

Editorial Summer Issue 2022

Power at your Fingertips to empower Others!

In the year 1989, the renowned journal *Social Science and Medicine* published an article titled “Information-Based Rehabilitation for Third World disability” by the late Mike Miles¹. Thirty years down the line the title of this manuscript could come in for criticism, yet there is an interesting and important concept it refers to, namely the focus on information-based rehabilitation. For those familiar with the debates of that time, it is obvious that Miles was playing with the abbreviation IBR in the title of his article; the supporters of Community-Based Rehabilitation (CBR) were adamant about the limited value of institutions and thus Institution-Based Rehabilitation (IBR). They understood the serious limitations of institutions to respond adequately to the needs of large numbers of people with disabilities and the isolated work of institutions with little community-level impact. Miles was playing with words and realised – being serious about the importance of information – that there was another meaning for the abbreviation IBR: one that would prove to be even more powerful than anything else related to whatever model of rehabilitation would be offered. He realised that development can be realised when people are truly involved and informed.

Coincidentally, I bought my first computer in the same year, and increasingly came to realise that if there was one thing needed to contribute to a fundamental process of change, it was to invest in developing the capacity of people rather than in setting up structures and projects. With videos becoming more and more common – even our Primary Health Care programme in rural South Africa knew this and had access to a mobile video unit – we understood the importance and power of information probably better than large numbers of health educators who, at that time, thought a poster was sufficient to inform people and/or change their mindset. Health professionals, who continued to invest in posters which became faded and thus illegible in no time, were not even in a position to do so.

In the eighties and nineties in South Africa, we also understood that information was of vital importance in the empowerment process of communities. Information was, as an initiated process, enabling the masses to gain power and extend it in such a way as to have a share in changing social, economic and political

1 Miles, M. (1989). Information-based rehabilitation for Third World disability. *Social Science & Medicine*, 28(3), 207–210. [https://doi.org/10.1016/0277-9536\(89\)90263-3](https://doi.org/10.1016/0277-9536(89)90263-3)

structures; and in so doing, to influence their own circumstances and participate in their own development.

Now, so many years later, we have information literally at our fingertips, along with the means to contribute to the much-needed system change whereby the poor get a more equal stake in the development of their country. Information is, in my view, fundamental to a process of change, but we seem to be only at the onset of understanding and using this to a certain extent!

On several occasions, and on different platforms, I have been indicating that often people with disabilities or their families, as well as rehabilitation cadre in low-resource countries, have limited (access to) contextually appropriate knowledge and information. Apart from the serious lack of knowledge and information, the poor documentation of information about simple but essential aspects of assessments, rehabilitation or development goals, and action needed to achieve these goals as well as monitoring data, is at times astonishing. This is particularly true for rehabilitation fieldworkers as well as many professionals who do not see the need or have the means or structures in place for documentation. At best, they have a manual registry or a client-based reporting system which is limited to minimal - and hard to read - notes made during an assessment, and maybe some interventions that are stated, but there is seldom an account of progress being made. Sometimes they have to fill out almost a dozen different forms with no idea about their purpose. Often, there is no purpose other than deriving generic data for an annual report, or reporting to donors, or storing the data for future research. It is seldom that clear documentation includes information about assessment, priority setting, goals, required interventions to reach those goals, referrals, as well as monitoring information. One may imagine the nightmare that evaluators face when trying to trace important information that simply does not exist. They are often confronted with cupboards full of files that grow larger by the day, but which never have and never will be used to learn from or be acted upon.

Although an exaggeration, the description above is close to the truth. During one evaluation assignment, I had to collect client documentation from underneath the bed of the CBR worker. During yet another evaluation assignment, I noticed that the fieldworkers were using 11 different ways to document data, e.g., an A-4 size registration book, various tally sheets, specific forms for specific conditions, and a form to write down individual rehabilitation plans and report on a regular basis on the progress being made.

While in some situations it would still be appropriate to continue working with manual client information systems, the opportunities have widened with the introduction of computers. Nowadays with rapid developments in digital or mobile health (m-health) applications, rehabilitation of people with disability as well as monitoring community development programmes focusing on the development of more inclusive societies have become increasingly possible and available. As such a Smartphone can become a tool that can revolutionise self-management in people with a disability and their families, while it can also be used for monitoring individual progress of personal and meaningful goals and development in various life domains. A Smartphone can make knowledge accessible to people in the most remote places of the world and it is high time that this happens. For too long, large groups of people with and without disabilities and rehabilitation fieldworkers have been deprived of information, whether deliberately or otherwise. People who have access to information and who are thus in power –with disability or not – seem at times to keep that information to themselves. The results are evident: masses of uneducated and exploited people hear the elite talking in terms they hardly understand. There are still large groups of people who are deprived of information and have no access to essential services. Health and rehabilitation professionals are often not willing to empower them and instead use their white coat or stethoscope to reaffirm the fact that they are the ones in power; many governments are not interested in empowering citizens because they too fear to lose their power; the elite of the disability movement may talk about empowerment but are comfortable with the position they have; and I often ask myself the question, “But who then is doing this?”

The answer probably is not only “who” but also “what” is doing it. Increasingly I believe it is digital information in the field of disability and rehabilitation that can play a considerable role in informing people and informing those who work in their interest. It is high time that we give knowledge back into the hands of parents of people with disabilities and children with disabilities. This can best be done by focussing on the transfer of information, knowledge, and skills.

The recently launched RehApp is a Smartphone application that that can contribute to filling the gap in a large variety of types of information related to disability, development, and rehabilitation. It is certainly not the solution to all the information needs of people with a disability and those working in rural and remote parts of low- resource countries, but it can be used to complement services.

However, more is needed to ensure that people with and without disability have access to and make use of essential rehabilitation services. Apart from the development of a quality allied health workforce such as therapists, governments need to invest in the (at times already existing) mid-level rehabilitation workforce including community volunteers, and build their capacity to become multi-functional and multi-skilled agents of change, problem-solvers and liaison persons. Governments, (I)NGOs and (community) colleges need to ensure that these workers have the necessary competencies, are given the right knowledge, skills and - digital - tools and resources to work with, and recognise them as an indispensable part of the workforce for at least the coming decades.

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