

Guide 3 Annex 2: Creating a network of champions



Photo credit: NLR

At the community level, positive role models can help to:

- Raise awareness about NTDs and the difficulties faced by those who are affected, and transform the image of NTDs and persons affected by them.
- Advocate for the rights of persons affected, for example by promoting the social, financial and educational rights of persons affected by a stigmatised health condition.
- Reduce stigma through awareness-raising campaigns.
- Be a source of information and support for persons affected and their family members – for example, recognise early signs and symptoms, refer for diagnosis and treatment and follow up to offer support with self-care techniques (if applicable).
- Support initiatives to improve care and to reduce stigma.
- Motivate others to uncover their potentials and to overcome difficult situations by showing them that it is possible to overcome difficult situations and to turn a weakness into a strength.
- Inspire others – looking up to someone who has made a change in the world will encourage others to do the same.
- Change people's outlook on issues and challenges.

Creating a network of champions



Photo credit: The Leprosy Mission Trust India

Individuals can become advocates in isolation, but networks of champions can bring additional levels of support. Networks of champions often have a coordinator. Their role may be to coach, supervise and support the champions and to ensure the champions are well trained. The coordinator can:

1. Identify and recruit champions.
2. Organise and train champions.
3. Provide ongoing assistance and multiple types of support to champions, including access to financial, technical and capacity-building assistance where necessary.
4. Distribute promotional materials.
5. Coordinate activities.

The coordinator usually serves as the point of contact for the designated champions and usually meets with the champions on a monthly basis to reflect.

Recruiting champions



Photo credit: Layla Aerts for Damien Foundation

There are several ways to identify a champion. Examples include:

1. Publicising, using advertisements in newsletters or at health centres, billboards etc.
2. Going out into the communities and recruiting through face-to-face interaction.
3. Drawing on networks to ask members of networks or partners to identify people who are interested in leading community change (it is also possible for people to nominate themselves).
4. Word of mouth.

Being a champion is usually a volunteer position. It is therefore good to stress early on that the rewards of the work are mostly practical and personal.

Encouraging women to become champions is particularly relevant for creating female role models.

Training



Photo credit: Lepira, Bangladesh

Once recruited, the champions should be trained, encouraged and supported to enable them to really become champions. Training may include lectures, observations, group discussions, practice and role play.

Training topics to build skills, competencies and knowledge include:

- In-depth knowledge about disease and local public sector services.
- Basic human rights and ‘nothing about us without us’ principles.
- Understanding what it means to be a champion, increasing confidence to be a (visible) champion and building leadership.
- Active listening skills, communication skills (including on how to give a talk to a group) and ways to challenge the assumptions people have.
- Practical ways to ‘step up’ as champion, including skills to identify health and social care needs and ways to have a proactive role in the community.
- Community mobilisation skills.
- A network of other champions from different communities.

For sustainability, it can be helpful to involve experienced champions in training new champions and trainers.

Roles and activities



Champions may focus on different levels or settings in their advocacy:

- The health facility (clinic, health centre or hospital) or service delivery, to make sure people access services and get good service.

- The community, to make sure people with the disease and/or mental health conditions are fully included in community life, its benefits and responsibilities.
- The legislative and national level, to make sure that laws include and protect individuals with NTDs and mental health conditions and respect their rights.
- Policy, to make sure that policies include and protect individuals with NTDs/mental health conditions and respect their rights.

As mentioned previously, each network of champions should have a coordinator who is responsible for coaching, supervising and supporting the champions.

The coordinator is responsible for forming networks or teams of champions and will also encourage champions to develop a local network of supportive peers. In addition, the coordinator and champions will work together to create a strategic work plan. The work plan should be based on contact with the community and persons affected who live in the community. Champions often set up and organise awareness meetings with support from the coordinator.

Examples of a champion's roles and activities include:

- To act as a signposting person on NTDs for local community groups – to let people know that they are available to talk to them.
- To make contact with and listen to people in the community, including persons affected. This can be done through friends and family, through attending community meetings or by setting up a small group.
- To increase awareness and understanding about NTDs and persons affected by them. This can be done by setting up and organising awareness meetings, projects, and community-led approaches. An example would be to give a (testimonial) talk about their condition at community meetings or at health fairs. Champions can also ask to be invited to existing meetings, such as community meetings, that were already going to take place.
- To encourage persons affected to stand up for themselves.
- To build the confidence, knowledge, skills and capacity of affected persons and their community members.
- To look for organisations that can provide support.
- To actively look for opportunities where people can learn from each other. When people understand each other better and realise their disease is 'just like any other disease', they are less likely to discriminate and tolerate discrimination.
- To provide feedback to local service providers on how they can improve their services, based on conversations with persons affected and their community members.
- To attend regular meeting with other champions.
- To attend regular one-on-one meetings with the coordinator, for example to reflect on awareness.