

## Equity and Inclusion in Health Programming

**Equity and inclusion are key issues for the Swiss Agency for Development and Cooperation (SDC), given its strong commitment to the Agenda 2030 principle of “leaving no one behind” and to achieving Universal Health Coverage. However, efforts to guarantee equity and inclusion face not only technical and material challenges but also social and political ones, especially in relation to governance and accountability.**

### Introduction

This Briefing Note summarises the results of a Learning Trajectory on Ensuring Equity and Inclusion in Health led by Erika Placella (SDC Health Advisor for Eastern Europe and Central Asia) with support from Alex Shankland, Hayley MacGregor and Gerry Bloom from the Institute of Development Studies (IDS), UK, and involving colleagues from Swiss Embassies and SDC offices in Eastern Europe and Central Asia and SDC Bern. The Learning Trajectory ran from May 2016 to November 2017 and was supported by the IDS-SDC Collaboration on Poverty, Politics and Participation within the SDC QA(P) department, SDC Eurasia Division, and SDC Global Programme Health. It aimed to increase awareness and understanding of these issues among SDC staff involved in the design, implementation and steering of health projects and programmes in the Eastern Europe and Central Asia region and to stimulate sharing of relevant knowledge and experience, in order to inform the development of guidance for future work.

The Learning Trajectory led to the identification of key challenges and principles to be taken into consideration at different points in SDC’s programme cycle. The guidance offered in this Note has therefore been organised according to the different steps in the Project Cycle Management (PCM) approach followed by SDC.<sup>1</sup>

### Learning Trajectory on Ensuring Health Equity and Inclusion in Health

SDC is committed to addressing equity and inclusion in all its areas of intervention, and they are key components of the implementation principles governing SDC’s Health Policy. In seeking to strengthen equity and inclusion in health programmes, SDC realised that there was not always a consistent understanding of key issues around equity, that there was a lack of clear and accessible guidance to help country offices and programmes to address equity and inclusion challenges better in practice, and that the innovative approaches emerging from different countries across the Eastern Europe and Central Asia region were not necessarily being shared effectively. This led to the decision to launch the Learning Trajectory on Ensuring Equity and Inclusion in Health.

The Learning Trajectory was initiated by the SDC health advisor for Eastern Europe and Central Asia and developed with conceptual and methodological support from IDS. It involved colleagues from the Swiss embassies and cooperation offices in Albania, Bosnia and Herzegovina, Kosovo, Kyrgyzstan, Moldova and Ukraine, as well as from SDC’s HQ in Bern.

<sup>1</sup> SDC Project Cycle Management Framework (Bern, Swiss Agency for Development and Cooperation, 2018)

Activities included:

- a webinar
- two Face-to-Face events, one in Tirana in September 2016 and one in Geneva in November 2017
- a presentation of both the preliminary findings from the Learning Trajectory and experiences from Moldova at a conference on Accountability for Health Equity at IDS in July 2017.<sup>2</sup>

In addition, SDC colleagues in Bosnia and Herzegovina and Kyrgyzstan, with technical support from IDS and inputs from SDC peers, analysed SDC-supported health initiatives in these countries, focusing on mental health and Non-Communicable Diseases respectively.

## Understanding Equity, Inequity, Health and Inclusion

According to the World Health Organisation (WHO), the concept of **health equity** implies that “everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential”.<sup>3</sup> When certain regions or population groups have systematically poorer access to health services or receive poorer quality of care, this can result not only in inequalities – different groups of people having different health outcomes – but also **inequities**.

Health inequities are inequalities that are not caused by inevitable differences in health status that result from (for example) sex, age or genetic susceptibility, but rather by unfair and avoidable differences in the distribution of health services and in the exposure to social determinants of health across different groups. These differences are often the result of historical processes that have left their mark on contemporary societies, shaping the scope for achieving greater equity. The most vulnerable groups in a given population are often affected by the ways in which various aspects of social difference, such as class, race and gender, can intersect to intensify their negative effects, as a result of political factors and power dynamics. This “intersectionality” can be an important factor in driving inequity.

### *Additional resource*

For a range of perspectives on health equity and Universal Health Coverage, including the challenge of intersectionality and the importance of taking historical processes into account, see E. Nelson, G. Bloom and A. Shankland, eds. (2018) ‘Accountability for Health Equity: Galvanising a Movement for Universal Health Coverage’ IDS Bulletin Vol. 40 No. 2 (<http://bulletin.ids.ac.uk/idsbo/issue/view/233>)

## Inclusion and exclusion

Efforts to tackle inequity have often gone hand in hand with an emphasis on **inclusion**. For many years, SDC and other agencies have tended to understand inclusion in health systems in terms of coverage, with a focus on identifying and reaching populations that currently lack access to, for example, immunisation or local primary care services. However, there is increasing awareness that inclusion is not only about the possibility of access but also the terms of access, as well as the quality of care on offer for different people. It is therefore important to think about the causes of **exclusion** from health services. In addition to physical accessibility, poorer people may be excluded by the costs of accessing care (both financial and in terms of time), by health systems factors related to the organisation of care or stigmatising attitudes, and by language and other social barriers that may exclude people who are members of ethnic and religious minorities.

<sup>2</sup> See <https://www.ids.ac.uk/project/accountability-for-health-equity-programme>

<sup>3</sup> See [http://www.who.int/topics/health\\_equity/en/](http://www.who.int/topics/health_equity/en/)

Some marginalised and vulnerable people may also self-exclude: that is, they actually avoid seeking out government health services because of their perceptions of the state, as well as avoiding private health services because of the way they feel that society perceives them. This may be because they fear discrimination, either related to their ethnic or religious identity or due to a health condition that may be associated with social stigma. They may fear being forced to make (illegal) payments to receive care at all, or being forced into debt by the costs of care. Undocumented migrants at risk of deportation may fear being exposed to sanctions from other branches of the state. Thus political and social factors influence how social difference and power dynamics mediate inclusion.

## How can Equity and Inclusion challenges be better addressed?

Tackling health inequities requires addressing not only epidemiological and demographic issues but also issues of policy, institutions, politics and power. These are key factors in health system governance, defined by the WHO as “a political process that involves balancing competing influences and demands”, within which it is very important to establish “transparent and effective accountability mechanisms”.<sup>4</sup> They are also key factors in how governance issues in the wider society, like decentralisation or corruption, can affect the structure and functioning of the health system.

In general, effective inclusion depends on building trust between communities and health care providers, and this is best achieved by giving marginalised people a say in how services are provided. However, since processes of exclusion and intersecting inequities tend to be driven by deeper structures of power in society, tackling them effectively also requires political strategies to be developed alongside health policies, programmes and projects. This includes policy dialogue, which may need to extend into other areas beyond the health sector to ensure that inequities and social determinants can be tackled within a multi-sectoral approach. Designing these strategies requires a strong understanding of the (often complex) social, economic and political contexts within which interventions are operating.

### Equity, inclusion and accountability in the health systems of transition countries

'Countries in transition from command to market economies face major challenges in the creation of new institutional arrangements for health system accountability for equity. These are associated with the speed and magnitude of the changes taking place. The health systems of many countries have experienced big increases in formal and informal market relationships. Many countries are implementing major reforms to systems of public financial management which are altering the relationship between local and national governments and many are also establishing new health insurance schemes. At the same time, patterns of inequity and social exclusion are changing as a consequence of economic reforms. The impact of health system reforms on access to health services is strongly influenced by actions taken by stakeholders to protect their interests. It is important that the design and implementation of programs aimed at strengthening health institutions take the dynamic context of transition into account.'

*Contributed by Gerry Bloom, IDS*

### Additional resource

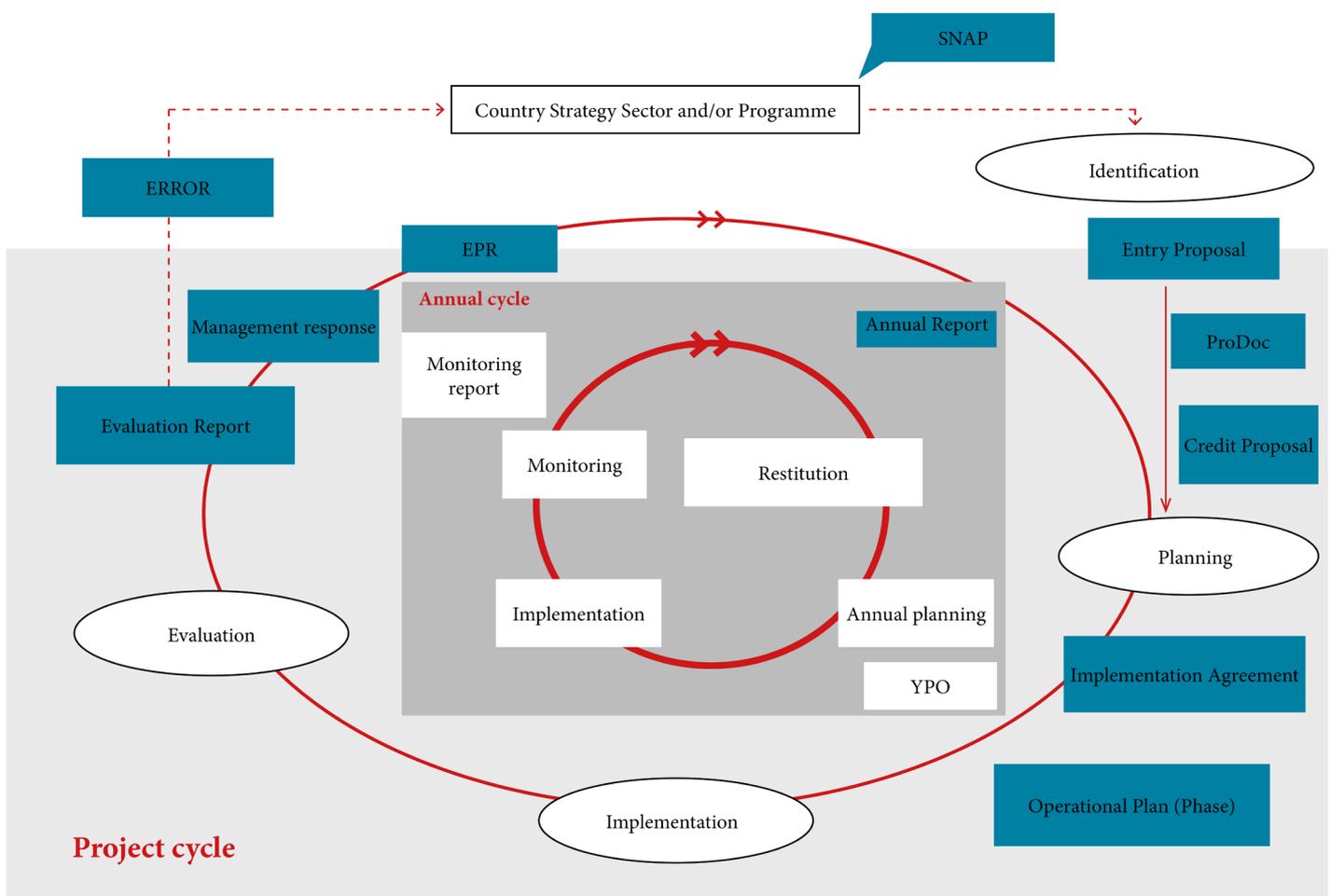
For more on the specific challenges of health systems development for transition countries in Eastern Europe and Central Asia, see B. Rechel, E. Richardson and M. McKee (2014) Trends in health systems in the former Soviet countries, Geneva: European Observatory on Health Systems and Policies ([http://www.euro.who.int/\\_data/assets/pdf\\_file/0019/261271/Trends-in-health-systems-in-the-former-Soviet-countries.pdf](http://www.euro.who.int/_data/assets/pdf_file/0019/261271/Trends-in-health-systems-in-the-former-Soviet-countries.pdf))

<sup>4</sup> See <http://www.who.int/healthsystems/topics/stewardship/en/>.

## Equity and Inclusion in the Project Cycle

SDC follows a Project Cycle Management (PCM) approach to its projects and programmes. This means that initiatives should be located within a broader context of strategic programming, that their implementation should follow a period of careful identification and formulation, that their progress and outcomes should be evaluated, as well as their delivery being the focus of monitoring and evaluation processes, and that the lessons from these evaluations should be fed back into the overall programming framework before the cycle begins again. This is summarised in the figure below, from the SDC Project Cycle Management Framework.

Source: SDC Project Cycle Management Framework, 2018



Addressing equity and inclusion issues should be built into every part of the cycle. However, the ways in which these issues should be addressed will vary according to the stage that a programme or project has reached. The following sections present guidance for each stage, summarised in a series of “key principles”. The final section follows the cycle back to strategic programming, and looks at how equity and inclusion issues can be addressed in country cooperation strategies, reflecting the need for multi-level approaches that identify the links between more narrowly-focused programmes and projects and the sector and country contexts in which they operate.

## Programme Identification

**Key Principle 1:** *Ensure that you understand not only statistical patterns of health inequality but also forms of social exclusion, the specific groups that are most vulnerable to exclusion, and the norms, social relations (including provider attitudes and behaviour) and networks that influence whether and how marginalised people access health information and care.*

The identification process should start with collecting epidemiological and demographic data and assessing how the burden of disease / ill-health is distributed. If preliminary analysis indicates that there are health inequities reflecting the greater vulnerability of some groups to infectious or non-communicable diseases, then it will be important to understand the social networks and relationships that influence disease transmission, access to information and care-seeking. This will require combining qualitative, ethnographic and participatory research with standard quantitative baseline surveys. Such research should ideally be conducted before intervention strategies are defined.

### **Additional resource**

For guidance on using qualitative and participatory research methods to understand the dynamics of equity and inclusion in specific contexts, see R. Loewenson, A. Laurell, C. Hogstedt, L. D'Ambruoso and Z. Shroff (2014) Participatory action research in health systems: a methods reader, Geneva/Harare: Alliance for Health Policy and Systems Research / TARSC ([http://equinetafrica.org/sites/default/files/uploads/documents/PAR\\_Methods\\_Reader2014\\_for\\_web.pdf](http://equinetafrica.org/sites/default/files/uploads/documents/PAR_Methods_Reader2014_for_web.pdf))

This preliminary research should also examine health care providers' attitudes and behaviour, which often play a major role in determining whether or not people from the target population trust them and willingly seek care. Health programmes commonly include Knowledge, Attitudes and Practices (KAP) studies for the target population, but it is less common for programmes to examine the attitudes and behaviour of providers. This is an important gap, because addressing these issues can be an important factor in improving uptake of programmes – an issue that emerged during the IDS review of SDC initiatives in Bosnia and Herzegovina (mental health) and in Kyrgyzstan (NCDs).

### **Understanding the role of health care provider attitudes in tackling Non-Communicable Diseases (NCDs)**

'People detected as "at risk" for NCDs can often feel blamed for their health condition. A focus solely on individual lifestyle can put across a message that they need to be more responsible and that their ill-health is their own fault. A discourse of responsible and irresponsible patient then creeps into the organisation and attitude of care in health centres. This can deter people from returning to health centres, especially if they are struggling to change their lifestyles, afford or access healthy food, or adhere to medication and other recommendations of treatment and prevention regimes.'

*Contributed by Hayley MacGregor, IDS*

## Programme Planning

**Key Principle 2:** *Ensure that you have identified the right implementation partners and potential allies to enable the programme to make a difference for equity and inclusion.*

A programme's focus on equity and inclusion should be reflected in its choice of partners for delivery. This means that tender documents should include requirements to address equity issues as well as specific deliverables such as baseline equity and inclusion assessments.

Involving other potential allies from government beyond the health sector, and from outside government, can also help to increase a programme's potential for impact. Identifying the key players inside and outside government who can shape relevant decisions on priority-setting and resource allocation for reducing health inequities, using tools such as Political Economy and Power Analysis (PEPA), should be an important part of programme planning.

### *Additional resource*

For guidance on using Power and Political Economy Analysis in programme planning, see A. Mejía Acosta and J. Pettit (2013) Practice guide: A Combined Approach to Political Economy and Power Analysis, Brighton: IDS (<http://www.ids.ac.uk/publication/practice-guide-a-combined-approach-to-political-economy-and-power-analysis>)

This analysis should identify key actors within government with whom it will be important to build strategic relationships in order to have more impact through more equitable resource allocation and decision-making. While most sector programmes will necessarily have the Ministry of Health as a key partner, exactly where the focal points are located within the Ministry will make a difference in terms of a programme's potential to influence equity. For example, if prior analysis has shown that spatial inequities in health outcomes reflect patterns of resource allocation between rural and urban areas, or between regions inhabited by majority and minority ethnic groups, then it will be important to build a relationship with planning and budget departments. Similarly, links with other ministries such as those responsible for education or social welfare will be important in building multi-sector alliances to address social determinants of health inequities.

Non-governmental actors such as civil society organisations (CSOs), research institutions and businesses can be key potential allies. In particular, at the formulation stage it will also be important to identify what formal or informal organisations may represent the interests of marginalised groups or people affected by particular conditions, and to plan how they can be engaged in design, delivery and evaluation. As discussed below, CSOs have a key role to play in advocacy for the interests of marginalised groups, but those who are involved in delivering government services may find it challenging to balance this with an advocacy role, especially in contexts that are experiencing a process of closing civil society space.

## Programme Implementation

**Key Principle 3:** *Ensure that programmes are both responsive and adaptive, with an approach characterised by "learning by doing" and governance arrangements that strengthen inclusion and representation of marginalised groups.*

Interventions can encounter unexpected obstacles and have unintended consequences, however well designed they are. As a result, programmes that are seeking to promote equity and inclusion may end up having the reverse effect: for example, a policy change to centralise chronic disease care might mean that people with complex health problems lose long-standing relationships with trusted health care providers, or the introduction of a specialist service for LGBTI people to improve access might single them out and thereby increase stigma. It is therefore important to take an adaptive approach and focus on 'learning by doing', and above all to ensure that target groups – and especially the most vulnerable – are involved in implementation as well as programme design and thus able to provide rapid feedback on problems as well as successes.

Given the link between strengthening accountability and tackling inequities, it is important for programme implementation to model ways of being accountable to the intended beneficiaries themselves. Local health committees and other participation structures are often used only to mobilise community contributions or transmit health-related messages, but they also have the potential to play a role in governance. Realising this role means ensuring that they receive regular updates on the project (including financial information wherever possible, in order to strengthen transparency), and also that they should have the right not only to provide feedback on positive and negative aspects of implementation but also to demand information on the responses that have been agreed to any concerns raised.

#### *Additional resource*

For a summary of recent research on accountability and governance in health systems, see D. Brinkerhoff, D. Jacobstein, J. Kanthor, D. Rajan and K. Shepard (2018) *Accountability, Health Governance, and Health Systems: Uncovering the Linkages* (<https://www.hfgproject.org/accountability-health-governance-health-systems-uncovering-linkages/>)

Participation structures do not always include people from all different segments of the community, and may be dominated by more locally influential groups or have a membership that lacks diversity in terms of age or gender. This means that it is important to ask whether they actually include representatives of the most vulnerable and marginalised groups, as well as of other priority groups identified by the project. The programme will need to ensure that these representatives have the support they need to collect the views, priorities and concerns of their constituencies and to keep them informed about what response these have received. Paying attention to pragmatic factors such as where and when meetings are held will also make a difference to how easy it is for representatives of certain groups (such as women with a lot of unpaid caring responsibilities or men who have to travel long distances to work) to participate in local committee meetings.

Beyond the local level, each programme will have its own management and governance arrangements to direct the overall implementation process. It is important to think about how these arrangements can themselves help to strengthen equity and inclusion by modelling more inclusive and responsive governance. For example, project steering committees or consultative fora can provide an opportunity to bring together representatives of different groups (such as senior bureaucrats, front-line health professionals and people affected by particular conditions) who may not normally have an opportunity to interact. As long as they are carefully facilitated to mitigate the risk that power relations will lead to some members being silenced or intimidated, such encounters can help to change attitudes and behaviour in ways that can generate impact far beyond the project itself.

#### **Equity and Inclusion in the project on Non-Communicable Diseases Control in Kyrgyzstan (2016)**

'From first reading, the term equity and inclusion in development projects looks very clear and applied by default. However, in most cases we are not fully addressing the equity/inclusion issues in our projects. The health system is considered to be equal for everybody, at least at the primary health care level. Yet, we can see that health services are designed to be provided as it is convenient for the health facilities. Also the service delivery system is not adapted to age and gender-specific needs of the population. Against this background, the NCDs prevention and control project in Kyrgyzstan aimed to introduce new approaches to ensure equity and inclusion, such as proactive outreach work of the family doctors/nurses to increase access to care in remote areas; designing health promotion activities with gender and age specific population needs in mind; and involvement of the Village Health Committees in the multisectoral council at district level to address health needs and problems of the rural population. When applying equity and inclusion approaches in health projects, it is important to have clear indicators to steer progress over the implementation period and adapt the activities accordingly.'

*Contributed by Elvira Muratalieva, Swiss Embassy Kyrgyzstan*

## Programme Evaluation

**Key Principle 4:** *Ensure that programmes have robust equity and inclusion monitoring systems that include opportunities for service users – especially the most marginalised and vulnerable – to provide inputs to programme evaluation and review, including commenting on health care worker attitudes.*

The indicators used for monitoring and evaluation will need to permit assessment of the programme's contribution to equity and inclusion. This contribution needs to be assessed at multiple levels, from output to outcome to impact. Ideally, impact-level evaluation would be able to draw on national data sources such as health management information systems, epidemiological surveillance databases and demographic and health surveys (DHS). However, it may not be possible to disaggregate such data to analyse some key issues for equity and inclusion such as the role of ethnicity, since in many countries (such as Kosovo, for example) the law does not permit recording the ethnic identity of patients. In such cases, it may be necessary to use proxies such as geographical location to disaggregate data, based on the localities with the largest concentrations of marginalised groups. Where existing data sources are inadequate, programmes will need to conduct their own impact studies, using both surveys and qualitative methods.

### *Additional resource*

For guidance on quantitative strategies for monitoring health inequalities using both population-based and administrative data, see World Health Organisation (2013) Handbook on health inequality monitoring with a special focus on low- and middle-income countries, Geneva: WHO ([http://apps.who.int/iris/bitstream/handle/10665/85345/9789241548632\\_eng.pdf](http://apps.who.int/iris/bitstream/handle/10665/85345/9789241548632_eng.pdf))

Strengthening equity and inclusion in the monitoring and evaluation of programme implementation at the activity and output level should emphasise feedback mechanisms such as beneficiary assessment and patient experience audits.<sup>5</sup> Taking a Participatory Monitoring and Evaluation (PME) approach will permit priority groups to provide real-time feedback on performance, and this can greatly enhance a programme's ability to adapt its strategies quickly and thereby increase their effectiveness. However, PME requires skillful facilitation and high levels of trust. Achieving this trust in turn means that the programme will need to ensure that managers, professionals and other more powerful actors are willing to listen and respond to concerns raised by marginalised groups, including their views about health-care workers, rather than disregarding them or even threatening reprisals.

Review and evaluation processes can provide a valuable opportunity to seek out the views of marginalised and vulnerable groups. A review that asks wider questions about structural drivers and determinants rather than focusing narrowly on programme performance can also help to identify key strategic challenges. The best source of information on the implications of these challenges will usually be the experience of service users themselves.

<sup>5</sup> See <https://www.shareweb.ch/site/Poverty-Wellbeing/addressing-poverty-in-practice/beneficiary-assessment> for guidance on Beneficiary Assessments, including how they can be used instead of external review

### **Inclusion and equity in external review with peer support of the Mental Health Project in Bosnia and Herzegovina (2017)**

'Specific focus on efforts and results of the project related to social inclusion and equity issues were added to the terms of reference for the review. This included the participation of persons with mental health disorders in designing and evaluating mental health services and in developing community-based interventions for fighting stigma and discrimination. It found that the starting point of the project was on reducing discrimination in access to services related to somatic health of psychiatric patients. Once this has been achieved, new areas of discrimination have been identified by these patients, such as in employment and access to mainstream social activities, and the project has designed interventions to address these challenges. It concluded that social inclusion and equity are and should remain the cross-cutting issues of the mental health reform in Bosnia and Herzegovina. Therefore, the new phase of the project has been planned in line with this.'

*Contributed by Maja Zaric, Swiss Embassy BiH*

## **Beyond the programme level: Equity and Inclusion in Country Cooperation Strategies**

**Key principle 5:** *Ensure that you understand the wider structural conditions shaping inequity and exclusion in the health sector and in the country as a whole, including not only barriers to change but also coalitions and alliances that have the potential to strengthen equity and inclusion.*

Social attitudes discussed above in relation to health care staff attitudes and behaviour – such as the stigma associated with mental health service users and notions of deserving and undeserving patients – will often be a reflection of widespread attitudes in society. Politicians' reluctance to resource specialist services for LGBTI young people, for Roma women or for older men living in rural areas may also reflect wider patterns of (often intersecting) age-, gender-, sexuality-, ethnicity- or regionally-based discrimination.

However, providing health services to groups with specific needs is complex and often expensive, and discrimination may not be the only reason why governments fail to deliver them. It is important to have a good understanding of the constraints facing the health sector, including human resource limitations and management capacity challenges. It is also important to understand the wider political economy of resource allocation within the government at central and local levels, including the effects of decentralisation on the division of resources and responsibilities.

### **Additional resource**

For an overview of recent European approaches to strengthening governance for action on social determinants and health equity, see C. Brown, D. Harrison, H. Burns and E. Ziglio (2014) Governance for health equity: taking forward the equity values and goals of Health 2020 in the WHO European Region ([http://www.euro.who.int/\\_data/assets/pdf\\_file/0020/235712/e96954.pdf](http://www.euro.who.int/_data/assets/pdf_file/0020/235712/e96954.pdf)).

Sector- and country-level analysis should not only be used to identify patterns of exclusion and inequity and barriers to change. It should also serve to identify entry points and potential alliances for strengthening equity and inclusion. As noted above, strategic allies may be found both within government and outside it, in civil society, the media or the private sector, as well as among organisations seeking to represent the interests of marginalised groups or people with particular health conditions. In general, a programme's long-term impact on equity and inclusion will be shaped by its ability to contribute to wider processes of structural change at the same time as delivering on its own focused and time-bound objectives.

### Integrating equity aspects in the development of a new Country Cooperation Strategy in Moldova (2016-2017)

'During the preparation of the new Country Strategy 2018-2021, SDC decided to have a stronger focus on inclusion and equity aspects. The process started in 2016 with a peer review of the current strategy, where we asked SDC peers to review specifically how well we were reaching excluded groups and how we could improve. Before starting to write the new strategy, we had an external consultancy done in early 2017 on the three domains of intervention to get as good data as possible on gender and other inequities. In the case of health, it was men in general having less access to health. Other priority groups include Roma, people with disabilities and the rural population. In health we decided that one way to redress inequalities is to strengthen accountability in the system. One logical partner is civil society, but Moldovan CSOs are mostly delivering services and dependent on the government. They are thus hesitant to hold authorities accountable. SDC therefore decided to not only work *with*, but also *on* civil society and create coalitions between independent watchdog CSOs and CSOs specialized in health.'

Contributed by Matthias Leicht-Miranda, SDC Moldova

This Briefing Note was written by Alex Shankland and Hayley MacGregor (IDS) with inputs from Erika Placella (SDC HQ), Elvira Muratalieva (Swiss Embassy Kyrgyzstan), Maja Zaric (Swiss Embassy Bosnia and Herzegovina), Matthias Leicht-Miranda (SDC Moldova) and Gerry Bloom (IDS) and incorporates feedback from two other IDS researchers acting as internal reviewers.

This Collaboration between SDC and the Institute of Development Studies explores how poverty relates to politics and power. It is supporting SDC staff in improving the quality and effectiveness of SDC processes and operations focused on poverty. The Collaboration uses an 'organisational learning and change' approach to accompanying SDC activities, which is reflective, demand-based and rooted in the realities of SDC's work. It runs until December 2018.

For further information please contact:  
Stephanie Guha at SDC-QA  
E [stephanie.guha@eda.admin.ch](mailto:stephanie.guha@eda.admin.ch)  
URL [www.shareweb.ch/site/Poverty-Wellbeing](http://www.shareweb.ch/site/Poverty-Wellbeing)

Swiss Agency for Development and Cooperation  
Freiburgstrasse 130  
3003 Bern, Switzerland  
T +41 (0)58 462 34 75  
E [deza@eda.admin.ch](mailto:deza@eda.admin.ch)  
URL [www.sdc.admin.ch](http://www.sdc.admin.ch)

Institute of Development Studies  
Brighton BN1 9RE, UK  
T +44 (0)1273 606261  
E [ids@ids.ac.uk](mailto:ids@ids.ac.uk)  
URL [www.ids.ac.uk](http://www.ids.ac.uk)  
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