The key importance of including faith-based health providers in a strategy for the development of appropriate assistive technology services around the globe

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Abstract

Faith-based health providers (FBHP) are major players in health care provision around the world. A 2015 series of articles in that premier British medical journal, Lancet, shone a highlight on the scope of these organizations which provide 20 to 70 percent of medical care in Africa South of the Sahara. Evidence indicates that care is provided without prejudice to people of all faiths. FBHP are well regarded by the populations they serve and often have provided quality medical care through several changes of government. FBHP whenever possible have transitioned to local ownership and leadership. In fact, there is a strong commitment to local education resulting in nursing schools and pan-African medical internships. Working with FBHP has enhanced the global response to HIV, malaria, neonatal health and Ebola. In many countries, there is a constant struggle with corruption resulting in funds not being used as intended by granters. FBHPs have received public recognition from local governments for their effective use of funds. They maintain a focus on serving the poor and have established ways to subsidize services for those unable to pay. At FBHPs, assistive technology (AT) services would be provided as part of a broader hospital system that can respond to other medical needs. Many have longstanding relationships with populations of over one million people and have community health programs which could identify and follow up with those needing AT services. FBHP have historically focused on acute care a transition toward more holistic care including rehabilitation is underway. However, many FBHP may lack knowledge of resources and training for appropriate assistive technology provision. This may be overcome through directed dissemination of information. FBHP are numerous and independent, making them potentially difficult to engage as a group. However, information could be shared through umbrella organizations which engage with many FBHP. An example of what is possible when a FBHP engages in assistive technology provision is the initiative by BethanyKids in Kenya. BethayKids grew out of the large FBHP hub at Kijabe and has a focus on surgical and rehabilitative care of children. They recently have broadened their focus to build capacity for appropriate wheelchair services. This was initiated through their rehabilitation facility at a boarding

school for children with disabilities. Staff and leadership received WHO wheelchair provision training. They built capacity through the Accelerating Core Competencies for Effective Wheelchair Service and Support initiative. They are now in the process of initiated wheelchair services through their Kijabe location and through the mobile clinic which visits 17 locations around Kenya. Their largest hinderance to appropriate wheelchair provision is the lack of a diverse and appropriate wheelchair supply. Including FBHP in planning and providing them with opportunities for training, education and AT supplies would have significant country-wide impact in each of the countries where FBHPs are working. Any plans to develop appropriate AT services in country where FBHP are working should intentionally include collaboration and coordination with FBHP.

Keywords

Health providers, Assistive technology, Wheelchair, Provision, Community.

Introduction

The importance of FBHP is evident around the world and is obvious even in developed countries where the names of many well-known hospitals and medical schools reflect their origin in faith-based initiatives *(1)*. A series of articles in Lancet, the premier British medical journal focused on the scope of FBHP in Africa south of the Sahara. That group is also be the focus of this paper *(2-4)*. In those countries, faith-based health providers (FBHP) were the initiators of modern health provision, and in spite of major changes in the health care situation, they have remained major players *(2-4)*. At the turn of the last century when there were few local resources, FBHP were run almost entirely by expatriate volunteers who committed many years to the people they served. Very early in their history, many recognized that some of the acute illnesses they were seeing could be ameliorated by prevention programs through public health and began programs in the surrounding communities *(5,6)*. They also began local medical training initiatives. As locally trained medical and administrative staff became available, more staff were hired from local populations, and FBHP moved to local ownership *(2)*. As FBHP moved toward locally sustainable funding, government funding has become key to their ongoing success *(2-4)*.

In short, these faith-based initiatives have provided parallel health care systems, working with local government initiatives *(2-5)*. Although it is difficult to estimate exactly how much of local health care is provided through FBHP in Africa South of the Sahara, it is clearly a significant amount. Across the African continent estimates range between 20 – 70% of services *(2)*. Evidence indicates that clients seem to view the health care provision by FBHP to be of better quality than that available at other centers *(2)*. A series of articles in Lancet has recently reviewed the impact of FBHP and has recommended methods by which public and faith sectors might collaborate more effectively *(2-4)*. Evidence indicates that working with FBHP enhances the global response to a health challenge. Partnership with international health initiatives has successfully included FBHP on several fronts. For

example, they are currently significant partners in the global response to AIDS, malaria, neonatal health and Ebola *(6-8)*.

FBHP have often been very involved in local medical education. Many of the larger hospitals are part of the Pan African Academy of Christian Surgeons (PAACS), training African physicians as surgeons through internships. In addition, many host nursing schools. Continuing education for medical personnel is also a focus, and expatriate long-term volunteers are recruited who have the medical and academic training to teach *(2)*.

Although FBHP are a large presence, they have sometimes been overlooked in strategies for appropriate AT provision. In countries with fragile infrastructure, challenges in delivering effective national health care abound, and the proportion of health care provided by FBHP is high *(2-4)*. In many countries, FBHP may be the most effective possible partners for global initiatives to improve AT provision. This is especially the case because there is often a constant struggle with corruption. There is always a danger that funds may go in directions not intended by granters *(8)*. In contrast, FBHPs have received recognition for their effective use of limited funds. Research publications have suggested that effective use of limited funds, and commitment to service by FBHPs may be enhanced by a shared intrinsic motivation through the shared faith-based organizational ethos *(2)*. This sometimes results in local government recognition. For example, at the opening of an eye clinic by Tenwek, a large FBHP in Kenya, President Kenyata was quoted in the Daily Nation as saying "*I have learned several lessons here. You will not be able to blind me again. I continue to warn officers who think they are in office to squander public money. We have seen the development here (at Tenwek), and it is clear that the money has been well spent*" *(9)*.

In the past there may have been apprehension that treatment and care came with a requirement to agree with the FBHPs spiritual world view, however research has indicated no evidence for this; instead, findings indicate that care is provided equally to all comers *(2)*. There has also been hesitance since it is sometime thought that these institutions are not nationally owned and managed; however, as mentioned above, evidence indicates that over the past 60 there has been a transition to national ownership and leadership *(2)*.

Approach

Strategies for appropriate AT services should include FBHP who have the capacity to scale-up significantly due to their long history of working effectively in country, commitment to medical excellence and extensive local networks. Significant and stable country-wide impacts could result. However, there are barriers. Historically, many FBHPs have often focused primarily on acute care responses to conditions which were immediate threats to survival. Resources are spent responding to water born illnesses, malaria, trauma, surgical interventions and so on. Although most FBHPs have rehabilitation staff, because of the focus on acute care, rehabilitation staff and medical directors may not be aware of resources that have become available over the last ten years. For example, they may not know of the guidelines or training and resources now available through the World Health

Organization's GATE initiative and wheelchair training programs. Very often both salaried and volunteer personnel are working long hours on limited pay. Commencing a new initiative is challenging. Wheelchair supply has also been a big barrier, and FBHP have often been limited to occasional donations of wheelchairs of uneven quality.

Because of their wide impact, and because FBHP have learned sustainable methods to provide health care in country, many will be able to scale up very significantly when they engage. It is essential to have understanding and buy-in from top leadership. The World Health Organization stakeholder training is addressing this requirement and could be utilized *(10)*. Unless leadership is engaged and fully understand the benefit of appropriate AT provision, it is very difficult for a program to go forward. Leadership of FBHP are often very aware that staff and budgets are stretched. The option of starting small and building to capacity in a stepwise manner is much more likely to be seen as possible. External funds for start-up costs would open doors.

Each FBHP has over time developed long-term ways of paying for staffing and services for their existing programs. These often include essential links to any local government health funding. Once up and running, AT program could become part of the fabric of services provided. However, because of the relatively high cost of wheelchairs, some sort of sustainable funding for a diverse source of appropriate high-quality wheelchairs would be necessary. Paying for the full cost of the wheelchairs and the shipping is simply not affordable to FBHP or their clients. If funds to cover wheelchair costs were available, and startup costs were available, many FBHP would be able to go forward to provide excellent local long-term care.

A benefit of linking AT provision to FBHPs is that it would then be part of an integrated hospital and community health system. The presence of multiple medical specialties is common at many FBHPs. This means, for example, that wheelchair users would not only have their AT needs met but would also become clients of a medical organization which could provide necessary surgical interventions and medical care. Community health programs in place at many FBHP could identify and follow up with those needing AT services. With some training, public health personnel and volunteers could teach life skills programs linked to the initiation of family groups dealing with disability. For example, children with cerebral palsy are often much more disabled than they would have needed to be if parents had been taught to do simple therapy as part of activities of daily life. Training programs are available which could be disseminated through rehabilitation and community health personnel and parent groups *(10-13)*. Roots in the community are especially important because those who need AT may be hidden by families *(14-16)*. This occurs partly because many cultures see disability as evidence of a curse or as the result of some shameful behavior by the person with a disability or their family. Community level change is necessary. FBHPs are in a unique position to facilitate that change with their long-lasting relationships to local populations. In addition, in many cultures the root cause of disability is thought to be spiritual, and much of the social isolation cannot be addressed by the

simple provision of a device. Modern medicine recognizes that health has social and spiritual aspects as well as physical aspects; these need to be addressed at the cultural level *(17,18)*. In Africa south of the Sahara, in many countries, the key social groups are religious. Because of their links with religious communities, FBHP are in a position to be agents of change with the ability to encourage inclusion in local spiritual communities.

Because FBHP are locally owned and managed, many now run on local funding with some supplementation from international donations. Levels of supplementation and methods to provide long-term sustainable health services differ at different locations. For surgical and medical services, local government funding is a key part of the picture in all countries where such funding is available. The intentional inclusion of FBHP in governmental and international plans for appropriate AT provision would very likely increase effectiveness.

Findings

The initiative by BethanyKids (BK) in Kenya is an example of what is possible when FBHPs engage in appropriate AT provision. BethanyKids is a compassionate Christian organization which focuses on transforming the lives of children with congenital conditions in need of surgery and children with disabilities. They are registered as a not-for-profit in Kenya, and their programs in Kenya are directed by Kenyan executives who lead their extensive Kenyan program and staff. BK headquarters in Kenya is at Kijabe and is part of the extensive FBHP center there. That center includes schools and training initiatives such as PAACS membership and a nursing school and has been a major player in the response to HIV/AIDS in Kenya. Clients come from all over Kenya and from neighboring countries.

Initially, BethanyKids was primarily concerned with surgical care. They have moved toward more holistic care, and now focus on improving long-term quality of life, health, and functioning in the community. For example, initially BethanyKids had provided surgical care to some children at a boarding school for children with disabilities. Several years ago, BK also arranged to provide rehabilitation, and assistive technology to the students at that school. There were over 150 students in need of appropriate wheelchairs. As part of that initiative, BK partnered with a research project on the comparative effectiveness of wheelchairs intended for use in low and middle-income countries. BK began to search for sources diverse and appropriate wheelchairs *(19-22)*. Several rehabilitation personnel were sent for formal training in appropriate wheelchair provision.

A key step, central to the growth of the program, was the inclusion of BK top administration in the World Health Organization wheelchair provision stake holder training. BK leadership began to see appropriate wheelchair and AT provision as essential long-term care for the pediatric population they serve. They found that AT provision also facilitates long term contact and referral back to BK medical services for ongoing issues that require medical and surgical care. This broad long-term view of care includes other aspects of care. BK has enabled the teaching of Clean Intermittent Catheterization (CIC) a procedure which allows those with spina bifida and spinal cord injuries to be continent. They initiated CIC

independently, but now have tied into the Spina-bifida and Hydrocephalus Association of Kenya, a group connected with the International Federation for Spina Bifida (IF). IF now supplies CIC kits through BK and helps to fund some of BK care of children with spina-bifida. BK also hired a mentor who was herself disabled as part of the chaplaincy program to encourage spiritual and social inclusion and wellbeing.

When it became available, they applied to be part of the Accelerating Core Competencies for Effective Wheelchair Service and Support (ACCESS) grant through World Vision. During the duration of the grant, more staff were trained, and BK wheelchair services increased significantly. ACCESS had a limited time frame, and the end of that time frame left BK without a source of appropriate wheelchairs. It was clear that complete dependency on one large grant was not sustainable. A diverse and integrated plan was needed. BK leadership sat down with consultants to put in place a three-year plan to proactively develop a wheelchair provision program. Initial funds for hiring staff and establishing a wheelchair provision facility in Thika were obtained through small grants. BK wanted a local sustainable way to pay their wheelchair provision staff, and they are in the process of addressing that challenge in a creative way. They have found that affordable buy-in on the part of families encourages ownership and value for their child and for the wheelchairs. Local families are expected to pay an affordable cost for wheelchair services. This is less than 10% of the total cost of the wheelchair, however, it enables a stable sustainable source of funds to pay the salary of a wheelchair provision team. Because some families are unable to pay even this small amount, a benevolence fund is being put into place to which families can apply for funding for the portion of this small cost they are unable to pay. This enables steady reliable local funding from each wheelchair provision to be available for paying the wheelchair provision team. Although the plan is still in the early stages of full implementation, last year BK provided over 1000 wheelchairs.

In addition to wheelchair services at their initial wheelchair provision facility in Thika, BK is in the process of initiating wheelchair services at two other venues: their mobile clinic which visits 17 locations around Kenya, and the large FBHP hub at Kijabe where BK has become the go-to organization for wheelchair services. For the facility at Kijabe, separate fundraising and grant applications are in process to enable the development of a larger rehabilitation wing which includes a wheelchair provision and wheelchair skills training area.

Since the ACCESS grant ended, BK has struggled to find a sustainable appropriate and diverse wheelchair supply. Complex duty requirements make bringing AT through customs into Kenya difficult. Although there is one type of locally made pediatric supportive wheelchair, these are too expensive for many families, and have very significant and dangerous quality control issues *(19,20)*. Chinese made folding hospital transport chairs are also widely available for purchase in Kenya. However, these are also expensive, and not appropriate for long-term use *(21)*. A supply of diverse and appropriate wheelchairs could be ordered from the Consolidating Logistics for Assistive Technology Supply Project (CLASP). However, the wheelchairs would need to be paid for, as would shipping costs and duty on

imported wheelchairs. BK has found this prohibitively expensive. Free Wheelchair Mission (FWM) provides wheelchairs free to port, making FWM chairs an affordable option, but the selection of wheelchair types is extremely limited. Two containers of Gen 2 and Gen 3 wheelchairs from FWM have been ordered and received. Research indicates that these FWM chairs work adequately for those with good upper body function *(22)*. However, BK also serves a pediatric population that includes children with complex seating needs. Using locally available materials, they have begun adapting some FWM Gen 2 frames by creating seat inserts for those with more complex seating needs. They have also been able to bring in smaller donations of other types of wheelchairs including some HoneyBee adaptive pediatric chairs from BeeLine; but the small numbers of these chairs are far from adequate for the population BK serves. An affordable, diverse and sustainable source of appropriate wheelchairs is very badly needed and is the largest barrier to effective wheelchair provision through BK.

Discussion

Although each situation will be unique, providing well thought through support to FBHP like BethanyKids could result in effective, stable and significant growth in appropriate AT provision. Any initiative to enhance appropriate technology services around the globe is incomplete without the inclusion of FBHP. Each organization will be somewhat different, but most FBHP will share a long-term commitment to excellent local service. Collaboration with leaders of FBHP at the local and global level is essential.

FBHP are numerous, making them potentially difficult to engage as a group. However, there are centralized organizations which are in contact with many of them. Interacting with these more centralized organizations may be very effective and result in a trickle-down effect. There are umbrella organizations such as the Christian Connections for International Health with 5000 facilities which are members. The World Medical Mission branch of Samaritans Purse with its strong relationship to over 40 faith-based hospitals; SIM with representatives working in more than 70 countries; the Christian Medical and Dental Association with members working in FBHP and secular health providers around the globe. Even at the clinic level, those advocating for change in AT services have found that stakeholder training is essential *(20)*. Once a strategy is put into place, it could be disseminated through these larger organizations. Strategies to encourage appropriate AT provision at FBHP hospitals could include information targeted specifically to FBHP leadership.

Well thought through initiatives aimed specifically at opening doors for FBHP to initiate or improve their services are of key importance. Collaborative planning for training opportunities and financial resources for the initial start-up of AT provision programs would open many doors. The lack of a sustainable and diverse source of appropriate wheelchairs is a significant barrier which must be addressed. It would be prohibitively difficult for each FBHP to pay for and ship containers of wheelchairs. Small in-country wheelchair

manufacturers are very often limited by poor economics of scale and poor-quality control making local supplies sporadic and often low quality. Without access to appropriate and affordable wheelchairs, appropriate wheelchair provision is simply impossible. Initiatives to improve wheelchair services should also include strategies which make it simpler to import wheelchairs and other AT supplies. Even higher resource countries import AT and wheelchair parts and supplies, so import laws that make this very complicated are counterproductive to the well-being of citizens of any country. Careful consideration of the scope of FBHP in the planning of any government or international funding initiatives for AT provision is of key importance. In fact, it would be effective if the FBHP were included in the planning of strategies. The implementation of these strategies could enable effective use of limited funds and would harness the capacities of FBHP. Their long history of working effectively in country and their extensive local networks could result in significant and stable country-wide impact.

References

1. Levin J. Faith-based initiatives in health promotion: history, challenges, and current partnerships. American Journal of Health Promotion. 2014; 28(3), 139-141.
2. Olivier J, Tsimpo C, Gemignani R, Shojo M, Coulombe H, Dimmock F, et al. Understanding the roles of faith-based health-care providers in Africa: review of the evidence with a focus on magnitude, reach, cost, and satisfaction. The Lancet. 2015; 386(10005), 1765-1775.
3. Summerskill W, Horton R. Faith-based delivery of science-based care. The Lancet. 2015; 386(10005), 1709-1710.
4. Duff J, Buckingham W. Strengthening of partnerships between the public sector and faith-based groups. The Lancet. 2015; 386(10005), 1786-1794.
5. Levin J. Partnerships between the faith-based and medical sectors: Implications for preventive medicine and public health. Preventive Medicine Reports. 2016; 4, 344-350.
6. Widmer M, Betran AP, Merialdi M, Requejo J, Karpf T. The role of faith-based organizations in maternal and newborn health care in Africa. International Journal of Gynecology & Obstetrics. 2011; 114(3), 218-222.
7. Greyling C, Maulit JA, Parry S, Robinson D, Smith S, Street A et al. Lessons from the Faith-Driven Response to the West Africa Ebola Epidemic. The Review of Faith & International Affairs. 2016; 14(3), 118-123.
8. Michaud J, Kates J, Oum S. Corruption and global health: Summary of a policy roundtable. Oakland: Kaiser Family Foundation, 2015.
9. Chepkoech A. Uhuru: Join us in a push for development. Daily Nation; National News, April 5,2018, p5.
10. McSweeney E, Gowran RJ. Wheelchair service provision education and training in low and lower middle-income countries: a scoping review. Disability and Rehabilitation: Assistive Technolog. 2019; 14(1), 33-45.

11. Elzeneini W, Waly R, Marshall D, Bailie A. Early start of clean intermittent catheterization versus expectant management in children with spina bifida. Journal of pediatric surgery. 2019; 54(2), 322-325.
12. Zuurmond M, O'Banion D, Gladstone M, Carsamar S, Kerac M, Baltussen M et al. Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. PloS one. 2018; 13(9), e0202096.
13. Nakamanya S, Siu GE, Lassman R, Seeley J, Tann CJ. Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. Disability and rehabilitation. 2015; 37(16), 1470-1476.
14. Mostert MP. Stigma as Barrier to the Implementation of the Convention on the Rights of Persons with Disabilities in Africa. Afr. Disability Rts. YB. 2016; 4, 3.
15. Puri M, Misra G, Hawkes S. Hidden voices: prevalence and risk factors for violence against women with disabilities in Nepal. BMC public health. 2015; 15(1), 261.
16. Njelesani J, Hashemi G, Cameron C, Cameron D, Richard D, Parnes P. From the day they are born: a qualitative study exploring violence against children with disabilities in West Africa. BMC public health. 2018; 18(1), 153.
17. Fombuena M, Galiana L, Barreto P, Oliver A, Pascual A, Soto-Rubio A. Spirituality in patients with advanced illness: The role of symptom control, resilience and social network. Journal of health psychology. 2016; 21(12), 2765-2774.
18. Harbinson MT, Bell D. How should teaching on whole person medicine, including spiritual issues, be delivered in the undergraduate medical curriculum in the United Kingdom? BMC medical education. 2015; 15(1), 96.
19. Rispin K, Huff K, Parra V, Wesley C, Wee J. An overview of a group of studies done in Kenya comparing two types of pediatric wheelchairs with 14-inch-wide seats. In Proceedings of the RESNA 2013 Annual Conference. 2013; 20-24.
20. Rispin K, Wee J. A paired outcomes study comparing two pediatric wheelchairs for low-resource settings: The regency pediatric wheelchair and a similarly sized wheelchair made in Kenya. Assistive Technology. 2014; 26(2), 88-95.
21. Rispin K, Wee J. Comparison between performances of three types of manual wheelchairs often distributed in low-resource settings. Disability and Rehabilitation: Assistive Technology. 2015; 10(4), 316-322.
22. Rispin KL, Hamm E, Wee J. Discriminatory validity of the Aspects of Wheelchair Mobility Test as demonstrated by a comparison of four wheelchair types designed for use in low-resource areas. African Journal of Disability (Online). 2017; 6, 1-11.

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