The World Psychiatric Association Presents

the wpa global programme to reduce stigma and discrimination because of schizophrenia

Schizophrenia - Open the Doors **Training Manual**

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List of Contributors

Editor:

Professor Heather Stuart, Queen's University, Canada

Contributors (in alphabetical order):

Professor Matthias C. Angermeyer, University of Leipzig, Germany

Professor Julio Arboleda-Flórez, Queen's University, Canada

Anja Esther Baumann, University of Düsseldorf, Germany

Sebastian Bernert, University of Leipzig, Germany

Professor Wolfgang Gaebel, University of Düsseldorf, Germany

Barbara Hocking, SANE Australia

Reinhold Kilian, University of Leipzig, Germany

Professor Julian Leff, Institute of Psychiatry, London, UK

Ruth Ross, Managing Editor of the *Journal of Psychiatric Practice*

Professor Norman Sartorius, University of Geneva, Switzerland

Professor Heather Stuart, Queen's University, Canada

Dr. Werner Schöny, Univ. Doz. Österreichische Gesellschaft für Neurologie und Psychiatrie, Linz, Austria

Beate Schulze, University of Vienna, Austria

Hugh Schulze, c|change inc, Chicago, USA

Cecilia Villares, São Paulo, Brazil

Dr. Richard Warner, Mental Health Centre of Boulder County, Colorado, USA

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Prologue

Purpose:

This training guide is intended to be a practical companion to Volume 1 of the World Psychiatric Association's Global Anti-Stigma program (see description of program materials in a subsequent section). It has been developed from the priorities identified by people with schizophrenia and their families. It provides "how to" information for people who would like to set up their own anti-stigma program. In addition, the technical tips, exhibits, and supplemental readings will be useful for those wishing to train others in anti-stigma program development, implementation, and evaluation.

By now, over twenty countries are participating in the WPA Global Anti-Stigma program entitled "Open the Doors". The program is multidisciplinary, collaborative, and international. It reflects a long-lasting commitment to stigma reduction rather than a campaign. Programs within respective countries are self-sustaining but receive technical support from the headquarters of the program and consultation support from all of the sites. Therefore, a second important goal of this manual is to capture the wealth of practical experience generated by these program sites. Groups interested in becoming an official participating site in the WPA Programme should contact:

Professor Norman Sartorius
14 chemin Colladon
1209 Geneva, Switzerland
e-mail: normansartorius@bluewin.ch

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

- The program will be implemented according to the steps outlined in this and other WPA documentation,
- That results of the program will be shared with WPA Member societies and other participating sites,
- Published materials created as part of this programme will be submitted to the WPA so that they can become part of the archives of this world-wide program,
- Local groups should consult with the WPA about publications destined for wide distribution,

- 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.

Organization:

This manual is a text in development. Additional versions may be released as knowledge and experience grows. We hope the experience of those involved in the program will contribute to its improvement and that program participants will continue to document their achievements. The general organization of the manual follows the progression of steps outlined in WPA's Volume I for how to set up an anti-stigma program, beginning with the decision to mount a program, then following through the various program design, implementation, and evaluation steps. The approach is modular. Each section is designed to stand on its own, so that it can be mixed and matched with other sections to customize the training experience.

Availability:

This manual is available in electronic form from the "Open the Doors" website at:

openthedoors.com

Open-the-Doors Committees and working groups:

Steering Committee

Ahmed M.F. Okasha, Chair (Egypt)
Norman Sartorius, Scientific Director (Switzerland)
Julio Arboleda-Flórez (Canada)
Juan J. López-Ibor, (Spain)
Costas N. Stefanis (Greece)
Narendra N. Wig (India)

Committee on the Identification and Treatment of Schizophrenia

W. Wolfgang Fleischhacker – Chairman after 5/97 (Austria)
Juan J. López-Ibor – Steering Committee Representative (Spain)
Timothy J. Crow (United Kingdom)
Paramanand Kulhara (India)
Jan Libiger (Czech Republic)
Michael G. Madianos (Greece)
Mario Maj – Chairman through 5/97 (Italy)
Michale O. Olatawura (Nigeria)

Committee on the Reintegration of Patients and their Families in the Community

Julian Leff – Chairman (United Kingdom)
Costas N. Stefanis – Steering Committee Representative (Greece)
Marina Economou (Greece)
Wolfgang Gaebel (Germany)
Ulf Malm (Sweden)
Vincent B. Wankiiri (Uganda)

Committee on Strategies to Reduce Stigma and Discrimination

Richard Warner – Chairman (United States)
Narendra N. Wig – Steering Committee Representative (India)
Anthony w. Clare (Ireland)
Sue Ellen Estroff (United States)
Julio Arboleda-Flórez (Canada)
Robert Freedman (United States)
Semyon Gluzman (Ukraine)
Trisha Goddard (Australia)
Driss Moussaoui (Morocco)
Michael Phillips (China)
Everett M. Rogers (United States)
Corrine L. Shefner-Rogers (United States)

Review Committee

Heinz Häfner – Chairman (Germany)
Norman Sartorius – Steering Committee Representative (Switzerland)
Istvan Bitter (Hungary)
Giovanni de Girolamo (Italy)
R. Srinivasa Murthy (India)
Ahmed Okasha (Egypt)
Charles Pull (Luxembourg)
Harold M. Visotsky (United States)
Greg Wilkinson (United Kingdom)

The program also relied on the technical advice of Jorge A. Costa e Silva, Director, Division of Mental Health and Prevention of Substance Abuse, World Health Organization, Geneva.

Open-the-doors program sites & Contacts:

Austria

SCHÖNY, Werner, Österreischischer Nervenärzte und Psychiater Wagner-Jauregg-Krankenhaus, A-4020 Linz, Austria.
e-mail: Werner.Schoeny@gespag.at

Brazil

VILLARES, Cecilia, UNIFESP, Departamento de Psiquiatria,
R. Botucatu, 740 3o andar, 04023-900, São Paulo – SP, Brazil.
e-mail : cvillares@psiquiatria.epm.br

Canada

HERRICK, Fay, Schizophrenia Society of Alberta, Calgary Chapter,
700-2310 2nd Street SW, Calgary, AB T2S 3C4, Canada.
e-mail: ssacc_advocacy@Phoneus.net

Chile

CACERES GONZALEZ, Carlos, Pampa Engariadora 3168
Iquique, Chile.
e-mail: carloscaceres2000@hotmail.com

Egypt

OKASHA, Tarek, Institute of Psychiatry, Faculty of Medicine, Ain Shams University,
3, Shawarby Street, Kasr El Nil, Cairo, Egypt.
e-mail: tokasha@internetegypt.com

Germany

BAUMANN, Anja, Psychiatrische Klinik der Heinrich-Heine-Universität,
Department of Psychiatry and Psychotherapy, Heinrich-Heine-University, Düsseldorf
Bergische Landstrasse 2 , D-40623 Düsseldorf, Germany.
E-mail: baumanna@uni-duesseldorf.de

Greece

ECONOMOU, Marina, University Mental Health Research Institute, Argirokastrou & Ionias, 66517, Papagou 156-01, Athens, Greece.
e-mail: stigma@compulink.gr

Italy

ROSSI, Giuseppe, IRCCS "Centro San Giovanni di Dio - Fatebenefratelli",
c/o Ist. S. Cuore di Gesù, Via Pilastroni, 4, 25123 Brescia, Italy.
e-mail: wpa.irccs@oh-fbf.it

Japan

SATO, Mitsumoto, Tohoku Fukushi University , 1-8-1 Kunimi, Aoba-ku Sendai, Miyagi 981-8522, Japan.
e-mail : mitsu@tfu-mail.tfu.ac.jp

Morocco

KADRI, Nadia, Centre Psychiatrique Universitaire Ibn Rushd, Rue Tarik Ibn Ziad, Casablanca, Maroc.
e-mail : n.kadri@casanet.net.ma

Poland

CECHNICKI, Andrzej, Day Treatment Centre, Collegium Medicum, Jagiellonian University, Pl. Sikorskiego 2/8, 31-115 Kraków, Poland.
e-mail: mzcechni@cyf-kr.edu.pl

Slovakia

NAWKA, Petr , Psychiatrická nemocnica, SK-07101 Michalovce, Slovakia.
e-mail : nawka@pnmi.sk

Spain

CUENCA, Olga, J.A. Llorente & O. Cuenca, Hermanos Bécquer, 4-6ª, 28006 Madrid, Spain.
e-mail: ocuenca@llorenteycuenca.com

Turkey

UÇOK, Alp, Istanbul Medical Faculty, Department of Psychiatry, Millet street,
34390 Çapa, Istanbul, Turkey.
e-mail : alpucok@superonline.com

United Kingdom

PINFOLD Vanessa, Project Coordinator, HSRD - Room H3 04,
Institute of Psychiatry, Denmark Hill, London SE5 8AF, UK.
e-mail: v.pinfold@iop.kcl.ac.uk

USA

WARNER, Richard, Mental Health Center of Boulder, County, Inc., 1333 Iris Ave.,
Boulder, Colorado 80304, USA.
e-mail: dick_warner@compuserve.com

Partnership Program - Australia

HOCKING, Barbara, Executive Director, SANE Australia, P.O.Box 226,
South Melbourne 3205, Australia.
e-mail : barbara.hocking@sane.org

WPA Program Materials

The following program materials may be downloaded in .pdf format from the openthedoors.com web site:

Volume I: Guidelines for Program Implementation

Volume I describes how to develop and implement a local program to combat stigma and discrimination as part of the international effort undertaken by the World Psychiatric Association. It address preliminary steps, the collection of information about program sites,

designing the program, acquisition or development of program tools, implementation and monitoring of the program, program evaluation, and planning action after the program ends.

Volume II: Information about Schizophrenia Relevant to Program Implementation

Volume II was created by a panel of international experts and reflects the state of the art in knowledge about schizophrenia, its causes, and its treatments. It brings together information about diagnosis, epidemiology, and treatment and relates it to how stigma develops and how it can be combated. To facilitate the use of this information in the development of anti-stigma programs, marginal annotations are included throughout the volume explaining the particular relevance of the information for reducing stigma and discrimination.

Volume III: Description of Program Implementation at Different Sites

Volume III is a work in progress which describes the experiences of the programs currently collaborating in this international network. It is intended to be used as a guide by those who are planning new programs so that they may benefit from the experiences of others as they work through the complexities involved in setting up and evaluating an anti-stigma intervention. Volume II will assist those who are looking for materials translated into different languages by facilitating contact with the programs that may have undertaken translations of program materials.

Volume IV: Compendium of Programs Aiming to Reduce Stigma and Discrimination Because of Schizophrenia or Mental Illness in General

This volume contains information on recent anti-stigma programs world-wide, collected by means of a postal survey. It focuses on programs of public information or education as well as those involving political action. This information is intended to help those implementing the WPA program to design their own programs and decide on the materials to be used. This compendium may also provide a basis for networking and may facilitate collaboration and sharing of knowledge locally and internationally.

Volume V: Annotated List of Materials for Use in Country Programs

This volume is an annotated list of materials and literature used in the country anti-stigma programmes. Materials are indexed alphabetically by title, author, audience, media, and language.

Educator's Guide

This guide was originally developed for educators and their students (grades 8-12) participating in the Canadian pilot program. It outlines the nature, treatment, and stigma attached to schizophrenia and can be formatted to fit individual site needs.

Brochures

A number of brochures were developed for the Canadian pilot program that are available on the web. They can be downloaded so that they can be adapted to local program needs. They include brochures targeted to the general public, health care professionals, and business leaders. They are action oriented and are aimed at easing the myths and stereotypes that surround schizophrenia.

Downloadable Logos

Open-the-Doors logos are available in .eps format in a number of languages: Arabic, Austrian-German, Chinese, English, French, German, Hindi, Italian, Russian, and Spanish.

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How to Get Started

This chapter provides an overview of the tasks involved in setting up an anti-stigma program. The main goal is to help the reader take stock of available resources and understand the steps that are necessary to get an anti-stigma program off the ground.

Why Anti-Stigma Programs Are Important

The essence of stigma is a negative and prejudicial attitude toward someone with a mental illness. Discrimination occurs when people with a mental illness are treated unfairly, or are denied their rights because of their mental illness. In the times of the Greeks, stigma was the act of branding someone to illustrate their social undesirability and to humiliate and shame them. People with a mental illness were seen as having less social value. These attitudes continue today and are expressed in different ways in different cultures. They create a vicious cycle of alienation and discrimination and can become the main impediment to recovery, causing social isolation, unemployment, homelessness, and institutionalization.

Stigma and discrimination have a long history and are not easily resolved. Therefore, undertaking an anti-stigma program is a major, long-term commitment. In 1996, the World Psychiatric Association embarked on a world wide program to fight stigma and discrimination because of schizophrenia called "Open the Doors". The aims are 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, and
- Generate action to prevent or eliminate stigma and discrimination.

By now the WPA Global program has established an international network involving over twenty countries, and it is growing with every year. Program sites are united by their common determination to fight stigma and discrimination in their respective cultures, and their common desire to increase knowledge about what works and what doesn't. Information about the materials available through this program are available on the website. The following publications describe the WPA program in more detail:

- Sartorius N. (1997) Fighting schizophrenia and its stigma. A New World Psychiatric Association Educational Programme. British Journal of Psychiatry, 170: 297.

- Sartorius N. (1999) One of the Last Obstacles to Better Mental Health Care: The Stigma of Mental Illness. In Guimón J, Fischer W, Sartorius N. (Eds.) The Image of Madness. Karger Basel-Freiburg: Paris, London, New York, New Delhi, Bangkok, Singapore, Tokyo, Sydney.

Assessing Feasibility:

Anti-stigma programs often begin with one or two interested people, or a small group, who provide the leadership and the time necessary to launch such a program. These initial organizers need to work through a series of preliminary steps to assess feasibility prior to making any public announcements about their plans. The goals of the feasibility assessment are to:

- take stock of the goals to be achieved and the work involved;
- assess buy-in and interest;
- develop a planning committee structure,
- conduct an environmental scan,
- establish preliminary work plans and time lines; and
- organize finances.

A clear understanding of the nature and extent of the proposed undertaking, including its cost and potential sources of funding, are essential to assessing whether a program is feasible.

Organizing Resources:

Stigma programs require two kinds of resources. Volunteers contribute their time and energy to make the program work (termed "in-kind" resources). In most locations, the bulk of resources for anti-stigma programs will be in-kind resources. Secondly, programs may need operating funds to cover real costs such as program materials, transportation to speaking events, or media costs. These funds will have to be raised from outside sources. Thus, you will need an overall plan for obtaining in-kind and external resources needed to develop and operate a program on an ongoing basis.

In seeking funding opportunities, keep the following in mind:

- develop clearly defined funding objectives as more specific requests are more likely to receive support,
- Identify in-house and in-kind resources and use these to create leverage for external matching grants,
- Make sure your program has a designated financial officer who is responsible for maintaining an up-to-date accounting of revenues and expenditures and presenting the program balance for regular review by Steering Committee and funders.
- Consider whether you will need the services of an external auditing firm or accounting procedures that go beyond the abilities of program members.

Writing A Funding Proposal & Program Plan:

In order to request funds, it will be necessary to write a funding proposal. A good funding proposal will include an itemized section outlining specific funding needs, expenditure lines for which funds will be required, as well as a clear accountability mechanism. Funding proposals should also contain a detailed description of the program plan as funders must know what they are getting for their money. A detailed program plan also ensures that the individuals who will deliver the program have a clear idea of their tasks and remain on track. It is the blueprint for action. If the program proves effective, it will assist others in setting up similar structures.

The main components of the program plan are as follows:

- the names and addresses of committees, groups members, and cooperating partners with a description of their roles and responsibilities,

- the auspices under which the program is being undertaken (such as the World Psychiatric Association Global Program to Fight Stigma and Discrimination because of Schizophrenia),
- the purpose of the program or its main goals,
- measurable objectives stating the outcomes that will be achieved,
- a review of the best practice literature positioning your program approach,
- the program approach and services provided,
- the evaluation structure,
- a budget and financial plan, and
- time schedule or multi-year plan.

Large financial requests may need to be accompanied by extensive documentation and many agencies have specific application forms and procedures to follow. If you request funds from several different agencies, you may need to re-write or re-format your funding request to meet each agency's particular specifications. Do not make the mistake of assuming one size fits all. Failure to tailor funding requests to agency requirements may result in a refusal of funds.

A shortened version of your program plan should also be kept on hand as this will serve as a basis for reports to sponsors and potential sponsors, journalists, and other interested stakeholders.

Enlisting Volunteers:

To be effective, anti-stigma programs require dedicated personnel to run them. In developing the personnel required for your program you should identify:

- individuals who occupy positions of power in relevant agencies, who can make decisions on behalf of their agencies and commit staff and resources to assist the programme.

- community opinion leaders that can provide broader political support for the program. These may include the Head of the Chamber of Commerce, a local newspaper editor, the Police Chief, members of the clergy, or local politicians. It is valuable to have people of prominence attached to the program who can command the respect of public and give credibility to the project. However, many community opinion leaders will not have the time or the interest to work with the program on a day-to-day basis, so their knowledge and influence must be harnessed in other ways.

They may be helpful in providing information about how to influence your chosen target groups; they may help in setting up events or disseminating information to target groups, or they may help the program forge links with other people who do have time and knowledge to devote to the program.

- consumers and family members. Involving people with mental illness and their family members is essential to the success of an anti-stigma program. Because they can describe their own experiences of stigma and discrimination, they add a vital perspective to all discussions. Their experience of mental illness and its social consequences makes them experts in identifying the most pressing issues. Consequently, their perspectives are essential in deciding on the type of anti-stigma interventions. Consequently, every program should have a mechanism built in to consult with consumers and their family members concerning the program activities and targets. Consumers and family members may also be willing to speak publicly about their experiences and their skills may be harnessed by developing a consumer speakers' bureau.

Developing Work Plans and Time Lines:

A range of people will be involved in your anti-stigma program. Some will be agency directors, some will be consumers, some will be busy politicians, and some will be business people. They will have different levels of knowledge, experience, time, and commitment. It is important to structure the work to allow for different levels of participation and to maximize individual strengths and contributions. You can do this by setting up different committees and work groups. One structure that has been used by many program sites includes:

- **An Advisory Committee:** The function of the Advisory Committee is to serve as a political soundboard and to develop goodwill for the project among important constituencies in the community. Members of this Committee should be opinion leaders who would be too busy to participate otherwise, but can function as important community levers.

- **A Steering Committee:** This committee will steer the program, including developing ideas, identifying opportunities, setting timelines, and obtaining funding. It should be composed of Directors of agencies and other important persons who are in charge of organizations that are relevant to the field of mental health and who can commit resources and personnel to the program.

- **A Local Action Committee:** This is the committee in charge of carrying out ideas proposed by the Steering Committee, distributing work tasks, keeping time lines, organizing activities, collecting materials pertinent to the project, carrying out research, and disseminating findings. Members of this Committee should be mental health professionals and researchers with a deep knowledge of the issues, representatives of consumers and families, as well as members of agencies in charge of treatment or funding of mental health services. One very important function of this committee is the costing of activities and the overseeing of the funding. Consequently, it is advisable that a member of this committee have some financial and accounting skills. It is the job of this committee to devise and implement the program's action plan.

Always recruit individuals to specific committees and be clear about the program's requirements and time lines. Make sure they understand the work involved so that they may make considered decisions regarding their involvement. This way, no one will be disappointed.

Creating By-in and interest:

Many people in the community will understand the importance of reducing stigma and discrimination. These include consumers, their family members, health workers, and those who are concerned about discrimination in general, such as teachers, newspaper editorialists, politicians, or business leaders. Their interest can be harnessed by describing the ways in which the stigma of mental illness:

- deters people from seeking treatment;
- worsens the outcome from mental illness (such as through adopting a negative self-image or by failing to comply with treatment); and
- worsens the quality of life of consumers and their families.

The enthusiasm of those interested can be heightened by linking your local program to the World Psychiatric Association's Global anti-stigma program, reporting on other successful programs, and tying your efforts to broader human rights movements.

Those who are interested in supporting the program may wish to discuss whether your program will address the stigma of schizophrenia alone, or the stigma of mental illness more broadly. This decision will depend as much upon the constitution of your initial group of planners and advocates, as the groups that you will target as part of your program. For example, whereas police officers may be interested in acute psychotic disorders such as schizophrenia, high school teachers may be more enthusiastic about education in the

broader field of mental illness. Similarly, employers may be more interested in disorders that are commonly encountered in the workplace, such as substance abuse or depression. Finally, the interests of the funding agent also may need to be taken into account. The World Psychiatric Association Program "Open the Doors" program is focussed on reducing stigma and discrimination because of schizophrenia. However, in two program sites, Germany and the United States, stigma was addressed within the broader context of mental illnesses.

One way to generate broad community interest is to invite a widely known public personality to support your activities. Suitable personalities include well-known figures who have suffered from mental illness and are willing to talk about the experience, or local celebrities who pledge support for your program. Alternatively, one may hold a press conference to launch the local program in order to command community attention and attract potential action committee members.

Exhibit 1: Generating Community Interest in Greece

In order to generate enthusiasm and create community buy-in, the Greek Anti-Stigma program organized a concert in the Herodium Theatre at the Acropolis in Athens featuring the internationally renowned Greek singer, Nana Mouskouri and John McDermott, a celebrated Canadian tenor. Well known personalities from cultural, health, and political realms attended the concert. In a ceremony following the concert, Professor Norman Sartorius of the World Psychiatric Association Open the Doors Program presented awards to Nana Mouskouri, who further committed herself to fighting stigma, the President of the Association of Patients, the President of the Families Association for Mental Health, and to the main sponsor of the international program. The concert programs contained information on mental illness and stigma.

Developing A Local Action Committee:

The composition of the Local Action Committee deserves special consideration because it may be the most decisive element in the success of your program. As much of the program's day-to-day work will be performed by Local Action Committee members, the success of your program rests largely upon their efforts. Most of the work will be volunteer. Therefore, Local Action Committee members must be committed to the goals of the program and willing to devote substantial time and effort to achieve them.

If the Local Action Committee is too small, the program's links to the community will be too restricted and the workload of individual members will be too great. A group of 20 members is large but still practicable. However, a group this size may need to split into smaller task groups to refine the action plans for different target groups.

The **chairperson** of the Local Action Committee should be:

- attached to an agency with good infrastructure support that can offer services such as secretarial help and telephone support;
- someone with local prestige who has skill in running meetings;
- able to get diverse groups to work together collaboratively; and
- someone who can make a long-term commitment to the program.

Regarding **membership**, it is important that the Local Action Committee include:

- Knowledgeable representatives of the groups to be targeted by the program. If the target groups to be selected for your program are not known at the time the initial Local Action Committee members are chosen, the committee should be augmented at a later time.
- People from relevant advocacy groups who already have an interest in stigma reduction. Building working alliances between different advocacy groups is a long-term benefit of an anti-stigma program. Some of the most valuable members of the Local Action Committee will be people who have, or have had mental illness and their family members. Since professionals will often have the time they

contribute to the program paid by their employers, and consumers will not, some discussion may be needed as to whether the time invested by consumers and family members should be reimbursed.

- A media or public relations expert. Such an individual is helpful in refining messages, designing media materials, and advising on cost-effective media approaches.

- A financial expert who can manage the financial statements and assist with funding applications.

- A researcher who can liaise with external survey firms and oversee data collection and analysis for needs assessments and program evaluations.

Regular communication with all members of the Local Action Committee is important for maintaining group cohesion and commitment.

Assigning Work Responsibilities and Monitoring Progress:

It is helpful if the Local Acton Committee splits into smaller task-oriented groups that are responsible for one aspect of the work plan. The task group can recruit additional members to help them with their work including members from their chosen target group. Clear goals and objectives must be developed for each target group. Without these it is impossible to monitor progress or judge success.

Someone should be designated to monitor whether these action steps are accomplished within the required time frame. This person may be the Chair of the work group. The action steps are updated each month as tasks are accomplished and new ones established. A simple "program planner" sheet is useful in monitoring the action steps. The headings on the "program planner" could be:

- Target group;
- Communication goal;
- Measurable objectives;
- Key messages;
- Media; and
- Action steps (task, person, timeline).

Keeping Task Groups Oriented and On Track

The Local Action Committee will need to ensure that action steps delegated to committee members are successfully accomplished. To maintain momentum, the Local Action Committee will need to meet at least monthly. Agendas sent out to group members prior to each meeting will focus discussions and assist participants in preparing for the meeting. Formal minutes are important for documenting the nature of discussions, providing reminders for actions to be taken, and outlining the nature of responsibilities and tasks conferred. However, for minutes to work effectively as a memory aide, they must be distributed to committee members soon after each meeting. Actions agreed to by members can be highlighted and completion deadlines included. When tasks have not been successfully accomplished, corrective measures can be taken or an alternate strategy developed.

Each successful milestone should be recognized and communicated broadly. Local media exposure and project outcome research results are useful in demonstrating the success of the various phases of the program. Program newsletter may be a useful way of communicating activities and progress and activities to local stakeholders.

Being an Effective Program Participant:

Committee members must follow through on program assignments and report back on their activities to the group. Regular meeting attendance is an important element of program participation and a reflection of program commitment. If committee members fail to attend meetings on a regular basis, the Chair may need to revisit their continued involvement.

Conducting an Environmental Scan:

It is important to have a good understanding of local health, mental health, and social services that may impact people with schizophrenia or their families. This information will provide the context in which the program will be developed and delivered and will help the Local Action Committee set priorities for action. Therefore, conducting an environmental scan will be one of the first activities undertaken by the Local Action Committee. The main issues to be considered include:

- The organization, financing, and availability of mental health services;
- Availability of social welfare and other disability benefits;
- Availability of psychiatrists and mental health personnel;
- Barriers to accessing necessary care;
- The role of primary care and general physicians in the care and treatment of people with schizophrenia;
- Availability of advocacy groups for consumers and their families;
- Housing options for people with schizophrenia;
- Employment opportunities for people with schizophrenia;
- Opportunities for developing working alliances between mental health professionals and local advocacy groups; and
- Availability of anti-stigma programs and resources that could be harnessed in the service of your program.

Keeping Track of Resources:

An agency with recognized financial systems should be made the repository for any funds received. For program accountability, it is important to maintain financial transparency and distance between the members of the committee and the accounting mechanisms. A financial expert will be indispensable in setting up these mechanisms.

Funders may have specific financial reporting requirements that must be met as a condition of funding. If a program has several funders, there may be different financial reports required at different times. In some cases, formal audits may be necessary and these costs must be factored into the program budget. It is important for program planners to have a clear understanding of what financial reporting requirements are tied to their funding contracts.

Prior to sending financial reports to sponsors and funders, these should be reviewed by the Local Action and Steering Committees. To maintain transparency and ensure that funds are being used appropriately, large or unusual expenditures should be made only with Committee approval. Otherwise, financial statements should be reviewed on a regular basis.

Planning for Sustainability

The aim of the World Psychiatric Association's Global program is to create programs with longevity, sustainable program structures, and permanent change. The key to sustainable

development of a programs against stigma and discrimination are their institutionalization. A programme starts because a group of people who are committed to the development of an anti-stigma program have come together and decided to work together for a considerable period of time. It order to be sustainable, the programme must find an institutional niche.

The niche is an administrative structure that is accepted by a durable institution. The **Office of the Program** could be a special anti-stigma unit in the Ministry of Health, for example, or a special office funded by a Foundation or other body with stability. The niche needs to be protected by appropriate administrative procedures and legal structures. Under no circumstances should the Office of the Programme be created by adding onto an official who already has full program responsibilities.

To be sustainable, the Office of the Program needs staff: voluntary workers, part-time staff, research assistants, and evaluation assistants. Most importantly, the continuity of the office will rest on having a person (or persons) with a stable contract. The service of that person—the administrative officer of the programme—must be continuous so that the Office can carry out its coordinating tasks from a stable base. The Office should also have archival space and access to meeting rooms and office equipment. It is unlikely that such a stable structure can be established quickly. Because stability takes time, the Local Action Committee **must** have this on their agenda from their first day of work.

Early in the process of program development, the Local Action Committee should evaluate which components of the program require funding and look for ongoing support for these elements. Typically in-kind resources and volunteer labour can be sustained over long periods, whereas cash infusions are likely to be sporadic and difficult to maintain. If an ongoing source of funding cannot be located, then Local Action Committee members should consider mounting a program using in-kind and volunteer resources from local programs and advocacy groups. Many community programs have anti-stigma activities as part of their official mandate. Coordinating these efforts to meet program goals can provide ongoing support for local anti-stigma efforts. Formal agreements between organizations and the local program to re-direct some of their activities to meet the anti-stigma program goals may be the most important source of sustainable funds.

Exhibit 2: Working with Existing Programs to Coordinate Activities

In the United Kingdom, there are several anti-stigma efforts underway. In addition, all health and social welfare agencies are required to promote mental health and combat psychiatric stigma and discrimination. This means that anti-stigma efforts are possible across a wide range of community settings with a variety of at risk and vulnerable groups. Indeed, many groups across the country deliver mental health awareness sessions with the goal of reducing stigma and discrimination. These include media watch projects, mass marketing poster awareness raising campaigns, stigma awareness cultural events, and the promotion of positive news and media images. The Mental Health Awareness in Action project has focused its energies on working in collaboration with these groups to both carry out and evaluate local anti-stigma interventions.

To create a program that is sustainable, the Office of the Program will need to develop and support several structures. In addition to the Steering Committee, Local Action Committee, and any working groups, the Office must also support the network of collaborating agencies, organizations, and institutions that will undertake the anti-stigma activities. Initially, these networks will be based on informal agreements. However, to be sustainable, agreements must evolve into formal partnership arrangements and contracts.

Networks do not survive if projects do not meet the common interests of the network partners, or if the program does not bring benefits to all of its members. The task of the Local Action Committee is to explore the interests of potential partners and develop programs and activities that will permit all members to benefit from their participation. Benefits might be of different kinds: a gain of otherwise unattainable information or knowledge, more visibility, better image, prevention of staff burnout, or fiscal advantages. Benefits may vary from time to time and from one organization to another. Changes in the leadership of an organization must be viewed as a signal to the Local Action Committee to re-examine the interests and benefit structure of the new administration.

To be sustainable, the Office of the Program must have detailed procedures that they use to support the anti-stigma program and create an organizational memory. The program must be carefully documented in a manner that will permit future leaders and staff to understand how to proceed and what errors to avoid. In particular, there should be mechanisms for creating the next generation of program champions and program leaders who can take the program into the future when current members move away or otherwise disengage.

The ultimate success of a program against stigma is the incorporation of rules against stigma into the hearts and minds of the population and into the statutes and bylaws of all

institutions which should participate in the prevention and elimination of stigma. Therefore, the goal should be to create structures and partnerships that will continue on a permanent basis. Such elements might include:

- a change in the local high school health curriculum to include mental illness;
- a change in the medical school curriculum;
- adapting "diversity" education programs in local high schools to include the mentally ill with other discriminated groups;
- the creation of a "stigma-busters" media watch group;
- the establishment of alliances between diverse advocacy groups and agencies with a common interest in stigma reduction;
- formation of a consumer speakers' bureau;
- the reinforcement of the stigma-fighting mission within an established advocacy groups;
- a change in institutional or health service policy, such as establishing new national or local emergency-room procedure for the evaluation and treatment of the mentally ill, or a change in the guidelines for the provision of the most recent anti-psychotic medications; or
- change in the rules of behaviour of the various Ministries, courts, hospitals, policy, and the many other agents of society who can generate stigma or contribute to its elimination to include anti-stigma activities and attitude building.

Chapter Summary:

In this chapter we have reviewed some of the preliminary decisions that must be made and the actions that must be undertaken in order to get an anti-stigma program off the ground. We have emphasized the importance of prior planning and have outlined a series of decision points and steps that we recommend be followed. The following check-list will help program organizers assess their own capacity to create and sustain an anti-stigma program.

Chapter Checklist

- ✓ Is there a small group of committed individuals who will provide leadership and the time needed to develop an anti-stigma program?
- ✓ Have we sufficient volunteer support and participation from consumers and family members, local mental heath administrators and agency directors, and community leaders?
- ✓ Have we a mechanism to consult with consumers and their families regarding the targets of the program?
- ✓ Do we have a committee structure that makes efficient use of our program volunteers.
- ✓ Do we have a work plan with clear responsibilities for each committee and work group.
- ✓ Do we have a clear idea of the resources that will be required and potential sources of support?
- ✓ Is there a system for regularly monitoring progress toward our goals?
- ✓ Is there community buy-in for this program (or a plan for obtaining it)?
- ✓ Is there a plan for program sustainability?

2

How to Assess Local Needs Using Qualitative Techniques

Stigma and discrimination are complex and multi-factoral. Relationships between knowledge, attitudes, and practices are not always straightforward or clear. Groups may have high levels of knowledge about a particular mental illness, yet still express negative attitudes, or they may express both positive and negative attitudes. It is not always obvious where to intervene or how to target interventions.

In addition, knowledge, attitudes, and practices differ from culture to culture and from group to group. Therefore, it is important to understand the knowledge, attitudes, and practices of target groups in order to design a program that will meet their needs. There is little value in providing additional information to individuals who are already well-informed but continue to think or act negatively.

Finally, to be successful, anti-stigma programs also must be acceptable to the groups targeted. If they are not, they will not have the desired impact. What is considered appropriate and acceptable may change from group to group and from culture to culture.

A clear understanding of local conditions and needs is required in order to successfully target a program. In this chapter we discuss the steps involved in conducting a needs assessment using qualitative data obtained from focus groups or in-depth interviews. Chapter 3 discusses the steps involved in conducting needs assessments using quantitative data obtained from surveys.

Using Focus Groups to Assess Local Needs:

Focus groups are group discussions involving 8-12 participants that are guided by a facilitator. Their purpose is to discuss a limited number of issues in order to identify a range of opinions and ideas. Originally, focus groups were used in market research to identify customer preferences so that products could be matched to perceived wants and needs, and effective communication strategies developed.

Effective anti-stigma programs must be based on the needs of specific groups. Interventions must be appropriately tailored to these needs, and communicated in ways that the group members will understand. Because focus groups start from the needs and experiences of those who experience stigma and discrimination, they help developers of anti-stigma programs address important and concrete needs. More specifically, they:

- empower consumers and family members by acknowledging their expert role and soliciting their assistance in defining effective interventions;
- help identify and recruit interested and qualified individuals for program task groups;
- involve members from all relevant groups in programme development so help sustain ongoing support throughout the program;
- help balance the interests of program planners with the perceived needs of the intended beneficiaries of the program.

Focus groups produce a rich body of data expressed in participants' own words. They allow respondents to qualify their responses and explain their reasoning. A guided discussion among people who share a central part of their experience encourages participants to articulate grievances and criticisms. The group dynamics stimulate thinking, promote a wider range of contributions, and yield information that may be missed or withheld in a structured interview or questionnaire. Therefore, in-depth information from focus groups is one important basis for targeting anti-stigma programming.

When to use a focus group

Consumers, families, mental health professionals, media representatives, health politicians and other groups all have different expectations regarding the outcome of anti-stigma efforts. The process of defining target groups and developing effective interventions will

require an in depth understanding of these different perspectives. Focus groups can be used at different stages in program development to:

- Generate ideas and concepts to be used as input for program planning. With their open atmosphere, focus groups are well suited for creating ideas. Based on these ideas, the basic concepts for the anti-stigma programme can be developed.

- Create anti-stigma messages including what information the programme will provide on mental health problems, which myths should be dispelled, and how the program will position the topic. Messages are the channels for bringing these points across. Focus groups can be helpful in developing messages and testing them with different target groups.

- Identify and create support. By inviting people with considerable experience in program development or funding, community leaders, representatives of government agencies, foundations, and possible sponsors, focus groups can be a first step in generating creative ideas for fundraising and for developing community buy-in. Focus groups also can be used to identify additional support that may be required for the program—a question that must be addressed at the outset of program planning, and regularly as part of routine program functioning.

- Monitor the program. People involved in the program should have a forum to regularly voice their experiences, concerns, and needs for support. Focus groups can be particularly useful for understanding the needs of project teams. Possible needs arising in the course of the programme include a need for training, consultation, additional staff, special expertise, and other resources.

Conducting a Focus Group:

Successful focus group meetings require careful planning and preparation. You should consider the following steps.

Step 1 : Formulate the main question.

It is important to be clear about the concepts or issues that you want to investigate. A good opening question for anti-stigma needs assessment is "When and where do people with schizophrenia experience stigma that is a consequence of the illness?" Having a clear understanding of the concepts such as stigma, discrimination, exclusion, disadvantage, or

anticipated stigmatization is particularly important as you will use these terms to pose questions to focus group participations and to generate discussion.

Step 2: Identify eligible focus group participants.

A thorough needs assessment will capture the views of different groups, such as consumers, men or women with schizophrenia, family members, health care professionals, clergy, news journalists, or film-makers. Plan separate sessions for each group. Participants who share similar key characteristics will more easily identify with each other's experiences. This will help participants feel more comfortable in the group and facilitate discussion. The goal is to create homogeneous groups of participants with respect to the key characteristics you have identified.

The number of focus groups required depends on your purpose. When exploring a broad and complex subject such as experiences with stigma, you may want to run several groups, continuing until you cease getting new information (termed saturation). This usually occurs within 4-6 groups. When addressing a more specific question, such as how individuals cope with stigma, you may need fewer sessions before you reach the saturation point. For an even more specific and concrete purpose, such as testing audience reactions to a slogan, or identifying needs for support in an action team, a single session with each target group may be all that is required.

Step 3. Develop discussion questions and probes.

Identify the main issues to be discussed and formulate open-ended questions for each issue. Each open-ended question should have a series of sub-questions and probes to assist the facilitator in generating discussion and eliciting a broad range of responses. The main questions, sub-questions and probes form the discussion guide. This is an important tool for the facilitator to orient the group discussion and manage the time.

An in-depth exploration of few concepts is preferable to a brief examination of a larger number of issues. Therefore, the number of issues to be addressed in a focus group should be limited to no more than three or four.

Questions do not need to be followed in strict sequence and probes should only be used if the group does not react to an issue or offers little information. Otherwise, the goal is to use the questions to initiate a natural and free flowing conversation among the group members. It is important to be as non-directive as possible to encourage a broad range of contributions.

Step 4. Select and train a facilitator and co-facilitator.

The facilitator is the main data collection tool. It is important to make a careful choice based on the purpose of the project, the characteristics of the focus group participants, and the type of facilitator that would best fit with the group to obtain useful data. A good focus group facilitator will create an open and tolerant atmosphere in which every participant feels free to offer opinions. They will have worked with groups in the past and have basic interviewing skills (attentiveness, preparation, skilful phrasing of questions, and genuine interest).

It is advisable to have a co-facilitator whose primary responsibilities are careful note taking and helping the facilitator generate discussion. Notes are the basis of the analysis so careful note-taking is crucial to the success of the focus group. It is best if all groups are carried out with the same team of facilitators. This will improve comparability of results across groups. If time constraints require several focus groups to be carried out simultaneously, careful training of facilitators should aim for a relatively uniform moderating style.

Step 5. Establish the groups.

Make personal or written invitations at least two weeks in advance of your group and confirm attendance. In your letter of invitation state the purpose of the group, the nature and benefits of participation, how the information will be used, and how individual's privacy and confidentiality will be protected.

Different recruitment strategies may be necessary for different groups. People with serious mental illnesses and their relatives may be recruited though mental health programs, advocacy organizations, or local mental health providers. Always invite more people than required to allow for drop-outs. Follow-up contact with participants, either through mail reminders or telephone calls will help to reduce drop-outs. Providing support for transportation costs and parking may increase your turn-out. Also, depending on the local context, it may be appropriate to offer small financial incentives for participation. In this case, additional funds have to be allocated for this in the overall program budget.

Exhibit 3: Focus Group Guidelines for Obtaining Subjective Perspectives on Stigma Experienced by People with Schizophrenia

Topic 1: Stigmatization Experiences

Opening question:

What has changed for you after you first developed schizophrenia? Tell me concrete incidences and stories that you experienced! [if necessary., probe: work, family, friends, education, everyday life]

Further questions (alternative):

Were there situations in which you felt excluded or misunderstood? [if necessary, probe: when? where? can you describe? other situations than you already described?]

Did you tell other people that you had schizophrenia? [if necessary, probe: whom? when? why? why not?]

How did people around you react when they found out you had schizophrenia? [if necessary, probe: withdrawal, interest, gossip, support?]

Topic 2: Suggestions for Anti-Stigma Interventions

Questions (alternative):

What should be done about negative stereotypes/discrimination because of schizophrenia?

How would you like people to react to the fact that you have schizophrenia?

How could these situations (described earlier) be avoided/improved?

What kind of information would be important?

Who/which groups in particular should be addressed?

[probe for concrete ideas when suggestions are given (e.g. story line of a film, contents of a newspaper article, strategies for political lobbying, etc.)]

Time the groups carefully so that they do not compete with other important local events. Arrange the focus group sessions to take place in a comfortable and easily accessible environment. Create a relaxed atmosphere for the discussion through informal seating, and by providing beverages and light snacks. Whenever possible, hold groups with consumers outside of the hospital or mental health program.

Step 6. Running the focus group session(s).

Before participants arrive, set up and test any technical equipment that you plan to use, such as a tape recorder or video camera. Start the session with an introduction by the facilitator. Explain how members were selected, the purpose of the project, how data will be handled, and how results will be used. Obtain informed consent to record the session.

Occasionally you will have more people in attendance than you anticipated. If you have too many people to run an effective group, split the group and have the co-facilitator lead the second group. If your attendance is low, you will have to reconsider your recruitment strategy. Too few group members may render the data incomplete and incomparable with other groups.

Begin the group with a general question and ask all participants to respond. A question about some aspect of their experiences will break the ice and create commonalities between group members. Then follow the discussion guideline you have outlined, using probes to generate more detail or to re-focus the discussion when it wanders off track. When the discussion is complete, thank the participants and solicit their advice on how you could improve future sessions.

Problems often arise in the course of moderating focus groups. Some of the most frequently experienced problems are as follows:

- The presence of a dominant group member. While they may provide a great deal of useful information, they may discourage other participants from entering the discussion, force agreement with their own views, or even attempt to take over the facilitator's role. If given too much room for expression, they are a major source of bias in focus group research. To diffuse this situation, be appreciative of the dominant individual's knowledge, but explain that the opinions of others are equally important. You may need to tell them firmly, but politely, to wait their turn to speak. Establishing clear ground rules for communication at the outset may help to prevent this problem.

- Censoring and conformity are common processes in group interaction. In focus groups, participants may withhold comments due to a lack of trust, or tailor statements in accordance with their perceived expectations of the facilitator or other members of the group. At the outset, asking participants to describe concrete experiences, rather than having them provide opinions, can reduce this propensity.

Exhibit 4: Invitation used in Germany

We would like to invite you to participate in our project against stigma and discrimination because of schizophrenia. In order to work successfully against stereotypes and negative images of mental illness among the public, we would like to learn from your experiences and decide, together with you, how to best proceed in reducing prejudice and negative reactions towards people with schizophrenia. We would like to talk with you and other people who have experienced mental health problems about your views and suggestions on this topic in a discussion session taking place on [date],[time] at [place], [room]. Please find enclosed a map giving you exact directions to the venue. The way to the room will be signposted.

Results of the discussion session are to be used as the basis for developing a programme against stigma and discrimination towards people with schizophrenia. In particular, we would like to address the following questions:

- How did your friends, colleagues and neighbours react when they first learnt that you had a schizophrenia? Both positive and negative experiences are important.

- What, do you think, are the sources and causes of negative images about people with schizophrenia and discrimination towards them?

- What can be done about negative images and discriminating reactions?

    - in your everyday life?
    - in the public sphere?

Please take a few moments to think about these questions before the discussion.

Please let us know by [date 2] whether you will be able to come to the discussion session by calling us at [phone number] or returning the reply slip at the bottom of the page. Would you kindly also get in touch if you are unable to attend.

- Focus group discussions may become heated as people begin to express different views. Two participants may begin to argue and exclude everyone else from the discussion. Working in smaller groups can overcome this problem. Assign the two people who are arguing to one group in order to encourage their cooperation. By making cooperation an explicit goal of the exercise, they will be faced with the possibility of group sanctions if they are unable to work together.

- Topics you wish to address may be too abstract for participants. This happens frequently when participants are asked to envision solutions. They may not see themselves in a position to implement change, or such solutions may be too far away from their every day problems to be readily grasped. This situation may be

alleviated by introducing games or stories. For example, you may ask the group to imagine that they are journalists commissioned to write an article on schizophrenia for a magazine, or consultants to a movie that features a character who has schizophrenia.

Exhibit 5: Example Consent Form

This focus group discussion is part of a needs assessment in preparation for an action programme designed to fight stigma and discrimination because of schizophrenia. This program is affiliated with the World Psychiatric Association's Global Program to Fight Stigma and Discrimination because of schizophrenia. We wish to learn about how people with schizophrenia are treated by others and develop concrete ideas on how stigma and discrimination can be reduced.

In order to work successfully against stigma and negative images of mental illness among the public, we would like to learn from your experiences and decide, together with you, how to best proceed in reducing prejudices and negative reactions towards people with schizophrenia. We would like to talk with you and other people who have experienced mental health problems about your views and suggestions on this topic.

With your consent, the information you give as part of the focus group discussion will be recorded. Recordings will be used to help us identify important themes. Data will be treated confidentially and will be used only by research staff. At no time will you be identified individually.

Consent

I, [name], I agree to take part in the above focus group in line with the conditions described the confidentiality statement.

I understand that the use of audio tapes and video footage will be used for the purposes outlined above.

I understand that I will remain anonymous and will not be identified in any way.

- Participants may feel embarrassed to share experiences. One option for overcoming this problem is to ask them to write down their views. A second option is to split the focus group into smaller subgroups, asking each one to prepare a brief report. These strategies will assist participants in becoming clear about what they have to say and allow them to be selective in preparing and making their statements. An expansion of this method is to have people write experiences down anonymously on identical sheets of paper, put them in the middle of the table, shuffle them, and let people draw statements to be read out. Unpleasant experiences are mentioned but without personal identifiers.

- With quieter participants, direct questions can be used to probe whether their silence means agreement, disagreement, unwillingness to say so, or whether the participant has nothing more to say.

Focus groups are intellectually and emotionally taxing for the facilitators. No more than three focus group sessions should be scheduled per week to allow facilitators sufficient time to debrief, review notes, identify themes to take up in the next session, look for improvements, and replenish energy levels.

Exhibit 6: Focus Group Checklist	
❑	Prepare a fact sheet explaining the purpose of the focus group, a confidentiality statement, and a consent form.
❑	Send the fact sheet and written invitation at least two weeks in advance
❑	Confirm attendance and give reminders close to the day of the group
❑	Get technical equipment (tape recorder, microphone, video camera)
❑	Prepare signs indicating the room location
❑	Organize the room for the session that is easily accessible for participants
❑	On the day of the focus group post signs showing people where to find the room
❑	Bring confidentiality statements and consent forms to the group
❑	Set up and test all technical equipment
❑	Organize the seating
❑	Organize beverages and snacks
❑	Welcome participants to the room

Analyzing Focus Group Data:

Material from focus groups can be used in a variety of different ways. Hence there are different levels of analysis, ranging from providing an overview of a broad issue, to the detailed analysis of one particular aspect of experience. Ensure that the data analysis strategy answers the main questions posed.

In-depth analysis

In-depth analyses are ideal when there are a small number of groups, the focus is relatively narrow, and the research question is specific. An example of a research question that is amenable to this analysis is: *How do families of people with schizophrenia cope with the fact that friends and relatives abandoned them after the illness begins?* A thorough analysis would use a full set of verbatim transcripts that have been prepared from tapes. The process is inductive. Categories are formed from themes that emerge when reading the text. Coding uses a cut and paste procedure. Relevant sections of the text are identified, cut, then summarized under a code name. The coding system evolves throughout the course of the analysis.

It is important to develop a coding guide that clearly defines the codes to be used and provides the criteria for what kind of information is to be coded under which heading. To ensure that codes are reliably identified, coding should be done by two researchers working independently. Resulting codes are discussed and discrepancies identified and resolved. The final step is the interpretation of patterns in the material. For example, one may look for types of people who react to stigma in a particular manner, or develop a typology of coping styles that could serve as the basis for a stigma coping training program for family members. Analysis can further be facilitated by breaking it down according to "sub-questions" to avoid including too many topics. Here, the text should be analyzed for one aspect at the time. Also, several computer software packages for qualitative analysis are widely available and facilitate coding by allowing simultaneous access to the coding system and the coded text.

Exploratory analysis

Exploratory analysis typically covers a broad range of issues derived from a larger number of groups. For example, one may be interested in identifying stigma experiences from consumers, family members, and mental health professionals. Given such a broad research objective, verbatim transcripts are not required. An analysis of the notes taken by the co-facilitator during sessions is sufficient. Notes are scanned for general themes or categories of experience. The categories that are produced in this way can then be illustrated with quotes transcribed from the tapes. A more detailed analysis is possible as a further step. For example, categories generated from the notes can be used as a guideline for coding transcripts of the sessions.

High level analysis

A high level analysis may be conducted to generate ideas, or to develop or test questionnaire or media materials. In such cases, transcription is rarely required. Instead, a more straightforward summary of the contents can be developed by selecting relevant information from the session notes. In addition, materials produced during the focus group session such as drawings, flipchart sheets summarizing the results of brainstorming sessions, or associative comments on a proposed slogan written down by each participant can be used. If the material provides information on a variety of topics, it is advisable to break up the analysis into manageable subsets. Topics relevant for analysis usually correspond with issues listed in the interview guide and the focus group objectives.

Exhibit 7: Summary of Focus Group Applications

Purpose	In-depth analysis of a specific research question	Explorative, broader sampling population	Concrete purpose, e.g. developing messages, testing questionnaire items, identifying needs for support in project teams
Possible questions	How do university students with recent onset of schizophrenia cope with stigma?	How is stigma experienced from the subjective perspective of people with schizophrenia?	What are the training needs of people with schizophrenia in working with the media?
Number of focus groups	2-4	4-6	1-4
Data analysis	In-depth analysis: use of a full set of transcripts Inductive coding: generating categories (coping styles) from the respondents' own words	Exploratory analysis: Coding of a set of notes Search for patterns of experiences. Use of transcripts possible for illustrative purposes	High level analysis: Select relevant information from the notes or materials produced in the focus group (e.g. flipcharts, drawings, etc.)
Duration	6-10 months	4-6 months	1-3 months
Cost	high	medium	low

Problems in analyzing focus group data

Focus group data are rich, complex, and the product of group dynamics. Therefore, focus groups do not lend themselves to understanding individual views or making comparisons between participants. If the goal is to understand a problem at the individual level, then an interview, rather than a focus group, is the better approach.

One challenge in the in-depth analysis of focus group data is that several participants may speak at the same time, making it difficult to distinguish individual statements on the tape or identify individual perspectives. A skilled facilitator may prevent this by asking people to repeat themselves or by stopping the discussion when participants speak simultaneously.

Interviewing Consumers & Family Members:

The individual face-to-face interview is the most extensively used method of obtaining information about individual experiences and attitudes. They have all of the benefits of focus groups with respect to supplying rich personal data, but differ to the extent that they do not build on group interchange and interaction. Interviews do not require participants to divulge personal information in public, so better protect privacy, and can allow for more in-depth understanding of lived experiences of consumers and family members. Interviews may be:

- **Structured**: Structured interviews contain questions with a fixed number of pre-established response categories. The aim of the structured interview is to describe facts as objectively as possible. The interviewer follows a pre-defined script and tries to avoid deviations that could bias the results. The interviewer's task is to ensure that all respondents receive the same set of questions, delivered in the same way, under similar conditions. The interviewer is prohibited from changing the wording of any question or the response categories. Standardized explanations are given when a respondent fails to understand a question or response category. Because they are given in exactly the same way, structured interviews improve comparability of results across respondents, over time (such as pre and post-intervention), and across different studies. However, they do not provide the richness of qualitative detail obtained using the less structured methods.

- **Semi-structured**: In a semi-structured interview, only the topics are fixed. The number, order, and wording of the questions may be open to variation by the interviewer. Semi-structured interviews are useful for exploration and to learn about subjective meaning systems. The role of the interviewer is not the neutral presenter

of pre-established questions. Rather, the interviewer is actively engaged in the interview, probing to clarify concepts, and extending the meaning of respondents' statements to ensure that they are correctly interpreted. The task of the interviewer is to motivate the respondent to say as much as possible about the discussion topic. Questions are open ended and may begin quite generally, becoming more focussed as the interview progresses. The course of a semi-structured interview cannot be entirely planned in advance. Thus, a major problem is that important points may be missed in the flow of conversation. The interviewer must keep the essential topics in mind and ensure that they are covered adequately. An interview guide will remind the interviewer of the main interview topics and provide sample questions to begin the conversation on these topics.

- **Unstructured:** Unstructured interviews are often used in combination with observational techniques in order to achieve a broader understanding of the world or cultural meaning systems of a target population. In program evaluation, they may be used in conjunction with participant observation to understand how a program is delivered. Like semi-structured interviews, they are free flowing. Unlike semi-structured interviews, they do not have a prescribed set of topics that need to be covered. Rather the goal is to uncover the areas that are of interest to the interview subjects. A good example is an oral history that has the goal of understanding the life history and living situation of a particular individual.

Chapter Summary:

In this chapter we have provided an overview of two qualitative techniques that can be used to conduct needs assessments for anti-stigma programs, as well as in a variety of other situations throughout the course of your program. Focus groups and in-depth interviews share a common strength in providing rich, detailed, qualitative data. The nature of the inquiry (whether it be at the group or individual level), resources available, privacy issues, and other respondent characteristics will help in the selection of methods.

Chapter Checklist

- ✓ Assess local needs using a qualitative approach.
- ✓ Formulate the main question
- ✓ s that will guide your qualitative needs assessment.
- ✓ Identify eligible participants.
- ✓ Develop questions and probes to be used by facilitators/interviewers.
- ✓ Select a facilitators (for focus groups) and interviewers (for in-depth interviews).
- ✓ Recruit participants and conduct sessions.
- ✓ Decide on level of analysis: in-depth, exploratory, or high-level.
- ✓ Use results to plan baseline surveys and focus program interventions.

3

How to Assess Local Needs With Surveys

Survey data can provide a broader context for the qualitative observations obtained through focus groups and interviews. Whereas qualitative techniques give answers to questions about "what", surveys answer the question of "how much". In most cases, surveys will form the second step in the needs assessment process. Once you understand the nature of the problem, knowing its frequency and distribution in a potential target group is essential to effectively focusing your program.

The WPA Program guide recommends that the Local Action Team undertake a baseline survey. The main aim of the survey should be to understand the scope, nature, and distribution of people's experiences with stigmatizing behaviours. Information on knowledge and attitudes may also be collected, however, these are less relevant as targets of change since they may be at odds with behavioural expressions of stigma.

The survey should be conducted prior to developing specific objectives and program materials in order to ensure that the survey findings guide the formulation of the program plan. Survey results should be used by the Local Action Committee to formulate and target interventions. It is not intended to be an epidemiologic survey. Therefore, it is important not to spend excessive time or resources on this activity.

The baseline survey is also essential for providing a benchmark against which the program's outcomes will be evaluated. This is described in more detail in Chapter 6 on Evaluating Program Results.

Working With Survey Research Firms:

The Local Action Committee may have members with experience in developing and conducting surveys. However, besides scientific and methodological know-how, the complexity of survey work requires considerable other resources, such as organizational support. Reputable survey firms have especially trained interview crews, and trained survey staff including supervisors and office workers, who are able to steer the survey through the field work. Some firms also have telephone facilities to conduct large telephone surveys. Committee members usually do not have these resources. This makes external survey firms an attractive alternative to conducting your own survey. Therefore, the Local Action Committee may wish to engage an external research firm.

The following sections outline the steps to be taken when engaging an external research firm from the perspective of a very close collaboration between the two parties in which all steps are closely monitored and supervised by designated Local Action Committee members. We recommend that a close collaboration be established to ensure that appropriate data are collected and appropriate analyses conducted to support the needs of the program.

Step 1: Select a survey firm.

In most countries, survey firms are organized in associations which can provide membership directories to help you locate a reputable firm. Select and contact several of the firms listed. Provide all of your selected firms with a project proposal detailing your survey and ask to be provided with a detailed cost estimate. Check each budget plan carefully to ensure that they are comparable and that all of the necessary tasks and their costs are listed. Keep in mind that the cheapest way is not always the best way. Good surveys are cost-effective compared to other forms of research, but rarely inexpensive. To obtain further information about the selected firms, contact former customers for a reference. Based on the cost estimate and references, select one firm.

Budgeting your survey

Many design decisions are affected by the budget available to conduct a survey. The following list provides an example for different costs that arise while conducting a survey. Its is not a complete list of all possible survey costs but might be helpful to set up one's own list to evaluate cost estimates provided by potential survey firms:

- Staff: The costs for the researchers who will be steering the survey through all of its phases, including but not limited to planning, supervision, monitoring, analysis, reporting, and any materials costs.
- Sample selection: This includes costs for creating or buying listings of sampling units.
- Pre-test: The interviewer and material costs associated with pre-testing your survey instruments and methods.
- Printing: Production costs for questionnaires, advance letters, thank-you notes, interviewer materials, interviewer manuals, and coding notes.
- Postage: Mail costs for mail-out surveys, advance letters, and thank-you notes.
- Interviewer Costs: Personnel costs for all interviewers, training costs, materials, travel, and subsistence.
- Data processing: Personnel costs for data entry, data checks, data editing, and any material costs associated with data processing.
- Data analysis: If not already covered by the costs of researcher time, additional costs may be charged for analysis and reporting.
- Fieldwork monitoring costs: If not already covered in researcher supervision.
- Quality control: Some firms will re-do a portion of the interviews as a quality control procedure.
- Follow-up of non-respondents
- Incentives for interviewees.

Step 2: Sign a contract.

Having received and carefully reviewed all cost estimates and selected a survey firm, it is advisable to fix all agreements with a written contract. The contract should include all tasks, responsibilities, deliverables, such as:

- sample design specifications and sampling frame,
- data collection specifications such as the number of respondents, interviewing mode, interviewing staff,
- interviewer payment,
- respondent contact procedures,
- interviewer training,
- quality control procedures such as re-interviews, reporting requirements, data deliverables,
- price for the survey, and
- terms of payment.

Step 3: Prepare for field work.

After contracting a survey firm, many other tasks must be planned and prepared before the field work starts. One important task is to organize the field work process. A schedule for the field work period that includes all the different tasks to be performed and their delivery dates should be set up. The underestimation of time needed to conduct a survey is probably the most common error in planning a survey, and it will have serious consequences for the success of the entire project if the time envisaged for the survey is insufficient.

Before field work can start, the survey firm has to prepare the sampling frame to get the contact information needed to enumerate the population and draw the sample. The sample selection process has to be monitored closely by the investigator to ensure that the chosen sampling frame represents the target population of interest to the program, rather than the one most easily accessible to the survey firm.

Ensure that the survey firm sends an advance letter to eligible households or individuals informing potential respondents that they will be contacted by an interviewer. Provide the survey firm with the wording for the advance letter and all other documents and questionnaires that will be used throughout the survey.

Interviewer selection, training and supervision

Next, select the interviewers and train them. For the interviewers, field work begins when they set out to the sampled household or individual. It ends when they return the completed questionnaire or when their efforts to obtain an interview finally proves fruitless. The weak spots in field work occur where the investigator or survey firm has only indirect influence on events such as when interviewers select target households or respondents or in the contact and implementation phases of interviews. Thus, interviewers have to be trained carefully in how to administer the questionnaire and how to contact respondents.

Survey firms often have a pool of interviewers from which to select possible interviewers for your survey. Ideally, the crew of interviewers selected should be of similar sex and age as your prospective respondents as this will reduce interviewer bias. It is also advisable to recruit and train a much larger number of interviewers than is actually needed for the survey. This permits the replacement of interviewers if needed, or the addition of interviewers during the field work to speed up the process without organizing further training sessions.

Exhibit 8: Advance Letter to Participants in a Telephone Interview

Dear Sir or Madam,

Researchers from [Organization name] are conducting a survey of people in [region/country]. The survey will ask for your opinions about mental illnesses and their treatments. This project is funded by [Name funders]. You will be contacted by telephone by an interviewer from [Name of external survey firm] to determine whether or not someone in your household is eligible to participate. Your household was randomly selected from [name source].

Those who are eligible will be invited to participate in an interview that will take about [Interview duration in minutes]. All participants will get a check for [Value of incentive] as token of our appreciation for their time and participation in this important project.

Your participation is very important. We want to include the ideas of a wide variety of people, but can only interview people from a limited number of households. Participation is completely voluntary. Results will be aggregated statistically so that no individual will ever be identified. Your responses will remain completely anonymous.

If you have any questions about the research project, please contact [Name of the contact person, position], at [Telephone number] or [Name of the contact person, position], at [Telephone number]. Thank you for considering this opportunity to participate in this important research project. We hope to talk with you soon.

Sincerely,

[Signature, of the person in charge of the project]]
[Name of the person in charge of the project, position]

Exhibit 9: Example for a Simple Field Work Schedule

	Weeks from the start											
Task	1	2	3	4	5	6	7	8	9	10	11	12
Specify information needs												
Create project proposal												
Create sampling design												
Select questionnaire or write items and scales												
Compose questionnaire												
Pre-test questionnaire												
Revise questionnaire												
Print questionnaire												
Prepare and copy materials (e.g., rating scale cards)												
Select survey firm												
Ship materials to survey firm												
Train supervisors and interviewers												
Data Collection												
Receive and sight-edit questionnaires												
Verify response of part of sample (re-interviews)												
Data editing and entry												
Create data analysis plan												
Run statistical analyses												
Inspect and analyze computer outputs												
Compose report tables and graphs												
Write narrative text of report												
Assemble and duplicate report												
Deliver final report												

Data collection may be longer if the sample size is bigger. (From: Alreck PL; Settle RB. The survey research handbook : guidelines and strategies for conducting a survey. 2.ed. Burr Ridge: Irwin, 1995.)

Interviewers have to be carefully trained before conducting their first interview. The training should familiarize interviewers with the questionnaire and all other materials used in the focus group investigation. In addition, interviewers must be informed about the purpose of the survey trained to follow all instructions and procedures given in the interview manual. To ensure data quality over the whole fieldwork period, it is absolutely necessary to look at every facet of the survey fieldwork. Effective supervision of interviewers requires both observing the process of interviewing, and checking the results of the interviews. Thus, mandatory checking routines should be implemented in the fieldwork process to assure frequent and early checks. Each interviewer has to be checked. If irregularities appear, the interviewer will need closer supervision and additional coaching or training.

There are two ways to pay interviewers: per interview, or per hour. Paying interviewers by interview means that those who are most productive earn the most, but this also encourages interviewers to rush through their interviews in order to earn more. A disadvantage of paying interviewers by the hour is that it can lead to longer interviews and longer breaks. An hourly payment requires more supervision. However, an important advantage of paying the interviewer by the hour is that respondents who are harder to reach and interview are not avoided by the interviewer. This can yield more contact attempts with hard-to-reach individuals and increase the response rate.

Step 4: Monitoring and control.

The essence of survey research is finding interviewees and persuading them to be interviewed. Good quality data are the prerequisite for all subsequent activities. However, at no stage in a project will you have less influence on the outcome than during data collection. It is sometimes difficult to tell what efforts interviewers have made to recruit interview subjects, and in face-to-face interview situations, the actual data collection is only partly controllable. If a survey firm is assigned to conduct the survey, you are even further removed from field work. Thus it is imperative to develop a plan for controlling the quality of the field work at all stages and to detect any errors that might occur. This is particularly important at the early stages of the survey, when mistakes can be corrected with little impact on data quality. Aspects of the research that the Committee members should ensure are monitored and appropriately include:

- contact records of the interviewer outlining contact attempts and the result of each contact;
- results of re-interviews with a percentage of respondents that have been cross checked to the original data;

- interview timing;
- non-responses, if feasible, by asking some key questions to those who choose not to participate;
- interviewer specific response rates;
- returned questionnaires to ensure they are complete; and
- data errors, identified by preliminary analyses of data that are entered as the project progresses.

Whenever inconsistencies or errors are detected, get back to the survey firm for clarification.

Some general remarks about the collaboration with external survey firms

Survey firms are businesses, so will attempt to maximize their profits. This may be in conflict with your needs for the highest possible data quality. During the field work process, a situation might arise where closer quality control is needed, but the budget for the survey firm is already exhausted. To meet your request, the survey firm will have to increase their effort without being paid. They will want to avoid implementing extensive checking routines after the survey has begun. Good collaboration with a survey firm is the cornerstone for a successful high-quality survey. This requires in-person and telephone contacts. Make sure that you leave sufficient time to build rapport and to remain involved in the survey process. Insist on being informed of all problems that occur and being a party to their solutions.

Analyzing Survey Data:

Although data analysis is one of the last steps in the survey process, it is advisable to plan the analyses at the outset. This will ensure that the right data are collected and in the form that is needed for the analysis. The complexity of survey analyses can vary. For assessing local needs, descriptive results showing levels of stigmatizing behaviours and practices in the sample as a whole, and in sub-groups defined on the basis of relevant social and demographic characteristics is usually sufficient.

Data entry and management

The first step in any analysis is to enter the data and ensure that it is correct and in the format required for the analysis. Survey analysis cannot easily be done by hand. Computer data entry programs are widely available. For individuals wishing to enter and analyze their own data, we recommend Epi Info which has been developed as part of a joint initiative between the World Health Organization and the Centres for Disease Control in the United States, and is freely available from the Centres For Disease Control website. This software contains all of the programs required to enter, verify, and analyze survey data including features for complex survey designs that require the use of population weights.

If an external survey firm has been contracted, you will receive a copy of the data file that has already been entered and cleaned. You may negotiate the file format. For example, if you wish to conduct additional analyses (outside of any contracted with your survey firm), you may wish to have your data file in a format that is compatible with Epi Info (such as .dbf) or any other software program that you are planning to use.

Judging the representativeness of the sample

Describing the socio-demographic characteristics of the sample by gender, age group, and any other social variable collected is one of the first tasks to be performed once the data collection and entry are complete. A comparison of the socio-demographic characteristics of the sample with similar data describing the characteristics of the population from which the sample was drawn will tell you whether the sample is representative. In many countries, population characteristics are available through national statistical reporting or census information.

The first table that you will want to have created is a comparison of your sample with the census population by gender and age group. Discrepancies of greater than 5% between the sample proportions and the population proportions are usually cause for concern since they may reflect a response bias (or error) in the sample data. Given that non-respondents and respondents may differ in their answers to the main survey questions, you may be left with an inaccurate picture of program needs. If the sample is not representative, then the results may be weighted to correct for any imbalances. The rationale behind weighting and the procedures and sub-routines required to conduct weighting are described in the Epi Info program documentation.

Describing stigmatizing behaviours and experiences

Once you are sure that your sample is representative (or have made the necessary corrections), you may begin the descriptive portion of the analysis. At this stage you want to understand the key characteristics of your sample with respect to your stigma and discrimination variables. Because stigma and discrimination are known to differ depending on gender and age, your analysis should examine these for each gender and age group, as well as any other characteristics that may be helpful for targeting your program. If you have a long survey questionnaire, you may generate a considerable number of tables. Thus, one of the important tasks for the research team is to decide, in advance, which descriptive analysis are the most important for targeting the program.

Exhibit 10: Age and Gender Distribution in a German Sample Compared to the Population

Characteristic	Sample % (Total)	Population % (Total)	% Difference
Age Group:			
▪ 18-24	10.5% (453)	9.5% (6,312,400)	1.0%
▪ 25-44	35.9% (1559)	38.9% (25,768,600)	-3.0%
▪ 45-49	23.3% (1011)	23.9% (15,848,800)	-0.6%
▪ 60-64	10.0% (434)	8.0% (5,295,000)	2.0%
▪ 65+	20.3% (882)	19.7% (13,067,400)	0.6%
Gender			
▪ Male	50.3% (2182)	48.2%(31,921,700)	-2.1%
▪ Female	49.7% (2157)	51.8% (34,370,400)	2.1%

The largest percentage difference between the sample and the population from which it was drawn is 3.0% reflecting a slight under-representation of people aged 25-44 in the sample. Since all of the discrepancies are under 5% this sample probably should not be weighted to correct for imbalances. However, to be sure, the researchers may wish to verify some of their key findings with and without the weighting procedure just to make sure that it does not appreciably alter the main results. Otherwise, the sample looks fairly representative.

Writing the survey report

Once the analysis is complete, findings should be summarized in a report that contains several sections. The Local Action Committee will be in the best position to write the first and last sections (Introduction and Conclusions). If an external survey firm was contracted, they will have to provide the middle sections describing the design and methods used. The main sections to be included in a survey report are as follows:

- Introduction: What was the purpose of the survey? Indicate why there was a need to conduct this survey, specifying the conditions and problems that have led to the collection of the data.

- Method: Who was asked and what was done? The methods section should contain sufficient detail for you or someone in another site to replicate this survey. The report will need to explain in detail how the survey was conducted, how the sample was chosen, how questionnaires were developed and tested, how data were entered and managed, and what analyses were performed.

- Results: What was found? This section should present each of the key tables. Each table should be introduced indicating why it was created (what it is supposed to show), and the highlights of what it does show. If statistics have been used, ensure that these are presented in a simple language that community stakeholders will understand. Graphs and figures are preferred to convey key or complex findings.

- Discussion: What does it all mean? Indicate how you interpret your findings with respect to your anti-stigma program. What do they mean for your intervention? How will you target your anti-stigma effort now that you have these results? What are your next steps? Are there any limitations to the survey that the reader should know that would help them interpret what you have presented.

If you are preparing your findings for an academic publication, you will want to check the instructions to authors for the journal you wish to target to ensure that you have used the correct style, format, and length. For other reports, it may be useful to follow a 1:3:25 rule: one page of bullet points outlining the key messages that can be used to give to key decision makers; a three page executive summary that you may need to provide to potential funders and the media; a 25 page detailed report containing all of the background and findings.

More information on the 1:3:25 rule can be found on the Canadian Health Services Research Foundation webpage at www.chsrf.ca.

Targeting the Program Using Survey Results:

Anti-stigma programs may either target changes at the interpersonal level in people's knowledge, attitudes, or behaviours, or they may strive for legislative or policy change. Stigma is complex and multi-factorial. Knowledgeable and enlightened people can still stigmatize. Therefore, improving fact-based knowledge or changing a popular misconception will not necessarily reduce stigma overall, and it may have little impact on discriminatory policies or legislation. The most effective anti-stigma efforts will be carefully targeted, aimed at changing the way in which specific sub-groups act toward people with a mental illness, or toward changing discriminatory policies. The most important changes are those experienced by consumers and their family members in their day-to-day lives.

The cost and the impacts of an anti-stigma program will depend on the targets and the approach to be used. The larger the population group to be reached, the more expensive and diffuse the message, and the smaller the impact. The more focused the population group, the less the cost, the more detailed and complex the message, and the greater the impact. Therefore, a key to success is a carefully targeted program.

The importance of targeting your program to achieve specific objectives with specific population sub-groups groups cannot be overstated. Stigma is not uniform. Different groups in the population hold different opinions and attitudes and behave in different ways. To fight stigma efficiently, groups that are most stigmatizing toward the mentally ill must be located and their behaviours clearly understood. The more precisely the target group can be defined in terms of behavioural correlates, such as socio-demographic, attitudinal, or experiential characteristics, the easier it is to develop other elements of the program plan.

Exhibit 11: Community Attitudes Toward People with Schizophrenia in Canada

Characteristic	Men % of 785	Women % of 868	Total % of 1653
Knowledge: To the best of your knowledge, what causes schizophrenia?			
▪ Brain disease	40.8%	47.7%	44.4%
▪ Other biological factor	13.9%	14.7%	14.3%
▪ Psychosocial factor	7.8%	9.9%	8.9%
▪ Don't know or exact cause unknown	37.5%	27.7%	32.5%
Attitudes: All things considered, people with schizophrenia frequently or often…			
▪ Can be successfully treated outside of hospital in the community	64.5	73.7%	69.9%
▪ Tend to be mentally retarded or of lower intelligence	8.2%	10.9%	9.6%
▪ Need prescription drugs to control their symptoms	78.8%	87.5%	83.2%
▪ Can be successfully treated without drugs using psychotherapy or social interventions.	36.7%	29.9%	33.2%
▪ Suffer from split or multiple personalities	46.9%	47.5%	47.2%
▪ Are dangerous to the public because of violent behaviour	14.4%	20.5%	17.5%
Social distance practices:			
▪ Would feel ashamed if someone in my family was diagnosed with schizophrenia	6.9%	6.6%	6.7%
▪ Would feel afraid to have a conversation with someone who has schizophrenia	11.4%	11.9%	11.6%
▪ Would be upset or disturbed about working on the same job as someone with schizophrenia	17.5%	14.9%	16.1%
▪ We be unable to maintain a friendship with someone who has schizophrenia	19.0%	17.1%	18.1%
▪ Would feel upset or disturbed about rooming with someone with schizophrenia	46.2%	47.7%	47.0%
▪ Would not marry someone with schizophrenia	71.9%	78.3%	75.2%

Exhibit 11: Continued….

This table shows a number of interesting patterns that could be used to target an anti-stigma intervention. First, the population is generally knowledgeable about the causes of schizophrenia. Therefore a public education campaign designed to improve knowledge is unnecessary and likely to be unsuccessful. Second, enlightened attitudes co-exist with stigmatizing attitudes suggesting that interventions will need to be complex and carefully targeted. Broad based population campaigns that use generic messages are unlikely to be cost-effective. Third, women are more likely to emphasize treatment using prescription drugs but also more apt to perceive a risk from violence from people with schizophrenia. Fourth, the closer the interpersonal relationship with someone with schizophrenia, the more uncomfortable people are. Most would not marry someone with schizophrenia.

Source: Stuart H, Arboleda-Flórez J. (2001) Community Attitudes Toward People with Schizophrenia. Canadian Journal of Psychiatry, 46: 245-252.

The number of target groups should not outstrip resources or the capacity of the Local Action Committee to address. For many programs, three target groups has proved to be a reasonable number, but one may be sufficient. Survey results should be used to segment the population into these smaller, more clearly defined sub-groups.

In choosing program targets, it is important to create opportunities to achieve small, early successes. This helps to maintain enthusiasm among group members and serves as an important evidentiary base for demonstrating to the community that stigma can be beaten. As successes accumulate, you may use these to solidify program resources and increase the program's local stature. Early failures can be devastating if you are also trying to consolidate volunteer time and develop a resource base. Begin small with relevant population sub-groups. An attempt to change attitudes and practices in the population as a whole may quickly outstrip the capacity of the local program and doom the entire exercise to failure.

Chapter Summary:

In this chapter we have outlined the steps involved in conducting the baseline survey work needed to target an anti-stigma program. We have emphasized working with an external survey firm as most Local Action Committees have neither the time nor the resources to mount their own surveys. In order to ensure high quality data that meets program needs, we

have also emphasized maintaining a close cooperation with the external survey firm in all aspects of the survey work.

Chapter Checklist

- ✓ Obtain a list of survey firms from a membership directory (yellow pages or advertisements), select a few, send them a survey plan and ask them to provide a cost estimation for the intended survey.
- ✓ Ask former customers about their experiences with the survey firm.
- ✓ Decide on a firm and make a contract that covers all duties, tasks, activities.
- ✓ Send copies of all materials (questionnaires, interviewer manuals.) to the survey firm.
- ✓ Insure that the survey is executed according to its design.
- ✓ Supervise interviewer selection and training.
- ✓ Sight-edit data immediately after data entry and review preliminary data analyses to detect errors and insure it meets your needs
- ✓ Keep in close telephone and meeting contact with the survey firm.
- ✓ Use data to segment your audience and target groups for intervention.

4

How to Create a Program

Synthesizing Available Information:

Once the Local Action Committee has completed the needs assessment process, understands the nature and extent of local problems, and has agreed upon specific target groups, the next step is to develop the interventions that will be used to fight stigma and discrimination in these groups. In order to ensure that all programs are based on the best available evidence for what works and what doesn't, the Local Action Committee should now conduct a literature review. The aim is to compile all state-of-the-art literature and materials suitable for an anti-stigma program relevant to the target groups chosen. Materials should be sought from sources such as community agencies, regional and country-wide healthcare systems, consumer and family initiatives, partners from other institutions, and the published scientific literature. Regional and country-wide libraries and other institutional database systems can be helpful. Published research and dissertations about stigma contain extensive reference lists. These can be reviewed to identify additional publications and materials. An extensive bibliography about stigma and discrimination because of mental illness, especially schizophrenia, can be obtained from the World Psychiatric Association's Global Stigma Program (www.openthedoors.com).

In reviewing the literature, the goal is to identify successful interventions that have been used with groups similar to those targeted by your program, and understand the ingredients for success. If you are planning to adopt an existing approach you need to ensure that it will work within your local environment, which may be different from the one in which the original program was developed and initiated. Evidence for program effectiveness in the literature may be contradictory, depending on the quality of the study design and the analysis used. Access to research expertise will be helpful to focus on the most promising approaches.

Developing Realistic Goals and Objectives:

Goals are general statements of aims. For example, the goals of the World Psychiatric Association's "Open the Doors" program are three-fold:

- Increase 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 stigma and discrimination against those with schizophrenia and their families.

After reviewing the local needs assessment data, the Local Action Committee will come to a consensus concerning the group or groups that should be targeted and the broad goals in doing so. From the review of the literature, they will understand which approaches are likely to be feasible within their community. With this background, short-term objectives may be formulated for each target group. Objectives are the specific and measurable ways in which your program will actualize the broader program goals outlined above. For example, you may wish to improve tolerant attitudes of high school students by 10% as measured using a particular attitudinal measure.

Objectives should be:

- Specific;
- Priorized;
- Feasible given available resources, personnel, and time; and
- Measurable to allow for an evaluation of the program against a percentage change from some baseline level or in terms of reaching a pre-defined threshold or criterion.

Once objectives are set, Local Action Committee members can keep an eye on the political, social and cultural events in their community in order to identify opportunities to promote the program's objectives through external collaboration. Collaborations will increase the scope and relevance of the program while reducing costs.

Focusing on a Target Audience:

Target audiences must be well-defined and specific, and intervention strategies must be matched to the needs of the target group. Different groups will have different needs.

Focusing on the needs of target audiences heightens the feasibility of the program as well as its probability of success. Use the results of the survey to segment target audiences by demographic, geographic, social, psychological and other relevant characteristics. It is important to anticipate whether different segments may react differently to your proposed intervention or may prefer different modes of program delivery.

It is important to focus on groups that have frequent contact with people with schizophrenia or their family members, and groups that create the strongest negative effects, because even small changes in these groups could make an important difference to the quality of life of people with schizophrenia. For example, people with schizophrenia may report feeling more stigmatized by health care professionals than members of the general public, or they may experience a particular housing or social benefit policy as discriminatory and especially damaging to their ability to live independently in the community.

Choosing a program approach:

When program objectives and target groups are clear, and when the Local Action Committee is well versed in the scientific literature outlining effective interventions, then a specific program approach can be chosen, adapted, or developed. The program approach must fit with the needs of the target group, must be acceptable to them, and it must be based on sound reasoning. If, for example, people in the general public are known to be highly knowledgeable about the causes of schizophrenia but still hold stigmatizing attitudes, it makes little sense to develop a public education campaign designed to further improve their knowledge of schizophrenia. If stigmatizing attitudes are deeply entrenched and difficult to change, then a 30-second radio commercial is unlikely to have sufficient impact. The program must have an internal logic that makes sense in light of what is known about the problem and potential solutions. In short, the intervention must be appropriate and delivered in a sufficient quantity to make a difference.

Connecting with Your Target Audience:

Every target group needs its own communication strategy which is designed to connect with them in the most efficient and effective way possible. For example, if young school children are the target group, then announcing an anti-stigma event in the local newspaper may not be the most efficient and effective way of getting the message across. Distributing posters at local schools, sports clubs, or other places where school children meet might be a better strategy.

Exhibit 12: Setting Up A Communication Strategies Group

In São Paulo, Brazil, a Communication Strategies Group holds weekly meetings. The team was created at the beginning of the project and is composed of people with schizophrenia. The group is coordinated by a mental health professional and receives regular collaboration from family members and media professionals. The group develops print material and outreach activities such as writing articles, creating a bulletin, organizing the program website, and giving interviews for local press and radio programs. The Team also works as a reception group, welcoming potential collaborators to the program, discussing strategies with representatives of target groups, and collecting ideas for future action. The work involves considerable reading and discussion concerning themes that will generate written material or messages. Print material available in English is translated and adapted by team members. The entire process is empowering. It builds self-confidence, reduces self-stigma, and creates a positive and fulfilling experience through active involvement of consumers who act as spokespeople for the cause of fighting the stigma of schizophrenia.

The form and content of the message is also important. Not only must it suit the objective of the program, but it must suit the particular communication style of the target group. A wide variety if strategies exist. Strategies that have been used in the context of the World Psychiatric Association's Global Anti-stigma program include, press releases, conferences, press kits, radio messages, television spots, announcements, articles in newspapers or journals, flyers, posters, brochures, information booths, letters, telephone communication, teacher manuals, classroom presentations, plays, panel discussions, workshops, and school art and poetry contests.

Working with External Media Experts:

Public relations experts with experience in planning media campaigns, especially dealing with "delicate" topics not easily accepted by the community, can be helpful. Often they will have regular means of contacting journalists. They are knowledgeable about how to set up press releases, press conferences, and other public events. They know who to contact and will have up to date addresses and mailing lists. Journalists may pay more attention to press releases provided by a known media expert.

Public relations experts are also knowledgeable about the technical requirements and equipment needed to produce and print materials such as flyers, brochures, and press kits.

They can help with the selection of target groups, matching media to these groups, and can assist the Local Action Team in segmenting audience characteristics and in creating concepts and slogans for public anti-stigma events. They will know about best places and times for public meetings and how to advertise these. In short, a public relations expert with media experience can be an invaluable advisor to the Local Action Committee, either as an external consultant, or as a committee member.

Creating Media Messages:

The Local Action Team will need to develop media messages in the form of illustrations, words, phrases, theme lines, or slogans to reflect the program's overall image and strategy. The goal is to develop a corporate identify for the program and consistently reflect this in all communications through logos and other graphic means. Therefore, media concepts should be part of a unified campaign with a single theme with common graphic and typo-graphic images that continually reflect the program's identify.

For example, if the central program theme is that schizophrenia is treatable, all communications should reflect this message in some way. Conversely, messages that are targeted to attitudes should include a common emotional element such as acceptance or tolerance. Messages should be stated briefly and clearly. Avoid all abbreviations. Always include a call-to-action with each message to allow members of the target audience to respond. In order to bring about change, it is important to tell audiences what they can do to make a difference. The strategies may be specific to the target audiences chosen. For example, strategies used by the business community to make a difference may include hiring policies that do not discriminate against people with mental illnesses, flexible working hours, better disability benefits, or employee assistance programs. Strategies used by high school students would be quite different and might include more appropriate use of language, compassionate response to their peers (rather than taunting), or better understanding of signs and symptoms so that they may approach a teacher if they are concerned about a friend.

Exhibit 13: Creating Action-Oriented Messages

A strategy used by the Canadian Pilot Program in preparing anti-stigma material was to include action-oriented statements indicating what each target group could do to make a difference. The basic information was the same for each brochure, but the target behaviours were different depending on the group. For example, the brochure targeted to the business community included a list of what "your business could do". These included items such as the following:

- Understand that many people with schizophrenia are qualified job applicants with many skills to offer, or
- Provide greater support for a family member living with someone with a mental illness.

Because those in crisis often experience strong stigma from front line emergency personnel, the brochure targeted to health professionals included the following action-oriented messages designed to provide better health care:

- No jokes or negative offhand remarks be made to the person who may already be suffering from paranoid delusions,
- The emergency room should have a private room or area where a person can be interviewed that is separate from those being treated for physical ailments, and
- The interviewing nurse or doctor listens—without prejudice—to the report from the person which may have bizarre or disturbing details.

In this way each target group is provided with a series of things that could be done to reduce stigma and discrimination. Complete brochures are available from the openthedoors.com web site.

Creating Print Material:

Program themes must be translated into complete messages and decisions must be made as to which media are best suited to communicate these messages to the chosen target groups. For communication in general, and print material in particular, the main rule is: The first impression is important! Achieving a positive first impression is half the success. Your materials must be eye-catching to your target audience. The design of the message (through illustrations, type, size, etc.) already conveys considerable information about your program.

The most successful print messages will address four items:

- Attention;
- Interest;
- Desire; and
- Action.

You first need something to attract attention, such as a visual effect or other eye-catcher. Interest can be generated with a creative catch-phrase or inventive title. The viewer must then feel the desire to accept your offer of information or participation in an event. Finally, the message must include details for action: what, when, where or how.

Attention, interest, desire and action are particularly important when print material are created such as flyers, brochures, or posters. For example, posters are an effective way to announce an anti-stigma event when distributed in the area in which your target group is located such as at bust stops, train and metro stations, institutions such as hospitals or universities, internet cafés, or pubs. Well designed posters with impressive headlines and pictures will attract attention.

The design of printed material should always be tailored to the needs of your chosen target group. For example, techno-style graffiti in violent and trendy colors would be a poor choice for a poster in a school for adult education inviting people to attend a psychosis seminar. However, the same poster may be a perfect choice if your target group is high school students.

Consultations with a graphic designer will help you design effective print materials and focus groups can help you assess the extent do which your materials convey the correct impression and meet the interests and needs of your target group.

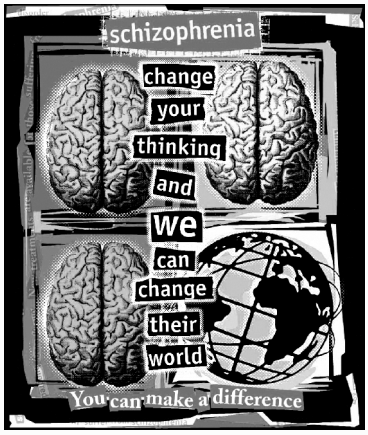
Pre-testing Program Materials:

It is important to test messages and materials among the target audiences before production. This will ensure that your materials are acceptable to your target audience and adequate to achieve your objectives. Only use the materials that you are sure meet the needs of your target group. If your program has targeted more than one group, you may need to have different approaches for each group.

Use focus groups to present your media concepts and messages to a cross-section of individuals who are drawn from your target audience. Your goal should be to identify the concepts and approaches with the most potential to attract attention and convey the correct message. Over time you will want to check back with your target audience using focus groups to ensure that you remain on track with your approach.

Exhibit 14: Pre-testing Program Materials Using Focus Groups

In preparation for a school-based program, Canadian participants commissioned a series of posters with anti-stigma messages. Posters were to be used in high schools in combination with other school activities, such as art and poetry contests, to raise awareness of schizophrenia and its stigma. Poster art was reviewed by Local Action Committee members and a favorite was chosen. Before going into production, however, focus groups were organized with high schools students to see which poster **they** preferred. Much to everyone's surprise, students unanimously selected the poster art that Local Action Committee members had considered to have the lowest audience appeal! The bold colours, graphic images, and flamboyant lettering caught their attention and the message caught their interest. This was the poster that was put into production.



Chapter Summary:

In this chapter we have reviewed the key steps involved in designing a program with particular emphasis on the need to focus on one or a limited number of target groups and develop program interventions and messages that are specific to the needs and interests of that group.

Chapter Checklist

- ✓ Review and synthesize available literature on best practices to determine what works, where.
- ✓ Develop realistic and measurable objectives that are consistent with the broad WPA program goals.
- ✓ Focus on a target group (or groups)
- ✓ Choose a program approach that is specific to the needs and interests of your chosen target group(s).
- ✓ Develop communication strategies that are eye-catching and interesting to target group members.
- ✓ Create messages that are action-oriented.
- ✓ Pretest all program materials on representatives of your chosen target group(s).

5

How to Implement Your Program

This chapter provides information on how to implement anti-stigma programs using different media. It is not exhaustive but rather focuses on the approaches that have been most widely used in the context of the Global "Open the Doors" program and demonstrated, through experience, to be most feasible or cost-effective.

Working with Television:

TV is the medium with the most "spread". If you get the opportunity to be present on TV you will have be able to reach a broad segment of the population. Because you can make your message visually appealing, television is also a potentially high-impact medium.

A challenge in working with television advertising is that you have a limited time in which to get your message across. Therefore, you need to create a message that will immediately arouse interest and leave people wanting to learn more.

There are a number of different possibilities for implementing anti-stigma messages on television. You might create one or more spots that could be presented during regular television advertising, either at the end or the beginning of a show. The ads have to contain key messages, such as mental illnesses are common and treatable or people with schizophrenia are *people* with schizophrenia.

A second approach is to try to get messages across in interviews with news reporters that are aired during the nightly news. These can deal with special themes such as new treatment approaches, innovative programming for people with mental illnesses, or social themes such as housing or employment opportunities. Try to place longer written segments in the accompanying television magazines. For this, you will have to make proposals for themes

that are interesting to the general public. It is also possible to combine television and radio messages. Television advertisements can be viewed or spoken over the radio.

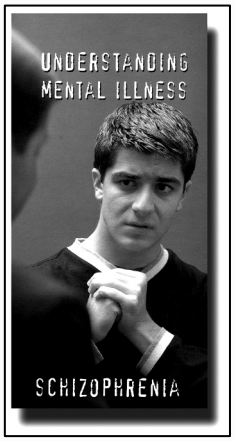
Evaluating the effectiveness of television messages can be accomplished by taking part in an overall opinion poll. The cost may be kept down by adding two or three questions about your advertisement: whether people can remember it, and whether they can recount the main message.

A second challenge in working with television is the price of the spot. It can be expensive. In general, the price will depend on the time at which you want your advertisement aired, and the season. It may be possible to negotiate for a price reduction as many television stations have this flexibility when addressing important social issues. It is advisable to work through a Public Relations agency as they will have experience negotiating with television stations, creating contracts, and may be better able to obtain a reduced fee. However, keep in mind that the Public Relations firm will also charge you for their services.

Finally, there are some general recommendations to keep in mind when purchasing television time :

- Insure that your budget has sufficient funds to cover the costs of television advertising.
- Work with a public relations agency to create a clear, good message, that will catch viewers' attention.
- Negotiate, in advance, for the best time and placement of the spot.
- Try to get a reduced price for advertising. If you cannot negotiate this yourself, work with a public relations firm.
- To reduce the costs of evaluation, plan to piggy-back several relevant questions on onto existing public opinion polls.
- Be sure that you get some additional time free of charge to place short reports in local or general news and perhaps also in magazines.
- Try to present some people suffering from schizophrenia or another mental illness who are willing to talk about their problem on television.
- Prepare, in advance, several brief messages concerning the main problems and your anti-stigma work. When your television spot is aired, you may receive telephone calls from other stations or news reporters who wish to follow-up and who will want to do this within short time lines.

Exhibit 15: Australia's *Home and Away*



SANE Australia adopted an innovative and proactive approach to television by approaching the producers and scriptwriters of a popular teenage soap opera with a script idea. In order to introduce young people to a 'friend' who develops schizophrenia, they created a story line where one of the regular characters, Joey, became affected with schizophrenia. The story developed and was ongoing for more than three months. Both members of SANE Australia and local clinicians advised on the script so the story was realistic. Non-stigmatizing behaviours were positively reinforced and Joey's successful recovery demonstrated positive outcomes.

In addition, SANE Australia's helpline number was given, a chat site on the *Home and Away* website created a link to the campaign, and the actor, Alex O'Han became involved in the publicity for the community campaign. Alex's images were used on posters and pamphlets and resources were readily available through a variety of community settings.

In the three months following the campaign, there was extensive national media coverage. There was a 100% increase in SANE Australia's helpline and online contacts. A total of 50,000 pamphlets and 3,000 posters were distributed and there was increased contact between SANE Australia and local family doctors. Schools now see the issue as relevant and are even helping SANE Australia raise funds. They have received wide acclaim from people with schizophrenia. The *Home and Away* creative team and actors also received wide acclaim including many congratulatory letters and phone calls.

Home and Away has a viewing audience of 1.5 million in Australia and 55 million world wide. By having one of the shows main characters become affected, then recover from schizophrenia, the show was able to transmit the messages that schizophrenia is an illness of young people and schizophrenia is treatable. They also showed how schizophrenia can be stigmatized, the effect stigma has on the person and the family, and, perhaps most importantly, they modeled 'good' anti-stigma behaviours.

Implementing a Radio Campaign:

Radio can be an evocative and memorable medium if used creatively, and radio advertising has advantages over other media. For certain target audiences, such as teenagers and the elderly, it can reach a broader number of people. This is typically referred to as "**reach."**

Some popular radio stations can reach as many people as television stations, but at a fraction of the cost. This lower cost then allows media planners to air your messages with greater "**frequency**." Greater repetition of your messages can lead to improved post-test scores for the number of messages noted and remembered by your target audience. The greater cost and economy also translates into the ability to have longer messages than are usually possible in television.

Compared to other media, radio also has some disadvantages as well. The nature of radio makes it a medium that is often used as a companion to other activities, such as doing chores or driving a car. This makes it all the more imperative that your message has the creativity and impact needed to capture your audiences' attention.

Like television, radio is a transitory medium. Unlike a message placed in a magazine, a newspaper, or on the Internet, it cannot be reviewed. Similarly, it is limited to content that can be read or presented in thirty or sixty seconds. Finally, because it is a MASS medium, measuring the effectiveness of a radio campaign requires a large population survey. This means it will be more expensive to evaluate the effects of a radio campaign than other more targeted interventions.

Negotiating with radio station(s)

To maximize effectiveness, radio messages should be placed on multiple stations. In some cases, a single company may own several different stations. Sometimes, these stations will have special pricing arrangements if radio spots are placed on several of their stations. However, because these stations may have dramatically different audience characteristics (or "demographics"), it's important to have a clear picture of the overall demographics and ensure that they match your program targets.

Most stations provide price discounts the more commercials you purchase, so you can achieve significant savings with quantity purchases. All of these costs will be presented on "**rate cards**". In addition, some countries have passed legislation requiring companies with radio licenses to set aside a certain percentage of their time for public service messages. Unfortunately, some radio stations leave these spots for late night or early morning slots where fewer listeners are tuned in. But this placement too might be negotiated with some stations.

Selecting a radio station

Before selecting a radio station, be sure to ask a few questions. Do the demographics of that station match the demographics of the target audience you hope to reach? You should carefully reconsider any station that cannot provide demographic information on its listening audience. How broad is the geographic reach of your radio station? Typically AM stations will have broader reach than FM stations. You may also want to consider whether there are particular programmes or times better suited for placement of your promotional messages. Some issue-oriented talk radio programmes, for example, might be ideal for your anti-stigma message.

A frequent measurement used by advertising firms and agencies is **cost-per-thousand.** This reflects the cost of a single placement divided by the number of listeners (in thousands) to that station at that particular time.

Selecting a message format

There are three main message formats:

- A pre-recorded message supplied to the radio station, or in some cases, produced BY the radio station to your specifications. Pre-recorded messages allow you control over how a message is spoken, delivered, and those elements surrounding the message such as music, or addition of other voices or sound effects to enhance the attention-grabbing nature of the spot.

- Announcer-read spots. Some radio stations also allow radio spots in the form of scripts that are read by on-air personalities. The advantage of this type is that a popular on-air personality can enhance the importance and credibility of your message. For anti-stigma messages this is a difficult balance to achieve. The goal is to ensure that the message is properly delivered so that stigma is not inadvertently increased through non-scripted comedy and jokes.

- A Doughnut. This is a hybrid of the first two. It allows you to have a pre-recorded portion at the start and the finish of the message with a central portion in which the announcer can read a scripted message.

Selecting a media schedule

When preparing a media schedule, it is useful to remember that rates are typically calculated in different "**day parts**". The morning and late afternoon times when commuters in urban centers are on their way to work are typically the most listened to, and thus highest-priced spots. Working from rate cards provided by the radio stations, you can often buy a certain number of spots at certain times of the day, or "**blocks**" of radio spots. To achieve the maximum efficiency from the placement of radio, repetition is extremely important. For that reason, it is generally recommended that radio spots be repeated over and extended period of time.

Implementing the plan

The following are three general recommendations to keep in mind when purchasing time for radio broadcasts:

- Be sure to plan on reserving the placement one full month in advance. Often, people want to place messages on the radio a week or two weeks in advance. While space MAY be available, the cost may be higher and placement may be in an undesirable timeslot.

- Ask the station to provide a schedule of times when the spots will be run so that a member of your working group can monitor the placement.

- To reach the broadest audience possible from a single station you may want to alter your media schedule in different "day parts" over the course of the programme.

Working with Journalists:

The task of working with journalists will be greatly simplified if a journalist is included in the Local Action Committee.

It is often feasible and productive for members of the Local Action Group to meet with the editorial board of the local newspaper. Such a meeting allows Local Action Group members an opportunity to describe the goals and activities of the anti-stigma program, and will increase the level of awareness of key staff of the newspaper concerning stigma and its consequences. For this meeting, it useful to provide the executive summary of your plan

highlighting the ways in which the newspaper could help you realize your goals. For example, this meeting could lead to:

- the publication of an editorial in the newspaper about stigma or about the program,
- an invitation for members of the Action Group to write a guest opinion in the newspaper,
- the provision of useful information to the Action Group about what channels to follow to publish their messages related to stigma and the program (e.g. press releases and letters to the editor).
- opportunities to communicate information to journalists about the ways in which the news media may inadvertently heighten stigma (e.g. association of mental illness with violence or the incorrect use of the term "schizophrenic" to mean "contradictory" or "split personality").

Journalists often complain that they don't know whom to contact when they want to write a story about mental illness. Therefore, your program should attempt to identify local journalists who are interested in the issue of mental illness and stigma and assist them in writing human-interest stories on this theme. Toward this end, it is useful to create a list of experts who can be contacted in such a situation, and to distribute the list to the local newspapers, radio stations, and TV news channels. The list should include people with mental illness and their family members (who have consented to be contacted), and professionals. The list can be sorted by category (e.g. schizophrenia, suicide). The list should be updated and redistributed at regular intervals.

Working with Schools:

The task of working with schools will be greatly simplified if a teacher, School Board member or pupils are included in the Local Action Group.

School-based programs are attractive because they often present the prospect of creating permanent policy change. Opportunities to change the health or science curriculum to include correct information about schizophrenia and other mental illnesses should be grasped eagerly. The creation of such an opportunity would require Local Action members to forge working alliances with School Board members, school principals, and teachers. Often a single teacher can make the difference in navigating the system and in advocating for internal change.

To gain access to high school students, Action Committee members should meet with school principals and teachers to promote the concept of stigma reduction in mental illness as an important element of the acceptance of diversity. Many schools have priorities to provide training in this area.

The point also can be made that mental illness is a neglected area in health education. It has been noted that elements of mental health as part of the curriculum on health in schools is not included or is underrepresented. Where it is included, the materials are often outdated or factually wrong. The teaching is commonly very theoretical and mental health elements are presented in a negative light, such as substance misuse, or the negative impact of masturbation, rather than focusing on positive aspects such as benefits derived from having a positive attitude to life, the planning of healthy recreational activities, or the enjoyment of friendships. School districts usually relegate mental health to the last years of schooling within the health curriculum and they may not too keen on revisiting the curriculum or participating with community initiatives.

Steps to tackle these problems include:

- School districts should be encouraged to review their mental health curricula and to start presenting mental health elements at a very early age as part of the health curriculum.
- District Mental Health authorities should invite school teachers for discussions on curriculum development and target enthusiastic teachers for further learning on early identification of mental difficulties.
- Oftentimes school psychologists do not interact with teachers at the level of curriculum and teaching of mental health elements. An increased cooperation between these two groups should be encouraged.

In working with students in the schools, suitable messages to communicate might be:

- No-one is to blame for schizophrenia (a message about causes);
- People recover from schizophrenia (a message of hope); and
- People with schizophrenia are <u>people</u> with schizophrenia (a message of humanity and caring).

It can be helpful to set teaching about schizophrenia in the general context of the acceptance of differences in the schoolroom, identifying stereotyping and stigmatizing attitudes to other conditions such as wearing glasses or physical defects, by conducting sensitization exercises.

Successful media for reaching students in the schools include:

- A speakers' bureau of people with mental illness, their family members and professionals.
- A teaching guide on schizophrenia for teachers, such as was developed for use in the Calgary, Canada, anti-stigma project.
- The WPA global anti-stigma project webpage (www.openthedoors.com) which has access doors for different types of users: teenagers, health professionals and consumers and family members.
- A competition for high school students to produce anti-stigma materials. Winners can be awarded prizes at a public award ceremony, winning materials can be used for anti-stigma posters on buses, and winning art can be displayed in prominent community settings, art galleries, and schools.
- Posters promoting the program and advertising the competition can be posted in the high schools.

For reaching teenagers outside the schools, suitable media include:

- Slides shown with the advertisements preceding the main feature in local cinemas. Such a program in Boulder, Colorado, proved extremely cost-effective in promoting messages which were recalled by very large numbers of the target audience.
- In the U.S., interior bus advertisements, like cinema advertisements, reach a predominantly younger audience.
- Radio stations that target younger listening audiences.

Working with Health Professionals:

People with schizophrenia and their families often identify health professionals as stigmatizing. Because they are in contact with them at a time of crisis or vulnerability, stigma and discrimination from health professionals can be particularly devastating.

Health professionals are notoriously busy and difficult to approach with mental health messages. Often, mental health is not a priority. Therefore, they present one of the most strategically located yet challenging groups for anti-stigma efforts.

In the Canadian Pilot Program, health professionals working in hospitals were targeted. Local consumers worked with local actors to create a play entitled "Starry, Starry Night" depicting what it is like to have schizophrenia. The play also depicts interactions with health staff at the emergency room. These were shown during brown bag lunch sessions in the auditoriums of each of the local hospitals. All staff were invited to attend. They were well attended (so reached significant numbers of their target audience) and the play was well

received. While originally intended only for this purpose, players have received multiple requests for additional performances and now travel all over the country giving performances to any interested audience. Recently they were placed on the program of the national psychiatric association where they were able to connect with psychiatrists and other mental health professionals.

It is also possible to connect with health professionals during their training, through medical and nursing school curricula. However, given busy teaching schedules, it may be difficult to obtain teaching time, at least initially. However, perseverance pays off.

Working with Families:

Throughout the world, families are the principal caregivers of people with schizophrenia, although the proportion of patients who live with relatives varies from nearly 100 percent in traditional societies, to less than 50 percent in western cities. The degree to which families are organized into associations also varies greatly. In the USA, for example, the National Alliance for the Mentally Ill has thousands of members and considerable political power. In many African countries, there is no national association for family caregivers. Where a national organization exists, there may well be a local group in the area chosen for the anti-stigma program. Liaising with such a group is an essential step in gaining co-operation of families.

Many families do not join support or advocacy groups, particularly working families and those who belong to ethnic minorities. Joining a group is itself an indication of openness about the term schizophrenia and a willingness to combat stigma. It is important to remember that many families have experienced blaming and rejecting attitudes from health professionals.

It is essential to give family organizations a clear message that the program will combat the myth that relatives can cause schizophrenia. Furthermore any approach to relatives' organizations should be made in the spirit of genuine equality and partnership. Treating family members as second class contributors to your program will inevitably alienate them.

Family members can provide valuable ammunition in the form of anecdotal experiences of being stigmatized, either directly through association with schizophrenia, or indirectly through the lack of provision of essential services and opportunities. Real life stories make more of an impact on public attitudes than campaign slogans, and can be used with permission, to provide material to journalists. It is also helpful to gain the agreement of a few family members to appear on public platforms to tell their stories.

Family members are useful allies in putting pressure on administrators to make change. Politicians are more likely to listen to relatives, who represent many votes, than to professionals who are perceived as acting through self-interest.

A representative of the local group of the relatives' organization should be invited to join the Local Action Group. An outline of the program, including the leverage family members can exert to influence local politicians and improve services, should be given to the representative to distribute to the relatives in their group. In short, family members should be welcomed as key players in your anti-stigma program.

Setting up a Consumer Speakers Bureau:

Just as anecdotal stories provided by family members are powerful, even more so are the first hand experiences of those with schizophrenia.

A speakers' bureau can be invaluable for addressing school classes, police, organizations of business people, health professionals, and other community leaders. Speakers' bureaus are typically collaborative endeavors. They usually comprise people who have experienced schizophrenia, family members, and mental health professionals. An important function of the mental health professional is to answer questions of a factual nature that a consumer or family member might not be able to answer.

Consumer speakers will often describe the experience of illness, but their very appearance as public speakers will demonstrate the reality of recovery. They may describe the problems of stigma and discrimination, but their presence is likely to evince feelings of compassion and an understanding that mental illness is a human problem that can affect anyone and everyone. They may talk about problems which are of particular interest to the community group to which they are speaking, for example, discrimination in employment, housing and law enforcement, but they should be trained to address such issues in a non-critical way which will not generate defensiveness in the audience. Our experience from the global program shows that consumer speakers can change feelings of social exclusion among audiences and improve attitudes.

Public speaking is a stressful event. People with mental illness can react to the stress of public speaking by experiencing an increase in symptoms shortly after the event. To minimize the likelihood of this reaction:

- consumers with a good stress-tolerance should be selected;

- consumers should be gradually introduced to the speaking experience by first observing, then speaking briefly, until they can participate fully without stress;
- speakers should be de-briefed after each presentation to see if they found the experience stressful; and
- a substantial number of speakers should be trained so that the demand on any one person is not too great.

It is important to have a coordinator for the speakers' bureau who:

- is directly accessible to those in the community requesting speakers,
- will maintain a diary of speaking engagements,
- will select and contact speakers for each engagement,
- will de-brief speakers after each engagement, and
- will ask the person inviting the speakers to provide an assessment of the event.

The coordinator could be a consumer, family member, mental health professional, or anyone else who is enthusiastic and well-organized. A successful consumer speakers' bureau is likely to develop a strong sense of shared mission. This sense of community can be nurtured and maintained by establishing contact between all participants through regular meetings, and through celebratory events such as an annual banquet.

Setting up a Media Watch:

Local and national advocacy groups can lobby the news and entertainment media to exclude negative portrayals of people with schizophrenia. Such groups are known as "stigma-busters" or "media-watch" groups. The stigma-busting approach calls upon members to be alert to stigmatizing messages in any medium and to respond appropriately.

The National Stigma Clearinghouse, begun in 1990 by the New York State Alliance for the Mentally Ill, is an example of such a program. The Clearinghouse collects examples of negative portrayals of people with mental illness from across the United States from television, advertising, films, and the print media. Members of the organization write or phone the responsible journalists, editors or others in the media, explaining why the published material is offensive and stigmatizing, and provide more accurate information about mental illness. The group also encourages local organizations to take local action and distributes a monthly newsletter summarizing recent negative media portrayals and the actions taken to inform people at the responsible media source. In this way the group educates other advocates about what kinds of media portrayals to look for and how to correct them.

An example of a successful stigma-busting intervention was the response coordinated by the National Stigma Clearinghouse to the advance publicity for the November 1992 issue of Superman comic reporting that the issue would reveal how Superman was to be killed by "an escapee from an interplanetary insane asylum". The Clearinghouse and other advocacy groups lobbied D.C. Comics, explaining that depicting the killer of the superhero as mentally ill would further add to the stereotype of mentally ill people as evil and violent. When the death issue hit the newsstands the killer was no longer described as an escaped mental patient or a "cosmic lunatic," nor depicted wearing remnants of a strait-jacket.

The National Alliance for the Mentally Ill, in the US, achieved similar success with a coordinated national response to the TV series "Wonderland." In the initial episode of this 1999 TV series set in a New York psychiatric hospital, mentally ill people were seen committing numerous violent acts such as stabbing a pregnant psychiatrist with a syringe. Following a NAMI appeal disseminated by e-mail to advocacy groups across the nation and a mass mailing by concerned citizens to the network, the producers, and the commercial sponsors, the show was pulled from the air after two only episodes, despite the fact that thirteen shows had already been filmed.

Stigma-busting groups have to tread a fine line between educating the media about inaccurate, stigmatizing messages on the one hand, and coming across as intolerant nitpickers, on the other. The stigma-busters' response should not be so mild that editors and producers harbor the misconception that their media content is accurate and harmless, nor so fierce that they generate fears of censorship by a vociferous minority group. All groups struggling with stereotypic images, be they based on race, gender, or disability status, have to cope with these issues of communication style and strategy. Involving a journalist or other communication professional in the media-watch program can help the group achieve the right balance.

A media-watch group does not need to be large or complex. One or two people can be designated as coordinators. They will establish links, perhaps by e-mail, to a broader group of interested advocacy group members who will immediately report instances of stigmatizing news reporting or entertainment content, whether they be local or national in scope. The coordinators will discuss the issue and devise an appropriate response. They may forward items of national scope to a national stigma-busters group or respond directly to a local newspaper or business.

An approach of gradual escalation has shown itself to be effective. Begin with a polite request, perhaps including a suggestion that the stigmatizing reference must have been inadvertent. A positive response should be rewarded with a letter of thanks from the media-watch group. Often those guilty of such an offense are appropriately concerned and may

later become supporters of the stigma-watch group. If the offender is unresponsive, increasing pressure can be brought to bear in gradual increments, escalating, for example, to consumer boycott if an appropriate response is not forthcoming.

Working with Community Neighbourhoods:

Local campaigns to influence the attitudes of a relatively small group of neighbours can be effective. They may be prompted by the establishment of a psychiatric facility in the locality, in which case they are best conducted by staff based in the facility. Each household should be visited and the residents offered a discussion about the facility before it is established. There is a body of opinion that raising the profile of the proposed development is likely to provoke prejudice and mobilize stigmatizing attitudes. However, the evidence from repeat attitude surveys gives no support to this view. On the contrary, establishing a facility without forewarning the neighbours is much more likely to create anger and hostile campaigning.

While doorstep discussions are useful, residents also need more permanent educational material. This can be made available in the form of pamphlets and educational videotapes. It is helpful to organize a public meeting in a neutral venue, such as a local church hall, however, cooperation with the religious body would need to be established. At the meeting, presentations should be given by the professional staff of the facility, by speakers from the consumer speaker's bureau, and if possible, by neighbours from another locale where a facility has been successfully established. Educational material should be freely available and refreshments help to create a relaxed atmosphere.

Working with the Police:

The police are extremely important local and national players in community services, and if used effectively, can contribute significantly to improving community mental health awareness. People with mental health problems come into contact with the police in both everyday situations and in crisis. Police often become first line mental health workers by virtue of intervening in domestic situations that are sometimes caused by a disturbed relative, or by arresting a mentally ill person and, on recognizing mental illness, bringing that person to a hospital emergency department. Yet, police officers are seldom knowledgeable of mental health concepts and often misinformed about mental illness as such. They view people with mental health problems as violent and perpetrators of crime. Whatever teaching is done is skewed toward these aspects. This bias especially affects junior officers who are then more predisposed to use unnecessary force because of overreaction to a perceived threat of violence. Working with the police in a campaign to raise public awareness may

help modify these stereotypes. Officers usually express dissatisfaction with how the mental health system responds to their own policing needs when they bring a mentally ill person to a hospital emergency department, and often resort to booking the patient in a police lockup on some kind of a nuisance offence instead of having to wait long hours with the patient to be seen by medical staff.

The police feel under-resourced and poorly informed about changes in the law regarding mental health issues. They feel under pressure to perform in a very difficult area of their work. While some police may have an awareness of the various aspects of mental illness and how people in distress may present, most would need more appropriate training and sensitization. Destigmatizing interventions among police officers are aimed at:

- better training in the recognition of mental pathology among potential detainees;
- increasing their knowledge of mental health legislation and the mental health system; and
- factual information on how to access the local mental health system.

Police training should be arranged through a police training department and be endorsed by senior management. It should form part of the police force's on-going training programme where officers have day release from police duties to attend training days. If possible, mental health education training should be a compulsory component of professional development. The mental health training programme should be facilitated by a partnership team involving consumers, family members, and people working in the field of mental health. This team should all be involved in planning their workshop presentations. All should be trained and debriefing sessions for facilitators should be a core part of the programme.

The programme should address the mental health needs of officers as well. Officers are cautious of seeking help for mental health difficulties, despite the pressures of their job, because it could affect their career progression. In general:

- Senior management should receive the mental health training alongside police officers and civilian members of the police force.
- The programme should be based on interactive workshops which are organized around key themes that communicate specific campaign messages. An 'intrusive thoughts' exercise (otherwise known as hearing voices) can be particularly useful. It is important to allow sufficient time for discussion, particularly when trying to address the link between dangerousness and mental illness.
- Police want tools to improve the support they provide to people in mental distress. Sessions should reinforce the professional skills police officers possess and attempt

to increase their confidence for working with people with severe mental health problems. Developing communication skills is an important area.

- Personal experiences are a powerful training aid but they need to be balanced, providing both critical appraisal (and recommendations for improving practice) alongside appreciation and understanding of officer skills and police constraints. The sessions should attempt to bridge the 'them' and 'us' gap.
- An information pack should be provided with additional information and follow-up work to reinforce your messages.
- The programme should be thoroughly evaluated and the results used to improve your training package for use with subsequent groups.

Influencing Policy Makers and Legislators:

In many countries, legislation tends to remain unchanged for decades. It may contain archaic bylaws, regulations, or stipulations from an earlier institutional era. Many legislative and policy guidelines make no mention of the recovery needs of consumers with respect to social welfare benefits, permanent safe housing, education and educational supports, employment and employment supports, or they are blatantly discriminatory.

Changing legislation is not a preferred activity for most politicians and bureaucrats. They are more interested in current issues and new legislative initiatives than on revisiting the old. Therefore, it behooves mental health advocates to bring to the attention of policy makers the inconsistencies and discriminatory aspects of old legislation vis-à-vis present trends in protection of rights of the population at large and of disadvantaged minorities. At the same time advocates should remain vigilant of possibilities of erosion of hard won entitlements or threats to rights to freedom, security, or confidentiality in new legislation.

Psychiatric professionals should attempt to work together with national relatives' and patients' organizations, where these exist, since they carry more political weight than do professionals.

Using Theatre Arts:

Theater is an ancient form of cultural transmission as well as a community release valve. From time immemorial, theater has been used to enlighten, teach, create fear, instill morals, chastise the powerful, and to incite the populace. It is a unique form of expression that can be used to advantage to teach and enlighten audiences about schizophrenia or other forms of mental illness. It has the capacity to convey sufferers in compassionate terms, as human

beings affected by illnesses that are not of their making. In the context of anti-stigma efforts, those best suited to convey this message are the consumers themselves. Organizing a troupe of consumer-actors must take several factors into account. Consumers may:

- not have advanced education as a result of their illness;
- not be able to engage in vigorous training required to act;
- feel uncomfortable representing their own illnesses;
- have difficulty withstanding the pressure of acting and of being in front of an audience; or
- feel overwhelmed and this may precipitate a relapse.

Organizing a large troupe of actors reduces the burden of acting on any individual member. It also takes account of the possibility that at any given time, some cast members will be unable to participate. Using low-stress presentations where each actor has a script to follow reduces the need to memorize parts and minimizes performance anxiety. Having a range of roles means that individuals can step-down from the more difficult parts if they don't feel up to the stress. Rotating through the different roles means that all of the cast members will eventually become familiar with all of the parts so that the actors become interchangeable. Consumers will learn when they can participate and when to abstain. The more they play different roles, the more they will feel at ease in their participation. A question period at the close of the performance will help to convey additional factual information, allow for friendly interchange, and reinforce the recovery message.

Exhibit 16: Integrating Diverse Groups and Raising Community Awareness

On September 15, 2002, the Polish program established a national day to inspire interest in local communities, draw media attention to schizophrenia and its treatment. Titled, the *First Day of Solidarity with people Suffering from Schizophrenia*, it drew thousands of people through symbolic doors erected in the streets. The doors were symbols of overcoming fear of schizophrenia. Among those opening the doors included prominent religious, political, and media figures. As well as attracting national media attention, the Day of Solidarity integrated local communities, consumers, their families, and others interested in fighting the stigma of schizophrenia. In September 2003, the Open the Doors program in Poland was recognized by the Ministry of Health as an outstanding program in the "Success of the Year in Health Care" contest.

Chapter Summary:

In this chapter we have reviewed ways of implementing an anti-stigma program emphasizing those approaches that programs have found to be particularly feasible or cost-effective. We have provided tips on working with different groups and given examples of how the Local Action Committee may work with or implement approaches with:

- Radio Stations;
- Journalists;
- Schools;
- Health Professionals;
- Family Members;
- Consumer Speakers Bureaus;
- Media Watch Programs;
- Community Neighbourhoods;
- Police;
- Policy Makers and Legislators; and
- Theatre Arts.

6

How To Evaluate Program Results

Program evaluation is a process designed to determine the merit, worth, or value of a program. The process typically involves an identification of relevant standards of worth, an investigation into program performance, and a comparison of actual performance against these desired standards. Typically there is also some attempt to understand the nature and consequences of any shortfall. Several iterations may be required before a complete understanding is achieved and, in complex areas such as stigma and discrimination, we may never acquire more than a partial understanding of the process of change.

Five Reasons to Assess Change:

Most mental health professionals are happy to assume that their programs produce the intended results. But, can we realistically assume that well-meaning people who institute a program will always make an important difference? If we are unwilling to accept this assumption, then we must consider ways of assessing the changes produced by the programs we offer. More specifically, we must be willing to evaluate whether our programs help, at a reasonable cost, and without undesirable side effects. Only by having this information, can we improve. Therefore, **quality assurance** is the first reason to assess change.

Second, everywhere budgets for programs are shrinking and funding for new programs is getting harder and harder to find. Increasingly, new programs must be argued on the bases that they meet an important need; that they can make a difference. Similarly, existing programs must demonstrate that they continue to meet their targets. Maintaining **accountability** for how resources are used and being responsible for achieving realistic results are the core of many evaluation efforts.

Third, in recent years, there has been a rise of **consumerism** in mental health. Most countries now have a number of consumer and family advocacy groups. The consumer movement has supplied an important impetus for program evaluation for it has placed increasing pressure on professionals to show that they are accountable for the funding they use, that their programs meet best practice standards, do not have unwanted side effects, and are responsive to consumer needs and preferences.

In light of these trends, **professional responsibility** is a fourth reason why we should assess change. Increasingly, professionals are held responsible for the quality and quantity of services they provide. Professional associations have been active in setting quality benchmarks, standards for care, and processes for centering services around consumer needs and preferences. Only by assessing the outcomes associated with the interventions they deliver, can professionals demonstrate that these responsibilities are being met.

Finally, evaluation of programs creates **new knowledge** about why certain programs work and others do not. To provide answers to the questions of how to reduce stigma and discrimination against those with schizophrenia, we will require ongoing critical assessment of anti-stigma interventions and their outcomes. If we knew how to reduce stigma and discrimination, we could immeasurably improve the lives of people with schizophrenia, their families, and contribute to stronger, healthier communities and cultures.

For these reasons, evaluation is a fundamental component of the World Psychiatric Association's Global Anti-Stigma Program. To date, program participants have developed a number of simple tools and techniques that can be used to evaluate their activities. These approaches have been used and adapted in all of the program sites so that knowledge about what works and what doesn't is accumulating. In addition, there are growing opportunities to enrich our understanding of cultural differences in stigma; both in terms of its causes and its consequences. These evaluation efforts not only assist in helping us understand how a particular program can be improved, they are creating a legacy of new and generalizable information about what can be accomplished in this important and challenging area.

WPA Program Evaluation Requirements:

All anti-stigma programmes working under the auspices of the World Psychiatric Association's Global program are requested to conduct systematic program evaluations. Their aim is to contribute knowledge concerning what works and what doesn't with respect to fighting stigma and discrimination world-wide. Four components of a WPA evaluation are:

Input: How much was invested (time, money and other resources)?

Process: What was done, what happened?

Impact: Effects on stigma and discrimination and unintended side-effects.

Outcome: Evaluation of the process and its effects in relation to the goals of the overall programme.

Questions to pose when designing and conducting your evaluation include:

- Did you reach your full target audience?
- Did you reach your target audience with enough exposures to ensure that the message was noted, recognized, and remembered?
- Did you make an important difference without unintended negative side effects?
- What was the final budget, including media production and placement?
- Was the budget adequate to meet the original stated goals?

In addition, programs are asked to establish and maintain a programme diary and a programme planner.

Programme diary

The WPA Programme Guidelines recommend that a member of the Local Action Committee be responsible for maintaining a programme diary. The diary is intended to provide an overview of program activities as they occur, through each step of the process. This can be accomplished by keeping notes at each meeting of the Local Action Group. The notes highlight issues and key decision points. They can be forwarded to other program sites to assist them in understanding the logic of decisions and in helping them to arrive at their own program. The program diary is a key tool in accumulating wisdom and experience and transmitting this throughout the global program network.

Programme planner

Each Local Action Group is requested to develop a standardized programme planner to allow for easy comparison between program sites. The planner, created in the third portion of the programme, will take considerable time and conversation to develop, but once completed, it will be a blueprint for monitoring all anti-stigma activities and allow clear, complete evaluation of the programme.

There are five elements of the Programme Planner:

- Selection of a target audience or audiences;
- Objectives and Goals for each audience;
- Key messages to communicate to each audience;
- Budget available to communicate to each audience; and
- Media selection necessary to reach the audience.

Measurable Objectives--A Key to Evaluation:

A fundamental requirement for program evaluation is having measurable objectives. Without measurable objectives, it is difficult to design an evaluation and impossible to interpret its results.

Objectives embody standards for change, but how much change is enough? Thoughtless selection of objectives can make it impossible for an evaluation to demonstrate success, even when significant change has occurred. Similarly, poor choice of standards can result in erroneous conclusions about a program's effects. Appropriate setting and interpretation of standards for program change requires advance knowledge about the level of change that can be reasonably expected. When choosing standards for change, there are several issues to consider.

- What if the criteria used to interpret change do not reflect the program's main intent? A clear understanding of the goals of the program are required to insure that objectives are reflective. If the program does not have a clear statement of goals, or if the goals seem unreasonable, then it is impossible to set reasonable standards for change, and any evaluation of outcomes is premature.

- What if the criteria used are relevant but they cannot be measured accurately? Many times it is difficult to find an existing standard measure that can be used to evaluate program outcomes. Existing instruments may be too long, too complex to implement, or inapplicable. In these situations, a new measure may be needed. The difficulty in using a new measure is that we don't know how much confidence to have in its technical merit. Is it measuring what we think it is measuring? Is it precise? Is it sensitive to change? These are the characteristics of a good measurement tool that cannot be taken for granted. They must be demonstrated with repeated use and critical assessment. The time and budget required to develop and test any new measures must be included in the program evaluation plan. If an evaluation fails to demonstrate expected results, one will never know whether it was because the measurement instrument was poorly constructed, imprecise, or insensitive to change.

Exhibit 17: Measurable Objectives

The objectives of the Canadian program were to improve knowledge about schizophrenia and positive attitudes towards those with schizophrenia by 10% among grades 9 and 11 high school students who were enrolled in the spring and fall semesters of 1998. Working with the Schizophrenia Society of Calgary, a one-hour presentation by a consumer and family member was given in junior and senior high school classrooms using a partnership model. The measurable Outcomes Achieved were:

- The proportion of high school students expressing no social distance increased from 16% to 22%.
- The proportion expressing the highest degree of social distance fell from 13% to 8%.
- The median knowledge score increased from 7 to 8 on a 9 point scale.
- The proportion of students achieving a perfect score increased from 11% to 19%.

- What if the criteria are relevant and can be measured with an existing instrument, but the program staff do not accept the measurement standard? Sometimes the goals and objectives of a program are clear and specific measures exist. However, program staff may not have confidence in the measure chosen. For a variety of reasons, they may have strong feelings about the validity of the measurement approach to be used. Even though the approach may have technical merit, the results will not be believed or used if the measurement tools are unacceptable to the staff. Selecting criteria and measurement instruments in close consultation with the program staff and key decision makers who are the intended users of the results are recommended to create enthusiasm for the approach. For these reasons, program evaluation works best when it is a participatory activity that involves all of the key stakeholders who are intended users of the results. It must focus on their needs and strive for compromise between technical rigor and acceptability.

Assessing Change with Qualitative Data:

Numerical results are important in any evaluation but these need to be interpreted within the context of qualitative (non-numerical) observations and information. Not only are qualitative data essential for framing the evaluation question and approach, they are key to understanding why something worked (or didn't), an any unanticipated negative consequences that may have occurred.

Program staff often feel that evaluation questionnaires, complex survey approaches, and statistical techniques are less sensitive and less powerful than their own personal observations and evaluations. The term "black-box" evaluation is commonly used to describe a situation in which quantitative outcomes cannot be interpreted in light of knowledge about how the program actually works and the processes it uses to achieve change. Whatever the result, the causal mechanisms must be understood in order to improve the program or reproduce it elsewhere. One must understand the essential ingredients of success and failure. Qualitative observations and data are essential for creating this understanding and furthering our knowledge about what works and why. The ideal is to integrate both qualitative and quantitative data in assessing program impacts.

Assessing Change with Survey Data:

Complex analytic tools are often useful in evaluating program change. However, the application of simpler techniques is sufficient for most evaluations. Indeed, it is more important to cultivate a culture of inquiry and critical assessment using simple tools, than applying complex analytic techniques that are poorly understood and overly sophisticated for the job at hand. Simple approaches are also more engaging to those involved in the evaluation and provide more readily understandable results.

A simple and widely used approach for assessing program impact is the survey. Surveys are planned attempts to gather qualitative or quantitative data from relevant people. They are used extensively in evaluation because they are flexible, cost-effective, relatively easy to set up and administer, and, with careful attention to detail, provide easily interpretable data. Indeed, a survey probably provides more information per dollar spent than any other measurement approach, so can be seen as a good evaluation investment.

Things to consider in survey design

There are several things to consider when designing a survey to ensure that the results will be accurate and useful. First, all surveys should have **clearly defined objectives** and contain questions that are relevant only to those objectives. Each question should be linked to a specific objective so that the designer is clear that all objectives have been covered adequately and there is no more data than is necessary. Unnecessary data increases the cost of data collection, places unnecessary burden on respondents (who may refuse to participate if the survey is too long), and poses challenges for the analysis that must incorporate and interpret disparate and potentially erroneous data elements.

Secondly, for a survey to assess change, **two comparable surveys** are required. The first survey must describe the state of affairs before the program was initiated (termed the baseline or pre-intervention stage), and the second must describe the state of affairs after the program has been operating for a sufficient period to produce effects (termed pos-intervention stage). They do not need to follow the same people over time, but they need to describe the situation at two points in time.

To be comparable, surveys must have identical questions, use the same survey methods, and target the same sample subjects. The same groups of people have to be eligible for both surveys and approached in the same ways. The assumption can then be made more

forcefully, that any changes observed reflect changes brought about by the program, not by changes in the survey design or methods. Causal inferences about program effects can be strengthened by surveying people who did not get the program (termed a comparison group) to make sure that they didn't change.

Survey method

In developing a survey, a number of important decisions have to be made. First among these is who will be surveyed. In the context of anti-stigma program evaluations, a number of important target groups have been identified by the various global program sites:

- Consumers of the program and their family members;
- Members of the local community;
- The general public;
- Health care professionals;
- Journalists;
- Business leaders;
- School children; or
- Teachers.

The second decision concerns how to draw the sample. If the group targeted is small, sampling may not be necessary as everyone can be surveyed. If a sample must be drawn, one must first enumerate all members of the group, then draw a selection from this list randomly. Enumeration of the survey population may be the most challenging part of the survey design, and for some groups, complete enumeration may be impossible. For large populations (such as the general population) random selection is used to help insure that a smaller sample will be representative of the population from which it is drawn.

Once a list of respondents has been created and a sampling plan employed, the next decision involves the method of administering the survey; whether it will be by mail, telephone, or by personal interview. Telephone surveys make sense if the survey population can be reached by telephone and if the survey questionnaire is short (no more than 15 minutes). Mail surveys may reach a larger portion of the survey population, but many individuals will fail to return mailed surveys giving a low response rate. Follow-up reminders can improve mail survey return rates. If the questions to be asked are complex, or much information is needed, then personal interviews may be the most feasible approach. Because interviews require highly trained interviewers, they can be costly. In choosing a survey method, it is important to balance data quality with cost, coverage, and feasibility.

The final choice to be made concerns the instrument. Telephone and mail surveys tend to be structured and emphasize numerical data. Interviews, on the other hand, can be more flexible and incorporate more qualitative data. Semi-structured questionnaires and interviews attempt to balance qualitative with quantitative responses.

Sample size

How many subjects should you survey? Sample size is based on a number of factors, including cost, feasibility, and the number of eligible respondents that are available to be surveyed. When surveys are being used to assess change, an important consideration is the magnitude of change that needs to be detected. The smaller the change, the larger the sample size required to see a difference. For example, to detect a 5% change from the first to the second survey in the measure of social distance used in the Open the Doors program, you may need up to 1600 respondents per survey. To detect a larger change in social distance (10%) only 500 per survey may be required, whereas only 200 may be needed to detect a difference of 15% between surveys. If a survey is not designed with an understanding of the magnitude of difference that needs to be detected, it may be too small and insufficiently powered to see an important change. This could lead to erroneous conclusions that the program did not have an effect. The worst that could happen is that a poorly designed survey fails to find a program effect when one exists, and the program is cancelled or under-resourced because it is deemed to be unsuccessful.

In many cases, the population available to be surveyed is small, such as the case of program participants or their family members. If there are insufficient numbers of respondents available to detect the expected amount of change between surveys (as described above), then a more qualitative approach should be considered. You may survey all participants to discover what their participation in the program has meant to them.

Creating and Adapting Questionnaires and Interview Schedules:

Survey instruments are usually easily obtained by searching the scientific literature. These are preferred over home-made measures because they have been peer reviewed and developed with attention to scientific detail. Unfortunately, program evaluators often find themselves in a situation that requires a measure to be created or adapted. This is because many programs are designed to change behaviours that are culturally unique (and measures may not be culturally sensitive), or the program may have goals and objectives that do not relate to any known published measures. Because it is easier to adapt a measure than create one,

and because there are an enormous number of measures available, evaluators should always assume than an appropriate measure could be found or adapted and search the literature with this in mind.

Exhibit 18: Recommended Core Content for an Anti-Stigma Community Attitude Survey

Many countries involved in the World Psychiatric Association's Global Anti-stigma program have used a standard questionnaire which has included the following types of items:

- Geo-demographic data used to identify the residence and socio-demographic characteristics of the sample
- Exposure to people with schizophrenia as those with higher exposure may have more tolerant attitudes or be more willing to change
- Knowledge of schizophrenia as those with more knowledge may have more tolerate attitudes and be more amenable to change
- Exposure to program messages to determine whether the program is connecting with the desired audience
- Preferred social distance from people with schizophrenia as changes in social distance are a key accomplishment for anti-stigma efforts

Copies of the questionnaire are available in several languages and may be downloaded from the program website: openthedoors.com

To design good survey questions, the purposes of the survey must be clearly understood. Questions must then be designed to elicit this information. They must be appropriately worded, understandable, meaningful to the survey respondents, use time periods that are appropriate for the baseline and post-intervention periods under evaluation, avoid words or phrases that may cause the respondent to react negatively or bias the results, and use appropriate rating scales for measuring the knowledge, attitudes, and behaviours under study. When adapting questionnaires from other cultures, it is important to remember that questions are asked in a social, cultural, and economic context and these must be appropriate for each new context.

Pretesting

Even when an instrument can be identified from the literature, it is a good idea to pre-test it on a small sample before taking it to the field. This is particularly important if the questionnaire has been translated from another language.

In order to identify problems that your survey respondents may have, pretesting must be done on a sample that is representative of the subjects you wish to survey. In developing the pre-test sample, you will also determine the feasibility of developing the sampling frame for the larger survey as any problems in enumerating your population will come to light at this point. Because the pre-test is conducted on authentic subjects, it will allow you to check for question clarity and determine if the length of the survey is manageable. A pretest is also useful for estimating your likely response rate and in so doing, the feasibility and cost of your survey. Response rates that are lower than 70% are considered to be problematic and would be difficult to publish in the scientific literature without some explanation as to why they were so low. Finally, you will be able to assess the reproducibility of your survey in terms of any barriers that may prevent you from administering it twice using the identical questions and format.

Some pre-tests are set up as interviews even though the actual survey will be administered using a paper and pencil approach. The interviewer encourages subjects to ask questions whenever they don't understand something, providing useful information on potentially problematic questions. In addition, the interviewer may probe at certain points to learn how specific questions are understood.

Exhibit 19: Survey Checklist

- ✓ Define the population to be sampled
- ✓ Create a sampling frame by enumerating all members of the population
- ✓ Specify the sampling method
- ✓ Determine the sample size
- ✓ Develop the survey instrument
- ✓ Pre-test the survey instrument and the survey methods
- ✓ Draw the sample
- ✓ Collect the data
- ✓ Summarize and synthesize the results

Identifying Lessons Learned:

If one learns from mistakes, then an important contribution of an evaluation is to identify and help explain things that did not go according to plan. Areas where performance was less than expected are just as important as areas where expectations were exceeded. Indeed, any unexpected outcome, whether positive or negative, should be fodder for lessons learned. This can be a difficult perspective to foster when there are competing pressures to demonstrate that a particular program has "worked".

Pilot programs may offer a safe haven where mistakes can be made, acknowledged, and studied without fear of retribution. It is often possible and highly recommended to implement a pilot phase for the first year of a new program. Pilot programs can be a valuable tool in creating a culture of critical assessment and learning; a culture that fosters quality improvement through self-review. Indeed, pilot programs can be legitimately understood as opportunities to make as many mistakes as possible, then learn from them!

What If the Program Didn't Work: Making Revisions:

Few programs are perfectly good or perfectly bad, so program evaluations often provide mixed results. Some things will work and others will not. If it is clear from the start that the purpose of the evaluation was not to terminate the program, but to help program managers and staff improve the way in which the program could be delivered, there should be sufficient goodwill to consider making program revisions. Having key stakeholders actively involved in the evaluation from the outset will promote richer interpretations and increase the likelihood that results will be used to make program improvements.

A number of situations can form impediments to this quality improvement cycle. Evaluators should look for these in advance for they suggest that evaluation results will not be used to make program improvements:

- Funders have explicitly asked for an evaluation in order to determine future funding. Not only will this reduce the willingness of staff to be frank about any problems they are having, the opportunity may not exist to make program revisions based on the evaluation results.

- Political pressures may be such that evaluation findings will be overshadowed by other concerns. Feedback concerning whether a program or particular aspect of a program worked may be only one of the factors inherent in a decision to change.

- Opposing factions exist within the program and are strongly polarized. In this context, evaluation findings are unlikely to support planned program change that everyone will agree upon.

- The evaluation did not incorporate sufficient qualitative data to pinpoint the program processes that should be revised. Consequently, there is insufficient understanding of what accounts for the program outcomes achieved.

The Role of Internal and External Evaluators:

Program evaluators can be internal or external to the program being evaluated. Internal evaluators are usually considered to be part of the program staff and may also have significant program delivery responsibilities. Internal evaluators have the benefit of greater depth of understanding about how the program functions and its unique socio-cultural context. However, they may find it difficult to raise critical observations concerning their co-workers or their parent organization. Because internal evaluators are members of the program team, internal evaluations tend to be participatory in nature. They work best when they are based on a model which involves self-reflection, critical appraisal, and quality improvement.

From time to time it may be necessary to obtain an external program review conducted by individuals who are knowledgeable about such programs but who are external to the program delivery. An external review may be a requirement of continued funding. Because they are conducted by external experts, results from external reviews may hold more sway with funders and decision-makers who may see internal evaluations as biased in favour of the program. Even when it is not a funding requirement, it is a useful exercise to undertake a regular external program review (such as every five years) as part of a program development and quality improvement strategy.

Ethical Issues in Evaluation:

People can be hurt by false evaluation findings. Findings that incorrectly show a positive effect when none exists are problematic if one considers that the funding for the program could have been used more effectively elsewhere. Findings that incorrectly show that a program has no effect when it does may result in an alteration or elimination of a beneficial program. Even successful programs may have unplanned side effects.

People who provide critical information to evaluations may also be hurt if their comments are identified or can be inferred back to them by knowledgeable co-workers. Staff members may worry about how their supervisors will react to negative findings. Consumers may worry about how their services might be altered if they make too many critical comments, or what will happen to the program if it is found not to work. Everyone involved in the delivery of the program may worry that the evaluation could point a finger at them or disrupt program activities.

Evaluations must be sensitive to these issues and strive to build trust. A participatory process that involves stakeholders is unlikely to generate such suspicion and ill effects, but evaluators should always be attuned to these possibilities and the fact that their results may damage the interests of one or more of the participants.

Experiments:

Unlike surveys, experimental evaluations may require that services be withheld from a group of clients in order to better see how the group receiving services has progressed. Withholding beneficial services from clients poses an ethical dilemma that must be carefully worked out with the assistance of local ethics committees and reference to codes of conduct for ethical research.

Ethics guidelines:

Most countries have national guidelines governing research involving human subjects. As well, there are a number of international ethical codes that can be used for guidance. Evaluations, particularly experimental evaluations, are not exempt from the ethical considerations outlined by these documents.

Chapter Summary:

In this chapter we have reviewed the importance of evaluating programs to assess to what extent they create desired changes in their target populations, commensurate with planners' expectations. We have also reviewed the World Psychiatric Association requirements for evaluation activities and recommend the following:

Chapter Checklist

- ✓ Choose measurable objectives and set realistic standards for change.
- ✓ Develop an integrated approach to evaluation that incorporates both qualitative and quantitative data so that it is possible to understand how much change occurred and why.
- ✓ When sample sizes permit, use identical surveys conducted before and after the program is implemented to quantify the magnitude of change in knowledge, attitudes, or behaviours that have occurred.
- ✓ When sample sizes do not permit, employ qualitative techniques to assess how the program has impacted participants.
- ✓ Use existing survey instruments and interview schedules wherever possible and avoid developing new measurement approaches and scales.
- ✓ Look for explanations for why things did or did not work.
- ✓ Learn from mistakes and revise the program in light of lessons learned.
- ✓ Wherever possible work with local ethics committees to ensure that all persons involved in the evaluation, and all data, are dealt with in ethically appropriate ways.

7

How to Communicate Your Findings

Disseminating Program Results:

There are many different ways to disseminate the results of an anti-stigma program such as through press conferences, press releases, and more formal presentations. Because the WPA anti-stigma programme is a global effort, those anti-stigma efforts conducted through this programme will be of interest internationally, as well as to the more targeted efforts nationally and locally.

International channels of dissemination

Internationally, all programmes routinely report the progress of their efforts to the World Psychiatric Association Stigma Steering Committee, chaired by Professor Norman Sartorius, Geneva, Switzerland using the means described in an earlier chapter. The progress made by the various programmes is documented and updated in Volume III of the overall programme materials available on the website. The program website (openthedoors.com) houses all program documents for the WPA Global program. In addition, the World Health Organization has an on-going anti-stigma effort underway and results of various sites are routinely shared with this organization as well.

National channels of dissemination

On a national level, Local Action Groups have often supplied editorials or information releases to national psychiatric and academic journals to announce the start of an anti-stigma effort in that country or region. These are often followed up with more formalized presentations of the program evaluation results. Some programs cooperate with other

national programs so disseminate their findings through this ready-made network. Alternatively, they may provide their own data and findings to advocacy and anti-stigma efforts across the nation. At its most basic this might entail including a link on the website of another program. The same kind of linkage is possible with other non-governmental organizations, as well as consumer and professional organizations.

Perhaps the most often used channel of disseminating information is through national conferences and conventions where members of the program provide a seminar or workshop on anti-stigma activities.

Press releases, in either video or print, can be sent to national media outlets in order to achieve coverage in magazines and newspapers nationwide. Press conferences to media organizations have also been used.

Local channels of dissemination

Press kits and press releases can yield publications in local media. These should always be preceded by a telephone call to ensure contact information, such as the address or spelling of the name, are correct. They should also be followed by a telephone call to ensure the materials were received and to inquire if there are any additional follow-up questions. Erroneous contact information is a common reason for information not being picked up by the media. Verbal presentations to local groups are also an important means of communicating activities and results. These can range from formal presentations at local meetings and conferences, to more informal presentations to local stakeholders, community leaders and potential funders.

Press Conferences and Releases:

Setting up a press conference

Setting up a press conference can be a complicated activity that may be more effectively done by a company dedicated to such work. However, limited budgets may not allow that kind of access to the media. Whether an outside agency is chosen or not, there are some basic guidelines that need to be followed:

- Schedule news conferences for mid-morning to allow reporters to meet afternoon deadlines;

- Avoid scheduling conferences on Mondays and Fridays;
- Provide the press with a compelling reason to attend such as new findings or time-sensitive information;
- Give ample lead time for the event (at least one week but not more than three), and follow up with a telephone reminder one or two days prior to the event;
- Always include a program contact name and number;
- Provide press kits with fact sheets, background information on schizophrenia, and biographies of speakers at your event;
- Have the conference in a venue accessible to the press and large enough to accommodate all participants and their equipment;
- Provide refreshments; and
- Start and end the press event on time to respect press deadlines.

Creating a press release

A press release has two main functions. First, it transfers information. Therefore it needs reference to a current fact or event to be communicated and it must be clearly marked as a press release. Secondly, it motivates journalists to report about your story or your concern in the media. Include a clear and significant headline to attract journalists' attention. Your headline must include the most important reference and the current reason for the release. Following this lead, provide answers to what, who, when, where, why. Background information presented in a factual style should follow in the main text. Press releases are not meant to be published entirely or exactly as written. However, a press release that is written in journalistic style that provides relevant information and supporting data has a greater chance of being reproduced. Additional materials such as brochures, flyers, or other materials support the journalist and help reinforce your program's corporate identify.

There are several guidelines that should be followed when formatting a press release. Press releases that do not follow this format may be viewed as unprofessional and ignored. Limit the press release to three or four double-spaced pages and answer the following six questions:

- 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 event take place);
- WHERE (did it happen, where will it take place);
- WHY (did it happen or will it happen); and
- HOW (did it happen or will it happen)

Editors treat the press release as an inverted pyramid. Generally they will cut from the bottom up to fit their format. Therefore it is important you answer the six questions as they appear. When preparing press releases, you should also remember to:

- Keep the headline to 10 words or less and TYPE IT ALL IN UPPER CASE;
- Type "FOR IMMEDIATE RELEASE" in the upper left-hand corner of the release; of if the release time and date are specific, indicate it in that place;
- Use the headline to let the reader know exactly what the release is about and its relevance to the reader (Answer: Why should I care?);
- Begin with the body of the text by identifying the city where the event is being held (e.g. Geneva, January 2, 2002;);
- Avoid complicated facts and figures;
- Avoid abbreviations and, if they must be used, clearly indicate what they mean;
- End the release with the name and phone number of a key contact person who can answer questions; and
- Always follow up.

Because editors and reporters receive a great deal of information every day, it is helpful to follow up with a brief phone call to ensure they received the information and inquire if they need any additional information.

Press kits

Press kits can be developed whether or not you have an event planned. Local Action Groups that lack a specific conference event or the funds to host a room for such an occasion, will nevertheless want to get press kits and other materials out to take advantage of the news media to disseminate their results.

Press kits are most often pocket folders which should be identified on the outside of the folder with the programme logo and contact information. Include a fact sheet on schizophrenia including personal experiences and the social effects of stigma and discrimination. Include a synopsis of your program plan and describe the global efforts of the World Psychiatric Association and any other local organizations that are involved. Brochures and informational materials are often included in the press kit as well so that journalists will have a broader range of information from which to take their facts. Whereas a full kit will contain a number of different elements, it is also possible to send only a press release to a media contact to report specific Local Action Group results.

Creating an Effective Presentation:

An effective presentation can help diffuse your findings to a broader audience. An ineffective one can sabotage an opportunity to communicate findings to your peers. However, after years of working in a program, the challenge of taking the most important data and creating an effective presentation can prove difficult. The following guidelines will help you create a presentation that is clear, effective, and memorable.

A good presentation starts with organization. Preparing yourself before a presentation allows you to most effectively communicate your message during the presentation.

Structure and organization

An audience will remember a limited number of facts from your presentation so it is important to emphasize a limited number of points. For example, you should be able to focus your presentation around five key points. When speaking academically oriented audiences, they will expect your presentation to use the following headings:

- Introduction or purpose;
- Methods;
- Findings or results; and
- Discussion or conclusion.

Presentations to non-academic audiences may vary this format accordingly. For example, if you were presenting your anti-stigma program to potential funders, you may wish to use the following format:

- The problem (what your program is trying to address);
- Best practices in the literature (what is known to be effective);
- Description of the program;
- Results of evaluations (or description of intended evaluation plans); and
- Budget and time lines (if the program is not yet underway).

To engage your audience, you may wish to start with a specific example such as someone's experiences with stigma, move to a general overview such as providing information on community attitudes, then follow by a repeat of the particular to reinforce the point. Another way of catching attention is to use a problem/solution approach, being sure to show the relevance of the problem to your audience.

Start with the last slide! Once you have developed your presentation, take your conclusion or summary and place that first. An audience will remember the first and last part of your presentation most clearly, so you want to ensure that you are placing the most important points of your speech at both the beginning and the end. Also, it helps you stay on task and remain organized.

Typeface and colour

When preparing materials for a screen presentation, there are some basic visual tips to remember:

- Serif typefaces, which are slightly more ornamental typefaces, are preferable for *print* materials. Research indicates this style can be 30% easier to read. However, Serif fonts lose their sharpness and appear muddy when projected onto a screen using a slide, overhead, or multi-media projector. Use SANS serif type for crisp and easy to read screen presentations.

- Color can help emphasize points, but only if use judiciously. When overused, it can prove distracting and take away from the main message. The same could be said for animations, sounds, and pictures.

- Avoid the use of ALL UPPERCASE. This can be more difficult to read and appear to be shouting.

Humor and quotations

The right amount of humor can go a long way to build rapport with your audience. It may also keep your audience interested and attentive. Too much, or inappropriately placed humour may be unsavory. Therefore, don't tell jokes for their own sake. Drop in your humor where it fits, relating to a point, or in a break between sections. Small amounts of humor or a irreverent comment from time to time can go a long way to liven a presentation, but don't push your luck! Rehearsing your presentation in front of real people is a great way to test the acceptability of your humor.

Like humor, appropriate quotations can make a noticeable impact on your audience. It is not always possible to find quotes that are directly relevant to your presentation, but it is often easy to find a series of quotes that complement or promote concepts that are part of your presentation. Don’t overdo it.

Rehearsing

To present the most professional image, you need to know your presentation material. Leaving the main script can make your presentation fresh, but wandering presentations that lack focus, or those that are overly dependent on working notes are never acceptable. Too much time spent reading notes may convince your audience that you are unprepared. Rehearsing your presentation can avoid these pitfalls.

Rehearsing includes more than just going over what you will be saying. Rehearse the entire presentation from beginning to end using the same tools and time lines. If you are using slides or a projector, and have access to the room you will be presenting in, rehearse there. If you can't access the room before time, make sure you get there early to ensure you are comfortable with the layout and the technology. If you plan to use a remote mouse, laser pointer, podium, or microphone, rehearse the presentation with these devices. Practice using a tape recorder or, better yet, in front of a video camera. This will help you spot flaws, distracting mannerisms, and idiosyncrasies. Committing the presentation to memory and performing it by heart can make for a stiff, boring delivery. You need to present, not to recite.

The day of the presentation

Never break in new equipment fifteen minutes before your presentation. Be sure you know how to use new technologies well in advance and make sure that any equipment you have ordered arrives in the room well in advance of the meeting so that you can make sure it is working appropriately. It is helpful to pre-arrange technical support and back-up in case there is an equipment problem before or during your presentation. Check out everything in advance, then check it again!

When giving your presentation, focus on your audience, not your computer or the projected image on the screen. Always face your audience and make sure that your view is not obscured by a podium, the cover of your lap top, or any other obstruction. Engage your audience by making eye contact. While it is important to move to keep the audience's interest, don't wander around the room. Wandering can be interpreted as a sign of nervousness. Similarly, if you look down at your notes too much, you will give the impression that you are trying to figure out what is next.

Stay in control of your presentation. You can do this using a few simple techniques. First, focus on a few people in your audience. Are they attentive? Evaluate their body language. Are they fidgeting or checking their watches? Are they taking notes? Napping? Paying attention to your audience will help you monitor and change your pace—speeding up or

slowing down the presentation as appropriate. Make note of any slides that seem confusing, those that generated clarification questions, or otherwise slowed down the overall pace and make sure these are revised accordingly for the next presentation.

With respect to pace, a general rule to follow is that every slide deserves at least 10 seconds and none should take more than 100. If you find yourself spending several minutes on one slide, consider converting it into several slides, recognizing that some charts or graphics may take several minutes to properly present. Don't leave an image up once you have moved on to other points. When you are done with a slide, move on. If you need to create filler space during or after your presentation, consider using photographs or pictures of your university, your city, or your area, but don't overdo it.

Regarding body language, don't hide behind a lectern. The only exception to this rule occurs during conferences where your talk is being simultaneously translated and the microphone that links to the translation equipment is attached to the lectern. Show your enthusiasm! If you look bored and uninterested, your audience will be bored and uninterested. Use gestures. Vary the tone of your voice. Look around the room. Move.

To draw attention to certain aspects of your presentation, especially charts and graphs, laser pointers can be useful tools. Be careful not to move them around too freely or to leave them on and wave them at the audience. When pointing, choose a place on the overhead and keep the beam steady. If you must move the laser pointer to another place on the slide, do so slowly so that the audience can follow the movement. NEVER make quick concentric circles with your laser pointer around and around the object you wish to highlight. This can be quite difficult and disturbing for an audience to follow.

Provide the audience with guidance concerning how you would like to address questions; during the presentation or at the end. Consider addressing points of clarification during the presentation and points of discussion at the end. In brief presentations, questions taken during the talk may derail your timing and your organization. Where appropriate, defer questions to later in the presentation. If you do not have the details necessary to answer a question, or if the question is too complicated to answer in the brief time available, you may ask the individual to meet you after the meeting or to correspond with you for more details. If you do defer a question during your talk, remember to address it in the question period. Give your audience time to formulate their questions and recognize that this may take some time after you finish speaking. Wait. If you want to make sure you are asked a question, you may ask a colleague in the audience to get the ball rolling. This will get others motivated.

Having adequate support materials may be crucial to your success. The more important the presentation you are making, the more important it is that you provide supporting

documentation for those who want it. This is particularly true if you are making funding requests. Having poor support materials, or none at all, will take away from your credibility. When all the other pieces of the puzzle are in place, don't limit the staying power of your message by providing it without the right support.

Finally, make absolutely sure that you do not run overtime. Finish early and make sure you do not encroach on the question period.

Exhibit 20: Presentation Guidelines

Points to remember when giving a presentation:

- Have no more than five key points.
- Lead with your summary finding.
- Always practice your presentation.
- While you are presenting, you should work to connect with your audience but control the flow of the presentations.
- If your presentation is indeed effective, your colleagues or members of the press may want to follow up. Be sure you have support materials available.
- Never run over-time.

Developing an Effective Website:

The Internet is a powerful information dissemination tool. The global nature of the Internet allows Internet sites to be accessed in many different places. It also allows your site to be PROMOTED in many different places. For example, to date the WPA anti-stigma program site openthedoors.com has been visited by individuals interested in schizophrenia and its associated stigma from virtually every country of the world. Unfortunately, the explosion in the use of the Internet in the last ten years has also led to an explosion in confusing technical jargon, particularly acronyms. Thus, before going further, it is important to clarify some key terms.

- URL – Uniform Resource Locator (previously Universal Resource Locator). The URL provides a standard way of specifying the location of a resource on the Internet. It is your Internet address. For example, the URL for the World Psychiatric Association's Global Anti-Stigma program is:

  www.openthedoors.com.

- Browser – short for Web Browser. This is a software application used to locate and display webpages. The two most popular browsers are *Netscape Navigator* and Microsoft's *Internet Explorer*. Both of these are graphical browsers, meaning that they can display graphics as well as text.

- ISP – Internet Service Provider. This is a company that provides access to the Internet, usually for a monthly fee. Local and national companies are available. Usually you would use a modem to dial in to the ISP's modem, giving you direct access to all of the Internet services available.

- IP – Internet Protocol. This is a unique number that reflects your specific internet address. Every machine that is on the Internet has a unique IP address.

Setting up an account

To establish a website you will need someone to host your files. Many clinicians and academicians have access to the Internet through their hospitals or universities and these systems may function as hosts. In addition, some Internet Service Providers (ISPs) provide complete packages that will allow you to register your web name and set up a website. Alternatively, a website where you can register your URL is: http://www.verisign.com. The WHOIS at this site is a worldwide database of URLs available.

Your Internet Service Providers (ISPs) will provide directions on how to upload the Internet files you develop to your website. You will require a special protocol to transfer these files (termed a FTP or File Transfer Protocol). This is a software program that allows you to move text and graphic files form your computer to your web host. These programs can be found on the Internet and downloaded for free.

Creating a webpage

You will be able to use both text and graphic images on your webpage. However, it takes longer to read text on a webpage than it does in hardcopy—research shows about 25% slower. Many informative websites are never read because they are overloaded with text. Therefore, you must edit your text to make it as quick and easy to read as possible.

In addition, some websites are confusing or difficult to navigate due to a misuse of graphics. Graphics that blink and bounce across the screen distract the reader. Banners and advertisements that have nothing to do with the content similarly overwhelm and obscure

your message. Confusing images can also mislead the browser, confusing it as to where to go in the website for more information, or it can leave them in a limbo of irrelevant information. Extensive graphics not only take a long time to download, they can obscure your message. The end result is that viewers move on.

Designing the webpage

Many of the elements of good design that apply to print also apply to the web, though some (such as file size and downloading speeds) are unique. The following guidelines will help:

- Identify your audience. It is important to know who your audience will be and how they may use your website. Are they members of the general public looking for broad overviews of mental health information, or academicians looking for research that might be provided in downloadable files with links to journals?

- Considering content, focus and define your website content; prioritize your information, as with an outline, structure your website to promote scanning for important concepts, and build in white space.

- Navigation is the term used for how an individual moves from page to page. Make sure the directions to other pages are simple, clear, layered (using site maps for example), and organized.

- With respect to design, choose background and text colours with high contrast. Consider that colours that may work well on a computer monitor may not translate well on the Internet or when a document is printed.

- Format the text consistently to aid readability. Avoid color changes, italics, and overly large text. Underlining may be mistaken for links to other sites. Each page should be consistent in design and leave sufficient white space between paragraphs to enhance readability. Use a table with one row and one column to centre your text on the monitor's display and to create left and right margins. Use compressed file formats for photographs and drawings.

- With respect to graphic elements, avoid textured backgrounds as these make reading difficult. Illustrate your content with simple, small, and stationary graphics. Avoid showy graphics that do not enhance your message.

- According to the informal rules of the Internet known as "Netiquette" it is recommended that you inform sites with whom you are including links. We would also recommend contacting those sites that have a similar content or mission to your program and request that they include the URL address for your site on their webpage.

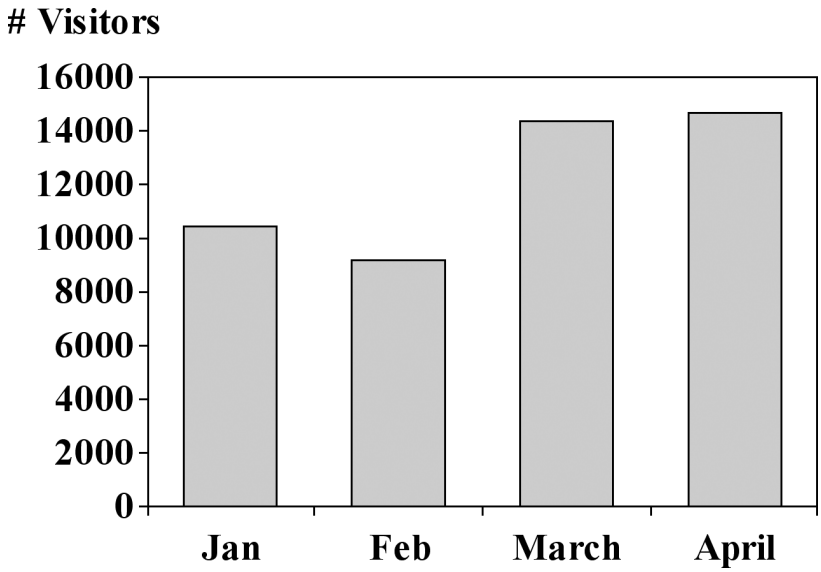
Writing for the Internet

Before writing, define the topic, its main idea, and its conclusion. These should be immediately visible and locatable. Main ideas should start at the top of the screen with supporting secondary information below. In this way ideas rule the structure. Simple constructions are best. Limit one idea to a group of words, whether a sentence, phrase, or paragraph. Consider presenting long text components in downloadable files. Insure that you have spell checked your work. Have the pages independently proof-read by a person who did not write the content. Always focus your message and invite feedback with a "mailto" for comments, suggestions, and questions, as this can only enhance your website.

Measuring success

How do you measure whether or not a website is successful? A measure that has come into popular use to describe website activity is the number of "hits". A hit is a measure of any activity on your website, although it is not always clear what activity is being measured so even small websites may have a high number of hits. A better measure is the number of visitors to your website, defined as the number of individuals who enter your site and spend three or more minutes there. When setting up the website account with your Internet Service Provider, be sure to ask them about their reporting capabilities. Many will allow you to view activity at your site.

Exhibit 20: Openthedoor.com Visitors 2002



In addition to tracking the number of visitors that have visited your site for more than three minutes, you also may be interested in those who left quickly and their exit points in the website. Areas that are the least popular may reflect navigation or content difficulties. Alternatively, you can track the areas in your website that are most popular. It may also be meaningful to know the proportion of visitors who return to your site more than once. In the case of the Open the Doors site, 12% of visitors have returned to the site more than ten times, suggesting to us that they find the content useful.

Finally, you may track the number of visitors by time of day or by country or origin using the ISP address. However, the anonymous nature of the Internet does make specific identification of a visitor difficult. For example, in the United States, the leading ISP provider is America On-Line or AOL. Those who view website statistics for activity geographically by State, will be surprised to see that Virginia ranks at the top of most lists. This is because Virginia is the headquarters for AOL and visitors are tracked *through* the ISP. This example holds true in different regions of the world, such as Asia-Pacific, where extremely high activity can be seen through Indonesia where a large number of Internet Providers are present. To ensure you capture data regarding visitors you may wish to ask for information and a password before allowing access. However, this will significantly cut down on the number of visits.

How to Publish Results--Insights from an Editor:

When seeking publication, most researchers are aware of the need to adequately document their statistical methods, ensure that results are clearly presented, and analyses are valid. However, many editors find that authors have a harder time with other elements of the publishing process. The following guidelines were prepared by Ruth Ross, Managing Editor of the *Journal of Psychiatric Practice*.

Research the publication

Chose a publication and see what kinds of articles they have been publishing, what topics have been prominent, and what topics have NOT. If the article you are thinking of submitting seems out of line with what this journal has been running, look for another publication. If you are interested in being published in a particular journal, read it regularly to get ideas of the kinds of things that interest them.

Carefully read the information for authors. You can usually find this in the journal itself or download it from their website. Be aware of length restrictions in particular. Most journals have fairly rigid page limitations.

Articles about specific special interest topics are best submitted to specialty journals, most of which have quite small readerships. If you are approaching one of the general interest journals—or the popular press—the article needs to have relevance to a fairly wide audience of psychiatrists. General medical journals also publish on psychiatric topics, but for those, you should be sure that the topic will be relevant and of interest to a wider group of physicians than just psychiatrists. For example, topics related to psychiatric complications of medical illnesses or treatment of primary depression tend to be of broader interest.

Organization

Make your organization clear. Organization of your material is key. We'll deal with several key elements of this organization:

- Introduction: Explain right up front the purpose of the paper and how it is organized. This may seem simplistic but is a great help to reviewers and readers in following the flow of the discussion. State the purpose and organization in a few simple clear sentences.

- Outline: If you can't outline the paper, it's not ready for publication. Use headlines and subheadings to make the organization easy to follow. Look at your outline and make sure it is logical—if you have a hard time following it, someone unfamiliar with the topic will find it impenetrable.

- Order of presentation: It is usually best to move from the theoretical to the practical. For example, if you are writing an update on the latest findings in treating bipolar II disorder, you would first want to discuss diagnostic issues so that readers will understand exactly what kind of patient you are talking about, and then move on to discuss the different treatment modalities. When you come to treatment, if you will be discussing medication and psychosocial treatments, discuss each separately and then consider the issue of combination treatment if it is relevant (unless of course the topic of the article is combination treatment).

- Conclusion: What is the Relevance? Provide a good conclusion. No matter how good a job you have done reviewing the literature, the reader still relies on you to come up with some kind of conclusion or synthesis. Think of it as: Why does it matter to the reader? "Now that you have told me all this, what does it mean for me clinically? How will it affect the way I treat my patients or run my practice?" Likewise, in writing a research paper, be sure your introductory material is relevant to the study you have done. Then, in your conclusion, discuss the clinical relevance of your findings and any suggestions you have for future research directions.

Proofreading is essential

A paper that contains typographical, spelling or grammatical errors, and incomplete or overly complicated sentences gives a bad impression and will put reviewers off. Simple clear declarative sentences are best. Avoid excessive use of the passive voice. Use your spell check program but don't rely on it exclusively. It will not pick up words that are spelled correctly but are not the right word in the sentence, such as if you type "right" when you mean "write". Be sure you use **its** (belonging to it) and **it's** (it is) correctly. People with an MD or a PhD should know the difference and it looks bad when they get it wrong—yet this is the single most common grammatical mistake I see. Remember that the apostrophe means something has been left out (i.e., the "i" in is).

References are key

This issue may not mean the difference between publication and rejection, but most reviewers equate sloppiness in references with general sloppiness, and are likely to suspect the quality of your overall presentation. Editors often spend a good deal of time trying to fix problems with reference lists and may reject a paper that appears to cause them additional work.

Be sure you include reference citations for any statements that would make someone ask: "Is there any support for this statement? What do you base that on?" Don't cite out-of-date research when there is more recent and relevant work available. If most of your references are more than 5-10 years old, this is usually a sign of trouble, unless you are doing some kind of historical review.

If you are drawing on clinical experience or expertise, say so. There is nothing wrong with using the first person singular or plural (i.e., my research, findings from our research group, etc). Some journals prefer that you say "this author's research" but many find it rather convoluted.

Follow the reference citation style and format specified by the journal. Be sure that there is a reference in the list for each citation and that every reference in the reference list is cited somewhere. Go through and cross check them as part of your final proofreading of the paper. Be sure that references include all the necessary information. Check for missing dates and titles that have obvious typographical errors.

Statistical methods

Describe statistical methods with enough detail to enable a knowledgeable reader with access to the original data to verify the reported results. Avoid sole reliance on statistical hypothesis testing, such as the use of p-values, which fails to convey important quantitative information. Give details about randomization. Describe the methods for and success of any blinding of observations.

Whenever possible, references for study design and statistical methods should be to standard works (with pages stated), rather than to papers in which the designs or methods were originally reported. Specify any general-use computer programs used. Put general description of methods in the Methods' section. Avoid non-technical uses of technical terms in statistics, such as "random" (which implies a randomizing device), "normal," "significant correlations," and "sample." Define statistical terms, abbreviations, and most symbols.

Chapter Summary:

This chapter has emphasized communication about your program activities, but particularly about your program accomplishments as judged from your evaluation data, emphasizing the importance of considering communication at local, national, and international levels. We have also provided tips and traps associated with:

- Press conferences and press releases;
- Press kits;
- Creating effective presentations;
- Developing effective websites; and
- Publishing in academic journals;

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Supplemental Readings

The following supplemental readings are provided for individuals wishing more in-depth technical knowledge on the points raised in this manual.

Data Analysis:

Aron A, Aron EN. (1994) Statistics for psychology. Englewood Cliffs: Prentice Hall.

Cohen J. (1998) Statistical power analysis for the behavioural sciences. (2nd edition.) Hillsdale: Erlbaum.

Lehtonen R, Pahkinen E. (1995) Practical methods for design and analysis of complex surveys. Chichester: Wiley.

Tabachnick BG., Fidell LS. (2001) Using multivariate statistics. (4th edition) Boston, MA: Allyn and Bacon.

Ethics:

CIOMS International Ethical Guidelines

World Psychiatric Association. Declaration of Madrid.

Evaluation:

Posavac EJ, Carey RG. (1992) Program evaluation: methods and case studies (4th edition). Englewood Cliffs, New Jersey: Prentice Hall.

Scriven M. (1991) Evaluation thesaurus (4th edition) Newbury Park: Sage Publications.

Focus Group Research:

Morgan, D. (1993) Successful focus groups. advancing the state of the art. London, Newbury Park: Sage Publications.

Morgan, D., Krueger, R. (1997) The focus group kit. columes 1-6. London, Newbury Park: Sage Publications

Krueger, R. (2000) Focus groups: A practical guide for applied research. (2nd edition). Thousand Oaks: Sage Publications.

Morgan, D. (1995) Why things (sometimes) go wrong in focus groups. Qualitative Health Research 5 (4): 516-523.

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Morgan, D. (1997) Focus groups as qualitative research. (2nd edition) Newbury Park: Sage Publications

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Templeton, J.F. (1987) Focus groups: a guide for marketing and advertising professionals. Chicago: Probus.

Quantitative Measures for the Assessment of Stigma:

Angermeyer MC, Matschinger H. Lay beliefs about schizophrenic disorder: the results of a population survey in Germany. Acta Psychiatr Scand (Suppl 382) 89:39-45

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Beiser M, Waxler-Morrison N, Iacono WG, Lin TY, Fleming JAE, Husted J. A measure of the 'sick' label in psychiatric disorder and physical illness. Soc Sci Med , 25, 251-261.

Cohen J, Struening E. (1962) Opinions on mental illness in the personnel of two large mental hospitals. J Abnorm Soc Psychol 64:349-360

Crisp AH, Gelder MG, Rix S, Meltzer HI, Rowlands OJ. (2000) Stigmatisation of people with mental illnesses. Br J Psychiatry 177:4-7

Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P. (1997) Public beliefs about causes and risk factors for depression and schizophrenia. Soc Psychiatry Psychiatr Epidemiol 32 :143-148

Jorm AF, Korten AE, Rodger B, Pollitt P, Jacomb PA, Christensen H, Jiao Z. (1997) Belief systems of the general public concerning the appropriate treatment of mental disorders. Soc Psychiatry Psychiatr Epidemiol 32:468-473

Lauber C, Nordt, Falcato L, Rössler W. Public acceptance of restrictions on mentally ill. Acta Psychiatr Scand 102 (Suppl 407):26-32

Link BG. (1987) Understanding labeling effects in the area of mental disorders: An empirical assessment of the effects of expectations of rejection. Am Sociol Rev 52:96-112

Link BG, Cullen FT, Frank J, Wozniak JF. (1987) The social rejection of former mental patients: Understanding why labels matter. Am J Sociol 92: 1461-1500

Link BG, Mirotznik JJ, Cullen FT. (1991) The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? J Health Soc Behav 32:302-320

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Matschinger H, Angermeyer MC. (1996) Lay beliefs about the causes of mental disorders: a new methodological approach. Soc Psychiatry Psychiatr Epidemiol 31 :309-315

Stuart H, Arboleda-Flórez J. (2001) Community attitudes toward people with schizophrenia. Can J Psychiatry 46 :245-252

Struening EL, Perlick DA, Link BG, Hellman F, Herman D, Sirey JA. (2001) The extent to which ccaregivers believe most people devalue consumers and their families. Psychiatr Serv 52:1633-1638

Taylor MS, Dear MJ. (1981) Scaling community attitudes toward the mentally ill. Schizophr Bull 7:225-240

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WPA Survey Questionnaire for use in the Global Anti-Stigma Program, openthedoors.com.

Survey Research:

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Dillman DA (1978) Mail and telephone surveys. The total design method. New York: John Wiley & Sons.

Fink A; Kosecoff J. (1985) How to conduct surveys : a step-by-step guide. Beverly Hills: Sage.

The Survey Kit. Thousand Oaks: Sage Publications.


ESQUIZOFRÉNIA
ABRAS LAS PUERTOS
سكيزوفرينيا (الفصام)
افتح الأبواب
SCHIZOFRENIA
APRI LA PORTA
स्किज़ोफ्रेनिया
दरवाज़ा खुला रखें
SCHIZOFRENIA
APRI LA PORTA
LA SCHIZOPHRÉNIE
OUVREZ LES PORTES
SCHIZOPHRENIA
OPEN THE DOORS
स्किज़ोफ्रेनिया
दरवाज़ा खुला रखें
ШИЗОФРЕНИЯ
ОТКРОЙТЕ ДВЕРИ
SCHIZOPHRÉNIE
ÖFFNET EURE TÜREN
ESQUIZOFRÉNIA
ABRAS LAS PUERTOS
SCHIZOPHRENIA
OPEN THE DOORS