In our own words: investigating disability in Morocco

by CHRIS MCIVOR

Introduction

Save the Children (UK) worked in Morocco for almost 40 years and for most of that time concentrated on the area of disability. Like many programmes elsewhere the organisation began its work as a response to an emergency. In the case of Morocco this arose out of two events. The first was the earthquake in Agadir, which devastated the southern coastal city in 1960 leaving thousands dead and many children orphaned and homeless. The second emergency arose out of the consumption of contaminated cooking oil in the Fez and Meknes area of northern Morocco in 1959 and 1960. Some 10,000 adults and children were left paralysed, resulting in appeals for assistance by the Moroccan authorities to external agencies and well wishers.

In later years, the principal intervention supported by Save the Children consisted in the establishment and support of a major residential institution for physically disabled children in the northern town of Khemisset. One of the first of its kind in Morocco, the school became one of the organisation’s ‘flagship’ projects. It was shown off to visiting royalty, to local and international dignitaries at every opportunity, and at its height consumed the vast proportion of the organisation's budget for the entire Morocco programme. Claimed one of its former expatriate staff:

I have been approached by many people, both Moroccan and English, who would dearly like to preserve the school in the form that the director created it and ran it for a quarter of a century. It was regarded by many as a bit of ‘Best of British’ in a foreign land and a wonderful example of our aid to a developing country.

Issues around sustainability and institutionalisation

The last sentence is revealing. In many ways the Save the Children programme in Morocco consisted in exporting a model of service provision relevant for the UK, to a location where the value of such a project was neither questioned nor investigated. Some of these tensions were to surface in later years, prompting the organisation to rethink its strategy, but not without leaving a certain amount of resentment and confusion behind.

One issue that arose was related to the problem of cost and sustainability. The kind of investment in staff and infrastructure reached a level of expenditure that could never be assumed by the local Moroccan authorities. At the same time some critics also questioned the spread of benefits generated from such a massive expenditure, relative to the small numbers of children who actually passed through the establishment. Claimed one programme officer:

Such a facility could only cater for an extremely small number of disabled children in the country, a maximum of 120 *people at any one time with an average intake of only 20 children per year. At the same time children who were blind, deaf or had learning disabilities were not even considered by the admissions board which regulated the school intake.*

It was also claimed that, as with establishments elsewhere, many of the children who passed through this residential facility became 'institutionalised', separated from their communities and families to such an extent that their later reintegration proved difficult. Some of the previous residents of the school complained of over-protective attitudes among its management and staff, an approach that reinforced their perception of difference to other children and made them feel that they were somehow 'apart'. When some of these children were later reintegrated into the ordinary school system they were not prepared for the hardships and ridicule among other pupils that sometimes accompanied this transition.

Our right to be heard

At the core of much of Save the Children's programme in Morocco for many of the 40 years it worked in the country, lay the fact that when designing its strategies and programmes in the area of disability it made little attempt to involve anyone but the expatriate professionals who thought they knew best about the interests of the constituency they were supposed to be helping. Even the later 'indigenisation' of the programme, the involvement in management decisions by local Moroccan staff, did not genuinely encompass the views, wishes, and opinions of disabled people themselves. While many of the interventions were well meaning, disabled people and their families were regarded for many years as project beneficiaries, as recipients of well meaning charity but not as partners in the process of identifying what would best assist them.

This inability or unwillingness to listen to disabled people is not an issue that was specific to Save the Children in its Morocco programme. The charitable models of care and protection that characterise much of the response to disabled people's needs in many parts of the world have only relatively recently been questioned by disabled people themselves. As with issues affecting children, for example, organisations are being challenged to adopt a more participatory, rights based approach to programming. The issue of equal treatment, social integration, improved access to services, respect for issues of difference is replacing a previous discourse largely framed in terms of charity and welfare.

Investigating disability

The realisation that both Save the Children, as well as several of our partners in key support ministries, remained ignorant about much of what faced disabled people in Morocco prompted the organisation to undertake a participatory study in the country in 1995. One of its key objectives was to ensure the genuine and meaningful inclusion of disabled people themselves in the research exercise so that a more accurate picture of their lives could help inform the future development and management of programmes.

An editorial team comprising Save the Children staff and several disabled people who represented different organisations, was formed that year to undertake the research and carry out interviews. Arising from this investigation, a publication in both English and Arabic was produced entitled *In Our Own Words*. The rest of this essay will focus on some of the issues raised during this process of consultation, and in particular the lessons learned from a programme of research that sought to include disabled people in the identification of the problems that affected them and the solutions they proposed.

Lessons learnt

Representation

One of the first issues to surface among the team of people selected to carry out the research and produce the publication, was the issue of representation. The disabled people in the editorial committee were identified through a number of indigenous Moroccan organisations set up to support the interests of their particular constituency. Yet it was clear that a certain elitism characterised many of these organisations, and that the focus on the particular disability that characterised their membership had left a whole range of other factors, such as poverty, gender, ethnicity etc., unaccounted for.

This meant that the original text submitted by several members of the research/editorial team failed to adequately represent the priorities of a large number of disabled people in Morocco. There was very little written, for example, on what difficulties were encountered within poor families, or what unique set of issues disabled women might face. A conscious effort, therefore, had to be made to spread the net of consultation much wider. A mechanism of communication also had to be developed whereby disabled people, who were illiterate, unemployed, less articulate etc., could have their concerns represented.

One issue that proved to be particularly contentious within the Moroccan context was the issue of how existing gender bias and discrimination added to the burden imposed on disabled women. The inclusion of this dimension within the study fuelled concern among some that the research was straying beyond its original mandate, and that in challenging the gender stereotypes prevalent in Moroccan society the publication might prompt a negative response that would reduce the impact of its focus on disability. But in the end the decision was made that an investigation of the stigma surrounding disability could not be divorced from a range of other prejudices and factors that confronted disabled individuals in their social context. Claimed a disabled woman from Rabat:

> *We are not saying that ours is the only problem. Both women and disabled people in general encounter difficulties and discrimination. But join the two issues together and you magnify the difficulty. Disabled women have a unique set of problems, which demand a unique set of responses.*

Hierarchies of acceptance

A second related problem around the issue of representation also surfaced in the course of the study. It became clear that in Morocco there was a kind of 'hierarchy' of acceptance relating to disabled people that was evident within disabled people's organisations themselves. At the top of the ladder, those who were physically impaired found it easier to gain acceptance from their families and communities. Those who had visual and hearing impairments found it more difficult, while those with learning and mental disabilities seemed to experience the worst rejection and discrimination, not only from so called 'normal' society but from other disabled people themselves.

Again, this was reflected in the initial study by a heavy focus on the problems facing physically disabled people. The views and opinions of those with visual and hearing impairments were rarely included. A decision had to be made to ensure that the research was inclusive of as wide a range of disabilities as possible.

This issue is common to other kinds of research focused around problems of discrimination. In the field of gender or childhood, for example, it is sometimes assumed that these categories define a unique set of problems that can be divorced from other sets of issues. Yet women and children belong to class, economic, and ethnic structures that can in turn create other kinds of bias that need to be acknowledged if either research or subsequent action aims to be truly representative of a wide range of opinions.

Considerable work, therefore, had to be done with the research team to alert them to the fact that many of the views expressed in the original study, had been solicited from key informants who largely had the same problems, backgrounds, and level of articulacy as themselves. While the final text reversed some of this original bias, in general the Moroccan study and subsequent publication inadequately addressed the issue of ensuring equitable recognition of the problems facing different sectors of the disabled community. While members of the research team were instructed to interview people with as wide a range of disabilities as possible, the tools used to gather this information were too blunt and insensitive to accommodate those people who through visual, hearing, or learning impairments could not adequately communicate during direct interviews.

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In discussions with groups of disabled children, for example, only those more articulate, assertive individuals spoke out, leaving a large section of other children's views and preoccupations ignored. The use of drawings, personal diaries, drama, and role-plays would have provided a more interactive and relaxed fora for bringing another set of views to the table. Claimed one member of the research team:

> *On reflection more and broader training on different techniques and styles of communication for all those involved with the gathering of information, might have helped to ensure that a wider cross section of disabled people would have had their opinions registered.*

Establishing trust

The original research schedule had envisaged a time span of several months to complete the interviews and focus group discussions, so that enough material could be generated to produce a publication useful for advocacy and programming purposes. Yet in the end it took much longer, partly because the time and effort required in carrying out a meaningful consultation and establishing the trust of people who had never been consulted before took longer than expected.

There was scepticism among many of the disabled people consulted, as to why they were being asked their opinions. Would the political authorities view their criticism as a sign of disloyalty to the Moroccan state? In recent years, the state had strongly and publicly expressed its commitment to social justice, improved welfare provision and integration of disabled people into Moroccan society. Several disabled children who derived a living from begging were worried about sharing their views, since they were already harassed by the authorities for conducting an activity that might negatively impact on the image the country wanted to project to Western tourists.

From those disabled children who had benefited from institutional care, like that offered by the Khemisset School, there was concern that they might lose their scholarships if they were seen 'to bite the hand that fed them'. In the end a significant amount of time had to be taken to win the trust of people, many of whom claimed that this was the first time their views had ever been solicited, and to reassure them that their opinions would be registered anonymously if they so wished.

One consistent question recurred throughout the discussions with disabled people, namely what would happen as a result of this exercise? Would better services be provided? Would aids and appliances now be readily available? Would access to buildings be improved? Several informants indicated that this was not the first time research and studies had been conducted, and that they had seen very little evidence of an improvement as a result of the previous exercises.

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Minimising unrealistic expectations in the context of any research is always problematic, and the answer to how this is best done is never an easy one. At a time when Save the Children was moving away from direct provision of disability services towards handing over its programme to local authorities, no guarantees could be provided that the views of disabled people would be listened to and respected. The only argument we could offer was that we hoped that disabled people's voices might promote change and more acceptance of their needs in Moroccan society, but that in the end this would depend on policy makers and structures outside our direct control.

Conclusion

Towards the end of 1995 *In Our Own Words* was published in Morocco, and subsequently translated into Arabic and distributed throughout the Middle East. The reactions were varied. Several ministries responsible for disability provision in the country found it too critical and unappreciative of the work carried out on behalf of disabled people in their country. In particular the language of rights and obligations seemed unwelcome to some, who felt that disabled people were now being ungrateful to those who had tried to help them in the past.

The response of several former residents of Khemisset School was also negative. Having benefited considerably from the opportunities for schooling and other assistance provided by the establishment, they found some of the criticisms raised about sustainability, lack of community involvement, issues around institutionalisation of residents etc. offensive to the memory of its original founder. Yet others were more accommodating of the criticisms offered, indicating that while they had personally benefited from the time they had spent in this establishment, there was no escaping the fact that the expenses incurred in running such a facility could have been extended to a much wider net of beneficiaries if more community based programmes had been developed.

Finally, one set of comments was received that could be interpreted as either criticism or commendation. Some readers complained that they were surprised and disappointed that no uniform view had emerged from the research and subsequent publication, and that it was full of contradictory and conflicting voices from which a single, coherent view would be hard to derive. Yet in many ways this confusion of voices represented for others one of the strengths of the publication. It indicated that the editorial team had genuinely sought to listen to what was being said and had transmitted the voices of disabled people in as honest and truthful a manner as possible. At the same time it delivered a clear message, namely that there are no easy solutions available, that the issue of discrimination against disabled people is a complex subject that is intolerant of uniform and simple solutions.

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NOTES

Chris McIvor was Programme Director for Save the Children (UK) in Morocco for three years. Subsequent to working in Morocco he occupied the same posts in both the Caribbean and Zimbabwe, where he is currently located.

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