



CLINICAL COMMENTARY

A community of citizens: disability rehabilitation in the Palestinian transition to statehood

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Abstract

Purpose: It has been widely argued that community based programmes offer considerable advantages to the classical institutional forms of health and rehabilitation services delivery. With about 10 years of experience in operating community based rehabilitation projects (CBR) for the disabled, the Palestinian experience points to potentially serious problems relating to the conception and operationalization of such programmes in real life situations.

Issues: Of importance is the issue of the impact of communal care on the already burdened lives of women, especially when such care is expected to be voluntary in nature. Caretaking in the Palestinian context, especially of the disabled, elderly and the sick, is a pre-defined sex linked role dictated by a patriarchal society and system of policy making that excludes women from economic and social life. The voluntary care aspect entailed in the CBR conception and practice, can and does contribute further to the exclusion of women not only from the labour force, but from most other aspects of life as well. This represents an apparent contradiction between the needs of two excluded groups, the disabled and women. The other problematic entailed in the communal model of caring for the disabled is the strategic and operational bias focusing on community, to the exclusion of the notion of social rights of all citizens, and the role and duty of state structures in the fulfilment of the disabled basic needs. Such an approach can only relegate the disabled rights back to their original place as charity. On the other hand, when CBR projects are operated holistically, in the context of social movements existing within power relation and with a broader democratic agenda engaging different groups—including a disability movement—as is currently taking place in Palestine, CBR projects can also turn into a mobilizing force for the social rights of all excluded groups.

Conclusion: Thus the question is not merely one of governmental involvement as opposed to the involvement of non-governmental organizations and charitable societies in community based projects. Rather, it is a question of the right to a decent life for all, in dignity and security, that citizenship and statehood promise, but have yet to deliver in many developing countries, especially in Palestine.

It has been widely argued that community based programmes offer considerable advantages to the classical institutional forms of health and rehabilitation services delivery. Advocates of community based programmes have focused on cost reduction and cost effectiveness of programmes, as the conception/strategy relies primarily on the training of families of affected persons, the use of local volunteers, and on the use of local resources.^{1–6} Indeed, in the context of continued serious poverty in the less developed countries, some argue that the community based model may be the only viable option for dealing with the needs of special groups.⁷ Consequently, the reduction of the cost of care-taking and rehabilitation at the community level is achieved, despite poverty. At the same time, the aim of integrating disabled individuals, the elderly and other people with special needs into their communities is also seen as an ultimate dignified and humane outcome of the community based strategy, keeping people with special needs from being segregated, and enabling them to take care of themselves. Thus, the community based approach advocates the ‘creation of a caring society’, and the programmes are executed with ‘equality, social justice, solidarity and integration’.⁸ In this framework, community based programmes are posited against the institutional form of care as the ideal model that can minimize, if not eliminate, the exclusion of special groups out of communal, social, economic and political processes.

Clearly, the basic tenets and some of the concrete practices emanating out of this model worldwide programme, can only be commended. However, it is also important to note that the fundamental paradigm of community based programmes can be problematic on more than one level. This paper focuses on the problem of gender equity and citizenship in terms of a

social contract between the state and its citizens, that includes the social right of people with special needs to be adequately cared for by state structures.

In Palestine, the rise of the disability movement emanated out of the inception and development of a relatively strong social action movement which took root in the Israeli Occupied West Bank and Gaza Strip in the late 1970s and 1980s focusing on: women's rights, the rights to health and other services—combined with the imperative of the national question and resistance to military rule.⁹ This disability movement was propelled to the forefront of national politics because of the specific circumstances of the Uprising period of the late 1980s and early 1990s, where thousands of young people were either killed or permanently injured during fighting with Israel. Written less than 2 years after the beginning of the Uprising, a study found that at least 4000 persons had been injured during this period. In one year alone, 2600 children were injured by army or settler gun fire; 11000 were beaten to the degree of requiring medical treatment, and 4000 were injured by rubber bullets in the West Bank.¹⁰ With the disabled having been much neglected until that time, they were suddenly catapulted to fame because of these devastating events. Disability and infirmity assumed political and social status in the eyes of the public, and those disabled were deemed national heroes with the full endorsement of the national political movement. Thus the articulation of social action for national resistance with these tragic events eventually led to the establishment of the General Union of Disabled People with 6000 members in 1992.¹¹

As a concept, community based rehabilitation was first introduced to the country in the late 1980s by Swedish Diakonia and later, in co-operation with Norwegian Aid for the Disabled (NAD), who worked closely with a team of local consultants as well as various groupings from within the social action movement prevailing at the time. Previously called Swedish Free Church Aid, Diakonia is a Swedish non-governmental organization working in the developing world, in the area of democracy and human rights, and especially in the area of disability rehabilitation in Palestine.

The author of this paper functioned as a consultant member of this team from 1989 until 1995, and continues to be informally attached to this team up until today. This initial team worked closely with disabled people and the local health social action committees as well as the local charitable societies to assist in the developments of the Union of Disabled People, as well as introduce and help operate CBR projects in all the regions of the West Bank and Gaza Strip. Today, and

under the leadership of the Central National Committee for Rehabilitation, an umbrella non-governmental organization which includes all the non-governmental organizations working in the care of the disabled, the CBR programme network covers 240 locales with basic rehabilitation services, where about 50% of the population lives.

In 1991, one of the principal authors of the WHO manual of instructions on how to set up and operate rehabilitation projects in the community,¹¹ was brought in to the country to initiate the process of building the CBR programme as well as strategy. The contributions of the WHO method were instrumental in initiating what became known as perhaps one of the best CBR projects in the world. However, even at the onset of the project, a strong debate was initiated in relation to the concept of voluntarism which was at the core of the CBR strategy when it was formulated in the early days.

To begin with, the Palestinian counterparts knew and understood very well the benefits and burdens of voluntarism. Having succeeded in mounting a major volunteer movement encompassing the domains of health, youth, agriculture and women's basic needs, the experience indicated the importance of voluntarism for mobilization and transformation purposes,¹² and the inadequacy of voluntarism for the continuity of service provision. The effective build up of basic services addressing the needs of those who need them most was seen as being linked to institution building and the development of systems that were capable of providing for the continuity, quality, supervision and programme development needs of constantly changing circumstances. That is, while voluntarism served its specific and important purposes, the system building imperative, especially in the context of Palestinian national aspirations, made the voluntary option non-viable and non-sustainable as well.

There is, however, another important dimension to this problem that prompted strong arguments against voluntarism for systematic, ongoing rehabilitation work by the Palestinian counterparts, some of whom were working closely with the disability movement, but also with the democratic women's and health movements as well. In Palestine then and now, the majority of community health workers and community rehabilitation workers were women coming from lower social classes and excluded groups. And when men were involved, they tended to do so in a supervisory, or periodic and sporadic ways, leaving the women to perform the daily tasks and routines, monitor the records, visit the disabled, contact local schools and health centres,

and, in a nutshell, maintain the viability and continuity of the programme. It was this particular initial focus on the voluntarism of CBR workers that was seen as gendered, in that it denied women the right to earn an income for services rendered to disabled people because of assumptions pertaining to roles in the labour force (no need for payments, low status of the work in question) and conceptions of a woman's place in society that does not respect gender, and is often contradictory to the fundamental principle of equity that is at the very heart of community based programmes.

It is true that the ideas put forth in the CBR model by the early 90s included the possibilities of payment in compensation for work, but the issue was left to 'depend on the policies of the country and the type of compensation given to the other community workers'. This, coupled with the conceptual flexibility of Diakona, and the very close working relationship with Palestinian counterparts it maintained, eventually enabled the Palestinians to argue for and develop a system of payment for specific, ongoing CBR activities, while maintaining a strong aspect of communal—men and women's—voluntarism for others. These developments at least partially explain the eventual substantial success of this model. However, our criticism stands in that, country policies, especially in the developing world context, are not exactly known to incorporate women's needs or rights. Leaving this important issue of compensation for the type of systematic work required by CBR workers to the country decision making and policy process effectively means opting out of including women in the formula of integration—especially labour force integration—that the very ethos of the CBR model is based on.

What is of interest for our purposes today, a good 10 years after the launch of the Palestine CBR programme, is that community based programmes launched in the different parts of the developing world appear to continue to rely on the principle of the voluntary work of community members in doing systematic ongoing work. An initial examination of the accessible international literature on community based programmes reveals that many community based projects continue to use volunteers for methodical and regular action, and often, there is no mention of the sex of these volunteers. Ironically, a further examination of the description of the work they do (helping rural midwives, weighing infants, providing family planning and reproductive health services, caring for disabled children and the disabled elderly at home etc.), indicates that many, although perhaps not all, must be women,¹³⁻¹⁵ and this reinforces the notion of gender blindness in

the conceptualization and operation of community based programmes.

Furthermore, in Palestine as elsewhere, it is women who are the caretakers of the family (parenting), the sick, older people and people with disabilities.^{16, 17} This pre-defined care-taking sex linked role is dictated by a patriarchal society and an unyielding patriarchal system of policy making both at the local and international levels, and contributes further, wittingly or unwittingly, and in fundamental ways, to the exclusion of women not only from the labour force, but from most other aspects of life as well. Women already suffer the heavy burden of housework and making ends meet in conditions of serious poverty in Palestine and certainly elsewhere, in addition to care-taking and productive roles. These care-taking and productive roles assumed by women in Palestinian society have been described as a high burden, especially in the absence of social support.¹⁸ The CBR and community based models however call for increasing their burdens, in as much as family responsibility for people with special needs really translates into the responsibility of women primarily, although not solely. Rehabilitation in the homes means that there is a need to learn more skills, to work more with the disabled at home, to deal with the daily problems of the elderly, whether they are problems of disability, health and otherwise, and to integrate disabled children into schools and societies at a time when the means for achieving all this in terms of time and energy, let alone the financial aspects, are not exactly evident. It is precisely here where this apparent contradiction between the needs of one excluded group (the disabled) and another (women the caretakers) lies, and requires a serious re-examination of the issue of voluntarism and family and communal care-taking by policy makers and programme operators alike.

It is the author's belief that assistance in training and supervision provided by the CBR workers to women who have disabled family members living at home have contributed to the decrease in the burden of care in some instances. A case in point is that of devising simple technical solutions allowing the disabled themselves to manage their own basic activities of daily living. It is also true that the Palestine CBR programme did contribute in real ways to helping women through educational and psychological support mechanisms to fend off some of the effects of the social stigma resulting from having had a disabled child. However, on the whole, the experience so far has shown that the burden of care is heavy, and increasingly so with the presence of disabled persons, especially the mentally disabled and the elderly. Given a fertility rate of 5.6 on the West Bank and an

astronomical 6.9 in the Gaza Strip (one of the highest rates in the world),¹⁹ compounded by poverty, it is clear to those who work closely in the field that the formula of community based programmes can increase further the burdens of already highly burdened women caretakers, and can exclude them further by decreasing their options of seeking even part time paid work. It is equally clear that the paradigm of community based programmes is not quite satisfactory in that, the way it is often operationalized in real life, does not allow for the needed space to raise the issue of who is ultimately responsible for disabled, elderly or sick members of society? Are they the sole responsibility of the family, and the burden of women?

This brings us to the second issue at hand here, namely the question of citizenship, with all that it carries in terms of rights and responsibilities. Ever since the French Revolution, the right to subsistence was declared as a right of citizenship in a system of modern secular welfare.²⁰ In 1950, T.H. Marshall, presented a rights-based definition of citizenship, with citizenship defined as a 'status combining rights and responsibilities' with the individual's potential economic contributions seen as irrelevant.²¹ In the Palestinian case, what citizenship entails is not exactly clear, especially in view of the current political setting, where statehood is still in the making, and its making is turbulent and quite violent at times. However, it has been argued that, given that T.H. Marshall's definition of citizenship as being 'full membership in a community', then it is possible, even in the Palestinian case, where so many still lack basic formal citizenship, to discuss rights as an outcome of membership within a stateless community.²² Others have put forth a local view of citizenship, delineating a legal relationship between the individual and the state that includes the concepts of individual rights as well as responsibilities towards the state. Furthermore, rights are defined as civil, political and social. Social rights include the right to basic economic and social welfare, as well as the right of full participation in cultural life, including the provision of work opportunities, education, and the fulfilment of basic needs of the citizen and the family.

Thus, on the one hand, a trend towards defining citizenship in this transitional Palestinian setting in terms of social rights, and not only political and civil ones, took shape in the 1990s and has been developing ever since. Such definitions emanate in part out of the discourse of social and political movements maintaining that, in the current Palestinian setting, the solution of specific social problems is a pre-condition for the solution of the national ones. On the other hand, the discourse of

the Palestinian Authority reveals a very different conception of social welfare as well as citizens rights. For example, an examination of the Palestinian 'General Programme for National Economic Development', 1994–2000, which contains a specific section on Social Welfare and Recreation, reveals a national policy on social welfare that differs substantially from the notion of citizenship with social rights which many of the democratic local non-governmental organizations that sustained the country during the years of occupation espouse.

To be more specific, this document contains serious omissions in terms of fulfilling the needs and rights of specific groups, including women and the disabled. Here, secure entitlements are primarily based on market productivity, seen as the benefits accrued to individuals' economic contribution to society. Social care also includes vulnerable groups, such as orphans, the poor, women with special circumstances and the disabled and the elderly, but the categories and the care are left flexible, unstable and insecure. That is, this division between entitlements by right that is linked to formal paid work and welfare allocations by need, virtually excludes women, the disabled and other marginalized groups, as for instance, those working in the informal sector, from this right of social citizenship. While this document stresses the right of workers to live in security and dignity once they retire, and for the rest of their lives, the non-market contributions of women, and their rights and the rights of the disabled for the same security and dignity of formal workers is left to be handled by the family, or charitable societies and other groups providing assistance to the needy. In all, whatever elements of citizens' rights are put forth in this model are simply undermined by its unequal treatment of different social groups.²³ A reading of the relevant and more recent Palestinian authority documents, including a summary of the Palestinian Development Plan, 1998–2000, as well as documents and statements pertaining to Authority social welfare plans and plans for poverty eradication in Palestine unfortunately reveal similar problems. Here, poverty is seen as a national problem, as opposed to also a specific problem of especially excluded groups within the nation. In essence, the discourse contained in these documents is characterized as conceptually marginalizing poverty, and women, as well as other excluded groups.

In Palestine these days as was the case a few years ago, those engaged in policy formulation, whether the local authorities or international aid agencies, stress the need for the development of democracy and citizenship in the country. However, a concrete recognition of

the social rights of citizens, seriously addressing inequities, and ensuring that vulnerable groups are taken as the responsibility of the nascent structures in terms of at least social welfare and protection, is still being omitted. It is as if this issue of fostering democracy and citizenship is a matter of pick and chose what is convenient to implement. Here, it is worth mentioning that, by lumping communities into one homogenous entity, the problematic of 'community' itself that is so often used by international aid agencies can in fact serve to obscure differences in the rights and interests of members of the same community. The 'community' approach can also serve to obscure differences in power relations that are so much part of the formula of inequality and inequity, even or especially at the community level.

This indeed is the terrain in which community based projects can, in real life, add insult to injury by maintaining and reinforcing the exclusion of the disabled, women and other groups with special needs. By operating vertical programmes, by not analysing power relations within communities, and by omitting to include the holistic view of combining the different elements of the strategy the way we understand it into one concerted effort, and in genuine cooperation with the democratic movement locally, such programmes may well end up propagating social inequities in ways that are contradictory to their original principles.

On the other hand, when CBR projects are operated holistically, and in the context of social movements existing within power relations, they can also turn into a mobilizing force for the social rights of all excluded groups, as is happening in Palestine today. That is, it is the different conceptualizations and strategies used in the implementation of CBR that is in question here. A strategy that focuses on family and community and on community hand-over, to the exclusion of an examination of the role of the state and the social right of the disabled, women and other excluded groups, without a concerted effort being placed in the area of developing a strong and effective disability democratic movement that can lobby and work for real change, actions in this area can only relegate the disabled right back to their original place as charity and or clients. This is precisely the realization that prompted the Palestinian disability movement—led by the Union of Disabled People, CBR workers and Support Team, community volunteers, and upheld by the local democratic movement—to work intensively on the development of a draft disability law that is rights based during the past few years. Vigorous lobbying, defended by a holistic, strong and effective CBR programme and a strategy with citi-

zen's rights as a fundamental principle, eventually led to the promulgation of this Law in the latter part of 1999 by the Palestinian Legislative Council. This document was later signed into law by the country's President.²⁴ Now the task at hand is to lobby for the development of the mechanisms for the effective implementation of the law. Thus the question is not merely one of governmental involvement as opposed to the involvement of non-governmental organization and charitable societies in community based projects, as some of the authors of the original WHO manual put it. Rather, it is a question of the right to a descent life for all, in dignity and security, that citizenship and statehood promise, but have yet to deliver in many developing countries, including Palestine.

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