PERSPECTIVE ON A PUZZLE PIECE

By

Helen Green Allison

The National Autistic Society
276 Willesden Lane
London NW2 5RB

Registered Charity No: 269425

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276 Willesden Lane London NW2 5RB Telephone 01-451 1114

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On 5 January 1952, a group of desperate parents crowded into a meeting room in London. They felt that the world had turned its back on their cerebal palsied children, labelling them ineducable. From their anger and frustration, the Spastics Society was born.* On 23 January 1962, a group of desperate parents crowded into the living room of 71 Torrington Park, North London, and from this meeting, the National Autistic Society was born. This was the first group of parents of autistic children to meet with the specific aim of founding a Society to represent the interests of their children. The immediate aim of the Autistic Children's Aid Society of North London was to establish a day and residential centre for autistic children. At that meeting, a representative of the Spastics Society spoke to us about the founding of that Society.

Although during its first year, our Society was much concerned with negotiating our affiliation with the then National Society for Mentally Handicapped Children, which promoted the interests of the mentally handicapped mainly through acting as a pressure group and by establishing recreational facilities, our Society, from the beginning, chose to act on the Spastics Society's model. Therefore, the first of our four main aims, stated in our first Newsletter was "to provide and promote a day and residential centre for the treatment and education of autistic or psychotic children". Although this was intended as a pilot scheme to demonstrate to the local authorities what could and should be done for our children, in later years we found ourselves establishing through our National Society and its affiliated Societies a network of schools and residential communities in order to meet needs which would otherwise not have been met.

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* The Spastics Society, News Release, 29 December 1986.

§ Paper presented at a Conference held at the University of Kent, 18-20 September, 1987 : Aspects of autism : biological research. Reprinted in 'Communication', Vol. 22(1), March 1988, p 6-9.

It is interesting when we look back to the foundation of our Society to recall that the designation "autistic" was not commonly accepted, even among those professionally concerned with mental handicap. Our children were also known as "psychotic" or suffering from "childhood schizophrenia" and the term "autistic" was virtually unknown among the general population. In 1962, the need for an independent society for our children was challenged on all sides - by parents and professionals who thought that the Society for Mentally Handicapped Children could adequately represent our children's needs and by those who doubted that there was any role or prospect of success for "yet another children's charity". Aside from having to convince people that there was indeed a need for "another children's charity", the founder members of our Society were facing not only the facts of their children's handicap, but also stresses deriving from the views held on it at the time. There was a widely-held view, based on a misinterpretation of Dr Leo Kanner's research, that the handicap was caused by "cold intellectual parents", in particular, "refrigerator mothers". The handicap was devastating - to be accused of causing it was tantamount to an accusation of child abuse. We were also told that unless the child was treated early and intensively, he would miss the necessary developmental milestones and he would therefore deteriorate irretrievably until there was no choice but to institutionalise him.

Twenty-five years ago, diagnosis was difficult to obtain, largely because of the widespread ignorance about autism, even among the medical profession. Then there was the second hurdle of securing the right to education. Before 1971, children suffering from handicaps other than those listed in the 1944 Education Act as being in the need of Special Education, were required to be tested by the age of five to determine whether they would benefit from teaching. Those not considered "educable" were placed in Junior Training Centres for the Severely Subnormal which were staffed by care workers rather than teachers, or in "Special Care Units" attached to them which were for the most profoundly mentally handicapped. My first encounter with the Medical Officer for my part of Middlesex instilled panic in me when he suggested that my son, Joseph, who at age four was mute, hyperactive and destructive, might be suitably placed in a Special Care Unit. I was fortunate in that Joe was eventually assessed by a Middlesex Educational Psychologist who knew about autism and deemed him "educable" which resulted in his placement in a small private class for autistic and emotionally disturbed children.

The founder members of our Society were drawn from three groups. One comprised those who belonged to a Committee of parents formed following a conference on "The Psychotic Child" in May 1961 organised by Judy Fryd, of the National Society for Mentally Handicapped Children. Another group derived from parents who had got in touch with me as a result of a broadcast I had given on BBC 'Women's Hour' in October 1961, and the third group were parents whose autistic children were attending the private nursery class in Hampstead with Joe. Parents from these three groups, plus any known to them whom they could persuade to become involved, joined together on 6 March 1962 in our second meeting at the home of Dr and Mrs O'Driscoll in North London. At that meeting we formed a "caretaker Committee" while a constitution was being drawn up. By our fourth meeting we had 42 subscribing members. At that meeting we adopted a constitution for "The Society for Psychotic Children", Michael Baron was elected Chairman, Henry Sainer was elected Honorary Treasurer, and I became Honorary Secretary.

The minutes of the Executive and General Meetings held in 1962 demonstrate that the seeds of practically all the Society's present activities, with the exception of the foundation of communities for adults, were planted that year. The nursery class which evolved into the Society School began then; the information and advisory service was set up; our first newsletter was issued; our first parents' leaflet was prepared; our first Parliamentary question was asked; we drafted our project and policy document outlining our plans for the treatment and education of our children; we made our first entry into the media; we set up sub-committees; and we appointed our first Area Organisers, who were later to found many of our affiliated Societies. In addition, a parent designed a very handsome Christmas card - a silhouette of the skyline of Jerusalem - and we sold 6,500 of them. We also changed our name to "The Society for Autistic Children". This was the first time that we had put anything to a vote; and it was possible to achieve the necessary three-quarters majority only by excluding those who had failed to pay their subscriptions. Lady Elliot became our Vice President during 1962. She became our President in 1967 and has continued to help us, not only by serving as a very effective Chairman on formal occasions but also by giving us her constant practical support, both in stimulating and maintaining parliamentary interest in issues affecting autistic people and also in tapping sources of financial help.

One of our main preoccupations during our first two years was to increase our membership in order to become a credible pressure group. We also needed substantial financial resources if we were to transmute our project from a document into a reality. Publicity seemed to be the best means of achieving these aims so one of our members, Ann Morton, arranged an interview with the editor of the "Evening News" who was a personal friend of hers. The result was a 3-column feature article written by Colin Frame entitled "Children in Chains" which, accompanied by pictures of two of the children, appeared in the issue of 9 November 1962. Its text included a description of autism, and a number of case histories, and ended with this impassioned appeal, "A newly-formed Society for Autistic Children has set to work to awaken the nation to the claims of these sad, lost little souls .... It is easy to feel pity for the child physically crippled ... Can't we feel pity too for the baby whose mind is locked? And urge, by weight of public opinion, that the nation should provide the keys that will, in the light of today's knowledge, unlock it?" The nation did very little, but the article resulted in our being deluged by incoming letters and phone calls from parents needing help, to which we responded with a torrent of outgoing letters and phone calls communicating our own experience and information gathered through correspondence with other parents. In other words, we found ourselves running a full-time information and advisory service before the year was out.

All this activity required an office and the back room of my house, which gradually filled with filing cabinets, tables and second-hand typewriters, served this purpose for the next four and a half years. For the first two years of so the "staff" consisted of myself (I became General Secretary in April 1962) and one voluntary helper. My first helper was Diana Seligmann, a parent of an autistic girl, and we worked, using our own portable typewriters and stationery donated form various sources, during any hours we could snatch during the day and from 8.00 pm until midnight.

It is fortunate that by the end of 1964, we had devised a reasonable system of information storage and retrieval because just after Christmas we had to cope with the results of the first publicity campaign organised on our behalf by professional experts. With the help of one paid secretary and several parents working on a part-time basis, I sent out up to a 100 letters a day. The paradox of it all was that although we increased our membership from 63 in June 1962 to several hundred by 1964, practically no donations came in. I felt that as we could supply only advice and information to parents who were desperate for help in the practical form of advocacy, diagnosis and education for their children, our publicity was a sort of confidence trick. Parents turned to us for help and all we could do was to give them some advice and tell them to help themselves.

I do not wish to give the impression that all the work of the Society was taking place in the office as this was far from the case. It was characteristic of our Society from the very beginning that many parent members were working on its behalf from their own offices or their own homes. Peggie Everard was recording parents' experiences of diagnosis and developing our register of schools and classes which would admit autistic children. She was also acting as an informal counsellor for parents in the management of their children. Lorna Wing was taking a leading role in establishing our policy on services for our children, developing professional contacts, writing and speaking on the nature of the handicap and laying the foundations for our Society's fine reputation among all those whose professional expertise could make a contribution to the welfare of autistic people. Michael Baron set up a tutorial class in his own home for autistic children and persuaded the Local Authorities to pay the fees. He also took care of all the legal aspects of the Society's organisation and, in due course, negotiated the purchase of buildings and supervised their adaptation for our first school. And there were many more, among them the Area Organisers working to recruit members and to persuade sometimes indifferent or obstructive Local Authorities of the needs of our children. There is a roll of honour of many who are now "upon another shore and in a greater light", among them, Michael Carter, Tony Hammond, Alan Pickard, Philip White, Inge Wakehurst and my dear friend Sheila Skeffington to whom so many present and future parents owe so much. The Society, with all it has accomplished, is their memorial. Almost all of us had our children living at home so that at one time or another we all had the experience of being tied up on the telephone trying to help another parent with their problems while our own autistic child was either wrecking the furniture or slowly cooling in the bath.

I should also not wish to give the impression that we did not find enjoyment as well as exhaustion from what we were doing. In the first place, we forged life-long friendships and shared the exhiliration that comes from pioneering new ventures. We also shared our practical experiences with our children and sick jokes which only we could appreciate - "we put him down for Ealing at birth".

Our decision to found a school of some kind was the chief factor which gave our Society momentum from the very beginning. However, it took some time for our ideas to evolve. There was no existing model in this country of a full-time school exclusively for autistic children. No one seemed to be thinking of specialised education for them beyond primary school age, and because the handicap was believed to be psychogenic in origin, the approach generally accepted for the teaching of our children was - with a few notable exceptions - child-led and permissive. Our "Project and Policy" document, drafted early in the history of the Society, set out a plan for a centre which was more like a hospital unit than a school, as it was to be under the direction of a psychiatrist. Our conviction that the way to approach our children through specialised teaching methods in a structured environment developed as we witnessed the success of Sybil Elgar's class in St John's Wood, and we therefore invited her to found our first school.

Sybil's class began with my son whom I sent to her, having failed to find any other parents who were willing to take up her offer to teach autistic children. Joseph was already attending a class in the morning and psychoanalysis in the afternoon, but he was still almost unmanageable, certainly by me. I warned Sybil when she agreed to take him that she should draw the curtains in her schoolroom to protect the windows. This she did and he knocked out all the lights so that they were in total darkness. Although she tried to persuade him to use her Montessori materials, he threw them all over the floor and tore up everything that he could get his hands on. After a fortnight, she wrote in her report "there is nothing I can do for this little boy". Before giving up, however, she decided to introduce a structured approach, controlling Joe by physically holding him if necessary, and giving him clear, simple instructions. He began to improve both in behaviour and comprehension and to the great joy of us both, he began to talk. Other parents, hearing of her success, asked Sybil to teach their children; the class became full-time and the Local Authorities were persuaded to pay the fees. Requests for admission outnumbered the places available before Sybil left St John's Wood.

I have always said that in order to start a school for autistic children you need one first class teacher and one dedicated parent with a head for figures - in the case of the Ealing School, these were Sybil Elgar and Michael Baron. Michael arranged for the purchase of two buildings in Florence Road, Ealing, with finance from a mortgage and from a generous grant from the Spastics Society through the Sembal Trust. The school, which opened in 1965 as the Society School for Autistic Children (later renamed the Sybil Elgar School) soon gained an international reputation as an example of how autistic children should be taught. It was Sybil, because of the many applicants she now had to turn away, who suggested that we found an additional school. Having seen what one first-class teacher and one dedicated parent could do, I thought of Wendy Landman (now Brown) and Sheila Skeffington, whose son she was teaching. Together they founded our school in Gravesend, which opened shortly after I had ceased to be the General Secretary of the Society.

In 1966, we became the National Society for Autistic Children and in 1967 the generous grant from the Carnegie United Kingdom trust, arranged for us by Lady Elliot, enabled us to move our offices to 1A Golders Green Road.

When I left the Society's offices, Sybil was already preparing to become a pioneer yet again, as she was giving thought to the establishment of a residential community for those children who would shortly be leaving the Society School. In 1974 the community was founded by Sybil and by parents of children at the school who had formed themselves into the Ealing Autistic Trust and raised the money to buy Somerset Court. This they did by raising second mortgages on their own homes, cashing in insurance policies and donating from their own personal resources as well as raising money from the public.

Throughout the history of our Society, we have urged that autistic children be diagnosed as a way of triggering off a whole range of activities on their behalf from advice to parents in the management of their children to directing them towards appropriate specialised care and education. I remember how, in the early days of the Society, we would recite like a litany the nine points of "The Schizophrenic Syndrome in Childhood" published in the British Medical Journal in April 1961; we also made every effort to direct parents towards clinics or hospitals where we knew their children could be seen by knowledgeable specialists. Despite our 25 years, diagnosis remains a major problem. Since the 1960s, the syndrome has become better known and understood but it is not only because diagnosis has become more comprehensive that the majority of our children remain undiagnosed. Following the 1981 Education Act, there has been an unwillingness to 'label' our children, thus depriving them of an opportunity for the specialised education they need. Problems also arise because autism is not an easy handicap to recognise or understand. How many of us are still brought up short by the workings of the minds of our children?

In deciding to include among our objectives the foundation of schools and of day and residential centres for adults, the Society has commanded a place as the leading authority on all aspects of the care and education of autistic people. With our affiliated Societies, we have established 15 schools which provide over half of the school places in this country specifically for autistic children. Although, unlike 25 years ago, all our children have the right to education, the Education Act of 1981 has not worked to their advantage. The majority of our children require education specially designed for their needs and although a small minority of them can be integrated into schools for normal children, "integration" for the majority means placing them in existing schools for those with mild or severe learning difficulties without the resources for specialised teaching which they need. The pressure for specialised school places for our children continues, particularly for those who represent the most severe behaviour problems, who are now the ones most frequently referred to our schools. All of our Society schools, with the exception of Broomhayes, have been founded as the result of the work of one or two dedicated parents, often with the cooperation of a professional. If we are to found new schools in the future, this will undoubtedly be the pattern. Some 34 education authorities provide specialised school places for autistic children - the Inner London Education Authority has the best record - but will they have the incentive, and the resources, to provide them in sufficient numbers? Despite the 1981 Education Act, our Society must continue to exert pressure on them to do so.

As has the Spastics Society, we have discovered that the greatest unmet need is the provison of services for adults. At present there are only eight specialised places provided by the public sector for autistic adults, whereas our Society, with its affiliated bodies is providing well over 200 places. The need for specialised services for autistic adults (hostels, workshops residential communities) is so enormous that it is difficult to see how it can be met only by the efforts of a small Society like ours. No doubt the pattern which has evolved in the past will continue - new services will be established by the work of a dedicated minority of parents with the advice and support of the Society. It would be gratifying to believe that these efforts could come about in partnership with local social services departments.

Another problem we face and will continue to face is that of "challenging behaviour", both in our establishments and as it affects parents. Now that the most severely disturbed autistic children and adults are being referred to our establishments, The Helen Allison School, ably assisted by other experienced professionals, has issued a working document for the Society on the use of sanctions by staff caring for autistic children and adults. The problem of violent behaviour by a significant minority of our children will remain with us for the forseeable future. Some people are now suggesting that in some cases the violent behaviour is a pathology overlying their autism and perhaps we should be pressing for special hospital units to be set up for the care and management of such people as their problems require medical and psychological expertise which cannot be provided by the Society.

There is much for the Society to do in developing the services it provides. I hope we can see the development of a visiting scheme which can ensure that after parents' deaths their children's welfare will be independently monitored by people who know about autism and its problems. Secondly, there is a need for a comprehensive advocacy service which can help parent members through all the crisis points of their children's lives from diagnosis, through educational placement and appropriate placement as adults. The need is particularly apparent in the minefield of the "statementing" procedure, as has been clearly shown by the research findings of the Spastics Society published by their Centre for the Study of Integration in Education. Advocacy services will be difficult to establish and maintain, but the Society with all the expertise it has built up in its Central Office is, I believe, equal to the task.

As it has during the past 25 years and as, I am assured the Spastics Society does, the Society will continue to derive its main motive power from parents. This is not to underestimate in any way the value of our professional staff both in our Office and in our establishments. We are infinitely grateful to them for putting themselves at risk both physically and professionally, as they so often need to do in a field as complicated and challenging as autism. But we need to be sure that we foster and encourage the talents of younger parents so that they may take over the future leadership of the Society. We also need to maintain - as we successfully do now - parent partnership in the management of all our establishments, and to be vigilant in helping parents retain their ties with their children. This is particularly important with autistic adults, in respect of whom we parents have no legal rights whatsoever. I would wish that all adult establishments, both those run by the Society and any founded by local social services in the future, would foster and encourage parental involvement. Those parents who wish to buy their children's clothes should be enabled to do so; and they should be consulted on matters concerning their children's personal, medical, and dental care, and their work experience. All adult communities should make every effort to assist parents who wish to have their children on home visits by providing escorts and helping with transport. It is important to remember that after all, staff move to other jobs, whereas parents and families provide the most stable and long-lasting personal relationships that our children will ever have. The Society and its establishments will soon need to consider how to handle the problems of bereavement, which some of our children have already had to face.

I have called this talk "Perspective on a Puzzle Piece" - the logo of the Society, and I therefore should give a brief history of it. It was designed by a parent member of the Executive Committee, Gerald Gasson, and the minutes of the Executive Meeting of 14 February 1963 read: "The Committee decided that the symbol of the Society should be the puzzle as this did not look like any other commercial or charitable one as far as they could discover". It first appeared on our stationery and then on our Newsletter in April 1963. Our Society was the first Autistic Society in the world and our puzzle piece has, as far as I know, been adopted by all the autistic societies which have followed, many of which in their early days turned to us for information and advice.

The puzzle piece is so effective because it tells us something about autism: our children are handicapped by a puzzling condition; this isolates them from normal human contact and therefore they do not 'fit in'. The suggestion of a weeping child is a reminder that autistic people do indeed suffer from their handicap.

If, in the future, we can invest in our Society even more thought, effort and commitment, our puzzle piece will, at least in this country, become no longer just a logo on a letterhead but a symbol of hope for autistic people and their families.