1 Background

There are countless examples of health programme failures that were designed without the involvement or participation of the people they were aiming to serve (Chambers 1997; de Konig and Martin 1996a; Bhatnagar and Williams 1992; and many others). One has only to visit clinics that appear to have ample equipment and trained staff but no clients to understand that something has gone wrong. Why do the people not come?

Other scenarios in other contexts are equally disturbing. Clients who arrive at services are mistreated or do not receive an appropriate response to their problem. They leave ashamed, confused or discouraged and vow never to return. Those who are well educated and can afford private sector services have the power to demand quality services and seek alternatives. Poor, marginalised, and uneducated individuals most at risk of health problems and higher fertility are left with few options and little bargaining power. Those who have access to public or private sector services (including traditional healers, traditional birth attendants, etc.) are often unaware of their right to quality services, are uncertain what to expect, and have not had the opportunity to actively participate in dialogue with service providers or other community members about health, particularly reproductive health, issues. Economic, sociocultural, linguistic, logistic, geographic and political factors limit access to information and services for many others.

Over the past twenty years, a shift from curative to preventive health programmes has led to increasing evidence that the prevention of disease is only possible when the community, families and social organisations collaborate. Global trends of democratisation, decentralisation, devolution and civil society building, increased information and communication flow and an emphasis on human rights are providing greater stimulus for client and community participation and are provoking the need to redefine their roles and responsibilities in many sectors, including health. Client and community mobilisation can be very effective strategies to facilitate client and community participation to improve health and to build individuals' and/or a community's capacity to address its needs. For example, community-based distributors of contraceptives, community pharmacies and other
community motivated strategies to increase access to contraceptive methods have extended the reach of family planning programmes to populations that had little or no access to other health services.

For the purposes of this article, we are defining community mobilisation as a process through which action is stimulated by a community itself or by others and is planned, carried out, and evaluated by a community’s individuals, groups and organisations on a participatory and sustained basis to improve health. This article reviews Save the Children/US and Johns Hopkins University’s experiences to date in two USAID-funded pilot projects that aim to increase community participation in improving health in rural areas of Latin America by building community and service provider partnership. In Puno, Peru the MOH-led 'Building Bridges for Quality' project is facilitating dialogue and action between service providers and community members to define and improve the quality of health care from a client and community perspective. In Oruro, Bolivia, communities and service providers developed and are using a community health information system named ‘SECI’ ('Sistema Epidemiologico Comunitario Informatico') that provides them with data upon which they can jointly make decisions, set priorities, plan activities and monitor their progress. Although both projects are in relatively early stages of development, they have achieved promising preliminary results and offer opportunities to learn about accountability through partnerships between communities and service providers.

Both projects follow a ‘Community Action Cycle’ process (see Figure 1) that has been slightly revised from what was originally used by Save the Children/Bolivia in the Warmi maternal and perinatal health project (de Konig and Martin 1996b; Howard-Grabman 1993).
Two important lessons relevant to this article were learned through the Warmi Project, which have helped to guide the design of the SECI and Building Bridges for Quality projects:

- Communities need to have access to relevant information on their health status and the actions to be taken that have or have not worked in other similar settings, to make informed decisions about priorities, to develop appropriate strategies and to be able to monitor their progress toward their objectives.
- A development approach to health based on a supply and demand paradigm (where external organisations work in parallel - some almost exclusively with service providers to build their capacity to deliver services and others who work almost exclusively with communities to increase demand for services and improve health behaviours), without paying attention to how these groups relate, can result in services that are not responsive to clients' needs and can lead to unrealistic client expectations. While there are important and valid reasons to provide assistance to communities and service providers separately, this paradigm does not allow for the possibility of sharing responsibility for health by establishing common objectives and building on the joint resources and commitment of service providers and communities.

The two projects presented below have attempted to address these concerns by adopting a partnership and team-building approach so that respectful dialogue and analysis can take place leading to joint action based upon common goals and objectives.

2 Community and Ministry of Health Information System Mobilises Joint Planning, Action and Monitoring: Experiences from Oruro, Bolivia

Oruro is located in the Bolivian altiplano (high plains) south of La Paz. The rural areas of Oruro are made up of sparsely populated, poor communities. Agriculture is a primary occupation, but production is limited in this area due to poor quality of the soil and harsh environmental conditions. Income from mining, once a significant industry, has been decreasing as prices have dropped and the cost to extract ores is increasing. National literacy is estimated at 86 per cent of the total population, with women less literate than men, and rural populations significantly less literate than urban populations. Government health services are underutilised, particularly in rural areas.

The Bolivian National Health Information System (SNIS) was developed primarily to serve as a national and regional planning system and is similar to national health information systems in other Latin American countries. The system was designed to capture information from health service sites (health posts, health centres and hospitals) at the 'area' level (several communities served by a health facility). The information is then moved up a vertical path to districts, departments (states) and finally the national level. The SNIS is not designed to show the health problems and specific demands of each community. Health planning is done by providers who apply set formulas to population variables. These formulas do not differentiate between communities, areas or districts; all districts plan in the same way using the same formulas. Although "Committees for Information Analysis" (CAls) have been instituted by the MOH as part of the Bolivian government's policy to support popular participation at the district level, community participation in these committees is limited to one or two representatives. The CAls are a positive step, but often community representatives do not understand the information presented and/or do not feed back this information to the broader community. Thus, the community does not participate actively in health planning.

2.1 Why establish a community epidemiology surveillance system?

As mentioned above, the SNIS was designed to meet the needs of health service planners at the national and regional levels. Because of its facility-based orientation, the SNIS does not register events that happen in the community, such as deaths, births, pregnancies and illness, when patients do not seek care in a facility. To estimate prevalence rates, more complete community data are needed in addition to service-based data. A community health information system that complements the SNIS can help to develop a more complete picture of a community's health. Health information belongs not only to health care providers, but also to the
community members who generate this information. Community members' participation in the interpretation and analysis of the information is critical. The system of service providers working with communities leads to better interpretation and understanding of the information, which leads to better planning and greater community participation.

2.2 The ‘Sistema Epidemiologico Comunitario Integral’ (SECI)

Save the Children (SCF), US/Bolivia initiated work in Oruro, Bolivia in 1995–96 as it was leaving Inquisivi Province, where it had been active for approximately ten years. In 1997–98, building on its previous experience, and with USAID funding through the Johns Hopkins University/Population Communication Services 4 Project, SCF worked with local health service providers and communities to develop a health information system that could provide health information to community members in a format which they could analyse and use to help improve their health. Pilot testing of SECI began in ten communities in Eucalyptus District of Oruro in September 1998.

**Project goal and objectives**

SECI's goal is to increase the utilisation of health services and improve household behaviours to improve the health status of women and children in rural areas of Bolivia.

**Objectives**

The project objectives are to:

- Increase communication between participating communities and health service providers through the use of a community and facility-based health information system to contribute to improved health.
- Increase participating communities' and health service providers' ability to analyse and use information to address community health problems.

To develop SECI, SCF/Bolivia, the MOH, and community members first conducted formative and participatory research. They reviewed previous experience with the Warmi project to learn from its successes and failures. They identified health problems and health concepts (what are the health problems that community members are aware of and what do they do when these occur, etc?). They then examined cognitive and quantitative concepts related to understanding of information, how information is shared, numeracy skills, perception of graphics, and other related planning and decision-making skills. Participants explored whether a health information system would be useful to them, how it should look and operate and which fora would be appropriate to use for information feedback and analysis sessions.

The resulting community health information system, SECI, consolidates primary health care data collected by community health promoters and health service providers using simple forms and community maps. The methodology facilitates increased communication between communities and health service providers first by bringing promoters and service providers together to consolidate the data. These then present the data in easy-to-understand graphics to the community, so that together they can obtain and analyse new information about community health problems and articulate health priorities that reflect the community's perspective. The methodology builds in a series of analytic questions and ways to present the data so that community members and service providers can compare trends over time, monitor progress and determine where alternative strategies are needed. Community representatives share the consolidated information, plans and strategies that have been developed and other results of these community meetings at the district level CAI meetings. As changes are implemented, the health information system will continue to help the communities and health staffers work together to monitor progress toward achievement of agreed objectives and to make decisions on municipal and community resource allocation.

Working with District, Regional and National Health and JHU staff, SCF has developed and is currently field testing the components of the health system, including a manual, problem picture cards, and pictorial ways of presenting quantitative information to literate and illiterate community members. Guided by a steering committee (which includes SCF/Bolivia, JHU/Bolivia, MOH and others), SCF is also working in collaboration with
Ministry of Health staff at national, regional, district and community level to develop a complementary software package that is currently being field tested. The software package consolidates community level data from health promoters with national health information system service-based data and translates this more complete epidemiological picture into graphics that can be used with communities. Designed to be fun to use, the software package helps service providers at the district level analyse the data in planning programme strategies.

Results

An evaluation of the six-month pilot phase was conducted in June 1999 in collaboration with Emory University. Quantitative evaluation methods included: a health facility survey of intervention sites and non-intervention control sites, random household survey of intervention and non-intervention control communities, and project document review (meeting records, field staff journals, etc.). Qualitative evaluation methods included: observation of SECT meeting, three focus group discussions in each community with SECI participants (men, women and mixed groups), interviews with key informants and review of project staff diaries that recorded meeting proceedings. Although data analysis is not yet completed, the preliminary results are promising.

In the ten pilot communities, a total of 2,334 people participated in regular monthly community meetings, into which SECT has been incorporated, to analyse their health data and plan solutions together with service providers. Communities and service providers acting together have been able to leverage increased financial resources from the municipal health budget for health services.

SECT meetings stimulated joint community and service provider action that led to a number of significant achievements to improve health services. Some examples of these achievements include:

- In Tarucamarca community, community members expressed their concern to hospital staff that, in spite of mass media promotion of the new national health insurance benefits announcing that services for children under five and pregnant women were now free, the hospital continued to charge for consultations. The district nurse explained that the hospital felt obligated to charge for the services because the mayor of the municipality had not reimbursed the hospital for its costs over the last eight months. Community leaders met with the mayor to insist that he pay what was owed to the hospital. The mayor reimbursed the hospital what was owed and services are now covered by municipal funds as per the national policy.

- In Huayllamarca, in a SECT meeting, community members lamented the poor conditions in the hospital. Save the Children/Bolivia offered to assist with $2,000 to upgrade the hospital, on condition that the community work with the mayor to contribute also. Community pressure to fund this activity led to inclusion of a line item in the Municipal Operational Plan for $6,000 to upgrade health services. The hospital and community are now making the improvements and the mayor’s office is disbursing the funds.

- In Amachuma, lay midwives became angry when they saw that the births they had attended were being classified as ‘yellow’ (risky) on the ‘health flag’ used in the SECI feedback session, and insisted that their deliveries be considered ‘green’ (safe). The community, midwives and health service providers arrived at an agreement that the births attended by midwives could be considered ‘green’, if the midwives successfully completed a formal training course in safe birth.

3 ‘Building Bridges for Quality’ Project: Experience from Puno, Peru

In many countries, a major barrier to clients’ utilisation of reproductive health care services is how health care providers treat them. Large cultural, educational and socio-economic gaps between clients and providers can lead to poor communication and interpersonal relations. Efforts to improve the quality of health services in developing countries have traditionally focused on strengthening clinicians’ technical skills and on upgrading facilities with equipment, supplies and improved physical structures. Less attention has been paid to interpersonal skills and relationships. Community members’ participation in defining and improving quality of care has often been minimal.
In rural areas of Puno, Peru, health services are underutilised. Those people who have used the services are often dissatisfied with the care that they receive. The results of a ‘Rapid Communication Needs Assessment’ conducted by the Johns Hopkins University/Center for Communication Programs indicated that clients’ satisfaction with health services was primarily determined by how they were treated by the provider. The providers’ concept of an ‘ideal client’ is someone who is responsible for his/her health, communicative, speaks Spanish and has attained a certain level of culture and education. In the rural areas of Puno, most clients do not fit this description. There is a large cultural and socio-economic gap between service providers and clients—the higher the provider’s educational level, the bigger the gap. Many providers recognise that their relationships with clients and communities need to be improved, but often they perceive that it is their clients who need to change. Few providers see the need for changes in their own behaviour. Communication between providers and clients is usually vertical, often paternalistic and infrequently horizontal. Clients are often afraid to ask questions and service providers do little to encourage them.

Generally, when client and community input on how they define quality is sought at all, it is through formative research focus group discussions or interviews. The resulting training curricula or protocols attempt to incorporate what is learned from this formative research. This approach treats the client/community as the object of services and not as active participant(s) in improving quality. While services may improve using this approach, the process does not foster community participation in, and ownership of, the services and may subsequently not lead to significant increases in utilisation.

3.1 A community mobilisation approach to build bridges for quality

In Peru, a community mobilisation approach to improve the quality of health services is emerging as an alternative. The ‘Building Bridges for Quality’ project, a joint initiative by the MOH in Peru, JHU/CCP (Population Communication Services Project) and SCF, is piloting a community mobilisation strategy to initiate a respectful dialogue between members of the Puno community and service providers to improve the quality of reproductive health services, and health services in general. Recognising that health care begins (and often stays) at home, this approach invites community members and service providers to enter into an ongoing, respectful dialogue about what constitutes quality services and how they can improve health and the quality of health services. The community and service providers identify priorities and develop strategies together to improve health services and practices. The underlying assumption is that if community members act as partners with health care providers to define quality and improve services based on this definition, the resulting services will more appropriately address the needs of the population, community resources can be mobilised to this end, and community members will ultimately develop a shared responsibility for their health services. Further, if the community can mobilise resources to help achieve this goal, community members will develop a shared sense of responsibility for health and health services that will ultimately result in increased utilisation and sustainability of health services.

**Project goal**

The goal of the Building Bridges for Quality project is to increase community ownership of public health services in selected project areas to contribute to the improvement of the population’s reproductive and general health.

**Project objectives**

During the 2–3 year project, project participants aim to:

- Increase the utilisation of public health services in selected project areas
- Improve client and service provider interpersonal interactions within health services
- Establish mechanisms and/or systems to improve coordination and collaboration between health services and community organisations.

The project objectives were purposely defined in broad terms to allow communities and service providers to develop their own, more specific objectives and indicators of success.
**Pilot site selection**

Three communities in Puno region were selected as demonstration project sites. Puno region was selected because of: (1) Puno government health workers' expressed interest in making positive changes to improve their services; (2) a demonstrated need based on health services indicators; and, (3) government health workers' positive previous experiences and training working with JHU/CCP on health communication programmes.

**Project activities**

To achieve Building Bridges’ objectives, the MOH in Puno set up a sub-regional team to plan, implement and monitor the project, with USAID-funded technical assistance from JHU/CCP and Save the Children Federation. Team members were trained in community mobilisation principles, facilitation skills, participatory techniques, interpersonal communication skills and other relevant topics. Three pilot sites in the Puno region were selected by the MOH based on interest in voluntary participation and demonstrated need for such an intervention. Participants from each of the three indigenous pilot communities included community members composed of traditional and informal leaders, youth, elderly people, women and men, the poor and interested others. Participants from these communities’ corresponding local hospitals, health centres and health posts were representative of staff and included doctors, nurses, midwives, technicians, etc.

In each pilot site, two participatory videos were made (one with providers and one with community members) to stimulate the development of a quality improvement plan. The videos document how each group defines quality of care, what their experiences have been and how they think quality can be improved. The videos contain interviews, group discussion, frank ‘testimonials’ and socio-dramas (skits) that depict an ideal client-provider interaction and a more real situation. JHU/CCP staff in Lima edited the videos so that they ran approximately thirty minutes. Local language conversation in Aymara or Quechua was subtitled in Spanish.

Every group had the opportunity to review its own video and determine whether changes should be made. During these meetings, participants reacted very strongly, as if they had held up a mirror to themselves and sometimes did not like what they saw. Recognising that the next step in the process would be to show the video to the other group (providers would show their video to community members and vice versa), debates ensued about whether to change the content of the videos or not. In all three sites, participants determined that even though they may ‘look ugly’, the reality was that there were many problems and that they needed to accept them in order to move forward. Thus, the videos remained as they were with slight changes in the music and in one case the addition of a community dance. During this meeting, the local MOH facilitation team also discussed the next meeting with participants to get their ideas on how they thought the meeting would proceed and to work out logistics regarding meeting sites, food and lodging. All groups expressed concern that the next meeting (when they were to meet with the other group) would provoke a ‘battle’ or ‘crash’. Relations between the individuals and groups were strained or non-existent.

Because of the highly sensitive nature of initiating this type of dialogue between such diverse groups, the project team developed a two-day agenda for the next meeting. The first day began with a fun presentation exercise that paired community members with service providers. Services providers then hosted community members on a visit to their health facility, where the participants learned about the services, providers, equipment and how services were delivered. Everyone ate lunch together and then left for the community where community members hosted the visit. The community members prepared presentations on their community’s history and its map. They led a ‘tour’ of the community and hosted mixed player soccer and volleyball games. All ate dinner together and the providers spent the night in the community at accommodation supplied by the community. Providers, community members and project staff each contributed several meals to feed the group.

The second day of the meeting began with an exercise on what it feels like to be treated well when you are sick. From this exercise, participants developed a list of elements of ‘buen trato’ (being treated well). Then the videos were shared to generate consensus on what ‘quality’ is. Participants engaged in an
exercise to define jointly the elements of quality health care, which resulted in the identification of from 6–9 quality categories (e.g. communication/how client and provider are treated, equipment and supplies, economic issues, etc.). These categories formed the basis for developing an action plan to improve quality. Action planning included determining desired results related to each quality component, negotiating strategies, identifying possible barriers and resources, and developing mechanisms and indicators to measure progress.

Action plans were drafted in all three pilot sites and were then shared with community members and service providers, who did not participate in the meetings. The plans were then finalised in a subsequent meeting. Community members and service providers have begun to implement the activities they outlined in the plans.

As anticipated, being 'treated well' was identified as a priority area to be targeted for improvement. According to participants from one project site, being treated well meant: being seen quickly, in a caring manner, helping to calm the pain (one woman spoke of the kind words and encouragement of a nurse who helped her during her delivery), being able to be with family members, speaking in a language that can be understood, use of and respect for traditional remedies and practices as well as 'modern' medicines, trust, friendliness, security, respect, patience and privacy.

Additionally, participants identified the need to improve equipment, have access to reasonably priced drugs, adjust time schedules, improve communication and coordination between community organisations and health services, improve health facility infrastructure, and improve transport so that providers can reach clients and clients can reach facilities. Draft plans address these issues with a variety of strategies that call upon the resources and input of both groups. In all three pilot sites, the participants proposed forming a joint committee to oversee activities and monitor progress. Other mechanisms, such as general community meetings, were proposed to keep the broader community informed and involved.

Results
Because implementation has only recently begun, impact to date is uncertain. However, there are positive signs that attitudes and practices are changing. In one hospital, staff took action on plans before they were even finalised, by posting public information on when specific doctors would be attending patients and the prices of services, and installing a suggestion box (all matters they had agreed upon with community members). The MoH is reporting increasing utilisation of health services in these pilot areas, but it is too early to draw any conclusions. Upon learning of the experience, neighbouring communities and towns have also begun to take action to improve quality. The MoH is now replicating the process in two additional regions and is considering launching a national-scale programme based on this methodology. Experience from many other community participation efforts demonstrates that the process of scaling up should be undertaken carefully, paying attention to establishing and strengthening systems to support local teams as they adopt new, facilitating roles that require an understanding of, and commitment to the principles and values of community participation and empowerment. Without this necessary shift in roles and attitudes, the methods and techniques can become mechanical and ineffective.

Many challenges will need to be faced in the near future as action plans are implemented. Observations to date suggest that the Building Bridges process is encouraging more and better communication between clients and providers. The fact that both groups have chosen to volunteer their time and energy for such an effort alone is indicative of significant attitudinal change and the potential success of such an intervention. The affirmation that community members as well as service providers are responsible for the quality of health services, and that there are many common areas of interest for improvement, is a big step toward collaboration. Further, the fact that participants in all pilot sites are committed to continuing to work together and have established and implemented action plans towards this end is encouraging.

4 Conclusion
The SECI and Building Bridges for Quality projects demonstrate the type of power, action and results that can be generated through respectful dialogue between service providers and communities and the pooling of their respective resources. Service
providers and community members have commented that they feel more supported in their efforts when they work together. This seems particularly true for service providers who recognise the weaknesses in the health system but feel powerless to do anything to change the system on their own. Creating a shared vision, goals and objectives through approaches that foster equity and shared responsibility between service providers and communities, such as socialisation and ownership of health information, and developing a jointly defined concept of quality of care helps to build a sense of teamwork and greater accountability.

A working hypothesis for both the SECI and Building Bridges projects is that changes made through participatory processes are more likely to be sustained, because both providers and communities can see results and have a vested interest and a role to play in achieving them. Preliminary results suggest the need to further document the processes and impact of these programmes as they mature, paying particular attention to the costs and benefits involved from both community and service provider perspectives, the potential for sustainability, and replication or adaptation on a larger scale and in other settings.

Note

Most community members understood Spanish but felt more comfortable speaking in their first language. Many providers did not understand Aymara or Quechua and, thus, the subtitling served as a means to helping them understand the language. Language barriers were a recurrent theme throughout the project and several strategies were used to try to increase communication and understanding, including translation, subtitling, use of non-verbal techniques like drawing, etc.

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Instituto National Estatistico-Demographic Health Survey (INE-DHS), 1998.