

Using participative techniques with people with disabilities

by David Thomforde

with a response from Sulemana Abudulai

Feedback is a forum for discussion in *PLA Notes*. It features articles which raise common concerns or challenges in fieldwork or training, together with a response from another PRA practitioner. Letters and articles are welcomed for this section, as are your comments on any of the issues raised by **Feedback**.

• Introduction

Although participative techniques are widely used, they have not often been applied to disability. People with disabilities have two challenges: they are the poorest in most communities, and are regarded as 'medical cases' by most development agencies. These factors limit their participation in planning and encourage a top-down approach to development planning 'on their behalf'.

This paper describes four one-day seminars, each organised for a different association of people with disabilities in western Uganda. The associations were established to represent subcounties, with areas of up to 400 square kilometres. The seminars had two goals: firstly, to generate information which would help the associations to plan their activities, and secondly, to see whether PRA techniques required modification when used with people with disabilities.

Methodology

Most of the participants were men and very few had 'gross disabilities' (i.e. completely blind or deaf, or severely crippled); most of the disabilities were minor, often the results of ageing. The activities at each seminar included the following:

- a map of the entire area covered by the association, including markers such as rivers and towns, but also features important to people with disabilities (rehabilitation services, income-generating programs organised by the associations, homes of members and officers). The maps were either drawn on paper or traced in the dirt;
- historical time lines of disability. Criteria for change included: number of beggars, amount of polio, percentage of disabled children in school etc.. Small groups rated how these had changed over the last 50 years;
- Venn (chapati) diagrams of institutions important for people with disabilities;
- choosing criteria and analysing how the lives of the participants had changed since the association was founded (this will be discussed more fully in the next issue of *PLA Notes*, Number 33, October 1998);
- listing of problems of people with disabilities, followed by pairwise ranking. This exercise was undertaken separately with groups of men and women;
- listing and ranking of plans that the participants wanted the association to pursue in the future; and,
- discussion of how the participants could monitor the progress of the association in addressing the above issues.

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• **Findings from specific activities**

The maps demonstrated the unequal distribution of leadership, membership and resources. In most cases, the association leaders lived in the town where the association was started, and most members lived near that town. Income-generating projects tended to be located near roads; there were few members from remote areas, and no income-generating projects in these areas. When questioned, most groups said that people with disabilities move towards roads in order to participate in income-generating projects and the association. Poor transport and communication in western Uganda make it difficult to integrate people in remote areas into activities. Yet there was no feeling that leadership and resources should be more evenly distributed.

The results of the historical timeline were general; individual participants could not remember how much change had taken place, but only the general direction of change. This was probably due to the preponderance of disability due to ageing. Most of the participants had not considered themselves disabled in the past, so had not paid attention to disability issues.

The Venn diagram brought out most of the important institutions for people with disabilities, including NGOs, hospitals, church groups, orthopaedic workshops and local government offices. Many participants had had no interaction with institutions outside their immediate area, so they had difficulty judging their relative importance. Most of the participants felt that they had been ignored by institutions which were supposed to care for them; they also felt they were not welcome at community activities due to the negative attitudes of other community members.

An analysis of changes in peoples' lives brought out the most discussion. Participants were able to pinpoint in which areas their lives had changed and whether the association had been instrumental or not. Generally, the associations were credited for improving the level of knowledge and unity among disabled people, but not seen as improving health, wealth or level of disability. In fact, in some cases, the

associations were seen as causing a decrease in these areas. This may be because the associations had raised expectations which they could not fulfil. Most of the associations were formed in recent years and operate without outside help. It may therefore be unreasonable to expect them to achieve much progress over such a short period of time.

There was no discussion of how the rest of the community had fared over the same time period. Yet most of the problems identified and rated as important (e.g. poverty, poor roads, no schools, disease, lack of training, etc.) were also problems shared by the community at large. The few problems identified which were specific to people with disabilities (e.g. schools unwilling to accept children with disabilities, lack of wheelchairs or crutches, etc.), were not rated as very important. The results for men and women were similar.

Many participants were illiterate. This created a problem in the different ranking activities, because the problems being addressed (e.g. lack of disabled leaders, poor roads, etc.) and solutions (e.g. make friends, register disabled persons) did not lend themselves well to written symbols.

Making future plans was a difficult exercise, because many participants had not taken part in this sort of process before. Plans tended to be either general ('get more united'), or to depend on outside sources for carrying out ('ask the government for assistance'). The monitoring activity was designed to generate some specific monitoring tools that the participants could use to track the progress of their associations. But, because of the general nature of the plans and dependency on outside sources, no tools were developed.

• **Reflections on using PRA with people with disabilities**

None of the participative techniques needed much modification for use with people with disabilities. The blind participants had the maps and charts described to them, and then verbally relayed their contributions. Hard of hearing participants had friends seated next to them to repeat information as needed. Participants with

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severe physical disabilities took part in small group activities, or activities on the ground, but had to verbally relay their contributions for activities taking place on a wall chart.

A more serious question involves the nature of the disabled population. Because people with disabilities are a small proportion of the population, bringing a group together inevitably includes people from a wide geographic area. Thus, in these seminars, the participants were not a community as such, but rather members of many communities united by an association. Their needs, problems, and priorities were diverse and context-specific, making it difficult to bring a focus to discussions.

The fact that many participants had minor disabilities due to ageing probably increased the lack of common purpose. A group of persons with gross disabilities may have generated a stronger sense of community, but blind, deaf and physically disabled persons would still have very different needs. Other than through the associations, there is often little interaction between different groups of people with disabilities, and little awareness of the needs of others.

The rationale of participative planning is difficult for many people with disabilities. In Uganda, as in much of the world, people with disability have traditionally been objects of charity rather than equal partners in development. Many of them have grown accustomed to this role, and have a difficult time when asked to give opinions or make plans. Their plans often consist of specifying where they will ask for help, rather than highlighting actions they can take to improve their situation. The associations are trying to overcome this, but themselves often fall in the trap.

• **Recommendations for working with people with disabilities**

A large publicity and mobilisation campaign is necessary for people with disabilities to attend a seminar. If possible, transport should be offered to people with severe disabilities. The campaign should be aimed at people with disabilities, but also at the broader community, so that more able bodied people can assist people with disabilities.

If participants are blind, the maps should have stones, gravel or other 3-dimensional objects to mark sites, either put in a map on the ground or glued to a paper. In this way, blind participants can review the map with their fingers. Where participants crawl on hands and knees, the maps should be made on the ground, and planks of wood can be laid across, so these participants can make their contribution without erasing features.

If many or all of the participants are deaf, communication can be difficult. A sign language translator can be used, but this only works where a common sign language is used. In most rural areas, each deaf person has his or her own set of signs which are used with neighbours, but which may or may not resemble those of other deaf people. Translation by individual neighbours will be necessary.

To increase the mutual awareness of problems, and increase the sense of unity of the participants, some special 'ice-breakers' should open the program and be used between discussions. These activities may help participants become more aware of the needs and problems of other participants with different disabilities, thus easing discussion and formation of unified goals. Some examples of exercises are listed below:

- sighted participants have their eyes covered and are guided by other participants, or try to walk on their own, to simulate blindness;
- participants have one arm tied behind their backs, to simulate an amputated arm, and are asked to cut food, do up buttons or fasten their trousers;
- participants are given earplugs and put in a room with people deep in conversation. This exercise works well to simulate the social isolation of deafness;
- to simulate arthritis, participants are asked to walk with stones in their shoes; and,
- walking participants use wheelchairs and try to enter and leave rooms with steps, demonstrating the physical isolation and difficulties in movement for those who cannot walk.

In the seminars described here, some participants were significantly disabled, some had more minor problems and some participants were not disabled, but were members of the

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associations because of having children with disabilities. These people often tried to dominate discussions. Participants with gross disabilities contributed little unless asked directly. Thus, where possible, activities should be limited to people with significant disabilities. However, disability is a concept without sharp delineations, and the current rebellion against the medical model of disability mitigates against the use of medical personnel to dictate who is disabled and who is not. Therefore the facilitator should try to separate out the people with significant disabilities for some activities so their voices can be heard with greater strength.

The above 'ice-breaker' techniques may also help, as will discussions where individual people with disabilities are asked to talk about their experiences and their treatment by the non-disabled world. Separating people into different groups by disability (seeing problems, hearing problems and physical problems) is also recommended, although it is often hard to mobilise enough people with disabilities to divide into groups of any size.

Practitioners who organise PRA sessions for people with disabilities must be ready for a long process; many people with disabilities must not only learn the PRA process, but they must overcome a lifetime of dependency habits before they can participate fully.

• **Conclusions**

There is clear potential for using participative techniques, after minor modification, with people with disabilities. These techniques could make a major difference in the lives of people with disabilities, so that they can become more involved in planning their futures. It is the attitudes of planners, and the attitudes of people with disabilities, rather than the techniques which must be changed.

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PRA and disability: a response from Sulemena Abudulai

I have found this article interesting and hope that its publication will encourage other practitioners who work with disability to share their experiences. David Thomforde's work in Uganda suggests that the methods associated with PRA do not need much adaptation to be used with people with disability. However, he also highlights that the ability of disabled people to communicate and participate is more challenging, and is not necessarily overcome through the use of PRA methods alone. It is on this point that I would like to develop a response, exploring how communication and participation affect the ability of disabled people to share in a development process.

Communication

There is often an assumption that target groups and communities will engage in effective dialogue with development agencies in the identification of problems, analysis of key issues and the formulation of strategies. Work in the disability movement has shown that people with disabilities, confined to the margins of society for so long, are often not encouraged to participate in community level discussions. In most cases they are not invited to PRA meetings nor are they considered a serious issue target group. This means that the outcomes from PRA within communities do not reflect the views, interests and concerns of disabled people. In other cases, not sufficient effort is made to involve people, such as those with hearing impediments, who can participate through the use of interpreters. This means group discussions will often marginalise those people with disabilities who do attend PRA meetings. Within different disability groups, it is often difficult to obtain disabled people's views on community-wide issues because decades of exclusion have often made them incapable of making contributions to discussions. This situation raises the need for organisations of/for disabled people to develop ways by which communication can be improved to ensure that people with disability participate fully in discussions. For example, focus group discussions could identify particular disabled people as distinct units for participation. Local interpreters of sign language can also be

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engaged to enhance participation by deaf people. Experience has shown however that the pace of work should allow for effective, rather than rushed, soliciting of the views of people with disability.

Participation

Experience has also shown that societal prejudices and poor communication can affect the level of participation of disabled people in PRA activities. Within the disability movement itself, participation may be affected by such factors as gender and literacy. For example, during focus group discussions, we have observed that literate blind people will tend to display inferior attitudes towards their illiterate counterparts; the views of women may also often be ignored. Good facilitation can overcome some of these problems, although the underlying attitudinal constraints may persist. Similarly, as people regarded as being on the margins of society, much work needs to be done to allow/encourage people with disability to express views on all issues affecting their communities and not to regard themselves as 'outsiders' in the system.

To overcome some of these problems disabled people and their organisations need to devise ways: of allowing disabled people to learn by being actively involved with one another, in their organisations and in the wider community; of ensuring that disabled people are involved in identifying problems and solutions at all levels; and to better understand and incorporate disabled peoples' perceptions of problems and solutions into the development process. It will be interesting to find out how other practitioners have overcome some of these challenges.

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The next issue of *Feedback* in October 1998 will also explore issues of participation, disability and development. If you have any comments on this article which you would like to share in the next issue, please send them to *PLA Notes* before the end of August 1998.