International Year of the Child
Sharing the care of handicapped children
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The Place of Voluntary Organisations
in Great Britain

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The nineteenth century was the age of the great philanthropists—Thomas Holloway and his fortune from highly suspect patent medicines, Samuel Morley rich from his mundane hosiery, Josiah Mason from his new steel pen nibs, the little dumpy Baroness Angela Burdett Coutts, with her inherited fortune from banking and her young charity secretary-cum-consultant Charles Dickens, the great Quaker Cadbury's and Rowntrees with their cocoa and chocolate, and the greatest of all, Andrew Carnegie, who brought unbelievable wealth from the iron and steel revolution in the New World together with his biting criticism of indiscriminate charity and his philosophy that 'the man who dies rich dies disgraced'. There was Dr Barnardo and the Scot, Thomas Guthrie, who founded the Ragged Schools in Edinburgh.

It is a fantastic and fascinating cavalcade of philanthropy but one that has now virtually ended in this country. Rich men have set up foundations during our life-time but there will be no more of any size. Consecutive Chancellors of the Exchequer have ended this.

The voluntary organisation as we know it today resulted from the upsurge of general social concern that took place after the First World War. A number of well-established organisations were set up around 1919 and they had the kind of democratic structure that, although sometimes thin in any real democracy, was at no longer dependent on somebody with a large bank account, but often on somebody with drive and enthusiasm, which is surely as it should be.

I am quite certain that voluntary organisations and the voluntary movement in general are an essential part of what has come to be known as 'the welfare state'. Aneurin Bevan said that it would be so when he was devising the National Health Service and I suspect that hindsight would have persuaded him that he was even more right than he thought at the time. No comments or criticism that I shall make of voluntarism, as some people with an insufficient appreciation of the English language have come to call it, should be construed as being based on any rejection of the principle that people who are unpaid or people who earn their livings with other jobs or who have families to care for or children to bring up have a great deal to give to their less fortunate neighbours or their neighbours' children.

The Disabilities Study Unit (1978) recently published the results of a survey of voluntary organisations for the disabled in the UK (excluding those concerned only with children). In carrying out this study we identified nearly 5,000 voluntary bodies—groups concerned with the welfare of disabled people. This may seem rather too many, especially if it is accepted that quite a few of them are, frankly, inefficient.

The day has passed when it was considered Christian and philanthropic to coss the disadvantaged person or handicapped child. I am not denigrating compassion, to my mind the sweetest of all virtues, but rather am I saying that in the latter part of the twentieth century compassion should lead to scientific and technical advances that will benefit a great number of those who have the disability or the disadvantage and not just the one who has moved our actual compassion.

There are innumerable responsibilities that the voluntary organisations can accept and, linked as voluntary organisations now are to central or more often to local government, many of these responsibilities will be sitting around committee room tables advising official bodies, representing to them the cause of the disadvantaged, and putting pressure on them to provide more or better services.

It has become almost a platitude that a voluntary association or a volunteer will develop a relationship with a client which is impossible for a professional from the NHS or from the Town Hall. But like most platitudes the real meaning has been obscured by over-exposure and I believe we should not say more than that the volunteer can bridge the gap between the layman, and particularly the more unsophisticated layman, and the expert, and can better communicate what the professional wants the
client to know. Volunteers, for the spread of whose existence I am pressing, must work closely and under the direction of professionals. We should remind ourselves that the voluntary association is not necessarily voluntary in the sense that it is composed entirely of unpaid, amateur laymen. The larger voluntary bodies do, of course, have their own trained professionals and the smaller ones should certainly have access to professionals employed by the local authority or by some other body.

As Byrne and Long (1976) said in Doctors Talking to Patients the doctor is both a product and a prisoner of his medical education and most doctors seem to work through a frame of references that requires both patients and themselves to fit a prejudged pattern. Like any other professional he has his professional jargon and is apt to forget that the patient or the patient’s family may not even recognise the long words, let alone the scientific slang. Fox (1974), in his admirable report, They get this training but they don’t really know how you feel, describes how, in order to evaluate the attitudes of the parents of handicapped children to doctors and social workers, he deliberately disguised himself as a ‘non-doctor’, calling himself ‘Mister’, wearing informal dress, usually tie-less, and never volunteering information on technical aspects of medicine. ‘Whatever you are’, he was told by one patient, ‘you are quite unlike a doctor, as doctors are quite unable to sit and listen’. Be that as it may, Fox developed a genuine rapport with the parents of handicapped children whom he interviewed and from this emerged the clear realisation that there is usually little real understanding between patient, or in this case parent of patient, and the professional, whether doctor, medical worker or social worker.

Of the large number of voluntary organisations for the disabled, not a few are inefficient in that there are no trained staff available to the organisation which had not understood that kind hearts and for that matter coronets are of little use by themselves in this technological and bureaucratic society of ours and can indeed provide more of a disservice than a service to the disadvantaged.

The provision of accurate and helpful information is a good example of a role for a voluntary organisation. The most frequently repeated claim in the Disability Study Unit’s Looking Forward (1978) is for more and clearer information. And this is underlined by the amount of misunderstood information seen in the actual replies given by officials of organisations who completed the questionnaire. To quote the report, ‘If they, who should be experts, are not understanding, how can their ordinary disabled members or clients be expected to hack their way through the jungles of officialese?’

All the information needed is, it is claimed, contained in the leaflets published and often widely distributed by government departments and backed up by extensive advertising in the press. This is true, but unfortunately many people do not read. Local authorities have learnt in the recent surveys of their handicapped populations that they achieve little by putting leaflets into letter boxes which never normally receive letters, or letting them lie in hallways of houses where correspondence, especially official correspondence, normally only spells trouble. They have had to employ organisations such as Outset to carry out door-to-door surveys merely in order to identify disabled people. How much more necessary will a face-to-face interview be when it is a question of guiding someone through the jungle of welfare rights or working out the arithmetic of cash benefits.

It is good to note that the DHSS has recently made a grant to the Salford Form Market Function for it to simplify a series of supplementary benefit forms and letters and to the Research Institute for Consumer Affairs to evaluate the new forms. This brings me to the nub of the matter. There is an important place for the voluntary organisation and this role of provider of information is suitable and, one might have thought, almost essential for a voluntary welfare organisation but it is one that cannot be carried out successfully without a training in the techniques of communication or without a detailed knowledge of our extremely complicated welfare system.

A major and welcome change during the past few years has been the growth of co-operation between government and the voluntary sector. This has produced a two-way collaboration in which at times central government seeks the help of the voluntary agencies both in consultation and in carrying out specific government policies while, understandably, the voluntary bodies also turn to and receive assistance from the government. During 1977-78, for instance, grants by the DHSS alone to 132 voluntary organisations totalled £3,500,000. More difficult to quantify is the amount of consultation between government and voluntary organisations. Consultations may often have taken place at the instigation of the voluntary organisation, but they clearly stem from the voluntary bodies’ belief that such a dialogue would not be resisted and that it would be to their benefit and to the benefit of their members.

I must emphasise that the training of the volunteer is not a threat to the status of the professional or his profession. The volunteer must always work under the direction of the professional and the relatively short, part-time training that he/she will be able to undertake will do little more than provide the professional with an extra pair of hands, but an extra pair of very willing hands, enabling the professionals to deal with the more sophisticated tasks.

To recapitulate, the voluntary organisation is an essential component of the welfare state. It must have a clearly defined and constructive role—not just a coach trip to the seaside in the summer and a visit to the panto in the winter—and be thoroughly efficient in the execution of its role.

Its role or roles must be complementary to the services provided by central or local government with whom it must develop a friendly collaborative relationship. In this way we shall get the best out of the welfare state for our handicapped children.

References
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Disability Study Unit (1978) Looking Forward. Occasional Paper No. 2. Fox, A. M. (1974) They get this training but they don’t really know how you feel. National Fund for Research into Crippling Diseases.