

# Community Involvement in Mental Health Research

## Document for discussion by RANZCP Community Collaboration Committee, put together by Robert Miller

### Executive Summary

**Overall Context.** This essay was written following a suggestion from the Community Collaboration Committee of RANZCP. It is based on wide consultation with persons in the community, involved in mental health care or research. The term “research” is used in a broad sense, including the “hard sciences”, the humanities, and initiatives coming from the community as well as that done within academia or health services.

**The Real Functions of Research.** Readers are reminded that the purposes of research are to improve our understanding of difficult topics, and to produce practical solutions to real issues, based on such understanding. However, in recent times the focus on these purposes has been lost, as institutional goals prevail over long-term goals of research.

**Subjects versus Participants:** If mental health research is to deliver its true functions, researchers must engage with the community on a basis of transparency and equality of status between researcher and persons recruited for the research. Terminology is important: Persons who are recruited should in every sense be seen as *participants* not as *subjects*. Many consequences follow from this, explored in what follows.

**The Currency of Persons:** Much scientific research is deliberately impersonal, and this is a strength. However, in mental health research, including that in “hard sciences” (such as brain research), it is important to engage with participants in a more personal way than has often been the case in the past. Researchers should treat participants as whole persons, and show willingness to listen to their accounts of lived experience.

**Barriers to Active Participation:** There are many barriers to active participation in mental health research. These include: the past history of insensitive care and abuse within mental health services; personal experiences which are difficult to understand; stereotyping of service users and their family members, and discriminatory attitudes; demoralization of potential participants arising from each of these factors; insensitive determinist language adopted by many biological psychiatric researchers; “ivory tower” attitudes in academia; administrative constraints aimed to fulfil goals of each institution, rather than the real mission of research; styles of communication fostered in academia, which avoid full and open debate with the community; ethics committees sometimes going beyond their brief. For research originating within the community, however, the constraints may be less: What is done may be focused more sharply on urgent practical matters.

**Building Bridges.** If true participation is to be achieved, and mental health research is to regain its standing, and fulfil its proper objectives, it will be necessary to engage in a continuing process of dialogue between the various stakeholders. In this process full acknowledgment must be given to the expertise of those with lived experience of various sorts, as a necessary complement to the expertise of researchers. This should make researchers more aware of defining experiences for service users and family members/carers, and may lead to shift of attitudes amongst researchers.

**Contrast between New Zealand and Australia.** New Zealand has developed a program to combat stigma and discrimination (“Like Minds Like Mine”), now with its own research base, whose success is recognised world-wide; but there are real problems in recruiting participants for mental health research in a wider sense. In one area of research - that on schizophrenia - Australia appears to be far more successful than New Zealand. If the strengths of the two countries could be combined, unique styles of research might develop.

**The Power of a Personal Narrative.** The philosophy driving the Like Minds Like Mine campaign in New Zealand is that when people with lived experience of mental illness tell their stories, in a setting where there are no power differentials, the doors to understanding and reduction of stigma start to open. The personal narrative approach is important in other areas of research, for instance in providing important insights to guide researchers in the harder sciences, and to direct research on service delivery

**Community Input to the Research Agenda.** The agenda for mental health research should not be left just to mental health professionals, but should have direct input from the community, which may draw attention to unresolved practical issues, as well as aspects of fundamental research which have hitherto been neglected.

**Higher education.** A move towards true community involvement in research is likely to have an impact on how higher education on mental health topics, and the sciences which underlie it are delivered.

**How to Approach Recruitment of Participants.** Two models are described in this essay. One, operating now in Australia is based on use of public media, but also relying on community ownership of the organization for recruiting participants. The other, which might sometimes have merit, would be for local mental health groups to act as the final “gate-keeper” in recruiting participants, with a lesser degree of coordination state-wide or nation-wide. Two research projects are described, from New Zealand, where recruitment of participants in substantial numbers was achieved. Several other steps may be helpful for successful recruitment: Willingness to discuss with participants some of the underlying concepts of mental illness and those driving the research; greater transparency of research design; encouragement of support persons to accompany participants, to allay their anxieties; gratuities or Koha for participants; sometimes, the offer to participants of co-authorship of reports of research. Feedback from participants to researchers is important, and researchers should respond to this and/or provide updates on the results of their research.

**An Open Forum for Discussion of Research Possibilities.** The possibility is raised of having a regular Open Forum, where researchers and community persons can discuss research at the stage of its being developed, covering the objectives of the research, what it would entail for participants, and research ethics. This could also be a forum where community concerns with implication for research could be brought to the attention of researchers.

**Protocols.** This essay concludes with synopses of a number of protocols for research which would engage with the community, and might get active, willing and well-informed participation.

## **I. Introduction.**

Research in psychiatry covers a vast territory, ranging from studies which are definitely in the “hard science” category to ones in the heartland of the humanities. They may use quantitative paradigms from basic sciences, or qualitative ones, where what is explored is the meaning people attribute to life events or social processes (and where language in literary descriptions, rather than quantities are of central importance). Hard sciences emphasise the impersonal, objective nature of results, while the humanities may realise that, to explore the meaning people give to events in their lives, it is counter-productive to be impersonal, that it is hard to be objective, and that even the separation of researcher and those being researched is hard to maintain. Terms other than “research” may be better to describe social processes of interaction in treatment. I thus use the term “research” in an expanded sense. These matters are important in developing strategies for engaging communities served by mental health services in active, willing, well-informed partnership. In addition, research in psychiatry (as in some other areas of medicine) faces severe challenges in the area of ethics, due to the vulnerability of many potential participants, and sometimes their inability to comprehend fully the nature of research which focuses on them.

There are some big areas not covered here, especially approaches to research involving indigenous peoples in Australia and New Zealand, a large and complex topic which deserves to be addressed by itself. The essay also has its biases, based on my own professional expertise (starting off in neurophysiology, before branching out into other areas), better knowledge of the scene in New Zealand than in Australia, and my understanding of psychotic disorders being better than that in other areas of psychiatry. In addition, I write as a researcher with a science rather than a medical background. Recruiting family members and service users into research programs is often more difficult for science-based researchers than for those working in clinical services. I welcome input from other people on RANZCP committees, as well as others outside the college who may read this essay, to correct any imbalances it might have.

## **2. The Nature of the Relationship Researchers Must Establish: Participants Versus Subjects.**

A central issue in developing strategies for mental health research, is the nature of the relationship between researcher and persons being researched. Here terminology is crucial. Are persons being researched “subjects”, or “participants”? The word “subject” implies (a) a clear separation between those being researched, and the researcher, and, (b) being “subject *to* someone else’s wishes. “Participant” implies a more equal balance of power.

Paradigms of hard science often emphasise its objectivity, and the clear separation of the researcher from what is studied. Those are strengths for that sort of research. In medical research, where bodily processes rather than the person him/herself are under study, this distinction can still be maintained. Thus the persons being studied are called “subjects”. However, for research in psychiatry, even if it is in a basic science area (such as brain biology), there are reasons to avoid such sharp separation.

(i) Even if what is being studied is objective biology (for instance brain electrical activity), it is usually necessary to obtain a variety of clinical data about the person, including his/her subjective experiences, as inclusion or exclusion criteria, or for

correlation with objective data.

(ii) Sometimes subjective reports are central to fundamental work. In psychiatry, “hard science” *can* be personal and sometimes *must* be.

(iii) To obtain information on subjective experience requires a researcher to develop a relationship with the person being studied, where the researcher is no longer unaffected by what s/he hears. In no other branch of medicine does the researcher need to engage so fully with the *person* being studied (as opposed to his/her biological essence).

(iv) To obtain active collaboration, a researcher may need to spend time gaining trust of the person being studied (see below). This may be impossible until a researcher shows that s/he is willing to join the person being studied in their often difficult journey (for instance by joining their struggles against stigma and discrimination).

(v) Given the wide history of abuses of psychiatry (and not least in research), it is mandatory that researchers convey their respect for the persons involved in their study, their appreciation of the contribution they make to research, and the understanding and practical benefits to come from it. Every effort should be made to eliminate differentials of power or status between researcher and the person who collaborates in the research. Part of this means that the norm should be complete transparency of what the research is about. There will be exceptions to this, but it still should be understood what is the norm.

*For these reasons, it is essential that persons who join researchers in study of mental disorders be referred to (and treated) as “participants” (implying equality of status, and potentially sharing in the benefits, directly or indirectly) rather than “subjects” (implying separation from the researcher, and a degree of dependence, or at least being “not fully independent”).* This conceptualization guides all that follows in this essay.

### **3. The Real Purposes of Research: Getting Research in Context.**

The purposes of research are to understanding issues which are difficult intellectually, and to address and solve important practical concerns. These two purposes are often (though not necessarily) linked. Much progress in bio-medicine has come via research, but that does not mean that all research necessarily does (or even should) lead to practical advance. Some research aims to obtain fundamental understanding, where practical spin-off is nowhere in sight. Some low-tech but important advances have no basis in research.

For many administrators and politicians research has become the be-all and end-all. In the process it has sometimes become dissociated from its real functions. It is increasingly assessed not in terms of either the light shed on difficult intellectual issues or possible practical outcomes, but in terms of internally focused criteria set up by learned journals, or those who compute citation rates and journal impact factors. Research is then done increasingly for personal, institutional and national aggrandisement, or for purposes of commerce. These are not the real purposes of research. To indicate how the original concept of science is being debased, consider the following: Good research with clear implications for practice, may never be implemented, cited, or even read. Countries with the “best” research in psychiatry do not necessarily have the best mental health services. For many institutions, when a researcher brings in a big grant, it is often the money, not the understanding or practical spin-off from the research which is valued. Many persons in the general public (including potential participants in research) know that the motives driving a researcher may be far from the historic mission of research, but are primarily personal and institutional goals. They may realise that much of the fuss made by media

about research, especially in the biomedical area, is advertising hype.

In psychiatry, in the last generation, *some* of the progress we have seen is based in research, but some comes in other ways, from the determination, courage and humanity of pioneers from the general public (when it may be low-tech and inexpensive), from the legal profession in pushing through the human rights legislation on mental health care, and, lately, in New Zealand, from the efforts of service-users (with government backing), crucial in developing programs to overcome stigma and discrimination.

*Here*, however I write in defense of real research done for its real purposes, and to analyse barriers preventing collaboration between researchers and those most directly affected by mental health problems - especially service users (“consumers”) and carers/family members. The tax-paying public should be served by research, and have good reason to ask for accountability; and it is they with whom researchers should be forging partnerships. How can research be presented more positively to the public to further its legitimate ends? How can public trust in research and researchers be restored?

#### **4. Building Bridges<sup>1</sup>**

Much medical research involves human participants, either because they have medical problems which research attempts to address, or because of genetic kinship with those with such problems. Persons unaffected by problems under study are also needed, as comparison groups, or to ensure safety of new treatments. It may be more difficult to recruit such “normal” participants than those directly affected by disorders under study.

Researchers, and these groups should be natural allies. However, for historical reasons, they find themselves in a different boxes. The interests of consumers and carers have come to diverge from those of researchers, and sometimes from each other. For researchers to get better engagement by the public, surveys of public opinion via usual methodology (“consulting with stakeholders”) will be of little use. What is needed is an extended process of “getting to know one another”, to build trust. This takes time. Irreconcilable differences *may* exist; but in such cases, it is even more important for groups to talk through contentious issues, not to win a battle, but to carefully define, and agree what *are* the divisive issues. When agreement is reached on those issues, it may become clear that there are other large areas where the groups *do* have common cause, and where collaboration can occur. Such dialogue may need guidance by persons skilled as facilitators, trusted by all sides. Sometimes it may not be possible to do this with a single facilitator. In this case, joint facilitation by two persons may be able to build bridges between groups, otherwise separated by unbridgeable chasms.

In building bridges it is vital to realise that, by no means do experts have a monopoly on relevant knowledge. There are multiple sources of knowledge, amongst which “lay knowledge”, be it of practitioners, service users, or carers should be acknowledged. The route to knowledge privileges neither experts nor lay persons, but involves a “dialogic” process between the two. This necessarily means that experts should abandon any pretension to scientific authority. At the centre of the scientific endeavour, there should be a more sensible and democratic discourse. A tradition of research, termed “Action research”, or Participatory research” has grown, based within communities rather than amongst experts, aiming to address the practical concerns of those communities. There is a need to link this with more academic or professional “mainstream” research.

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<sup>1</sup> This heading has nothing to do with a series of mental health conferences held in New Zealand, with the same title.

## **5. Differences between Australia and New Zealand**

In New Zealand, in recent years, there has been a degree of fragmentation within the mental health professions. Polarisation has developed between advocates of psychosocial causes and those favouring biogenetic ones, particularly in study of psychotic disorders. This has prevented collaboration between researchers, service users and carer groups, and has slowed down programs for recruiting participants for serious research. On the positive side however, an innovative program has developed to combat discrimination and stigma. Perhaps it was needed more than in Australia. I am not well informed about the scene in Australia. However there may be fragmentation there for another reason - the split of health providers between public and private sectors. In one important area however, namely research on schizophrenia, I do know that Australia is far ahead of New Zealand in recruiting people with a diagnosis, their family members and others, for a wide variety of research projects. *Perhaps, if the different strengths in the two countries could be combined, a quite unique approach to psychiatric research might emerge.*

## **6. Problems Preventing Active Participation.**

(a) *Fears and anxieties.* Major mental illness is associated with a great deal of fear and anxiety amongst the general public, and especially amongst consumers and carer groups. This has three main origins: *Firstly*, it is based on fear of human problems which persons affected find profoundly difficult to understand. I make comments on this in section 14(d) below. *Second*, some of the fear is well-grounded in a history of serious abuses which have occurred in psychiatric institutions, themselves a regrettable consequence of the vulnerability of persons with major psychiatric problems. Such abuses are well documented in New Zealand in the 1960s-80s. Comparable abuses are known to have occurred in Australia (Chelmsford), Canada (at the Allan Memorial Institute in the 1950s-60s), or in Russia (at the Serbsky Institute in the later Soviet period), to say nothing of the Heidelberg Psychiatric Institute during the Third Reich. (I have visited each the last three institutes, and have worked for some months at the Allan Memorial Institute; so what went on at those places has some reality to me.) Often these abuses have involved the State (or in the case of the Allan, another state) interfering with, or using mental health services for its own ends. Probably most psychiatric facilities in most countries have “skeletons in their cupboards”, if one goes back one or two generations. In many countries, the idea of psychiatry as an agent of personal health care is still quite foreign, and psychiatry is seen entirely as an arm of state control. We have no grounds for complacency in our own countries. These facts are important for research on immigrant communities. The wider challenge is to re-invent psychiatry as truly one of the “caring professions”, and to promote research in *that* context, rather than as the impersonal face of state control. The *Third* source of fear is more general, the grossly insensitive determinist implications of so much of today’s biological language, especially when applied to human behaviour and thought. Members of the public who hear such talk may not be able to say what is wrong, but for sure they know that *something* is wrong.

(b) *Demoralization.* People with lived experience of mental illness are often deeply demoralised. This may be the result of on-going symptoms, but also of past experience of abuse, stigma and discrimination. Even if symptoms are minimal, they may want to keep themselves to themselves, lose any sense of personal agency, or that they can do anything

to help their plight. They would prefer to have as little to do with psychiatric services as possible. Even less do they want to participate in research.

(c) *Ivory tower attitudes of researchers.* The image of the “ivory tower” is commonly used to criticise academia. In my view this accusation is to a large extent accurate, in the sense that many researchers in academia live their lives confined to academic communities, with attenuated links with wider communities outside their walls. This is of course *not* the case for disciplines with practices in the community (medicine, clinical psychology etc,) but for many science-based researchers who have little direct interplay with the general public it creates serious barriers. Moreover, basic sciences stress their essentially *impersonal* nature. This makes it hard for researchers to engage with the public in matters so essentially personal as is much psychiatric research. Indeed some basic science researchers choose their career just to avoid the messiness of dealing with human persons in research. I make particular points here about brain science. It *is* an important area for psychiatry, along with many other sorts of science, but it is a difficult area, and tends to frighten people. In the Australia Schizophrenia Research Bank (which now has a very large register of potential volunteers) I hear that it is much easier to recruit participants for research with a social or psychological flavour than for neuroscience- or brain biology-based projects. The situation is even more difficult in New Zealand. This may be because neuroscientists make no attempt to place their science in a context of personal wholeness or lived experience of any sort; or if they do, it is with brutally simplistic notions of what it is to be human.

(d) *Administrative constraints on research.* The constraints on research in academia or health systems have increased greatly in the last twenty years. Administrators (perhaps trying to cover their backs) appear afraid of backing anything which might be wasteful, and so avoid risks. This is unfortunate, since real research is inherently risky; mistakes from failing to back a winner are more serious than sometimes backing a loser. The hurdles researchers must now negotiate include specifying outcomes (rather than outputs), or pathways for “knowledge transfer”. Most funding is contestable, and is so competitive that it leads researchers to adopt a defensive approach, guarding against any weakness, rather than making risky proposals with big opportunities. Administrators in academia dislike research which brings in little money (because they take a large top-slice for their institution). Research which costs little (such as fundamental theoretical research) may have great potential in the long term, but is no longer even considered to be research. Every discipline and sub-discipline (and their journals) have their own do’s and don’t, narrowly and defensively focused on their little bit of academia, and missing the wider picture. Politicians (increasingly echoed by the public) criticize academia for its ivory tower attitude. Policies (such as research assessment exercises) are then developed to force researchers into “the real world”. Actually those policies often make it worse, not better. To have one’s research publications assessed (sic), by evaluation of “impact factor” of the journal means that researchers substitute *that* (and similar) goals for the real functions of research (see section 3 above); so they become separated further from the coal face of psychiatric problems.

(e) *Communication by researchers.* Many universities, and research institutions are playing a competitive game, and researchers, willingly or unwillingly get caught up in the same game. Thus their “communication” with the general public is filled with inflation and bombast, avoiding forums where there can be honest presentation, and fully public

questioning by critical audiences. To get away from this, researchers need to break free from constraints of their institution and its PR people, and speak directly, freely and candidly to the public. This would be a great education for many researchers.

(f) *Ethics Committees.* Ethics committees play a crucial role in guiding biomedical research involving human participants, and safeguarding such research from abuses. They trace their origins to the Nuremberg trials after World War II, and since then have grown in number and influence. There is now however concern that they may sometimes go beyond their brief. I am aware of several issues: (i) Ethics committees may scrutinise methodology of projects, since badly designed projects involving humans is not only bad science, but are unethical. However, scientific assessing committees generally have greater expertise on this than ethics committees, who should not usurp the role of the former. (ii) I hear of ethics committees being used to implement government policies, which seems to be going beyond their brief of giving ethical scrutiny to projects submitted to them. (iii) Requirement for clearance by a formally-constituted ethics committee may be excessive for some projects (for instance interview-based projects), where the risk is minimal, and conducted as much for education as for results of the research. Supervision by an academic HoD may then be sufficient. (iv) On “informed consent” some immigrant groups (from eastern Europe, former Soviet Union, East Asia), would interpret the signing of a consent form as putting themselves in the researcher’s power. This may not be the message one should convey. Reluctance to sign such forms may also apply to non-immigrant groups outside academia and health services. These forms may be interpreted by indigenous people in ways very different from what is intended.

(g) *Conclusions.* There are now considerable constraints on research in academia or health services. Carers and consumers know this. One spokesperson for a consumer support network in New Zealand writes: “There is still strong opinion in consumer circles . . . that much research is one-way, with consumers providing valuable insights thru their own experiences and this being used for often dubious reasons (and someone else’s credit) by the researcher. Many service users are both sick and suspicious of the endless forms/surveys/personal information data they are required or requested to complete with little or no obvious benefit to them. It is so important that any research that concerns the service user experience has integrity and a purpose that is going to be of REAL value to all participating parties.”

Constraints may be less for free-lance researchers detached from these institutions. Free-lance researchers know the constraints in academia and health services. Even if they have links with these institutions, they may realise that they are freer if they deny such links. Recently I was actually advised (by a person in an academic department of psychiatry) for a project I am considering (project [vi] in section 17 below) to become affiliated not with an academic department or a District Health Board, but with an organization directly linked to government; and to work via a regional ethics committee not linked directly either to academia or any single DHB. I must also say that I have recently been finding, with pleasant astonishment, that some of the least constrained and innovative studies on practical matters in the mental health area in New Zealand are done by people working freelance, in retirement, or in private sector organizations (such as *Phoenix Research* in Auckland), with few links with academia or health services. On fundamental research this is not mainly true. Nevertheless my own work on the brain



theory underlying schizophrenia could be completed only by resigning a secure academic position to work freelance.

### **7. The Māori consultation process in New Zealand, as a model to follow elsewhere.**

In New Zealand, researchers initiating most research projects which receive public funding are required to take part in a Māori consultation process, to ensure that interests of Māori are not overlooked. This has developed since the 1980s as part of a broader political process to redress historic grievances suffered by Māori. In research, it means that researchers should say in grant applications how a proposal is relevant to Māori, and in due course to present themselves to relevant Māori groups to respond to questions. The rationale, as I understand it, is more about ensuring transparency than to act as a gatekeeper. I do *not* object to this. In fact, I think it is a model to be followed elsewhere, and what I suggest below (section 16), for engaging with service users and carer groups is an adaptation of this form of consultation. It is necessary in the mental health area for reasons similar to those underlying Māori consultation.

### **8. The Currency of Personal Relationships.**

There is a vital principle in recruiting participants: Treat participants as whole persons not just as representatives of groups. “Consumers” (a.k.a. “Service Users”) and carers all have complex stories, sometimes harrowing, always fascinating, all different. Service users rebuild their lives in amazing ways, again all different. There is much to learn from their stories (see section 13, below). This is the strength of the Like Minds movement (see below), or Julie Liebrich’s book “*A Gift of Stories*” (to which I contributed). Many such people *do* want to tell their stories, in their own words, and often are willing to do so in public, rather than through a filter of psychiatric or academic terminology. Often the buck stops (or should stop) with the psychiatric profession, though government policies may be the real issue.

### **9. Stereotyping:**

To stereotype people is a natural way to summarise and simplify one’s attitude to them. We all do it. I’m sure I do it sometimes; and I also am stereotyped. I am stereotyped by mental health professionals as a consumer, and by consumers as a mental health researcher (and, for God’s sake, a neurophysiologist! Surely . . . he can’t be *human* . . . can he?). I won’t have a bar of any of them. Researchers should adopt more intelligent approaches to those who participate, taking time to get to know people individually, their journey through life, and not just in relation to mental health issues. In any group sessions for “reconciliation dialogue”, all participants should be alert to the danger of stereotyping those in other groups, and should listen carefully to what is actually said, rather than what they imagine is implied.

### **10. Attitudes of Researchers**

As already stated, research on mental illness and mental health takes a vast variety of forms. The skills and attitudes needed in such research are equally diverse. Some skills are technical and intellectual, but I focus here on *attitudes*. For better and for worse, these

are acquired in part from role models in formative years (during medical and other education). Apart from this, some people have instinctive talent, other researchers are not so good, yet excel elsewhere in research. Speaking personally, I believe I have an ability to relate to some people as potential participants better than can many researchers, but I also realise that many others, including many working in the mental health professions are far better than I am, or ever will be. Mental health professionals, including researchers should be capable of honest self-evaluation of their strengths and weaknesses in establishing rapport with participants. Many skills are needed in psychiatric research and the depth of humanity needed to build trust at the coal face of mental health services is not the only one. Researchers should know their limits and engage persons in research teams who have skills in this area which they may themselves lack. There could even be designated specialists, to assist researchers, although this might turn out to be a way of avoiding the real need for the researchers themselves to *earn* the trust of the people they work with. There are professions right outside academia or health services (especially those focusing on pastoral care) where the focus is on building relationships despite big divides. Mental health researchers could learn from these professions.

### **11. Defining Experiences for Carers and Service Users.**

For service users and carers there are several defining experiences. The most universal, for both carers and consumers is stigma and discrimination, experienced on many sides, from many agencies, and at many levels. Many researchers are quite unaware of the prevalence and power of this. All they know is pressure from their institution (and their own ambition) to “do research”. If they are going to do research to fulfill its *real* purposes, that is to increase understanding, and to deliver practical solutions, they should show willingness to join forces with service users and carers in their biggest battle, against stigma and discrimination, and *uncaring* attitudes of agencies supposedly set up to help them. Other defining experiences are more specific: For service users, the experience of committal to a psychiatric hospital (with all its formalities) is never forgotten. Likewise experiences at emergency psychiatric services, in seclusion rooms, or of finding oneself in hospital, not knowing how one got there, are defining events. For carers, equivalent searing experiences are waiting at an emergency psychiatric service for news of a loved one, often in the middle of the night, after long periods of growing anxiety. Researchers seldom share these experiences, but should know that *these* are the events which define basic attitudes in the people who join them as participants in research. If they could show that they were “on side” with respect to those issues, recruiting participants would be easier.

### **12: Definitions of terms:**

Potential partners in the research endeavour come from different places, with different formative experiences, and therefore different expectations of what is “normal”. Therefore, key words - respect, discrimination, crisis, stigma, role of leaders - may have different operational definitions for different participants. What is a crisis for a family member or service user may be normal for a front-line psychiatrist. We may not know how the way we behave amounts to discrimination. We may be dumb-founded to realise that what is self-evident to us, is not so to other people, with different life experiences. The process of dialogue involves exploring such differences, and, beyond that, finding

where partnerships can be formed.

### **13: The value of listening, for researchers and for research**

(a) *The philosophy of the New Zealand Like Minds campaign.* In New Zealand in the last fifteen years, as a spin-off from the Royal Commission on Mental Health Services of the early 1990s, a movement has developed (with government backing) to combat stigma and discrimination related to mental illness. A guiding philosophy is that the doors to understanding and reduction of stigma and discrimination start to open if people with lived experience of mental illness can tell their stories, in public (though usually in small groups) in a context where there is no power differential between the presenter and audience. Then, the shared humanity of all present becomes the guiding light. This movement is now being recognised world-wide as breaking completely new ground in the mental health area. I have recently been engaging with people in this movement, and am immensely impressed. People with lived experience of mental illness are trained as “Like Minds Presenters”. I have met some of them, and joined their sessions. Some have substantial impairments, may never have been employed, and their education has been curtailed by illness, yet their work in this campaign gives them status, and “mana”. Speaking personally, I want to join forces with them, and in due course train as a Like Minds Presenter. The philosophy based on equal status of presenter and audience does not sit easily with medical styles of education (see section 14, below).

(b) *What should be on the research agenda?* Service users and carers have a vital role in focusing attention of researchers on their agenda for research. In another area, HIV/AIDS, where international conferences are generally much larger than psychiatry conferences, persons most directly affected have for a long time been closely involved in the science and the politics of those meetings. World-wide this has not happened much in psychiatry, but should happen. Carers and service users may focus on very practical issues, while clinical and (especially) science-based researchers may investigate fundamental questions, far from service delivery. Research is needed at both ends of the spectrum, and at many stages in between. A chasm needs to be bridged. Basic science researchers need know the perspective of service users, and the steps between what *they* do, and service delivery. They need to be kept aware of the reality of the problems they think they are studying, to focus their minds on what, with their own expertise, they can contribute. In the next three subsections I draw attention to areas where the contribution of carers and service users may be of vital importance (some expanded in parts of section 17):

(c) *First-person experience.* Listening to first-person accounts is part and parcel of clinical psychiatry. Its role in research is, I suspect, neglected. It is often inexpensive, yet may be fundamental to other work. There is still much to do, and learn from persons, who, now in a stable state of mind, can speak with reflective insight on past experiences. For basic science researchers with good grasp of normal brain functions to hear vivid first-person reports of symptoms of mental illness can be immensely illuminating. To a prepared mind, small details may make sense of complex issues: True explanations may arise. In addition, almost by definition, mental disorders change a person’s “sense of self”. This varies greatly between people, even with no psychiatric problems, in quality as well as “quantitatively”. It is challenged in different ways by different symptoms and disorders. Better understanding of this is needed, so that clinicians can guide their

patients to a better way of viewing themselves. This is clinical research, to be done by psychiatrists or clinical psychologists. Those willing to explain their symptoms and mental processes should be taken on board as true partners in a joint exploration. They may be invited to be co-authors of what is published (see below).

(d) *Pharmacology*. For basic scientists (in this case pharmacologists) to hear first hand the experiences patients have with specific medications may be immensely illuminating, to a researcher with a prepared mind. Research here overlaps with that in the previous subsection. It includes not only experiences on starting a new medication, but those on switch of (or on withdrawal from) a particular medicine. Different medicines, supposedly in the same class, may have different subjective effects, which need to be documented. Patients with experience of several medications in a class are most qualified to provide such information.

(e) *Service delivery* Carers and service users know better than most mental health staff the failings in service delivery, and are strongly affected by them. Any one story may not point to a particular remedy. However, if similar themes recur, and can be identified, there may be clear pointers on how services can be improved. Systematic analysis of service failures is as important as in (say) analysis of aircraft disasters. In any large mental health service, a researcher (or group) could be charged with listening to, collating, and drawing conclusions from what went wrong.

#### **14. Initiatives in higher education related to research.**

Psychiatric training starts with medical education, which traditionally has been based heavily on personal or institutional authority, with a strongly hierarchical social culture. Some attempts are being made to change this in medicine generally. In psychiatry, because of its personal, relational and social dimension, this is needed more than in general medicine, and, I believe, the impetus in the Royal College is already stronger than in general medicine. (Palliative care is another area where traditional boundaries may now be becoming more permeable.) The traditions of general medical education may be “a millstone round the neck” of persons currently attempting to develop a very different style of education in psychiatry. This changed focus will impact on research, as on other areas of psychiatry.

Equality of status between researcher and participant, and on community-aspects of research may also not come easily to basic science researchers, or quasi-scientific administrators, trained to be as *impersonal*, and sometimes as competitive as possible.

Another educational issue for research relates to non-medical bioscience courses. Undergraduates in health science courses should, in my view, be given closer awareness of lived experience of persons with relevant health problems, not least in psychiatry. Without it, students become mere technocrats, never seeing the human realities of what they deal with. This in turn affects their choice of research area, and their skills as researchers.

#### **15: Strategies for approaching and involving participants in research.**

There seem to be two ways to recruit persons as potential participants in research, described in the first two subsections below. The third section highlights two projects I know of in New Zealand which have successfully recruited participants in significant

numbers. (I also know of several good projects which did *not* develop their full potential, due to the difficulty in recruiting participants, and of several good researchers who moved overseas in part for this reason.) The remaining five sub-sections deal with specific issues in engaging participants as true partners in research.

(a) *Nation-wide, or regional data-bases.* From limited experience in New Zealand, if one suggests to service user groups that a nation-wide data-base be set up to help recruit participants for research on psychotic disorders, the reaction is strongly negative. The fear is that such data-bases could easily be misused at some future date. Given the history of abuse in the mental health sector in the not-too-distant past, that is understandable, but probably not an entirely fair reflection of mental health services as they operate at present. In one area of mental health research - that on early intervention and preventive psychiatry - it is particularly restricting, because such research often needs to follow individuals over a number of years, with high rates of follow-up. This is probably true for research related to preventive strategies generally, not just in psychiatry, in part because information gathered might be sought by life insurance companies. However, in view of the history of psychiatry, and the fact that life insurance agencies seldom include coverage of mental illness, this source of anxiety may be more acute in psychiatric research than in other areas.

In Australia, the scene is different. In 1998 NISAD (Neuroscience Institute of Schizophrenia and Allied Disorders, later the Schizophrenia Research Institute) set up a Schizophrenia Research Register for New South Wales. By the year 2000, the Register contained 400 individuals as potential volunteers for research in this area. By 2008 an enlarged organization ASRB (Australian Schizophrenia Research Bank) recruited participants from a wider region. The aim is to build a register of potential volunteers with 4000 persons. This has enabled over 200 research projects to be conducted. People with schizophrenia, and their family members are recruited via media adverts, in-patient and outpatient treatment services and NGO support agencies. They take part in a clinical and neuropsychological assessment, donate a small blood sample and, for those that meet criteria, have an MRI scan of brain structure. During the consent process, volunteers can nominate if they would like to be contacted on future research projects. The data collected is stored in a purpose-built database and specimen repository. Scientists with prior ethics approval for projects can apply to access the ASRB data, samples and/or volunteers. Volunteers that meet the criteria for an approved study are contacted (usually via mail) from the volunteer participant list by the ASRB on behalf of the scientist. If they agree to participate, contact details are forwarded to the scientist, who then contacts the participant to invite them into the study. In this way the ASRB provides a supplementary recruitment resource for research projects and, because of its broad recruitment method, can reach participants that may not be available through traditional recruitment strategies. A crucial feature is that the ASRB is not a national register, but rather, because it is publicly funded via charity and NHMRC, is owned by people with schizophrenia and their families. For example, the Schizophrenia Fellowship strongly supports the ASRB and were engaged in its establishment.

(b) *Local Mental Health groups as Final “Gatekeepers”.* An alternative approach to recruiting participants would be to ensure that the real “gate-keepers” overseeing the recruitment process would be at a local level (for instance the coordinators of local mental health groups, persons that each consumer knows and trusts). This would mean

that researchers should be willing to make contact with these small groups, and engage in discussion with them, rather than putting public adverts in media outlets to recruit participants. This method may be a better way for New Zealand to go, in view of the apparent difference in public attitudes to research in this area, compared to Australia. The process might start as a large number of small sources for recruitment. As confidence in the system is gained, it is hoped that a central source of information could grow, which would not contain much detail on individuals, but would collate aggregate data for each local group (including, at least, total numbers, broken down by gender and age).

(c) *Two examples from New Zealand where service users were successfully engaged in research participation.* In both the cases, the area of research was schizophrenia, one of the more difficult areas for recruiting participants, and the researchers, studying for doctoral theses, were non-medical (making recruitment more difficult). In both cases, my estimate is that a key element in the success of the recruitment process was the deep humanity of the researchers themselves.

The first example was research to pilot a new psychological instrument to assess non-psychotic traits associated with schizophrenia (see 16[viii] below). After obtaining ethical clearance, it was easy to recruit participants from local drop-in centres and the like, and over 150 such people took part. However, although most of these would have had a diagnosis in the schizophrenia spectrum, initially hardly any would give consent for the researcher to go to the case notes to obtain the official diagnosis (which was crucial to the research). However, the researcher spent a lot of time over the next 18 months hanging out in those drop-in centres, and getting to know their clientele better. Then, when more definitive results were sought with an improved version of the instrument, she had won their trust, and almost everyone she asked gave consent to obtain the diagnosis (~140 in total, including 75 with the schizophrenia diagnosis).

The second example was a neuropsychological project investigating cognitive performance in Māori participants with schizophrenia (and comparison participants from the same population). The researcher himself was Māori. They were recruited from community mental health centres in South Auckland and Wellington. With the exception of one centre in Wellington, all centres were specialist Māori services, and all participants with schizophrenia (including those in the aforementioned centre in Wellington) had a Māori case manager. In all, 110 Māori participants were recruited, 54 diagnosed with schizophrenia (who all knew their diagnosis), plus 56 controls.

(d) *The need to discuss concepts of mental illness with potential participants.* In New Zealand in recent years there has been resurgence of a divisive politicised approach to mental health, which was prominent in many countries in the 1960s and 1970s. In particular it emphasises the split between bio-genetic and psycho-social causes of mental illness, as if they were polar opposites. The film “*One flew over the Cuckoo’s Nest*”, is widely regarded as a good educational movie, despite the fact that the film was made in the 1970s about practices in the 1950s<sup>2</sup>. I do not know whether such ideas, and politicization of psychiatry have such wide currency in Australia. At least in New Zealand, it is essential that researchers: (i) know about public attitudes, which are likely to be shared by potential participants; (ii) can convey the reality, that today most psychiatrists, and many other mental health professionals see both bio-genetic and

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<sup>2</sup> Although mental health services are, I believe vastly better overall than those depicted in this film, I would not like to assert that what the film depicts is totally in the past, or that attitudes and practices shown have completely vanished.

psychosocial factors at work jointly to cause mental illness; (iii) find language to defend and explain this complementary approach. One way to do this would be as follows: “We all try to understand our experiences in terms of whatever we already know and understand. However, we all start from different knowledge bases, so the understanding we reach will differ greatly from person to person. Those differences need not be a source of disagreement and conflict. If the experiences on which each person’s conclusions are based are genuine and valid, the conclusions are probably valid, but not the whole truth<sup>3</sup>; and then the different viewpoints are likely to be compatible, complementing each other.” This approach is common sense. Human beings *are* made up of mind and spirit; but they are *also* made up of flesh and blood (and nerve cells). Every culture has to face the conundrum of how the two fit together, and they do it in diverse ways; but any reconciliation which ignores one or other side of human nature is bound to be inadequate, and may lead to polarization and conflict. The real task is then to work out *how* they complement each other.

In view of this conceptual issue, it may be appropriate, when potential participants are being recruited for a research register, to ask what sort of research they are most likely to agree to be involved in. Alternatively, for someone who has declared that they are a potential volunteer, it may be best to invite them to participate initially in projects with which they are more comfortable (probably of a psychosocial nature), and where they have a chance to tell their personal story to an attentive listener. Only later, when a degree of confidence has been earned should they be approached for more biology-based projects.

It was mentioned in section 6[c], above that biological projects tend to frighten people, because the biology of brain function is more technical, and further removed from commonplace explanations of mental distress. While research projects are not the time to address those issues, least of all by researchers with no clinical background, there may be approaches which researchers could adopt to help participants overcome a fear of what is not understood. It has to be based on solid understanding (not on “soft soap”, which they may well see through). However, that can be at a variety of levels (not necessarily in terms of fundamental biology, although sometimes it can be); wise and helpful words can be offered at many levels from broad and non-technical, to more detailed accounts. Since researchers with a clinical background have more experience than most basic science researchers, there may be need for researchers of diverse backgrounds to discuss this issue, so that informal guidance can be conveyed to researchers with no clinical background.

(e) *Design of research studies.* Many research studies, as currently designed, are by no means fully transparent to participants, and occasionally involve deliberate deception (if only transiently). I hear reports from service users involved in research that, on reflection, they realise that parts of the study design deliberately hid the intentions of the researcher. Along with that realisation are sown the seeds of distrust. Some researchers are shocked, when, in public forums, service users challenge these aspects of study design, as if they were being asked to “reveal trade secrets”. I realise that some research findings in the past have relied on incomplete transparency, and that some important results required deception. I am not in any way trying to debunk such research, much if

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<sup>3</sup> I am talking about the validity of their *experiences*; but it may be necessary to point out that attributions of *causes* of a person’s mental problems may require a much bigger body of evidence.

which is high quality, the foundation of present understanding. However, today more people have higher education, have access to and can understand research papers, and this will include many service users. These trends can only increase in the future. In addition, a research style which is manifestly open and transparent is far more likely to attract participants than one which presents the image of “faceless scientists in white coats” (which may be one of the biggest barriers preventing active participation). By greatly increasing the transparency of research studies, I suggest that there is more to be gained than lost, both from their greater willingness of people to be involved at all in research, and from improved use of the reflective insight of participants. In the future, therefore, I suggest that there should be a shift towards much greater transparency in study design. In any case, this is likely soon be inevitable, a necessary consequence of really treating the persons involved in research as active participants, rather than subjects.

(f) *Support by family members.* If a research participant has volunteered for a project, but is hesitant or anxious, it may be important to involve a support person (family member, or “significant other”), to accompany the person to a research session, until trust is established, and such persons may also contribute to a wider and better understanding of the life experiences of the participant.

(g) *Gratuities or “koha”:* Participation in research is more likely to occur if a gratuity or “koha” (Māori word with similar meaning) is offered to participants. I suggest that this should be standard practice for research into major mental illness, especially in view of the difficult finances of many service users. It could be a gift voucher, and should not just be payment for expenses (for instance for travel). Costs should be built routinely into grant applications. Even if the amount per subject is small, it may mean a lot to those participants, and in any case is an important symbol of the relationship.

(h) *Co-authorship.* In some situations, participants should be invited to be co-authors in research publications (or be given tangible recognition in some similar way, in the “write-up” of research), provided it is a genuine partnership, and not tokenistic. The comment I have heard, from a service user, suggests that this is especially appropriate when first-person accounts are used, and participants have revealed personal experience. In a recent publication of mine (actually on pharmacology of antipsychotic drugs). I incorporated first-person anecdotes into a technical scientific argument. This “raised some eyebrows” of reviewers, but I got away with it, and, I suggest, should be accepted in scientific publications in this area, as a way to get closer to the “primary evidence”. There is however a corollary: The *anonymity* of peer review (to which I object anyway) becomes a truly grotesque power imbalance. Referees should sign their names.

(i) *Feedback evaluation.* Research participants should be given the opportunity of giving feedback on how they felt about their participation in each research project. Researchers should respond to the feedback, and in any case should report back in person to their participants the results of their research.

## **16: The concept of a regular “Open Forum” for discussing research possibilities.**

In early September 2010, in Palmerston North, New Zealand, as part of a research meeting on schizophrenia, it is intended to include a workshop on Research Participation. Apart from the researchers who regularly join in these meetings (which occur annually) it is hoped that there will be a strong contingent of invitees, both service users and family members/carers. This workshop is likely to discuss many issues raised in this essay. It



may also be possible to devote some time for researchers to give “thumbnail sketches” of research they would like to do, were there a suitable number of volunteers to participate in the project. If this workshop is a success, it might become a regular part of these annual meetings, an “Open Forum”, where researchers and interested community members (service users, carers and others) can come together to discuss projects at a developmental stage. These need not be focused just on schizophrenia, however broadly that is defined. On the agenda would be the benefits and hazards of each project for consumers and carers, thinking long-term as well as short-term, and especially on the ethical aspects of projects. Transparency on ethics, and a chance for full discussion is especially important for projects whose eventual implementation would be in the field of public health or preventive psychiatry. In no sense would this forum have a “gatekeeper” function, but could establish a climate of transparency for mental health research. Researchers would be under no obligation to join in such discussions, but if they did, their participation could be mentioned subsequently when they apply for grant funding. This could also become a forum where community concerns with implications for new research could be brought to the attention of the research wing of RANZCP.

## **17: Protocols**

To conclude this essay, I make a number of suggestions of possible research projects which would engage participants (both consumers and family members/carers) in a way which they could appreciate more perhaps than many of the projects initiated in research communities. These projects are divided into several broad categories. Some are my own ideas, including one or two I am actually trying to set in motion myself. Others are projects I have heard in recent meetings with leaders or spokespersons for community mental health groups.

### *(a) PUBLIC HEALTH*

(i) *Impact of the Like Minds campaign*: The Like Minds Like Mine (LMLM) campaign, aiming to combat stigma and discrimination, has been running in New Zealand for over ten years. This includes a TV advertising strategy (usually as 45 second “adverts”, but occasionally as longer sessions), and sessions at a local level where service users, trained as presenters, engage with audiences from the public, or selected groups, to talk about experiences linked to mental illness. The campaign does not refer much to diagnostic labels, but, especially in the local sessions does not shy away from the conceptually difficult issues of psychosis or schizophrenia (though with emphasis on personal account of experience rather than diagnoses). LMLM has been linked with much good research, undertaken by a social research business (*Phoenix Research*), in Auckland. This has documented public opinion about mental health issues, with specific investigation of youth, employers and managers/supervisors, as well as perceptions of service users, concerning discrimination, and self-stigmatization. In many such areas, shifts over time have been documented. Some of the research covers in depth one-on-one interviews. In a review on their research, the lead author Alan Wylie makes three points (a) that overall shift of public attitudes takes a long time; (c) that TV adverts are the only way to reach the mass of the populace; (c) Nonetheless, certain key community groups (especially professions in regular contact with clients with mental health problems) may, in the end, have over-riding influence on general attitudes. I am not up-to-date with all this research, and some of it is done for guidance of the LMLM program, rather than as documents for

public consumption. Nevertheless, there may be other areas for this research to explore (including attitudes of such key professions as police, teachers, lawyers, people behind social welfare desks, etc). Surveys have presented basic descriptive data in considerable detail. In some of the *Phoenix* surveys, data are collected on the effect of the TV advertising campaign, and there are some comments on the impact of the local sessions. The latter, though with small *overall* impact, are likely to have more impact at an individual level than the TV adverts, and, if targeted at key professional groups, may produce some important movement in public attitudes. More sophisticated methodology, including correlations between attitudes of respondents (especially in these key groups) and their exposure to LMLM local sessions, may give better understanding of the impact of the LMLM campaign. I suspect that there has been no attempt to do this so far. To do it would require conducting more focused surveys of people who *have* attended LMLM sessions, to compare them with matched groups who have not. This may however give a guide on how the TV campaign could be modified to have more of the personal impact of the local sessions.

(ii) *Effects of stigma and discrimination on cognitive function.* Various mental disorders are said to be associated with impaired cognitive ability (often not separated from limited intelligence). However, since many persons with these disorders also suffer severely from effects of stigma and discrimination, any impairment due to an illness is confounded by associated stigma and discrimination. A design to tease out these separate effects is to involve groups who have a definite mental disorder but with varying degrees of documented discrimination; and also groups of severely discriminated individuals with no definite mental disorder. Interviews and more formal testing of cognitive abilities in standard tests could then reveal how far (and which) impairments are intrinsic to a disorder, as opposed to their being a product of stigma and discrimination.

(iii) *Multi-perspective examination of crisis management.* A project is currently under way, initiated by service users and affiliates looking into the management of crises in the mental health field, taking into consideration many perspectives, those of service users, carers, mental health staff of various sorts, police and others.

(iv) *Barriers to service delivery.* The questions here are: What causes long delay in obtaining treatment? What are the barriers? Are there cultural or ethnic differences? How does Mental Health Legislation work in practice?

(b) *SUBJECTIVE REPORTS*

First hand descriptions of abnormal mental states and experiences, as primary evidence to understand those states may be an area where service users could be willing, active and very informative participants. It may be very fundamental research. Some of that research is about spontaneously-occurring abnormal mental states. Some of it might reveal underlying personality traits, which might be precursors of more definite illness, of potential use in early intervention (see below). Other aspects are on details of subjective responses to psychoactive medications or other agents. One project in which I have slight involvement is to explore subjective effects produced in normal participants by ketamine (as a possible model of psychopathological states). Two projects mentioned below are on response to antipsychotic drugs.

(iv) *Switching from typical to atypical antipsychotic medications.* Atypical antipsychotic drugs were developed in order to achieve antipsychotic effects or prophylaxis, without unpleasant motor side effects. It is now widely perceived that they have other advantages

in the cognitive domain, perhaps enabling thought processes to occur with greater clarity than before. This is documented to some extent in standard neuropsychological tests, but these are poorly suited to characterise the essence of any changes. A useful project would then be to get first person interview-based accounts, from persons well-stabilised on typical medication as far as psychosis goes, but then switched to modern medications for several years.

(v) *Withdrawal of different antipsychotic drugs.* It is my belief from study of pharmacological literature that different antipsychotic drugs are not identical, regardless of the differentiation into “typical” and “atypical”. This belief is confirmed by personal experiences on withdrawal of different medications, where subsequent subjective experiences, and their time-course of emergence are different. Another project, perhaps conducted along with project (iv), above would then be to interview persons who have long experience of taking different antipsychotic drugs, and (no-doubt) periodic attempts at withdrawal from them.

(vi) *“Hearing voices”: Understanding is healing.* For people who hear voices, the fact of hearing voices (rather than experiencing inner verbal thoughts, which is more normal) may be distressing (regardless of what the voices are actually saying). If a robust explanation of the fact of hearing voices can be obtained, and conveyed to voice-hearers in non-technical language, it may relieve their distress. My own theoretical work on this suggests an explanation, based on basic neuroscience, and I have already tried, with a few voice-hearers, to offer the explanation, to help reconcile them to the experience. Feedback so far has been encouraging. I am currently trying to arrange for this to be done more formally, with video-taping of such sessions, so that the principles and practice of what I am doing can be discussed with mental health professionals.

#### (c) PHARMACOLOGY

[see also projects (iv) and (v) above]

(vii) *How wide is the range of individual optimum dose for antipsychotic drugs?* Clinical experience suggests that the minimal-effective or optimal dose of antipsychotic drugs varies from patient to patient by ten- or even twenty-fold between the most and the least sensitive. Almost nothing is published on the range of variation of sensitivity, despite these drugs having been used for more than 50 years. (Dose-finding studies report aggregate rather than individualised results.) To document it needs careful longitudinal study of a few widely-prescribed drugs in a number of individual patients, where psychotic relapse on dose reduction, and restabilisation on increase is well documented. In New Zealand, I am informed that case notes are rarely good enough for this to be done retrospectively. The project might therefore need to be done prospectively, especially in people still in institutional care, where good documentation is possible. However, another approach, at the community level, would be to conduct interviews with well-stabilized, thoughtful patients, (probably in the middle years of life, or elderly) about experiences with these medications. Some may be able to document quite precisely the relation between dose reduction and psychotic relapse.

#### (d) PREVENTIVE PSYCHIATRY/EARLY INTERVENTION

(viii) *Trait markers and preventive approaches in psychiatry.* Research on schizophrenia clearly shows that, in addition to active psychotic states, there are many non-psychotic trait markers of an underlying predisposition. The distinction between state and trait aspects of mental disorders may apply to other disorders (bipolar disorder, depressive

disorder, anorexia nervosa etc) although not yet defined so well as in schizophrenia. In schizophrenia, trait markers are generally assessed with methods of experimental psychology. A doctoral student of mine (Kate Ball) is about to submit a thesis in which an instrument was developed and tested, based on simple statements about everyday habits, preferences, problems and areas of above-normal ability, to assess the non-psychotic traits of schizophrenia. The results show that the instrument has the potential, if adapted for use in adolescents, to screen and to some extent predict risk of psychotic breakdown. This approach to early detection has not yet been widely explored. To develop the instrument to the point where it can be *used* in such a context would be a long process where hard ethical issues as well as scientific ones should be addressed. The significance here is that the same method could be employed (and probably in the same project) for screening for risk of a variety of mental disorders of the “neuro-developmental” type, with onset in adolescence or early adulthood. This would involve collaboration with community groups over a number of years, not only to recruit young participants from groups at elevated risk, but also to engage in transparent discussion of ethical issues, at an early stage.