edited by
Bruce D. Kirkcaldy

Chimes of Time

Wounded Health Professionals

Essays on Recovery

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Chapter 4

Steps towards better collaboration between stakeholders to promote mental health and to alleviate disablement due to mental illness

Robert Miller

The 'Wind of Change' in Today's Psychiatry

In February 1960, the British conservative Prime Minister Harold Macmillan gave a speech in Cape Town to the South African Parliament. It included the following sentences: "*The wind of change is blowing through this continent. Whether we like it or not, this growth of national consciousness is a political fact.*"

He was of course speaking about colonialism and apartheid. It is a singularly appropriate metaphor for what is happening in psychiatry today. Suddenly there is public realization of the depth of discrimination and prejudice which has dogged mental illness from time immemorial. At last, the tectonic plates are shifting. In the past, the lives of many affected by mental illness have been blighted by insensitive, demeaning and alienating public attitudes and mental health services. Today the aspirations of such people, which hitherto lay hidden beyond the horizon, are coming centre stage. The Wind of Change which is now blowing in psychiatry, though not yet by any means global, is becoming quite international. These are heady days for those involved. At last we have some influence, even some power; but we should not overplay our hand. We need wisdom to go with that power.

Some of my own Story

Let me say a bit about my own background, as context for what comes next. I was born in Sheffield, an industrial city in the north of England in 1943. At grammar school, I went into the science stream and in my last year at school, in the school library, I found a book by J.Z. Young, professor of anatomy at University College London, a leading British biologist of that era, called *Doubt and Certainty in Science* – the published version of his 1954 Reith lecture series. At age 17, I was introduced to the idea that all the impressions which flit through our minds,

moment by moment, were linked to mechanisms in our brain, which might be comprehensible. I was 'hooked' – no other word will do; and I've been thinking about that ever since.

In 1961 I enrolled as a medical student at Oxford University, and was becoming very interested in research on the brain; and by 1965 was doing my first research study, recording from single nerve cells in the brains of anaesthetised animals. However, other things were happening. Even in my school days I had been a moody youth, and at Oxford I suffered a remarkable succession of mood swings. Before going to the clinical part of the medical course I acquired a B.A. degree in physiology. How I managed it, considering my health at the time, I don't know. I found myself at University College Hospital, London, in 1966, trying to be a clinical medical student, but badly disabled by psychiatric symptoms. After some complex events which need not be described I was prescribed tricyclic antidepressant medicines and went home to Sheffield while they took effect. Two weeks later, suddenly, I became floridly psychotic, and was committed to the mental hospital in Sheffield, under the authority of Erwin Stengel,[1] then professor of psychiatry there, and two years from retirement. I have no hard feelings about Stengel. He himself knew what it was like to be a refugee, and I now regard him as a man of solid integrity, and a real pioneer in some areas of psychiatry.

It was late November when I was committed. The day after I arrived in hospital, I heard that snow was forecast. I explored the hospital grounds, saw the front gate open, so I bolted, I did a runner, as they say – or as the euphemism has it – I eloped. (Unfortunately, I had no-one to elope with!). I could move fast in those days, headed home, collected by tramping boots and an anorak, and set off for Australia. I didn't get there of course on that occasion, but I legged it about 30 miles over hill country in the Peak district, overnight, during which there *was* a snow storm. This *was* in part a suicide bid; but the fact that I covered such a long distance on foot also has a pharmacological side – was it mania, a not uncommon side effect of tricyclic antidepressant drugs? Was it akathisia caused by

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1   A few details about Stengel may interest readers: He was born in Vienna in 1902, and graduated in medicine there in 1926. He got to know Sigmund Freud around this time. In 1933 Hitler came to power in Germany, and in 1938 moved to annex Austria. At that time Stengel was working under Julius Wagner-Jauregg, who had received the Nobel prize for his idea of treating tertiary syphilis by giving people malaria. In 1938 Wagner-Jauregg joined the Nazi party, and later was involved in the sterilization program for supposed genetic disorders. Stengel was Jewish, and didn't like what was happening, so, as a refugee, he fled to England. He was interned on the Isle of Man during the war, and then had to repeat his medical qualifications to practice in Britain. Later he became founding Professor of Psychiatry in Sheffield. In the 1950s he translated various works of Sigmund Freud into English, including the latter's book on aphasia. He was interested in the history of psychiatry, and wrote on the *origin* of Freud's ideas (especially their debt to the British neurologist John Hughlings Jackson). Working for the World Health Organization in the 1950s he contributed to improvements in classification, and insisted on the use of operational definitions, to make diagnoses more reliable. He was a pioneer in making the topic of suicide an acceptable subject for research in Britain, and wrote a book for the general reader on how to cope with suicide or attempted suicide in a relative. (Until 1961, it was against the criminal law in Britain to attempt suicide.) He died in 1973.

antipsychotic drugs? (I had been given a hefty whack of chlorpromazine by now). Eventually, I phoned home on a frosty morning, and my father met me and took me back in the car. The upshot was that I consented to go back to hospital, not as an in-patient, but as a day patient, where I was for the next six months.

I was out of action for several years. Eventually I retrained as a scientist, at Glasgow University in Scotland, in the Department of Zoology. Then, as a post-doc back in Oxford, I began to specialise in brain science. In 1973 I had another brief spell in hospital, as a result of stopping my medications, in the course of which I was actually told the diagnosis – schizophrenia, as I could have guessed anyway – and was shown it written in the case notes, so that there could be no misunderstanding. After that, about 1974, the idea took hold of actually researching psychotic disorders. I emigrated to New Zealand in 1977, to a job in the Anatomy Department in Otago University, and apart from teaching, pursued my research there for many years. My objective was to bring together my understanding of how the brain works, with personal experience of psychotic illness. This was almost entirely theoretical work, based around academic libraries. However, I resigned my job in Otago in 1999, to continue research work in a freelance capacity. As a result, I was able to complete my big book on the theory of schizophrenia (Miller, 2008). I am now aged 68, and moved north to a rural region of the North Island of New Zealand, called 'the Wairarapa' three years ago.

Since I moved north, I have become involved in psychiatric politics in a way I could never have anticipated. I was invited as a community representative on to committees of the Royal Australian and New Zealand College of Psychiatry. It is a privilege to sit on those committees. It allows me something never possible when I was in academia, where I was always a square peg in a round hole – the chance to influence matters related to psychiatry on which I care deeply. It has also stimulated me to formulate views on many issues which previously were beyond dreaming. However, while I pay a big compliment to the Royal College for its courage in inviting mavericks such as myself on to its committees, when I'm there, my job is to say it how I see it, and how it is conveyed to me by the many people I meet; and if that happens to be challenging, even on fundamental issues, that too is part of the job.

How I landed up in New Zealand

Let me back-track to explain how I came to New Zealand. In the early 1970s, when I got out of hospital the second time, and started to form the ambition of doing research on psychotic disorders, I knew I had a significant health problem. I realised what public attitudes were like, and that I would face discrimination, especially in getting a job. So, I decided, very deliberately, to play the issue with a dead straight bat. No concealment, complete transparency. There were three reasons for this: (i) If I was to be taken seriously as a researcher, I never wanted to be compromised, on the grounds that I had hidden things about myself. (ii) By being completely open, it would force discrimination out into the open, when it would be easier to deal with. (iii) In seeking employment, if I did land a reasonable job, it was likely to be with a boss who had some appreciation of the personal issues I faced. Friends in Britain at the time were worried about the line I

was taking. Forty years later they say: 'You were right Robert, and we were wrong.' But here, I'm not trying to give general advice. Everyone in this situation must take their own decisions and play their own game, mindful of the social context in which they take their decisions.

As a post-doc in Oxford, I had to consider options for a secure job. After discussion in my department, I was directed towards a prominent researcher in another department. I was not impressed by what was on offer, partly because I really wanted to focus on library-based theoretical research, rather than what I foresaw as the treadmill of experimental research. So, I applied for another post-doc position in a different university. The underlying reason to move from Oxford, more of an instinct than a conscious choice, was different. In Oxford, of course there were top-class researchers, better than I would have found elsewhere – but I needed space for personal growth. Like a delicate sapling in a forest of tall trees, in Oxford I would never be able to grow into who I might become. When I told my Head of Department that I was thinking of moving away, he was not pleased. His words were quite revealing. He said: "*Morally speaking, who is responsible for this decision?*" I replied (of course) "*I am*". That line … ('Morally speaking, who is responsible?' …); it conveys the effortless sense of superiority of some Oxford professors (not all, I should say. Some helped me greatly). In effect he was saying "*You're in a dodgy situation. You'll never get a job anywhere else. We offered you protection, and you rejected it.* "And when, predictably, I said "*I am responsible*" he could then wash his hands, and wait to say, "*I told you so*." Well, of course it didn't work out the way he expected. He implied a lot in that remark, but wouldn't say it openly. He concealed his tracks. That's not so nice.

A couple of years later, in the mid-1970s, I was applying for lecturing jobs. In my applications I mentioned the gap of several years in my CV, due to psychiatric illness. At one interview, in front of a large panel, I was asked "*What was the nature of your illness?*" I replied: "*It was a schizophrenic illness*". I was offered a temporary lectureship. Six months later, after another application, I got a cable from a far-away place called Otago, New Zealand, offering me a job there. I went to see my then Head of Department, and asked: "*Should I accept the job?*" He replied, very straightforwardly. "*Yes you should. With your health record, you don't stand a chance of a permanent academic job in this country*". I went out of his office and down the road to the post-office and cabled a reply to Otago, accepting the job; and that's how I came to be here, the best decision I ever took, I should say. Compare that remark with the curly remark I have just described: Which was easier to deal with? Actually the second was more wholesome and honest, and helped me to make a key decision, although it reflected a terrible state of affairs at the time.

A Recent Meeting

Jump forwards to 2011, and my current political activity. Consumer involvement in the health industries has grown rapidly in the last twenty years, and is now a major force in many countries and many medical specialties. This has been propelled from many quarters. One field where the alliance between consumers, researchers and clinicians made particularly notable achievements is HIV/AIDS. The current strong alliance in that field was forged in the 1980s and early 1990s, ahead of

consumer movements in other areas of medicine. In Britain, a key figure at this time was Nick Partridge (now Sir Nick Partridge, CEO of the Terrence Higgins Trust [THT][2]). More recently, he has been using his experience in organizations concerned with community involvement in the health services and health research generally, outside the area of his initial commitment.[3] On 7th November, 2011, I was privileged to meet him and learn of his experiences at the offices of the THT on Gray's Inn Road, London. I particularly wanted to make this contact, to learn what I could of relevance to Mental Health Consumer Groups in New Zealand, Australia and elsewhere.

The field of HIV/AIDS has a number of similarities to the mental health area, which make comparison interesting, but also significant differences. *Similarities* include the following: (i) In both areas, there has been a 'culture of denial'. Vicious circles of fear and ignorance amongst the public have hindered the mounting of effective health programs. In the mental health area readers of this chapter will be familiar with this point. In the HIV/AIDS area, there have been powerful taboos over open discussion of sexually transmitted disease, homosexuality, and sexuality as such. (ii) Both specialties have been regarded as 'Cinderella areas' of medicine. (iii) In both areas there has been unhelpful (and sometimes scurrilous and sensational) reporting in print media. (iv) Both areas have attracted their share of dangerous activists, using media outlets with considerable skill to promote agendas which are either simplistic or, in terms of scientific evidence, manifestly incorrect. Sometimes they use their illness-experience for self-promotion, or to convey a sense of their own embattled victimhood or martyr status. (v) In both areas community activists have had to break through resistance of senior clinicians and researchers reluctant to work alongside community spokespersons, sitting, as equals, on the same committees. (Nick Partridge described his experiences in the 1980s, as the sole community voice, on committees full of eminent professors). (vi) Nevertheless, in both areas persistence has paid off. It is now realised that fresh viewpoints from community people may highlight weaknesses in current research or practice, such as expensive research that is going nowhere, or the inability of experts to integrate other areas of valuable expertise into their own thinking.

Differences include the following: (i) Mental Disorders only sometimes become matters of life and death; HIV/AIDs from 1980 up to the late 1990s *was* such a matter, and on a large scale. (ii) HIV/AIDS is a more discrete and precisely defined condition in terms of medical science than are most mental

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2   www.tht.org.uk.
3   One of these in called INVOLVE (www.invo.org.uk *"National advisory group to the Department of Health, established in 1996, part of the National Institute for Health Research. Supports and encourages active involvement of the public (e.g. patients, carers, service users) in NHS, public health and social care research."*) Nick Partridge is also involved with the JAMES LIND ALLIANCE. (www.lindalliance.org *"To increase the focus of research on questions and priorities shared by patients and clinicians about the effects of treatments in which there is no commercial interest; To promote working partnerships between patients and clinicians, to identify their shared priorities for research; To ensure that important questions are not overlooked because of emphasis on chronic but not acute health problems; severe but not common health problems; and disease-specific but not cross-cutting issues, such as social support."*)

illnesses. Community activism related to HIV/AIDS could therefore focus on research, and especially on decisive clinical trials, in the hope of finding a cure, or at least an effective treatment. In the mental health area, disorders are more diverse, more difficult to define, and more complex conceptually. Fundamental research from which effective treatment or cure of mental disorders might emerge inherently has a slower tempo. Community activism has therefore tended to focus on service delivery, or the relative merits of established clinical approaches or strategies of treatment. (iii) Psychiatry both historically and today has been split by a deep philosophical division, between the '*somatikers*' and the '*psychikers*' in the nineteenth century German-speaking world, and its equivalent today of bio-genetic versus psychosocial views on causation and treatment. There *have* been such splits in the HIV/AIDS area, for instance by those who deny the viral aetiology, but in most countries this is now mainly confined to fringe groups. Divisions are by no means as old and deep-rooted as those within psychiatry.[4] (iv) In psychiatry, but not in the HIV/AIDS field, psychiatrists have had the power to commit patients involuntarily,[5] which has made it more difficult for consumers and psychiatrists to work together. Even when committal is not the issue, the relationship between doctor and patient is fundamentally different from that in any other area of medicine: A psychiatrist very often finds he has to protect a patient from him/herself. (v) HIV/AIDS is definitely an unmitigated illness. In contrast, many mental illnesses combine, in an inseparable mixture, definite (sometimes severe) impairment in one area of psychological function with unusual, (even outstanding) talent in other areas.

Several things combined in the HIV/AIDS area, leading to a fruitful collaboration of consumers, clinicians and researchers. The sexual liberation of the 1960s and 1970s, which led to increased openness about sexual matters, set the scene for this. Without that, the collaboration might not have developed. Amongst the gay communities in North America this led to emergence of a vigorous political force. In the mid-to-late 1980s, as the nature of HIV/AIDS became clear, there was a growing sense of apprehension and urgency, shared jointly amongst groups themselves at risk, clinicians and researchers. No-one knew how big the problem would become. Amongst consumers, there were many young, articulate and energetic activists. These included Terrence Higgins himself, one of the first in Britain to grasp the size of the problem represented by AIDS, and who died from AIDS. These developments produced a social context

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4   Another parallel in the field of infectious disease is relevant here: *Myalgic encephalomyelitis* (ME: 'Chronic fatigue syndrome'). This has been variously regarded as a psychiatric disorder (perhaps a form of depression), or as a viral disorder. Interestingly, the passionate insistence of consumers is that ME *does* have a biological basis, not a psychological one, an emphasis exactly the opposite of that which often prevails amongst consumers of mental health services.

5   In modern times, in many jurisdictions, it is not the psychiatrist him/herself who has this power, since initial reports by psychiatrists are subject to routine legal review. It also needs to be said that, in today's world, the occasions when these powers are needed involve a small minority of patients, mainly those with psychotic disorders, compared to a generation ago. Nevertheless, the memory of the past lingers on in the public mind. (Acknowledgements to Professor Rob Kydd for drawing my attention to these points).

where researchers and clinicians in the neglected fields of STD and infectious diseases knew they were on the frontline of a very important battle. If they were to respond adequately, they had to join forces with community people in pushing through their research agenda. Nevertheless there were stormy scenes at large international AIDS conferences in the late 80s and early 90s. There was tension between consumer groups and researchers, with mass demonstrations in Bethesda, Maryland outside NIH, and outside Wellcome and MRC head-quarters in London. The consumers' role proved decisive in the politics and science at big research meetings, by pointing out that much research was irrelevant: They shaped the course of much subsequent research. The hardest group of professionals to bring on board were those, excessively concerned about rigour of research, who wanted absolute proof before turning lab findings into clinical trials or clinical trials into routine treatment (an unfortunate consequence of the thalidomide disaster in the 1960s). However, by the mid-1990s, with the Terrence Higgins Trust playing a leading role, research studies were conducted involving close collaboration with researchers, on trial design, recruitment, and rapid dissemination of results. By 1996 highly effective antiretroviral drugs were available, which by now have reduced the death rate by 70%.[6]

The Interface between Consumers, Researchers and Clinicians in Mental Health

Emergence of the consumer movement in the mental health area has a rather different history, and is not yet as coherent a force as developed earlier in the HIV/ AIDS field. (i) Early community pioneers in the mental health area, starting in the 1970s, were not consumers themselves, but rather family members in bodies like the National Schizophrenia Fellowship in the UK, and similar organizations in New Zealand, Australia and elsewhere. Activism amongst consumers came later, probably because it took some time for them to overcome their own fears, related to the climate of stigma and discrimination. When this happened, separate organizations tended to emerge for consumers and family members, naturally enough since there are genuine differences of interest between the two. There were antagonisms between the respective groups, and also between consumers and psychiatrists. This is still true to some extent. There *is* however some coming together of the different stakeholders, and, amongst community consumer groups in the mental health area, there *is* now a body of vigorous, articulate activists, keenly interesting in being better-informed, and willing to challenge orthodoxy. However, there is far from a united front amongst consumer groups on basic

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6 It should also be said that, in the crisis of the AIDS epidemic, the stringency of usual FDA procedures for ethical scrutiny of new medicines was relaxed and approval of new medicines thereby expedited. The campaign to persuade FDA to relax its usual procedures was led by a community activist, Martin Delaney, and has since been extended to anti-cancer drugs.

(For details see: http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/ HIVandAIDSActivities/ucm134331.htm#.T-vs2o5VA5Y.email). (Acknowledgments to Professor Tim Peto).

philosophy. Few activists are able to assimilate biogenetic and psychosocial models of mental disorder into a coherent viewpoint. (The same can of course be said about researchers.) There is no unanimity on respective roles of psychotherapies versus biology-based treatments. (ii) Psychiatrists in most countries have been reluctant to engage with consumers. International conferences on fundamental aspects of psychiatric research have been slow (compared to AIDS conferences), in bringing consumers into their midst. The reasons are discussed later in this chapter. (iii) There has never been the sense of urgency in the mental health field, seen in the early years of the HIV/AIDS emergency. However, some psychiatrists now fear that the 'metabolic syndrome' linked with some new antipsychotic drugs constitutes a 'time bomb', which may soon lead to a major epidemic, and feel that urgent response is needed now. (iv) The ingrained scepticism of some researchers may parallel that in the HIV/AIDS field (for instance when absolute proof is demanded that early intervention improves long term outcome, before such programs are implemented). (v) Fundamental research on the biological mechanisms of mental illness is unlikely to attract a high level of enthusiasm from consumer groups (much though such research may be needed), partly because it seems so far removed from their own daily struggles.

Compared with the HIV/AIDS field, in the mental health area, active collaboration between consumers, clinicians and researchers lags far behind. How can active collaboration be brought about in the field of mental illness? There are lessons to be learned from the history of collaboration in the HIV area.[7] In the next three sections I discuss changes that I believe are needed. These comments are addressed partly to mental health professionals. Although I am not really one of them, I meet them often as friends, and often try to put myself in their position and imagine the pressures they are under. The comments are also addressed partly to researchers, of which I definitely am one, but with a background different from the vast majority of such. I devote more space to addressing the approaches to be adopted by consumers and other community people. Here I *am* to some extent one of them, but with a different background from most of them. Finally, I make some comments addressed to all these groups on the nature of the interactions from which may grow real partnership.

A Challenge to Mental Health Professionals (Clinical and Research Staff)

The unwillingness of mental health professionals to embark on true partnership and collaboration with community-based activists is true of some, but by no means all such professionals. While many psychiatrists are open to collaboration, there *is* a need for a shift in the attitudes of many mental health professionals. When there is unwillingness (in my view) it is partly because psychiatrists (and others in mental health professions) do not yet recognise that their patients can be intelligent commentators on the issues involved, and perhaps also because those professionals are at some level aware that their own research concerns are far

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7   I hear also that in the Alzheimer's field, there is also quite fruitful interaction between families and researchers/clinicians.

removed from those of the consumers (whose interests research *should* be serving). Sometimes it is because consumer organizations have been poorly informed, and poorly led by those held up as spokespersons, a point discussed further in the next section. It has then been difficult for psychiatrists and others who *do* want to engage with community groups to recognise the activists in these groups who *are* well informed and fully aware of the complexity of mental disorders and their treatment. I offer the following comments about areas where a change of approach by professionals might help the coming-together of the different stakeholders.

Openness and Transparency

At the interface between community activists and mental health professionals, several factors may hinder the development of true partnership. *First,* clinicians are used to dealing with patients in a clinical encounter, but the interaction with community activists is not a clinical encounter, and different guidelines apply. In a clinical encounter, there may be a tendency for clinicians to refrain from responding, but (inwardly) to interpreting what is said in terms of psychiatric disorder. However, in committee, or in public meetings, service users may feel free to disclose personal stories, which they would not expect to be made public, were it a clinical encounter. They would appreciate, and are likely to respond positively, if such openness were to be reciprocated – for instance if clinicians or researchers were somehow to take the community people into their confidence. This may be difficult for professionals who somehow think they are crossing professional boundaries; but if it *were* possible, it would lead to freer discourse all round, from which all would benefit. If openness is *not* reciprocated, consumer activists may conclude that a clinician has something to hide. Who can blame them?

Second, and perhaps more important, in the research field, and perhaps even more in the clinical field, people are not used to being really open with their own colleagues, except within the bounds of their professional relationship, because of the social dynamics and styles of training in their own field: These may be dominated by competition and hierarchy of relationships, which do not favour open communication across political frontiers. If service users can effectively challenge such a constrained approach to relationships, more power to their elbow (in my view); and they may even be able to introduce those clinicians to a more open style of social dynamics.

Third, there is always the implication that 'we are too busy' to respond openly to all and sundry. It is certainly true that consultant psychiatrists usually *are* very busy people; and yet this does not explain the systematic brush-offs one might get at times (such as international conferences) when the pressure is less. Clinicians and researchers are reminded of what their real mission is, to help their patients; and in the days when community psychiatry is becoming the main interface with patients, psychiatrists should not ignore opportunities for exchange of views with people who come to the subject in a quite different way. Indeed, when, as is often the case, there are not enough psychiatrists for the demands placed on them, and the workload seem impossible, one strategy is for you – as a professional – to take those concerned community people into your confidence, give them some training, and invite them to join you as collaborators in the areas where they can

help, perhaps in a voluntary capacity. They may be eager to join with you on such a basis. It may be hard at first, but will pay off handsomely down the track. I have seen this principle applied in Hong Kong, where the number of psychiatrists per head of population is far less favourable then in most Western countries, and there is little other alternative. It is also my experience that some of the really big figures in psychiatry, who are probably busier than anyone, *do* somehow manage to build up those many contacts, although necessarily they may be rather brief in their communications.

Fourth, there may be a rejection of statements of service users because they have political import (thereby betraying the 'ivory tower' attitude often fostered in academia). This is a cop-out. It is likely that the issues really *are* political, and should be discussed in that context. You cannot keep politics out of psychiatry.

Last, in some mental health services, there appears to be knee-jerk attitude of negativism to any positive suggestion. This may be a continuation of attitudes prevalent in the days of the large mental institutions. A more up-beat approach is needed if the full benefits of community engagement are to be realised.

Medical Authority as an Impediment to Rational Discourse

Some consumers may be intimidated by medical authority, and this is not helpful. Others have the courage, tenacity and knowledge-base to be more challenging. However, the *only* basis on which true partnership can develop across the frontier is that of rational discourse; and the *only* authorities which can be assumed in such discourse are abstract principles – sound evidence, sounds reasoning, and sound ethics. Personal or institutional authority, or the authority of a discipline have no role. The starting point for interaction between different stakeholders, must then be one of equality of status and rank. If experts are to be treated as authorities, their authority has to be earned, in interaction with each person individually, not to be taken as a given; and of course it is not only the professionals who are experts: Those with lived experience of mental illness also have their own expertise.

Technical Detail and Jargon

People from the wider community who happen to be users of psychiatric services or caregivers of impaired relatives, may object to impenetrable technical jargon which they do not understand, and which appears to be impersonal, denying the drama and the trauma of their own lives. Sometimes, to be fair, opaque language is used so that lay people can *not* understand, or even as a cloak to hide the fact that the speaker him- or her-self doesn't understand either. As far as possible, therefore, opaque language *should* be avoided. In such situations for a professional to say 'I do not know', may inspire more confidence in other areas, than to try to pull the wool over the eyes of consumers (who of course soon see through the ploy). If an expert has anything worth saying it should be possible to explain it to an audience of intelligent lay people, in a way that the audience not only understands, but on which it can offer constructive criticism – and at the interface between community activists and mental health professionals, you *are* dealing

with intelligent lay people. It is vital that you, as professionals, can somehow expose yourself to the possibility of intelligent, constructive criticism from outside your own field.

Strife about Diagnostic Labels

Diagnoses have a different role in general medicine from psychiatry. Historically diagnoses do not start off as scientifically precise concepts, but as names for syndromes – the coming-together of various symptoms – and it is only slowly that these are refined to become precise concepts, corresponding to disorders with known causes. In general medicine, diagnoses are often more precise than in psychiatry, reflecting the fact that the disease entities there are usually better understood. In general medicine, diagnoses are important for the researcher and the clinician – to guide treatment, to indicate prognosis, and as a focus for public health measures – but also for the general public, potential patients, for whom a clear diagnosis provides a basis for understanding and self-education. This is especially the case for disorders where the diagnosis is precise and clear, for instance for relatively rare genetic conditions. In psychiatry diagnoses are important for researchers and clinicians, although for clinicians I suspect that broad categories are often more important than fine distinctions; and, once the broad categories are decided, treatment is judged more on an empirical try-it-and-see basis, than by reasoning from fine diagnostic distinctions. For patients – those who experience mental illness – diagnoses may be less important than in general medicine. This is partly because, as just indicated, concepts of mental disorder are at present far from well-established. Future research *might* resolve such issues – I hope so – but it won't happen quickly. Another reason for questioning of diagnoses in psychiatry is a more permanent one: In psychiatry, the unique personal characteristics of each individual, their personality, are of far greater importance than in any other area of medicine, except perhaps general practice. Diagnosis may indeed be *inherently* stigmatizing; many consumers think it so. One can sum this up by stating that medical practice deploys the traditions both of the natural sciences, and their tendency to be objective and impersonal, and also the traditions of the humanities which have more of a focus on the individual and his or her unique history, in all its complexity; but in psychiatry the balance is shifted somewhat towards the latter, while not ignoring the contribution of the natural sciences. So diagnostic terms have different roles for different stakeholders – the scientists, the clinicians, the direct consumers, their family members, the statisticians, those who consider finance of health care, and the medico-legal experts. It does not help, therefore, when documents like DSM in its various editions, provide systems for diagnosis that are used to serve all stakeholders equally.

Challenging Behaviour and Challenging Words from Community Activists

This may be based on genuine, unresolved anger, perhaps of long standing. Given the complexity of mental health care, and the pressures on staff, there are bound to be areas of unresolved hurt for some ex-patients, as well as areas where service

users have a lot to be grateful for. Challenging behaviour by consumer activists may also be a deliberate attempt to test the mettle of those with whom they are dealing. This is fair enough: If anyone should be adept at de-fusing unresolved anger, it is the psychiatrists or other experts in psychological medicine. Part of the interchange with professionals may then be for service users to test whether this is actually the case.

Speaking personally, I know how to challenge psychiatrists, aiming to 'encourage' (and sometimes provoke) them to move closer towards true partnership. Although I have no tangible victories yet, I know I am being at least partially effective, when I listen not so much to what is being said, but to the silences, the times when psychiatrists can come up with no immediate answer. However, silences are not what I want – which is open, robust and rational discussion of issues at stake. Then, in the market place of ideas, I say firmly, 'may the best arguments prevail'. I also hope that I can accept with good grace convincing arguments against my own views, put forward by people who have expertise and experience beyond my own; but let's *hear* those arguments. Silences, or ignoring views which are difficult to assimilate with one's own, are not rational strategies. On the other hand, to say openly and honestly 'that is difficult for me to accept' *is* a rational strategy, since it opens the door to mutual exploration of contentious issues. Even open expression of anger by professionals, as their last defence, is preferable to being ignored.

A Challenge to Mental Health Consumers and Family Members/Carers

Here, I want to challenge service users and carers, my aim being similar to that of the last section, to foster true partnership with the other stakeholders.

Philosophical Polarization

There is, in my view, a need for service users and others, in their role as mental health activists and advocates, *to be better informed.* First of all there is need for better understanding at the philosophical level. All cultures have to wrestle with issues about the relation between body and spirit (or soul), or equivalently between brain and mind. In the areas of mental health and mental illness, this becomes the contemporary debate between bio-genetic versus psychosocial concepts of causation, and their respective application to treatment of mental disorders. Sometimes consumer advocates strike a decidedly ideological stance, strongly favouring psychosocial models, and rejecting biogenetic ones. They may see themselves as pitted against an army of faceless advocates of a pure biogenetic philosophy in the psychiatric professions and their researchers, aided and abetted by the pharmaceutical giants. As a result, such voices may force sharp polarization upon the debate, which is unhelpful. It may be fuelled by headline-hungry news media, who like to present the polarization between advocates of biogenetic and psychosocial approaches to psychiatry as primarily a political struggle. This may sell newspapers, and activists may use dubious ploys to win short-term political advantage. I admit that on occasion the relation between consumer activists and mental health professions *may* to some extent become a political struggle, where

the real issue is one of power imbalance; but the consumer activist movement won't gain any ground in the long term unless it is based on more balanced arguments, and on the most solid science, whether biological, psychological, social, or preferably on research which assimilates all three. The reality is of course that psychiatrists come in many shapes and sizes, with many philosophical shades. They do not fit the stereotype just described: Many earnestly search for the complex middle ground, where biogenetic and psychosocial models of mental disorder are fully integrated with each other. Most of the above comments also apply to divisions between different professional groups involved in mental health. These divisions (for instance between clinical psychologists and psychiatrists in some countries) become ideological battlegrounds, which, when it occurs, is also not helpful.

There are several reasons why this philosophical polarization emerges, and why consumers and mental health professionals are (or appear to be) on opposite sides of the divide: Possibly these polarized attitudes reflect a throw-back to the dualism of the classical Greek philosopher, Plato, carried forwards two thousand years later in ideas of the French philosopher, René Descartes. In this dualism, brain and mind (a.k.a. 'body' and 'soul'), were held to be so completely separate that they could each be effective as independent causes influencing one another. In the nineteenth century German-speaking world, where battles raged become the *somatikers* and the *psychikers* on the right way to conceive mental illness, protagonists on both sides of the debate based their arguments on mind/brain dualism (Beer, 1995). Belief in such a strict separation is not widely held nowadays, either by philosophers or by scientists, whether they work as neuroscientists studying brain mechanisms, or as research psychologists studying functions of the intact brain in terms of behaviour or subjective experience. In addition, polarisation and rivalry between professional groups involved in mental health may arise in part from the way different disciplines are defined within universities, which hinders the much-needed integration of obviously-related fields.

Psycho-social ways of comprehending mental disorders *do* seem easier to understand and *are* closer to common sense than ones based on brain science. Neuroscience is very technical. Competent researchers in this area need extensive education and training, and there are many sub-specialities, each requiring their own expertise and knowledge base. This area may offer the most fundamental understanding of mental disorders, but its impact is necessarily in the long term. Mental health consumers often have had breaks of several years at critical stages in their lives. This is likely to have made such extensive higher education and training difficult to acquire. Thus, few community activists in the mental health area can be expected to be 'up-to-speed' on such a technical area. Even under the most favourable circumstances, consumers can be expected to grasp the detail in only a few areas of neuroscience. With such an imbalance in requisite knowledge (and therefore in power) between researchers and consumers, it is hardly surprising that there is a degree of polarization between the two, favouring polemics rather than mutual understanding. Therefore, the hard question must be asked: How can one reach a situation of equality of knowledge in the discourse between consumer activists and researchers? I address this question shortly.

Underneath all the scientific technicalities, there *may* be a deep but unstated clash at a philosophical level. Behind the impenetrable jargon of the neuroscientist, there may seem to lie attitudes which appear to dehumanise us all, to reduce human nature to no more than a slight upgrade of a purpose-bred laboratory rat, or to the status of a deterministic machine which denies anything like freewill. Much 'brain talk' we hear is a simplistic, insulting caricature of human nature. It is seemingly a deliberate assault on our sensibilities, by virtue not so much of the technicalities, but of its underlying philosophy. So, brain science, as commonly purveyed, is inherently frightening to many people. This depends a good deal on the world view of each scientist, and each community person with whom they interact. It may then be at this level, rather than at the level of technicalities, where lies the real challenge from biological psychiatry, as perceived by consumers. Yet the focus, as presented by researchers, usually tends to be on technicalities, and on glossy false-colour images from brain scanners (and many similar show-piece displays), rather than underlying concepts.

There are many things to be said here. *First,* the fact that psychosocial approaches to understanding mental illness seem closer to common sense does not mean that such approaches bring one closer to underlying realities. Those realities may be complex, requiring much subtlety before they are properly grasped; and it is undoubtedly the case that many of experiences with which psychiatrists deal are very far from common sense. If neuroscience approaches seem frightening, so also, if truth be told, are some of the realities of mental illness, until we grow familiar with the details, and how they relate to one another.

More fundamentally, can one really support the notion that 'psychosocial approaches are good; neuroscience is bad'. It is an easy slogan to repeat, like the sheep in George Orwell's *Animal Farm*, forever bleating "*Four legs good; two legs bad!*"; but is it really helpful? For myself, I think we need both, and consumers as well as researchers and clinicians need to explore the intellectual territory where both are simultaneously under scrutiny and in interaction. To coin a phrase, 'Mind without brain: It's a 'no brainer'!'

Why is it a no-brainer? I answer with truisms. We *are* made up of mind and spirit, but we are also made up of flesh and blood, and also of neurones. I venture to assert that even the most vehement denier of biological psychiatry, the most ardent ideologue of psychological approaches, might have just a little bit of electricity, even a little bit of chemistry in their heads, as well as the aesthetic, emotional, cognitive, and moral sensibilities embodied by such physical processes. This 'duality' is accepted in most cultures. I use the word 'duality' here, to distinguish it from the 'dualism' of Plato and Descartes, in the same way as does Harold Turner (1998). For the Maori of New Zealand it is part of the foundation of their metaphysics, which actually is more complex than duality: For them, the metaphor for health is a table with four legs, physical, psychological, spiritual, and lastly, social (or ancestral), all part of a single and indivisible functional unity. It is only in the western, and particularly the Anglo-Saxon world, with its tendency to dichotomise all issues into polar opposites, that we artificially make a split between two things that obviously go together as inseparable parts of a single organic unity – ourselves.

How then *do* the two go together? The most fundamental science is physics. That is where the natural science tradition started, and where scientific explanation becomes most rigorous. The primary language of the natural sciences now extends well beyond physics, but so far is only just beginning to incorporate psychology and psychiatry into its common language. By saying this, I am in no way trying to belittle these disciplines, just putting them in historical perspective, implying that these are the contemporary growing points of the scientific enterprise. In physics, a form of reasoning grew which I call *'cross-level explanation'*. Arguments are presented by which phenomena known at a 'higher level' are accounted for by premises at a lower level. Often these premises are quite hypothetical initially, because their examination is far beyond techniques currently available. An obvious example (but there are many more) is the relation between the gas laws at an 'upper level' (relating pressure, volume and temperature of a gas) and their explanation in terms of movement and collision of molecules (a concept which was initially entirely hypothetical).

For me, the relation between mind (=psychology) and brain (or neurobiology) is like that: Things to be explained at the upper level may be any of: psychological or behavioural findings, symptoms and signs, and, with some qualifications, first person accounts of a person's own experiences. Premises at the lower level, on the basis of which explanations might be made, are about functioning of nerve cells, their electrophysiology, the dynamics of their transmitter substances, and the interactions emerging in networks of nerve cells. I *do* believe such cross-level explanations are possible in psychiatry, and have ventured to propose some such myself. If so, the idea of having to choose between biological and psychosocial models of mental disorder becomes absurd. The two always, and necessarily go together. The real problem then is not the very notion of neuroscience or brain science in service of psychiatry, but *bad* neuroscience bent to this end, bad neurobiology, with simplistic metaphors parading as explanations, turning out to be empty rhetoric when examined in detail. One should also realise that there is also much bad psychosocial research. That also should be exposed.

There are good reasons, which might appeal to consumers, for supporting a continuation of fundamental neuroscience research directed at the understanding of mental illnesses. Quite apart from the possibility that this might lead to better treatment, it is likely that, at rock bottom, the reason why callous treatment, and sometimes frank abuse has often flourished in mental institutions, is in part because the staff there have a truly profound lack of understanding. This may also touch those staff in a very personal way, since serious mental illness challenges our basic ideas of what a person is or can be. Better fundamental understanding would be one way to help prevent those abusive environments from developing.

Even many of the most esteemed researchers are, in my view, to a degree floundering, or trying to impress by their use of impenetrable jargon. They may try to convey a sense of their own confidence and importance, way beyond what can be justified by the fine print. This may be to avoid revealing their lack of real understanding, their failure to provide real explanations (as exemplified in physics), or so that they can gloss over the big issues – which are philosophical, rather than in the realm of scientific technicality. This shallow behaviour is also a

response to the pressure many of them are under to raise research funds for their institution. An emphasis on simplistic metaphors for mental disorders (such as 'chemical imbalances') rather than more difficult and subtle concepts may also be promoted by the pharmaceutical industry to promote sales, or use of medications in larger doses than necessary. (Note here that I am not categorically opposed to the pharmaceutical industry, and in a small way do sometimes seek pharmaceutical company sponsorship for scientific meetings. I do not stereotype drug companies by assuming that 'they are all the same'. They are not all the same. Some companies have very reputable, indeed impressive company histories, others not so.)

What is needed is *good* biological science in aid of psychiatry, neurobiology which is rigorous on its own terms, in terms of its evidence and reasoning, and not transgressing ethical norms. It should be capable of being presented to mixed audiences including consumer spokespersons and family members as well as researchers and clinicians, neither talking down to the former or offending them in terms of philosophy, nor appearing naive and unscientific to the latter. Today such presentations are rare, but are not impossible. Traditions need to be developed to make them possible more often.

Of course there are also general questions of philosophy, not to be confused with those answerable within traditions of the natural sciences. These include the question of whether the behaviour of the physical world (including each of our own brains) is *really* subject in finest detail to the remorseless determinism of causal laws. I do not think this is an answerable question, although, in decisions of our day-to-day affairs, we all take our choices on the issue from time to time, as items of faith (but not always in a consistent fashion). The other question is on the general relationship between subjective and objective worlds, the view 'from within' and 'from without'; but again I think that to be a metaphysical question beyond anything answerable within science. Nevertheless, in the mental health area, we ignore either of these perspectives at our peril.

Let us return to the question posed above: How can one reach a situation of equality of knowledge for discourse between researchers or clinicians and consumer activists? Is it possible that, as in the AIDS area, consumers can effectively challenge the paradigms of research? Here are a few suggestions:

Technical Terms and Jargon

Neuroscience, as admitted, is a technical and difficult area for non-specialists. Can consumers get an overview which helps them make meaningful contributions to dialogues with biological researchers in psychiatry? There are several issues here. Perhaps there is a need for training courses, with plenty of opportunity for discussion, involving consumers as both learners, and as teachers or facilitators. However, this is at best only a partial remedy, and there are many other areas where consumers and carers can have influence without this. Suppose, however, that you find yourself in a forum which does allow extended discourse. (At present, in my experience, this happens rarely, but it might become more common in the future as the need for such discourse becomes more widely recognised.) If this happens, you may be bamboozled by technical jargon. Do not be fobbed off by claims of expertise and authority. Point out, politely, yet firmly, that the

language is opaque; but be fair! Technical language develops in any profession, a necessary shorthand for conciseness and precision, like texting for young people, and equally incomprehensible to those who aren't into it. Whatever its motives, it arouses suspicion from the so-called 'ignorant' public with whom that profession has to deal, just as does text lingo for many adults. Nevertheless gentle pressure may encourage the use of more transparent language. This may be a way to 'level the playing field', to improve communication between different stakeholders, and, at the same time, to improve your own education on research topics. If however, you seem to be getting nowhere, and a gentle approach fails to shift prevailing professional attitudes of superiority and authority, it may be the time to use your considerable collective power. The history of activism in the HIV/AIDS area shows that this can move mountains, when rational arguments fail.

The Context of Neuroscience Research

If one then gets to the stage where cutting-edge science is presented in relatively plain language, the next step would be to examine its place in a broader context. If several presentations are given on related matters and seem to be based on quite different perspectives and assumptions, the various speakers might be challenged to assimilate each other's findings. This might be possible for you, even if you don't follow the fine details, and it may encourage some cross-fertilization between disciplines. In addition you might ask about how results relate to broader theories of whatever is being studied, using a wide variety of methods. Researchers in biological psychiatry need such challenges because they are not encouraged by styles of research administration to think more broadly about large-scale theories. In addition, in biological psychiatry, most conclusions are based on correlations, not reasoned explanations as they might be in physics. A fair line of questioning is then to ask how the evidence presented *explains* symptoms or other aspects of the mental disorder referred to. This approach may stop those over-confident researchers dead in their tracks.

Diagnostic Labels

For mental health research a central area of concern is the role and status of diagnostic labels. Here you may be on secure ground, because, from your own experience you may well have received a variety of different diagnoses from different psychiatrists for the same illness. More technically, the research literature shows most official psychiatric diagnoses to confer risk of another such diagnosis – so-called 'co-morbidity'. Not to stretch the point too far, one might suggest that the strongest risk factor for any psychiatric diagnosis, is already to have another one! More seriously, the extent of co-morbidity, and the lack of reproducibility of many diagnoses suggests there is something fundamentally flawed about the concepts from which official psychiatric diagnoses flow. I have written elsewhere at greater length on this topic (Miller, 2011, 2012a,b). Here, all I need to add is that a little personal recall of your own experiences with psychiatric diagnosis may open up the dialogue. Psychiatric diagnoses at present are almost ways based on

'conventions of wise men', not on proper scientific reasoning. I am not categorically denying their usefulness, but they need considerable refinement, perhaps to come in future years.

Practical Relevance of Biological Research in Psychiatry

Next one might ask about the relevance of research to matters of practical concern. I have already suggested that neuroscience research may offer the most fundamental understanding of mental disorders, but, since its tempo is slow, the pay-off is likely to be in the long term. Unfortunately this argument is used to justify inordinate expenses for *any* research, with little attempt to balance expenses against likely outcomes. So, one could ask researchers: 'How much did it all cost?' and to explain and justify the costs of their research. If it is very expensive, and only for the distant future, you might want challenge its relevance, or suggest that the money could be better spent, or even that it is mainly done to promote the career of the researcher and his team. Since you may know the inadequacies of mental health services, due to their underfunding, you may be able speak straight from the heart. A line worth remembering comes from John Maynard Keynes, the economist who contributed greatly to understanding the causes of the great depression of the 1930s. He was writing about classical economic theory, but his line is also relevant to much of today's research. His line was 'In the long term we are all dead!' In other words, he pointed out that some of our problems may be so urgent and immediate that what happens in the long term is quite irrelevant.

Addressing the Underlying Philosophical Issues

If one has reached a stage of genuine discourse on scientific issues, the door may be open to debate bigger issues of philosophy, already mentioned. Here you may be on stronger ground than most scientists. Personal experience of major mental disorder puts you in a privileged position in discussing the relation between mind and brain, and also on the much more problematic question of determinism. You are likely to see these issues (particularly the second) as stark realities at the coal face, not as academic niceties for professional philosophers. If you have thought through your own experiences well, and can express yourselves thoughtfully, you may be able to force some rethinking of basic attitudes amongst the researchers you interact with.

For these areas where your influence can be exerted, any movement you produce will necessarily be slow. However, it is not only in areas of science and underlying philosophy where extended discourse is needed. There are other areas where progress can occur on a much faster tempo, and where your contribution may be quite critical.

Service Delivery

Here you have a vital role to play, in drawing attention (for instance) to crises which were handled badly, lack of coordination between different parts of mental heath services, and gaps in the services. Thankfully, this is an area where in many countries, consumers and carers already play an important role. Active

collaboration in shaping modern mental health services is in full swing in many places. Since the partnership is often working well, there is little more to say; and you will no doubt be aware that most mental health services are underfunded, and their staff overworked. While research studies often have a slower tempo than in the HIV/AIDS area, this is an area where relatively rapid improvement may be expected from engagement of service users in policy development for mental health services. Related to service delivery issues, a more strategic area where a coalition of clinicians, researchers, consumers and family members *might* emerge is to use their collective influence to encourage a stronger *research culture* in clinical services. This might then increase the possibility that what is known to work well in the best services is emulated more widely.

Programs to Reduce Stigma and Discrimination

Here again you have a vital role to play. While public anti-stigma campaigns using the broadcast media influence many people, the more personal messages told by people with lived experience of mental illness, in smaller forums, are likely to have a more profound impact on those who hear these stories, even though they affect a smaller number of people. As a public health program, both are needed. A similar comment can be made in relation to youth suicide: Carefully planned community-based public health campaigns have been implemented in some places, which considerably reduce suicides and attempted suicides. There too, personal accounts from people who have been on the brink, and have come back to lead rich and fulfilled lives may be very influential (Hatim, 2005a,b). Like public health measures to combat infectious disease (especially building and maintaining proper drains and sewage systems), these initiatives are never-completed works, not one-off jobs. They need to be maintained year after year, decade after decade.

Social Policies which Impinge on Mental Health

Here we get into central areas of political debate. While emphasis often focuses on shortcomings of personal mental health care, there is a largely unexplored territory which might be called 'public mental health', or 'mental health of a society'. It is easy to argue that most national policies on social and economic issues, for better or worse, have impact on mental health. Examples include policies which widen the income inequality in a society; which, in the name of 'efficiency' force through policies for fulfilling targets, as though employees are mere cogs in a state or business machine; excessive competition and certain management styles in public institutions and businesses; noise pollution in public places, and excessive noise levels at public events; legislation related to the gambling industry; school education which over-emphasises academic success at the expense of emotional development and 'life education'; the widening currency of violent imagery in entertainment and video-game industries, as precursors to real-life violence; failure to recognise psychological and cognitive diversity in educational establishments, business and other workplaces; social welfare policies which limit earnings for those on sickness or invalid's benefits, which results in people being caught in a 'dependency trap'. The list could easily be extended. On many of these issues it is

likely that community voices added to those of the professionals can bring about change at political levels which the professionals by themselves, however well-intentioned, cannot achieve; and make no mistake, it *does* mean that the combined voices of consumers, carers and mental health professionals enter central debates of any nation's politics.

Help in Recruiting Participants for Research Studies

This is mentioned last, not first, because, it is not likely to be very successful until other strategies have been successfully deployed. However, research *is* a fundamental way from which future improvement in health services will come, and much research requires active, willing, well-informed participation by those who might benefit most, indirectly if not directly. Consumer and carer advocates have an important role in bringing service users, family members and others as potential research participants (including comparison groups) together with the researchers themselves, who are keen to explore new ideas about cause and treatment of mental disorders. A longer account of this area was recently written (Miller, 2010). To highlight just one area, clinical trials of new medications and other innovative treatments, *may* produce important advances; and clinical trials *might* be possible without involving major pharmaceutical companies, and at a faster pace than most drug development (as happened in the HIV area). However, this would depend on forming a solid coalition between consumers and researchers, with shared perspectives and common purpose over-riding philosophical splits of the past.

Other Issues for Consumer Activists Working at the Interface

Look after your own Health as 'Number One' Priority

You may be vulnerable; and political activity of any sort can be cruel and unforgiving, especially when dealing with big issues. So choose carefully when and how to become involved, and develop your personal support networks. It is easier to be strong, and unshaken by public criticism in political debate when you know the people whose views you are representing. *They* give you strength. It also helps you to stay cool if you understand your opponents' perspective and manner of thinking.

How to handle Anger from the Past

Anger *should* be expressed, and in public. Unless it *is* expressed it will fester to become a perennial running sore. The lines from William Blake's poem '*The Poison Tree*' sum it up excellently:

> "I was angry with my friend
> I told my wrath; my wrath did end.
> I was angry with my foe.
> I told it not; my wrath did grow."

However, if you express anger, do it thoughtfully, with full understanding of your own feelings. As when declaring your love for another person, unless you understand your own emotions, it will appear incoherent and ineffective. But if we do understand our own emotions, and reason and emotion become well coordinated, the combination may be an unstoppable force. The aim is then certainly to *convey* anger, but without being inwardly consumed by it, and even to speak from a position of inner calm. If that can be achieved, it means that, when listeners start to respond positively to the message you deliver, it is emotionally easy for you to change tack, and reciprocate with a positive message which invites collaboration.

Don't make a career out of anger. A story from a previous generation is relevant here. During World War II, Wilhelm Furtwängler was conductor of Germany's most prestigious orchestra, the Berlin Philharmonic. He was in disfavour in the immediate post-war period, because he was thought (wrongly) to have been an active Nazi collaborator. As with many people of integrity, he found himself in an impossible and very ambiguous situation in that regime. The violinist Yehudi Menuhin worked hard to rehabilitate Furtwangler in immediate post-war years, which itself aroused criticism. On one occasion, Menuhin found himself playing to survivors from Belsen concentration camp. A heckler in the audience shouted angrily: 'Go on, play for the murderers!' Menuhin responded with a brief speech, including the following words: 'I cannot blame anyone for his bitterness. You have suffered too much; you have lost parents, children, brothers and sisters. I have been spared this torture. And still I do say that you simply cannot rebuild your life upon your suffering.' (Burton, 2000). His eloquence carried the day, and he was received with rapturous applause. Issues within today's mental health sector are by no means as grim as those to which Menuhin was responding, but the principle is the same.

Don't personalise the anger. The forces at work, as psychiatry emerges from the asylum era, are larger than any individual, as were those which set up the asylum policy 200 years ago. Mental health staff of former years, almost as much as the inmates of those asylums, can be seen as victims of a policy they had no hope of challenging. All of those involved should be included as potential participants in the process of healing (even if they do not want to join in it). We may be swept along by the exciting times where at last we see long-sought change emerging; but we should always think strategically, with long-term focus, rather than just seeking immediate victories, including personalised victories.

Discourse within Consumer Groups

Within activist groups, get used to listening to opposing viewpoints, and to the disciplines of democratic process. Learn about the discipline needed in committees, committee procedures, and don't let other activists get away with anything less. There is also, I believe, a need for more unity amongst consumer groups, with less knee-jerk oppositional politics by service users pitting themselves against the psychiatric profession and the pharmaceutical industry. In saying this, I am not saying that either of these are beyond criticism, but criticism should be fair, balanced, well-informed and rational. Don't over-emphasise minor issues,

and don't look to consumer or family groups for your little slice of power in the group. There are bigger issues at stake, where the common purpose should be of paramount importance.

Build Bridges, foster Useful Alliances

These may be between any of the following: service users, family members, researchers, media people, politicians, commercial enterprises and activists in other health- or disability-related areas, or social advocacy groups in the wider community.

Sometimes there is antagonism between community groups which needs to be healed. One of the sharper splits within community groups interested in mental health is between people with lived experience of mental illness, and their own families. As already noted, there *are* legitimate differences of interest here, but also there are areas of common interest. The differences are sharpest on matters of privacy and control. Service users (and I am one) are usually adults, wanting to run our own lives, and take our own decisions. We need no protection. We all make mistakes; but we want to learn from *our own* mistakes. We cannot learn from those of other people made on our behalf, including those of our parents.

Parents, on the other hand (and I am one), want the best for our offspring. We may be able to see trouble brewing for them, and want to advise, warn and protect against real dangers. We may have heard about over-protective parents, in areas of mental health and disability – and a protective reaction is quite natural, although not necessarily the wisest. Looking at the history of medicine, there are also plenty of precedents where medical professionals adopted over-protective attitudes to patients; and they too had to learn the hard way about how to do it better. So, a word of advice to parents – never offer advice! … *but,* be prepared with wise words when they are asked for; and also realise that each person's world of disability is one you can never fully know. Each disabled person has to work out for themselves the best strategy, but perhaps with support and gentle guidance along the way.

Some of the more intractable problems created by mental illness are unresolved issues within families. Apart from issues of privacy and control, there may be ones arising from times of crisis. Because parents may have been involved at very critical times of committal to a psychiatric hospital they continue to harbour unresolved guilt feelings. Such times of crisis may have a bad impact on family relationships for years to come, because, at the time, they were so frightening and intense that no-one subsequently can find ways to talk about them. In addition, because the world of each individual's disability cannot be fully grasped by anyone else, those with the disability may get angry that no-one else understands their situation. This also can lead to rifts between parents and offspring. Mental health professionals, or a skilled facilitator with another background may have a special role in helping to bring together family members, where events such this have led to separation and estrangement, the aim being to resolve the anxiety, guilt and misunderstanding surrounding those events. I suspect it rarely happens, and this may be one of the factors making it difficult for groups (respectively) of consumer

activists and family members to work together on the policy issues where they have common cause.

Challenges addressed equally to Professionals and Community Activists

As already noted, the relationship between psychiatrists (and other mental health staff) and patients is different from that in any other area of medicine. Even with the most conscientious attention to ethical principles, there *is* a power imbalance. However, when it comes to collaboration between *former* patients, now acting as consumer activists, and mental health professionals, the game is different. The power imbalance which existed formerly *is* an inevitable source of tension; but it is certainly possible to get beyond this tension. This requires movement on both sides of the divide. The professionals need to radically shift the approach they adopt in dealing with actual patients, inviting their former patients to adopt stronger positions, as respected partners of equal status. I know from my many friends in mental health professions that this is possible. To the consumers (former patients), I say: 'Go easy on the shrinks!' They have a difficult job to do, easily misunderstood, often in the face of much public misunderstanding, and they are overworked. Try to see things from their point of view as well as your own.

The Need for an Extended, Disciplined Process of Dialogue

It is to be hoped that the different stakeholders, despite vast differences in life experiences, can get to know each other as friends, colleagues, and (I would like to say), comrades in arms, fighting on a different front perhaps, but in the same campaign. To bring this about, what is needed is a prolonged, thoughtful, and carefully considered process of dialogue, so that, despite the differences in perspective, the communality of cause becomes the dominant factor, and all can start to work together. Especially when there is the possibility of conflict, such dialogue may need skilled facilitation by mediators knowledgeable about the field, but not identifiable with any particular viewpoints or factions within it. The aim would then be for concerns to be expressed calmly and rationally, looking for rational responses, and with willingness to ask questions if responses seem excessively defensive, or not rational. Everyone should strive to be fair in their criticism. Consumers should try to put themselves in the role of a busy psychiatrist, trying to make wise decisions in the face of considerable uncertainty, large workloads, and the possibility of public criticism or worse. In such dialogue, it may be needed to go over the same ground repeatedly, so that active reflection on issues already discussed can lead to more constructive solutions. If people on both sides of the divide *can* move towards each other, and develop a shared perspective of the whole field, I believe that, in psychological terms, it may mean profound healing for all participants.

Conferences

Apart from small informal meetings, the times when a lot of networking, and 'meeting of minds' takes place is at conferences of various sorts. Their focus may be on medical science and research, or on professional matters or health politics. Medical or research conferences are usually large, the program full, registration fees substantial. The environment is often crowded and noisy, and in plenary sessions presentations are often to some extent showpieces, with little chance of real discussion. In the mental health area, if the real objective is to build bridges between professionals and community spokespersons with very different life experiences, this is usually a most unsatisfactory format for meetings. The registration fee is likely to be right outside the budget of service users, aimed at people with medical salaries, or institutional backing. The program is rarely set up for extensive discussion to reconcile opposing viewpoints. If the meeting is large, with most participants being professionals, it is likely to be intimidating for service users, who will make up only a small minority of participants. Since many consumers have perceptual problems, such as noise sensitivity, it may be physically unpleasant, and therefore, for a four- or five-day conference, quite exhausting. In other words it is far from the best environment for service users to show their strengths, and may be the worst possible environment.

Here, for consideration, are some alternative guidelines to make research meetings more user-friendly for service users.

- Aim for small inexpensive conferences, perhaps one- or two-day meetings, with no more than fifty or sixty participants. The meetings can however occur more often, and with more specialised focus than at the large international gatherings. Small meetings are anyway easier to organise, and financially less risky.
- Small meetings will also minimise the noise and overstimulation of big meetings, which effectively silence any consumers who, against all odds, manage to be there.
- In promoting such meetings it is important to encourage a roughly equal mix of consumers, family members, researchers and clinicians, perhaps along with mental health administrators, case managers, and others influential in engineering research partnership between service users and researchers.
- If a large proportion of participants are scheduled as speakers (which is easy to arrange in small meetings), this encourages the 'meeting of minds'.
- With this aim also in mind, a relatively 'open' program, with ample time for discussion of each paper, and plenty of time between sessions for people to get to know one another is also recommended.

Conclusions

The times we live in are ones of historic change for psychiatry and other mental health professions. The past was dominated by the asylum era which stretched from the early 1800s (in Britain) to the second half of last century. The legacy of that period is still with us, and, in some sense, will be with us for a long time to come (just as, in the UK, the legacy of the workhouses, set up in the

years after 1834, and phased out between 1930 and 1948, has barely faded from public consciousness). At present however the psychiatric profession in many countries is attempting fundamental recasting of its social role, reaching out to communities and hoping for continual and fruitful dialogue and partnership. Part of that shift, aided in part by availability of medications with far fewer unpleasant side effects than in the past, is that the relation between psychiatrist and patient is changing. It can now, as in other areas of medicine, be based on genuine trust and collaboration.

A stumbling block in the transformation, which prevents the profession gaining the respect and trust needed in the process, is the emotional legacy from the past. Criticism of psychiatric services and mental health professions may then be based not on styles of practice now emerging, but on folk memories and lay understanding about large mental institutions of the past, and professional attitudes which sometimes flourished in those environments, perhaps rehearsed unhelpfully by the entertainment industry and other media outlets. There are ways to address, and move beyond the legacy inherited from those times, which will hasten the day when those memories are consigned to history, and are no longer influential and of practical importance. In the process of 'letting go' of the past, it may be necessary to hear the truth about those times, told openly in forums where there is no thought of retribution or litigation. There are many stakeholders whose voices will need to be heard. The transition will occur gradually over decades. If we are all aware of the historical shift now in progress, and its probable time scale, the transition can be expected to go ahead more smoothly, more rapidly and in a more wholly positive way.

Acknowledgments

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