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Developing the Programme

The World Psychiatric Association (WPA) Global Programme against Stigma and Discrimination because of Schizophrenia was started in 1996 when I became President of the WPA. Initially, we saw it as a policy initiative, not as a specific programme.

My colleagues from the Executive Committee of the WPA (in particular, Professor Juan Jose Lopez-Ibor, then President-Elect of the WPA) and I spoke with possible supporters of an operational arm to the anti-stigmatization policy, including staff of foundations, government agencies, directors of health programmes and representatives of pharmaceutical companies.

While many lauded the initiative, few expressed an interest in joining the effort and even fewer were willing to contribute to a programme in a concrete way. Not so Mr R. Postlethwaite, at the time Vice-President and Director of the Neuroscience Department of the Eli Lilly and Company. He, like others expressed his strong approval of the idea but also sought support from within his company. Dr M. Xilinas, at that time working with Eli Lilly and Company in Geneva, provided invaluable help in the administrative arrangements that followed and WPA soon received a formal confirmation that Eli Lilly would provide some funds to support the initiation of the programme. This enabled us to start the Global Programme and to help its development in the first set of countries that were keen to join the effort.

Thus, in 1996 we brought together a group of people whom we felt could help in the development and implementation of a programme against stigma. The group that met in Geneva included psychiatrists, social scientists, communication experts[1] as well as representatives of family and patient organizations, and government representatives. It reviewed the preliminary plans for the programme, and identified individuals and organizations that could be focal points for its development at country level. The group was invited to address several key, strategic questions including the following:

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[1] Among them Mr H. Schulze who remained fully involved with the programme throughout and is a co-author of this book.

1 What conceptual framework should the programme adopt?
2 Should the programme be directed to stigma related to a particular disease or to mental illness in general?
3 Who should carry out the programme on a national level?
4 How should the activities composing the programme be selected?
5 What administrative structure should the programme have? Should it be managed by the WPA Executive Committee, outsourced to an agency independent of WPA or carried out by some other arrangement?
6 How long should the programme last?
7 What relationship should be established with other anti-stigma activities underway at the time or initiated at a later date?
8 How should the success of the programme be evaluated?

The guidance received from the group concerning these issues was invaluable in the finalization of the plans for the programme. These will be briefly reviewed, under the headings of the questions presented above.

What conceptual framework should the programme adopt?

Since the early work by Erving Goffman on stigma (Goffman, 1963), many definitions of stigma have been put forward. For the anti-stigma work of the WPA, elements of earlier research and experience were synthesized into an operational model that describes the vicious cycle of mental illness, its stigma and consequences (Sartorius, 2000).

This model has several advantages. First, it acknowledges that 'stigma' should be viewed as one of the important disadvantages created by illness and making it more severe. Second, it stresses that stigma is part of a vicious circle and that it will continue to grow unless the circle is interrupted.

Third, and this is perhaps most important, the cycle identifies access points where interventions might be undertaken and where there is room for action by professionals, social services, hospitals and community agents. The model further shows that there is no one who could not contribute to fighting stigma and its consequences.

The vicious cycle of stigmatization

The model implies that a marker (a visible abnormality) that allows the identification of a person can be loaded with negative contents by association with previous knowledge, information obtained through the press, and memories of things seen in movies or heard in the community.

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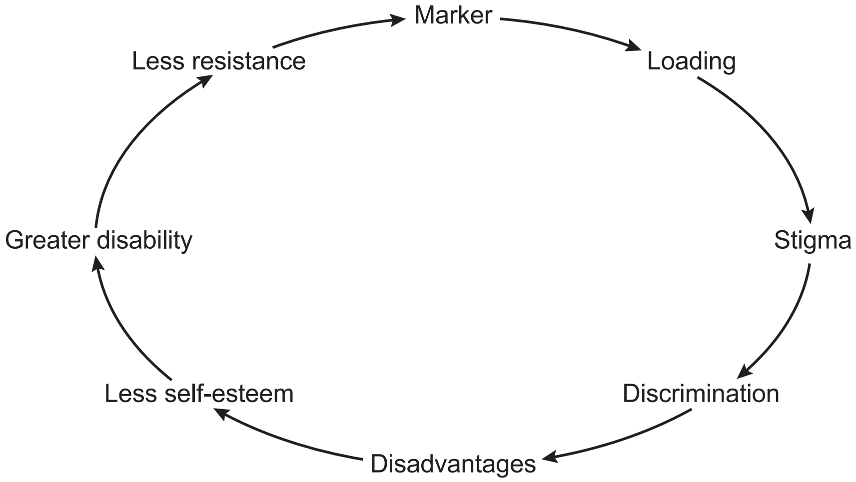


Cycle of stigmatization for the individual.

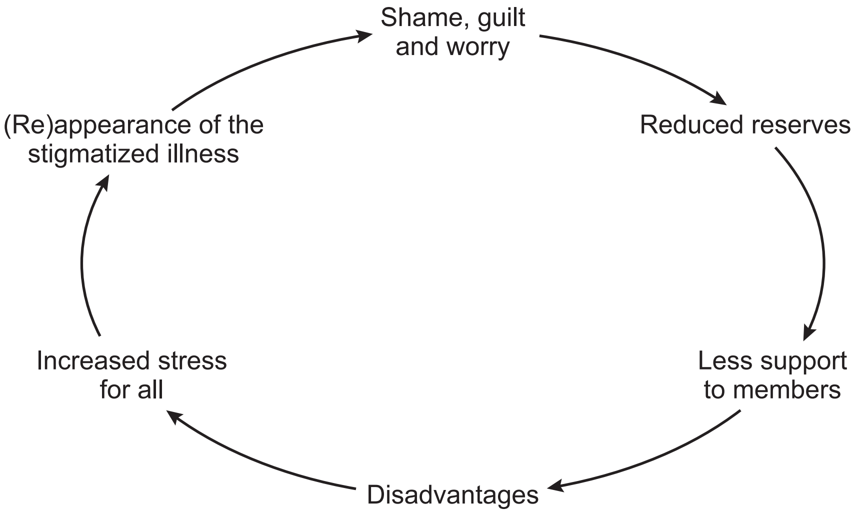
Once the marker is loaded in this way, it becomes the stigma and anyone who has it will be stigmatized. Stigmatization may lead to negative discrimination which in turn leads to numerous disadvantages in terms of access to care, poor health service, frequent setbacks that can damage self-esteem, and additional stress that might worsen the condition of the consumer, and thus amplify the marker, making it even more likely the person will be identified and stigmatized.

This cyclical model also implies that an intervention at any point might stop that process. Thus, if it proves impossible, for example, to remove stigma it is often possible to focus on removing discrimination by legal and other means.

In other instances, it might become possible to improve treatment and rehabilitation services to a level at which they can offer help to the consumer and the family, and support them in living with the illness. Sometimes it is possible to remove the marker – as in the case with extra-pyramidal symptoms that can appear as side-effects of certain type of medications, but do not appear with other treatments. In some instances, there is enough time and opportunity to educate the community in a manner that will decrease the negative loading of the marker.

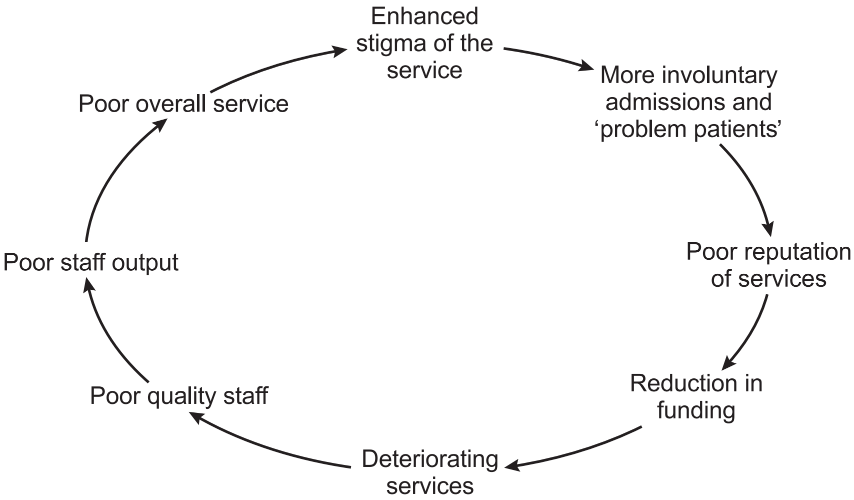
A similar cycle can be constructed for families and caregivers. Yet it differs in significant respects.

The shame, guilt and worry that family members can feel adds to stress on the group. This might be just the parent and the child with the illness or encompass a much larger extended family, close friends, coworkers and/or neighbours. The increased stress may reduce the individual's or group's reserves – in terms of emotional and often financial resources, and in terms of time that can be spent with members of the family who are not suffering from the illness. The reduced reserve



Cycle of stigmatization for the family.

means that family members will have less support in times of need and that as a consequence links among family members can be broken or perhaps even irrevocably severed. This increases the stress for all members of the family or social unit which may lead to a relapse or reappearance of the stigmatized illness. In a manner similar to the circle described for the person with the illness, the family may also lose self-esteem and confidence in itself which makes care more difficult and possibly less effective for those members of the family with the illness.



Cycle of stigmatization for mental health services.

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Mental health professionals may not be surprised to see this vicious cycle mirrored in the area of mental health services as well.

Family members and those who have developed early symptoms of the schizophrenia, may avoid seeking psychiatric help for a variety of reasons. This may be due to misunderstandings about the illness, its course or the treatments that might be used. But as a number of groups in the WPA programme found in country after country, this may also be due to previous stigmatizing experiences (e.g. dismissive treatment in a hospital emergency room that might include accusations in front of family members of the use of illegal drugs).

Whatever the reasons, by not seeking early treatment, patients may later be admitted involuntarily often with severe forms of acute psychosis. As a consequence, the psychiatric unit or emergency room can come to be seen by other hospital officials and by the population as a holding area for 'problem patients' for whom psychiatric care can do little.[2] The deterioration in reputation of the services in the hospital leads to a reduction of funding.

With a reduction in funding comes a deterioration in services and increasing difficulty to maintain or hire good-quality staff. Poor performance by staff contributes to the overall negative perception of the psychiatric service. As the reputation of the service deteriorates, as word spreads of these poor services, those who may be experiencing early symptoms – or their family members – further stigmatize psychiatric services and delay treatment, perpetuating the vicious cycle.

The impact of the cycles we have described extend beyond those immediately involved at each stage. These cycles reinforce stereotypes, increase cynicism in members of the community, and further diminish hopes of those living with mental illness that things will improve.

These cycles of stigmatization are not isolated from each other. A family that has lost hope and self-esteem will find it more difficult to seek help and realize its right to help. This will not only worsen the situation but also contribute to the perception of weakness of the family and all of its members, and lessen their ability to become active participants, along with the healthcare professionals, in the recovery of the family member with schizophrenia.

These interrelated cycles of stigma and discrimination because of mental illness illustrate specific points for intervention. The next question becomes one of how finely focused the interventions should be.

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[2] With the current tendency to reduce the number of in-patient facilities, it is often necessary to admit severely disturbed chronic patients with comorbid conditions, both physical and mental (e.g. drug abuse). This further reduces the number of beds available to the service and heightens the threshold for admission for those with early forms of illness who would particularly benefit from appropriate help and treatment.

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Cultural differences between industrialized and developing countries

In the 1970's, the World Health Organization (WHO) carried out a major international collaborative study on Schizophrenia (International Pilot Study of Schizophrenia, IPSS and WHO). The study demonstrated that schizophrenia could be found in all nine countries studied (US, UK, India, Colombia, Nigeria, Denmark, Czechoslovakia, USSR and China); that the incidence of schizophrenia did not show much difference among countries, and that the course and outcome of schizophrenia was better in *developing* than the developed countries. Other studies undertaken in the same countries (and some others) confirmed these findings (WHO 1979, Sartorius 1996). The explanation of these findings evaded the investigators: they examined the frequency of stressful events for patients and expressed emotions of family members but the new findings did not help. It might be that the different forms and levels of stigmatization in Third World countries made the difference. It is hoped that a study to explore this hypothesis will be carried out.

Focus on schizophrenia or on mental illness in general?

There are strong arguments for either of these two options. It could be argued that taking all mental illnesses as a target might – if the programme is successful – help incomparably more people than the prevention or removal of stigma concerning a single disease such as schizophrenia. A point in favor of the broad focus could also be that the general public does not make a distinction between mental illnesses and that therefore engaging support of a wide section of the population might be more difficult if a psychiatric label is used in defining the focus of action. Targeting many mental diseases, it was felt, might help to engage a larger number of patient and family organizations. The question of equity also arises if only one disease is selected as a target for action: why should other illnesses not receive the same benefits of a campaign?

The WPA programme decided to take only schizophrenia as a focus for the programme. The arguments for it are numerous and seem to prevail over the reasons for taking all mental diseases as the target. Schizophrenia as a syndrome is a paradigm of mental illness and the general public when asked to describe a mentally ill person invariably lists symptoms such as delusions and hallucinations – hallmarks of schizophrenia – as the defining features of a 'madman'. Stigma related to schizophrenia is more pronounced than the stigma attached, say, to anxiety states or dementia of old age. A success in the prevention or removal of stigma related to schizophrenia would show the way to those fighting to remove the stigma of other mental illness and indeed of other stigmatizing illnesses (e.g. leprosy or syphilis).

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The selection of schizophrenia as the central focus of the programme makes the definition of the programme activities less complicated and the evaluation of success easier. Although some non-governmental organizations – for example the World Schizophrenia Fellowship – did excellent work to help people with schizophrenia there was at the time no coordinated international project by a professional or governmental organization that dealt with the disease and could attract the attention of the government and other authorities to the need to support care for people with schizophrenia and their families – arguably the most wretched group among those struck by mental illness.

Who should carry out the programme on country level?

Experience from previous studies and in particular from the international studies on schizophrenia one of us (Norman Sartorius) had coordinated while working at the WHO strongly suggested that the guarantee for a success of a study or other project at country level is not the commitment of the government or of an institution but *the decision of an individual or of a small group of people to carry out the project*. The support of the institutions and governmental agencies is helpful and often necessary but never sufficient. The programme thus expanded to countries in which there was a small group of people willing to lead the action and maintain it over years.

The groups that we sought were to be small. As a rule of thumb, we said, the group should be a size that would allow it go for a meal together in a single car. Such an action group was to ensure support of a larger group of patrons – persons of importance and influence – that could be invited to become members of the Advisory Group for the programme and were likely to be willing to meet at regular intervals (but not too frequently) to receive reports of the action group and to help it by advice, comment and influence to carry out the programme.

How should the activities of the programme be selected?

The advice of the group at the Geneva 1996 meeting was to develop a set of specific plans that would be offered to the action groups in the countries together with an estimate of the time necessary and allowable for the execution of each activity in the plan. This would essentially be what has been described as a collaborative project (Sartorius and Helmchen, 1981). It was felt that this would help to maintain the identity of the programme and facilitate the exchange of experience and evaluation.

As it turned out this advice was neither realistic nor very helpful. Consultations with the potential heads of action groups in the countries and with others involved in similar work indicated that a different strategy was necessary. This new strategy seemed dangerously similar to a plan for confusion as it turned out it became a hallmark of the programme and its most useful feature.

In brief, the strategy of the programme became the reliance on the advice of persons most directly concerned with problems related to stigmatization and discrimination. In each of the sites the first step of the action groups was an exploration of consequences of stigma and discrimination for people with schizophrenia, their families and others who were involved in the provision of care and in the rehabilitation of those disabled by schizophrenia and its consequences. This preliminary exploration usually resulted in a long list of complaints and problems reported by those concerned. The action group then examined the reports and divided them into those that were due to stigma and discrimination, and others that had little to do with them. Among the former group of problems the action group selected targets for action using several criteria: the probability that the problem can be resolved relatively quickly (the more difficult to resolve the less attractive was it for the programme, particularly in the beginning), the likelihood that the problem can be tackled by the action group (with the support of the Advisory Group), the availability of support for work on that problem – either in the form of influence or concrete support of an institution or agency.

The results of proceeding this way were that the programme sites have selected different targets for action and that the speed of their progress varies. This might be seen as a disadvantage, particularly for reporting about the programme and for its evaluation. These shortcomings are however significantly outweighed by the fact that it is easier to find support for the programme that is locally relevant, and that the action group and other participants in the programme knew that they were working on problems that were particularly important for their area. A moral advantage of this way of proceeding was also that action was harmonious with a main objective of the programme – that of contributing to the self-esteem of persons affected by schizophrenia by giving them an opportunity to decide on the course of action and participate in it, thus treating them as equal and making them partners in the programme development.

What administrative structure should the programme have?

The administration of a large-scale programme must be in a single location and the coordinating office has to function continuously from the same place. In view of the fact that the central office of the WPA was traditionally moving to the home site of the Secretary General, the office of the Global Programme against Stigma was separated from the WPA Secretariat and placed in Geneva. A Steering Committee of the programme was created to give its strategic guidance and streamline activities. It was chaired by the President of the WPA and composed of five persons, of whom one was the Scientific Director of the programme. The Office of the programme maintained close collaboration with the Secretariat of the WPA that was also keeping the accounts and ensured auditing. The Steering Committee created four working groups (listed on page xv) dealing with:

1 the distillation of knowledge about schizophrenia and its treatment,
2 the rehabilitation of the patient, and the diminution of stigma and discrimination in the immediate surroundings of the patient,
3 stigma and discrimination in society at large,
4 the review of materials produced by the other three groups.

A web site was created in 1998 to leverage the information already developed and also to provide a global 'brand' – a unified look-and-feel – for the overall effort.

The chairpersons of the action groups in the countries functioned as the parliament of the programme in that they examined, discussed and approved proposals for programme activities reaching across the sites.[3] An instruction guideline was drafted giving a sequence of steps in the programmes at country level. (See Appendix I.) The sequence – for example concerning the formation of the action group, the collection of information, the establishment of the Advisory Group – was recommended for all sites: the timing of the steps as well as the selection of activities at country level was left to the decision of the Local Action Groups and their partners. Annual meetings of all the Heads of sites and biannual meetings of the Steering Committee often together with the Chairpersons of the working groups also served to facilitate the coordination and conduct of the programme.

How long should the programme last?

The Geneva meeting was divided on that question: while some thought that the programme should have the nature of a campaign lasting at the most 2 to 3 years, others felt that the programme should have a longer perspective. The advocates of the former drew attention to the fact that the funding available to the programme were very limited and that planning for a long-term project without a secured source of funding and a strong institutional backing would be an exercise in vain. The advocates of the longer perspectives drew attention to the need for a lasting engagement in all efforts aiming to change attitudes and to the fact that the initiation and conduct of international projects takes a much longer time than activities at a one-country level.

In reality, and to the surprise of many, the programme continued growing and becoming stronger over the years. Now in its tenth year of existence the programme

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[3] For a listing of members of the Steering Committee, Working groups and Heads of sites, see xxi–xxiii.

still strongly attracts new groups and is expanding its activities. In some of the sites the tempo diminished, for a variety of reasons – personal, financial and political. The unavoidable attrition has however been much less serious than feared. The recognition of the fact that the decrease of stigmatization and discrimination needs a long time and that short campaigns can bring more disappointment and problems than no campaign at all also contributed to the credo that a programme against stigma must be planned to last for a number of years, much longer than other activities in the field of health.

What relationship should there be with other efforts dealing with problems of stigma and discrimination?

The WPA programme had the advantage that it could examine a variety of efforts to combat stigma and discrimination because of mental illness in various countries. Some of them were directed against a specific illness, others had a broad focus. Some dealt with mental illness only and others with increasing tolerance for those who are different. Most of them were short lasting, some had a solid backing of an institution or an organization, and others started independently and worked without much support. Each of these actions against stigma contained some useful message or experience that could be employed in building the WPA programme: none however was sufficiently close to it to require fusion or other arrangements nor was there much competition for funds or other resources with these programmes. The Geneva meeting therefore recommended that the WPA programme staff should assemble descriptions of as many programmes against stigma and discrimination as possible and ensure an exchange of information with those that were active. Making an effort to include already advanced programmes under the aegis of the WPA did not seem fair to those who developed their programme – because they might lose some of their visibility – nor useful to the WPA programme which had to develop its own strategy and tactics being, potentially the largest and most innovative programme in existence.

How should the programme be evaluated?

The question of evaluation of success attracted much attention during the Geneva meeting. The usual comparisons of achievements with the objectives seemed appropriate in some instances but not in others. The essence of the WPA programme was that it was not a multinational study but an action programme and a model from which others could learn. The second of these aims imposed the need for evaluation of the success of each of the component activities so that those who wanted to learn from the WPA effort could select those of proven usefulness