

REDUCTION OF STIGMA AND DISCRIMINATION BECAUSE OF SCHIZOPHRENIA

In 1996, the World Psychiatric Association (WPA) embarked on a Worldwide Programme to Fight the Stigma and Discrimination Because of Schizophrenia.

Stigma attached to schizophrenia creates a vicious cycle of alienation and discrimination for those who suffer from it and often for the members of their families. Stigma can become the main cause for social isolation, inability to find work, alcohol or drug abuse, homelessness, and excessive institutionalization, all of which decrease the chance of recovery.

To counteract stigma and prevent the WPA programme will aim to:

- Increase the awareness and knowledge of the nature of schizophrenia and treatment options;
- Improve public attitudes to those who have or have had schizophrenia and their families;
- Generate action to prevent or eliminate discrimination and prejudice.

The programme will establish an international network of individuals and centres united by their determination to act against stigma and discrimination and thus give people with schizophrenia a chance to live a life of acceptable quality. The network will facilitate the exchange of experience and learning; it will also be instrumental in the wide distribution of knowledge and in advocating for the interests of people with schizophrenia.

The programme will develop a variety of materials necessary to:

- Improve public information about schizophrenia
- Facilitate community involvement
- Enhance knowledge of mental health and healthcare workers about schizophrenia and its treatment
- Educate and support family members and friends
- Change legislation and ensure equitable healthcare coverage

This programme is being developed by experts from many countries involving representatives of non-governmental organisations (e.g. associations of patients and their families), and governmental organisations. Its structure includes:

- A Steering Committee overseeing the programme chaired by Norman Sartorius, president of the WPA; the members of the Steering Committee also serve on the four technical committees to facilitate coordination and exchange of information;
- A Committee on the Identification and Treatment of Schizophrenia assembling information on diagnosis and treatment of the disease;
- A Committee on the Reintegration of Patients and their Families in the Community concerned with strategies for reintegrating those with schizophrenia into their families and the community;
- A Committee on Strategies to Reduce Stigma and Discrimination producing materials and proposals for fighting discrimination and stigma at a societal level;
- A Review Committee that will annotate, integrate, and streamline the materials produced by the other committees and by national groups.

The programme will be distributed throughout the world and will be sensitive to differences between cultures by combining internationally and locally produced materials. Materials will be prepared in local languages, with slides and handouts for teachers, videotapes, television programming, interactive computer instructional software, and sample materials for use in public lectures and reference materials. An Internet distribution of the programme is being considered. Several articles describing the development of the programme have been published (Sartorius 1997 a, b, and c). The effectiveness of the programme will be assessed on an ongoing basis (Sartorius 1997).

The programme presented here contains two parts: an outline of steps for action programmes and a summary of knowledge about schizophrenia annotated for use in programmes against stigma and discrimination. The programme document should be used in conjunction with the description of programmes undertaken at the national level and with the 'tool kit' containing materials that can be useful in programme implementation.



- [1] Sartorius N. Fighting schizophrenia and its stigma: A new World Psychiatric Association educational programme. *Br J Psychiatry* 1997;170:297.
- [2] Sartorius N. Fighting schizophrenia and its stigma: A new World Psychiatric Association educational programme (in German). *Neuro-psychiatrie: Klinik, Diagnostik, Therapie und Rehabilitation*. Band II-1997.
- [3] Sartorius N. Fighting schizophrenia and its stigma. *Community Mental Health* 1997; 33(4): 373.

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The programme also relies upon the technical advice of
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of Substance Abuse, World Health Organization, Geneva.

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Organisation of the Programme Document

The programmer document is divided into three volumes.

Volume 1

Guidelines for Programme Implementation outlines a series of steps for developing a programme to reduce stigma and discrimination because of schizophrenia and includes an estimate of the time needed to complete each step. While it is expected that the time required may vary from site to site, it is recommended that sites follow the sequence as specified and complete all steps.

Volume 2

Information about Schizophrenia Relevant to Programme Implementation, contains facts about schizophrenia selected on the basis of their relevance to such programmes. In this part of the programme document, messages of particular relevance to the reduction of stigma and discrimination are highlighted in the margins. The information in Volume 2 will be updated regularly to reflect new research findings and the experience of those participating in the programme at different sites.

Volume 3

Description of Programme Implementation at Different Sites, contains a series of descriptions of stigma-reduction programmes conducted in participating countries. These exemplify how the outline provided in Volume 1 of the programme document can be implemented in a specific location and context.

This programme document has appendices that enlarge on points in the main text. These are given in parentheses in bold type.

VOLUME I

Guidelines for Programme Implementation

It is recommended that each site follow the steps in Volume 1; however, it is expected that the time taken to complete the steps will vary from one setting to another.

This part of the programme document describes how to develop and implement a local programme as part of the international effort undertaken by the WPA to combat stigma and discrimination because of schizophrenia.

The following chart lists all the steps involved in developing, implementing, and evaluating a local programme along with a proposed timetable for completion. Steps that are to be undertaken simultaneously are listed together at the same point on the timetable.

It is anticipated that the implementation of the programme, as indicated in the timetable, will take approximately 2 to 2½ years. It is, of course, recognized that the actual time needed to complete each step may vary from site to site; however, it is recommended that local groups complete each step in the order specified. The timetable is divided into the following major phases:

- I. Preliminary Steps
- II. Collection of Information about Programme Site
- III. Designing the Programme
- IV. Adaptation, Development, Pretesting, and Revision of Programme Tools
- V. Implementation and Monitoring of the Programme
- VI. Evaluation of the Programme
- VII. Planning Action after Programme End

| Weeks | Step | CHECK BOX | DATE COMPLETED | Weeks | Step | CHECK BOX | DATE COMPLETED |
|--------------|---|--------------------------|-----------------------|--------------|---|--------------------------|-----------------------|
| | I. PRELIMINARY STEPS | | | | IV. ADAPTATION, DEVELOPMENT, PRETESTING, AND REVISION OF PROGRAMME TOOLS | | |
| 0–6 | 1. Site Selection | <input type="checkbox"/> | _____ | | 26. Baseline Survey | <input type="checkbox"/> | _____ |
| 7–10 | 2. Identification of Local Project Coordinator | <input type="checkbox"/> | _____ | | 27. Selection of Available Media Materials | <input type="checkbox"/> | _____ |
| 11–12 | 3. Briefing of Local Project Coordinator | <input type="checkbox"/> | _____ | | 28. Agreement on Central Theme and Programme Concepts | <input type="checkbox"/> | _____ |
| 13–20 | 4. Establishment of Initial Planning Group | <input type="checkbox"/> | _____ | 65–68 | 29. Development of Message Concepts | <input type="checkbox"/> | _____ |
| 21 | 5. Planning Group Meets with WPA Representative | <input type="checkbox"/> | _____ | | 30. Decision on Production of New Materials | <input type="checkbox"/> | _____ |
| 22–24 | 6. Production of First Draft of Local Action Plan | <input type="checkbox"/> | _____ | 69–70 | 31. Pretest of Message Concepts | <input type="checkbox"/> | _____ |
| 25–28 | 7. Nomination of Local Action Team Members | <input type="checkbox"/> | _____ | 71–78 | 32. Development of Media Materials | <input type="checkbox"/> | _____ |
| 29–32 | 8. Invitation to Local Action Team | <input type="checkbox"/> | _____ | 79–80 | 33. Pretest of Materials | <input type="checkbox"/> | _____ |
| 33–34 | 9. First Meetings of Local Action Team | <input type="checkbox"/> | _____ | 81–84 | 34. Finalisation of Communication Materials | <input type="checkbox"/> | _____ |
| 35–38 | 10. Review of Draft Action Plan | <input type="checkbox"/> | _____ | | | | |
| | II. COLLECTION OF INFORMATION ABOUT PROGRAMME SITE | | | | V. IMPLEMENTATION AND MONITORING OF THE PROGRAMME | | |
| | | CHECK BOX | DATE COMPLETED | | | CHECK BOX | DATE COMPLETED |
| 39–46 | 11. Development of Site Description | <input type="checkbox"/> | _____ | 85–104 | 35. Consensus Building | <input type="checkbox"/> | _____ |
| | 12. Assessment of National Health/Mental Health Policies and Services | <input type="checkbox"/> | _____ | | 36. Implementation of Programme by Local Action Team Members | <input type="checkbox"/> | _____ |
| | 13. Review of Institutional Capabilities (including currently available mental health services) | <input type="checkbox"/> | _____ | | 37. Coordination of Implementation Schedules with All Team Members | <input type="checkbox"/> | _____ |
| | 14. Analysis and Description of Communication Resources | <input type="checkbox"/> | _____ | | 38. Maintenance of Programme Diary | <input type="checkbox"/> | _____ |
| | 15. Review of Prior and Existing Stigma-Reduction Programmes and Materials | <input type="checkbox"/> | _____ | | 39. Monitoring | <input type="checkbox"/> | _____ |
| | III. DESIGNING THE PROGRAMME | | | | VI. EVALUATION OF THE PROGRAMME | | |
| | | CHECK BOX | DATE COMPLETED | | | CHECK BOX | DATE COMPLETED |
| 47–48 | 16. Formulation of Long-Term Goals | <input type="checkbox"/> | _____ | 105–120 | 40. Post-test of Knowledge, Attitudes, and Behaviour | <input type="checkbox"/> | _____ |
| 49–52 | 17. Formulation of Short-Term, Site-Specific Objectives | <input type="checkbox"/> | _____ | | 41. Evaluation of Programme | <input type="checkbox"/> | _____ |
| | 18. Obtain Communication Consultant | <input type="checkbox"/> | _____ | 121–130 | 42. Review of Overall Outcomes | <input type="checkbox"/> | _____ |
| | 19. Selection of Target Audiences | <input type="checkbox"/> | _____ | | | | |
| 53–56 | 20. Agreement on Potential Messages | <input type="checkbox"/> | _____ | 130 | 43. Obtaining Additional Support and Funding | <input type="checkbox"/> | _____ |
| | 21. Selection of Media | <input type="checkbox"/> | _____ | 131–134 | 44. Documenting the Project | <input type="checkbox"/> | _____ |
| 57–60 | 22. Preparation of Work Schedule for Overall Programme and Team Members | <input type="checkbox"/> | _____ | | 45. Replanning for Future Development (Applying the Lessons) | <input type="checkbox"/> | _____ |
| | 23. Development of an Organisational Chart | <input type="checkbox"/> | _____ | | | | |
| | 24. Preparation of Budget | <input type="checkbox"/> | _____ | | | | |
| | 25. Contact World Psychiatric Association | <input type="checkbox"/> | _____ | | | | |

I. PRELIMINARY STEPS

There are two options for using the instructions outlined in this document. In some cases, local groups, psychiatric societies, or institutions may want to tailor this programme to their own needs and use it without officially participating in the World Psychiatric Association (WPA) Programme. We request that groups wishing to use the programme in this way inform the WPA of their efforts and provide appropriate acknowledgement of the WPA materials while conducting their project. Groups interested in becoming an official participating site in the WPA Programme should contact Professor Norman Sartorius at the Département de Psychiatrie, 16-18, Bd de St. Georges, 1205 Genève, Switzerland.

Being recognized as an official participating site requires an undertaking that:

- a) the programme steps outlined in this document will be followed.
- b) that the results of the programme and the experience gained will be fully shared with WPA Member Societies and with other participating sites.
- c) that published materials created as part of this programme should be submitted to the WPA to become a part of the archives of this worldwide programme.
- d) that, whenever possible, the Local Group should consult with WPA about publications destined for very wide distribution. When more than one programme is operating in a country, consultation between such programmes concerning publications is obligatory.
- e) that the use of the WPA programme materials and all help received from the WPA, from donors, and other participating sites will be fully acknowledged in all presentations of the programme.

1. Site Selection

Site: a town, city, province, country, or larger area in which the programme is implemented.

The following factors should be considered in selecting a site for the programme:

- **Geography.** A working group's efforts should be able to cover the area/region under consideration. Other questions to consider: Do local media cover this specific region? Are there times when the geographic or climatic conditions divide the area or disrupt communication? Are media from other regions likely to disrupt the programme?
- **Language.** Can materials be cost-effectively developed in a single language? Will programme participants be able to communicate using the same language? Are there significant minority group influences? Is the area socially cohesive?
- **Political and economic situation.** Is the site politically unified? Is the central governmental ready to support the programme? How willing are local political and financial entities to initiate and sustain the programme? Are there significant economic variations between different parts of the area?

- **Long-range potential.** Does this effort have a chance to continue in the area and to radiate to other sections of the country? Factors to consider in evaluating this question include: similarity of language; acceptability of results (cultural relevance); the existence of traditional exchanges between the programme area and other areas of the country or other countries.
- **Availability of Support.** Are a sufficient number of individuals likely to remain interested in the programme over a long period? Are there institutions or organizations likely to support the programme?

2. Identification of Local Project Coordinator

Once a site has been selected, a local coordinator for the project should be identified who has:

- Local acceptability
- Good standing in the community
- Access to an institutional base with a pre-existing infrastructure (e.g., adequate administrative support)

This individual must be willing to commit considerable time and effort to the programme for at least 3 years. It is also helpful if the coordinator or the institution involved has some experience in organising community programmes.

3. Briefing of Local Project Coordinator

The local coordinator should be briefed about the efforts of the WPA Programme to date. The coordinator should be given materials related to the project and should meet with members of the WPA Resource Group. The local coordinator should also be given the opportunity to visit a site in which the programme is underway. If the group will be officially participating in the WPA Programme, it is the responsibility of the local coordinator to maintain liaison with WPA.

4. Establishment of Initial Planning Group

The local coordinator will convene the Initial Planning Group. The Initial Planning Group should include a small number of individuals selected on the basis of their interest in the programme and knowledge of the issues involved, and their access to financial and political resources, consumer groups, and relevant local treatment organizations. This group should consist of four to five people (i.e., a number who are able to meet over dinner or travel in the same vehicle). Ability and willingness to work in a team is a key quality, given the long-term nature of the programme.

As soon as the Initial Planning Group is established, the local project coordinator will brief the group on the WPA effort in detail. The briefing should be given to the group when they are gathered together and sufficient time should be allowed to arrive at a common understanding of the project.

5. Planning Group Meets with WPA Representative

The WPA International Resource Group (IRG) consists of people who have worked on the development of the programme. The Group is chosen by the Steering Committee and includes members of the Committees for the programme, individuals who have been involved in the programme in different countries, and other experts. They provide advice and support and bring expertise from one site to the next.

After the Initial Planning Group has been briefed on the experience of the project in other countries, key issues important to success, and integration with global efforts, a meeting with members of the WPA International Resource Group (IRG) should be organised. The WPA/IRG representatives should plan on spending approximately 1 week's time with the Initial Planning Group (over a 2 to 3 month period) to ensure continuity and iterative dialogue. It is expected that each new site will have access to two experts of the WPA/IRG.

6. Production of First Draft of Local Action Plan

After this meeting with the WPA/IRG representatives, the Initial Planning Group should agree on broad objectives and develop a two- to five-page outline of tentative goals and proposed interventions including financial, budgetary, and administrative considerations. This document should contain a brief discussion of plans for establishing a Local Action Team. This planning document will then be reviewed by the WPA and future Local Action Team members.

7. Nomination of Local Action Team Members

The following groups should be among those considered in selecting possible nominees for the Local Action Team:

- Patient and family advocacy groups
- Legal professionals
- Journalists
- Health care professionals
- Legislators
- Influential members of the community (e.g., business leaders, religious leaders, etc.)

In order to best capture full community consensus, the planning group should consider sending invitations to those who might initially be considered adversarial, but whose ultimate involvement will be helpful.

The group should appoint a member of the group to create a programme diary in which the step-by-step process of the group is recorded.

8. Invitation To Local Action Team

Invitations to join the Local Action Team should involve a two-part process:

- A letter of invitation from the Local Project Coordinator
- A letter from the representative of the WPA Task Force welcoming the member when the invitation is accepted.

The Local Action Team should also begin to develop a wider network of advisers and consultants whom they can call on.

9. First Meeting(s) of Local Action Team

More than one meeting may be required in order to ensure the consensus and commitment of all members to the programme and to develop a single, unified effort. The agenda for the first meeting of the Local Action Team should include:

- Opening remarks
- Introduction of participants
- Description of overall WPA stigma-reduction programme and of experiences from other sites engaged in the programme
- Presentation of broad action plan
- Agreement on how the Local Action Group will work
- Tentative timetable of project

10. Review of Draft Action Plan

The Local Action Team should scrutinise the first draft of the local action plan that was developed by the Initial Planning Group. Enough time should be allowed to discuss and agree on the meaning of the terms used, the implications of the objectives, and the most acceptable ways of intervening in the community. The Team should also try to identify the time required and expected outcome for each step and create a checklist or worksheet to track their progress. Once this draft action plan has been agreed upon, the group should collect information necessary to adapt the plan to the local situation.

II. COLLECTION OF INFORMATION ABOUT PROGRAMME SITE

11. Development of Site Description

In Appendix A to Volume 1, you will find instructions for conducting a survey and a discussion of the types of information recommended for analysis. A full sample survey is presented in the appendices of Volume 3.

What follows are broad guidelines for collecting information. This process should involve well-informed members of the community as well as all other available sources of data. It will often be necessary to accept estimates since collecting the data in a systematic manner would be too time consuming. Exactly what information should be collected will depend on its relevance to the project. Note that the demographic information should not be averaged, but should be identified relative to population distribution (e.g., a country's literacy rate averages may hide important difference between urban and rural settings). It may be necessary to augment some of the information gathered with mini-surveys, focus group discussions, and other methods of qualitative research. (See Appendix A for a sample of the types of information that might be collected.)

After the information is collected, a narrative should be developed. This narrative should be an engaging profile and not simply a list of facts and estimates. It should include reasons for the programme as well as pointers for action (e.g., for selecting target audiences).

The site description should include:

- Demographics
- Education
- Economic Features
- Geography
- Social Characteristics
- Cultural Characteristics
- Attitudes Toward People with Schizophrenia

12. Assessment of National Health/Mental Health Policies and Services

In Appendix B to Volume 1, you'll find a sample survey for deriving information on health policies and services.

The team should assess the general health and mental health policies in the site area as well as the healthcare services that are currently available to those with schizophrenia, including the quality of inpatient facilities. The findings of this survey may be useful in developing messages that target inequalities in the existing healthcare delivery system. A sample survey of baseline information to be gathered concerning health policies and services is provided in Appendix B.

13. Review of Institutional Capabilities (including currently available mental health services)

The purpose of Step 13 is to create a database of names and addresses of people who are willing to help the project.

During the implementation of the programme, it may be possible to involve existing institutions. When this is undertaken, it will be important to establish who is able and willing to speak to target audiences. (For example, an educational authority might speak to teachers. The director of a hospital might speak to the doctors or gather them together for instruction.)

14. Analysis and Description of Communication Resources

A list of specific media and communication resources to consider is supplied in Appendix C to Volume 1.

The purpose of this step is to gather information about available media and communication resources. A list of specific resources to consider is supplied in Appendix C to Volume 1. This group should examine these resources and determine the most effective way to reach various target groups in the site area (i.e., which media should be used). It is especially helpful to identify and try to make contact with individuals who can be helpful to the project and who may have an interest in it (e.g., media executives and directors; medical editors and commentators for newspapers and local radio and television stations).

15. Review of Prior and Existing Stigma-Reduction Programmes and Materials

The Local Action Team should amass a full complement of materials suitable for an intervention against stigma that are already in existence in various media (e.g., films, posters, instructional leaflets). These materials should be sought from sources such as community agencies, churches, the healthcare system, the media, NGOs, and libraries. A list of materials produced in various countries is available upon request from Professor Norman Sartorius at the Département de Psychiatrie, 16-18, Bd de St. Georges, 1205 Genève, Switzerland.

III. DESIGNING THE PROGRAMME

16. Formulation of Long-Term Goals

After the analysis is completed, the next step is to establish long-term goals relative to awareness, knowledge, and action. The overall objectives of the International Programme are:

- To reduce or eliminate stigma and discrimination because of schizophrenia
- To improve the social acceptance, community integration, and quality of life of people with schizophrenia and their families and caregivers
- To increase the contribution of those with schizophrenia to society.

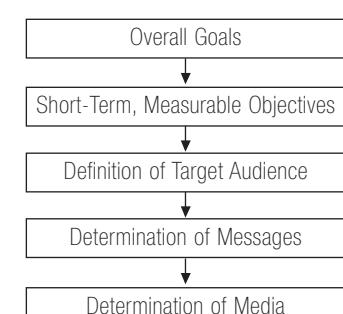
The Local Action Team should discuss these objectives and be sure that they have arrived at a common understanding of their meaning, and that they have found them relevant and acceptable for their community.

17. Formulation of Short-Term, Site-Specific Objectives

Short-term, measurable objectives that are specific to the site and relevant to target audiences should be formulated next. These objectives, which will form the basis for assessment of the project, should be specific, realistic, prioritised, and progress towards them should be measurable. They should be formulated in a manner that will allow for an evaluation of the programme and a comparison with baseline (see step 26).

Each step in designing the programme should be seen as part of an iterative process in which short-term, measurable objectives relate to long-term goals and to specific audiences, messages, and media (see Figure 1 below).

Figure 1 Sequence of Decisions



18. Obtain Communication Consultant

It is helpful at this stage to consult someone with communication expertise who has experience in performing surveys and planning media campaigns that are acceptable and successful in this particular community. This individual or company can help the team project the costs of the project (see Step 24).

Local groups will need to determine their goals and target audiences in relation to the cultural characteristics of the site. As a rule, the more sharply defined the target audiences, the easier it is to evaluate the effectiveness of the efforts.

19. Selection of Target Audiences

The target audiences should be segmented by demographic, geographic, social, psychological, or other relevant characteristics as defined in Step 11.

Examples of possible target groups include:

- Clinical officers/medical assistants
- Community leaders
- Emergency room physicians
- Employers
- Families of people suffering from schizophrenia
- General physicians
- Landlords
- Medical students and residents
- Nurses
- Police and corrections officers
- Politicians and legislators
- Portions of the general public segmented by age, income, or social class
- Psychiatrists
- Social service workers
- Students and teachers
- Traditional healers

20. Agreement on Potential Messages

Appendix E to Volume 1 lists examples of some of the kinds of stigma and discrimination that occur because of schizophrenia.

The Local Action Team should develop a list of possible messages to be delivered to the target audiences. Messages that overlap relative to the target audiences should be clearly identified. In the process of identifying messages, the group should explore:

- Frequent causes of stigma or discrimination (in the setting in which the programme will take place). Some examples of the kinds of stigma and discrimination that occur because of schizophrenia are given in Appendix E.
- Reasons for not getting treatment or other help.
- Common myths and misunderstandings.

Four categories of message should be considered:

- Messages to provide accurate information (e.g., schizophrenia is treatable)
- Messages targeted at an attitude, not a fact; these messages will have a more emotional component (e.g., acceptance of people with schizophrenic illness)
- Messages to improve people's skills in handling situations in which they may encounter people with schizophrenia (e.g., situations in which they would currently be unable to cope with unusual behaviour such as acute excitement in a public place)
- Messages intended to change behaviour (e.g., providing increased access to emergency care or employing a person who has had schizophrenia).

21. Selection of Media

The group should review target audiences to determine which are the most appropriate media to communicate to them. The communication consultant (see Step 18) should be helpful in doing this. Messages should then be reviewed relative to the medium being considered. For example, certain messages might not be appropriate for billboards. The team should do a pilot assessment of the effectiveness of various media for different target audiences (see Appendix F).

Appendix F to Volume 1 provides a sample of a pilot assessment of media effectiveness.

Appendix G to Volume 1 provides a press conference kit.

22. Preparation of Work Schedule for Overall Programme and Team Members

The work schedule should be organised to include the timing and sequence of each proposed action and a schedule for each Local Action Team member. The work plan should also be structured to allow flexibility in implementation. The schedule should include personnel, materials, production schedules, field work training, equipment, travel, and evaluation.

The Local Project Coordinator and Action Team should consider ways to ensure that their initial enthusiasm and motivation are maintained. For example, they should identify feedback mechanisms, set up regular meetings, and give members full responsibility for specific tasks so that they can feel true ownership of tasks they consider important. Using members of the Action Team as consultants for programmes at other sites may also help maintain motivation. Once the schedule is developed and agreed upon it may be helpful to hold a press conference to announce the programme to representatives of the media. Appendix G provides samples of materials that can be used for such a press conference. Members of the local team should be given an opportunity to speak about the tasks they have undertaken.

23. Development of an Organisational Chart

The organisational chart should be presented graphically and should indicate specific responsibilities and tasks as well as who reports to whom and how activities will be coordinated.

24. Preparation of Budget

Step One: Zero-Budget Exercise

The team should assume a zero dollar budget—that is, discuss actions that can be taken using existing infrastructure and public communication tools (e.g., public service announcements; inclusion in existing in-service training for emergency room physicians; using speakers at professional meetings and conventions to reach groups of public health professionals).

The participants themselves need to determine what their participation will be and how they might best use their expertise and contacts in the community to help achieve the goals of the programme.

Step Two: Determination of Baseline Expense

In this step, the team should determine what expenses are absolutely necessary for initial, low-budget action items to initiate and maintain the programme.

Step Three: Determine Budget

The team should then determine the price tag of other action items that are necessary to achieve the stated goals.

Step Four: Review of Budget, Goals, and Action Plan

The team should review the available budget—in relation to the timetable and action plan—and determine how best to use available funds for leverage. For example, money might be invested in a campaign to generate additional funds from community action groups and local businesses. The team should also initiate fund raising efforts. Suggestions for fund raising are provided in Appendix H.

25. Official Recognition from World Psychiatric Association

At this point, the Action Team should submit the materials they have assembled in Steps 1-24 and a description of the way in which the project will be implemented to the WPA and request recognition as an official participating site in the Worldwide Programme to Fight the Stigma and Discrimination Because of Schizophrenia.

The proposal should be sent to:
Professor Norman Sartorius at the
Département de Psychiatrie, 16-18
Bd de St. Georges, 1205 Genève,
Switzerland.

The proposal will then be considered for WPA sponsorship by the Steering Committee (during the trial phases of the programme) and by the Executive Committee (once the programme is released). Groups who would like to implement the programme without WPA programme sponsorship should also contact WPA to acknowledge that they are using material produced by WPA and inform WPA about the outcome of the programme.

Appendix I to Volume 1 provides general instructions on how to conduct a baseline survey. A sample of a baseline survey performed in Calgary can be found in Volume 3.

IV. ADAPTATION, DEVELOPMENT, PRETESTING, AND REVISION OF PROGRAMME TOOLS

Many of the steps described in the following section will be undertaken at the same time. For example, at the same time as the baseline survey is being done, the Action Team will also be reviewing the central theme and specific objectives of their programme in light of the results being obtained from the survey, deciding on the specific messages that will be central to the programme, evaluating existing media materials, and determining which important messages are not included in existing materials.

26. Baseline Survey

After the preceding determinations have been made, the Action Team should undertake a baseline survey to measure knowledge, attitudes, and behaviour. This survey should be done at the same time as materials are being developed. Information gathered during this baseline measurement will help inform the media messages and ensure that the messages that are developed are relevant for the local community. The baseline survey will also provide data against which the outcomes of the programme can be measured (see Step 17).

27. Selection of Available Media Materials

Appendix J to Volume 1 contains a listing of materials available from various agencies. Volume 3 of this programme will contain items produced specifically for the WPA Worldwide Programme.

Before embarking on the creation of new media materials, the team should thoroughly examine existing available materials gathered in Step 15 to see if their stated messages and the media in which they were developed are appropriate for the programme. This will eliminate duplication of efforts, build upon the successes of previous programmes, and minimise cost.

28. Agreement on Central Theme and Programme Concepts

The Action Team should spend time at this point reviewing once again their understanding of the central theme and specific objectives of the programme and considering whether the material they have found will be useful and usable in the programme.

29. Development of Message Concepts

Examples of thematic concepts and sample messages are listed in Appendix K to Volume 1.

In formulating messages, it is important to be sure that the messages do not inadvertently increase stigma or create negative effects (see Appendix L for further details).

The technical information supplied in Volume 2 (which will be updated on a regular basis) should be adapted in a way that is appropriate to the needs of the site and its specific programme objectives.

Pretesting should be conducted as focus groups or “person-on-the-street interviews” and should not rely on the personal, aesthetic judgements of group members or their friends.

Message concepts should be appropriate to the targeted audiences, relative to their needs and level of knowledge (e.g., information on medication side effects might not be appropriate for high school students, but would be for caregivers). Facts should be stated briefly in an easily comprehensible style. Messages that are ambiguous or require a great deal of explanation should be avoided. All messages should include a call-to-action. Phone numbers, addresses, and other means of communication should be provided to allow the target audience to respond.

In composing message concepts, the group should also think about how it will evaluate whether a message was effective; the formulation of outcome indicators can thus be linked to message development.

30. Decision on Production of New Materials

The team then needs to compile a list of message concepts that are central to the programme (see Step 29) and identify those concepts for which it has no communication materials (see Step 27). The team can then decide what new materials need to be produced and estimate cost of such production.

31. Pretest of Message Concepts

To achieve effective communication, it is crucial to test messages among audiences for whom they are intended before production. The opinions of experts, government officials, or friends are not a sufficient guide to ensure effectiveness. Pretesting and subsequent, often multiple, revisions of materials are as important to communication projects as evaluation and diagnosis are to the provision of health and mental health services.

It is recommended that the concepts be pretested with groups or individuals who are representative of the intended audience to identify the concepts with the most potential. Give special attention to pictures or other nonverbal materials since these are easily misunderstood.

32. Development of Media Materials

The team should then convert concepts into complete messages and decide what media it will use for each message (e.g., radio announcements, booklets, posters).

In selecting the media it is important to carefully balance the goals of reach versus frequency. For example, television is an excellent medium for reaching large numbers of people with low cost per thousand (CPM), but it is not as effective as radio for generating greater frequency for the same cost per thousand. Professional meetings are excellent forums for reaching very targeted audiences. The possibility of measuring outcomes should also be considered in selecting media.

Appendix L provides a list of factors to consider in developing media messages.

33. Pretest of Materials

Complete messages and materials should be pretested for comprehension, recall, strong and weak points, personal relevance, and sensitive or controversial elements with representatives of the intended audience before final production. Programme staff at all levels must be flexible and ready to make unanticipated changes as a result of testing.

34. Finalisation of Communication Materials

After pretesting the materials, the group should draw up a complete production schedule and media plan for the materials. The group should decide in what order the materials will be released to ensure a smooth flow of communication. For example, advertisements should not be released until follow-up materials are ready to be distributed to those who respond.

V. IMPLEMENTATION AND MONITORING OF THE PROGRAMME

35. Building Local Support and Consensus Building

After materials have been pretested and are being prepared for distribution, a parallel effort to build consensus and support among influential members of the community should be conducted. This consensus building has a three-fold purpose:

1. To ensure the formal approval of those who will help implement the programme in the community
2. To involve professionals and politicians who might not have been able to participate in the earlier planning process. These individuals should be shown clear evidence of the results expected in the community. If this presentation is done well, this effort should also enlist the help of new members who will assist in the implementation of the programme.
3. To leverage the assistance of politicians in moving efforts from a local to a national level—and ultimately, to a global level.

36. Implementation of Programme by Local Action Team Members

While Step 35 is being conducted, the local action team should:

- Schedule and integrate distribution of messages and materials through appropriate channels to maximise impact.
- Train those who will be using materials, as needed. For example, it is far preferable to have teachers attend a half-day symposium conducted by an expert in the field than to simply distribute teachers' guides. Speakers' bureaux operated by people with schizophrenia or their families have been successful in communicating with groups in the community. Such groups can benefit from training.

37. Coordination of Implementation Schedules with All Team Members

During meetings at this point, the team should decide on specific arrangements for implementing schedules and circulating reports so that no key personnel or group will be surprised by the appearance of any materials, and actions can be coordinated.

38. Maintenance of Programme Diary

The programme diary (introduced in Step 7) should be updated on a regular basis. This information will be essential during the evaluation phase and for future implementation of the programme both nationally and as part of the knowledge base of the global anti-stigma effort.

An example of a stigma reduction intervention in London provides an illustration of how these five levels of evaluation are applied. In this intervention (Wolff, 1997), neighbours of a new group home for people with mental illness in South London were canvassed door-to-door and provided with educational materials about mental illness, including videotapes and written materials. Social events were also organised. This programme was then evaluated using the following criteria:

- Input: Production of videotapes, written materials, discussion sessions.
- Process: Did neighbours view videotapes and read brochures?
- Output: Did neighbours' fearful and rejecting attitudes decrease?
- Impact: Did neighbours make friends with patients?
- Outcome: Did patients have a better quality of life as a result? Did the community accept the patients and was it satisfied with its decision? (In fact, 13% of neighbours made friends with patients or invited them into their homes.)

[1] Wolff G. Attitudes of the media and the public, in Leff J, ed. Care in the Community: Illusion or Reality? New York: Wiley; 1997

39. Monitoring

The group should compare project outputs with the original work plan and budget. This will help project leaders identify and correct problems before they become obstacles. Monitoring should cover:

- The volume of materials produced (e.g., quantities of brochures and newsletters printed).
- The distribution in media (e.g., ensuring advertising spots are run as agreed).
- The attendance at presentations and verifying that training sessions were conducted.
- The function of the teams and adherence to work schedule and budget.
- The relationships with other agencies, including service providers and cooperating or hostile organizations.
- The quality of the products and process.

VI. EVALUATION OF THE PROGRAMME

40. Post-Test of Knowledge, Attitudes, and Behaviour

The post-test should be formulated before the basic survey is conducted and there should be a correspondence between the two so that the effects of the programme can be evaluated (see steps 16 and 17, and Appendix D).

41. Evaluation of Programme

Evaluation of the programme should examine the *input* (how much was invested), the *process* (what was done, what happened), the *output* (the effects of the intervention), the *impact* (effects on other areas or actions), and *outcome* (an overall evaluation of the process and its effects in relation to the broad goals of the programme).

Be sure to consider this final checklist:

- Are you reaching your full target audience?
- Are you reaching your target audience with enough exposures to ensure that your message is noted, recognised, and remembered?
- What is the final budget, including media production and placement (see Step 24)?
- Is this budget adequate to meet the original stated goals?

42. Review of Overall Outcomes

The overall outcome of the programme should be reviewed and the findings described in order to plan for future activities or assist planning at other sites. The team should recall overall and short-term objectives at this stage and examine the programme diary as well as other written materials developed in the programme. The Local Action Team should conduct the analysis jointly. This analysis should include:

Review and Analysis of Each Stage of Programme

This step should be done to evaluate the work in each step of the programme. This will allow the groups in other sites to learn from the experience of others.

Analysis of Effect on Proposed Audience and Broader Community

Was the intended outcome achieved? Were there other, unintended results of the programme?

Analysis of Media Effectiveness

The group should evaluate the effectiveness of the media they selected. There are many methods that can be used to assess media selection (see Appendix F).

Changes in the System

In addition to assessing whether the objectives have been reached, the team should consider:

- Changes in the legal system. Were laws protecting the rights of psychiatric patients enacted? Were new laws drafted?
- Changes in portrayal of people with schizophrenia in the media. Were fewer people with schizophrenia portrayed as villains in television shows or movies? Have there been more news stories that stress the importance of early diagnosis or the importance of reintegrating those with schizophrenia back into society?
- Changes in employment of those with schizophrenia. Have employment figures for those with schizophrenia increased?
- Changes in support for families. Has there been an increase in the number of support programs for families?
- Changes in funding. Has the amount of the government's financial support for mental health care increased?
- Change in government's administrative structure. Have there been changes in administrative bodies (e.g., appointment of an official specifically concerned with patient rights?)

Changes in National Environment

If the programme was done only in a part of the country, have there been changes in national environment? Did news of these local efforts reach other areas of the country and influence others on a broader scale?

Identification of Strengths and Weaknesses

This section should provide specific examples and hindsight wisdom.

Evaluation of Skills Acquired by Local Personnel

Has training produced long-term benefits among individuals who interact with those with schizophrenia, such as law enforcement officials and emergency room personnel? Would some of these individuals be useful as trainers in the future?

See Appendix D for specific outcomes measurement

Examination of Linkage to Other Mental Health and Healthcare Initiatives Locally and Nationally

Are there ways we can disseminate successful interventions to other areas, such as providing high school teaching materials to teachers over a broader area?

VII. PLANNING ACTION AFTER PROGRAMME ENDS

43. Assuring Continuation of Work After the End of the Programme

The group should now look for additional sources of financial support both to extend the current programme and to implement additional initiatives. It should also attempt to enforce and support networks that have been created and provide active participants with ideas on support in the future.

44. Documenting the Project

A *meeting or press conference* should be held to disseminate results and recommendations to all those who participated in the project. Such an event would also allow those who have heard of the programme's success to learn more and become involved in the ongoing effort.

A *written summary* of the process steps undertaken in the action programme and an account of outcome should be produced and could be written up in a manner that will facilitate its widespread use. A specific report should also be provided to the WPA for use in further dissemination of the model around the world. Efforts should be made to publish the results of the programme in well-read scientific journals.

45. Replanning for Future Development (Applying the Lessons)

Can lessons learned from the project be applied to future stigma-reducing activities? What results of the assessment should be incorporated into the programme design?

Appendices to Volume 1

Appendix A

Instructions for Conducting a Site Survey

The purpose of the site survey is not epidemiological; rather the goal is to get a clearer idea of the characteristics of the site so that programme efforts can be effectively targeted. It is therefore important not to spend an excessive amount of time on the survey nor allow it to become too detailed.

Who Conducts the Survey?

The Local Action Team may first want to determine which of its professional members have experience in developing such research tools. The group may also decide that they want to engage the services of an outside research agency. Care should be taken that the survey is done in a way that can be repeated so that the effectiveness of the programme can be clearly measured during the assessment phase.

Who and What Is Surveyed?

There is, of course, often a trade-off between the completeness of the information gathered and time and budget considerations. However, the survey should aim to give a clear picture of the community's knowledge, attitudes, and behaviour to guide action and allow measurement of results. The survey should determine both:

- What is the stigma and discrimination because of schizophrenia now (see Part II of Volume 2 for a detailed discussion of the origins and extent of stigma and discrimination.)?
- What knowledge, attitudes, and behaviour should be changed? The survey should be broader than the intended action, since the efforts of the project may have an impact in areas unanticipated during the planning process. For example, while teachers and high school students may be part of the identified target audience, our messages will also reach the parents and siblings of these students and other members of the general public, whose behaviour may change as a consequence.

Information that Should be Obtained

a) Demographics

Age and Sex: The distribution of the population of the site by age and sex should be ascertained, using the age groups: 0-15 years; 16-29 years; 30-65 years; 66+ years.

b) Education

- Structure of the educational system
- Proportion of the population in school (at all levels)
- Differences/profile of those in various levels of school
- Methods for communicating with teachers and administrators
- Social class distinctions in the educational system
- Literacy rates

c) Economic Features

- What percentage of people live under the poverty line?
- How important is the barter economy?
- What is the geographic distribution of economic resources?
- What are the main sources of income for the population?
- What is the level of unemployment?
- What percentage of the population is employed by others?

d) Geography

- What is the geographic distribution of the community (e.g., urban vs. rural dispersion)?
- What are the climate and topography of the region and how do they affect accessibility (i.e., are all areas equally accessible to health services and media year round)?

e) Social Characteristics

The team should identify opportunities for and impediments to communications, including:

- Is the community socially cohesive?
- Are there festivals or gatherings providing opportunities for communication?
- Are there social networks in place for communication and action?
- Does the community provide support for the poor and indigent? If so, what type of support is provided?
- Do NGOs or social action groups exist in the community?
- What consumer and family groups exist in the community?
- Are there religious and/or business organizations that can create events and opportunities for socialising and communicating?
- What is the predominant family size/profile (e.g. single parent households)?
- What are the patterns of drug and alcohol use in the area?
- What are the crime rates in the area? Are there significant differences between areas (e.g., parts of the town) in these or other respects?

Cultural Characteristics

The team should consider questions about the cultural beliefs and customs of the site that may affect the outcome of the programme, including:

- What are the common cultural conceptions about the causes of mental illness?
- What are the prevailing political and religious ideologies concerning causes of mental illness?
- Who is generally believed to be responsible for giving help and support to the disabled?
- Do traditional healers or practitioners of alternative medicine have an important role in the treatment of mental illness?
- What are the cultural norms concerning social behaviour (e.g., is someone who does not work and earn his own living not a fully accepted member of society, or is there tolerance toward people who are dependent on others for their needs)?
- What is the prevailing family system—intergenerational or a preponderance of one-generation or single household families?
- Is the area largely industrial and urban or rural and agricultural?
- Do rural families in the area provide care for their disabled members?
- How important a role do religion and churches play in the culture and society of the area?
- Are the charitable activities of local churches limited to their members or do they reach a wider population?

Attitudes Toward People with Schizophrenia

Although these mini-surveys may lack statistical significance in strict quantifiable terms, they are rich resources for messages and statements that might be used in the communication of anti-stigma messages.

In some settings it may be impossible to gather data specifically on schizophrenia.

In such cases, the group should survey attitudes about severe mental illness.

Are results available from studies on attitudes relative to mental health in general and schizophrenia in particular?

It may be necessary to carry out an informal mini-survey of the attitudes of particular groups within a community. Such a survey might include:

- Small focus groups
- Visits to prisons
- Discussions with legislators
- An analysis of newspaper reporting of mental health issues over a year in widely-read journals
- Attitudes of medical students
- An anthropological survey of folklore relative to mental health issues
- Letters to various users of psychiatric services and their relatives asking for instances in which they have experienced discrimination.

Since attitudes may vary from one social group to another, it will be necessary to evaluate attitudes on a group-by-group basis according to a distribution of groups that is relevant to the particular community.

Appendix B

Survey of National Health/Mental Health Policies and Services

The team needs to gather baseline data on the health and mental health policies and services of the site. In gathering this information, the team should consult legislators, local social services offices, hospital administrators and directors, and representatives of the insurance industry. The main questions to be considered are:

- What are the main features of the mental health treatment system?
- Which are the responsible authorities at local, regional, and national levels?
- What are the methods of financing and organising services (i.e., who pays for mental health care)?
- What is the insurance structure?
- Are equal benefits provided for mental health treatment as for other medical conditions? If not, which areas are particularly unequal?
- Is disability aid available?
- Who provides formal care for persons with mental disorders (i.e., professions involved)?
- Are there any population groups that are currently not receiving care or for whom care is inadequate?
- How many psychiatrists practice in the area and how are they organised?
- What training in psychiatry is given: for psychiatrists? general medical students?
- Is there some in-service training in general for psychiatry?
- How many general practitioners are in the area?
- How many homes for the elderly are in the area and how are they organised?
- What is total number of beds used for psychiatric care in the community?
- How many people with schizophrenia are in institutions (including inpatient hospital facilities, nursing homes, residential facilities, etc.)?
- Are patients with psychiatric illnesses frequently treated in facilities outside the site area?
- What access to care do families of those with schizophrenia have?
- Is homelessness a problem? If so, are any measures taken to help the homeless?
- What services are available? Outpatient? Inpatient? Transitional? Rehabilitation?
- How are inpatient and outpatient resources allocated?
- Do institutions dealing with mental disorders provide patients with opportunities for vocational training?
- Are there sheltered workshops that will employ people diagnosed as having a mental illness or impairment? Is there a waiting list? If so, how long is that list?

- Do working relationships exist between the mental health service and other health services?
- If so, how close are these alliances?
- How much do those working in the healthcare system know about schizophrenia?
- What laws and legal practices regarding the care, treatment, and confinement of people with schizophrenia are used in the area?
- Is there involuntary treatment? Confinement?
- What rights/protections are in place for people with schizophrenia?
- What are the circumstances surrounding people with schizophrenia who are in jail, prison, or who have committed crimes?
- Can they (and do they) receive treatment while in penal institutions?

Appendix C

Survey of Communication Resources

It is important to obtain information about communication opportunities. For example, in rural areas (if these are to be included), there may be fewer television or radios per capita. The following information should be gathered to identify available media and communication resources:

- Names of editors and medical columnists of local newspapers
- Executives and directors of local radio and television stations
- Number and proportion of households with television
- Number and proportion of households with radios
- Media most frequently accessed by various target groups in the site area
- Radio and television networks
- Private and public channels and stations
- Provisions for broadcasting public service announcements
- Most accessible channels and stations
- Percentage of country covered by different channels/stations
- Broadcast languages used
- Proportion of local versus imported programming
- Proportion of automobiles with radios
- VCR penetration
- Satellite penetration
- Print media
- National daily newspapers and their circulation
- Consumer magazines and their circulation
- Comic books sold
- Other popular media
- Attitude to foreign media
- Influence of foreign media and media from neighboring areas

Appendix D

Recommendations for Outcome Measures

Introduction

Project assessments should be undertaken in terms of realistic measurable outcomes which are spelled out in the project objectives. These can be seen as a continuum affecting knowledge, attitudes, and behavior of members of the target audiences, including service providers and influential groups.

Outcome assessment steps include:

- Measure and track audience awareness, recognition, comprehension, recall, and practice using appropriate and affordable research techniques to obtain rapid feedback
- Analyze results in terms of specific objectives
- Make necessary revisions in project design.

Outcome measures will have to be designed locally, at least in part. The basis for this formulation will be the listing of examples of discrimination by the Local Action Group and the ranking of the challenges in the daily life of people living with schizophrenia and their families. The Local Action Group will need to record changes in the lives of these individuals that have most probably been related to the programme.

In addition to measuring outcomes based on these indicators, it will also be necessary to assess success in changing some of the processes underlying discrimination. The list given in this appendix presents suggestions in this regard. The local action group should rate these suggestions from most to least relevant and then assess the difficulty of obtaining the necessary information at the site.

Overall Goals

1. To increase knowledge and understanding of schizophrenia among the general public, key community figures, and policy makers.
2. To improve the social acceptance and community integration of people with schizophrenia.

Recommendation

Each subcommittee of the project should develop its own overall goals and some examples of measurable objectives. Below, we list goals and some possible objectives for the anti-stigma group. Each subcommittee's list of goals and objectives should be sent to the group chairman.

Examples of Measurable Goals

To increase knowledge among the general public concerning the causes of schizophrenia.

Measure: Knowledge survey of the general public.

To increase the awareness of the general public that schizophrenia can be episodic and treatable.

Measure: Telephone survey of the general public.

To decrease by X% the number of people who perceive people with schizophrenia as violent.

Measure: Survey of the general public.

To change judicial attitudes regarding people with schizophrenia and law enforcement.

Measure: Attitude survey of police, attorneys, judges.

To increase the number of decision makers using person-first language (referring to "people with schizophrenia")

Measure: Text analysis of policy documents and articles in the media.

To increase education in high schools about schizophrenia.

Measure: Survey of recent teaching practice of high school health and science teachers. Knowledge survey of high school students.

To increase discussion of schizophrenia among the general public.

Measure: Content analysis of popular media articles.

To increase the access of people with schizophrenia to social resources.

Measure: Survey of social agencies (subsidized housing, vocational services, etc.) to assess proportion of recipients who are people with schizophrenia.

To reduce the number of people with schizophrenia in jail.

Measure: Survey of local jail population.

To increase the general public's active tolerance for people with schizophrenia.

Measure: Survey of sample of people with schizophrenia to assess:

- 1) Proportion employed
- 2) Length of residence in current accommodation
- 3) The number of work schemes that bring patients into contact with the general public.

To develop a local anti-stigma advocacy ("stigma-busters") group at each site.

Measures: A stigma-buster group has been established.

A stigma-buster group has been in existence for 6 months.

A stigma-buster group has achieved a success.

To establish a consumer speakers' bureau at each site.

Measures: A speakers' bureau has been established.

A speakers' bureau has been in existence for 6 months.

A speakers' bureau has given X presentations.

To increase by X% the number of employers who hire people with schizophrenia.

Measure: Employer survey.

Appendix E

Examples of the Kinds of Stigma and Discrimination that Occur Because of Schizophrenia

Stigma and discrimination because of schizophrenia can take many forms. It is important to obtain local accounts in each of the programme sites of ways in which stigma is expressed, as well as the ways and places in which discrimination occurred.

In producing this account, the local action group should rely upon information obtained from patients and their relatives. Human rights activists should also be consulted.

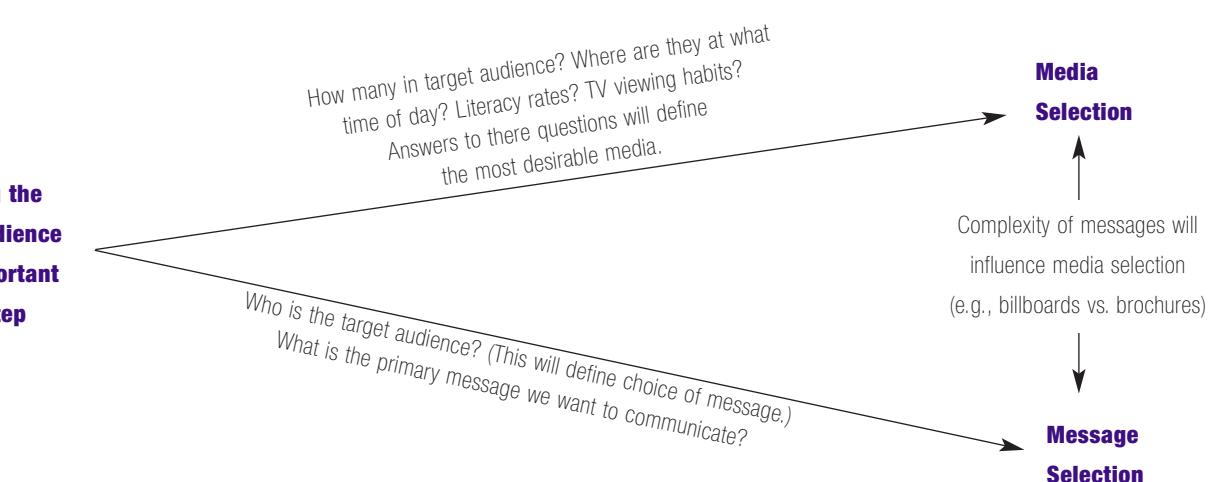
Healthcare workers—including psychiatrists, family physicians, and social workers—should also be consulted, particularly those who practice in the community and are in regular contact with patients. Observations from social scientists should be taken into account, particularly if they have been active in this area (e.g., dealing with the plight of the homeless.) Theoretical and overly general formulations should be avoided and an inductive method—beginning with the personal experiences of those most concerned—is recommended.

In considering stigma and discrimination, the Local Action Group should be aware that positive as well as negative stigma and discrimination should be recorded. An example of positive discrimination might be the protection of people with schizophrenia from losing their employment when an industrial plant is downsized.

Discrimination based on fact should be distinguished from discrimination based on prejudice and various false beliefs.

Appendix F

Advantages and Disadvantages of Various Media Slides/Binders



Advantages

- Relatively low cost
- User familiarity with the technology

Disadvantages

- Dependent upon slide projector and presentation environment
- Less uniformity of presentation
- Dependent upon availability of knowledgeable presenter

Brochures (16 to 24 Pages)

Advantages

- Can be shipped virtually anywhere
- Low to moderate cost

Disadvantages

- Limited amount of information content
- Language dependent
- Likely to be disregarded unless content is very distinctive.

Pamphlet/Book (36+ pages)

Advantages

- Comprehensive information with more space for case histories
- Access-quality publication will be retained on bookshelf

Disadvantages

- One person, one book
- Static presentation

Comic Books

Advantages

- Popular and widely read in some countries
- Of particular interest with larger populations of lower socio-economic classes

Disadvantages

- A challenge to produce so that the message is creatively and effectively embedded in a popular story
- Culture specific, idiom dependent

Audiotape(s)

Advantages

- The verisimilitude and emotional power of audio
- A controlled presentation

Disadvantages

- No visuals (or limited to explanatory companion brochure)
- Linear format, does not lend itself to quick access

Film/Video

Advantages

- High visual content for even greater verisimilitude and emotional impact
- Higher learning with greater sense stimulus

Disadvantages

- Dependent upon variety of videotape technologies
- Language barriers (overdubbing or subtitles)

Multimedia

Advantages

- Near encyclopedic content with easy access to necessary information
- Synergies of video, text, and sound with multiple language capability
- Active participation vs. passive learning

Disadvantages

- Dependent upon personal computer availability
- Relatively higher cost for fully realized video input

Web Site

Advantages

- Zero postage for distribution of materials
- Readily lends itself to constant updating and active data gathering

Disadvantages

- Dependent upon computer and phone lines
- Information content may be limited
- Reaches a limited group of the population

Teleconference

Advantages

- A national or worldwide event
- High visibility for conference participants

Disadvantages

- A one-time event
- Highly dependent upon logistics for presenters and viewers
- Logistical problems of immediate translation

Media Matrix

| | Reach | Information Content | Language Dependence | Retention/Repetition | Capital Investment |
|----------------|----------|---------------------|---------------------|----------------------|--------------------|
| Slides/Binders | Moderate | Low - Mod | Moderate | Low | Low |
| Brochure | High | Moderate | Moderate | Moderate | Low - Mod |
| Pamphlet/Book | High | High | Low - Mod | Mod - High | Mod - High |
| Audiotapes | Moderate | Moderate | Moderate | Low - Mod | Moderate |
| Film/Video | Moderate | Moderate | Moderate | Moderate | Mod - High |
| Multimedia | Moderate | High | Moderate | High | Mod - High |
| Web Site | Moderate | Moderate | Mod - High | Mod - High | Moderate |
| Teleconference | Low | Low | Mod - High | Low | High |

Reach is defined as the number of people who will receive and be able to use the materials based on technological (not language) considerations.

Information Content is defined as the amount of information that will "fit" in a particular medium.

Language Dependence is defined as the degree to which the programme depends upon a written or spoken language.

Retention/Repetition is defined as the ability to re-visit the information and the ability to retrieve a particular piece of information (for example, the linear nature of audiotapes is more limiting than printed material in which one can "turn to" a particular piece of information).

In addition to this overview of media, Media Buying Agencies can also supply comparative information that will better enable you to evaluate particular media for a particular target group.

It will be important to connect local communication experts and discuss the above table to decide on the media to be used. Their comments as well as experience with media on the local level should be recorded.

Some forms of communication are not included in this chart. These should be added wherever possible (e.g., comic books, folk songs, theatre, puppet theatre, plays and playacting.)

The variety of measures that can be used to evaluate communication effectiveness is almost as great as the number of communication firms who conduct such evaluations. We give just a few examples of the kinds of measures that can be used to evaluate one medium in comparison with others. Certain qualitative measures can take into consideration the media vehicle's audience size adjusted by a scale of values reflecting:

- Audience characteristics in relation to a segmental (targeted) strategy
- Intermedia differences
- Intramedia differences
- Advertising unit differences

Gench (1970) defined five factors to consider in measuring the effectiveness of a media vehicle:

Editorial climate: the authority or believability of the publication.

Message fit: the appropriateness of the message to the medium and target audience.

Technical capabilities: a qualitative measure of a particular vehicle in comparison with others in the medium (e.g., clarity of the FM over the AM signal in certain geographic regions).

Competing messages: presence of other advertisements for the same or similar advertisers that may add to confusion and message clutter.

Target population receptiveness: Gench comments "The social context in which a media vehicle is viewed or read can make a difference. Some communication may be intended to reach the entire family as a group. Thus, evening television would be more desirable than daytime television, magazines, or newspapers."



[1] Gench DH. Media Factors: A Review Article. J of Marketing Res 1970; 7:216-225.

Appendix G

Creating a Press Event

1. News Conferences

The news conference is an opportunity to provide timely, relevant, and important information to the media. It is important that your message or event be of major importance. A mistake many communications teams make is the overuse of the news conference, which will only result in journalists and media representatives coming to view subsequent press events (which may, in fact, be more newsworthy) with skepticism.

Speakers should be chosen carefully. Two speakers will provide a focus for attendees, with other sources available to the press for comment after the conference. A notable person with credentials upon whom the press can rely for reliable information will increase attendance and coverage.

The conference should be limited to 30 to 40 minutes with at least 20 minutes allotted for questions. Speakers should be available to the press for individual comment after the conference itself.

The following guidelines based on experience in the United States, Canada, and some European countries may help you organize a successful press conference:

- Schedule your news conference for mid-morning. This allows reporters time to meet afternoon deadlines.
- Choose a familiar site that is centrally located in your community to hold your conference. Or choose a prestigious setting that is relevant to your event/message.
- A Tuesday, Wednesday, or Thursday is the best day to schedule a press conference.
- If your news conference allows for advance notice to the press, send out media advisories 1 week prior to the event. Always include the address of a contact person and a phone number for more information.
- If your news conference is being held in response to a breaking event or news, your issue will be of major significance to the media. If you do not receive a significant amount of interest from the media (in the form of some verbal acknowledgment from representatives of both print and broadcast media), you should reconsider holding the press event.
- Use your local news advisory services. In many countries, the wire services run listings of news events so that the press can determine what to cover. Find out the deadline for inclusion in the Daybook and send written notice to the Daybook Editor prior to the deadline. (A Day-book is a document that is updated daily and lists new stories that are being considered.)
- Hire a photographer to cover the event. Many local publications will be unable to send a photographer, so your ability to provide the reporter with a photograph will improve the reporting and your relationship with the reporter.

- Provide press kits. Press kits should include fact sheets and background information about schizophrenia. Also provide a copy of the prepared remarks of the speakers. Include biographies of your speakers in the press kits.
- Prepare your speakers for dealing with the media. Give each speaker a time limit for his or her remarks. Hold a mock press conference to practice and ask the speakers questions you believe are likely to arise. Rehearsal is very important. Schedule time for it.
- Make follow-up phone calls to the press (1 to 2 days in advance for newspaper editors, 1 day for radio news directors, and the same day for television assignment editors), since television schedules change frequently.
- The venue for the press conference should be large enough to accommodate all press and camera crews. The room should have good lighting, even though most camera crews will bring additional lights. Position the podium or head table to allow an unobstructed view from anywhere in the room. Chairs should be arranged to provide the media with a clear view of the podium or head table. Supply a remote box for multiple sound output for recording devices. Arrive at the site at least 1 hour in advance to make sure every last detail has been arranged.
- Have a press registration table complete with sign-in sheets and press kits, which will allow you to survey the media attendance for the conference, further cultivate your relationships with the press, and enhance your ability to follow up with reporters after the conference.
- Provide refreshments for the press, especially if the conference is mid-morning.
- Start your news conference on time and end it when scheduled. Reporters have very tight schedules and you can damage your reputation with representatives of the press by not being punctual or letting your speakers talk too long.

NOTE: As mentioned above, if you cannot gather enough attendees together for the press conference or if the announcement is an update of information previously released, you may want to send a Press Kit to appropriate Editors in the print and broadcast media.

The Press Kit

Press kits should be compiled for specific events or to provide background information about schizophrenia and the relevance of the announcement to be made. Prepare extra kits and keep them on file to send to reporters who request additional information. (A sample is included in the media toolkit and a list of contents is given below.)

The Press kits should include:

- News release (for specific event).
- Fact sheets on schizophrenia (usually one to two pages): focus on key points concerning the personal and social impact of the stigma of schizophrenia.
- The programme's goals and objectives.

- Background information on the World Psychiatric Association and the organizations involved in your local effort.
- Brochures, newsletters, and other outreach materials.
- Questions & Answers document to answer some of the commonly asked questions about schizophrenia and the stigma surrounding it.
- Resource materials might also include articles about schizophrenia, information on your local action group, or speeches given by someone in your group.

The media kit folder is usually a two-pocket folder, which has the news release on the right hand side to ensure visibility. All materials should carry a date of printing at the bottom of the last page to avoid old releases being picked up and rerun.

The News Release

The news release is intended to focus on the key aspects of your story. It should be limited to two or three double-spaced pages. Other documentation will provide technical or additional reference materials; the news release should be very much targeted to the announcement of the day.

When reviewing a news release, editors treat it as an inverted pyramid—generally they begin cutting from the bottom up to fit the information into the format. Therefore, the first paragraph should contain the main ideas of the story, with each subsequent paragraph elaborating on the key information in the first paragraph.

Writing the News Release

Content of the release

It is important to try to answer the following six basic questions as well as providing a news hook (with some local relevance to the reader) in the first paragraph:

- WHO (is involved, or to whom did it happen)
- WHAT (was said or done; or what is going to happen)
- WHEN (did or will the story or event take place)
- WHERE (did it happen, where will it take place)
- WHY (did it happen or will it happen)
- HOW (did it happen or will it happen)

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- Always type your release, double-spaced.
- In the upper left-hand side of the release, type "FOR IMMEDIATE RELEASE"; or if the release time and date is specific, indicate the release date.
- Keep the headline of the release short (10 words or less) and TYPE IT IN ALL UPPER CASE. The headline should let the reader know exactly what the press release is about and its relevance/importance to the reader.
- The body of the text of the release should begin with the city where the event or conference is being held (e.g., Geneva, January 2, 19__).
- Limit your release to no more than four pages. Number each page. At the bottom of each page (if additional pages are listed) type "MORE". On the last page of the release, type "###" or "-30-" to indicate the end.
- Do not split a sentence between pages.
- Include approved quotes from authorities on the issue in your release.
- If you use abbreviations or acronyms of any kind, be sure to spell out the full name, title, or phrase (e.g., World Psychiatric Association [WPA]).
- Your press release should end with the name and phone number of a key contact person who can answer questions.

Follow-Up

Whether you have held a full news conference or have sent out a press kit to editors and reporters, follow-up is key. Out of respect for their time, keep your follow-up call brief. Ask if any more information is needed and what kind of coverage may be expected.

Appendix H

Fund-Raising Guidelines

Obtaining funding for printed materials, seminars, and other expenditures in a public communication campaign is a challenge. Ultimately, proper funding can make or break a programme.

Several guidelines are important to keep in mind as you develop a fund-raising programme.

- Develop a clearly defined goal. The more specific the request (e.g., raising money for a specific seminar or educational programme), the more likely you are to receive a positive response.
- Set a specific monetary goal. Estimate all costs in your programme so that you can give potential donors a clear understanding of your ultimate target.
- Identify in-house resources. Are there members of your local advisory group who have access to funding?
- Develop a list of potential outside resources.
- Consider the following options (depending on local restrictions in the donation of money, your programme options may be more limited than those listed below):
 - Annual campaigns, so that potential donors can plan their giving in advance.
 - Planned giving programmes. This term is used to describe pre-planned forms of donation such as wills and bequests (often as a percent of the estate of the donor)
 - Pooled income funds (a trust agreement in which money is transferred to the organization's pooled income fund directly)
 - Trusts: some individuals may choose to make your programme the beneficiary of a life insurance policy which will transfer funds upon the owner's death.
- Your programme may use some of the following fund-raising strategies:
 - Personal solicitations: members of your group may approach individuals on a one-on-one basis.
 - Direct mail; this will allow you to reach a larger number of potential donors, although less personally. (The fund-raising letter is particularly important. It should get directly to the point and present a clear plan of action.)
 - Telemarketing: like direct mail, this allows you to reach a broad number of people with the added benefit of a phone conversation. However, it may be more difficult to reach people as directly as mail. Calls will also need to be repeated.
 - Special sponsored events: these can include awards programmes or dinners that might include a "silent auction" for donated materials.

The Solicitation Package

Material should be prepared for individuals considering a contribution.

The package should clearly explain:

- The goals of your fund-raising campaign
- Why your programme is important
- The specific benefit the donor will receive (e.g., publicity)
- The effectiveness of your organisation
- Several options for support or participation
- The long-term value of the programme

Follow these guidelines for writing the solicitation letter:

- Keep the letter to one page.
- Use clear concise language.
- Use letterhead with the organisation's main phone number.
- Address letters to the appropriate person. Do NOT write "Dear Sir or Madam".
- Capture the reader's attention in the first sentence. State project goals in the first paragraph.
- Outline only the highlights of your request. Details may be covered in the proposal itself or discussed at a future meeting.
- Show how your programme addresses key concerns for the reader.

Along with the letter, you should provide: a prospectus summarizing the project, support and informational materials on schizophrenia, and a donor request card the donor can fill out and return.

Corporate Recognition

Corporations and foundations often respond well when their company achieves greater visibility from the donation. A "Corporate Giving Plan" establishes tiers of potential donations and might be constructed this way:

- Corporate Sponsor: \$15,000 and higher
- Corporate Benefactor: \$10,000 to \$15,000
- Corporate Patron: \$5,000 to \$10,000
- Corporate Donor: \$2,500 to \$5,000
- Corporate Contributor: up to \$2,500

Appendix I

Baseline Survey of Knowledge, Attitudes, and Behaviours

A variety of methods can be used to obtain information about knowledge and attitudes as well as some reports on behaviour. The three cheapest methods are mail surveys, telephone interviews, and focus group interviews. Other types of surveys, such as house-to-house surveys with personal interviews, are less economically feasible. The following matrix provides an overview of the general advantages and disadvantages of different research methods:

| Measurement consideration | Mail Survey | Telephone Interview | Focus Group |
|---------------------------|--|---|--|
| Population | Allows you to approach larger numbers of people but with a one-time opportunity for response | Allows you to reach a broader population but often requires repeated call-backs | For smaller, more well-defined groups |
| Biased response* | Can be segmented geographically | Allows for random dialing | Some small group bias |
| Item construction | Must be carefully worded, since there is no opportunity to clarify responses to questions | Interviewers can clarify questions; open-ended questions are allowed | Generally open-ended to facilitate open discussion |
| Costs | Low per-person cost | Modest per-person cost | Higher per-person cost |
| Speed | Responses arrive within 1-2 weeks; analysis of written questionnaires takes additional time | Dependent upon number of interviewers; analysis will take additional time | Responses are immediate, but analysis of qualitative data can take considerable time |

* Biased response refers to how data might be segmented (perhaps a positive characteristic for your research) or skewed (the negative)

Appendix J

Thematic Concepts and Sample Messages

The team will need to select a single unified theme for the programme, as well as specific messages related to that theme that target selected audiences. In this appendix, we present a number of thematic concepts that might be chosen as well as samples of targeted messages related to those concepts. Here are some examples:

Theme: Schizophrenia. The one thing it IS is treatable.

Message to general practitioners: Effective treatments for schizophrenia are available that have far fewer side effects than older medications.

Messages to teachers:

- Schizophrenia can be treated effectively. People can regain their ability to function in society.
- Schizophrenia is a biological illness that can be treated.
- Students need to learn to be tolerant and helpful toward those who are different.
- Students should be taught not to laugh at or ridicule those who are different.

Theme: Schizophrenia. Open the Doors.

Sample messages to police:

- Bizarre or abnormal behaviour may be a symptom of mental illness.
- When you see someone who is behaving very oddly, consider having a doctor evaluate them or take them to the emergency room, but not to jail.

Theme: Schizophrenia. Look closer; you'll see the human being.

Appendix K

Factors to Consider in Developing Media Messages

Once the team has decided what messages need to be communicated to the target audiences, a media plan can be developed to determine the most effective media to select to achieve the stated goals. The following general measures can be used to select one medium over another (Sissors 1997)

- Optimum number of prospects
- Optimum amount of frequency
- Lowest cost per thousand (cpm)
- Minimum waste (non-prospects)
- Within the specified budget

Traditional measurements of a particular vehicle's effectiveness (e.g., gross rating points or Nielsen ratings for television) can be helpful. However, when messages are being placed on a pro-bono or discounted rate, trade-offs are to be expected. For example, print ads may appear at the back of a magazine or television ads may be aired late in the evening well after prime time viewing hours. While the cost is attractive, your message will reach a more limited viewership. *For example of messages developed for the anti-stigma campaign, consult the Media Toolkit available from the WPA.*

In creating the actual messages, the team should consider some of the maxims and tips that copywriters and graphic designers have developed for the creation of ads. For example, Russell and Lane (1996) outlined the following principles for creating effective headlines in print advertising:

- Use short simple words, (usually no more than 10 words)
- Include an invitation to the prospect to become involved
- Use an action verb
- Give enough information in the headline so that the prospect who reads it learns something

Russell and Lane give the following guidelines for reviewing advertising copy:

- Develop a copy strategy: what to say and to whom.
- Does the message position the problem and its solution clearly?
- Does the message promise a benefit for the prospect?
- Does the message tie to the overall strategy?
- How strong is the execution of the "Big" idea? Is it bold and unexpected? Is it visually arresting? Is it single-minded?

Kaatz (1995) presents a checklist that the team can use to review the messages it has developed:

- Have you learned everything you can about the problem and solution, or service, offered?
- Have you clearly defined your target audience and its needs?
- Have you written to your target audience as you would to a real life person and not a research statistic?
- Have you promised a real benefit and backed it up with a reason why the person will receive this benefit?
- Have you recognised that the prospect's time is valuable by getting right to the point?
- Have you made certain that what you said relates to your unique challenge and cannot be easily transferred to another?
- Have you avoided saying more than necessary?
- Have you written with excitement and enthusiasm so your prospects will say: "They really believe in what they are saying"?
- Have you rewarded your prospect by making it easy and fun to take time with your message?
- Have you remembered that the message is the centre of the advertisement, not the advertisement itself?



- [1] Kaatz R. Advertising and Marketing Checklists, 2nd Ed., NTC Business Books; 1995.
- [2] Russell J, Lane W.R. Kleppner's Advertising Procedure, 13th Ed. Prentice Hall Press 1996: 516-517.
- [3] Sissors J. Advertising Media Planning. NTC Business Books; 1997.