

Fifty years of Scope

This year the UK charity Scope (formerly the Spastics Society) celebrates 50 years since it was founded. In a very compact country the national organization is very prominent, (unlike the more regional structure of its American counterpart UCP) and it is one of the largest disability charities in the United Kingdom. The relationship between health workers and the Society has not always been an easy one, but it has in my view been an extremely profitable one for both sides.

Some ten years later I myself was invited by the late Dr Ronald Mac Keith to join the editorial staff of what is now the Mac Keith Press. It amuses me to recollect, given all the talk there's been since, that I had no notion at that time that there was a 'medical model' of cerebral palsy. After medical training and some paediatric training, my first concern was that I knew nothing about CP nor any other disability. Acute paediatrics was what we had been taught and indeed what most paediatricians practised. I was strongly recommended to give up the speciality because it had no future!

It was against this background that Ronnie Mac Keith had realized that what was desperately needed was education and training of not only doctors but all personnel in the health field. He perceived that disability was more than just a health problem. Almost my first task was to help him with a paper on the needs of adolescents and he wrote:

'Every handicapped child, adolescent or adult deserves the best possible help, whether his or her handicap is of the body, the mind or the emotions, whether...it is single, double or multiple. All handicapped people deserve to have the best bodily function that medicine can give them, the best intellectual achievement and satisfaction that education can give them, and the most satisfying human relationships and the best adaptation to this physical and social environment that he or she can hope to achieve. These ideal aims are far from being achieved by many non-handicapped members of our society; but it would be wrong to set a lower standard of attainment for the cerebral palsied than for oneself.'¹

Some of the language (e.g. 'handicap') has changed over the years, but for that time this broad approach revealed the breadth of Mac Keith's vision. Again the journal was to the fore in altering some of the unsatisfactory language and in that same year we find a letter recommending that the terms 'mongolian idiocy', 'mongolism', and 'mongoloid' should no longer be used.²

Recognizing this need, Dr Mac Keith approached the then Spastics Society and recommended that they should do something to try and improve the training of health personnel in the field of disability, and persuaded them, moreover, to take the broad approach to disability and not be simply restricted to CP. At the time that was imaginative because the ignorant view was that CP was just a motor disorder. The fact that, these 40 years later we now know so much of the comorbidities, such as epilepsy, autism, severe learning disorders, that occur with CP was not obvious then to the founders of the Society.

Dr Ronnie Mac Keith was running the first CP advice clinic

in London and I went to that, but more importantly he sent me to spend time with Margaret Morgan, the employment officer from the Spastics Society who was running courses to assess the training, employment, and vocational possibilities for adolescents with CP. Attending these courses as a helper and not in any medical capacity I was able to participate in the group discussions with these young people and learned an enormous amount from them about the adequacy – or inadequacy – of the help they had received not only from health but from all service providers.

Much time has been spent on the issues of the models around the field of disabilities. I have previously animadverted on the use of the word 'models'.³ People don't have models of disabilities – they have disabilities. And it is our task – those of us working as professionals in the field – to try and provide as good a service as possible, without however denying the primacy of the person with the disability and his/her family to make the decision about what service they want. It is perhaps worth reminding ourselves of the recommendations made in 1997 following a workshop of the European Academy of Childhood Disability.⁴ The first was that: 'Services should be based on the needs and aims of the family and child rather than on particular orientations or organizational structures favoured by professionals. Clearly there is a balance between professional skills and information and the role of service users in determining service content and organization. However, in the past the involvement of clients in service planning has not been sufficient. Professionals have a responsibility to facilitate development of services to meet an individual's needs.'

A second recommendation, I'll mention, is one which has a sting in the tail for health professionals: 'Certain services or facilities should be available as a basic right in a caring society, rather than these having to meet a strict scientific test of effectiveness.'

It is difficult for health providers in these days of cost cutting and auditing of all services, always to support the provision of a service when there is no good evidence that it works. However, the philosophy is right and it echoes that 1962 statement that we should provide as good a health service as possible to meet the needs of all children.

These are some of the philosophies the Mac Keith Press has helped to develop over its 45 years of existence and it has played its part in participating with Scope in the way their thinking has developed over the years.

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