

CHAPTER 8

People with Disabilities ‘Owning’ CBR

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SUMMARY

This chapter seeks to share the views and wisdom of a national organisation of disabled people (National Union of Disabled Persons of Uganda (NUDIPU)), concerning the participation of people with disabilities (PWDs), in the development of CBR programmes in Uganda. It traces the historical development of CBR programmes in Uganda and relates this to the UN position on the role of people with disabilities and their organisations. It uses several examples from the CBR development initiatives in Uganda, to analyse the role of disabled people and examine the criteria necessary, to nurture the feeling of ‘ownership’. It leads the reader through the rationale for NUDIPU’s conclusion, namely, that involvement of disabled people is essential at every level, if CBR programmes are to be effective and sustainable.

INTRODUCTION

The National Union of Disabled Persons of Uganda (NUDIPU) is a non-Government umbrella organisation of persons with disabilities that brings together persons from all categories of impairments, including

those with physical, sensory and mental impairments. NUDIPU's mission is to create a unified voice of PWDs to influence the development and provision of services in favour of PWDs in the country. It does this in close co-operation with the government, NGOs and the general public, through advocacy for equalisation of opportunities, involvement and participation in policy planning, and implementation of disability programmes.

In Uganda, the Government and NGOs have been running small rehabilitation initiatives since pre-independence. This has been a big challenge. Early initiatives often centered around the charity model, which basically isolated PWDs into homes where they were protected and cared for. This did not have a positive impact on the communities from where these individuals came, and did not empower PWDs. Vocational institutions and sheltered workshops followed and at first, added some value to the few individuals involved, but did not prepare the environment for adequate integration of the beneficiaries. With time, these institutions became too costly to run and they declined in importance, as they could not meet the overwhelming demands of PWDs. Worse still, the skills they offered became less competitive in both, the formal and informal labour market.

In the last two decades, CBR has developed and become accepted as the most comprehensive strategy for rehabilitation, as it not only targets the individuals with impairments, but also aims to interact with the whole community by utilising the local resources and enlisting the involvement of most of the players. The United Nation's position concerning the role of disabled people and disabled people's organisations is made clear in the Standard Rules for the Equalisation of Opportunity for Disabled People (UN 1994). It is the intention of this chapter to examine the development of CBR programmes and uses the UN rules as a yardstick for evaluation in relation to the participation of PWDs, in these programmes. It is through this process, that NUDIPU has clarified its position and established its conclusions and recommendations.

THE UNITED NATIONS POSITION ON THE PARTICIPATION OF PWDS AND THEIR ORGANISATIONS

Four of the UN Standard Rules on the equalisation of opportunities are particularly relevant to the potential role and participation of disabled people in the development of CBR programmes.

Rule 1 Section 4. says that, “*States should invite persons with disabilities, their families and organisations to join in public education programmes concerning disability matters.*” This awareness-raising role is a very important component of CBR, as it facilitates the community to change their negative attitudes, thus creating a friendly social environment for PWDs, and helping to minimise the possibility of segregation and exclusion.

Rule 3 recommends that PWDs and their families be actively involved in programme design for their own rehabilitation, right from the word go. Rule 18 re-emphasises this in relation to organisations of PWDs and says that they should be encouraged to participate in every initiative concerning them, by any service provider, the State or NGO. Involvement in a programme at a later stage, often means that PWDs become passive recipients and do not understand the values of the programme, let alone agree with them. This minimises the chances of them feeling a sense of ownership for the programme.

Rule 4 requires that in the provision of appropriate assistive devices, persons with disabilities be encouraged to participate in the design and production of appliances. If this does not happen, the appliances are unlikely to perform the function for which they are required and will therefore, not be used by the person concerned.

Rule 18 emphasises again that organisations of PWDs should be encouraged and supported to participate in every initiative concerning them by any service provider, the State or NGO.

THE HISTORICAL PERSPECTIVE IN UGANDA

In Uganda, active CBR was started by Mrs. Nightingale Kalinda in 1989, with an organisation called Community Based Rehabilitation National

(CBRN). She herself, was physically disabled and an occupational therapist by profession, and hence, was involved with both medical personnel and PWDs. CBRN had projects in Mityana, Katwe in Kampala and Kayunga in Mukono. They targeted mainly the physically impaired and a few children with mental/cognitive impairments. The main features of this programme were rehabilitation through physiotherapy, occupational therapy and counselling. It also stimulated the formation of self-help groups, some of whom still exist today. Although this programme had a long lasting impact on the individuals who received the services, it did not have a multiplier effect as a rehabilitation programme. The individuals were only recipients of the services and were not imparted rehabilitation skills to carry out rehabilitation for others. The groups that remain are the income generating groups. Additionally, in an evaluation by Oxfam who was one of the funders, they identified that there were no benefits for blind and deaf people, who were thus marginalised. This situation was not sustainable and there was limited involvement of other stakeholders in the programme. When CBRN could not continue in the communities, the rehabilitation process stopped until other players came in and started afresh.

Another experience was that of the Uganda Society of Disabled Children (USDC). USDC introduced their programmes in a number of selected districts and enlisted the participation of PWDs in community work, especially in awareness campaigns. Some of them were trained as volunteer rehabilitation workers in the community. They also supported the local DPOs, through various training programmes and funding for their capacity building. This approach enabled PWDs and their organisations to own the CBR programmes and participate actively. They were also involved in monitoring and evaluation of the programmes at the local level. However, one shortcoming of the USDC programme was that it lacked inputs from national organisations of disabled people. In fact, for a long time, the national DPOs saw USDC as an organisation that did not involve disabled people, because PWDs were not involved in the programme design. In reality, USDC had a comprehensive outlook. They had services for most impairment groups such as infants, school

going children, for the blind, for the deaf and for mentally and physically handicapped people. USDC also supported hospitals to strengthen referrals.

Another important player in the field of CBR is the Government of Uganda, who entered the scene in 1992. They started programmes in Mbarara, Bushenyi and Kabale districts. At the National level, only NUDIPU was involved in drawing up the guidelines for their CBR activities. Uni-disciplinary organisations were not involved and they felt left out and un-appreciated. Also, at the implementation level in the districts, the local organisations were not actively involved in the management of CBR programmes. This led to serious resistance by some prominent DPOs, whose representatives in the Southwest saw CBR as a foreign concept and one that did not meet their needs. They did not see CBR workers as partners.

While the Government trained some disabled people as CBR workers, they were not facilitated to participate actively in the programme. In contrast, community development assistants, as government employees, were facilitated and paid some top-up allowances. This led to a perception that the involvement of people with disabilities was just a form of 'window dressing', which caused a lot of resentment, and as a result, CBR did not have an impact on the organisations of PWDs at the community and district levels. Although a few individuals were being used as resource persons at different levels, leaders of the organisations did not recognise this as an involvement of their organisations. The DPO stalwarts were constant critics of the programme and for a long time, government supported CBR was not accepted by most of the adult PWDs, who had already organised themselves in associations.

Secondly, the Government programme targeted physically impaired people. For instance, it had no services for blind people until specialised services came later as separate programmes. This was seen as marginalisation by the groups concerned and for a long time even the Uganda National Association of the Blind (UNAB), did not see CBR as their programme. It was also discovered, that the majority of the

beneficiaries had been children, although there were many adults who could have also benefited.

One of the latest players in CBR programmes in Uganda, is Action on Disability and Development (ADD). This programme is unique in that, it has been implemented by DPOs and has PWDs as CBR workers. This has been greatly welcomed by these organisations and by the PWDs in the communities where they are active. Unfortunately, many of the national DPOs were not involved in the initial planning and although the local organisations feel an ownership, the activities miss out on the influence that could have been offered by the national DPOs at the national level.

Another player in the development of CBR in Uganda, is the Cheshire Homes. One of the ways in which they involve PWDs is through the formal employment of qualified PWDs. They also give further training to build their professional capacity to do their work. However, again at the national and local level, DPOs are not involved. Although the efforts and work of the Cheshire Homes is appreciated, in the opinion of NUDIPU, establishing relationships with DPOs would enhance their work.

Community Based Alliance (COMBRA), is another player whose major activity is the training of CBR workers. Right from the beginning, they have involved PWDs in leadership, in the design of the curriculum and in actual training, which has made the training relevant and useful to all the participants. Although their relationship with many PWDs in their individual capacities is strong, their relationship with DPOs has yet to be explored and utilised to the fullest.

THE CURRENT SITUATION

In the last four years, the trend has been changing for the better. Most of the prominent players in CBR, are open to recognising the need to involve the beneficiaries in the development and delivery of rehabilitation services themselves. One prominent development is the new approach to the involvement of PWDs and their organisations. The government

programme has opened up and now involves most of the major stakeholders in the planning and development of programmes at the different levels. The national organisations are represented on the steering committees, with each organisation having a large role to play, supported by appropriate resources. Their organisation has been decentralised to the district levels and lower levels. Even at the district level, PWDs are involved in the planning, which was not the case earlier. The government CBR programme has also addressed the problem of marginalisation of the different impairment categories of PWDs and has different services for the different groups. It is envisaged, that the government CBR programmes will register more successes than ever, if this kind of arrangement is enabled to function. USDC is also beginning to involve National organisations on different committees, at the national level. For example, their committees on advocacy.

With these few examples, it is clear that although initiators of CBR projects may recognise the desirability of participation of PWDs at all levels of a programme, the reality is different, due to many barriers which have to be identified and overcome.

THE POSSIBLE BARRIERS

Unfortunately, the attitude of most rehabilitation providers towards participation of PWDs is still negative. Many still believe that PWDs can only be recipients of the services and not participants, in the whole process. Most of the initiators have a professional bias, they do not believe that their skills can be transferred to beneficiaries who are not professionals, and so they tend to reserve provision of services to traditional professionals, who are in most cases medical people or social workers. As a result, most persons with disabilities do not have the requisite skills to provide the specialised services. The professionals also fear, that giving up their knowledge will put their job and position in jeopardy. Some players see DPOs as competitors, therefore, they tend to protect their territory.

NUDIPU'S POSITION IN RELATION TO THE ROLE OF PWDS AND DPOS

In the view of NUDIPU's mission, we strongly advocate that every rehabilitation programme provides for involvement of PWDs in the programme design, implementation, monitoring and evaluation. It is strongly advocated that the position adopted should be that, there is *"nothing about us without us"*. In this context, any rehabilitation programme that does not involve PWDs and their families in the identification of needs and appropriate interventions, is considered irrelevant and will not have a significant and sustainable impact on the community. As a voice for PWDs, NUDIPU encourages all the service providers to open up and collaborate with DPOs.

We acknowledge the efforts of the Rehabilitation section in the Ministry of Health in Uganda, which has never started any disability programmes without involving DPOs right from the national level to the remote district levels, where they are working.

We do believe that when programmes are designed for PWDs without them being involved, there are a lot of missing ingredients, which can only be articulated by the prospective beneficiaries. Their involvement in the implementation plan is paramount, if they are to receive the maximum benefit.

NUDIPU believes that communities easily appreciate the service when the target population is actively involved with the other members of the community, in the programme. The other recipients of the services easily accept them, especially when the programme is still new in the community. The programme will have a multiplier effect, i.e. the DPOs and the community will sustain the CBR activities long after the external provider (facilitator) has left the community, because the skills, philosophy and the attitudes of the people remain in the community.

It is the view of NUDIPU, that CBR projects that do not involve beneficiaries right from the beginning, are seen as belonging to the external provider or the local initiator and not belonging to the people. As a result, the PWDs and the community tend to take a dependency

role and when the CBR initiator goes away, the activities collapse. From NUDIPUs experience, if PWDs are involved, they become the chief advocates and jealously protect the programme with a strong belief, that it is theirs.

RECOMMENDATIONS

NUDIPU recommends six strategies to strengthen participation of PWDs into CBR:

1. At the beginning of a new programme, the CBR service provider should identify all the stakeholders and clearly define the framework for involvement of both, organisations and individuals. This ensures that no important stakeholder is left out.
2. To enable persons with disabilities to ‘own’ the programme, the CBR service provider should systematically introduce the concept to PWDs, the expected benefits, the resources involved and what would be their role, until they have understood the concept. Transparency, here is very crucial. NUDIPU’s experience here is that most players are not transparent about the resources involved. When people with disabilities have understood the basic concepts, then one can begin to involve them in the subsequent stages, such as needs assessment and the planning processes.
3. The programme should also strengthen the capacity of both DPOs and key individuals to participate meaningfully. This can be done through training of individuals, not only in the basics of CBR, but also with professional training in the relevant areas such as medical, social work, community development and education etc.
4. The CBR programme should be flexible enough to be able to build on already existing initiatives of the DPOs in the community. When the existing initiatives are ignored by CBR, it is seen as a parallel programme, which threatens their initiative and they can become protective about their programme and hence un-cooperative.
5. PWDs should be appointed on different technical committees of the programme.

6. PWDs who have relevant qualifications should be employed to implement the programme. This is not advocating for simply humanitarian employment. We need to give preference to competent PWDs in the labour market. There are several advantages to this, which include the following:
 - Disabled people employed in this way can act as role models. It provides an opportunity to test their commitment and challenges them to venture where others would fear to tread.
 - Disabled people employed in a CBR programme will feel a great sense of ownership, they have great opportunities to become innovative, given their personal experience of being disabled persons and they work with maximum enthusiasm and volunteerism, when the need arises.

CONCLUSION

For a CBR programme to be successful, it needs to be built on the following:

1. Appreciation and understanding by all stakeholders, from the national to the district levels, which include the community, important personalities and the ultimate beneficiaries.
2. The needs addressed by the programme should be the needs agreed upon, between the local participants, the PWDs and their families, the organisation and the provider. Similarly, the intervention must be based on what has been agreed upon as appropriate, by all parties.
3. The provider should ensure that constant dialogue takes place so that important issues are not ignored.
4. If the CBR programme claims to serve all categories of PWDs, then it has got to ensure that all categories have specified benefits. This can only be done when deliberate efforts are made to consult all stakeholders.

In conclusion, therefore, DPOs should have a stake in the development, implementation, monitoring and evaluation of all CBR programmes at all levels. It is the belief of NUDIPU, that this will serve to maximise the effectiveness and sustainability of CBR programmes.

REFERENCES

UN (1994). *The Standard Rules on the Equalisation of Opportunities for Disabled People*. Geneva.