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## **Whose Health Is It Anyway?**

My family used to believe that the Lake District poet, William Wordsworth was one of our ancestors. It is not true, but I am attracted to him and to his sister Dorothy. It was Dorothy who told her brother about the daffodils she had seen. It was William who then wrote the celebrated poem about daffodils:

I wandered lonely as a Cloud  
That floats on high o'er Vales and Hills,  
When all at once I saw a crowd,  
A host of golden daffodils;  
Beside the lake, beneath the trees,  
Fluttering and dancing in the breeze.

William turned his sister's everyday experience into something special and with more meaning.

I plan to share some images from my everyday work experience as a health service manager in the UK. I hope you can turn it into something with more meaning.

I want to walk with you, not through a field of daffodils, but through selected images from my work experience. I want to use them to think about health; who owns it and who is responsible for it.

I have been a manager of services in the mental health field in the UK for 35 years, in both the state and non-governmental sectors. I have no specific professional discipline or training – I am in the long British tradition of amateurs who muddle through!

My career started as a Child Care Officer working with families in need of long-term support. Alarmingly, I had no training, although I was supervised.

I was working in a deprived and isolated former mining area on the west coast of Cumbria, between the English Lake District and the sea. The communities had lost their reason for existence when the mining of iron ore and coal ceased, but they continue to exist.

The villages were inward looking and cut off. They seemed to have no over-arching logic or sense of place. They were about existence and survival; deprived and depressed.

I sometimes think of Sheila, and of my attempts to help her to take some control of her life and to strengthen her sense of self. I think also of my recommendation to my manager that Sheila was right that she could no longer cope and that her son, John should be taken into care whilst she focused on his baby sister.

We did not “take” John away; we responded to her request. She was a single mother in very poor housing, with a minimal income and no prospect of that changing. However I wonder what it did for John and what happened to him. We dislocated and fractured his life, his core relationships and his roots. I am sure we gave him better accommodation and better food, but at what cost?

My next job was in Scotland where I opened a new “transitional care” hostel for young people leaving institutional care. Its role was specifically to help young people to rebuild a sense of self-value, as part of helping them to move forward and to establish themselves in the community.

In this job, I met many people who could have been John. They came from children’s homes, or the penal system, or psychiatric hospitals. They arrived with no real sense of self and their identity was in what they did that day: fight; drink; drift or self-harm. It seemed that at least in these things they felt real.

We tried to respond to them as individuals and to create a community that supported each other in more positive behaviour. We used the environment and relationships to help reinforce their sense of value and to look to the future.

For me one simple image conveys much. People would arrive with a black polythene sack containing a few clothes and, perhaps, a single cherished object or faded photo. For many, when they left us we would have to transport them with a large car full of their new possessions. The new possessions were not of great financial value, but they seemed to be symbols of a person beginning to establish a past and invest in the possibility of a future.

So, from those two jobs there are images of health which are little to do with physical well-ness but much to do with wholeness and the way in which context, experience and personal history sustains it or erodes it.

I next spent a decade in a non-governmental organisation working in the field of mental health across Scotland. We set up housing, employment, training, and social support schemes. We also ran some educational programmes and lobbying campaigns.

I had a strong feeling that we were intruders into the professional world. We were helping people to re-establish themselves in relationships and in the mainstream of society. This was largely seen by professionals as helpful and appropriate. However some of our service provision and other activities directly challenged the traditional treatment approach because that seemed to us to have created greater difficulties for people as they returned from treatment to life.

Our services were not part of a formal, statutory sector and we were not clinical professionals in a conventional sense. However we did bring a kind of professionalism to our work. We had a coherent framework of knowledge and experience and we operated with standards and controls. I believe that our different definition of ourselves and our role from that of the traditional professionals [*different*, not better or worse] gave us a different kind of relationship both with the people who used our services and the people around us in the wider community.

We were positioned between the mainstream community (and peoples’ experience of living) and the professional system (and people’s experience of treatment). From that perspective, some of the risks and benefits of the treatment system looked different from the perception of some clinical professionals. They also looked different from the perceptions of some of the general public. It seemed to us that both the professionals’ desire to treat, and the community’s desire for a resolution to the person’s oddness or difference missed the heart of the problem – the distressed individual’s search for ways of managing themselves. Both were insensitive to the thoughts, perceptions and feelings which were the reality of their life experience.

I then moved into the National Health Service in what was then a Regional Health Authority for a population of some 3.5 million people in the north west of England. My role related to the strategy for learning disability and mental health services. For both, this was a critical time for the policy of closure of large hospitals. There was a great deal of policy making and action – but perhaps at the expense of meaning.

“Community care” was seen as meaning “services not in hospitals”. “De-institutionalisation” was seen as closing large 1000 bed hospitals. The notion that community life involves presence in social networks, and that care involves relationships sometimes got lost in the design of services. The new services were often little more than what used to be done in hospital buildings now being done elsewhere - or not done at all. The new locations were invariably smaller and perhaps less remote than the old hospitals, but if 'institutionalisation' is a process and an experience, they were no less 'institutional'.

A small group had championed a learning disability strategy for the area that was committed to enabling care for living in community. It was focused on people having ordinary lives, lived ordinarily, though with extraordinary support in order to achieve that. Of course such support costs more money than warehousing people in large units. It also means that more people are discomfited by closer encounters with deviance and difference. Cost and public discomfort are powerful factors, and they consistently threatened to outweigh the benefits in life and health for the individuals involved. The principles and values of the strategy, and the focus on what mattered to individuals as they sought to live their lives, was maintained only with a great deal of effort and political skill from a hugely committed but very small group of activists.

In my next job, I found myself managing what had been one of the largest of the large mental illness hospitals throughout a period of fundamental change. We worked very closely with our local authority social service partners and with the voluntary sector, in order to build new services in the communities the hospital had traditionally served. We closed huge old buildings and sold off much of the site. We managed a massive change programme for the hundreds of staff.

Two abiding images stick with me. One is of the man, who I am ashamed to say I can no longer name. I would spend time with him from time to time. He would bemoan the loss of the world he had so valued and appreciated: a ward of 50 people in the 1000-bed hospital where he had been watched over by impersonal and detached asylum attendants. Nothing I had to say or to offer would persuade him that the world we were creating for him was better than the world he had lost. I can rationalise about how differently he would see things when we had helped him make the transition, but my guess is that he did not make the transition.

I lost touch with him, but I suspect that his personal coping mechanisms were too deeply rooted in a world which was no longer available to him. The scale of change was too much for him, too late. My fear is that at some point the pain that we created for him as we “improved his lot” gave him only the option of killing himself.

The other abiding image is of Steve, a former senior nurse, as institutionalised as many of his patients, who was frightened and disorientated about moving into new services with new and different demands. However, he actually found huge fulfilment in his new career. He began working with natural social leaders in the deprived neighbourhoods and run-down inner city estates. He mobilised them to help build relationship and support to members of the local community who were struggling with their mental health, including some who had moved out of the hospital. He jump-started social networks of genuine care in the community.

Later this took him further into a world of social enterprise, using latent capacity and experience in apparently deprived and “hopeless” neighbourhoods in order to develop healthy communities that were able to reach out and engage those who were distressed and on the fringe of society. From being part of the institution’s clinical fraternity, he became part of a network of community workers and social activists. His activities were totally different but he personally remained very clear that what drove him was exactly that which had led him into

nursing – he was part of a team effort to find ways of easing the distress and disorder of people whose mental health was challenged.

My next role took me to a much more closed world. I had responsibility for a high-secure psychiatric hospital, having been built like a high-secure prison and now operating as a blend of prison and hospital. It was a challenging and challenged place. My belief (perhaps subsequently proved to be at least partly wrong) was that the place had acquired some of the disorder of the fractured people within it, and had a self-sustaining dysfunctionality. Whether or not that was true, it was certainly a place in which rules and boundaries were paramount.

It was a setting which could not function on trust or values. It had developed a tangled web of policies and protocols to govern everything. However, the consequence was that both staff and patients were deprived of that which marks them out as individual persons and human beings. Individuality and the risk of normality were too dangerous, but they are the basis of responsibility. Those things that make life outside meaningful and purposeful, seemed to be too de-stabilising and dangerous inside.

I do not know whether it really is the case that some people's disorder is such that it can only be managed in a disordered environment. Perhaps it is necessary to strip out the tacit assumptions and subtle nuances that form part of the governance of "normal" settings and relationships. In a sense, here is not the place to explore that. I simply want to share my experience that there can be not only therapeutic communities which can foster personal growth and change, but also counter-therapeutic communities in which the dynamics sustain not growth but ever increasing levels of dys-function and dis-ease.

My next job was a change of direction. I led a team working across mental health services in the North West Region of England whose role was to support local service change and development. During this time I found that I was increasingly interested in those services that supported social inclusion and integrated specialist mental health input into wider aspects of social life. I was also keen to see some of the insights of mental health clinicians being used to inform services that relate more widely to health and illness.

I therefore moved into a new role in a Primary Care Trust. These are new local NHS organisations responsible for improving the health of the population. They receive the government health funding for their population, with which they 'commission' services for primary or secondary care. PCTs also directly provide some community services – mine included the full range of mental illness services. I believed that locating the delivery of mental health services in the heart of the agency with mainstream health responsibility would bring benefits in the approach to both mental health and wider health and well-being.

In reality, I am not sure that the theoretical advantages materialised at all for the people we served. In any event, before we had time to be sure, the cycle of reorganisation that so besets the NHS hit us again. The organisation was split and its parts merged with others. However what was already apparent, was that there were common issues across many sets of services for people with long term conditions, whether mental illness, diabetes, asthma, arthritis or whatever. To state it too simplistically, these conditions all highlighted the limitations of a traditional medical model of patient care. They are where health and social care [in its broadest sense] most obviously must integrate.

With the reorganisation, I chose to move into my present role in which I have responsibility for public engagement for the Primary Care Trust that now serves a population of 500,000 across 6,800 sq kms. It includes market towns and the picture post card Lake District, (complete, at the time of writing, with its host of golden daffodils!) but it also includes 16% of the population living in Local Authority wards among the most deprived 20% in the UK – including the village in which Sheila lived and in which her grandchildren and possibly great grandchildren may still live.

In Cumbria, we are beginning a process of re-configuration designed to build health promotion and health care around individuals and their communities. We want to build stronger communities that are more able to support the health of their members, with less people needing to call on primary care. We want to develop the capacity and capability of our primary care, so that fewer people need to access more specialist care. We want to shift resources [money, people and skills] down into primary care and communities in order to support this. At the same time we want to focus and consolidate the most specialist services in order that when specialist care is needed, it is of the highest standard.

We have a clear vision of more care of the right kind, in the right place, at the right time in order to help people stay healthy and to manage their ill-health whilst maintaining their lives, relationships and identity. We *want* more effectively to meet health needs of the county's population today. But we *know* we have also to meet the future challenges: in 20 years time there will be 30% more elderly people.

Currently there are dramatic differences in health status and life expectancy across the county. For example, at local authority ward level there is 19.5 years difference between the average life expectancy in the best and worst wards. Unless there is radical change, these inequities are set to increase. But as we lead this process, I can confidently expect to be vilified as a "heartless manager" set on destroying the NHS through pre-occupation with money, central control and short-term benefits. We are sure to generate marches through streets to "save our services". These will be led by the articulate and more affluent middle class. They will fight to maintain the reassuring safety blanket of the status quo. They will resist change and the transfer of resources, thereby creating an opportunity cost to be carried by the more vulnerable and less influential. It is those more vulnerable people who will then continue to have more avoidable illnesses and to die prematurely.

I apologise if I have been too self-indulgent in the images I have selected from a walk through my career, but I hope that they provide raw material for our reflections on health and responsibility. I said that it is for you to take my anecdotes and make them into more meaningful 'poetry'. However, let me start to draw out some of the themes that I see, in the expectation that, in our further discussions, you will build on them.

I was concerned all those years ago about how Sheila could be helped to make sense of her life and to take some control of it. I instinctively felt that both she and the community she represented had to achieve some sense of identity and purpose, some increase in self-esteem and some degree of self-determination. At the same time, I was party to a decision, by professionals, that it was in John's best interest to be taken into care – and away from that community.

Sheila and John seem to have set running themes about health that I have grappled with in various ways throughout the rest of my career. These themes are about individuals and communities and about the different vantage point of individuals and clinicians.

Sheila was a person in her own right, with the usual human blend of strengths and weaknesses and of rights and responsibilities. But it seemed to me to be an inescapable fact that the social, economic and geographical realities of her immediate community played a central part in how she made sense of her self and sought to live out her life. It is too simplistic to suggest that she was totally imprisoned by the realities of her village; but it is equally simplistic to consider her independently from those realities.

And John? I suspect that it was neither "right" nor "wrong" to have taken him into care. I do know that the price he may well have paid is the kind of dislocation that the young people I knew later, with their black rubbish sacks of possessions, seemed to have paid. Whatever the risk and benefit that the professionals took into account when making the decision, I wonder if we rolled them forward to think of what sense he would make of himself and his world as an adolescent who would have to build on this dislocation.

In the hostel for young people and later in the neighbourhood work of Steve, the ex-nurse, I experienced the positive, supportive capacity of communities. I saw how they could work in ways that supported vulnerable members, whilst also developing more strongly as a community. It is not a rosy story of an entirely benign community transforming all its members' lives for the better, but I saw the positive dynamic that had real mutual benefit and appeared to support both personal and community health and well-being.

In the High Security Hospital I think I experienced the converse. There the dynamic was negative, as individuals, both patients and staff, were caught in powerful currents within the community. These currents were not those of support and the acknowledgement of individuality, with all that involves. They were de-personalising and, in being so, seemed undermining of both personal and community health and well-being.

Those are harsh words to say of a hospital. I need to acknowledge that my perception of it may well reflect something of how personally challenging I found the experience of working there. In any event it was a very special facility that has to contend with some of the most profoundly challenging and disordered people and issues. Clinicians in such a setting are expected to operate at the focal point of the most complex web of clinical, legal, moral and ethical tensions.

Clinicians in mainstream psychiatric services do not face such extreme complexities. But that is not to say that their lives are simple. Many of them come from a history and mind-set that is shaped around the profound commitment of the clinician to their individual patient; one to one. Either implicitly or explicitly, there is a sense that the professional has the knowledge and skill to diagnose the patient's condition, to treat it and in some sense to "make it better". Knowledge, power and, in some sense, ownership.

I know that this is another over-simplification but there is at least some truth in it. It is a mutually satisfying arrangement. It re-affirms the professional's sense of their role and, perhaps, of themselves. At the same time it is re-assuring to the patient who is potentially anxious and whose personal boundaries are going to be crossed. It works well in this sense.

It works less well if you take the view that the patient is a person with a past and a future, who is currently coping with a whole set of roles, relationships and responsibilities, and doing so with a mix of skills and weaknesses. In the midst of this, the person has some particular health issue, and the skills or knowledge of the clinician will be potentially helpful in addressing this. I know it is an obvious point to make to this audience given your interests.

The reason I make it, is that I seem to have encountered many mental health services in which clinicians were working with great skill and dedication but showing little knowledge of, or interest in the social setting in which their patients have to live. Their interventions produce some benefit for their patients but miss what appears to me to be a critical dimension, which is seen as either not relevant or as being the responsibility of someone else. What does being treated for a mental illness mean if it leaves you still struggling with getting a place to live, with caring for other people, and with finding meaningful activity?

My lay definition of *mental illness* may make the point. I think of mental illness as a disorder of thoughts, perceptions and feelings *and* a disruption of social roles, relationships and behaviour. Treatment needs to be about both the inner and outer worlds.

This was the problem with the way in which the policy of community care tended to be implemented; it was too often seen as a matter of service re-location, not service re-definition which would address both inner and outer worlds. Perhaps seeing it in these limited terms did not challenge the comfortable traditions about clinicians and patients and about the ownership of services.

Across my various experiences, I had developed a personal working definition of *mental health*. I see it as relating to the coping capacity that each of us has, with which we integrate our inner and outer worlds. Working in the Primary Care Trust reinforced for me the relevance of this across many health conditions and issues.

If I am right in seeing the inter-dependency between an individual and their social context, and if health is to be seen in rounded, holistic, whole-person terms, there are implications that go to the very heart of the relationship between the people and their health-care system, in the case of the UK, our National Health Service.

My current work in Cumbria is part of a fundamental re-shaping of the relationship between people and their health service, and, as part of that, a shaping of the way the NHS works.

I deliberately used the phrase “re-shaping the relationship between people and their health service”. It is a relationship; and in relationships rights and responsibilities flow both ways.

The NHS collectively, and its clinicians individually, does have skills, knowledge and resources that are of particular significance for health. It has an obligation to deploy these in ways that support the capacity of people and communities to sustain health and to manage ill-health. And individuals and communities have an obligation to draw on the skills and knowledge available, to inform their choices and to understand the implications of their actions. A recent major economic study strongly suggests that the UK will only be able to sustain its current kind of health system if the services become much more productive, *and* if the public becomes much more engaged in its own health and pro-active in discharging individual and collective responsibility.

When I think about responsibility and health I am thinking about health in a rounded sense, arguably more related to the resilience that derives from my comfort with myself, (who I am and where I fit) than just to my absence of illness. I am thinking of today, but I also acknowledge that today is a product of yesterday, and the struggles and achievements of the past inevitably echo in aspects of our contemporary experience. Our contemporary experience will itself then become our history.

And so, how do I answer the question I posed as my title: 'whose health is it anyway?'. The answer, for me, is that it is part of a common-wealth. It is importantly mine, but not exclusively mine. It is inextricably linked with the communities of which I am part – but does not belong to them. It forms part of the social capital of those communities which can be aggregated all the way up from neighbourhood to nation. It definitely does not belong to the clinicians or health service managers, but their knowledge and skills are vital contributions to it, and are again part of the social capital alongside the contributions of other kinds of knowledge and skill. As a health service manager, I hope I am able to make some contribution to orchestrating a way of working that does not just balance the books or meet the targets, but which enables the realisation of the inter-dependencies. That way my contribution will have been not just about delivery of health care today, but also about the growth of individuals and communities into a healthier future.

Having started with the first verse of the poet who is *not* my ancestor, in which he caught and transformed the image from Dorothy's walk, it seems appropriate to end with his final verse. It may provide a sense of symmetry to this paper; it may evoke a sense of peaceful contemplation, and may remind you that your task is now to take my images and turn them into something of substance:

For oft when on my couch I lie  
In vacant or in pensive mood,  
They flash upon that inward eye  
Which is the bliss of solitude,  
And then my heart with pleasure fills,  
And dances with the Daffodils.