Report and Commentary on Workshop on "Diagnosis in Psychiatry", Brentwood Hotel, Wellington, 16th July, 2012.

Robert Miller

"The Sabbath was made for man, not man for the Sabbath"
(attrib: Jesus Christ).

"The most fundamental form of human stupidity is forgetting what we were trying to do in the first place" (Friedrich Nietzsche).

"Men are forever creating organizations for their own convenience and forever finding themselves the victims of their home-made monsters"
(Aldous Huxley, 1950)

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I.   SUMMARY

On July 16th, 2012 a one-day workshop on Psychiatric Diagnosis was held at the Brentwood Hotel, in Wellington. The opening speaker was Dr John Crawshaw, Director of Mental Health, and the keynote speaker was Professor (emeritus) Allen Frances of Duke university, a leading figure in the development of the American Psychiatric Association's document, DSM-IV. Other scheduled speakers included a neuroscientist, several with lived experience of mental illness, a caregiver, psychiatrist/academic, general practitioner, and mental health law experts. Participants other than scheduled speakers were equally divided between professionals and people from the wider community. Many had multiple roles, although some groups involved in mental health care were not well represented. About half the scheduled time was spent in open discussion of the issues surrounding psychiatric diagnosis. A great diversity of views was expressed. Participants were respectful listeners to each other's opinions, and greatly valued the openness and diversity of views expressed, and the opportunity to express and hear such wide-ranging views in a safe environment.

Although the views heard on 16th July were not well coordinated, this report uses the records obtained on the day, and feedback comments received to give a more coherent account of the issues discussed. The report also uses supplementary information to fill in gaps in what was presented on 16th July, and especially to clarify how psychiatric diagnoses are currently being used in New Zealand, in both clinical and non-clinical settings.

We heard expressions of support *for* the process of diagnosis in psychiatry from various directions. Diagnosis (or a related process) is an inevitable requirement in any health care system, in that it provides a common language. Diagnoses may bring a sense of assurance to those with a mental disorder, and, at least in broad terms, helps guide clinicians to the best approach to treatment. Diagnoses may also help individuals and families in self-education and self-understanding, and help them to make contact with other people facing similar issues.

We also heard many *criticisms* of diagnosis from both professionals and community people. Some criticisms were on the manner in which diagnoses were conveyed in clinical encounters, and how they were used in current practice. Such criticisms were expressed in different ways by different stakeholders. They include: poor styles of communication, with diagnoses sometimes conveyed in an insensitive, stigmatizing and depersonalizing manner, or reinforcing rather than minimizing the inevitable power imbalance in many clinical encounters; poor reliability of diagnoses, with different diagnoses or shifting diagnoses from different psychiatrists for the same illness. Often a diagnosis is *not* a good guide to the best treatment. It tends to be a permanent label, which can be used for stigmatizing individuals so labeled (especially for some of the more pejorative diagnoses). It enables some patients to obtain unhelpful "secondary gains", including allowing them to escape from their proper sense of personal responsibility.

Some criticisms of diagnoses were more fundamental. These included questions over what is being classified in diagnostic systems (persons, disorders, or varieties of human distress and misery); questions about whether the medical concept of illness or disease is really an appropriate way to characterize mental disorders; and questions about whether the various disorders defined in official diagnostic system are valid as scientific categories. A

number of further difficulties arise in practice from these fundamental flaws. These include over-reliance on diagnoses for various purposes, which would not occur if the insecure status of the diagnoses was more widely understood. These extraneous purposes include access to services in healthcare systems (which might be accessed better in other ways), and use of flawed diagnostic concepts in research. In particular there is a danger that psychiatric diagnoses can be used unwisely in administrative systems, as if they were as robust as diagnoses in other areas of medicine, and can serve similar purposes. Allen Frances spoke forcefully about the dangers of what he called "diagnostic inflation". This arises from many pressures, some of which involve fundamental flaws in the diagnostic process itself, but which are compounded by many financial, administrative, social and political pressures. These criticisms lead one to ask whether current diagnostic systems in psychiatry are robust enough to bear the heavy weight placed upon them.

Various remedies are suggested to the shortcomings of the use of diagnoses in practice. These include clarifying the principle that, in psychiatry, diagnosis itself is not sufficient to define a person's problem: The "formulation" is an additional essential component, which defines all the individual circumstances which have a bearing on how an illness affects each person. Better styles of communication are needed if this combination is to be used to best effect. It is also necessary to make a clearer dividing line between clinical and administrative uses of diagnoses, so that over-emphasis on diagnosis outside clinical settings can be kept in check. Allen Frances presented a variety of ways in which diagnostic inflation can be kept under control.

For the more fundamental flaws in the process of diagnosis, re-thinking is needed on several fronts. These include clarification of what is being classified, of the concept of "mental *illness*", and the methods by which classification of mental disorders is to be achieved. On the latter issue, the author of this report urges that psychiatry should learn from the early history of the natural sciences, so that it validates concepts only in so far as they can be used in strong explanations of the phenomena of mental disorder. None of these issues can be resolved in the short term; and some require radical long-term reorientation, not least in the way research is done. Lastly, it is suggested that there needs to be a clearer division of roles in using diagnoses. Concepts other than traditional medical/psychiatric diagnoses might be better when dealing with mental disorders in non-clinical settings.

A number of shortcomings were identified in the way the workshop ran on 16th July, most of them unavoidable, but which should be recognized in planning future workshops. There was considerable enthusiasm about the way the workshop ran, and a widely-felt wish that discussion on psychiatric diagnosis should continue, building on the momentum created on 16th July. This could involve on-line dialogue, and also follow-up meetings, ideally without much delay. In any such future meetings, it should be possible to organize the discussion in a more sharply-focused manner, and to arrange discussion concentrating on the deeper areas of potential division between the different stakeholders. Although some at the workshop doubted that any consensus could be reached, the constructive tone of all present makes this an objective worth pursuing. A number of possible political initiatives were suggested arising from the workshop. Large professional organizations overseas determine the form of the major international systems for diagnosis such as DSM and ICD. This report will be

circulated overseas as well as in New Zealand. It is hoped to engage overseas experts in discussions about diagnosis, and to play our part in whatever emerges in coming years.

Kites Trust was closely involved in the planning and underwriting of this workshop. Sincere thanks are given to this Trust, and to their staff for their hard work before, during and after the event, which made it such a successful occasion.

PART I. SYNOPSIS OF WORKSHOP ON 16TH JULY

I. Aims of the Workshop; The Setting; The Program; Breakdown of Participants; Aims of This Report.

Background and Aims: Diagnosis in psychiatry has never been very satisfactory; dissatisfaction is expressed in various ways by different groups, whether scientists, mental health professionals, or concerned people from the wider community. In the past, such dissatisfaction could be hidden, because psychiatry itself was often a hidden, secretive profession, closely linked to the existence of large mental asylums, generally kept remote from public scrutiny. Today, with improved treatments, better understanding of many mental disorders, better awareness of the terrible harm often done by asylum environments, and increased emphasis on human rights and ethics, the face of psychiatry is changing. Psychiatrists are reaching out to the communities they should be serving, hoping to establish a relationship of trust and respect, as has usually been the case in other areas of medicine. Given this, the subject of Psychiatric Diagnosis is a prime area for discussion, an area where the most fundamental issues about psychiatry, and the most practical ones are jointly in play, an area where professionals of many types, and concerned people from the wider community are all vital stakeholders, and important players in any debate. With this in mind, the idea of bringing together the diverse stakeholders in a broad-ranging discussion of the complex and troubling issues about psychiatric diagnosis began to take shape.

Two circumstances gave impetus to the idea. *First,* we learned that Professor (emeritus) Allen Frances, of Duke University, North Carolina, was visiting Australia in July 2012. He headed all the committees which put together the DSM-IV (Diagnostic and Statistical Manual, fourth edition) of the American Psychiatric Association, published in 1994; and, as the fifth edition (DSM-V) is soon to published, he has become a vocal public critic of the new document, especially of what he sees to be "diagnostic inflation". *Second,* the Wellington-based mental health advocacy N.G.O., *Kites Trust*, saw the merits of a workshop with Allen Frances as a keynote speaker, and was prepared to underwrite the costs of bringing him over to New Zealand. We were thus able to work together to plan a workshop on Psychiatric Diagnosis, as a one-day event in mid-July, to suit Allen Frances' travel schedule.

Priorities: In planning the workshop, we had several priorities in mind. Uppermost was to have a 50/50 split between mental health professionals of various sorts and community people (activists, spokespersons, those with lived experience of mental disorder, caregivers and family members affected by these disorders). To achieve the right balance, we explained this priority in our initial publicity, asked potential participants to say which stakeholder group they belonged to, and explained that final decisions over which participants would be invited would be based on getting a good balance. In addition, it was important that the workshop allowed plenty of time for wide-ranging interaction and discussion on the complex issues involved, rather than having a program dominated by scheduled speakers. The program which emerged had most of the scheduled speakers in the morning, with more time allotted to open discussion as the day progressed. Lastly, we did not want the workshop to include too large a number of people, since this would have changed the character and

openness of the discussion. The conference room available at the Brentwood Hotel in Wellington was suited for up to 80 people, and in the end, most places were filled.

Participants: There were 73 whose affiliations we could identify, plus a few more we could not identify. They included:- 7 psychiatrists (including the keynote speaker, Allen Frances, the Director of Mental Health, John Crawshaw, and Professor Graham Mellsop); mental health nurses (4); clinicalpsychologists (2); mental health team leader/service manager/operations manager, including one leader of early intervention team (8); Ministry of Health policy developer (1); GP/mental health coordinator in primary care (2); social worker (1); "Tutor": (1); 13 who identified themselves as "consumers" (who almost all had additional roles: consultant-contractor-advisor [8], researcher/neuroscientist [3], patients' rights advisor [1]); Maori mental health specialist [1 – unable to be present on the day]; lawyers/District Inspectors for Mental Health (2); Family members (4 – one also working in an N.G.O.); Staff in mental health N.G.Os (9 – 3 as managers/leaders, 1 as a research evaluator, 1 as family/*whanau*[1] worker); Members or coordinators in the government-sponsored "*Like Minds Like Mine*" anti-stigma program (7).

The *Program* ran as follows:
9.00 a.m: Maori Welcome by **Tane Rangihuna**
9.10 a.m: Opening the Workshop. **Dr John Crawshaw,** Director of Mental Health, emphasizing both the merits of psychiatric diagnosis, and the dangers if not applied correctly.
9.20 a.m: I spoke next for 20 minutes, with the title *Psychiatric Diagnosis in the Context of the History of Science.* This gave a historical context to our workshop, but also emphasized current problems from a community perspective. (see Supplementary Document 1).
After a break for tea/coffee, the next speakers were community spokespersons, two from the *Like Minds* team in the Wairarapa – **Daniel Real** and **Julie Channer**, both with lived experience of serious mental disorder, and now vocal contributors to the anti-stigma program. (The text of Julie's presentation is available as Supplementary Document 2) The third speaker here was **Virgina (Ginny) Port**, from Hutt Valley, who spoke as a parent of a daughter with a complex on-going problem. (The text of Ginny's presentation is available as Supplementary Document 3)
11.00 a.m: **Professor Allen Frances** spoke and engaged with all other participants for the next 80 minutes, speaking without notes, in a fully interactive way, fielding questions from all-comers, and sometimes referring to his Power Point slides on the theme of diagnostic inflation, but not as a prepared speech. In the last ten minutes of this session (before lunch) the other speakers in the morning's session joined him as a panel, to respond to questions on their own presentations.
12.30 p.m: Lunch
1.30 p.m: **Professor Graham Mellsop** spoke, giving his perspective on diagnosis, how the last forty years was a "history of *no progress*", and also giving a wealth of empirical data from researches conducted by him and his colleagues, on uses of, and attitudes to

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1 For non-New Zealanders: "whanau" (pronounced: fah-now), Maori word, meaning "extended family".

psychiatric diagnosis from different professional and community stakeholders. This session included time for discussion.

2.30 p.m: The next session included four brief presentations: **Mike Sukolski**, a consumer advisor (mental health) within Hutt Valley District Health Board, drew an analogy with literary theory between the *story* and the *plot* of a novel, the former being an account of events in chronological order, the latter, as reconstructed and given significance by the author. In psychiatry, it tends to be the psychiatrist, not the patient, who is the "author", and the idea of a collaborative approach to interpreting the narrative is little used, but was recommended by Mike. (His presentation is available as Supplementary Document 4.) **John Edwards,** is a lawyer with close involvement in investigation of abuse claims in asylums, and in negotiations over compensation (and now a District Inspector for Mental Health). He explained that, formally at least, diagnoses were not needed when the Mental Health Act was used. For him, diagnoses *were* useful; but (he said): "Courts like things to be nice and neat in boxes; but I am less interested in diagnoses than in individuals' right to have appropriate treatment." **Helen Rodenberg,** a Wellington-based G.P. spoke of dilemmas in her practice, over whether or not to give a diagnosis. Her decisions were based less on clinical realities, and more on the likely impact of a diagnosis on a person's life and future prospects. **Kate Diesfeld**, also a lawyer and District Inspector, spoke of how the Mental Health Act was used, and how diagnoses, although not officially required for use in this Act, have many other influences, often hindering a person's recovery or reintegration after a period of illness. She also spoke of the danger of diagnostic inflation and "therapeutic creep". (Her presentation is available as Supplementary Document 5.)

After a break for tea/coffee (3.30pm), our final discussion (facilitated by **Tane Rangihuna**) had, as prompts, the following questions: "Can a single system of diagnosis serve the interests of all stakeholders?" "If not what are the alternatives?" "Putting learning into action – how will what we have heard today change the way we think, respond and work" and "Where to from here?"

Feedback-Evauation: After the workshop, participants were invited to complete a feedback/evaluation form, which allowed plenty of space for free comments. It also asked those responding to identify which stakeholder group they belonged to. Thirty-seven participants completed the form. They included 15 identified as "clinician/health worker**;** 9 as **"**consumer/*tangata whaiora*[2]" plus 7 others who combined this with other roles (field worker; field worker/peer support manager; field worker/clinical health worker; Clinician-health worker/administrator-manager; self employed consultant; mental health trainer); 3 as field workers; 3 as "administrator/manager: 1 as lawyer; 1 as clinician/manager ; 1 research evaluator (not academically affiliated).

Synopsis of emotional tone at the workshop; and aims of this report.
At the workshop itself, and in the feedback/evaluation forms there was a vast diversity of comments on diagnosis. My job here is to bring some coherence to all the views expressed. Let me explain my approach to this task.

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2 Maori: "Tangata Whaiora": meaning "People seeking wellness"

First: Everything that was said was based on first-hand experience, whether as a clinician, one with lived experience of illness, a caregiver, or in other ways. That fact assures us all of the validity of everything that was said.

Second, in the discussions themselves, and in feedback comments, there were some expressions of dismay and doubt that it would ever be possible to reach a consensus. I disagree with this viewpoint: If everything that was said has the validity of first-hand experience, apparent differences of perspective cannot be true disagreements, but different parts of a complex kaleidoscopic picture. There was little (if anything) that I could identify on the day as real disagreement, at an emotional level. The challenge for me (to change the metaphor) is to take what seems to be a "can of worms" (all writhing vigorously) and "weave it into an illuminating - even a beautiful - living tapestry", in which we all make our contribution.

Third: The records of the workshop included the text of some of the presentations, Power Point slides from two of the presenters, notes taken by various people assigned to the task (which was especially helpful for the discussion sessions), plus my own notes and personal recollections of the day. In places I quote things that were said. These are not verbatim quotes, rather the gist of what was said; and nothing is attributed to individual persons, except to scheduled speakers (when we have the text of their presentations). On some topics I supplement these sources of information from relevant publications, including those of some presenters.

Fourth: This report starts with an overview of the workshop, leads into the perceptions of participants on the advantages of psychiatric diagnoses, the inadequacies of diagnoses in practice, fundamental flaws which may exist in the process of psychiatric diagnosis, and the dangers which commonly derive from misuse of diagnoses, or are inherent risks deriving from their fundamental flaws. Towards the end of this report, I make suggestions of possible remedies for problems with diagnosis, how to retain the benefits yet avoid the weaknesses and dangers of diagnosis, and how to move to resolving the most fundamental problems.

Fifth: In making these recommendations, I am often trespassing into unfamiliar territory, in areas where I have no experience. I have the temerity to do so only because there are few others who *do* have experience to bring together the diverse perspectives of all stakeholders, or who dare go beyond their area of specialization in the attempt to bring coherence to the overall picture. So, I approach the issues as a logician on the basis of what I knew already, all that I have learned in preparing for this workshop, at the workshop itself, and in reading done later. However, any conclusions I reach, or recommendations I make should be seen as matters for open discussion, not definitive statements. Adopting proper journalistic practice, the accompanying document (*Synopsis of Workshop on 16th July*) attempts to be straight reporting, whereas the present document is more of an extended editorial, that is one person's attempt to analyse, interpret and comment on the complex issues involved.

Sixth: This report is quite lengthy and complex. This is necessary if some coherence is to be brought to this complex and fraught area. It is hoped that, by presenting the full diversity of views, participants can come to appreciate each other's viewpoints better, and collectively can move towards a consensus. Without such a lengthy document each participant would be inclined to cling to their prior opinions, without assimilating those of others at the workshop.

Seventh: On my use of language in the report, I use that with which I feel most comfortable. I realize that this is a sensitive issue for some at the workshop, and I hope I am not offending them. However, I ask them to bear in mind that we *were* a very diverse group, and any attempt to standardize terms would not satisfy everyone, would probably read in a

stilted way, and would not communicate very well. As I write later, I think we can all be better advocates if, whatever terms we prefer (and I have my preferences), we try to be "multilingual". So, we should let the exact wording of what people say wash over us, like "water over a duck's back", but try instead to get at their real meaning. However, I tend to use the word "patient" just in the context of a clinical encounter between a physician and one of his/her clients, and use other words ("service user", "consumer", *tangata whaiora,* etc) in other contexts.

II. Overview of the Strengths of the Workshop.

The workshop was widely appreciated by its participants, with many gratifying expressions of thanks. I begin by summarizing these positive responses:

(i) *Diversity of contributions to the workshop.* The diversity of views expressed, and the openness and mutual respect shown by everyone at the workshop were widely welcomed. The safe environment for all participants (who sometimes spoke in quite personal ways) was praised by several of those responding in the feedback forms.

(ii) *Questions were raised over whether, with such diversity, consensus can ever be reached.* It certainly cannot be reached without sincere efforts at mutual understanding of each others' views. A process of discourse was started on 16th July. How far consensus-building can go is a matter for the future. This report may be an important step in the process.

(jjj) *The scheduled speakers.* There was general support for the selection of speakers, and the clarity and thoughtfulness of their presentations. In the feedback forms everyone of them was singled out for praise by one or more of the respondents, and there were hardly any negative comments.

(iv) *Selection of participants other than scheduled speakers*. The first priority in planning the workshop had been to have a 50/50 split between professionals and community, and this worked well. The diversity of stakeholders present was generally appreciated.

(v) *"Cross-fertilization".* There was general appreciation from clinicians and health workers (who sometimes expressed pleasant surprise) of having such open and robust contributions from *tangata whaiora;* and likewise there were a number of expressions of surprise from the latter, that clinicians could be so open, accepting, and self-critical. This indicates that this workshop was a rare and valuable event, quite different in its power-relations from situations in which members of these two groups normally meet.

(vi) *Diagnoses provide a language.* The most fundamental and basic benefit accruing from using diagnostic terms, is to provide a language. We *think* mainly through the medium of language. Mental disorder is an area where new language is needed, and with which we all struggle. Words for diagnoses allow families and *tangata whaiora* (as well as professionals) to "put a name to the face of a disorder", as one of Mellsop's respondents put it. Without this, all concerned may feel that they are "fighting a fog", or "chasing ghosts". But, one may also ask, is the language robust enough to bear all the weight put on it? Is there

any value in new terms, if they serve to confuse and stigmatise, rather than clarify, and if nothing tangible flows from them?

(vii) *There are both benefits and dangers from diagnosis.* There was widespread, near unanimous appreciation that use of diagnoses in practice may be inadequate; and that dangers as well as benefits may flow from psychiatric diagnoses (and from widespread adoption of official systems of diagnosis). The potential for real abuse based on diagnoses was recognized by many. Some service-users spoke of benefits of diagnoses they received. More (perhaps) spoke of harm done to them by diagnoses. Those speaking positively often spoke of less serious diagnoses they had received, those speaking negatively often referred to major diagnoses - especially schizophrenia - which are more likely to be the basis of stigmatization. There were a few exceptions to this pattern. Views heard at the workshop may not have been representative of a wider constituency. However, views canvassed in research studies of Graham Mellsop and colleagues (see below) may correct any imbalance at the workshop. In any case, it is important to find ways to avoid the dangers of diagnosis, or inadequate ways in which diagnoses are used, while retaining their benefits.

III. Shortcomings Of The Workshop On July 16th

From comments received in feedback forms a number of shortcomings were identified in the workshop. Most were inevitable, given the way it was set up; but they should be borne in mind in planning any further workshops on this topic.

Sound quality for scheduled speakers was poor, especially for those at the back of the room. The original plan had been for presenters to speak from the middle of the long wall of the rectangular room, with a small number of broad arcs of seating. This would have been a more "democratic" arrangement, and would have avoided problems with sound. However a decision was taken late in the day to move to another room, where this arrangement was not possible, and presenters had to speak from the front of the length of the room. Back speakers would have been an improvement, but we didn't realize there was a problem until too late.

Several people asked for *certificates of attendance*, a matter which has been addressed by staff at *Kites Trust.* A clinician/health worker wrote: "Important that a certificate be produced in building up a portfolio, so that consumers know we health workers are at least attempting to understand this subject".

Some groups were not well represented at the workshop, with few psychiatrists, or mental health nurses attending, few clinical psychologists, few lawyers or administrators, no-one from Ministries of Social Development or Justice, and (I think) no-one concerned with the financial side of mental health services. Amongst non-professionals, there were far more service users than family members/caregivers. Nevertheless the primary objective of having a 50/50 split between professionals and community people was largely met. In planning the workshop, it was not the intention to have such biased representation. However, in view of comments received about poorly-represented groups at the workshop, in places, I amplify what was said on the day with published evidence (especially that from research of Graham Mellsop and colleagues).

Related to this a comment, from an administer/manager was: "To some extent the workshop was attended by the 'converted'. Would have been more interesting/challenging if more pro-diagnosis people attended. Not sure how one encourages attendance by more pro-diagnosis people" Another comment was: "I did have some feelings of (dare I say) hopelessness with regard to whether discussions like these will have any effect on changing the system that is currently used. This feeling was possibly enhanced by the lack of number of psychiatrists and mental health nurses present here today." Other comments followed on from this: "Much was not new to this audience – e.g. personal stories about good and bad of diagnosis. The *Like Minds* research on labels could have been mentioned." (This comment has now been followed up, and articles in the two *Like Minds* newsletters are incorporated into this report.) From a mental health trainer, there was the following comment: "There seemed to be a lot of arguing about pro's and con's of diagnosis which could go on and on, but ultimately not be resolved – perhaps not the most constructive use of time". All I can say to that is, "I hope this is just the start; We haven't finished yet".

A comment, from a clinician manager, asked for "more information about what DSM-V changes might be, and what implications they might have". Another comment (from a clinician/health worker) said: "Yes! It was a good workshop and very mind stimulating! Please send us copy and notes on the presenters. It will be a good resource".

In retrospect, the *feedback/evaluation form* could have asked for more detail on the groups to which people belong. Amongst professional groups the form used the umbrella term "clinician/health worker", and did not distinguish psychiatrists from other clinicians.

This report will of course be circulated to all participants, and a number of other interested people, in both New Zealand and overseas.

IV. Where to From Here? Practical Suggestions for the Next Move.

Balance of Participants: In the 50/50 balance amongst participants we seemed to have hit upon a formula to be strenuously developed in future meetings. More than one consumer wrote along the lines of this comment: "Keep the discussion going – keep the psychiatrists attending, and get more of them". Another wrote: "More from the psychologists's view". However, from a research evaluator (non-academic) we read: "I'd love to be part of future discussions. Consumer involvement is critical" "I think the client/consumer perspective is really important and I wonder whether person-centredness/consumer perspective needs to be a critical thread in further discussions about diagnosis and classification". For future forums the balance of participants might be varied on each occasion, either deliberately (or "just as it happens"), including encouragement of more psychiatrists, psychologists, lawyers and representatives from government ministries to participate.

Style of discussion: There were some suggestions that this could be improved in future workshops: Several people suggested that richer interaction might come by breaking up into smaller groups for some of the time, each of which mixed up different sorts of stakeholder. In planning the workshop, we considered this possibility, but finally did not opt for it. That may have been the correct decision for a first workshop; but the discussion might progress further at later workshops if this suggestion was adopted. At the end of the workshop I

summed the day's events up in the single word "chaos", to which a comment was received, from a clinician/health worker in an evaluation form: "from chaos comes clarity, understanding, respect, equality and more respect".

Agenda for future forums. Some comments emphasized *core* items for the agenda of future meetings (ones relevant to most stakeholders); others were more specific, and perhaps not of such wide relevance. Amongst the former we heard from a clinician/health: "From this conference, I think there needs to be more sensitivity and clarity about what diagnosis is for, and its importance to individuals." From someone identifying as "consumer/peer support manager/family-whanau" we heard: *"*It would be good to have moved on from repeated statements of strong views and hear more ideas on what changes might be envisaged for a better future system or perspective". From a clinician/health worker: "This is an evolving process." He also asked: "How sensitive is it, especially to clients?" The answer to that question depends on the emotional tone at each meeting. As noted earlier, there was little disagreement at an emotional level on 16th July, so there may be little cause for concern. However, one clinician/health worker asked future meeting to "explore more about core beliefs and attitudes of participants". That may be more challenging for all. There was also a call, from a clinician/health worker for "discussion around individual concerns re diagnostic criteria in greater detail".

Amongst the more specific issues mentioned in feedback forms were: "More on culture" (Administrator/manager); from consumers: "It would be good to have forums on: medication; compulsory treatment"; "Hold a workshop like this for consumers/*tangata whaiora* so they could ask questions to the professor". Some of these topics go beyond the subject of diagnosis, and require forums to be set up in a different way. Obviously Allen Frances had inspired the confidence of consumers, but we should all realize that it was our great good fortune to have him at our workshop on the 16th, and this cannot be easily re-arranged for a future date.

Political initiatives: If we run another workshop on a similar theme, it is important to try to get it accredited as Continuing Professional Development by RANZCP. This would encourage participation by psychiatrists or trainee-psychiatrists. A lawyer wrote: "Important to get critical psychiatry perspective debated in all New Zealand hospitals, clinics, medical schools." A clinician/manager wrote "I would be interested in hearing more about the role of diagnoses, and for discussion similar to today being conducted in mental health services, because this might mean that how diagnosis is actually used (or not used) may be able to be changed." Lastly, a consumer wrote advocating "adopting these discussions into clinical training with registrars". This is a timely suggestion, since RANZCP is about to launch a new training program for psychiatrists. John Crawshaw, who opened our workshop is also the Chair of the RANZCP Board of Education, and I am the community representative on that Board. I will mention it at the next meeting, scheduled for 8th/9th November.

The "research evaluator (non-academic)" wrote: *"*Support Allen Frances' call to influence politicians. How can we band together to do that?" There was also a call (supported by at least one a clinician), that a message be sent to RANZCP that it reject DSM-V. However, it was also pointed out that this might be taken to imply that participants at the workshop accept DSM-IV. In fact RANZCP does not endorse *any* particular

diagnostic system, although it is likely that the college will be debating the merits of DSM-V. I *am* considering putting before the Community Collaboration Committee of RANZCP the possible misuse of rating scales in supposed mental health assessment of pre-schoolers (part of the "B4School" health survey program). I am also considering submitting a proposal for a 90-minute symposium on Psychiatric Diagnosis, a follow-up to our workshop, at the next congress of RANZCP in Sydney, in May 2013. Since this report will be distributed to people who were not present at the workshop, including overseas experts, debates deriving from the workshop may have an international outreach.

Practical suggestions for a follow-up meeting on diagnosis: "Repeating the experience would be the best practical way forwards" (Psychiatrist) "Definitely support another hui[3] and would attend. . .and before next year (administrator/manager). "Agree that sooner would be better – we can build on the momentum" (from the researcher/evaluator, non-academic). The suggestion was also aired that the topic of diagnosis be promoted for the next meeting of *Building Bridges,* which meets every third year, the next being in 2013. "Have the themes for *Building Bridges* been decided next year?"; and (from a clinician/health worker): "Why isn't *Building Bridges* building more bridges across our divides?" One who identified as a clinician/health worker suggested planning a conference around alternative approaches to diagnosis. In the meantime there was general support at the workshop to use a website/blog to keep the debate going, a view echoed in several of the feedback/evaluation forms.

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3 For non-New Zealanders, this is the Maori word for a meeting, a forum, or a conference.

PART II. EVIDENCE, ANALYSIS, COMMENTARY AND RECOMMENDATIONS ON ISSUES INVOLVED

I. Benefits and Current Inadequacies in Psychiatric Diagnosis.

(A) *Introduction: Who Can Give Psychiatric Diagnoses, and Using What System?*

In New Zealand, a small number of activities are protected or restricted under section 9 of the Health Practitioners Competence Assurance [HPCA] Act. Diagnosis is *not* one of these. Usually it is psychiatrists or G.Ps who give psychiatric diagnoses, but clinical psychologists are trained to diagnose mental disorders, are expected to be able to identify potential diagnoses, engage in the process of differential diagnosis, and be aware of diagnostic standards. *De facto,* since G.P's are seldom responsible for initial assessment of major mental disorders, the diagnoses they use for their patients are often those given by specialist services. This may change in coming years, as mental health care shifts to primary health organizations. Likewise, clinical psychologists often work in multi-disciplinary teams which include psychiatrists, so they also are likely to work on the basis of diagnoses made by psychiatrists. For most psychiatric disorders, diagnosis uses one of the international systems. Officially in New Zealand, the World Health Organization's system, ICD-10 (International Classification of Diseases, tenth edition) is supposed to be used, and this *is* used for collecting health statistics. However, for clinical practice the American Psychiatric Association's system DSM-IV (Diagnostic and Statistical Manual, fourth edition) is used more commonly.

(B) *Perceived Benefits of Receiving a Diagnosis: Consumers and Caregivers.*

Since benefits of psychiatric diagnoses were probably under-represented in views heard at the workshop, my records of the workshop are amplified from published literature, subdivided according to the stakeholder groups concerned.

(i) Service users. Service users at the workshop who spoke of perceived benefits from diagnoses they had received did not go into much detail of their reasons. However, several possible benefits can be envisaged: By providing a basic language diagnoses may give a sense of security (that "someone understands what I am experiencing"); diagnoses allow self-education and foster self-understanding; service users appreciate that diagnoses may help guide clinicians towards the right treatment options, and (within a particular health system) may be the "key which opens the door" to certain services. For specific problems which have only recently come to prominence (such as dyslexia), official recognition is greeted favorably, as is the need for clear diagnosis in order to access support services in schools and universities. Some people self-diagnose, on the basis of information obtained from the internet, suggesting that diagnosis *is* valued by many *tangata whaiora.*

Very little has been published on attitudes of service users to diagnoses they receive, how diagnoses are conveyed, and the impact it has on them. However, one presenter at the

workshop, Graham Mellsop (and his colleagues), have conducted unique research on this topic, in the New Zealand context[4]. This was based on discussion in "focus groups" (with a total of 70 participants), this being the best way to survey views of this group. The study was not quantitative and so may not be representative. On receiving a diagnosis, some patients felt relief and hope, they felt that their problems were validated, their sense of isolation reduced ("I am not the only one"), and they had something on which to base self-education (for instance, from one person with a bipolar disorder, who wrote: "I went to the library to read up all about it").

Another source of information about benefits of receiving a diagnosis is a survey conducted in 2009 in the *Like Minds Like Mine* anti-stigma network within New Zealand[5]. The report includes the following quotations, as perceived benefits:

"When I was first diagnosed, having the label made sense of what was going on for me . . .finally I had a term and a reason, to explain what was happening in my head"

"It gave me words to describe how I was feeling. It also gave me somewhere to belong, in that there were other people like me and support groups I could contact."

" . . .through this labeling I have been able to seek advice, research, and get better treatment . . .and it has also helped me to explain my illness to family and friends."

"I can research and read other people's experience of it too. This is very important to me – to develop a lot of understanding about the condition and to find out how others cope in a similar situation. For me, knowledge is power".

 (ii) Families/whanau. One speaker at the workshop (Ginny Port), spoke thoughtfully of the benefits of diagnosis, based not only on her own experience, but that of other family members, and those with a diagnosis (in all cases of Borderline Personality Disorder). For some, having the diagnosis helped greatly in giving a name to what had been a long-time problem, in guiding patients towards a mode of treatment (especially Dialectical Behaviour Therapy [DBT]), to assist their own self-education, and in explaining symptoms. Parents struggling to bring up children with some form of autism may be grateful when a diagnosis is given, and support services then rally round to assist.

Just as for service-users' views, there is little published about family members' views about psychiatric diagnosis. Graham Mellsop and colleagues again provide evidence in the New Zealand context, from interviews of 58 persons, based on a structured questionnaire[6]. Over three-quarters of those interviewed thought diagnoses were "useful", although half saw both positive and negative sides to diagnosis. Positive consequences included relief at identification of their condition, which meant that treatment could begin; help to understand

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4 Moeke-Maxwell,T, Wells,D. Mellsop,GW (2008) Tangata whaiora/consumers' perspectives on current psychiatric classification systems. *International Journal of Mental Health Systems* 2,7.

5 *Like Minds* newsletter, no 37, June 2009. Acknowledgements and thanks to Cate Hennessy and the *Like Minds* management for permission to quote from this newsletter.

6 Laird,B, Smith,B., Dutu,G, Mellsop,G. (2010) Views and experiences of family/whanau carers of psychiatric service users on diagnosis and classification. *International Journal of Social Psychiatry.* 56, 270-279.

a disorder; empowerment in dealing with it; better alertness to symptoms in an effected relative, leading them to learn better coping strategies, including ways to offer support, and crisis resolution by family members. Family members became less judgmental and "blaming", more tolerant, with better empathy. They recognized that a diagnosis can lead to appropriate treatment, including medications, and created opportunities for education and learning more about an illness (from the internet, pamphlets and books).

(iii) Longer-term benefits of receiving a diagnosis. Few if any positive effects appeared over the long term, as perceived by *tangata whaoira,* according to Laird et al (footnote above). However, Moeke-Maxwell et al (2008; footnote above) found that longer-term benefits included realizing that, once a diagnosis was given, this made possible medication and various forms of psychotherapy or counseling, which were reasonably effective. Follow-up was generally appreciated. In the 2009 survey conducted by *Like Minds Like Mine*[7], over half of respondents (53.7%) thought that labeling their mental illness had helped their recovery. However, this was balanced by the fact that a similar percentage – 58.8% - felt that labeling had hindered or been harmful to their recovery. Since this study did not distinguish between diagnostic and everyday-speech labels, it is possible that these two sets of responses referred to different sorts of label, and so may inconsistent with each other.

Caregivers became more pro-active once a diagnosis was given. Service users and their families took more responsibility for managing their illness and taking medication, and they started to develop their own independent living arrangements. They came to understand the impact of their illness on their own families. However, most of these benefits were due to engagement with mental health services, not specific advantages of a particular diagnosis.

(C) *Perceived Benefits and Actual Uses: Professional Groups*

(i) Psychiatrists. Allen Frances thought that in the U.S.A. serious mental illness can now be diagnosed fairly accurately, which leads to quite effective treatment. The same is probably true in New Zealand. With regard to actual uses, Mellsop and colleagues[8] give valuable information on use of diagnostic systems in New Zealand: 90% of psychiatrists use DSM-IV routinely for diagnosing major disorders (Axis-I), while few use ICD-10 (although this is the government-recommended system). The usual reason given for this preference is not the superior validity, or ease of use of DSM-IV, but that this was the system on which the clinician was trained. (56% of respondents were aged between 35 and 50.) The primary purpose for which they used diagnostic systems was to aid communication amongst themselves (51% of respondents), and to inform patient management (16%). Only 8% used diagnoses primarily for communication with consumers[9], although as many as 40% accepted

7 *Like Minds* newsletter, no 37, June 2009.
8 Mellsop,G. Dutu,G. Robinson,G. (2007) New Zealand Psychiatrists Views on Global Features of ICD-10 and DSM-IV. *Australia & New Zealand Journal of Psychiatry,* 41,157-165.
9 In the introduction to DSM-IV we read: "The utility and credibility of DSM-IV require that it focus on its clinical, research and educational purposes… Our highest priority has been to provide a helpful guide to clinical practice. An additional goal was to facilitate research and improve communication of clinicians and researchers… and as an educational tool for teaching psychopathology (page xxiii)" It is not clear from this whether communication between clinicians, or between them and their patients is the more important aspect of "clinical practice". Since the "consumer revolution" in

the value of diagnostic systems for use *by* consumers. Scarcely any used diagnoses primarily as an indicator of prognosis. Only forensic psychiatrists favored the idea that use of diagnostic systems should be limited to psychiatrists and doctors.

(ii) Clinical psychologists. In New Zealand, DSM-IV is used "routinely" by 63% of clinical psychologists, and "sometimes" by a further 32%, in relation to major disorders (Axis-1). As with psychiatrists, their preference is related to the system they were trained with. About one third use ICD-10[10]. Primary uses to which DSM-IV is put include: Communication between professionals (77% of respondents); Communication with clients (39%); To inform case management (55%); To indicate prognosis (44%). For these purposes (and others: see below) diagnosis appears to be given more weight by clinical psychologists than by psychiatrists. However, in clinical psychology practice, the emphasis is to develop explanations of distress in individuals; diagnosis tends to occupy a secondary place in assessment. Potential diagnoses may help guide assessment, but contribute little to development of a reasoned intervention plan.

(iii) Mental Health Nurses: According to Mellsop (workshop presentation), mental health nurses value diagnoses for several purposes: For discussion within their clinical team (94% overall; 50% "highly"); For gaining access to services requiring a diagnosis (84% overall; 52% "highly"); When reviewing medication options (83% overall; 32% "highly"); For bio-psycho-social assessment and to inform treatment planning (78% of respondents overall for each; 30% each "highly"); To facilitate consumer-clinician communication in building a therapeutic relationship (70% overall; 29% "highly"). As Mellsop points out, nurses also routinely use diagnoses to formulate treatment plans, in communication with family, G.P's and their own team, and to contribute to admission/discharge criteria.

(iv) General Practitioners. G.Ps can give psychiatric diagnoses, but apparently rarely use diagnostic systems[11] (never/rarely: 82%; half the time: 8.8%; often/always: 9.1%). The following factors were relevant when they *did* use a diagnosis: Choice of pharmacological treatment (always/very often: 70%; sometimes: 18%); Communication with other health workers (67%/24%); Assistance in decisions regarding referral: (55%/29%); Providing patients with a label for their symptoms (52%/36%); Assessing the safety of the patient or others (48%/33%); Medico-legal documentation (36%/33%); Other factors (24%/47%). Since diagnostic systems were rarely used, it is probable that G.Ps often use diagnoses that do not correspond to any such system. Reasons given for G.Ps neglect of diagnostic systems are considered below.

(v) Legal uses of diagnoses. In many countries, justice systems make use of diagnostic labels derived from official systems. In New Zealand, invoking the Mental Health Act, or authorizing a Community Treatment Order does *not* require a psychiatric diagnosis, these being based on other, non-medical criteria (a fact which surprised some service users at the

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psychiatry had barely begun at the time of publication (1994), it may have been the former which was uppermost in the writers' minds.

10 Lutchman,R, Mellsop,G., McClintock,J, Gayler,K, Gaffaney,L (2007) New Zealand psychologists' perceptions and opinions on the use of the current classification systems of mental disorders. *New Zealand Medication Journal,* 120, 4-5.

11 Lillis,S., Mellsop, G, Dutu,G (2008) General practitioners' views on the major psychiatric classification systems. *New Zealand Medical Journal*, 121, 30-37.

workshop). Nevertheless, in practice, if a person has a psychiatric diagnosis, it may increase the likelihood that he or she meets criteria for compulsion. In New Zealand, mental health nurses regard diagnoses as important when invoking the Mental Health Act (Mellsop, workshop presentation: 66% overall; 29% "highly"). Psychiatric diagnoses, as given by psychiatrists or G.Ps, are influential for many other official, legal, or quasi-legal purposes, even when not formally required, with substantial personal, social, or political impacts[12]. Sometimes diagnoses enable access to services, sometimes they limit or constrain those who are diagnosed.

Advantages (for patients) of having a psychiatric diagnosis include gaining access to benefits, payouts from Accident Compensation Claims, or individual support in school and university education. When a service-user authorizes an "advance directive" this is likely to apply only to consequences of a stated diagnosis.

Disadvantages (for patients) include the potential for the State to expand its coercive power over people deemed to have a psychiatric diagnosis: Mental health may be raised in decisions over custody or guardianship of children, and psychiatric diagnoses may then be influential in court proceedings. When people apply for employment, according to the letter of the law, discrimination on grounds of a psychiatric condition or history is illegal under the Human Rights Acts. However, many people may not want to invoke protections of this Act in relation to employment, because of the emotional toll of doing so. Stigma associated with revealing a psychiatric diagnosis may have important adverse effects, even if (or because) a person does not file a complaint.

In other areas, deciding whether a medicine is being marketed for "off label" uses (which is illegal in the U.S.A.) is based on diagnoses. Likewise the need to declare "off-label" uses for clinical trials as "research" is based on diagnoses. Whether all these uses for diagnoses are benefits or disadvantages depends on whose views are sought; but from the perspective of a whole society, they are all sanctioned socially and/or legally. In so far as the validity of the relevant diagnoses are questionable, so too are the legal uses to which diagnoses are put[13].

(vi) Financial and related uses within health services: No-one could speak from this perspective at the workshop, and nothing was mentioned on the topic. However, in many jurisdictions, funding of psychiatric treatment (whether by medication, psychotherapy, or other means) is denied, unless it is "proven therapy" for a specified condition, as defined by official diagnoses. Health insurance payouts are usually related to specified diagnoses (although in many jurisdiction, mental health is not covered). In New Zealand the Accident Compensation Commission requires psychiatric diagnoses in certain cases, in relation to "mental harm" done by an event, a situation or a person. Decisions to allow medicines as safe for use in New Zealand are authorized by MEDSAFE, and state subsidy for their purchase is authorized by PHARMAC. Both are based on proven efficacy for specific

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12 Eriksen,K. and Kress, V. (2005) Beyond the DSM Story. Thousand Oaks, CA: Sage Publications. Page xiv.
13 Mellsop,GW, Diesfeld,K. (2011) Psychiatric diagnoses in legal systems; an issue of validity. *Medicine & Law* 30, 517-557*; Mellsop,GW, Fraser,D., Tapsell,R. and Menkes,DB (2011) Court's misplaced confidence in psychiatric diagnoses. *International Journal of Law and Psychiatry, 34, 331-335.*

diagnoses, in psychiatry as elsewhere in medicine. With growing use of Key Performance Indicators in the health sector one might ask if psychiatric diagnoses play a part in these. I am told that they are not so used at present, the probable reasons being partly that they are viewed as unreliable, and partly because not all District Health Boards collect such data. However work is in progress to incorporate diagnoses into K.P.Is, and it is probable that they *will* be so used before long.

(vii) *Statistical purposes. Statistics New Zealand* collects no information on psychiatric diagnoses. However, since 2008, the *Ministry of Health* has developed the *Programme for the Integration of Mental Health Data* (PRIMHD), a national database of information collected by D.H.Bs to support policy formation, monitoring and research. Information coded in this database includes psychiatric diagnoses coded through various systems (including DSM-IV and ICD-10). The statistics are then used for funding or policy decisions. If the categories used for such statistics are flawed, to the same extent will be decisions dependent on them. In studies by Mellsop and colleagues (as presented at the workshop), clinical psychologists were found often (55%) to see diagnoses as providing a basis for collecting statistics, and nurses valued diagnoses "as required by their employer for statistical monitoring".

(viii) For research and scientific purposes. Mellsop et al (2007) reported that only 10% of New Zealand psychiatrists use a diagnostic system to facilitate research. This may be because few psychiatrists in New Zealand are involved in research. However, it may be because only 8% thought such systems reflected aetiology or pathology of mental disorders. In contrast, clinical psychologists (who include research experience in their training) mostly (68%) found diagnoses facilitated research, and diagnoses were useful for conveying information about aetiology/pathology (56%). Likewise nurses valued diagnoses for research (53% overall; 32% "highly"). Allen Frances suggested that DSM-III/DSM-IV had not been good for research; but this may not be entirely true: Useful research on Dissociative Identity Disorder (DID) and Post-Traumatic Stress disorder (PTSD) for instance would not have flourished had these diagnoses not been specified in DSM.

(D) *Inadequacies of Diagnoses in Practice: Stakeholder Groups.*

Many shortcomings identified below are qualifications of (or comments on) points made in the previous section. These are not hazards of the very principle of psychiatric diagnosis (a topic considered below) but rather ones which might be avoided or resolved with suitable adjustments in practice. The present section is subdivided according to stakeholder groups concerned, and next section according to specific issues.

(i) Tangata whaiora. Initial relief after a diagnosis was given sometimes changed to disappointment, disillusionment and anger, when a diagnosis did not lead to a cure[14]. This is a criticism not of psychiatric diagnosis *per se* but may indicate poor explanation by psychiatrists of what diagnosis signifies, how it differs from diagnosis in general medicine,

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14 Tess Moeke-Maxwell, Debra Wells, Graham W Mellsop (2008) Tangata whaiora/consumers' perspectives on current psychiatric classification systems. *International Journal of Mental Health Systems* 2,7.

and what is possible in contemporary treatment. Disillusionment might also grow as service users find that a succession of different diagnoses is given by different psychiatrists. Several comments in the evaluation forms made the point that diagnosis seems "to be a hit and miss process", a view echoed by some clinicians who acknowledged that the process was so fluid that it must be confusing for service users. There was some surprise amongst service users that they agreed with these clinicians on this issue. It *may* reflect poor practice, but more fundamentally reflects inadequate classification systems. Sometimes shifts of attitude are more ambivalent: A service-user at the workshop said: "Diagnosis is not a good thing; it did explain my suicidal attempt, and turned me into a 'consumer'; but it gave me job[!], and made me a tough advocate for other down-trodden users."

Many *tangata whaiora* said that what was often forgotten in the process of diagnosis was their personal stories, individual identity and purpose in life (see below). Diagnosis classifies persons into groups, insidiously leading to neglect of this personal focus, and sometimes to stigmatization. Kate Diesfeld said that to receive a psychiatric diagnosis impacts upon a person's sense of self and identity, and influences their hopefulness for the future. She spoke of "the necessity of *Hope,* regardless of 'diagnosis'." A major issue is then whether (and how) this emphasis can prevail, without losing positive aspects of diagnosis. How to instill hope, regardless of diagnosis?

The survey on "labels" conducted amongst the *Like Minds Like Mine* community provides evocative statements about negative aspects of diagnosis[15]. That survey was about any sort of label to do with mental illness, not just diagnoses. However, most comments appear to refer to diagnoses. They include the following:

"Labeling tends to focus on the negative aspects of mental health issues, rather than balancing it with the strength, resilience, insight, self-understanding and hope for a better sense of well-being, which are also vital components in balancing mental health".

"It becomes a role or set of expectations about how you expect (and are expected) to behave".

"It has distanced people from seeing the person that I am, rather than just the illness that I suffer".

"Your own personal recovery can be hindered by the treatment from others, who see you as a 'risk' or 'unstable', and that you will never be the same again."

"Sometimes in the very low times, having the label drags me down and I think that I'll never be well again, as I have this mental illness".

"It changes the way I saw myself – into a sick person, a mental patient – which made it hard to believe that I had self-worth, or that I could recover".

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15 *Like Minds* newsletter, no 37, June 2009; reproduced with permission.

To be fair, many of these comments reflect the effects of receiving a diagnosis, *combined with* the prejudices a person might already harbour about mental disorders, picked up from the school playground and later. I can speak with feeling on this: During my own periods of illness, there was nothing I experienced that I would call cruel or abusive; yet those periods were permeated by intense fear – based largely on my pre-existing prejudices. Many people in the *Like Minds* survey thought that all labels were stigmatizing, but many comments about stigma referred to derogatory "everyday-speech" labels or to media distortion using labels, rather than to more specific use of diagnoses. Nevertheless, some at the workshop wanted to abandon diagnosis altogether. One consumer said "DSM is not a bible and didn't need to be picked up in New Zealand".

Objections to diagnosis raised some wider issues. A consumer said thatdiagnosis enabled misuse of the Mental Health Act and allowed human rights to be violated". Misuses and violation of rights *have* occurred, a fact to which several of those at the workshop could bear personal witness; but it is uncertain that this is a fault in diagnosis itself, but rather personal failing of those who implement the Act (see below), or who are responsible for consequences flowing from its use. Another service user mentioned that rates of compulsory admission peaked in 1954, then dipped, but have recovered to the same level in recent years. Our attention was drawn to the fact that "bad stuff is not just in the past, but is still happening". This is accepted, but it is not clear how it relates to the process of diagnosis.

(ii) Family members: Due to the small number present at the workshop, family members' voices were not well represented. One family member who *was* present stressed the need to focus on "the person" rather than "the diagnosis", and was surprised to find that clinicians present at the workshop thought the same way. Another wrote: "It was interesting to hear how little G.Ps use classification systems, and how much psychiatrists struggle with them". In this context a Danish study[16] reported some years ago the criticism from family members, that diagnosis and prognosis of patients with psychotic disorders was unsatisfactory, too vague or too scarce. Other comments were that diagnoses were conveyed without offering hope, having negative effects which were compounded when associated social stigma was also pointed out. This could lead patient and family to deny the validity of the diagnosis.

(iii) Psychiatrists: Several clinicians at the workshop (and in evaluation forms) voiced the view that diagnoses in psychiatry are not as valuable in guiding treatment as they are in general medicine. One said: "Whereas diagnosis for heart disease is a good guide to treatment options, it is not so valuable for this in the case of mental illness." This view was echoed by many *tangata whaiora*. In addition most psychiatrists in New Zealand prefer a system with far fewer options for diagnosis than the 400-plus in DSM-IV (77% preferring less than 100 options)[17].

(iv) Clinical psychologists. Although many clinical psychologists used classification systems (mainly DSM-IV) routinely, 55% did not think that the systems they used

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16 Nordentoft M. Branner J. Schultz V. Hancke B. Skougaard K. Buchmann J. Dencik K. Scharf H. Bachmann H. Vinding HR. (1993) Relatives of psychotic patients: effect of group discussions and group education]. [Danish] *Ugeskrift for Laeger.* 155, 3122-3126.
17 Mellsop,G. Dutu,G. Robinson,G. (2007) New Zealand Psychiatrists Views on Global Features of ICD-10 and DSM-IV. *Australia & New Zealand Journal of Psychiatry,* 41,157-165.

represented psychological explanations of their client's presentation[18]. They made little use of the multiple axes in DSM-IV, using Axes I and II routinely, but seldom Axes IV and V, which they saw as vague and of little use clinically. While 39% of clinical psychologists continued to use the present DSM axes, 41% would like axes whose priorities were more useful guides to treatment or case management. 10% wanted axes more relevant to understanding pathogenesis. In the future, they hoped for systems which accommodated individual differences, with more behavioural definitions and systematic descriptions, less complex in theory, and serving as better guides to inform treatment. The wish for systems that take more note of individual differences agrees with the desire expressed by many not to lose sight of the uniqueness of each person. However, some may see this as pulling simultaneously in opposite directions – emphasis on both classification into groups *and* on individual identity.

Clinical psychologists use diagnostic systems in different ways from psychiatrists. They use them for inter-clinician communication (somewhat more than do psychiatrists), and for all other purposes (communication with clients, in relation to aetiology/pathogenesis, to inform case management, prognosis, research and statistics) more than do psychiatrists. This could imply that clinical psychologists have greater faith in diagnostic systems than do psychiatrists, although evidence discussed below does not support this.

(v) *General Practitioners:* Evidence from focus groups documented which issues were important for G,Ps in psychiatric diagnosis. Official systems of diagnosis were very little used by G.Ps. A variety of reasons were given for this[19]:

"Limited experience and knowledge of schema" (75% agree).

"Too complex" (66% agreed; but this was less so in those with most experience);

"Too rigid" (57% agreed. This correlated positively with the age of the practitioner, but negatively with their level of experience).

One G.P. (reported by Mellsop) wrote: "I see it as being overly complicated, I see it as being a bit artificial in that, if someone doesn't meet the time criteria for a particular illness, I am not going to wait two extra weeks until they meet the criteria before I start them on appropriate medicines; so it is there as a guide, but a guide I don't use very much."

"Doesn't reflect mental illness seen in general practice" (51% agreed). One G.P. (reported by Mellsop) stated: "I suspect the criteria were written by partialists [specialists] who receive a filtered population that have already been worked over by other people from primary care."

"Poor reliability of coding between practitioners" (44% agreed; this correlated strongly with age of GP, and years since graduation).

On the purpose of diagnosis, 49% agreed that the official systems were "not management focused"[20]. This view was affirmed more by female G.Ps, but less by those of either gender

18 Lutchman,R, Mellsop,G., McClintock,J, Gayler,K, Gaffaney,L (2007) New Zealand psychologists' perceptions and opinions on the use of the current classification systems of mental disorders. *New Zealand Medication Journal,* 120, 4-5.
19 Lillis,S., Mellsop, G, Dutu,G (2008) General practitioners' views on the major psychiatric classification systems. *New Zealand Medical Journal*, 121, 30-37.
20 Meaning "focused on patient management", rather than "health service management".

with most experience. They saw management, not diagnosis as the purpose of consultations. Diagnostic labels were sometimes useful in informing management, but, as a group (according to one G.P.) "we're less interested in diagnosis, and more interested in *function* with most of our chronically mentally ill".

Other factors relevant to whether and how a diagnosis was given[21] included the fact that often diagnoses had already been given" (by a psychiatrist), patient acceptance of diagnoses, knowledge of a patient's past history and family. On the relation between their practise and wider society, comments relayed to Mellsop included: "Its a life long saga, isn't it really, of, you know, is it anxiety or is it depression or is it just general life struggles, and it's all sort of interwoven, intermixed…" "I am more focused on how that patient is going to cope, how she or he is going to get along when she gets home and how things are going to go and what is going to happen in the next week and if they can come back and see me, I am more concerned with that kind've stuff than I am with the label itself."

One service user at the workshop raised the issue of whether the switch of psychiatry to primary health care was a good thing, making the clear statement: "G.Ps are usually not so good at diagnosis, and do not have so have so much time as specialists." Allen Frances, on a Power Point slide (not shown at the workshop) makes the point (presumably for U.S.A.) that primary care M.Ds prescribe 80% of psychotropic drugs, but have little training or interest in psychiatry, and little time to evaluate symptoms or history. They tend to favour pill solutions, are easily influenced by drug companies, 'opinion leaders', and patients. Another of his slides (not shown) gives clear advice: "Prohibit initial prescription of antipsychotic by primary care doctors". However, as I understand it, plans currently being developed for New Zealand would still involve specialist services for most initial assessments and diagnoses, including initial prescription of antipsychotics. Primary health care facilities would take over only for much of the subsequent management.

Most psychiatrists (74%) thought that G.Ps should use the same diagnostic system as they did, only 26% opting for a modified simpler system. Amongst G.Ps, as many as 93% thought that the same system should be used for primary and secondary care. However, compiling comments of both groups suggests that this is hardly possible, since G.Ps seldom use official systems; and one psychiatrist's comment (relayed by Mellsop at the workshop) was that "G.Ps rarely use our bibles!" Mellsop's paper on G.P attitudes to diagnosis concludes as follows:

> "It is apparent that GPs are faced with an 'unworkable system' in current schema-based methods of classification that are externally imposed. Similarly, methods of classification designed principally for primary care use would equally represent an unpalatable solution to those in secondary care. Of further consideration are the missing voices; those who suffer from mental illness and the social networks that support them. It is timely, therefore, to begin new conversations regarding the purpose of diagnosis, the purpose of classification and the primacy of management. Such conversations need to involve the society in which we practice."

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21 from Mellsop's Power Point slides

(vi) Nurses: Mellsop reported no adverse comments in his workshop presentation. There may however be important views from this group yet to be documented.

(E) *Inadequacies of Diagnoses in Practice: Particular Issues*

(i) *Style of communication.* Many comments were made at the workshop about the need for careful communication by professionals with patients and their families, especially on how diagnoses were communicated. There was much criticism of failings in this area. The value of a diagnosis depends on how it is communicated and explained. In particular it is important for clinicians to explain to patients and families that, in the present state of understanding, diagnoses are not very precise and replicable, and so do not have the significance of diagnoses in other areas of medicine in determining treatment. However, as discussed later, diagnosis in combination with "formulation", when well communicated, may be much more valuable.

When diagnosis is over-emphasized or its precision exaggerated, it can be stigmatizing, and an obstacle to free communication between psychiatrist and patient. It may hold back patients from speaking freely, and for some diagnoses may make a psychiatrist reluctant to raise the question of diagnoses. In that situation it may be the patient who first raises the issue, and who (perhaps with information from the internet) may self-diagnose before a diagnosis is confirmed by a psychiatrist. Comments received include a plea that the time of conveying a diagnosis should be used for communicating over a wider domain (which could include the "formulation"): "for communication of symptoms (but in plain language)". "A person's experience is the root, and the beginning of the diagnosis procedure." Classification systems like DSM-IV have the aura of "objective science", but if a diagnosis is conveyed sensitively, the process becomes more the "art" than the science of medicine. In conveying a diagnosis, it was important for a psychiatrist to explore each person's history with respect to previous diagnoses ("where we have been, and where we are going to").

Active listening was stressed by several people. "The tutor (that is the clinician) may become the learner, and the patient becomes the teacher." "Experts need to learn from people who are experts on themselves". Daniel Real's comment struck a chord: "My cat came and sat on my bed when I was unwell. Listening is not hard: My cat can do it. So. . . treat me the same way that my cat does". This has much truth in it, but yet good listening can be a very active process: Small comments interjected while listening can convey not only that a person's story is believed and fully understood (itself contributing to healing), but can also help a patient to understand themselves better.

Evidence reviewed above prompts comments about the process of communication. Data of Mellsop and colleagues showed that only 8% of psychiatrists used diagnoses to aid communication with patients, yet 40% were content for diagnostic systems to be used *by* patients (presumably with little guidance, and therefore perhaps with some degree of confusion). On the same theme, it is noted that psychiatrists seem rarely to engage in communication about diagnoses with patients, while clinical psychologists do so routinely. One must therefore ask if communication with patients on the subject of diagnosis is part of the job description for psychiatrists? Surely it should be? It is also

striking that the most usual purpose of classification systems for psychiatrists is found to be inter-clinician communication, with all the other purposes being minority ones. This raises the question of how clinicians *do* use these systems for communication amongst themselves? What do they discuss related to a diagnosis, other than the fact of a diagnostic label? Moreover, if clinicians rarely use diagnostic systems for clinician/consumer communication, one may ask why there is such concern and anxiety about diagnoses from some consumers? Perhaps the answer is exactly *because* the time of conveying a diagnosis is *not* used to convey and discuss all the other related information.

As noted above, clinical psychologists use diagnostic systems in different ways from psychiatrists. They use them for communication with other clinicians somewhat more than do psychiatrists, and for that with their clients, much more. This might imply that they are more involved with relating to patients on a one-to-one basis than are psychiatrists.

(ii) *The Centrality of the Concept of the Whole Person*: The importance of retaining a focus on the individual person was widely voiced at the workshop from both community and professional groups. One person put it in a perennial context, quoting Hippocrates: "It is more important to know what sort of person has a disease than to know what sort of disease a person has." We heard from a family member how she always tried to focus on the person, not the diagnosis. We heard from an administrator/manager that "diagnosis is not the identity of people" We heard from a research evaluator in an N.G.O: "I keep thinking about how diagnosis/classification/services are there for people, consumers, *tangata whaiora*. We need to reduce the gap in how these systems are falling short and becoming so divorced from the people they're serving." Her fear was that a "diagnostic/classification system is 'owned' by health professionals and that the ingredients in this 'animal' are people's experiences. People's experiences are reduced, manipulated and bent into something else completely. So, where's the validity?" Allen Frances also stressed the need for greater acceptance of the diversity of individual differences, and noted an unhelpful and growing intolerance (in U.S. society) for these differences, for eccentricity, and for developmental lags in some young people.

(iii) Issues about power relations. Some comments were received in feedback/evaluation forms about the relationship between diagnoses and power relations between service users and psychiatrists. These came both from *tangata whaiora* and clinicians, both of whom seemed to accept the complexity of the issue. From consumers we heard the following: "Issues to do with power discrepancies were *not* addressed." "The issue of power, in the hands of psychiatry, was not fully explored today, neither was the reality of madness". These comments perhaps acknowledge differences in the situation when service users are patients compared to when they are advocates or activists. However, one consumer was disappointed to hear from one presenter that "these 'very sick' people need compulsory treatment/detention" Clinicians' comments included: "Working in partnership, instead of clinicians knowing 'what's best' for clients all the time! – Partnership means power is interchangeable." "Balancing power between professionals and people accessing services." One clinician commented that "patients are now more equal to doctors – especially when they research their condition on google and the internet."

(iv) *Poor reliability of diagnoses.* Allen Frances commented that "in the U.S.A, diagnosis was a joke before 1980, with no consistency of diagnoses, and no common language. DSM-III provided that common language, not without its weaknesses, but arguably better than before." After 1980, using DSM-III or DSM-IV, reliability improved greatly. However, even under research conditions consistency between clinicians is far from perfect. Routine use by psychiatrists outside research settings reveals more striking inconsistencies[22], and use by G.Ps (even if they use the same system) is likely to be even more problematic. Allen Frances (in one of his slides) referred to the "fuzzy boundary between bipolar and unipolar disorder". Confirming reports from service-users at the workshop (both Daniel Real and Julie Channer), diagnoses frequently change over the course of a person's illness[23]. One person, quite typical for service users, is quoted by Moeke-Maxwell et al (2008):

> They didn't quite know where to put me so I started with factitious disorder, post-traumatic stress syndrome disorder, depression, borderline personality disorder, and schizophrenia. So, yeah, I have sort of done the rounds a bit.

In diagnosing young people, DSM-IV diagnoses derived by using three different interview schedules give widely differing rates for the proportion of 9-16-year-olds with a diagnosis[24]. While the quest for reliable diagnoses reduces confusion for some, it has drawbacks, even as a matter of principle: Reliable diagnosis is often achieved by standardizing every aspect of the diagnostic process by concentration on objective, observable facts. This means neglecting the subtleties and uniqueness of subjective personal experiences[25]; so, "validity is sacrificed on the altar of reliability."

(v) Current Diagnoses are Poor Guides to Treatment. At the workshop, Julie Channer quoted her father as saying that "treatments can be different for the same 'diagnosis'. A drug that works for one individual won't necessarily work for another." Graham Mellsop echoed this by pointing out that 40 years ago (a time of great optimism in psychiatry) it was thought that there was a good relationship between a diagnosis and the treatment which would be effective (neuroleptics for schizophrenia; antidepressants for depression; lithium for bipolar disorder; anxiolytics for anxiety; and family therapy for eating disorders). Today, such distinctions are much less clear-cut. For schizophrenia, many different approaches are used (neuroleptics, antidepressants, anxiolytics, mood stabilizers, family education and psychotherapy, C.B.T. or E.C.T.), and for depression the same is true (with antidepressants, neuroleptics, C.B.T, E.C.T, mood stabilizers, family work, and psycho-education all being used). To some extent Mellsop may be being too hard on his own profession, since different treatment approaches are used for different aspects of each disorder in relatively specific ways. This represents increasing sophistication of treatment, and not necessarily a blurring

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22 Cheniaux E. Landeira-Fernandez J. Versiani M. (2009) The diagnoses of schizophrenia, schizoaffective disorder, bipolar disorder and unipolar depression: inter-rater reliability and congruence between DSM-IV and ICD-10 *Psychopathology.* 42,293-298.
23 Rabinowitz J. Slyuzberg M. Ritsner M. Mark M. Popper M. Ginath Y. (1994) Changes in diagnosis in a 9-year national longitudinal sample. *Comprehensive Psychiatry.* 35,361-365; Chen YR. Swann AC. Burt DB (1996) Stability of diagnosis in schizophrenia. *American Journal of Psychiatry.* 153,682-686.
24 Angold A. Erkanli A. Copeland W. Goodman R. Fisher PW. Costello EJ. (2012) Psychiatric diagnostic interviews for children and adolescents: a comparative study. *Journal of the American Academy of Child & Adolescent Psychiatry.* 51, 506-517.
25 Fuchs T. (2010) Subjectivity and intersubjectivity in psychiatric diagnosis. *Psychopathology.* 43,268-274.

of diagnostic boundaries. For instance, as I understand it, C.B.T. is used for *persisting* psychotic symptoms, while antipsychotic medicines are still favoured for initial stabilization of psychotic states. Anxiolytics are used as sedation during initial stages of antipsychotic treatment, so that sedation need not be achieved using excess doses of the latter. However, it must be admitted that, while broad diagnostic classes may narrow down treatment options, there are many exceptions. Thus, clinical criteria on which diagnoses are made often do not identify the best treatment. Beyond that, a clinicians' skills are often empirical rather than rational, based on the principle "suck it and see", rather than "make the treatment fit the diagnosis".

(vi) Permanence of a psychiatric diagnosis as a label. Many people regard a psychiatric diagnosis as more difficult to shake off than a criminal record. Julie Channer spoke strongly on this:

> A huge concern I do have with the handing out of diagnoses, besides what I feel is a questionable level of accuracy in doing so, is the label that is given. So, rather than saying the person has schizophrenia, they become 'the schizophrenic'. This subtle difference in statement can have extremely damaging effects. For one, it is handed out almost as a life sentence. Very little hope is given with the diagnosis, and the label is actually never removed. The person is labelled as the illness, and as a result, the person ends up losing their identity. This has a huge long-term effect on a person that takes a long time to recover from, if at all. In a time when we are endeavouring to reduce stigma and discrimination, these labels do not help in the process.

Mike Sukolski expressed the same concern, in his line: "Whatever happens to the illness, it comes and goes, the diagnosis sticks." A lawyer at the workshop made the point, perhaps by way of explanation, that "Some patients want to undo diagnoses made 10-20 years ago. The fact that someone made that diagnosis at that time remains a piece of history." However, given the skepticism of many (including clinicians such as Graham Mellsop) about the robustness of concepts on which diagnoses are based, there may be justifiable concern over the certainty of such supposed "facts".

Allen Frances was quite sharp on this issue: "For psychiatric diagnosis Murphy's law applies: If something *can* go wrong, it will." "It is easy to give someone a diagnosis, but very difficult to undo the process; yet it may have lifelong impact." He was particularly concerned about the long-term impact of a diagnosis on young people, and said that every diagnosis in a young person should be temporary, not permanent.

Diagnoses do not have such long-term impact, or give rise to such concern for other life-long conditions (asthma, diabetes, allergies etc) as is the case for psychiatric diagnoses. This is closely related to our belief in the enduring nature of personal identity; and it is also related to the question of whether psychiatric diagnoses are "intrinsic to the person him/herself" or are "imposed *upon* the person". These issues are discussed below.

(vii) Secondary gains (for some service users), from having a diagnosis. Having a psychiatric diagnosis – especially the lesser diagnoses – may provide "secondary gains": Sometimes this is built into our administrative systems – a diagnosis becomes a "ticket" to

assist claims for insurance, state benefits etc – and so is hardly an inadequacy of diagnosis itself. However, Allen Frances maintained that, in the U.S.A. "It has become fashionable to be 'Aspie'." Family members often know the person with a diagnosis better than anyone else, and know they sometimes use the fact of having a diagnosis in a questionable manner. On this basis, the insight was shared at the workshop, that "A B.P.D. diagnosis might become a self–fulfilling prophecy for some." In other words, when a person knows their own diagnosis, and the corresponding behaviours associated with it, it may give that person an excuse for behaving in ways which otherwise they would avoid. Along the same lines, two of Allen Frances' slides (not shown) referred to "Psychiatric disability as a convenient way to explain the lack of jobs or added job stress", and in forensic settings "diagnoses were being used to reduce criminal responsibility", and "to explain 'mad' political acts - the Unabomber and Norwegian Terrorist". These secondary gains should be seen as unintended disadvantages of diagnosis.

(ix) Service user objections to particular diagnoses, especially "schizophrenia" and other psychotic disorders. Several *tangata whaiora* raised concerns about use of the diagnosis of schizophrenia. "This diagnosis is hard to have without being stigmatized. Hearing 'schizophrenia' is hard as a result." Kate Diesfeld mentioned one service user she had represented who expressed the hopelessness that descended when told that he had a diagnosis of schizophrenia. A participant said that her mental health would have been very different if the schizophrenia diagnosis had not been placed on her. It took her into an institutional environment where fear and control rather care and kindness predominated. "If, instead, openness and compassion predominated anything might be possible." Another service user spoke of the depressing effect of being told she had a borderline personality disorder. Like schizophrenia, this diagnosis is highly stigmatised, and both are viewed in the popular imagination as incurable, and perhaps untreatable. However, another person said that being given the borderline personality disorder diagnosis had helped her.

This debate raises two important issues: The validity (scientific, or validity in other ways) of the diagnosis of schizophrenia; and the way toxic organizational cultures develop within institutions hidden from public scrutiny. The first of these issues is considered in the next section (V[C]). The second issue may not be an inherent problem with the diagnosis of schizophrenia, but often has been (dependent on the integrity of each country's mental health systems, and of each institution). How stigmatizing diagnoses such as schizophrenia and borderline personality disorder *are* depends in part on the collective experience, and history of mental health care in each country; but it is admitted that these diagnoses often *have* been used to stigmatise and discriminate, and in many countries. On the other hand, these diagnoses *can* be given, calmly, clearly, with reassurance, and in a way which avoids stigmatization. The complex issue of the merits of the schizophrenia diagnosis are discussed in my submission to the enquiry currently in progress in the U.K. on the name "Schizophrenia" (Supplementary Document 6).

The stigmatizing potential of diagnoses for psychotic disorders extends to assessment of whether people are *at risk* of psychotic disorders. In DSM-V, it is proposed to introduce the diagnosis of "psychosis risk syndrome". Concern has been expressed about the negative

impact of this with respect to both "self-stigma", and discrimination (for instance in health insurance)[26]. It is also questionable whether *any* diagnosis should be defined by risk of, rather than actuality of a disorder. Screening for risk, which is sometimes important, is not the same as giving a diagnosis.

V. Fundamental Flaws of Psychiatric Diagnosis.

(A) *A Flawed Idea of What is Being Classified?*

The issue here was succinctly stated by a psychiatrist at the workshop: "Is what is being classified the nature of human beings? . . or of diseases? . . .or of the range of human misery and related problems?" He noted that attempts to classify diseases end up classifying human problems and associated misery, which is then very hard to do. DSM-III and DSM-IV *do* include distress and disability as criteria for diagnosis, but ICD-10 does not. However, as Mellsop et al (2011) note "The shift to symptom-based operationalized diagnostic criteria introduced by the DSM-III removes the patient's context from diagnostic consideration. This makes it increasingly difficult to differentiate normal distress from mental disorder"[27].

Notably, in the Introduction to DSM-IV we read: "a common misconception is that classification of mental disorders classifies people, when actually what is being classified are disorders that people have". In other words, the conditions being classified are viewed as "imposed on the person" rather than as "an intrinsic part of a person". The choice made in DSM can then be used to justify the humane preference for usages such as "a person with schizophrenia" rather than "a schizophrenic". In addition, such a choice might avoid the implied permanence of a psychiatric diagnosis. The issue here is related to one in general medicine, on whether disorders involve invasion by some kind of external influence (such as an infectious agent), or rather, reflect some sort of imbalance *within* the organism. In general medicine, different disorders fall into either of these categories. However, for what is called "mental illness", neither of the supposed benefits of the DSM conceptualization is really fulfilled in practice: DSM diagnoses may still be stigmatising, and imply permanence. I believe this is partly because the DSM conceptualization is not correct. Whether these conditions really are "diseases" is discussed below. Here however, I suggest that in fact these conditions *are* ones reflecting "imbalances" (within a person), and are therefore "intrinsic parts of the person", and not ones "imposed upon a person". The pioneer psychopathologist Kurt Schneider[28] held a similar view, as expressed elegantly in the following quotation:

"Psychosis, and in particular schizophrenia, always involves an over-all change, and therefore individual phenomena have only a limited claim for review in themselves. . . A psychotic phenomenon is not like a defective stone in an otherwise perfect mosaic.

26 Yang LH. Wonpat-Borja AJ. Opler MG. Corcoran CM. (2010) Potential stigma associated with inclusion of the psychosis risk syndrome in the DSM-V: an empirical question. *Schizophrenia Research,* 120,42-48.

27 Mellsop,GW, Fraser,D., Tapsell,R. and Menkes,DB (2011) Court's misplaced confidence in psychiatric diagnoses. *International Journal of Law and Psychiatry, 34, 331-335.*

28 Schneider,K. (1959) *Clinical Psychopathology* (transl. from Schneider K [1949] by M.W.Hamilton and E.W.Anderson) Grune and Stratton, New York and London, p.95.

Psychotic individuals . . .are no less closed microcosms than normal persons, or the bodily organism itself, and as such they have their own particular principle of unity."

However, as discussed below, I do not view most of these conditions as "diseases" as the term is used in general medicine. An "imbalance" *might* include abilities *better* than normal as well as impairments. By such a re-conceptualization I seek to avoid the stigmatising influence of diagnostic labels.

With regard to choice of words ("a person with schizophrenia" versus "a schizophrenic") like the authors of DSM-III/DSM-IV, I strongly prefer the former, but for different reasons. My choice is based not on whether an illness is "imposed upon a person" rather than being "intrinsic to the person", but because the former usage is of greater therapeutic benefit to patients: One way to encourage the re-integration of a person, whether sick or healthy, is to treat him/her as an integrity, and then help them develop the best integrity they are capable of. The former usage encourages patients to reintegrate their personality as far as they can, whereas the latter tends to dismiss a patient as permanently "invalid" as a person.

(B) *Improper Use Of The Concept Of "Disease", "Illness", Or The "Medical Model" Of Mental Disorder?*

Using the concept of diagnosis in psychiatry implies "illness" or "disease" as certainly as when I ask "Have you stopped beating your wife?" I imply that you have a wife, and that you beat her. The implication that mental disorders are like physical disorders, and that the same medical approach[29] should be applied, goes back to the nineteenth century, and was explicit in the writings of Emil Kraepelin. One of his axioms was that mental disorders are best understood by analogy with physical disorders (particularly infectious diseases, many of which came to be understood for the first time in his lifetime)[30].

This implication, and the medicalized approach to mental disorder troubles many people with lived experience of such disorders. It is also questioned by some clinicians. A typical response from a clinician/health worker at the workshop read:-

"I found the word 'illness' (mental illness) was used a lot. I believe in 2012 this approach is not acceptable and unreal. 'Illness' is not the correct idiom; it needs adjustment to be more truthful – like 'condition', 'position', 'formulation', 'prothesis' This word 'illness' is also the reason for the over-use of the archaic word 'patient'".

There are several reasons for questioning the analogy between mental disorders and diseases in general medicine. None of them make the claim that mental disorders do not exist, nor do they deny the possibility of a fully scientific approach to understanding such disorders.

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29 I tend to use terms other than the "medical model" although that is used widely in these debates, because it can be used imprecisely to mean a variety of different things.
30 Young,A. (1995) The DSM-III revolution. Chapter 3, in *The harmony of illusions: Inventing post-traumatic stress disorder*. Princeton University Press, Princeton, NJ.

(i) What is called "mental illness" is frequently an inextricable mix of impairment or vulnerability with talents and giftedness (although the latter may be hidden because of the weight of stigma, related to a diagnosis). I believe this to be true even of severe disorders such as schizophrenia, or, in many cases, for what Mellsop refers to as "the unlikeables" (mainly personality disorders): Given the right environment, those strengths may come to the fore. Many historic figures of great importance would have fulfilled criteria for one (or several) DSM diagnoses. The fact that there is often such a complex mixture is scarcely compatible with medical notions of illness or disease, nor with that of system-based pathology (see below). Indeed, I have heard one of those present at the workshop say "I never felt that I was ill, until I had been given a diagnosis; the 'illness' came after, not before the diagnosis".

Mike Sukolski's made a stronger statement: "No one, I believe, actually *experiences* mental *illness*. What people experience is the *diagnosis*. Experienced too of course are the consequences of a diagnosis." For myself, I see the force of this argument, and yet I *do* think the concept of "illness" may be relevant. In section IV(A)(i), where benefits as perceived by *tangata whaiora* were discussed, the quoted remarks of service users show that they often identified their problems as an illness of some sort, whatever their views became in the longer term. Likewise, a long time go, when my own severe problems were emerging, I *did* identify this as "illness" (yet was afraid of seeking professional advice, because I thought, probably accurately, that professionals would neither understand, nor be able to offer much help.) Much later, as I came to understand the nature of my problems, I came to accept what I have just written, that those initial severe problems were inseparably linked with some special strengths in my own psychological make-up.

(ii) In general medicine, diagnosis is based on symptoms revealed in the clinic or on laboratory findings. In either case data refer to specific systems of the body (cardiovascular, respiratory etc), particular cell types, specific chemical constituents, or biological processes, not to the whole organism. This makes such medicine more "scientific", since systems, constituents and processes of the body are better understood than the organism as a whole. Following the medical fashion of using system-related symptoms, Kraepelin held that classification of mental illnesses must be based on which faculty of the mind was involved[31]. However, this assumes that different faculties of the mind - such as those of "mood" and of "cognition" - are strictly separate. This contradicts the idea of human personhood as a complex integral of all his/her psychological faculties. It also defies common sense since different mental faculties clearly have profound influence on each other; and, in psychiatry, it flies in the face of evidence: Manic-depressive illness - supposedly a primary disorder of mood - includes disorder of cognition, while schizophrenia – supposedly a primary disorder of cognition – includes abnormality of mood.

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31 A view which derived from the writings a century earlier of the philosopher Immanuel Kant (see Berrios,GE and Beer,D [1995]; Unitary psychosis concept). In: Berrios,GE & Porter,R (eds) A history of clinical psychiatry : the origin and history of psychiatric disorders . Chapter 12, pp.313-335.

(iii) In general medicine, symptoms can be identified as "pathological" with respect to operation of the corresponding system, not with respect to the whole organism. In psychiatry, following the medical style, "diagnoses" based on subjective experiences (said to be "symptoms") are (in theory) linked to particular faculties. However, many such experiences (e.g. "hearing voices", "thought withdrawal", "thought insertion") are quite common, and some are accepted in many cultures as "gifts", yet not clearly definable as pathological with respect to the faculty they are said to belong to. They are then over-pathologised as symptoms. The whole concept of *psycho*pathology is thus hard to define. In what sense pathological? It would be absurd to see it just as *statistical* deviance from the norm. Towering intellects of history, whom we all praise, would then all be severely ill. While the intention may be to assign the abnormality which constitutes psychiatric symptoms to specific mental faculties, the flaw in this assignment makes it easy to transfer them to whole persons. Then, symptoms (and the diagnoses derived by combining symptoms) are no longer just medical assessments of abnormality in specific systems, but highly evaluative judgments of a whole person. They are not just scientific evidence of illness, not just system-based pathology, not just a matter of health, but matters of personal validity, social acceptability, and sometimes of moral rectitude. Profound confusion results from mixing "scientific" and health status with evaluation of personal validity, social acceptability and/or moral worth.

(iv) In general medicine, assessment and giving diagnoses (such as diabetes) does not, by itself, change the illness or its symptoms. The fact that you know that you have diabetes, and have had tests to prove it, does not alter the functioning of your pancreas. However, in psychiatry, the faculty which (putatively) is disturbed (a person's mind) is the same faculty by which the same person takes in the fact of a diagnosis; so of course, the operation of that person's mind is changed by that fact. In the immediate context of a clinical encounter, Mike Sukolski put this well: "The person undergoing assessment. . . reacts to the assessment, *to being assessed*, and *not* to the possibility of illness." Part of that reaction is instinctively for a person to hide what is going on from the psychiatrist, to present the most coherent outward appearance of him/herself. Some however, use the opportunity to exaggerate their abnormality. Thus there is a sort of "uncertainty principle" in operation: A person cannot be assessed, or learn the name of his or her disorder, without that person's state of mind, and the diagnosed disorder being changed. From comments quoted above (especially in relation to psychotic disorders), that change is usually highly detrimental.

(v) It has been said that "People seek psychotherapy for the demoralization that results from symptoms, rather than for symptom relief . . .[Psychotherapy] achieves its effects largely by directly treating the demoralization and only indirectly by treating symptoms of overt psychopathology"[32]. To a considerable degree the same is true when people consult a psychiatrist. Thus mental health professions appear to be responding in part to genuine disablement, but in part to iatrogenic effects of their own

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32 Porloff,M.B. (1986) Frank's "Common elements" in psychotherapy: Nonspecific factors and placebos *Am J Orthopsychiatry*, 56, 521-530. (p 522).

diagnostic systems, originating from a flawed adoption of a medical conceptualization of mental disorder.

It could also be said that the medicalized approach to mental disorder makes it difficult to factor in the uniqueness of each person, a factor arguably of greater importance in psychiatry than elsewhere in medicine. However, for skilled clinicians, these two emphases should not be incompatible. Therefore this point is left for discussion later (section V[A]: *Diagnosis in relation to formulation*).

(C) *A Flawed Approach to Scientific Validation Of Specific Concepts Of Mental Disorder.*

Even if there were no flaws in what is being classified, or in the implications of "illness" or "disease", the actual classes of mental disorder used in psychiatry are very problematical. Their status as scientific concepts is poorly validated in terms of how concepts are validated elsewhere in science, or elsewhere in medicine. In introducing the workshop I described the manner in which concepts were validated in the natural philosophy tradition, where concept validation and explanation become part and parcel of the same process: In that tradition, concepts are validated only in so far as they support strong explanatory arguments. In the next few paragraphs I contrast this with methods used for classification in psychiatry, or for validating concepts in psychology.

The style adopted in *psychiatry* derives from Kraepelin, over 100 years ago, whose approach to classification is captured in four principles[33]:

(i) Mental disorders are best understood by analogy with physical disorders.
(ii) Medicine's first step was to classify, and psychiatry must begin there also.
(iii) Classification of mental disorders demands careful observation of visible phenomena.
(iv) *Classification is a necessary first step to understanding aetiology*

Seventy year later (as described by Mellsop) Robins and Guze[34] put forward their own criteria for validating concepts of mental disorder. This should be based on five sorts of evidence: Clinical features, Pathogenesis, Clinical course, Prevalence in relatives, and Investigatory markers. In its emphasis on observable, visible phenomena, this list is distinctly Kraepelinian in style. The same emphasis was continued in DSM-III and DSM-IV, where all diagnoses were operationalized as explicit criteria. At the workshop Mellsop stated that "Classifying means creating, defining and conforming boundaries between concepts" (a statement also appearing in one of Mellsop's recent publication[35]). Mellsop went on to describe how the time of Robins and Guze's paper was "a period of great hope and optimism". The directions seemed clear. The availability of apparently specific treatments,

33 Young,A. (1995) *The harmony of illusions: Inventing post-traumatic stress disorder* (chapter 3: The DSM-III revolution). Princeton University Press, Princeton, NJ.
34 Robins E. Guze SB. (1970) Establishment of diagnostic validity in psychiatric illness: its application to schizophrenia. *American Journal of Psychiatry.* 126,:983-987.
35 Mellsop,GW, Fraser,D., Tapsell,R. and Menkes,DB (2011) Court's misplaced confidence in psychiatric diagnoses. *International Journal of Law and Psychiatry*, 34, 331-335.

and advances in techniques for study of structure and function of the brain, and the psychological expression of brain function, promised that provisional disease categories of the time would soon be validated in robust manner. However it was not to be.

As DSM-III and DSM-IV came into use, it became clear that many patients diagnosed with these systems fulfilled criteria for several diagnoses: "Co-morbidity" was more-or-less the norm. This co-morbidity often has various socio-economic disadvantages, especially educational ones as a background. Service users find co-morbidity very confusing, as Julie Channer affirmed. While there *are* cases of two truly independent disorders coming together in one person, almost certainly the high overall rate of co-morbidity indicates mainly an inadequate system of classification, not true co-morbidity. In addition, despite explicit criteria for diagnoses, most clinicians have "favoured diagnoses" which differ from one clinician to another. Criteria might be used in such a flexible way that they lead to "popular epidemics" such as ADHD, Aspergers, Delayed P.T.S.D, and Dissociative Identity Disorder. Moreover diagnostic consistency over the years of a person's disorder was often lacking.

A rather abstract topic should be clarified here: "Typology" – the principles underlying classification – can use several approaches. In his Introduction, John Crawshaw referred to two such principles: We may put names on specific entities which seem "prototypical" of a larger class though not identical to any particular example of them; or we may look to split up all those entities into sharply separated categories. Psychiatry (and medicine as a whole) has usually tended to use the first of these approaches. This befits the realities of a clinical encounter, where flexibility is needed. On the other hand, the legal profession (and to a degree DSM-III and DSM-IV), dealing with the same human beings and related conceptual issues, generally prefers sharp categorical distinctions. A third principle comes mainly from psychology, especially as it tries to formalise human personality differences: It tries to define *dimensions* – continuous measures, each conceived as like a ruler measuring where a person measures up on that dimension. If one has several different personality dimensions of this sort – say three - each individual's personality can then be envisaged as a position in a hypothetical - say three-dimensional - space. Classification in medicine as a whole uses either sharply defined categories, such as most infectious diseases, or dimensions, such as blood pressure (with a somewhat arbitrary cut-off on this dimension to define hypertension). In psychiatry, it is unclear whether classification should be categorical or dimensional. In both psychiatry and other areas of medicine, there is also, in the background, a decision to be made about whether a person's problem is sufficiently serious to be regarded as "clinically significant". This is mainly a measure of their distress, rather than the severity of underlying causal processes. This decision has a fuzzy boundary, again reflecting the need for flexibility in clinical encounters.

Specific instances in psychiatry where there is debate over categorical versus dimensional classification include mood disorders. Should psychiatrists use separate categories or continuous variables ("dimensions")? Personality disorders have been notably difficult to classify, it being unclear whether to use categories, or personality "dimensions". Dimensions have been favoured by psychologists for "normal" personality, but the systems developed in psychiatry, notably in DSM-III and DSM-IV, for personality *disorders*, have preferred categories. In either case, questions remain about which - or how many - categories or dimensions were to be used.

Experienced clinicians also realise that, diagnoses given by their less skilled colleagues may sometimes reflect the clinician's own *moral* perspective. Mellsop referred in particular to the "unlikeables", including personality disorders such as narcissistic, antisocial, borderline and paranoid personality disorder, hubris syndrome (also referred to by Kate Diesfeld), or explosive disorder. Giving diagnoses attributed to trauma, especially when it occurs in families, might seem to imply that someone (especially someone in the family) is to blame, as was habitual practise in the years before DSM-III. The supposed objectivity coming from using explicit criteria in DSM-III and DSM-IV was thus far from the reality. Mellsop summed up the dismal history of attempts to improve classification since 1970, as *"A History of **No Progress**"*.

What has gone wrong? Whether one refers to Kraepelin's maxims, Robins and Guze's criteria or the simple statement that "classifying means creating, defining and confirming boundaries between concepts", basic questions remain unresolved. If classification precedes understanding of aetiology (as Kraepelin asserts to be necessary), on what principles, and under whose authority is that initial act of classification to be done? For the Robins and Guze criteria, why select just these five? Others might be added, such as the response to treatment; and even for these five, many different approaches are possible. Thus, "clinical course" might mean short-term episodic pattern, or evolution of a patient's disorder over years (which mean quite different things). "Clinical features" might mean "as observed in a single clinical interview" (the style adopted in the British *Present State Examination*), or might take account of events in the last few weeks or months (the style of DSM-III). If we wish to "create, define and confirm boundaries", we must ask, on what basis, and what is the rationale for that basis?

The issue of concept validation applies not only to concepts underlying diagnoses, but also to symptoms from which diagnoses are derived. We have a single word for "delusions", and another for "hallucinations", and no doubt all experiences which each word designates have something in common. Nonetheless, different experiences, each given the same label may be very different in their essence, with quite different underlying mechanisms.

Underlying all these questions is the fact that historically the medical profession has relied on personal authority to make hard decisions. In psychiatry we still rely largely on Kraepelin's authority; but personal authority is no substitute for scientific reasoning. The collective wisdom of the committees which put together DSM-III and DSM-IV, while not to be casually ignored, still relies to a considerable degree on personal authority. In other areas of medicine, the recent trend to "evidence based" practise is implicit acknowledgement of the serious flaws inherent in relying on personal authority of physicians in making hard decisions; yet evidence alone does not necessarily validate concepts of disease. In the natural science tradition, as I explained in my own introduction, it was a *measured balance of evidence and reasoning* which was used to validate basic concepts[36].

Does the discipline of *psychology* (or its subdivision *clinical psychology)* fare any better? In psychology (and extending into psychiatry) various methods of concept validation have

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36 See my essay: *Concepts of Mental Illness and an Invitation.* (accessible at: www.robertmiller-octspan.co.nz)

been proposed and widely adopted. The seminal paper is that of Cronbach and Meehl[37]. The methods proposed there include "predictive validity", "concurrent validity", "content validity" and "construct validity". Some of the methods rely on correlation with external referents, others on internal correlation between measures of different aspects of a construct. Some are based on *logical* relations of the measures themselves, rather than their statistical associations. In almost all cases, however, the external referents, or the premises behind the logical relations are not themselves grounded in the common language of the natural sciences. They are usually at the same organizational level as the thing to be explained. Thus, even with scrupulous application of psychologists' methods of validation, concepts so validated are, to a degree, "free-floating", with elements of circularity in the definition.

Such circularity need not be objectionable. *Every* version of truth is based somewhere on circularity of arguments, since there is no indubitable premise on which arguments can be based. Truth is not an eternal, unchanging mansion in the sky (or anywhere else); it is forever a "construction site", a work in progress, where we are the builders. What is constructed varies from one era to another, from one culture to another, and differs substantially between people. Nevertheless this does not mean that anything goes, and that all versions of truth are equally valid. For precise reasoning about the natural world, the natural science tradition, and its basic conceptual language, while falling short of absolute truth, is by far the best we have, and encompasses more within its reach than any alternative. It is therefore greatly to be desired that both psychology and psychiatry strive to assimilate their findings and concepts within the basic conceptual language of that tradition. In psychology there are some areas of the discipline where this has been possible[38]. In psychiatry there are no areas yet where such assimilation has been achieved, and has been accepted. These are currently the vital "growing points" in the whole natural philosophy tradition.

III. Dangers Flowing From Fundamental Flaws Of Psychiatric Diagnosis.

(A) *Using Diagnoses To Access Services.*

According to Mellsop's presentation at the workshop, nurses use diagnoses a great deal access to services for their patients. (Data were not presented on the extent to which psychiatrists and clinical psychologists use diagnoses for this purpose.) One might ask here if this is putting the cart before the horse. A system set up purportedly for clinical uses but often questioned by practitioners (and others) is taken at face value by administrators as a condition for service users to get access to services. There might be more accurate ways to determine access to services.

(B) *Use Of Diagnoses In Psychiatric Research.*

Undoubtedly diagnoses as defined in official systems are widely used in psychiatric research. They may be the *sine qua non* for having research studies published in academic

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37 Cronbach,L.J. and Meehl,P.E. (1955) Construct validity in psychological tests. *Psychological Bulletin,* 52, 281-302.
38 These are linked especially with the names Donald Hebb and Peter Milner.

journals. Again one can ask: Isn't this putting the cart before the horse? A proper role for scientific research is to construct the reasoning by which concepts are defined. In areas such as psychiatry where classification is clearly flawed, this should be a *primary* role of research, taking priority over *using* existing systems of classification *for* research. However, all or most psychiatric researchers accept official systems as a basis for research without question, and without doing fundamental theoretical work to improve those systems. As a result, many research studies end up exploring the dubious merits of the diagnostic system itself, rather than the naturally-occurring realities of mental disorder (if such there be). This problem is closely related to incentives offered in academia to encourage publication, a topic well outside the agenda of this report[39].

(C) *Misuse Of Clinician's Systems By Administrators And Other Non-Clinicians.*

People who take major political decisions often do so in the face of considerable uncertainty. For their peace of mind, they need to believe that they are taking those decisions on a rational basis, rather than as intuitions. This is understandable, since they may have to defend their decisions in public. However, these administrators are not (and cannot be) experts in all the detail of systems for which they are responsible. They therefore adopt expertise and ways of thinking from elsewhere, sometimes without grasping all the caveats, qualifications, the "ifs and buts" known to the real experts. It is natural that decision makers adopt the paradigms (and prestige) of "science". In Western societies, since not long after Isaac Newton, the idea that socio-political decisions can be taken "rationally" on the basic of "social science" styles of reasoning has been growing steadily, sometimes with disastrous consequences. To conform to Newtonian models of "science", it is felt important to express data in quantitative or categorical terms, even if the numbers in official statistical tables are not real quantities (as a mathematician would understand the term), and the categories are not sharply separated (that is, are not real categories).

Administrators are responsible to the public for running mental health systems, and in recent years have increasingly used systems of diagnosis developed by the psychiatric professions. The primary purpose for which systems such as DSM-III and DSM-IV were invented was to aid clinical practise. (This is clearly stated in the Introduction to DSM-III.) However, an unintended consequence of the development of explicit, categorical systems for diagnosis like DSM-III, DSM-IV and ICD-10 is that, once they appear in print, they are taken by administrators to have the authority of rigorous science, when experts in the field know well their many limitations, and how far they fall short of this ideal. As a result, these systems are now used by administrators for purposes far removed from those for which they were designed, overlooking the limitations known to the experts.

Such adoption of systems designed for one purpose to serve another goes back well before DSM-III. The International Classification of Disease was originally designed for collecting internationally-valid mortality statistics, and its use was limited to this in its early editions; but, in later editions, it has been used in many countries as a supposedly reliable

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39 But see Robert Miller (2010) *The Subversion of Higher Education.* Lulu Enterprises, Morrinsville, N.C.

system for diagnosis in clinical practice and many related administrative decisions. DSM-III and DSM-IV were initially designed primarily for clinical purposes, but, at least in the U.S.A, psychiatric diagnoses became such seemingly "hard data" that they were the basis for many financial, legal and administrative decisions, well beyond the original intentions undrlying the system. Before the growth of biological psychiatry, psychoanalysis and psychotherapies were becoming so lengthy and expensive that health insurance companies limited such therapy first to "just 30 sessions", and later to "just 10 sessions"; and since ~1980 it has been necessary, if *any* form of therapy (whether biological or psychological) is to be funded from state coffers, that it be for a specific disorder, and to be of proven effectiveness for that disorder. Thus, whatever the validity of a psychiatric diagnosis judged by scientific criteria, the fact that it has a precise name and an operationalized definition, makes it possible first to examine the efficacy of treatments for this "condition", and then (perhaps) to receive state funding.

In the U.S.A., a new drug can be brought on to the market only to treat a specific diagnosis, not a specific symptom, which appears to ignore the fact that, in psychiatry, there is no other basis for defining diagnoses than as combinations of symptoms, and that the status of many psychiatric disorders as illnesses or diseases (as the term is used elsewhere in medicine), is, to say the least, shaky. Some administrative requirements have consequences which are absurd. In one District Health Board in New Zealand, I hear that administrators are required to provide higher authorities with ICD-10 diagnoses for all patients within six weeks of their initial referral. This is despite the fact that, in psychiatry, it may take several sessions (and weeks) for a psychiatrist to build a working relationship with a client, let alone to make a clear diagnosis. Moreover, although ICD-10 is the officially recommended system in psychiatry, most clinicians use DSM-IV, which includes, for some diagnoses, a criterion that symptoms have to have been occurring for at least six months before the diagnosis can be made (and access to treatment obtained)!

At the workshop on 16th July, one psychiatrist noted that in New Zealand, "many external agencies require a diagnosis for positive and negative reasons (courts, insurance, access to treatment, or denial of treatment)". He rightly asked "Do we have any control over this?" Allen Frances himself admitted, in the course of the workshop, that the teams working on DSM-IV anticipated, even in the planning stages, that the system would lend itself to abuse in forensic contexts, and by administrators and those who finance health care. At that stage however, they presumably anticipated that the advantages would outweigh these disadvantages.

(D) *Diagnostic Inflation.*

Allen Frances spoke strongly at the workshop about Diagnostic Inflation, especially with regard to childhood or developmental problems[40]. Implicitly he was at times critical of the impact that DSM-IV itself has had, although he was one its chief architects. He presented data to show that, currently, in any one year, 20% of the U.S. population gets a DSM

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40 See: Batstra,L, Frances,A. (2012) Diagnostic inflation. Causes and a suggested cure. *Journal of Nervous and Mental Disease*, 200, 474-479 (Supplemtnary Document 4).

diagnosis, 50% across a lifetime[41]. A new US study reports that an amazing 83% of young people meet a DSM-IV diagnosis by age 21[42]. In Europe the lifetime risk of any disorder is 43%[43]. In New Zealand by age 32, the risks for anxiety disorder was 50%, of mood disorder: 40%, and of substance dependence: 40%[44].

He suggested that there has been an unnecessary manufacture of psychiatric epidemics: of Attention Deficit/Hyperactivity Disorder (ADHD: 3-fold increase since publication of DSM-IV in 1994[45]); of autistic disorders (20-fold increase, partly resulting from the inclusion of Aspergers disorder within the autism spectrum[46]); of Post Traumatic Stress Disorder (PTSD)[47]; of bipolar disorder (with 2-fold increase, partly as a result of adding the "Bipolar II" in DSM-IV); and especially of childhood-onset bipolar disorder: with a 40-fold increase)[48].

Diagnostic inflation may be may a greater problem in the U.S.A. than in New Zealand. The G.P. Helen Rodenberg said at the workshop that it was not a major issue in New Zealand. While the U.S.A. and New Zealand are the only countries that allow direct-to-consumer marketing of medications, she thought that direct-to-patient advertising was by no means such a problem here as in the U.S.A. However, she agreed with Allen Frances that the major mental disorders were not being recognized and adequately treated. Another comment suggested that diagnostic inflation was not unique to psychiatry, but had been occurring for some time across medicine, driven partly by "defensive medicine", with excessive concerns

41 I assume these figures are from the National Comorbidity Survey, published in 2005, based on surveys carried out between 2001 and 2003, which give prevalence of 29%, (12-month) and 48% (lifetime),for at least one mental disorder.
42 I cannot source this statistic. Allen gave me the name of the lead author as Adrian.Angold. The following study was published in May 2012, but gives figures substantially less than the 83% he mentioned: Angold A. Erkanli A. Copeland W. Goodman R. Fisher PW. Costello EJ. (2012) Psychiatric diagnostic interviews for children and adolescents: a comparative study. *Journal of the American Academy of Child & Adolescent Psychiatry.* 51, 506-517.
43 de Graaf,R, ten Have,M, van Gool,C, van Dorsselaer,S. (2012) Prevalence of mental disorders and trends from 1996 to 2009. Results from the Netherlands Mental Health Survey and Incidence Study-2. *Social Psychiatry & Psychiatric Epidemiology,*.47, 203-213.
44 Oakley Browne, MA, Wells,JE, Scott,KM (eds) (2006) *Te Rau Hinengaro: The New Zealand Mental Health Survey.* Wellington, New Zealand: Ministry of Health. NB: The data I get from this publication (Figure 10.1, p. 190 are different from, and substantially less than those presented in Allen's Power Point slide. At age 32: Any disorder: ~43%, anxiety disorder: ~28%; Mood disorder: ~13% Substance abuse: ~19%. However, Allen's data come from a subsequent study (Moffitt,TE, Caspi,A, Taylor,A., Kokaua,J., Milne, BJ, Polanczyk,G, Poulton,R. (2010) How common are common mental disorders? Evidence that lifetime prevalence rates are doubled by prospective versus retrospective ascertainment. *Psychological Medicine,* 40, 899-909) arguing that retrospective data collection (as in the Ministry of Health publication) misses a large number of cases of short-lived illness, for which there is unreliable recollection and under-reporting.
45 Centers for Disease Control and Prevention (2010) Increasing prevalence of parent-reported attention deficit/hyperactivity disorder. Among children. *Morbidity and Mortality Weekly Report* 59, 1439-1443.
46 I have not been able to source the 20-fold increase claimed by Allen Frances. Between 2002 and 2008 however a mean 78% increase was documented, across 11 sites in USA (Wingate M, Mulvihill B, Kirby RS, et al (2012) Prevalence of Autism Spectrum Disorders— Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report Surveillance Summaries* 61(3), 1–19.
47 I cannot confirm this. Indeed, statistics for lifetime prevalence of PTSD in the USA appear to have remained relatively steady in the last 18 years – 7.8% of the population in 1995; 6.8% in 2005; 6.4% in 2011 (see Pietrzak,RH, Goldstein,RB, Southwick,SM, Grant,BF (2011) Prevalence and Axis-1 comorbidity of full and partial posttraumatic stress disorder in the United States: results from wave 2 of the National Epidemiologic Survey on Alcohol and related Conditions. *Journal of Anxiety Disorders,* 25, 456-465.
48 The increase in U.S.A. is partly spurious because childhood bipolar disorder was not recognized in DSM-III, appearing for the first time with DSM-IV-text revision in 2000. Since then there has been a four-fold increase (Liebenluft,E. and Rich,BA [2008] Pediatric bipolar disorder. *Annual Review of Clinical Psychology* 4, 163-87), probably driven in part by increasing rigor of application of DSM-IV-TR criteria, as the new official diagnosis became known.

over safety, to avoid litigation. Allen felt that, at least in the U.S.A, this trend was now reducing, with fewer (probably unnecessary) tests. In psychiatry, he felt that diagnosis was less important to patients than to other stakeholders.

Allen's particular concern was over-diagnosis in school children of ADHD and childhood bipolar disorder. He understood well the pressures to have a diagnosis coming from teachers and parents, given the large class sizes, and the over-worked lives of parents in many cases. However, he regarded psychiatric diagnosis as increasingly problematic the younger the person, difficult in adolescents, very difficult in children, and often meaningless in pre-schoolers. Over-diagnosis in young people is a growing issue in New Zealand, and will probably soon be so in Australia. Allen drew attention to the health screening policy for pre-schoolers which has been running for a few years in New Zealand, and alerted us to its being promoted across Australia. The behavioural/psychological component of this screening program is *not* promoted as pre-emptive identification of mental disorders, but may actually be coming to be used to serve that purpose. In addition, Allen was also concerned that, when diagnostic criteria are changed, there is increased childhood prescribing of antidepressants. When the health survey "B4School" was introduced in New Zealand in 2009, the use of antidepressant drugs in children increased[49].

Part of the background to diagnostic inflation is that there are no objective laboratory tests for mental disorders; all is based on conventions on the number and intensity of symptoms, for which the threshold is easily adjustable ("a fuzzy boundary with normality"), and in Allen's opinion, often set too low.

Diagnostic inflation is driven partly by pharmaceutical companies, with aggressive drug company marketing direct to M.Ds, and professional associations, especially for on-patent drugs, and when launching new on-patent drugs, from which companies get most of their profits. Primary care doctors, who prescribe 80% of psychotropic drugs in the U.S.A, are prime targets. This applies in a dangerous way to disorders of children such as ADHD and childhood bipolar disorder, for which, in the U.S.A, medications are promoted for "off-label" uses, with direct advertising to parents (and for ADHD – to teachers). Life's problems are re-defined as "chemical imbalances". Most of the companies' finances go into marketing (and related legal costs), not research. Many so-called "new" drugs are "me-too" drugs, that is, slight modifications of pre-existing medicines, which allow prolongation of the patent life of the original chemical entity, but with little research-based innovation. Marketing focuses on long-term use, with neglect of conditions (such as many infectious diseases) which, once effectively treated, need no further treatment, and generate no further profits. Side-effects or withdrawal effects are too-easily confused with symptoms of an illness, leading to over-prescribing and poly-pharmacy. Psychotropic medicines bring huge profits (antipsychotics – at $16 billion per annum – the fourth highest of all drug classes; antidepressants - at $11 billion – the fifth highest; anti-anxiety drugs, the eighth highest).

Allen had misgivings over the power over government of disease awareness campaigns, which exaggerated the rates, severity and the costs of mental disorders. He was sceptical of over-enthusiastic opinion leaders, or experts practicing "defensive medicine" and anxious

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49 http://www.stuff.co.nz/national/education/7159932/Ministry-hides-tests-real-purpose

not to miss any cases, both of whom, in their area of specialization, contributed to diagnostic inflation. Epidemiological research commonly uses lay interviewers, to keep costs down, and often bases its results on interviewees' self-reports. There is then no filter for the clinical significance of distress or impairment, and this inflates the rates of many disorders. It can only provide an *upper limit* for the rate of a disorder, but is often presented as the *true* rate. In all this, there is no overview of the impact on health costs, wise allocation of diagnoses and resources, and public health. Public media contribute to inflation, by popularizing some mental disorders and glamorizing problems of celebrities, leading to contagion for some diagnoses. Media and advertising pressure towards perfectionism may make people who fall short of the ideal think they have a mental illness. Misuse of legal systems to reduce criminal responsibility, to increase damages in civil cases, and to avoid judicial sanctions may also lead to over-diagnosis (see above under *Secondary gains"* from diagnosis).

Allen Frances was also sceptical of consumer advocacy groups in the U.S.A. Consumer groups have tended to widen the boundaries of diagnoses (sometimes using self-diagnosis check-lists) and to attract people who don't have a diagnosis. These groups gain power by their numbers, receive drug company funds, are more credible lobbyists than drug companies, yet often pursue the same goals.

In the U.S.A, as the importance of DSM diagnoses became exaggerated, their original purposes were distorted by the administration dependent upon it. So, since an autism or ADHD diagnosis was needed to obtain support from school services, there was pressure on psychiatrists to make these diagnoses. "There was too tight a linkage of the diagnosis to the eligibility for school services"; and since a PTSD diagnosis was needed for health insurance payments, there was likewise pressure on psychiatrists to make this diagnosis. Disability payments may be linked to a diagnosed mental disorder, although flaws in this are shown by the fact that the number of such payments grows in parallel with unemployment rates.

DSM-V is set to increase further the number of diagnoses, and to decrease the thresholds for those already in use. Small adjustments to thresholds for many diagnoses will create millions of patients (Allen predicts). DSM-V is setting out to turn normal anxiety into a distinct disorder, makes temper tantrums of youngsters and teenage eccentricities into psychiatric disorders, and turns normal grief of bereavement into major depressive disorder. The distinction between normal distress during bereavement, and a real disorder in recently-bereaved people will be lost, if the cut-off point between normal and pathological grief is reduced to a duration of depressive symptoms of only 2 weeks. Likewise for "major depressive disorder" criteria have been relaxed, to the extent that, in Allen Frances' view, "it is now no longer either major, depressive, nor a disorder". By "medicalizing the stresses, worries and disappointments of everyday life the pool of normal becomes a small puddle". Healthy people think they are ill, exposing them to stigma, reducing their expectations and ambitions, limiting their sense of personal responsibility, and "creating the impression that we live in a sick society".

The consequences of diagnostic inflation, at least in the U.S.A, are numerous and large-scale, including excess prescription of psychotropic drugs (especially in children), avoidable complications as side effects, overdoses and emergency room visits, and of course, many increases in associated costs. There is over-diagnosis of minor conditions, so people think

they need medications when they don't (because of the high placebo response rate for mild or moderate disorders). At the same time, there is under-diagnosis and under-care of the major psychiatric disorders. There is poor allocation of scarce resources in health services, and misallocation of mental health, school and other services. *"Psychiatric treatment", he says, "is very effective when targeted for proper indications. Diagnosis can cause more harm than good when not really needed."*

To these strong comments, I offer a few qualifications and caveats. Many of the bad practices referred to by Allen Frances are features of American health care, which is very different from the systems in New Zealand. In particular, the role of primary care seems to be different, and may be less disciplined than in New Zealand. Nevertheless, the potential for diagnostic inflation in New Zealand is acknowledged. Many issues to which Allen Frances drew our attention are "matters of degree", unobjectionable in moderation, malevolent when pushed to excess. Over-diagnosis in children is a major concern, yet, for a disorder such as moderate or severe autism, the diagnosis can be made early, and can then lead to support being made available, which lightens the family burden. Community pressure groups (in my experience) can often achieve valuable, necessary changes, which mental health professions by themselves, however much they want the same thing, cannot achieve. As Allen admitted, joining support groups is attractive for social reasons, and the stigma related to mental illness is reduced by the numbers in such groups; but these are hardly disadvantages given the crushing weight of stigma in the past (and still today). Although much media portrayal of mental disorders is unhelpful, media popularizing of mental disorders *can* be as much a positive as a negative influence, and at its best is a significant contribution to anti-stigma campaigns, and promotion of public mental health. (Allen himself recommends using the media to combat diagnostic inflation). In New Zealand, organizations such as *Supporting Families in Mental Illness* (SFNZ, Inc) are extremely careful about their dealings with drug companies, well aware of the potential for their organization to be used by these companies, and careful about conditions under which they accept sponsorship.

(E) *Misuse Of Psychiatric Diagnoses To Depersonalise And Stigmatise.*

Most of the distortions just described are not personal failings of administrators, but rather unintended consequences of political and administrative systems set up by personnel some distance removed from the places where their policies are implemented. However, misuse of psychiatric diagnoses and other labels to depersonalise and stigmatise patients in care in psychiatric facilities *does* reflect personal failings of some staff. When new linguistic use is standardized as part of any administrative or political process, it usually involves setting up new power-based relationships. It may implicitly define "in-groups' and "out-groups", it marginalizes, insults or patronizes some groups, while turning other groups into élites. In addition one can argue that past abuses in mental asylums (which are probably still occurring in some facilities) is related partly to the shaky scientific status of most psychiatric diagnoses. When systems of diagnosis are severely flawed, the idea that treatment regimes having a (somewhat) rational relation to diagnoses cannot be sustained and implemented and gradually. In place of the "authority of reason", a culture of hierarchy, secrecy, connivance and brutality may grow. It is beyond the scope of this report to give details of the ways in which diagnoses are misused in this way, but in New Zealand such abuse and such anti-

therapeutic cultures in asylums are well documented. These are personal failings, or systems failures related only indirectly to diagnostic systems themselves. Nevertheless, if we had more robust and well-validated diagnostic systems, it might help to avoid the development of such abusive and toxic organizational cultures.

(F) *Summary.*

Some of the unfortunate side effects of flawed diagnostic systems discussed in (A) to (E) above, are specific to the U.S.A, others to New Zealand, while others may be more universal problems. The basic question posed by all of the issues raised is this: *Are current diagnostic systems in psychiatry robust enough to bear the heavy weight placed upon them?*

(IV) Cultural issues.

These were not well explored in the workshop. One participant (identified as an "administrator/manager") wrote in the evaluation form: "More on culture". However, Ginny Port made the comment that "Nowadays there is also much more understanding of cultural differences." These few comments can be amplified from data of Mellsop and colleagues, on the views of psychiatrists and clinical psychologists on the cultural appropriateness of diagnostic systems in use. Forty-eight percent of psychiatrists regarded these systems as useful and reliable regardless of a patient's culture or ethnicity, yet 66% thought them sometimes difficult to apply trans-culturally, and 32% thought them "over-embedded in European cultural concepts and values." Clinical psychologists were reported as thinking that current classification systems obscure the complex relationship between culture and mental disorder, and ignore the existence of indigenous languages. Some clinicians complement the classification system by also using the *Tikanga Maori* Model and the *Te Whara Tapa Wha* Model for case formulations and treatment planning[50]. In the future, many clinical psychologists hoped for diagnostic systems that consider cultural identity and ethnic belief systems. Allen Frances mentioned the WHO study showing "that the best places to be schizophrenic were where there is no Western medicine", which would indicate something unhelpful flowing from this diagnosis in Western countries. However a recent study[51] has raised questions about the generality of the WHO study.

(V) How To Retain The Benefits And Avoid The Harms, Misuses And Dangers Of Diagnosis

In previous sections, it is clear that there are some benefits to diagnoses, yet, in practice, there are often inadequacies and outright dangers, and there may be problems in principle, with the very notion of diagnosis in psychiatry. In seeking remedies, I separate issues where improvement in practice is needed, from those requiring more fundamental revision of the

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50 Lutchman,R, Mellsop,G., McClintock,J, Gayler,K, Gaffaney,L (2007) New Zealand psychologists' perceptions and opinions on the use of the current classification systems of mental disorders. *New Zealand Medication Journal,* 120, 4-5.

51 Patel,V., Cohen,A., Thara,R. and Gureje,O (2006) Is the outcome of schizophrenia really better in developing countries? *Revista Brasileira di Psiquiatria* 28, 149-152.

very principle of diagnosis. Let us start with easy matters first, those where improvements *in practice* are possible.

(A) Diagnosis in Relation to Formulation.

In his Introduction, John Crawshaw made the point that it is easy to over-rate the value of diagnosis. By itself it seldom specifies exactly how a patient should be treated. Additional factors are needed for this, including his or her whole life story, personal strengths and weaknesses apart from the diagnosis, and current life situation. Using these matters as well as diagnosis to plan treatment is referred to as the "*formulation*"[52]. Diagnosis is only the beginning. Allen Frances spoke along similar lines: "A diagnosis should only be given when clear and necessary. It is only a small part of the process and it has been given too much power; but we should not dismiss the importance of diagnosis." Mellsop and Clapham Howard[53] expand on the relation between diagnosis and formulation:

"Diagnosis is an inescapable factor in the clinical process. It carries significance for service users and those who support them, but, as a logical conclusion to the clinical assessment, it is insufficient, and cannot stand alone. The formulation is a summary of the information gathered via the assessment process(es). It provides an extensive, individualistic and idiographic context to aid understanding of what is occurring for this person at this time, and why this may be so. As such, it provides a wealth of information that is not just useful to developing the recovery plan, but essential to it. Thus, while the diagnosis may suggest a particular course of action, as part of a comprehensive recovery plan, this will be underpinned by the narrative provided by the formulation."

Mike Sukolski spoke eloquently on this topic: He started by distinguishing between the *story* (the list of events in chronological order, as they happened), and the *plot* (the list of events in order of presentation by an author, that is, as they are told).

"The *story* consists of the facts of the matter, the events under consideration, gathered by observation, by attentive reading, or by interrogation and astute questioning; any physician who does this will, or should, get the same results. Of course there is a prior selection process, decisions already taken about what will count as the relevant events in a person's life; the incidents that arouse suspicion; the bona fide facts of the matter.

The storyteller is the diagnosing clinician, and not the person undergoing assessment. This is the root of the problem: The person undergoing assessment is not granted, must not be allowed, the *authority* of their own story. . . .Yes indeed, someone is plotting! And it isn't me. The story is mine; that much I grant you; but

52 Mellsop,GW, Banzato,C. (2006) A concise conceptualization of formulation. *Academic Psychiatry,* 30, 424-425.
53 Mellsop, G., Clapham Howard, F. (2012). Utilizing psychiatric diagnosis and formulation in the clinical process: Meeting the needs and expectations of service users, Psychology - Selected Papers, Gina Rossi (Ed.), ISBN: 978-953-51-0587-9,: http://www.intechopen.com/books/psychology-selected-papers/diagnoses-and-the-clinical-process

what is this? Could someone be plotting *against* me? . . .In whose mind does the meaning of my story dwell?"

As a way to resolve this imbalance, Mike suggested that "the way forward will be, and can only be, through creation of an inter-subjective space in which the diagnosing clinician and the person undergoing assessment can come each to approach the other. It is a necessary *inter-dependence*, a *mutuality-of-interest* that must be vigorously entered into, unequivocally endorsed, resolutely defended." In this context, I hear from a medical friend in Britain (not a psychiatrist) that there are moves there exploring the idea of case notes being co-written between doctor and patient. No-where would this be more appropriate than in psychiatry.

All areas of medicine combine diagnosis and formulation; but in psychiatry formulation is more important than in any other area. Within such a complex field as mental health, with so many factors contributing to a person's illness, it means that professional help is likely to be highly individualised, even though diagnosis in terms of a class of disorder may be the first step. So diagnosis means something different in psychiatry from general medicine. This principle is not well understood by many professionals or the wider community. As a result, there is a gap between mental health service users' expectations and what can be realistically provided by diagnosis alone. For service users at the workshop who thought that diagnosis was of little help to them as patients, it may be that the balance between diagnosis and formulation had been too heavy on diagnosis (and all that it implied) and too light on formulation based on individual life story and personal circumstances. From comments made at the workshop about the insensitive manner in which diagnoses were sometimes conveyed to patients, there is room for improvement in this area. What the roots of that problem are – inadequate training of some psychiatrists, excessive work-load in their working environment, excessive emphasis on diagnosis at administrative levels at the expense of formulation - are matters for speculation. However, as explained below, it may help if the important role of formulation is better appreciated by those in administrative positions and by those who use diagnoses in implementing policies about mental health. In addition, where medication is concerned, even the combination of diagnosis and formulation may not point to the best treatment: It may be necessary to work this out empirically; and there may be more specificity between a treatment's effectiveness and a *symptom* rather than an actual diagnosis.

In the U.S.A, prior to DSM-III, there was arguably an imbalance in the other direction, which at its best may have led to more personalised care (via the "formulation"), and at its worst may have allowed arbitrary containment in mental hospitals with scant relation to diagnosis. Achieving the right balance between diagnosis and formulation, to give a diagnosis set within the context of the person and their unique history, may address many of the complaints about diagnosis documented above.

(B) *Communication Skills, Active Listening and Terminology.*

Poor communication in conveying a diagnosis and related information has already been highlighted as a significant issue leading to dissatisfaction amongst *tangata whaoira*. To obtain benefits without causing harm, it was seen as crucially important *how* clinicians communicate diagnoses to service users, especially in relation to psychotic disorders. It was

also thought important to explain that diagnosis is only a first step to defining a problem; perhaps to explain the relation between diagnosis and formulation; and how the combination is to be used for planning future care and support; and that "cure" is seldom the objective. Sometimes it is necessary to say the same things a number of times on different occasions, in different ways, since an initial meeting may be a time of stress for patients. Some participants at the workshop asked for greater recognition of the range of human diversity, to avoid unnecessary pathologizing of people and experiences seen as different from normal. Regrettably, diagnoses *are* sometimes used to stigmatise, including by mental health professionals: The solution then may lie partly in the professional bodies which select, train and accredit professionals. Apart from overtly stigmatizing attitudes, professional training may, unfortunately, lead those so trained to being more fluent in their own technical language than in "plain English". Workshops or training sessions to help professionals in this respect are needed, and in New Zealand there are initiatives led by service users to develop such courses.

Although some terminology is clearly stigmatizing, and should generally be avoided, attempts to "standardize" language should also be avoided. We should not try to be too precise or too precious; there are many stakeholders here all used to different terms and concepts; so all players should try to be "multilingual". Admittedly, special care is needed in administrative language, and in official documents, but this language should not become obligatory in clinical practice, let alone in N.G.Os. Even in official documents intended for the readership by the public, every effort should be made to use "plain English", or its equivalent in the other languages used by New Zealanders.

(C) Administrative Versus Clinical Uses Of Diagnoses

Misuse (or misinterpretation) of diagnostic labels by administrators for purposes different from the clinical ones for which those terms were primarily designed was discussed above, as one of the more serious unintended consequences of the process of diagnosis. Proper limits need to be set (and emphasized) on the significance of psychiatric diagnoses, and the limits on official uses of systems initially set up primarily for clinical purposes. The nature of the problem is clarified in part, when the relation between diagnosis and formulation is understood. It may be that administrators are transferring the concept of diagnosis as used in general medicine (where diagnosis is often quite precisely related to treatment options) to psychiatry, without realising that the relation there is conditional on many factors (revealed in the formulation). Thus the proper balance between diagnosis and formulation needs to be explained to administrators, so that facts of diagnosis do not allow them to wield too much administrative power, or for power to be wielded in ways inappropriate to clinical realities.

The details of this are well beyond my grasp. How can the process of formulation and its relation to diagnosis be built into administrative thinking in a way which permits clear decision making (and possibly improved decision making)? How could the *combination* of diagnosis and formulation (rather than just diagnosis), be the basis for access to specialist services in psychiatry? How can the subtleties of changing symptoms and requirements (which may not fit neatly into the initial diagnosis) allow flexible access to other counseling and treatment services? How can a proper balance between diagnosis and formulation be introduced into the policies not only of health service administrators, but also of health

insurance industries, disability, and accident compensation payment, or school services (to name but a few)? These are matters for continuing discussion.

(D) Possible Cures To Diagnostic Inflation

Allen Frances is clear, that, since diagnostic inflation has many causes, many strategies will be needed to curb the excesses. He makes the following recommendations:

Within the psychiatric profession, he recommends tightening the systems for diagnosis, focusing on continuity of care, and on disorders with proven response to treatment, better practice guidelines based on evidence, emphasis in medical school training and in "continuing medical education" on ways to resist drug company marketing and increase awareness of ethical standards. He also advocates a system of "stepped diagnosis[54]" in clinical practice: For people who, at first presentation, give no evidence of major mental disorder, and whose problems have an uncertain diagnosis, with no risk of suicidal or violent behaviour or other urgent problems, the first step is to gather baseline data, not to give a diagnosis. This data may be about the background of stressful life events, medical illness, or alcohol or substance abuse. The second step is to "normalize" the problem, without minimizing it. That may means reformulating the problem as far as possible as a relatively normal response to life's stresses rather than as an illness; diagnostic terms should again be avoided. The third step is "watchful waiting", with follow-up, and perhaps weekly telephone calls. This step makes full use of the "powerful healing effects of time, support, and placebo". The fourth step ("minimal interventions") may include referring patients to what are judged useful self-help books or websites, but still avoiding diagnoses. Step five ("brief counseling") involves brief programs in C.B.T. or problem-solving therapy. Only at Step six ("definitive diagnosis and treatment"), when there is obvious persisting distress and impairment, is a diagnosis needed, along with more intensive treatment and secondary care. These guidelines appear to be aimed more at G.Ps than specialists, and may apply more in the U.S.A. than in New Zealand. However, some of the implications of saving diagnosis to later stages in assessment may apply in New Zealand, when, at least in specialist services, there may be administrative pressure to report a diagnosis too soon.

Measures *to control drug company marketing* include elimination of industry-funded "education", direct-to-consumer advertizing, gifts, trips, meals etc for prescribing doctors, and free samples. He suggests that the drug company support for community advocacy groups should be eliminated along with disease awareness campaigns, and bigger fines for off-label marketing (for instance of medications for children). He recommends using public media against the drug companies, by publicizing their abuses and fines, stories about over-diagnosis, the value of healing over time and placebo effects, and encouraging journalists to be skeptical about industry media releases.

To control *administrative misuse of diagnosis,* he recommends that insurance companies allow the first six visits without having a diagnosis, that school services be linked to specific

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54 See: Batstra,L, Frances,A. (2012) Diagnostic inflation. Causes and a suggested cure. *Journal of Nervous and Mental Disease*, 200, 474-479.

educational deficits rather than a diagnosis, and that access to disability payments be based on both a psychiatric and an O.T. assessment, focused on *impairment*, not on a diagnosis.

He recommends *quality control* for prescribers, with close monitoring of their prescribing habits, to limit polypharmacy, identifying high prescribers and publicizing those who cannot justify excessive prescription.

These recommendations refer, of course to the U.S.A. Readers may identify which of them are relevant to New Zealand. These are matters for continuing discussion. Overall Allen Frances emphasizes that mental well-being is not just about psychiatric illness but also requires adequate housing, employment and social programs. For people with a disability, provision of vocational training, job placement and jobs are also needed.

(E) Issues Requiring A Fundamental Rethink.

Now we come to the hard part. Readers are reminded of a question already posed: *Are current diagnostic systems robust enough to bear the burden placed upon them?* Even if all the above recommendations and adjustments to current practice were implemented, some issues (especially fundamental ones discussed in section II) remain unresolved. Here are some suggestions:

(i) What is being classified?

As I suggested above, from a strictly scientific point of view, it would be helpful if community groups could grasp some points which the psychiatric profession (at least in its diagnostic systems) may not yet have fully grasped: Without making any implications about illness, social acceptability, or personal worth, people *do* differ intrinsically in their psychological make-up; these differences *are* intrinsic to those persons; when these lead to psychological difficulties, those difficulties are not really "illnesses imposed from outside a person", as DSM-III might have us believe; and the differences *can* be identified. In the theory of normal personality a variety of personality inventories (such as the Myers-Briggs system) are becoming well known, and many people find them helpful and informative about themselves and the people they meet. What has been called "mental illness" might then be better re-conceived mainly as the more extreme aspects of various personality dimensions (despite the fact that DSM identifies personality *disorders* apparently without reference to this long scientific tradition exploring normal personality variation).

(ii) The Concept of "Mental Illness".

One experienced consumer advocate, spoke at the workshop against the whole concept of diagnosis, regarding DSM as "A book of insults". She sought a concept different from diagnosis, asking: "Is there another framework, which acknowledges our experiences and is not stigmatizing. In this context, a recent presentation in New Zealand[55], referred simply to "helping the person, not treating the illness." Mike Sukolski's whole presentation can be read as a powerful argument for replacing the notion of diagnosis with a different concept. I

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55 Roberto Mezzina, Conference of Royal Australia and New Zealand College of Psychiatrists, Wellington, 19-21st September, 2012.

followed this up by pointing out some important differences between mental illness and other forms of illness. For mental illness, vulnerabilities and weaknesses may be inextricably linked with positive things – advantages over normal, even exceptional talent. I too sought a different model: "Illness" may not be the concept we need for our labels, and "diagnosis" is not always helpful in that it implies "illness", an unmitigated "negative". It can lead to false assumptions about "cure", rather than recovery and growth[56] - living with one's weaknesses and developing one's strengths.

    At this point in the workshop discussion, I referred to precedents from educationists. In higher education, and secondary schools, at least in British/Commonwealth traditions, exam results were expressed by a system of categorical grading (for instance, for university degrees: "First class, 2.1, 2.2, 3rd-class"). However, there have also been attempts to develop a more informative and helpful system, a semi-formal "qualitative transcript" (or *Record of Achievement*[57]) which encapsulates both strengths and weaknesses of each person. The same principle could be used in psychiatry (suitably modified). These ideas were not developed further in the discussion at the workshop in relation to psychiatric diagnosis, but some suggstions can be made:

    Some of my recent discussions have suggested terminology different from that of "illness", such as "cognitive specialization". This would have definite clinical advantages, in that it would try to identify each person's strong points, which can then be developed further, encouraging success, not failure; and of course, nothing succeeds like success itself - it feeds on itself (and conversely, nothing fails like failure). The analogy with educational concepts can be carried further: Due to the administrative, financial and other pressures to which universities have been exposed in recent years there has been considerable "grade inflation"[58], a concern which parallels the "diagnostic inflation" in psychiatry. The usual school or university exam, like many psychiatric assessments, is stressful, and does not bring out the best in students (or patients). One educationist[59] in the U.S.A. wants the final assessment for a degree to be uplifting and validating, "a value-added boost, as they leave the class". Transferring the metaphor of that consumer advocate to the mental health area, the system for psychiatric diagnoses could then become, in part "a book of complements", to be used in an uplifting, positive way. Lastly, the idea was mentioned above of case notes being co-written between doctor and patient. In the educational field, similar suggestions have been made that student assessment would be improved if it included each student's own claims about what they have learned or achieved, this to be worked out in collaboration with staff from the institution (to ensure it is serious, honest, and defensible - for instance at a job interview)[60].

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56 I prefer the word "growth" to "recovery". It *is* an endless journey until the day we die, always trying to construct for ourselves a better-integrated sense of who we are, whether or not the journey includes mental illness.

57 Broadfoot, P. (2001) Empowerment or performativity? Assessment policy in the late twentieth century. In: *Education reform and the state: Twenty five years of politics, policy and practice.* R. Phillips and J. Furlong, London, Routledge/Falmer, pp. 136-155.

58 Robert Miller (2010) *The Subversion of Higher Education.* Lulu Enterprises, Morrinsville, NC. (Chapter 6: "Student assessment")

59 Van Buskirk,B. (1997) On publish or perish, pedagogy, and getting a life - synergies and tensions. In: André, R and Frost, P.J. (eds) *Researchers hooked on teaching. Noted scholars discuss the synergies of teaching and research.* Foundations for organizational science, Sage Publications, London, pp. 57-77.

60 Knight, PT (2002) The Achilles' heel of quality: assessment of student learning. *Quality in higher education* 8,107-115.

(iii) Categories of "Illness".

In section II(C) (and in my Introduction to the workshop) I argued that the categories of mental disorder which have been widely used are by no means robustly validated by scientific reasoning in the way that concepts in the natural science tradition are validated. In section III(B) it was pointed out that the priorities of researchers were poorly focused. They use systems of diagnosis for their research efforts, apparently assuming them to be valid (although their weaknesses are obvious to most experts), when their proper research focus should be to *re-form and recast* those diagnostic concepts so that they *are* more robust. I suggested that this reform *is* possible, but would involve development of a completely new research tradition in psychiatry. This would involve a serious commitment to theory, the maxim being that the only way in which a scientific concept can be validated in a way which will stand the test of time, is when it is defined in such a way as to support strong explanatory arguments. This applies not only to concepts underlying diagnoses, but also sometimes at a lower level, to the underlying symptoms. Although far from a solution to all the problems besetting psychiatric diagnosis, this approach could provide a long-term solution to some of the most fundamental ones. I want to provide some detail on how I envisage that this might occur.

For many mental disorders, diagnoses are based on florid symptoms (striking psychotic symptoms, severe depression, people with anorexia nervosa starving themselves to death etc). These are severely abnormal mental *states,* which are usually transient; but underlying them is a variety of on-going personality traits, usually less disabling than the florid symptoms of severe episodes of illness, and present before, during and after these episodes. A metaphor to describe the distinction between the state and trait aspects of mental disorders is to refer to abnormal states as "mountain peaks"; the traits can then be regarded as the "broad plateaux", from which the peaks arise. Another metaphor refers to florid psychosis as "the fever of schizophrenia".

Classification based on the peaks of florid illness clearly is flawed, in view of the high prevalence of co-morbidity, and the instability of diagnosis over the long-term course of many illnesses. Information on underlying traits is very abundant for some disorders (such as schizophrenia), but is more scanty for many others. Nevertheless, since traits are enduring aspects of a person's psychological make-up, they are likely to be more important for classification and more fundamental to understanding than are the florid symptoms of severely abnormal states. What information on traits *is* available reveals a great deal of overlap amongst diagnoses (but also sometimes sharp differences in underlying traits between official diagnoses). My guess is that, if classification of mental disorders were based on association or divergence of these traits, it would look very different from the current system of classification, and probably much simpler. It would bring together many disorders where, with current diagnostic systems, diagnosis is beset by unruly patterns of co-morbidity.

Such a revised approach to classification would also enable more rigorous research. This is because states of florid illness are characterized in terms of "symptoms", as detected in the clinic. In contrast, although the underlying traits *may* be defined in terms of symptoms, they are characterized mainly in terms of laboratory findings using methods of experimental

psychology. Often these methods involve precisely-timed presentation of stimuli, stimuli whose exact shape, size etc is known, and observation of precise timing of responses. In other words, unlike most symptoms as reported clinically, they use the basic language of the natural sciences. Thus, in the search for fundamental understanding and "cross-level explanation" of psychological findings in terms of basic neurobiology, a focus on the traits offers more hope than focus on symptoms (especially those of florid mental disorder). In the end, such research might identify either categories or dimensions for describing mental disorders, but in either case they are likely to have stronger scientific validity than those currently used, because they would have been defined by proper scientific explanations, using robust scientific reasoning.

In addition, in practice, if diagnoses are based on symptoms, they are relatively unreliable (or other problems may arise if reliability is artificially enforced by adopting the style of DSM and other operationalized systems). In contrast, use of experimental methods by which traits have been documented might offer the possibility of a less flawed method of diagnosis in clinical practice, in some future system.

This new approach cannot be expected to deliver its fruits overnight. It will take a generation of research done in a quite different way from almost all current research – meticulous theoretical research, complemented by carefully-chosen empirical studies to fill in gaps in the scientific reasoning. There is no time like the present to start this new strategy.

(iv) Division of Roles; Division of Systems

The final discussion at the workshop had, as one prompt, the question "Can one system of diagnosis serve the interests of all stakeholders?" To a degree this was set up as a "rhetorical question", expecting the answer "No", although at least one person voiced the view that there was no point in having *any* system if different people used *different* systems. This seems to be the way in which DSM-IV has come to be used in the U.S.A, the same system for a wide variety of disparate purposes. However, in Britain and commonwealth countries, it is a fact that we already use different systems. In a haphazard way some psychiatrists in New Zealand use ICD-10, some use DSM-IV. I believe that the same is true, and to a greater extent, in Australia. More deliberately, legal and judicial decisions are generally based on different concepts and terminology from medical/psychiatric decisions. So, legal terms such as "insanity" do not signify diagnoses, and are not used for medical purposes. In Britain the term "psychopathy" is used for legal/judicial purposes, but is not part of the psychiatrist's *clinical* vocabulary.

A particular issue is whether terms for mental disorders should be sharply separated categories, or rather concepts with more fluid boundaries, sometimes formalized as dimensions. Because of the way legal, financial and administrative systems must operate, categories are preferred rather than dimensions, otherwise decisions become subjective and indefensible. However, clinical realities may require a more flexible approach; and scientists may generally prefer a dimensional to a categorical approach, simply because it enables more information to be gathered than when a dimension is arbitrarily carved into categories. Usually clinical data expressed dimensionally are better predictors of outcome that when the same data are split into categories.

The suggestions I offer here build on a principle that already exists, that is, separate concepts and different terms for the medical and the legal contexts; it also takes note of the fact that some services for people disabled by past mental illness – such as employment services – find little use for diagnoses. Allen Frances, in making recommendations on how to reduce diagnostic inflation includes similar suggestions (for instance that access to school services be linked to *educational* deficits rather than a diagnosis, and that access to disability payments focus on *impairment* rather than diagnosis).

For scientific research, researchers need as much empirical information as possible. Therefore, if valid dimensions (or *possibly* categories) can be found, research should be based on *them*. If they cannot be found, the scientists need access to the raw data, not data filtered through a mesh of insecure rating scales and diagnostic systems. They might then start to build up, from the foundations if necessary, the reasoning needed to arrive at last at valid categories and dimensions.

For clinical purposes, a process of careful negotiation is needed, often shifting subtly as a patient's stages of recovery develop. As a basis for this, some sort of qualitative assessment of a person is needed, including their strengths as well as their weaknesses, their life story, and current social situation. This would blend diagnosis and formulation. Some patients may want above all to be treated as an individual, and may be harmed by mention of diagnoses; some may ask for diagnoses, preferring sharp categories; others may wish to understand more deeply, and would value discussion on what diagnosis actually means in psychiatry. It is a clinician's skill to judge which of these is most appropriate (and when). To develop that skill, clinicians should be fluent with diagnostic systems, and the debates on scientific and other topics related to these system, as well as having skill in assessing individuals as unique persons, and in the underlying ethical issues.

For legal, financial and administrative purposes, sharply defined categories may be needed for most decision making, but not necessarily diagnoses. Categories may be based on assessment for a variety of other purposes, incorporating a clinician's formulation, an O.T's assessment of disability, impairment and work-readiness, assessment of educational needs for "special needs" children in schools, or (in forensic and judicial settings or for advance directives) a person's degree of personal responsibility, fitness to plead (etc). If diagnoses *are* to be used, it may be possible to find ways of deriving these from clinical assessments and the qualitative transcripts developed by a clinician; diagnoses may *have* their place, but they should be kept in their place, and not used against clinicians as an administrative lever.

Supplementary documents:

(i)   My Introduction.
(ii)   Julie Channer's presentation.
(iii) Ginny Port's presentation.
(iv)   Mike Sukolski's presentation.
(v)   Kate Diesfeld's presentation.
(vi)   My submission to the U.K. Schizophrenia enquiry