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LETTER TO THE EDITOR

COMMENTS OF THE COMMUNITY-BASED REHABILITATION AFRICA NETWORK REGARDING THE SPECIAL REPORT FROM THE INTERNATIONAL REHABILITATION FORUM*

Sir,

We would like to comment on the paper by Haig et al. (1) on behalf of the Community Based Rehabilitation Africa Network (CAN). We are the Executive Committee of that organization and are from 7 different sub-Saharan African countries. We currently represent 281 community-based rehabilitation (CBR) programmes from 27 countries in Africa.

We agree wholeheartedly that services and support for people with disabilities and their families in Africa need more resources and provision, and that services and support are best rendered by multi-disciplinary teams. We would, however, argue that these teams should have a much wider membership than indicated in Haig et al.'s article and, importantly, that they should always respectfully include disabled people and their family members as major players. There are a number of other issues in this article that also raise our concern, as follows:

- The article uses a narrow and outdated conceptualization of disability, which focuses on "impaired body structure and functioning" (2) and reflects a charity/medical model approach rather than the rights-based approach of the United Nations Convention on the Rights of Disabled Persons (UNCRPD) (3).
- Linked to this is an equally limited view and understanding of CBR, which seems to ignore the extensive body of work that exists about the nature and development of CBR (4, 5) and fails to make the distinction between physical medicine and the various different rehabilitation specialisms. Contrary to the perceptions communicated in this article, CBR does not seek to deliver specialist "physical medicine" services, but rather to facilitate referral to such services when appropriate and lobby for them where they do not exist. CBR also seeks to promote access to existing mainstream services such as education, employment, and mainstream health services, and to exercise positive influence on the social and contextual aspects of disablement (6).
- We cannot see anything to be gained by comparing people with disabilities in Africa to penguins in other parts of the world.
- It may be true that there are very few physiatrists in Africa, but this does not mean that 78 million people with disabilities in sub-Saharan Africa are un-served; there are other stakeholders in this multi-disciplinary endeavour who are working together to make a difference. For example, many African governments have ratified the UNCRPD and have policies in place to support provision of service development for disabled persons. In Malawi, for example, disability has been recognized as a cross-cutting issue and a special "Ministry of Social Development and People with Disabilities" has been created, through which the national policy on the equalization of opportunities for people with disabilities is administered. Malawi runs a national CBR programme with 5 components: health, education, social, livelihood and empowerment. This is because Malawi looks at people with disabilities holistically and not just from the health perspective alone (http://www.fedoma.org/). Kenya has a *Disability Act* that waives the pay-as-you-earn (PAYE) tax for some disabled groups, requires 5% of employment opportunities to be offered to disabled people, and has a National Disability Fund of 200 million shillings per annum to support people with disabilities who cannot work (http://www.nfdk.or.ke/).
- Given the above evidence we would like to suggest that the low response to the survey reported in this paper is more likely to be an indication that this method of data collection was inappropriate for the task, rather than evidence that there is nothing happening to improve disabled people's lives.
- We recognize and appreciate the advanced technical ability and power of physiatry as a potentially major player in seeking to improve disabled people's lives, but we are concerned that the article does not reflect respect and understanding for the value of other roles; an understanding that no one group can have all the answers to the multi-dimensional and dynamic challenges faced by people with disabilities (7). If the aim of the article was only to examine physiatry then it would have been wise to omit rehabilitation from the title and aims.
- The fact that physiatry is practised and takes a leading rehabilitation role in other parts of the world is not, in our view, a convincing argument for doing something similar in African countries, where the cultural context is so different, and when no evidence-base exists to support such action.
- We acknowledge that multi-disciplinary teams need leaders, but we are not convinced that this role would be best taken by physiatrists. It is our view that the leader of such a group needs to understand and appreciate the role and value of all the players. We do not find this understanding demonstrated in this paper.
- It is our perception that people in Africa have adopted CBR because of its appropriateness to local cultural conditions and situations. It is not true that CBR has been adopted because of lack of funds. CBR is not cheap, but rather a

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potentially cost-effective way of assisting the majority of disabled persons (8, 9).

We would like publically to support the World Health Organization (WHO) policy of CBR as we feel that this approach embraces the diverse nature of disability and promotes a strategy that is democratic and empowering. We acknowledge that much work still needs to be done to improve CBR training, implementation and evaluation, but would like to invite physiatrists and other interested parties reading this to become active members of the Community Based Rehabilitation Africa Network (CAN) (www.afri-can.org), so that with their additional expertise we have more chance of achieving this.

We encourage interested parties to facilitate the development of the multi-disciplinary and multi-sectorial teams required to make sure that we all come together with disabled people and their families to help make better lives for us all, lives lived amongst people who offer respect, understanding and inclusive practices, where opportunities are provided for promoting productive lives that are appreciated, valued and have less pain and suffering.

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RESPONSE TO LETTER TO THE EDITOR BY HARTLEY ET AL.

Sir,

We are grateful that our work has gained the attention of the African and British rehabilitation experts who have written a response letter. Their experience and dedication to the community provide important insights into our paper. We hope to respond here to a number of issues.

The derogatory use of the term "charity/medical model" to describe our viewpoint is most concerning. In fact no relationship between medicine and charity is made in our paper. On the contrary we use the economic argument that the number of Mercedes automobile owners in South Africa is evidence of wealth that can support medical rehabilitation. We state, "Caring and thoughtful non-governmental organizations should look at policies that grow locally-trained expert physicians and allied health professionals who will make a living carrying out rehabilitation and teach others to do the same."

This unexpected accusation may reflect a prejudice on the part of the writers. As reflected in many of the key documents referred to in our article it is a basic tenet of the field of rehabilitation medicine that we are subservient to the goals of the persons served. Without any home-grown rehabilitation doctors, and with a long history of nepotistic colonial leadership, our African colleagues cannot possibly be expected to trust that this is true. They would do well to look outside of Africa where physician leadership of rehabilitation teams is less autocratic than what they may expect and where rehabilitation professionals typically sustain themselves without charity.

A valid concern is about self-determination of people with disabilities and their important needs within the community. It may help the writers to understand that we view our thesis, the lack of rehabilitation medicine specialists, as a small segment of the overall crisis of disability, in which civil rights, vocational opportunities, and consumer education are all critically important and more within the expertise of the community organizations. By definition community-based programs do not represent the wishes or needs of hospitalized persons with newly diagnosed disabling conditions. It would be rare for a consumer in a hospital bed after spinal cord injury to opt for community care or physiotherapy on a general ward over comprehensive medical rehabilitation lead by a physician specialist. However, in Africa these consumers are not given informed choice and their voices are not heard in the debate over resources. Where medical and vocational resources come from the same budget, it would appear that the community-based organizations have a conflict of interest and an unfair advantage over these newly disabled consumers. The real solution is to increase the resources, not to debate the relative value.

The authors contend that the 78,000,000 Africans with disabilities are indeed served, citing legislation regarding civil liberties in certain countries. This claim is hard to reconcile with observations in the African communities we know, including Malawi and Kenya. Unfortunately disability laws are unevenly enforced. However, our paper discusses medical services, not civil liberties. Laws that require medical reha-

bilitation as part of basic healthcare rights are difficult to find in Africa, and rehabilitation is often ignored in the ministries of health or higher education because they view all of rehabilitation as social.

There were a number of comments about physiatry. It is natural for colleagues in fields such as physical therapy to advocate for their own leadership. Allied health professionals often do lead rehabilitation teams. However, where rehabilitation medicine specialists are available they typically become the leaders. This is not by chance nor by some political power play. The process that leads to specialization in physiatry develops some of the most competent and most dedicated leaders in rehabilitation. The technical knowledge gained from 4 years of medical school and 4 years of specialty experience, including medical diagnosis and treatment of disabling conditions, formal education related to each of the allied health professions involved in rehabilitation, and training in team leadership are important. These are also people who have been filtered through the highly competitive process of acceptance and completion of medical school, and who then chose rehabilitation medicine over other more prestigious or lucrative careers available to them.

Competency and dedication does not imply blanket authority. The hallmark of a great team is flexible leadership based on the circumstances of the moment. In the community others may be more expert and on some teams persons besides the physicians may be more talented leaders. In the end, physiatrists, community rehabilitation workers, and others really only act as foremen, organizing the team to do the work of the person who has requested their service.

It is difficult to justify the claim that Africa is served better with the current uniquely African model of care which excludes physiatry, when the rest of the world is doing better. Our African colleagues may fear this model because medicine and academic politics in Africa are typically more hierarchical than in some other places. Precisely because of this, Africa uniquely needs rehabilitation medicine to represent rehabilitation within that hierarchy. In addition to the services they deliver, physiatry medical school faculty model the role other physicians must play in optimizing ability and participation. The academic productivity of rehabilitation scientists without physiatry on the continent has been weak. Addition of a physiatry perspective can only help.

These colleagues also struggle with comments on CBR. Our goal was to point out the inadequacy of CBR in providing sophisticated medical rehabilitation services, not to dismiss its effectiveness in vocational rehabilitation or community integration. However, there are critics of CBR overall. Turmusani et al. (10) conclude from their review, "Many programmes have been unsustainable and it has been difficult to evaluate their full usefulness to disabled people". We have great faith in CBR as practised in one of the few methodologically sound randomized trials to show a positive effect, and as practised in many Asian and Latin American countries. Yu et al. (11) describe in great detail the intimate relationship between physiatry and CBR programs, which they felt was needed for success of their project. We find no rationale for denying Africans the opportunity to experience the benefits of CBR within the context of this proven model.

Whether pictures of penguins or the facts stirred our colleagues to write, we are grateful that they entered the debate. The absence of rehabilitation medicine in Sub-Saharan Africa remains a tragedy. We hope that those whose lives and livelihoods have centered on a different model can find it in their hearts to embrace change for the sake of the people of Africa.

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