is their job to help people with their illness and that others should address other elements of people's problems. I believe that to be shortsighted and fundamentally flawed thinking. However. It is of little importance what I think! I would however contend that the evidence

available suggests that without a 'Whole Life' approach we are merely dressing the wound, important in itself but wasted if we do not attend to the bigger issue. In the UK there has been a growing awareness of the huge cost of mental health problems to the state. 40% of all incapacity benefit (900,000 people) goes to people with mental health problems. Mental; Health is undoubtoubly the major cause of 'unhappiness' and family breakdown and costs 2% of the total GDP of the UK with a total bill of around £17 billion p.a. in terms of lost work days, care, economic loss and premature death and disability. That is before one takes into account the human cost of suicide, other consequences and the wider issue of well being in the population.

Whilst we all understand that mental health has been a lower priority than other issues there is a growing understanding, certainly in the UK that, as influential economist Professor Layard reported:

> "…Mental health…it is at least as important as poverty"

He went on to demonstrate the very real link between mental well-being and 'happiness' as the route to social inclusion. and thus less cost to the state. It is my contention that if we wait for altruism to improve services we will wait forever but there is an opportunity by working in a 'Whole Life' way, by harnessing local communities and by giving people their status as citizens we can take a huge step away from the notion that mental health problems are just about health care. It is only then that we can expect to see true recovery and true social inclusion. For politicians and senior bureaucrats there is a new incentive to radically rethink the way services are delivered if they are to achieve the double benefit of better services **and** a reduction or at least slow-down of mental health costs and with the prospect that what money is spent will produce lasting benefit and more social cohesion. I would contend that we, as health professionals may not be as concerned about the national costs but it is a powerful lever to demonstrate that radical change brings both financial, healthcare and social benefit. Increasingly the notion of social capital is being accepted and in the UK we have certainly seen a greater interest at the highest level to reduce Social Exclusion by re thinking the approach to mental health. Indeed the UK government recently appointed a national Minister for Social Inclusion to give a cross government focus on the issue….perhaps a 'Whole Life' approach in Westminster!

Thus, in approaching service change and development I suggest that Social Inclusion must frame everything we do. The second key factor, especially in places like Cornwall and Sardinia is to accept the need for locally accessible services; services that can connect with local communities and have the autonomy to do what works locally, not what works somewhere else. At the end of the day, Sardinia must find its own solutions, and do things the Sardinian way. However, the importance of looking further afield and learning from others cannot be overstated. Certainly, in some of the work we started in Cornwall drew upon what we had learned from Trieste, Cavan and Monaghan, Lille etc. It is why collaboration and networking is central to the work of the International Mental Health Collaboration.

Because Cornwall's population is dispersed and spread widely we attempted to deliver services in localities but recognized that more specialized services needed to deliver to bigger, but still recognizable populations resulting in a sort of pyramid of services across the County. This only works if the whole is managed, integrated and coordinated effectively. Service Users have no interest in having to find their way through a maze of access points and where possible we want people to have a single entry point, not governed by bureaucracy and 'referral'. The 'Whole System' should ensure that people get what they need and want with the minimum of difficulty and, most importantly that they remain in control of their lives and care and have real choice about the help they receive.

Thus the Trust for its population of 550,000 cascades services into local communities of around 45,000 people, then Districts of about 184,000 population, then East and West each with around 275,000 population and finally countywide with a population of 550,000. It shapes it services as set out:

- 12 local integrated mental health teams (45,000 population) Members linked to primary care teams
- A range of supported living places in each locality
- 3 Assertive Outreach Teams (184,000)
- 3 Community Teams for older people
- 3 Mental health recovery Units/Teams (Including Social Inclusion workers)
- 3 Crisis/Home Treatment teams (184,000)
- 2 new in-patient units on general hospital sites (Total 149 beds)
    - 83 acute (reducing to 50 by 2007)
    - 16 intensive care (reducing to 10 by 2007)
    - 50 places for assessment for older people (reducing to 40 in 2007)
- 2 Crisis Houses
- 1 Community Forensic Team
- 1 Addictions team
- 1 Community Eating Disorders team
- 1 Early Intervention team
- 1 Psychiatric Liaison team
- 1 Sanctuary House
- Primary care Workers

Of course community networks and alliances are extensive and crucial to the inclusion agenda and the concept of 'Whole Life'. We built up strong alliances with service user groups, family groups, community centres, local commerce, local schools and churches and gave responsibility to local managers to develop and build those community networks.

The core local service and main point of access to services were the Local Mental Health Teams comprising:

- 1 manager/co-coordinator
- 1 senior psychiatrist
- 1 junior doctor
- 5.5 Psychiatric Nurses
- 1 social Worker
- 0.5 Psychologist
- 0.5 Occupational Therapist
- 2 Social Inclusion (STR) workers

The gradual reductions of in-patient services have in part funded the development of more dispersed services in the community. Whilst having sufficient investment for services is important it must be understood that change is not dependent solely on increased and new investment. Often less expensive community options are considerably cheaper than services that rely on hospital care, not to mention huge pharmacological bills paid to that monopolistic industry.

By reforming and developing more holistic choices it is possible to divert resources from traditional healthcare provision to community support, especially as it would appear that better outcomes are achieved by having more locally responsive integrated services. It is a circle of improvement that by developing more socially inclusive, local services there is less demand for lengthy stays in hospital thus allowing a transfer of resources into new services. Already we are seeing results, which are far better than anticipated. Service

users have said in surveys that they feel that they are getting better services; people are staying out of hospital longer and an increasing number of people with long term problems are finding employment, good housing and meaningful roles in their communities. The number of people requiring out of area hospitalization in Forensics and eating disorders has reduced dramatically through the work of Community teams. The relatively new Home Treatment and crisis services has seen bed occupancy fall by 30%

Service Users have re affirmed to us that it is not always the help of a doctor, nurse or social worker that is needed; perhaps just someone who has the time and knowledge to help them to access what the community already offers; perhaps having a job will give them the respect and sense of well-being (not to mention the money!) to feel a full citizen.

Cornwall is a very ordinary place, it is not special, it hasn't got special people but it has the will and the determination to change the way it tries to help citizens who have mental health problems. It needs to find the 'Cornish' way to do it just as Cavan and Monaghan have found their way, Trieste has found its way and Sardinia will also find its own way.

It is my belief that in constantly asking the questions 'Are we working with the whole person? Are we respecting his/her wish to enjoy all the benefits of citizenship and liberty? that we are all well on the way to improving the social inclusion, health and well being of our communities and perhaps, most importantly we will be striking a blow against the stigma and discrimination that comes of treating mental health as simply a disease which communities need protection from. I hope that in years to come people will point to the mental health services in Sardinia and say, "They are the best in Italy"

I will leave you with my own personal view that where there is determination, vision and strong leadership service users and staff alike will respond positively. Some will say "ah but this is Sardinia, it won't happen here!" but that is what was said in all the places where change took place.

By getting everyone informed, involved and included and giving a clear message that there is 'no going back' the myths of mental health can be demolished, the doubters will be convinced and we have a good chance to really move from the Tyranny of Patienthood to Citizenship for people with mental health problems.

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