Policy Dialogue on

Sexual and Reproductive Rights of Persons with Disability: Barriers and Enablers

Panelists:
Dr. Kiran Rupakheti, National Planning Commission
Dr Gunanidhi Sharma, Ministry of Health and Population
Mr. Deepak Raj Sapkota, Karuna Foundation Nepal
Ms. Sarita Lamichhane, Founder-Prayatna Nepal

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Dr Baral: Nepal government has introduced various policy frameworks to ensure right to health for the Persons with Disability. Today we will discuss the status of implementation of policies and legal frameworks, results and support system. In particular, we will discuss with experts what ought to be done to ensure health rights of persons with disability, who have been marginalized.

I would like to welcome the panelists.

Dr. Kiran Rupakheti from National Planning Commission, Social Development and Governance Division. He is contributing for designing plan for women, children, senior citizen and persons with disability.

Mr. Deepak Sapkota, Executive Director of Karuna Foundation Nepal. He is a social campaigner contributing to ensure rights of children, women and senior citizen and persons with disability from non-government sector.

Dr. Guna Nidhi Sharma, Ministry of Health and Population, Policy Planning and Monitoring Division. He has been contributing to policy formulation and planning of policy and programs of the Ministry.

Ms. Sarita Lamichhane, Founder, Prayatna Nepal. She has been advocating for sexual and reproductive rights of persons with disability.

Let's proceed with the discussion. As I mentioned earlier, let's begin with the policy frameworks introduced by the Government of Nepal. My first question goes to Dr. Kiran Rupakheti. You are formulating plan at NPC. In particular, you have been working on the policies for excluded and marginalized community such as children, and senior citizen. Would you please share with us what sorts of policy and legal framework government has introduced and has implemented to ensure rights of persons with disability?

Dr. Rupakheti: The topic we have been discussing is quite important. Constitution of Nepal has incorporated various provisions related to inclusion of backward community and classes. One of the group is persons with disabilities including women. The constitution has ensured women's rights to sexual and reproductive health and safe motherhood as a fundamental right. Act related to rights of persons with disability has ensured protection of persons with disability from inhuman behavior, physical or emotional violence, sexual abuse, exploitation from family member, guardian or any other person. Another important milestone is the reproductive rights of women with disability. This act has mandated provision for rights of women with disability on sexual and reproductive health. Following this provision, in 15th periodic plan, we have incorporated the provision that priority should be given to such group. The plan clearly mentions about persons with disability. However, we have felt that little has been mentioned particularly about women with disability. So, an action plan is being developed by the Ministry. The action plan aims at providing equal access to persons with disability including women to reproductive rights.

Dr Baral: Has Nepal government ensured participation of persons with disability in policy formulation process based on principle of inclusion?

Dr. Rupakheti: Compared to past, there have been some progresses. The government has been engaging with various organizations and networks working in disability. In various committees envisions by the act, there has been representation of such organizations. In addition, federal and local governments have been providing conditional grants to such organizations for awareness raising and rehabilitation of the persons with disability. However, we still have many things to do.

Dr. Baral: I will get back to you again. I want go ask Dr Guna Nidhi. Dr. Kiran said state has formulated policies and acts to ensure rights of persons with disability based on principle of inclusion and has tried to ensure their rights. The evidence show that person with disability have been marginalized and excluded since long in terms of health service. The evidences also show that there are several limitations of persons with disability to access sexual and reproductive health rights. You are with policy making and resource allocating body. Would you please share with us what policy and programmatic initiatives ministry has taken to ensure health rights of persons with disability?

Dr Sharma: I want to build on Dr. Kiran's statements. We should reduce use of the term exclusion following inclusive principle adopted by the constitution of Nepal. If we look at policy provisions, our constitution and legal provisions are inclusive. In implementation aspect, there are problems and challenges which Health Policy and 15th plan has tried to address. In terms of service delivery, there have been some problems. MOHP is aware of these circumstances. MoHP is implementing these legal frameworks though. For example, following federalism we have established a unit related to disability in the department of health services. This unit looks after prevention of disability, rights including reproductive right. We have been also partnering and collaborating with non-government organizations working in disability and organization of persons with disability. It has been also prioritized in the policies that all health facilities including basic health service centers and those providing specialized service should be disability friendly.

Dr. Baral: We will talk later what special provisions should be in place to ensure access to quality health service to persons with disability. I want to ask Ms. Sarita Lamichhane. You have been working for rights of persons with disability. How have you been observing the status of access of persons with disability to policy formulation, resource allocation and implementation based on principle of inclusion?

Ms. Lamichhane: Thank you for this opportunity. First let's talk about policy. A clause of Safe Motherhood and Reproductive Health Act has ensured sexual and reproductive health rights for persons with disability. There was participation of persons with disability while formulating this act. However, while drafting bylaw rule, there was no participation of person with disability. Several provisions of act have not been reflected in bylaw. In terms of access, National Building Code incorporated provision of disability-friendly physical infrastructure. After Nepal government ratified Convention on the Rights of Persons with Disabilities (CRPD), there have been some attempts to ensure access and rights of persons with disability. There have been some initiatives to include persons with disability in policy formulation. However, majority of our health facilities are not accessible to them. Understanding of access has been limited to the construction of ramp only. Little attentions have been paid towards access to document, information platform such as website, easy-to--read format etc. Posters are mainly used in health sectors to provide certain information, as we believe the picture speaks itself. The Government of Nepal has classified disability into 10 types. But poster or photo cannot communicate to all types of disability. For example, poster may be useful for person with deaf or hard of hearing, intellectual disability, physical disability, autism spectrum disorder. But it cannot address to those who have vision Impairment. So these are some of the challenges.

Dr. Baral: I want to refer to what Dr Guna Nidhi mentioned earlier - we have urged in the policies and programs regarding making health services disability friendly but what Sarita has just mentioned regarding how it is necessary to ensure that health services are disability friendly. Do you mean this needs to be explicitly defined as well as health services are not disability friendly for all kinds of disabilities?

Ms. Lamichhane: National Policies and legislative measures have given ample space to concerns of people with disability. Despite the policy provisions and legal frameworks, it is necessary to revisit these policies and programs and address the gaps.

Dr. Baral: If there are any one or two changes that needs to be amended in these policies? What kind of change would you suggest?

Ms. Lamichhane: Changes are required from the data entry process, while entering the data of service recipient at the health facility, we need to maintain record of person with disability such as number and type of disabilities. If this provision would have been incorporated in the bylaw or policies, we will have some data to assess the status of people with disability. Another is disability friendly services should take into account the severity of disability status. There needs to be monitoring mechanism of service providers who provide services to people with disability to understand the accessibility component. If we are to incorporate these provisions, there will definitely be conducive environment for implementation.

Dr. Baral: Very good points have been raised by Sarita specially on having a mechanism of data entry of person with disability who visit health facility. This is lacking in our policy. If it was there in policy and provisions, it would have led to influencing our guidelines and policies to ensure inclusive, accessible, friendly services for people with disability. We will definitely get back to this point in a while. I would like to turn to Deepak. You've been working in the non-government sector since long. The Government of Nepal has emphasized coordination, collaboration and partnership in all of its policies and programs. You also have been working in collaboration with the government to co create disability friendly services, could you place your views on what are the strengths and where do we need to improve and move forward?

Mr. Sapkota: Before I answer this question, I want to touch upon little bit of background. When we talk about disability in Nepal's context, we don't have exact data on prevalence of people with disability. Census conducted in 2011 shows 1.97% prevalence, whereas WHO suggests the actual figure is much higher such as 15 percent.

Dr Baral: In Nepal, the government does not have the actual figure of the prevalence of people with disability?

Mr. Deepak: No we do not! That's what I feel too. When we don't have the actual figure itself, how can we focus on what kind of policy or programs is needed?

Dr. Baral: The 2011 census has mentioned 1.97% isn't it?

Mr. Deepak: But WHO has mentioned 15% as the figure in the global scenario and we might fall in between that range. Another thing I would like to touch upon is - what Sarita said earlier regarding classification of disability into 10 types by government of Nepal. Physical disability as we understand also has its own subgroups. Within that category, there might be person with only one arm, person without two arm, person with one arm and one leg. Under each classes of disability, it has its own issues and needs. Services differ as per the type of disability.

Dr. Baral: So is it right to say that we do not have clarity on the classification and level of severity of different type of disability?

Mr. Sapkota: It's not like we do not have the clarity on the classification itself but what I am trying to say is 10 classifications on the type of disability are there but it is not right to develop policies and programs focusing on disability as a whole itself. Single policy for all disability may not work.

Dr. Baral: So Policies need to be on the basis on multiple classifications?

Mr. Sapkota: Yes, when we develop programs we need to look into the basis of its level of severity and the classification of disability. Another thing is people with disabilities are scattered in various communities and households. They need some assistance to put forward their opinion at any platform. I believe the policies and our constitution is very progressive. It is one of the most progressive constitutions in regards to the space given to disability.

Dr. Sushil: The main law has provision of inclusion of disability?

Mr. Sapkota: Yes, I can say that. It is very progressive. While developing guidelines, policies and programs, we definitely need to take into account our capacity and should set the milestones accordingly. Currently, it is difficult in terms of tracking our progress.

Dr. Baral: We lack in terms of prioritizing our plan, and do not meet our objectives in reality because we plan ambitious which affects the intended results. Is that correct?

Mr. Deepak: I won't plan should not be ambitious. Plan should be ambitious but it should match with the reality as well. It should consider capacity to execute plan.

Dr. Baral: With that being said, is there partnership, collaboration and inclusion while developing such plans and programs with non-governmental organizations working in this sector?

Mr. Deepak: If we look at the budget and program at the provincial and local level in regards to disability sector, it is very minimal and has tokenism system. What we have tried to do is being a non-governmental organization – we have three limitations; we have to seek funding by ourselves,

we have certain time to accomplish the tasks, and we work in the area of supporting the government, not as a counterpart of the government. What Karuna Foundation, where I am affiliated with, did was cooperate, support and train government at all three tiers of government. We had meetings with two provincial governments. We proposed an idea of disability prevention and rehabilitation program along with resources for co-creation. In Nepal, we have established one of the most successful models, where provincial government, local level and non-governmental organizations worked together to establish a disability prevention and rehabilitation program in province one. This model has received a lot of positive feedback. However, in terms of collaboration, it is there a problem of duplication. For example, seven multiple organizations have been working on same issue with different names. The government should not prohibit or ban them but government can systematically engage them. They should set priority and engage them in the remaining area or recommend them to work in another province. But I think government is not in this position. Unless this happens, collaboration and support won't achieve the result.

Dr. Sushil: Based on the discussion so far, we can conclude that policy frameworks and legal provisions are in place. However, there are area to improve to make these policies and provisions more inclusive and participatory. I want to ask Dr Rupakheti, what are the basis of ongoing plan formulation?

Dr. Rupakheti: Mainly the basis for plan formulations are the constitutions of Nepal and Nepal government's international commitment. For example, Nepal has ratified Convention on the Rights of Persons with Disabilities (CRPD). We consider national policies and international commitments while developing plan. If you look at 15th periodic plan, we have separate section for persons with disability.

Dr. Sushil: Sarita pointed out lack of disintegrated data is creating limitation in policy and plan formulation. Is this reality?

Dr. Rupakheti: Yes, there is nothing to hide. This is reality as Sarita said. For example, if patient visits hospital, he/she is not asked if he/she has any kind of disability. This is the area we have to improve. Some progresses have been made. For example, census 2021 has incorporated disability information to some extent. But we don't have disintegrated data of 10 types of disabilities.

Dr. Baral: What are other limitation beside data?

Dr. Rupakheti: We have some limitations. After we commit something at international forum, we have to take certain action in that area. So we are requested to include that action in periodic plan and policies. Generally, plan is also a dream. Sometime all dreams may not be achieved. Sky is limit. plan reminds us our commitment.

Dr. Baral: We are conducting this discussion in the context of international day of person with disability. This year's slogan puts emphasis on leadership and participation of persons with disabilities toward an inclusive, accessible and sustainable post-COVID-19 world. This is social, political and economic agenda as well. What NPC has been considering these aspects when it comes to policy formulation?

Dr. Rupakheti: State is moving ahead towards inclusiveness. For example, civil service act and by-law paved way to inclusion. For example, in past, there were less number of people with disability in civil service. But they are increasing now. Over the period of time, we are increasing participation of people with disability in civil service. We are making physical infrastructure disability friendly. However, the pace we are moving ahead is not enough. We have some resource

limitation, there have been some barriers to implement international commitments. We need to scale up the resource. When it comes to leadership, not only in government organization, we need to think how many civil society organizations led by person who does not have disability worth-mentioning number of employees who have disability

Dr. Baral: Mr Sapkota wants to share something on this?

Mr. Sapkota: I want to share an experience. Province 1 has announced disability prevention and rehabilitation program. Karuna Foundation is one of the partners of this program. While working practically, we understood, until and until stakeholders are well informed about their rights and can put forward their opinion, policies cannot work alone. So this program has formed group persons with disability in each ward, collected their data prepared individual profile of 25,000 persons with disability in seven districts. We have been trying to ensure, in partnership with province one, participation of at least one person with disability at cluster level while formulating plan.

Dr. Baral: I would like to turn to Dr Guna. Specially in the context of sexual and reproductive health, a lot of issues has been raised in this discussion. Right now we are in the middle of COVID-19 pandemic. During the time of pandemic more light has been shed on the restriction for people with disabilities to access health services. What evidence we have seen is, in times of crisis like COVID-19, persons with disabilities face more barriers in accessing sexual and reproductive health services. It is also true that, sexual and reproductive health issue is not discussed in our society. So, in order to move forward in tackling this issue what are the ways forward? What are the restrictions faced by people with disability?

Dr. Sharma: You mentioned about COVID-19. In any kind of disaster, we experienced in the past that persons with disability and other marginalized groups are normally face accessibility issue. We had similar experience in 2015 earthquake. During COVID-19 pandemic, we have formulated policies and guideline to increase access of people with disability to health services. Despite understanding this need, there were some limitations. We had limitation of information while designing program. Although we have lack of disintegrated data, we have to design program based on available information.

Dr. Baral: Existing Health Information Management System does not include disintegrated data of persons with disability in its system. Is it right?

Dr. Sharma: Census is a biggest source of data. every census is improving. So data has also been added. Disability has been categorized under Social Security policy. Such information are also recorded at local level while they receive their entitlements. Probably we might have to improve HMIS for integrated data for specific intervention in disaster and pandemic. Otherwise we have to follow blanket approach. We have to work on that.

Dr. Baral: During federal structure, local government have role to provide basic health care service, do you mean they have opportunity to generate disintegrate data?

Dr. Sharma: They have opportunities. For example, ward chair can take lead to initiate data collection and create data base.

Dr. Baral: Has anything been done in this regard?

Dr. Sharma: Some local levels have initiated this. For example, Province 1 has created profile of persons with disability. However, there has been less awareness towards social development as local levels have other priorities of development. But collecting data at local level is not huge task. We have 6,743 wards. they can generate data at local level. We can use those data at national level as well. But it is impactful for targeted intervention at local level.

Dr. Baral: I will get back to you again. I want to ask Ms. Lamichhane. You are a client of health service as well. As a user, you might have also received sexual and reproductive health service based on need, what is your experience while taking such services? What are you experiences while accessing government health services?

Ms. Lamichhane: Please cross check and add if need be. In some of the government health facilities there is some sense of awareness that has been initiated. Few of my friends have reported while visiting Bir hospital that they did acquire free of cost services. But there are challenges, in our health facilities, there is no management of sign language. I'll give you case. A woman went to the health facility for abortion, during the third month. The health service provider did not understand what she was trying to communicate, the doctor instead provided her with an iron tablet. The woman thought it was an abortion related tablet so continued taking the medicine but initially later she gave birth to the baby. The thing that I am trying to point out is that due to gap in miscommunication, as there was no sign language interpreter present, there are restrictions as such. Contraceptives are attributed to family planning and married people. This always may not be the case. There is also need to re-visit these terminologies. As there is gap of unmarried people not going to access these services just due to term coined, in both public and private health facilities. There has been initiation of ramps in the facility. However, in regards to visual impairment service seeker will not know where to access the ticket.

In the case of Gorkha Hospital, as far as I know, an audio keeps playing in regards to where you can access certain services. If the federal hospitals, could follow such steps it would be helpful for people with disability. In terms of labor bed, for women who are on wheelchairs it is not accessible. Another issue which was shared by a pregnant visually impaired woman mentioned that when she went to the access health service, the health care providers asked her about her blindness rather than her pregnancy. Even regarding her diagnosis report, it was mentioned to her family member that she can be left at home and one of the member from the family could collect the report. This would definitely make the women feel insulted as she is pregnant and has rights to know about her pregnancy.

Dr. Baral: How I understand is, there are provisions in the policies but there are restrictions in terms of implementation. May that be in terms of infrastructure, health service provider's capacity or in terms of accessing other health services that are not disability friendly. What kind of collaborations is being made with non-governmental organizations?

Ms. Lamichhane: Organizations such as Marie stopes International has been assisting in terms of accessing Sexual and reproductive health services. However, all the centres are in second floor and there are no wheel chair services. Recently, Family Planning Association of Nepal have been providing free of cost sexual and reproductive health services in Kathmandu from every clinic for people with disability. There are other organizations that have been working in terms of providing awareness but I see some gap in terms of partnership – do the participants who participate in programs understand the whole package. Now what is really important is that the health care providers are trained on how to behave with people with disability when they come to receive the

services, it is necessary to conduct programs with the health service providers itself. Another important aspect is, while providing information or jingles that is shared from various mediums. How is it being communicated with people with disability. It is time to make government document accessible to people with disability.

Mr. Sapkota: You raised a very practical issue. There is a problem while implementing awareness raising program. If MOHP incorporates such programs or policy documents, it is easier to raise awareness. Quite often awareness issue is considered as an additional task or perceived as responsibilities of non-governmental organizations when they approach government officials. It is very crucial to take a co creation approach.

Dr. Baral: We have been exchanging these ideas in the context of international day of persons with disability. We have focused on policies, their implementation, challenges and way forwards. Now May I ask Dr Rupakheti to provide opinion on some way forwards.

Dr. Rupakheti: I think the discussion is very fruitful. One thing we did not discuss here is attitude of mass people towards disability. Still there is a misconception that persons with disability can do nothing, they are burden. Even in a family of persons with disability, such perception prevails. We should go towards changing this misconception on attitudinal as well as behavior level. Another is- most of the action on the issue we discussed here can be addressed from non-government organization and local level. Non- government organizations are extended arms of the government. We should make local level aware of these thigs. We should incorporate these issues in development plans. Ultimately two things we discussed today are investment for increasing access such as disability friendly infrastructure. This should be implemented federal, provincial and local level. National planning commission should specifically deal disability issue in next periodic plan. There is intersection within the disability. For example, women or women with intellectual disability might have been treated differently. So we need to address or minimize such gap in next plan.

Dr. Baral: Deepak what do you think needs to be done?

Mr. Sapkota: Dr. Rupakheti mentioned NGO as an extended arm of government. What we can do is National Planning Commission could keep the record of NGOs in different provinces and local level who could support government on disability related issues. For example, in province 1, there are 25 NGOs working in disability, we can plan how to engage them. While doing so they feel recognized and government can mobilize them accordingly. Province one is investing 150 million rupees for disability prevention and rehabilitation at 59 local levels. This should be linked up with federal government. Federal government should encourage such initiatives, if there are shortcoming, we need to improve. Government has been providing social security scheme including educational grants to persons with disability. There are around six hundred thousand populations of persons with disability. They are scattered but have been in government record. So we can pull the data together, and make policy oriented towards them. It can be exemplary.

Dr. Baral: Now I want to get back to Dr. Gunanidhi, what should be the next step to ensure the implementation of disability friendly policy framework?

Dr. Sharma: We need to improve policy and legal frameworks identifying the area of improvement. Another important aspect we discussed today is regarding disintegrated data. We need to identify the area of improvement; such as source of information, documentation so that it will help in the decision making process. We have 761 governments. We should strengthen

partnership with non-governmental organizations so that we can increase access of people with disabilities. We have now 10 categories of disability, we may also extend these categories to 20 as part of further analysis that will lead to informing policy decisions. Each health facility should be universally disability friendly. We can further define what disability friendly really is. We should do nationwide assessment of health facilities. We often talk about physical disability and physical access and less attention has been paid towards other disabilities. In overall we have progressive policies but they are lacking in terms of implementation. We have to gradually mitigate these challenges.

Dr Baral: I will get back to Ms Lamichhane now. How do we ensure that people with disability have access to quality health services along with sexual and reproductive health services? What is the way ahead?

Ms. Lamichhane: First thing what we need to focus is on the fact that persons of disability have been deprived to enter the medical education sector, so we need to push ahead with this agenda that persons with disability enter the medical education. This will help in ensuring the health services are provided are disabled friendly.

Second point that I want to share is regarding the flow of information, the means and medium of information should be disability friendly. We at Prayatna are also ready to ensure that websites that provide information could be disability friendly and can be accessible. If anyone watching this wants their website to be audited and ensure it is disability friendly, we will prioritize and work on making it disability friendly.

Third point is regarding training. Training courses/packages that are provided to the human resources should incorporate multiple dimensions of disability.

Fourth point is that, for example the trainings that were conducted in Banepa and Sanga hospital, there must be exposure visits, while providing training to health service providers. To replicate and ensure disability friendly services are equipped.

The fifth point is, all the health policies and plans that are being developed should be scripted in Unicode version as well. Unicode in pdf format would not be accessible. So should be in doc format from all relative health agencies in regards to information on sexual and reproductive health.

Sixth point is regarding poster – if poster is being developed it should be developed with audio description or should be explained with captions.

Seventh point- Discussions similar to this should embed sign language interpretation along with subtitles. So it would be accessible by everyone. Thank you!

Dr. Baral: Thank you! In the context of International day of people with disability which is celebrated on 3rd December, we conducted this discussion on this issue with the concerned stakeholders. The program was conducted with the joint initiation of Karuna Foundation Nepal and HERD International. It is now time to conclude this discussion. A lot of issues has been raised. Opportunities has risen during this discussion. I am hopeful that this discussion will direct towards obtaining positive results in achieving equal access to quality health services and sexual and reproductive health services for people with disability. Thank you all to the respective panelists for their time and opinion. We will keep working on this, pushing the agenda forward altogether. I am Dr Sushil Baral, Thank you and goodbye!