

**Ethics of Screening for Risk of Mental Disorders:  
Discussion. 2.00 pm Tuesday 19<sup>th</sup> November 2013  
NZSRG meeting, Auckland Medical School.**

*Origins of the Discussion:* This discussion grew from my own long-time interest (going back to the 1970s) on the merits of early detection and early intervention for incipient psychotic disorders. This interest has however been qualified in more recent years by my growing awareness of many difficulties in implementing such programs, related to both ethics and detailed practicalities. The title for the discussion was about mental disorders generally, but the focus naturally was on more serious disorders (schizophrenia, bipolar disorder and related conditions), and, as far as schizophrenia is concerned, implies that screening might be carried out in the years before onset, that is early teenage years.

*Wayne Miles's summary:* Wayne, the chair for this session, apart from being an experienced psychiatrist, is also a member of the National Ethics Advisory Committee. He sees ethics as the way to understand and evaluate the "moral life" in professional practice and in other settings, not a way for institutions or organizations to "protect themselves from risk". In this context, our discussion was intended to focus on the morality of screening, encompassing both general principles and person- or group-specific issues, not so much on the legality of screening (although legislation is sometimes relevant), or on cost-benefit analysis of specific programs. Wayne commented afterwards that "the discussion regarding ethics of screening for risk of mental health disorders was wide ranging and covered a multitude of linked and sometimes competing principles. . . .A summary from any one of us must contain our personal biases, with differing views dependent on different experiences". The sharp example given was, on the one hand, the views of family members whose son/daughter has committed a serious offence whilst unwell, contrasted with views of a person who had traumatic experiences in a supposed treatment setting. Despite strong feelings on issues discussed, many participants could distance themselves from personal experiences sufficient to see the merits of diverse arguments, even if they were competing; and so the tension existed as much within individuals, as between them. My own comment after the discussion was that I felt a sense of "information overload", and Wayne suggested that, given the diversity of points made, that would have been a universal experience. Wayne did not see (and indeed did not expect) any particular underlying outcome from the discussion, except to say that the ethical considerations *are* important; and that it is unlikely there will be "one size which fits all". In so far as many of us simultaneously embraced arguments for and against, none of us had a clear view of the right answer, except that there was a need for as many people as possible to be aware of the conflicting pressures. The fact that there are usually a number of competing considerations means we all need to be alert to - and engaged in - the discussions about who is screened, by what method, by whom and for what purpose.

*Arguments in Favour of Screening for Risk Mental Disorders.* After Wayne introduced the session I spoke of my own experiences, and the conclusion I had reached by the mid-1970s, quoting this passage from something I wrote at the time:

“What an arduous and dangerous journey it was for me before anyone could prescribe drugs in the right group! . . . In so far as this illness should be thought of in biological terms, an adequate treatment was available. What was missing was an adequate diagnosis. An important aim for research therefore seems to be the discovery of an objective means of correct diagnosis. And when that has become possible, the idea of preventive treatment for those at risk, might be worth considering”.

I added however, that I now qualify most of what I wrote then, and do not support the idea of pre-emptive medication before someone is clearly on the verge of a psychotic breakdown.

Florence Leota supported my line of argument on the basis of her own experiences – of a son who, in retrospect, was becoming unwell years before a diagnosis was given, and whose life (and hers) could have been immeasurably helped, had it been possible to identify the problem, and intervene effectively at an early stage. Others present spoke of a need/desire for early detection so that families can understand more about what they are dealing with, and perhaps have more information on how to address difficult behaviours, and minimize the likelihood of negative outcomes.

*Arguments Against Screening for Risk Mental Disorders.* In my introduction, I also spoke of dangers of early screening. Some of my concerns were general ones, such as the question of whether truly informed consent could be obtained from young people in early teen-age years. I had heard that there is an ethical guideline - and I was not clear how widely this is accepted - that parents should not give consent on behalf of their children. A similar issue may arise here; but, given this, one should then ask if young people in early adolescence - who do not yet know much about themselves or about human nature generally, let alone about abnormal psychology - can give truly informed consent?

I also spoke of my awareness of uncritical over-enthusiasm for preventive medicine, and “early intervention” as a fashionable buzz-word, without cool appraisal of advantages and disadvantages, costs and potential benefits; and, in other areas of medicine, there are well-documented examples of hazards of such over-enthusiasm (over-diagnosis of supposed breast cancer; in Britain, over-diagnosis of early-stage dementia, in New Zealand recently awareness of misjudged screening for rheumatoid heart disease; and BMJ has recently been running a series of articles under the heading “too much diagnosis”).

Many of those present expressed concern about potential harms of ‘labeling’ in terms of psychiatric diagnoses, that it could have an unnecessary negative impact on someone. For instance, if a person was identified as at “high risk” for developing schizophrenia, what might it mean for them personally? Is there risk of setting people on a self-fulfilling course, because they internalise the label? - “I’ve been told I’m such, so I’ll act in the manner dictated by that diagnosis and I can’t avoid it”<sup>1</sup>. Others spoke of stigma associated with psychiatric labels, especially schizophrenia, and how easy it was to switch from seeing a person as having experience of a disorder to their being *defined*

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<sup>1</sup> To me, this seems very plausible. The actual manifestations of psychotic disorders do vary from one culture to another, as if to fit cultural stereotypes of “what it is to be mad”.

by the diagnostic label.

At this point, I think I referred to three principles which emerged from the debate in San Francisco, when it became possible to screen for someone who was HIV-positive. Who should be screened, and under what conditions? The three principles were: (a) The test should be voluntary; (b) There should be written consent; (c) Legislation was passed to make it a criminal offense to break confidentiality on test results. Without such safeguards, it was judged that it would not be acceptable to the public. The politics relating to this policy was extremely intense<sup>2</sup>, but was more open and transparent than any debate of similar issues I have heard in New Zealand.

Views on this at the NZSRG meeting were diverse. Some thought that diagnostic labels can be useful to help navigate health systems, to access what care is available (sometimes in terms of official administrative criteria needed to gain access). Labels also provide pathways to self-education, and to advocate for support and additional resources, without using it to define oneself, or one's child within that limited context.

Some other parts of the discussion made assumptions about a number of interlocking questions: the stage and age at which screening might be conducted, who should be screened, the methods to be used, how reliable the screening method should be before it should be used, and what intervention might be offered for those thought to be at risk. If any method reached a stage where implementation was to be envisaged, a cool look at cost versus benefits (including looking at the financial side) would also be essential.

*Stage at which screening/intervention is best conducted.* This question was not explicitly dealt with on the day, but in principle screening could be carried out at three different stages:— (a) well before any clear problems have arisen; (b) in the “prodromal phase”; or (c) after illness onset (to reduce duration of untreated psychosis). I take it here that there is no problem with the third approach, reducing the duration of untreated psychosis (although the ways to do this may be debated). Pat McGorry's approach is to identify emerging problems during the prodromal phase, using clinical data, perhaps supplemented by genetic screens, biomarkers etc.

*Level at which screening/intervention might be delivered:* Screening might be envisaged to occur at three different levels: (a) Mass screening and intervention of a whole age group; (b) screening and intervention of selected at-risk populations; or, (c) the same principles internalised in the thinking of every clinician, to be delivered one-on-one as needed. Many in the discussion seemed uncomfortable with the idea of screening at a whole-of-an-age-group level. The example I had given was screening 4-5-year-olds as part of a *B4 School* health check for behavioural and emotional difficulties. The same arguments probably apply also to teenagers in relation to psychotic disorder, where there are serious issues of both adverse impact of screening, problems of false positives and cost/benefit ratio.

As a selected at-risk group, adolescents are the obvious target for incipient psychotic disorders, but how, and in what setting? . . . through schools? . . . or where else? In principle it might be possible to screen earlier using biological or psychological markers, but none are yet available, and this suggestion may be making more out of the genetic

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<sup>2</sup> See Siplon, PD (2002) *AIDS and the Policy Struggle in the United States*. Georgetown University Press, Washington DC.

evidence than it can honestly bear. However, screening directed at 14 or 15 year-olds, *already accessing health systems*, and showing some signs of distress, or whose behaviour has “changed”, or becoming more withdrawn or disassociating themselves from things that previously provided enjoyment, might be more appropriate.

Should this be best seen as a deliberate screening program for a targeted group, or a service provided one-on-one in routine clinical encounters? Most people agreed that there is not one method that is totally acceptable at present, but perhaps a combination of these two approaches might have merit. Early detection and intervention as a part of regular clinical services would probably mainly avoid the difficulty of informed consent in a more formalized early detection/intervention program.

*Possible Methods of Screening.* There was limited awareness of how early detection and intervention might effectively work. As an example of what might become possible for detection even before the prodromal stage, I described Kate Ball’s doctoral thesis work. This example was given mainly to illustrate what might be possible, and also the difficulties in such endeavours. She and I developed an instrument with 96 items about everyday experiences, preferences or aspects of daily life which might be different from normal. All were quite innocuous items, based on my own theories of the biological basis of non-psychotic traits of schizophrenia. Kate used the instrument on several hundred people, including about 85 with a confirmed diagnosis of schizophrenia and matched people from the general community. Over half of the items gave statistically significant group differences in the direction predicted by theory, with hardly any counter-theory items. Any single item was a poor predictor of group membership, but when the best 13 items were used together, their combined predictive power gave correct group assignment in about 85% of cases for both the schizophrenia and control groups. This is as good as can be achieved in research conditions using the full range of psychotic symptoms in conventional diagnoses. Participants in Kate’s work were in the middle years of life (age 25-50). An obvious next stage might be to revise the instrument for use with adolescents, screen a cohort of young people known to be at heightened risk (perhaps because they had other family members with the disorder; perhaps referrals from primary health or early intervention services), follow them up for 10-15 years, and find who becomes ill. Then one could look back at the original data to discover which combination of items were the best predictors. Then . . . one might have a useful screening instrument, not 100% accurate, but as good as many existing screening programs. Well, that is the theory. . . . but of course severe practical difficulties, and ethical dilemmas might stand in the way of the project, not only in implementing it, but even in the ultimate objective itself.

A major issue is the predictive power of a screening tool, and getting the right balance between the proportion of false positives and false negatives. Not all people with early symptoms or evident risk factors go on to experience further symptoms or disorders. One might accept a high proportion of false positives (“over-diagnosis”) if the screening tool is innocuous, the danger posed by a diagnosis is severe (eg bowel or breast cancer screening), and the success rate of known interventions high. If screening poses its own risks or discomforts, if the danger is less severe, and intervention only moderately successful, one might accept screening that missed a lot of cases, but made few false positive predictions. Alternatively, one might avoid trying to make any predictions well in advance of their possibly coming true, in view of their uncertainty, to wait until earliest

actual symptoms appear before intervening.

The dilemma - on the one hand the pain of *not* getting help, especially in the prodromal phase, and on the other, of misinterpreting (or over-reacting to) adolescent behaviour - was illustrated by an anecdote: A young man suspected of taking IV drugs (as his father saw it): The evidence:- He had sold his bike and raced inside to put on a long sleeved shirt, which was interpreted as raising money for his habit, and concealing the site of IV self-injection. The actual story was of a responsible young man who had lost his job, so he sold his bike to pay off debts, and used leftovers to get a tattoo and was covering that up! A powerful story about asking, but not assuming.

Apart from issues of balancing false positives and false negatives in any screening method it is likely that the items in the instrument Kate and I devised might identify other problems - perhaps as different combinations of items, or at the other extremes of scores for particular items; and the whole approach, supplemented by additional items, might then be used for screening for incipient problems far more widely than envisaged in Kate's work (aimed at schizophrenia). There thus might be a rationale for "spreading the net for screening more widely". But should it be done anyway?

For schizophrenia and related disorders, we have no well-validated predictive instruments at present, so we cannot estimate the right balance between false positives and false negatives for any screening tool. However, we can identify significant risks of screening: The impact on a person if they are wrongly identified as at risk. This includes stigma and self-stigmatization, if the person him/herself knows the test result, and of overt discrimination, for instance by employers, life insurance companies (etc.) if they know the test results. The third of the guidelines coming from screening for HIV status is relevant here, if suitable legislation could be passed. To have been found "at risk" may also mean that someone may be treated as if they actually have the relevant problem. It should not mean this, but it might be hard to avoid the shift. That this is possible, again suggests that it might be better to wait until an obvious mental health issue emerges, rather than trying to predict too soon.

*By Whom and in What Setting?* The point was made by some that screening and early intervention methods can be unobtrusive, carried out by occupational therapists, social workers, youth workers, school guidance counsellors, etc (as well as by GPs, and other medical professionals). Some combination of screening of at-risk groups, and, one-on-one screening as needed seems to follow from this. A clinical psychologist spoke convincingly about the second of these as his preference, as the way to deliver basic principles of early detection and intervention (and he convinced me). Innocuous methods such as a version of the Ball/Miller questionnaire approach might still be useful in this setting. If so, there would be much to gain from revising the instrument for use with adolescents, and trialing it, even if it is not to be used in a mass screening program.

*What interventions could be offered?* We talked about the purpose: What would happen, for instance, if Guidance Counsellors were involved in screening? What interventions would help most? If someone is in early (prodromal) stages of actual illness, referral to specialist services (perhaps a specialist early intervention clinic) may be best. For those showing signs of distress and impairment, which cannot yet be defined, except (very roughly) with a screening tool such as that just described, other forms of

innocuous intervention may be appropriate. These include establishing helpful liaison between a young person and a mental health service, to be used if and when a person starts to become more obviously unwell; or giving a young person an idea of more serious signs of impending illness for future reference. . . . “If you experience this . . .or this . . .or this . . .come and see us right away. We really would be able to help.” Help may be offered in terms of mastering associated issues for teenagers about socialising.

*Ways to minimise harm or risks of screening:* Several important points were raised:-

(i) Before any screening processes should be implemented beyond the research stage, proof would be needed of the benefits of intervening early in those assessed to be at risk. At present, we heard, for schizophrenia, there is some evidence for this, but it is not yet wholly convincing.

(ii) On the danger of stigma and labelling in terms of “at risk status”, associated particularly with “false positive” identifications, it was pointed out that, for a person to be so labelled reflects bad practice anyway, treating the person as the same as the diagnosis, not as a “person who has the diagnosis”.

(iii) There was strong feeling that if any screening was undertaken, it was important to ensure that there were resources/systems in place to respond prior to screening and that needs could be clearly identified so any intervention offered could be targeted appropriately.

(iv) One opinion was expressed thus: “I think my personal reflection is that if any type of screening were to be undertaken, it would require a great deal of sensitivity from the workforce and an ability to begin to grasp the complexity and nuances of the potential impact for an individual and within their family.” This is a significant condition: Best practice may be a long way from average practice.

*Public Relations Aspects:* This was linked to a general societal understanding (or lack of it) about mental health issues generally and specifically about what a diagnosis of schizophrenia actually means. There was support for using diagnostic labels to help individuals navigate the health system, and also for work advocating for support and additional resources, without using it to define either oneself, one’s offspring, or any diagnostic group, in that context. A careful strategy would be needed to get the former, without disadvantages of labeling. All this was linked to a need for improved general societal understanding about mental health issues generally and specifically about what a diagnosis of schizophrenia actually means.