Regd. Under the Kamataka Societies Registration Act. Karnataka Act No. 17 Registration No. 25/67-68

#### PRESIDENTIAL ADDRESS

#### Presented by



DR. M. JAYARAM 2012, HYDERABAD

The city of Hyderabad was established in 1591 AD on the banks of river Musi at the tip of the Deccan plateau by Sultan Muhammad Quli Qutb Shah. Hyderabad was once a global centre of diamond and pearls trade and even today it is known by the sobriquet "City of Pearls". Times have changed. Diamonds and pearls have largely given way to computers and medicines. Hyderabad is a major centre for information technology and biopharmaceutical industries today. It is a very well developed modern day busy metropolitan city, but with its mind solacing Birla mandir, tranquil Hussain sagar, mouth watering Hyderabadi biriyani, the world famous Charminar, UNESCO heritage site of Chowmahalla Palace, and old Golconda fort as well as wine, the city of Hyderabad has retained its old bewitching charm. We are proud to come to this historical city for our conference and I thank each and every member of the organizing team led by my friend Vijay Nandur.

The profession of speech and hearing is very demanding and the professionals even more. My fellow professionals have been urging ISHA to take a more pro-active position on many issues relating to the profession and professionals, but have not always been satisfied with the response. I have also been one of them, but now I am on the other side of the fence. Suddenly in the office of the President of the Association, I am faced with the question of what difference I can make to the association and as its President to the profession. While thanking you for reposing your confidence in electing me as the President of ISHA, I also request all of you, more particularly those with whom I have to closely



Regd. Under the Kamataka Societies Registration Act. Karnataka Act No. 17 Registration No. 25/67-68

work as President, to continue to show the same confidence and trust that you showed in electing me as President. Together we can make a difference.

An attitude is a hypothetical construct that represents an individual's degree of like or dislike for something. Attitudes can be positive or negative and our perspective towards a specified target can have far reaching significance for the target. I am talking about attitude here because the attitude we show towards disability and disabled will have profound implications for the life of the disabled. The issue in focus here is empowerment of the disabled or what I call 'enabling the disabled'. The central and the State governments have several schemes for the disabled, have enacted 4 major parliamentary acts, and have established several national and regional institutes as service centres for them. Needless to say that a lot of money is spent on issues relating to disability and on the disabled.

Yet, the life and the living standards of the disabled in this country, in general, have not changed significantly though there might be some exceptions. United Nations has pointed out that Governments, the world over, have not shown the same concern to include persons with disabilities in the planning of strategies and policies that affect their lives that they have shown in making some material or legal provisions. However important it is to give material benefits to the disabled, it is not sufficient to ensure their well being. A more important strategy would be to make efforts to draw on their experience and understanding of the problems they face. The disabled or the caregivers know what is best for them and therefore, they must be involved in the decision making process. Efforts to empower and enable people with disabilities have met with limited success so far not only because the State has not done enough to integrate the disabled into the mainstream at every level, but also because, in the Society itself, despite the lip sympathy, there is an inbuilt resistance from the 'normal' members to this process. There is a tendency to view these differently abled as 'not normal' and even today, the response that a disability condition most consistently evokes is 'sympathy' rather than understanding. This has resulted in their exclusion from participating fully in all aspects of political, social, economic and cultural life. Legal provisions which our country has put in place for a number of years now may help in this regard, but only a little. It is our attitudes which are important than provisions - legal or economic. There has to be sea change in our attitudes to achieve the noble idea of integration of the disabled into all spheres of public life and to consider them as equal partners. As Sir Winston Churchill once said 'attitude is a little thing that makes a big difference'.



Regd. Under the Kamataka Societies Registration Act. Karnataka Act No. 17 Registration No. 25/67-68

Let me further emphasize the issue I am propounding. Our country has made reservation for disabled in both the employment and the education sector. The statistics reported by ministries of the central and state governments on the number of children with disabilities in India's educational institutions reveal that only a tiny fraction of them obtain admission in schools and colleges. Many schools refuse admission to them on several grounds: First, in the mistaken belief that such children would be better off in 'special' schools not realizing that special schools will permanently isolate them. Second, the managements of several schools are pressured into denying admission to such children by parents of the 'normal' children. Third, and the most important, reason is that managements, whether private or government, are not prepared to put in place some additional infrastructure required to take care of a disabled child which may cost them some money. The institutions are not prepared to invest in such "non-productive" ventures for the sake of just 2 or 3 children. The result is that disabled children are denied their opportunities in spite of the legal provision and are isolated. As a sequel, the isolation of people with disabilities continues into employment. The private sector is reluctant to employ people with disabilities. Though the record of the public sector on this score is marginally better, most of the schemes of the Government to train disabled for employment are limited to teaching them basket-weaving or candle making, even when many of them may have the knowledge and skills to pursue successful careers in teaching or research or developing software. I shudder to think what would have happened to Prof. Stephen Hawkins if he had been born in this country. The man who understands the nature of time better than anybody - living or dead - and who is considered the greatest scientist of the 20th century after Albert Einstein would have been just a 'vegetable' here instead of the veritable scientist that he is now. There is a need to change our perception of people with disabilities there is a need to change our attitudes. We need to realize that the cost of managing / rehabilitating a disabled person who is isolated from the mainstream is much more than the cost of managing such a person who is part of the mainstream. Any effort to empower these differently abled must be based on drawing them into the mainstream. There are gains to be derived from the full integration and participation of persons with disabilities in every aspect of life. Clearly an attitudinal change is called for to achieve this.

Another issue the implementation of which requires a change in our attitude is the issue of evidence-based practice. We clinicians know that evidence-based practice involves integrating clinical



Regd. Under the Kamataka Societies Registration Act. Karnataka Act No. 17 Registration No. 25/67-68

expertise with the best available clinical evidence derived from systematic research. Evidence-based practice involves, according to Strauss and Sacket (1998), asking clear, focussed questions specifying the patient or problem being addressed, the intervention being considered, an alternative treatment for comparison, and the clinical outcomes of interest. The clinician must then search for the best evidence to answer these questions.

Using a breadth of empirical data in making informed clinical decision is of critical importance, now and hereafter, in the light of the mounting pressure for accountability in our profession. This pressure would only grow as the awareness level of our clinical population and their caretakers grows. The day is not too far when our clinical population would ask us the uncomfortable question of what he/she got in return for the money / energy / time they spent on therapy. Also, the clinical population may ask for empirical evidence when faced with a choice. In addition, there is an emerging trend of specialized certification in identified clinical areas. Empirical evidence through evidence-based practice is a *sine qua non* for the sustainability of such certification programs. Evidence-based practice brings about clarity and precision to our decision-making and obviates the need for trial-and-error approaches to decision making. Informed clinical decision procedures can also be employed in a novel way to judge the development of clinical skills in the students' community. Simply stated informed clinical decision is in the best interest of the client whom we are serving.

A number of resources are available that provide systematic reviews of the methodologically rigorous and clinically useful studies concerning the effects of health care. For example, we have Cochrane Database of Systematic Reviews, and the Cochrane Controlled Trials Register. The Database of Abstracts of Reviews of Effectiveness is a full text database containing critical assessments of articles from a variety of articles. References relevant to our field can also be found in these resources.

Yet, in spite of the availability of resources, we find that we have made almost no attempt to implement precepts of evidence-based practice in our profession in this country. Students at the Masters' level in other countries complete two courses on evidence-based practice while we have, at the best, one unit in a paper. No attempt seems to have been initiated, forgive me if I am wrong, even to develop a database which is fundamental to any evidence-based practice. In fairness to our clinicians, it should be stated that the literature assessing clinical intervention in speech-language



Regd. Under the Kamataka Societies Registration Act. Karnataka Act No. 17 Registration No. 25/67-68

pathology is composed predominantly of studies that do not employ randomized clinical trials (Peach, 2004) and this may have hampered the development of databases. Randomized clinical trial studies are considered the 'gold standard' of efficacy research. Withholding of treatment to any individual diagnosed with a problem is construed as an ethical breach and therefore, not many randomized clinical trials have been attempted even in the global context.

The American Speech-Language and Hearing Association has amended ASHA Code of Ethics to explicitly address the research circumstances that support the ethical conduct of randomized clinical trials. Some randomized clinical trials have been conducted as a result. Perhaps, we may take a leaf out of their experience. In conclusion, I would say that there is evidence that the speech and hearing community elsewhere is increasingly becoming aware of the value of informed clinical decision and has begun to respond. If it has to accelerate, there has to be an attitudinal change in us to view and respect our clients and their interests as the core of our professional practice. My dear friends, it is not my intention to force my opinion on you in any way. I will be happy if some of you feel that what I have spoken until now is worthy of consideration. On the other hand, if anyone of you can show with logic that my views are not pertinent, then you be happy that I have learnt in the process. In any case, my dear young friends continue to dream. Dreams are not taxed. They are the first steps to any achievement. I assure you that your dreams are not just yours, they are mine too.

All the best and thank you for listening to me