



Guidelines to reduce stigma

Guide 1



What is health-related stigma?

2011

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Introduction

This Guide is part of a series of four Guides to reduce stigma. The Guides are for all managers, health and social workers and service staff who have to deal with stigma in leprosy and other health conditions. These Guides provide evidence-based and best-practice information from different disciplines, and recommendations for field workers on how to reduce stigma against and among affected persons and in the community.

This first Guide provides basic information on stigma, its causes, manifestations, and effects. The second Guide describes when and how to assess stigma using qualitative and quantitative methods and instruments. It also explains how to use the instruments. The third Guide provides recommendations on how to develop an approach for reducing stigma. Through the use of a roadmap, several steps are discussed for reducing stigma related to a particular health condition. The fourth Guide explains the use of counselling at a basic level in dealing with stigma. It provides an explanation of different techniques and approaches for counselling persons affected by stigma.

For supporting documents: www.infolep.org/stigma-guides

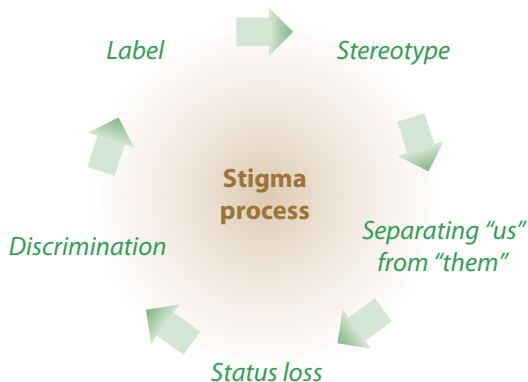
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What is stigma?

Stigma is a negative response to human differences. These may be obvious visible signs or differences in behaviour, or they may be more subtle. If these are related to a health condition, we call this response 'health-related stigma'.

The people who are perceived to be 'different' are often labelled, e.g. as a 'leprosy sufferer' or 'mental case'. Society tends to have stereotypes that go with these labels, particular views of what such a person is like (very contagious, cursed, sinful, rejected by society in the case of leprosy; or dangerous, unreliable and not able to take decisions in the case of mental illness). When such a stereotype is attached to a label, people tend to no longer see the actual person, but only the stereotype. The person is reduced to the stereotype. People then tend to separate themselves by using expressions such as "people like that" – "us" versus "them". This in turn often leads to loss of status of the stigmatised person and to actual discrimination. Stigma can take on different 'faces'. It may be very subtle, particularly in the early stages, for instance when people start asking questions of a person, or when they gossip about someone. At the other end of the spectrum is overt negative behaviour, often called discrimination.



Sarah is 19 years old. She works as a housemaid. Her employer hears that she is getting treatment for leprosy. The next time she comes to work, he calls her and says “you don’t have to come to work anymore. We don’t need your services”.

This is a form of stigma often called **discrimination**, also called **experienced** or **enacted stigma**.



We talk about discrimination when people are treated differently because of their health condition or other perceived differences, such as ethnic background. Discrimination is an act of stigmatisation. In this case Sarah got fired because she has leprosy, and not because of any inability to perform. Discrimination may occur

in different settings, such as the community, at home, in the workplace, in the media, in legislation, and in health and social services.

Jonathan is 34 years old. He sells food in the market. He has just been diagnosed with HIV. He is now concerned that if people find out about his condition, nobody will buy his food.

This is another form of stigma; it is called **‘anticipated stigma’**, also called **‘felt’** or **‘perceived’ stigma**.

Anticipated stigma is the perception, expectation or fear of discrimination and the awareness of negative attitudes or practices in society. This may be felt by the affected person. Sometimes, an action may be interpreted as stigmatising, while the intention was completely different. For example, someone may leave the room for a totally unrelated reason when a person with a stigmatised condition enters, but the latter feels it is because of them, and is distressed. The net effect often depends on the perception, not necessarily on whether the perception was accurate.

Anand is 27 years old and was diagnosed with leprosy a year ago. People in his community believe leprosy is a curse, only those who have committed sins in their past can get leprosy and that persons with leprosy should not participate in religious festivals. Anand starts believing this about himself. He stops going to the temple, does not leave his house anymore and believes he must be a bad person.

This is yet another form of stigma, called **self-stigma**, also called **internalised stigma**.

When someone has been stigmatised, or perceives stigma for a long time, they may start to believe what others say and think about them. As a result they may experience loss of self-esteem and dignity, and / or fear, shame, hopelessness and guilt. People may consciously or unconsciously accept diminished expectations about themselves, and start behaving the way people expect them to behave. In the end, this leads to social exclusion in the same way as discrimination. Participation restriction and social exclusion are examples of the impact of stigma.

These examples of stigma are only a few of the many ways people can perceive stigma. When this occurs because someone has a health condition (such as leprosy, HIV/AIDS, mental illness, disability, epilepsy, sexually transmitted infections, and many other health conditions), we call it **'health-related stigma'**.



People often think of stigma as a mark or blemish, some more permanent characteristic of a person. This is also the original meaning of the word 'stigma'. However, research into the experiences of stigmatised persons and the effect of interventions to reduce stigma has shown that stigmatisation is a dynamic social process. This process can differ from person to person, depending

on the culture, disease, a person's status or character, and the way the condition develops. Some people may be stigmatised for more than one reason. Common examples are women, poor people or HIV-infected persons who use drugs or who are homosexual. Such 'multiple stigma' is also known as 'layered stigma', as if a person is covered in several layers of stigma.

What are the causes of stigma?

There are many different causes of stigma. These may vary according to the health condition. The most common ones are discussed here.

Fear

Fear is a common cause. This may be fear of catching a disease that is infectious (or perceived to be so), such as leprosy or HIV / AIDS. In the case of leprosy, it may be fear of the physical consequences that can result from leprosy; in the case of HIV / AIDS, it may be fear of death. It may also be fear of people that are thought to be dangerous, such as people known to have mental illness. Unpredictable situations may also cause fear, such as with people with epilepsy. Fear can lead to stigma among members of the public or among health workers, but also among people who are affected with the condition themselves. The latter may fear the social consequences of disclosure of their condition. This is in fact fear of stigma. This is common in persons affected by leprosy or HIV / AIDS and may lead to self-stigma. An example is the fear of not being able to marry or of one's children not being able to marry on account of having leprosy or a mental illness.

Unattractiveness

Some conditions can cause people to be perceived as unattractive, particularly in cultures where outward beauty is highly valued. In that case, people with visible impairments on their face, such as missing eyebrows, or a collapsed nose, as may occur in advanced cases of leprosy, may be rejected just because of the way they look. People with facial skin lesions or burns may be treated likewise.

Unease

Very visible conditions may make people feel uneasy or uncomfortable. They may not know how to behave in the presence of a person with such a condition and therefore choose to avoid the person. These can be small things, such as not

knowing how much to look at a person. Looking too much may be perceived as staring; not looking enough may be perceived as avoidance. Difficulties in communication can also be a source of feeling uncomfortable. This may happen in contact with deaf people or with those who have difficulty speaking, e.g. due to cerebral palsy or aphasia.

Association

Stigma by association is also known as 'symbolic stigma'. This may occur when a health condition is associated with a condition that is perceived to be undesirable. Examples are conditions that are associated with commercial sex work, illicit drug use, a particular sexual orientation, poverty or loss of employment. One condition may also become more stigmatised, because of association with another condition. A good example is that of tuberculosis and its association with HIV / AIDS.

Values and beliefs

Values and beliefs can play a powerful role in creating or sustaining stigma. Examples are beliefs regarding the cause of a condition, such as the belief that leprosy is a divine curse or is caused by sin in a previous life. Religious values regarding sexual relationships and marriage may cause HIV-related stigma if HIV



is perceived to be the result of marital infidelity. Cultural beliefs that leprosy or mental illness is hereditary may cause whole families to be stigmatised. Particular cultures may hold particular stereotypes or prejudices regarding people with certain conditions. These may concern the way people behave, whether they are reliable, faithful, etc. Based on these, negative attitudes may pervade a whole society.

Policies or legislation

Policies about how and where conditions are treated may cause stigma. This is typically seen when conditions are treated in separate locations such as a leprosy clinic or clinic for sexually-transmitted diseases set apart from the rest of the hospital. Special clinic days or hours in an outpatient department can have the same consequences. Other examples are immigration or employment policies requiring people with certain conditions to declare their status. Laws may be discriminatory, allowing divorce on grounds of the spouse having or developing a particular health condition or banning people from public office, elections or land ownership.

Lack of confidentiality

Unwanted disclosure of one's condition can be due to the way test results are handled or due to deliberate disclosure by health staff or careless handling of confidential data. This may be completely unintended, such as the sending of a reminder letter or a visit by a health worker in a vehicle marked with the programme logo.

Who stigmatises?

Stigma can come from anyone; family members, neighbours, employers, classmates, fellow believers in church or at the mosque or temple, but, importantly also from health workers. Stigma from health workers can be particularly hurtful, since they may be the people a person turns to for help.

People often do not realise that they stigmatise. They may use certain words that are experienced as stigmatising by those affected; for example a preacher referring to 'lepers' in a church sermon. This may also be true of certain behaviour like avoiding talking with a blind person or someone in a wheelchair, because you feel uncomfortable about what may be appropriate to say. It can be helpful to examine your own attitudes by asking yourself questions, such as "would I accept a glass of water from someone who is HIV-positive?" "Would I invite a person affected by leprosy for dinner in my home along with other guests?" "Would I accept an invitation to eat at their home?" It is important to realise how far-reaching the impact of stigma can be on a person, their family or even the whole community.

An organisation of people affected by leprosy organised training for their members in a reputable hotel. When participants arrived, some of them with visible disability due to leprosy, the manager of the hotel suddenly refused to let them stay in the hotel. According to the hotel manager, this was for the sake of the other guests. The training was called off.

This is an example of how **an organisation can stigmatise**. This example is also a form of **discrimination**, where persons affected by leprosy were denied their right to stay at the hotel.

Nina is a health care worker who has just been assigned responsibility in an HIV/AIDS programme. She does not feel comfortable with this new assignment because she thinks that people living with HIV/AIDS are “victims” of their own bad lifestyles. She believes that they have been involved in sinful behaviour. Nina is in the HIV/AIDS programme orientation training. She still has a strong belief that people living with HIV/AIDS are bad and that they can easily transmit their disease to other people. She is angry with them because of their perceived behaviour and does not want to meet with HIV/AIDS-affected persons during the field training. She finally withdraws from the training.

In this example, Nina has a negative attitude towards people living with HIV / AIDS and she gives negative labels to the people concerned. Nina shows a **personal attitude** that is associated with a **stereotype involving morality and behaviour** towards a certain health condition. Such **emotional reactions can cause others to also avoid or distance** themselves from those affected by that health condition.

Nina is afraid of being infected by people living with HIV / AIDS. She perceives them as dangerous and withdraws from the training.

This is a form of **perceived stigmatisation**.

What are the effects of stigma?

Stigma has many different effects on the person who is stigmatised, on their family and on the community. It may also affect the programmes available to serve those affected.

The effect of stigma may be psychological. For example, a stigmatised person can feel fear or shame, which can lead to anxiety and depression. Due to this, or because of discrimination or anticipated stigma, they may no longer take part in any social activities. This limits social participation and leads to social exclusion.

Social exclusion or discrimination in turn may result in an economic burden for the affected person and their household and thus cause or aggravate poverty.



Stigma or anticipation of stigma may cause affected people to conceal their condition. The burden of keeping this secret, of being ever watchful and careful, taking evasive actions and 'living a lie', takes an emotional toll. In addition, non-disclosure to family means loss of emotional and social support. Because of stigma, many persons with a stigmatised health condition do not seek help. This delays the diagnosis and treatment and may worsen the health condition. The risk of disability may also increase. Stigma thus hinders the effective treatment and care of the person.

In the case of infectious diseases, stigma can complicate efforts to control the disease. It can cause delay in diagnosis and treatment, which may prolong transmission in the community. Stigma may also be a barrier to preventive behaviour, for instance proposing to use a condom being suggestive that one is HIV-

positive. This silence and denial inhibits prevention programmes. People may not change their behaviour, because doing so would expose them to stigma. In addition, patients may not adhere to treatment, if clinic attendance or regular medication leads to awkward questions and potential exposure to stigma. This increases the risk of further disease transmission, disability and drug resistance.

Overall, stigma is likely to have a negative impact on the quality of life of affected persons, their family, health programmes, and on society through the above mechanisms.



What can be done to reduce stigma?

Once we understand how stigmatisation works, we can take relatively simple measures that will help to reduce stigma! The first is to make people aware that we may stigmatise without realising it. The second is to avoid labelling persons with a certain health condition, and to recognise and avoid using stereotypes. To address stigma more systematically and on a larger scale, we need to use specific intervention strategies.

Interventions can address the person affected by leprosy themselves, but can also address their family and/or the community, health workers and health policy makers. Some interventions only aim at one level (for instance at the affected person), others at more levels simultaneously (such as the affected person, their family and the health workers). Research has demonstrated that interventions which target several levels at the same time are more effective in reducing stigma.

Sometimes, a relatively small change can reduce stigma significantly for affected persons. For example, the ability to prevent chronic wounds through self-care can be a trigger to empower persons, increase self-esteem and social status, and, as a consequence, reduce stigma. But, in other cases, stigma reduction demands a larger carefully designed intervention programme and more time. For example, setting up a programme of socio-economic self-help groups. The intervention strategy of choice will depend on the situation, including cultural aspects, health conditions, persons affected, or persons who stigmatise.

Approaches for interventions to reduce stigma at different levels

Level	
Person	<ul style="list-style-type: none"> • Treatment • Counselling • Cognitive-behavioural therapy • Empowerment • Group counselling • Self-help, advocacy and support groups
Between persons	<ul style="list-style-type: none"> • Care and support • Home care teams • Community-based rehabilitation
Organisation	<ul style="list-style-type: none"> • Training programmes • (New) Policies that are patient-centred and have integrated approaches
Community	<ul style="list-style-type: none"> • Education • Contact • Advocacy • Protest
Government	<ul style="list-style-type: none"> • Legal and policy interventions • Rights-based approaches

**A brief description of each of these can be found on the supporting website*

www.infolep.org/stigma-guides

How to set up a project targeting multiple levels is discussed in Guide 3. The programme described in Guide 3 combines different stigma reduction strategies. In Guide 4, it is explained how to counsel people who experience stigma.

How can these Guidelines be of help?

The *Guides to reduce stigma* are written for people who have to deal with stigmatised persons or conditions, such as health workers and social workers working in peripheral or district level health centres. If you are not sure whether these guidelines would be of help, ask yourself the following questions:

1. Are people with a particular health condition stigmatised in this community?
2. In what way? Which of the kinds of stigma described above may be a problem?
3. Would it be useful to know the extent or severity of the stigma? For example prior to implementing measures to reduce stigma?
4. Would it be necessary and possible to undertake specific action to reduce the stigma that exists?

If you have answered 'yes' to questions 1, 3 or 4, these Guides may be helpful to you. The second Guide will provide you with the necessary knowledge and tools for measuring stigma. Separate guidelines deal with interventions (Guide 3.) and counselling (Guide 4.).

Further reading

Please see the website www.infolep.org/stigma-guides for:

- supporting documents
- stigma assessment instruments including translations
- links to websites
- further background reading
- persons you can put questions to (by email)
- practical tools and guides



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