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Implications of the World Report on Disability for responding to communication disorders in Brazil

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Abstract

The World Report on Disability has resulted in major shifts in healthcare policy in different national scenarios. The current paper seeks to elucidate some of the changes regarding communication sciences and disorders with the ultimate goal of improved service delivery for persons with communication disabilities in Brazil. The inherent national diversity presents major challenges to both planning and service delivery. The task of identifying under-served populations and the specific barriers to access to services and resources is not straightforward, particularly given that 200 million people reside in an area of over 8.5 million km². To address this need, changes have already been implemented, namely increased participation of professional and scientific associations related to communication sciences and disorders. Wylie, McAllister, Davidson, and Marshall (2013) offered a provocative analysis in their recent paper and their positions are further discussed within the current document. The bio-psycho-social model of disability should be the foundation for both public agencies and the academy to enhance this area of concern in research, professional training, and service delivery. The real challenge seems to be providing services with the appropriate level of complexity and specialization required for each unique scenario.

Keywords: *World Report on Disability, World Health Organization, Clinical education, cross-cultural, disability.*

Introduction

The Brazilian-Portuguese language version of the World Report on Disability was released in February 2012 during an international seminar with the proposed purpose “to identify the challenges to the implementation of the report’s recommendations aiming at the promotion of equal opportunities for persons with and without disabilities” (WHO, 2012, p. 21). Nearly 1000 individuals attended, representing 15 countries and 23 Brazilian states, as well as involvement from offices such as the United Nations secretariat for the Convention on the Rights of Persons with Disabilities, the Human Development Network of the World Bank, the ICF Research Branch, the São Paulo State Secretary for the Rights of the Persons with Disabilities, and the Health Ministry; a clear demonstration of the substantial national and international impact of this report. Participants in this seminar were afforded state-of-the-art augmentative communication devices according to their needs in order to enhance input and provide ample opportunities for communicative exchanges during discussions regarding the document. However, such technology is

not readily-available to most in Brazil. There has been a clear, steady, and consistent movement led by the Brazilian government towards improved access and quality of services provided to persons with disabilities. However, implementation is challenging given Brazil’s geography, population, and socioeconomic diversity.

In this paper we discuss some of the issues involved in these proposed changes, with particular emphasis on communication sciences and disorders as suggested by Wylie, McAllister, Davidson, and Marshall (2013). We will start by considering some of the challenges in planning and implementing service-delivery initiatives in Brazil. The task of finding under-served populations and the specific barriers to access to services and resources is not simple for a nation of 200 million people residing in an area of over 8.5 million km². Some changes have already been implemented, and the participation of professional and scientific associations related to communication sciences and disorder in Brazil has been both meaningful and encouraging (Bazzo & Noronha, 2009; Penteado & Servilha, 2004).

People with disabilities in Brazil

Considering that disabilities refer to difficulties met by an individual in one of three areas of functionality: disorders in body structures and functions, limitations in performing certain actions such as walking or eating, and restrictions in participation in activities such as studying, having a job, or using public transport (World Health Organization and The World Bank, 2011), a disability may be a temporary condition for almost anyone. The severity, duration, and interference on personal independence or self-reliance will depend, among other factors, on environmental resources and demands. These issues certainly require careful consideration in a country as large and diverse as Brazil.

Differences observed in Brazil can hardly be described just in terms of being part of the Minority or Majority World. Some data place Brazil undoubtedly in the former group. Data provided by the World Bank (The World Bank, 2012) indicate that the Brazilian economy has one of the world's fastest growth rates and has the world's sixth largest gross internal income; both appear to have impacted healthcare delivery. For example, life expectancy in Brazil has increased dramatically and is comparable to the US. The ratio of speech-language pathologists and audiologists per inhabitants in Brazil is 1 to 6,020 (Sociedade Brasileira de Fonoaudiologia, 2012). Although the Brazilian ratio is below the American (1/2,200) and Canadian (1/4,700) ratios, it is over the European average (1/6,600) (American Speech-Language and Hearing Association, 2012; Canadian Association of Speech-Language Pathologists and Audiologists, 2012; Standing Liaison Committee of E.U. Speech and Language Therapists and Logopedists, CPLOL, 2012).

However, contrary data suggest that Brazil may be considered part of the Majority World. Although the annual Brazilian *per-capita* income has grown steadily in the last few years, it is still very low and the index of child mortality under 5 years of age remains high. Diversity within the country likely contributes to these findings. If we consider, for example, one of the poorest states of the northeast region, Piauí, with a population density of 12 inhabitants per km², 58.9% of residents fall below the poverty line according to the Health Ministry website. In contrast, in São Paulo, 167 inhabitants per km², only 14.8% of the population falls below the poverty line. Disparities in wealth are greater in the poorest regions and states. Identifying needs and providing health, educational, and social services to people with communication disabilities (PWCD) in such diverse contexts undoubtedly constitutes a challenge that must be met with consistent planning, public policies, and constant action.

Who are the under-served populations and what are the barriers to providing services to them?

The Unified Health System (SUS—Sistema Único de Saúde) was launched in 1988 to guarantee health

services of prevention, treatment, and rehabilitation to all Brazilian citizens (Ministério da Saúde, 2012). The Unified Health System has programs directed towards specific populations such as children, women, workers, elderly, indigenous people, and also to persons with disabilities (physical, auditory, visual, and intellectual). A national survey (Ministério da Saúde, 2012) conducted in 2002 identified that 14.4% of the population had some level of disability. By 2010, the proportion of people with some disability within the population had increased to 23%. Although some methodological limitations and bias must be considered, one hypothesis for this apparent increase may be related to increased awareness regarding the functional aspects of disabilities; potentially, the result of national and regional educational campaigns and informational programs.

Zoellick (2012), in a presentation of the World Report on Disability, attributed this increase in the number of persons with disabilities to factors such as population ageing and an increase in chronic diseases (diabetes, cancer, mental diseases). However, we must consider that progress in medical care during and immediately after delivery also has improved resulting in increased survival, but also an increased number of infants with disabilities requiring care. There is clearly the need for specific directions, technical arrangements, and creative solutions to meet the needs and challenges posed by the Brazilian diversity. Global issues must be addressed by Brazilian professionals in communication sciences and disorders within the context of national needs.

The need for culturally-appropriate data is one of the aspects that must be addressed with some care as simple translation or adaptation of tests and protocols may be inadequate and insufficient. For example, tests used to assess English-speaking children may produce significant differences in diagnoses if administered to Brazilian Portuguese speaking children. Critical linguistic factors (including the number of words in each language) and cultural specificities must be taken into account.

The operationalization of the International Classification of Functioning, Disability and Health (ICF, World Health Organization, 2001) is another challenge to professionals around the globe and must be faced by Brazilian professionals and researchers. More adequate functional analysis allows for the identification of intervention priorities and, therefore, optimization of intervention resources. Brazilian scientific and professional associations in speech-language pathology and audiology have been associated with public agencies to increase the use of the ICF, but they still must reach a larger number of professionals and students.

An important task of speech-language pathologists and audiologists would be guaranteeing adequate communication between PWCD and health and educational services providers. This issue is

complex; education and health students must receive at least a basic training to improve their abilities to comprehend and communicate with PWCD. In addition, professionals already working in health-care and education should increase their understanding for complementary and specific training about communication disabilities and specific strategies to ensure equal opportunities to access health and education resources by PWCD. Also, finally, persons with disabilities and their families must not only receive the best possible service to guarantee efficient communication, but also be informed of their rights to services that are adapted to their needs in all areas of health and education.

Challenges in service delivery for PWCD

The challenges regarding delivery of health and educational services in a country as diverse as Brazil should be analysed in terms of barriers to be overcome. If we consider two states of Brazil, some of the complexities related to service delivery can be clarified. Amazon is the largest state of Brazil, with over 1.5 million km² and 2.2 inhabitants per km². In Rio de Janeiro state, the demographic density is 365 inhabitants per km². Medical emergency services reach only 55% of the total Brazilian population. It is easy to imagine that persons living in Amazon have less access to these services. On the other hand, health services in Rio de Janeiro are overwhelmed and crowded; illustrating two vastly different barriers to service delivery. Therefore, different solutions must be proposed to solve these problems. The establishment of accurate information regarding each region, specific population, and profile of health services are one first important step. However, progress has been made in this regard. In particular the education of professionals responsible for the diagnosis and treatment of communication disorders, the field of speech-language pathology (SLP) and audiology (A) in Brazil, named *Fonoaudiologia*, comprises both a clinical/therapeutic approach to communication disorders and audiology and was officially recognized on 9 December 1981 (law No. 6965) (www.cffa.org.br). According to the most recent definition approved at the plenary of the Conselho Federal de Fonoaudiologia (CFFa) (Federal Council of SLP & Audiology), March 2004,

SLP & A is the study of human communication, as far as development, training, disorders and differences are concerned, related to aspects involving peripheral and central hearing, vestibular functions, cognitive functions, oral and written language, speech, fluency, voice, oral myology functions and swallowing (www.cffa.org.br).

University programs have existed in Brazil since the 1960s. Undergraduate training is a 4-year Bachelor of Science program and requires at least 3700 hours

of coursework with at least 1800 hours of supervised practice. In 1996, 2 areas of specialization were established: language, audiology, voice, oral myology and public health. Since 2011, the specialties of dysphasia and school-based speech-language pathology were also recognized. A specialty certification requires a minimum of 500-hours of coursework and a specific test. This certification must be renewed every 5 years. There are ~90 undergraduate programs and 70 specialization courses; however, for master's degrees and doctorates, only 10 programs exist, and 80% of them are concentrated in São Paulo State. Academic opportunities are not equally offered, potentially limiting service delivery and distribution of updated technology.

Changes and evolution

An overview of health and educational data in the four mentioned states is presented in Table I. This table illustrates some of the challenges and how they are being met by national and state policies, illustrating the macro-level of analysis and its impact on changing drives and forces.

These data regarding four states illustrate some of the issues to be addressed. The Family Health Program (PSF) is one of the many outreach programs developed by the Health Ministry. A basic team of health professionals, usually a paediatrician, general practitioner (primary care physician), and nurse, visit every home, providing basic health information, and attempt to identify persons at risk for health problems. From Table I, it is clear that this service has been reaching more people in the poorer states (Amazon and Piauí) than in São Paulo and Rio de Janeiro where a significant proportion of the population have private health insurance. Interestingly, no significant differences are reported between these regions with regard to the proportion of people that report good or very good health or chronic diseases. High levels of illiteracy may also be a major barrier to appropriate health services; this issue is currently being addressed by several outreach programs.

Table I. Health and educational data in four Brazilian states.

	Amazon	Piauí	São Paulo	Rio de Janeiro
Family health program	52.0%	83.7%	28.9%	17.4%
Good or very good health	81.6%	73.7%	81.3%	79.6%
Dentist in the last 12 months	37.4%	36.8%	45.2%	36.3%
Physician in the last 12 months	58.9%	63.8%	72.7%	69.5%
Chronic disease	24.6%	28.6%	33.7%	35.1%
Private health insurance	12.9%	12.6%	40.1%	34.0%
Illiteracy	7.02%	23.4%	4.7%	4.0%

Data adapted from: Ministério da Saúde (2012); www.portalsaude.saude.gov.br

Despite the large amount of data on general—publicly available—health services, there is no information regarding PWCD. This evident gap poses limits to strategic initiatives from both the Academy and health agencies. Critical to this initiative is a major national effort to gather these essential data. Although an enormous amount of data regarding the several health programs and the persons receiving these services provided by the Unified Health System (SUS—Sistema Único de Saúde) has been obtained, and, although speech-language pathology and audiology services are part of this system, there are no available data regarding the number of persons receiving these services within the public health system. This issue must be addressed; scientific and professional associations can be driving forces at the meso-level.

There are three main professional and scientific official institutions for SLP and Audiology in Brazil: the Conselho Federal de Fonoaudiologia (CFFa; 2012) (Federal Council of SLP & Audiology), the Sociedade Brasileira de Fonoaudiologia (SBFa; 2012) (Brazilian Society of SLP & A), and the Academia Brasileira de Audiologia (ABA; 2012) (Brazilian Academy of Audiology). These three institutions are actively working to improve access to high quality SLP and A services in all regions of the country for PWCD. They have been working with health agencies and other federal offices, for example, to develop guidelines regarding the minimum time of intervention in different disorders, diagnostic criteria, and instruments to intervention follow-up. The auditory health program that provides hearing aids and/or cochlear implants (through the Unified Health System) to all persons with hearing loss, depending on their specific needs, is also conducted with the co-operation of these institutions.

At the micro-level, individual work and intense participation in broader programs and initiatives are very powerful driving forces of change. They include an important educational program for dyslexic children; a large and comprehensive program for children with cleft palate and their family (starting before the first surgery and continuing throughout recovery); several awareness campaigns about vocal hygiene and prevention; intensive action toward the implementation of the newborn hearing screening to all children at risk; and participation in multidisciplinary teams that are developing protocols for health services addressed to persons with autism spectrum disorders, with Down syndrome, or who are at risk of violent situations. It is clear that there is a lot to be done, but several actions have already been taken (Barros & Oliveira, 2010; Rochelle, Moreira, & Mota, 2009; Souza, Cunha, & Silva, 2005). The results of each one of these actions should be carefully assessed to determine the need for changes or adaptations to these efforts, as well as the possibility of its application to other situations.

Final comments

The analysis proposed by Wylie et al. (2013) highlights the limitations that many people in both Majority and Minority countries face with regard to access services related to diagnosis and treatment of communication disorders. The biopsychosocial model of disability should be the foundation for both public agencies and the academy to enhance this area of concern in the research, professional training, and service delivery (World Health Organization and the World Bank, 2012).

A certain amount of knowledge and specific professional training is required for SLP/Audiologists working with Minority world populations. The proposal that middle-level workers, assistants, and other health professionals may respond to the responsibility of filling the gap is neither fair to the population needs nor sufficient to address the complexities of Majority world populations. How much is this rationale effectively a driving force to change on a global perspective? Adjustments from imported models should seek equal opportunities of high quality services—or at least a clear notion that anyone receiving less than that continues to be under-served. Less expensive services are rarely the ideal economic alternative—they may demand more time, be less effective, and have limited outcomes, ultimately not serving PWCD to reach their full functionality. The real goal should be to provide services with the appropriate level of complexity and specialization demanded by each situation.

There are many important challenges, and currently Brazil is facing the following concerns: to maintain the quality of undergraduate programs and to attract students that are willing and able to face modern complexities in this geographic area; to open new possibilities for graduate programs all over the country in order to reduce the country's disparities in services; to ensure quality of services and equity of wages, since reduced salaries are non-attractive; to enlarge health insurance companies' coverage of services in SLP and A, now limited to only 25 sessions; to expand initiatives on health and education; to impose continuing education for professionals; to ensure distance education is available using new methods and technologies; and to start new specialization areas. Educational institutions in SLP and A should be also considered a Meso-level driving force for change as they are clearly involved in updating educational aims, methods, and training supervision to empower the new professional to deal with current and future challenges of providing high quality services to people that need them, using all the available technological resources to overcome social, geographical, and educational barriers.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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