

Miss Cughtred & Mr. Ravensdale.
Dear

ASBAH Ltd.

At the last Committee Meeting I was asked to re-distribute a Paper I sent to all Committee members in November 1968. It was thought this would help in preparing our Plan for 1970, and in planning an Agenda for the proposed General Meeting in London in January 1970.

In the enclosed version, I have listed:-

1. Those items in the original Paper which I consider we could perhaps start work on in 1970 within a modest Budget, but given dynamic management.

2. Those other items which we must probably regard as impossible to commence in 1970.

I think it would be a mistake to announce an intention to deal with any items at all, unless our intention is real and unless we can see our way clear to do so.

The following extracts from my letter to Committee members dated November 29th, 1968 seem to me to be still relevant:

The launching of ASBAH in April 1968 "met with limited success, but it did provide a platform, however small, from which we could move forward. There was also a very great deal of public sympathy created by the World in Action film and the ITV Appeal, as was evidenced by the very considerable number of press-cuttings from local papers which we received at that time.

"Since then there has been a serious loss of impetus and we have not sufficiently expanded our operations or our outlook in the meantime. I feel the time is now ripe for a concise re-statement of the aims the Committee had in mind in 1967.....I am aware that the enclosed lists are not exhaustive and there are no doubt important omissions.

"It is clear from the attached that the expenditures envisaged are colossal. It is also quite clear that Public Funds to achieve these aims will not be available in anything like adequate amounts under the present or any foreseeable economic circumstances in this country. What we require is a vast, but not unattainable, degree of public support..... and a comprehensive fund-raising programme.

"In particular we need to create a climate in which it becomes the fashionable thing to do to support ASBAH." (As Shelter have done in the lifetime of ASBAH Ltd.) "We also need to undertake the very difficult task of creating fund-raising groups at all levels of society throughout the country - an operation which will probably take two or three years to take effect, given the necessary degree of enterprise at the start, and preferably supported by some novel form of fund-raising as well as well.

"I am aware that the achievement of these aims might be said to be a utopian dream. I do not accept this view, nor do I agree that any of the items listed are unattainable, given the necessary degree of public support.

"Most members of ASBAH are only waiting for the Committee to show again the kind of enterprise and ambition we promised in January 1967. If we fail to do so, what will the Spina Bifida and Hydrocephalus Problem be like in ten years' time?"

Yours sincerely,

LIST ONE.

A. Medical Needs.

1. The financial support of the S.B. Research Society and any developments therefrom.
2. Adequate information channels for Midwives and District Nurses in all areas, to ensure immediate action is taken after birth, and to prevent the giving of disastrously false information and prognoses - or even no information at all.
3. Adequate training and information publications for physiotherapists, and others in the ancillary medical services, who are concerned with the manifold problems arising throughout childhood.

B. Equipment Needs.

1. Skilled investigation is needed, to meet the needs of present-day life, into walking frames, "chariots", tricycles and toys generally. There are numerous prototypes in use.

C. Welfare Needs.

1. Special provision is needed for the orphaned SB & H child and this is an urgent need in certain areas around the main treatment centres. The provision of a "home" rather than an institution atmosphere is an over-riding requirement, if the orphaned and handicapped child is to have a reasonable chance in life. (In 1967 a group of wealthy persons in North London proposed to set up a Trust to provide help in this field. Two members of our Committee attended an informal first meeting of this group. Where is it now? If it has died, can it not be re-constituted under the same or different people?)
2. The most pressing needs of parents are often quite unsophisticated but none the less real. They can be and are met by the simple process of meeting others facing the same problems, especially meeting those whose children are growing up. Every incentive must be given to encourage the growth of more local Branches and the holding of local meetings.
3. A vast amount of information still needs to be published in the form of leaflets and booklets, covering the complete range of problems which may be faced by the affected family and its medical advisers. A considerable expansion of LINK is also planned for the future. Requests for information form a very large part of all local Secretaries' post, and of that going into City Road.

D. Educational Needs.

1. Research into the forecast future needs year by year. We have found this cannot be done by an insert in LINK. We should find some other method.
2. Active co-operation with educational research projects, such as that started under the G.L.C. in 1968.

E. Vocational Training and Employment.

(As long as a year ago, this problem was causing grave concern at Chailey Heritage. The problem will become insoluble if we do not commence work on it now. This is one problem where we can still be in time.)

1. Considerable work is called for in the development of new courses to meet present-day needs. E.g. speed-writing, computer-programming, punched-card operation, printed electrical circuits etc.. These will call for close contact with those administering the (few) present Training Centres.

F. Branch Needs.

1. Provision of an adequate advisory service for Branch Officers on such matters as Administration, Finance, the Medical and Welfare problems of their members and other matters. This will entail close personal contact, perhaps by a Branch Liaison Officer.
2. Advise Branch Officers continually on contacts with Local Authorities, especially County and County Borough Health, Education and Welfare Departments.
3. Where possible, ensure that local Officers are competent to cope with the work put upon them. In particular ensure that parents of young handicapped children are not burdened indefinitely with the task of administering growing Branches, so creating further problems both for the Branch and for the family itself. Such is the result of our present structure and in many cases the Branch or the family suffers. Too many local Secretaries are seriously over-worked in their spare time.

G. Overseas.

1. The active encouragement of the growth of similar organisations overseas should rapidly become an important feature.

LIST TWO.

A. Medical.

1. Research into Causes, methods of treatment and problems arising after initial treatment, especially re hydrocephalus and kidney failure.
2. Establishment of many more Treatment Centres at which comprehensive follow-up treatment can be made available.
3. Initiation of more post-graduate courses promoted by ASBAH. (If ASBAH cannot in the long run provide vast funds, there seems little likelihood of any other organisation doing it for us. The Health Service can hardly support its present essential requirements and services.)

B. Equipment.

1. Further work is needed on Calipers, fastenings, crutches etc. especially as regards weight, folding, expansion, flexibility, speed and convenience.
2. Wheelchairs - broadly as in 1. above.
3. Invalid cars.
4. Aids to independent living - kitchen equipment, long-handled tools, bathroom fittings etc.. Much work has been done already by various bodies. ASBAH must do its quota.

C. Welfare.

1. There is need for a great expansion in the field of Welfare Workers.
2. Provision of Play Schools and Day Nurseries.
3. The establishment of a substantial Benevolent Fund to meet permanent as well as temporary calls for help, including financial and other care for members' children who may become orphaned or in other need.

D. Education.

1. Creation of a climate in which, where appropriate, the admission of SB children into normal schools becomes the accepted policy, wherever it is in the best interests of the child.
2. Provision of special facilities - e.g. ramps, lifts.
3. Encouragement of special classes for the PH in normal schools.
4. Provision of more special Units and Special Schools.
5. Research into the best educational methods available.

E. Training and Employment.

1. Provision of more Special Training Centres.
2. Provision of Residential Centres near the Training Schools.
3. Aptitude Testing in collaboration with Universities.

LIST TWO (Continued).

F. Branches.

1. Encourage the rapid growth of new Branches and the sub-division of present ones where needed.
2. Assist various local projects which have been or ought to be started to meet particular local needs.

§.

G. Overseas.

1. The encouragement of research work of all kinds should be supplemented by the free flow of information.
2. International Conferences should naturally form a part of this work at all levels, not only medical.

Notes: The items in List Two have been abbreviated.

Since the comment was written a year ago that, if ASBAH cannot raise vast funds, there seems little likelihood of any other organisation doing our job for us, I have been told by someone who may or may not have been in a position to know, that this is not the case. I was given to understand that one or more of the "major charities" was standing aside to see what ASBAH made of the problem before stepping in, with or without the co-operation of ASBAH. My personal inclination is to disregard this information.

F. G. Armour.

"Our Plan for 1970"

LIST ONE

A. Medical Needs.

1. The financial support of the S.B. Research Society and any developments therefrom.
2. Adequate information channels for Midwives and District Nurses in all areas, to ensure immediate action is taken after birth, and to prevent the giving of disastrously false information and prognoses - or even no information at all.
3. Adequate training and information publications for physiotherapists, and others in the ancillary medical services, who are concerned with the manifold problems arising throughout childhood.

B. Equipment Needs.

1. Skilled investigation is needed, to meet the needs of present day life, into walking frames, "chariots", tricycles and toys generally. There are numerous prototypes in use.

C. Welfare Needs.

1. Special provision is needed for the orphaned SB & H. child and this is an urgent need in certain areas around the main treatment centres. The provision of a "home" rather than an institution atmosphere is an over-riding requirement, if the orphaned and handicapped child is to have a reasonable chance in life. (In 1967 a group of wealthy persons in North London proposed to set up a Trust to provide help in this field. Two members of our Committee attended an informal first meeting of this group. Where is it now? If it has died, can it not be re-constituted under the same or different people?)
2. The most pressing needs of parents are often quite un-sophisticated but none the less real. They can be and are met by the simple process of meeting others facing the same problems, especially meeting those whose children are growing up. Every incentive must be given to encourage the growth of more local Branches and the holding of local meetings.
3. A vast amount of information still needs to be published in the form of leaflets and booklets, covering the complete range of problems which may be faced by the affected family and its medical advisers. A considerable expansion of LINK is also planned for the future. Requests for information form a very large part of all local Secretaries' post, and of that going into City Road.

Continued.....

D. Educational Needs.

1. Research into the forecast future needs year by year. We have found this cannot be done by an insert in LINK. We should find some other method.
2. Active co-operation with educational research projects, such as that started under the G.L.C. in 1968.

E. Vocational Training and Employment.

(As long as a year ago, this problem was causing grave concern at Chailey Heritage. The problem will become insoluble if we do not commence work on it now. This is one problem where we can still be in time.)

1. Considerable work is called for in the development of new courses to meet present day needs, e.g. speed-writing, computer-programming, punched-card operation, printed electrical circuits, etc., These will call for close contact with those administering the (few) present Training Centres.

F. Branch Needs.

1. Provision of an adequate advisory service for Branch Officers on such matters as Administration, Finance, the Medical and Welfare problems of their members and other matters. This will entail close personal contact, perhaps by a Branch Liaison Officer.
2. Advise Branch Officers continually on contacts with Local Authorities, especially County and County Borough Health, Education and Welfare Departments.
3. Where possible, ensure that local Officers are competent to cope with the work put upon them. In particular ensure that parents of young handicapped children are not burdened indefinitely with the task of administering the growing Branches, so creating further problems both for the Branch and for the family itself. Such is the result of our present structure and in many cases the Branch or the family suffers. Too many local Secretaries are seriously over-worked in their spare time.

G. Overseas.

1. The active encouragement of the growth of similar organisations overseas should rapidly become an important feature.

LIST TWO

A. Medical.

1. Research into causes, methods of treatment and problems arising after initial treatment, especially re hydrocephalus and kidney failure.
2. Establishment of many more Treatment Centres at which comprehensive follow-up treatment can be made

3. Initiation of more post-graduate courses promoted by ASBAH. (If ASBAH cannot in the long run provide vast funds, there seems little likelihood of any other organisation doing it for us. The Health Service can hardly support its present essential requirements and services.)

B. Equipment.

1. Further work is needed on Calipers, fastenings, crutches, etc. especially as regards weight, folding, expansion, flexibility, speed and convenience.
2. Wheelchairs - broadly as in 1. above.
3. Invalid cars.
4. Aids to independent living - kitchen equipment, long-handled tools, bathroom fittings, etc.. Much work has been done already by various bodies. ASBAH must do its quota.

C. Welfare.

1. There is need for a great expansion in the field of welfare workers.
2. Provision of Play Schools and Day Nurseries.
3. The establishment of a substantial Benevolent Fund to meet permanent as well as temporary calls for help, including financial and other care for members' children who may become orphaned or in other need.

D. Education.

1. Creation of a climate in which, where appropriate, the admission of SB children into normal schools becomes the accepted policy, wherever it is in the best interests of the child.
2. Provision of special facilities - e.g. ramps, lifts.
3. Encouragement of special classes for the PH in normal schools.
4. Provision of more special Units and Special Schools.
5. Research into the best educational methods available.

E. Training and Employment.

1. Provision of more Special Training Centres.
2. Provision of Residential Centres near the Training Schools.
3. Aptitude Testing in collaboration with Universities.

F. Branches.

1. Encourage the rapid growth of new Branches and the sub-division of present ones where needed.
2. Assist various local projects which have been or ought to be started to meet particular local needs.

G. Overseas.

1. The encouragement of research work of all kinds should be supplemented by the free flow of information.
2. International Conferences should naturally form a part of this work at all levels, not only medical.