
A Journey of Hope

The development of a voluntary agency's services for intellectually handicapped children

Alan Kendall

*Divisional Director of the North West Division of Dr. Barnardo's, based in Liverpool, U.K.
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RESUME

This paper traces the development of services to intellectually handicapped children and their families provided by Dr. Barnardo's North West Division in the U.K.

It has been a journey with and for the families and children. The milestones and lessons of the journey are described. It is a journey with still some way to go. It is a journey of hope — hope for better things for them now and in the future.

INTRODUCTION

Barnardo's, the largest child care agency in the U.K., was founded over 100 years ago by Thomas John Barnardo. As a medical student in London, Barnardo saw the sad plight of orphaned and destitute children living in the most appalling circumstances. He began to help them by developing residential and other services which eventually spread across the nation. He was always concerned for handicapped, sick and incurable children and opened a number of homes and a hospital particularly for their care. By the time of his death in 1906 he had cared for over 6,000 children and had helped over 250,000 others, and had developed a network of residential homes providing services of all kinds.

After his death the organisation he developed, now administered by a lay council, continued the work he had begun.

Barnardo's from its beginning, like most voluntary agencies, had to be prepared to respond to the changing needs of the day. In the U.K. these needs have changed as the welfare state developed more and more social provision, especially in the field of child care and the support of the family.

Following a major examination of its role and structure in the late 1960's Barnardo's decided that its work in the future lay in providing child care services of a specialist kind in particular areas of the country where the need was felt to be the greatest. One of these areas was the north west of England and a divisional office was set up in Liverpool. A review of the services in the north west area in the early 1970's revealed that a major area of social need was in providing care for intellectually handicapped children. As in most areas of the country, the main service then was a hospital based one, and there was a need to look to providing different types of community provision. Barnardo's decided to commit a good deal of its resources in the north west to caring for intellectually handicapped children and their families.

PRESENT SERVICES

The services that the north west division provides to intellectually handicapped children

and their families makes up about 2/3rds of our total work. There are 4 major groups of services. The division runs 6 residential projects which are for long stay, respite care and holiday care. Through its 4 (soon to be 5) family support projects, over 400 families in the north west are given support through a wide variety of support services. The division's two fostering projects are supporting over 75 placements of intellectually handicapped children with substitute families. The fourth service is new. It is an advocacy service aimed at assisting those families who have received help through the family support services.

These services didn't happen by accident. One thing led to another. That's the journey. A journey that at times has excited us, saddened us, worn us out and made us feel enormously privileged.

RESIDENTIAL SERVICES

When we started to look at providing services in the early 1970's, setting up residential services was a natural starting point for us. We had a long tradition of providing residential care to non-handicapped children.

In co-operation with local authorities our first decision was to build new residential projects in Liverpool and Salford. These units were to provide accommodation for 18 intellectually handicapped children, each to be built in 3 semi-autonomous living units accommodating 6 children. Delays were considerable, but unavoidable. The Liverpool home was opened in 1978 and the Salford one in 1979.

But the pressure on us in the early 1970's to provide residential places for intellectually handicapped children was enormous. So we looked to the only provision we had — our already existing children's home accommodation. From 1970 onwards we began admitting intellectually handicapped children and placing them in our ordinary children's homes, where the majority of children were not handicapped. Here, intellectually handicapped children grew up sharing their lives with other non-handicapped children. That policy of integration lasted for over 10 years. It came to an end when the demand for residential care for non-handicapped children virtually ceased. All our residential services are now exclusively for intellectually handicapped children.

Those children who came to live with us in the early days of our development did so much for us. They taught us hope. They showed us that given a fair chance they could develop beyond anything that had been expected of them. They spurred us on to develop more services.

In 1975 two significant things happened:

We came under the influence of the services of the Eastern Nebraska Community Office of

Retardation (ENCOR) in the U.S.A., following a visit from two of their staff members to the division. I was able later in the year to visit the United States and see their work.

The second important development of 1975 was the opening of a small residential service in rented accommodation in Skelmersdale, Lancashire. This was to be for 6 intellectually handicapped children. I was so impressed with the work of ENCOR, especially the development of their 'core and cluster' type residential services that we developed such a model at Skelmersdale. That was the first of its kind in the U.K. It now consists of 4 houses, each providing a home to 3 intellectually handicapped children.

We developed the experiences at Skelmersdale in the last residential project we started in 1983 — the Croxteth Park Project. This is a small residential project providing care to 8 profoundly intellectually handicapped children, who also have accompanying serious medical difficulties. These 8 children are cared for in 4 bungalows, 2 children to a bungalow. This project has been supported by the Department of Health and Social Security, as an experimental project to assess whether children with such profound handicaps and medical difficulties can be cared for in community settings. We believe that we have shown that they can and that they develop superbly well.

A chance happening in 1972 had a very significant effect on the whole service development of the division. Our staff took part in a survey of families in Liverpool. One of the findings indicated that the families interviewed found it very difficult to have a holiday, many never having done so for over 6 years. Some families had never had a break from their intellectually handicapped son/daughter.

At that time we were looking at the possibility of an alternative use for a children's home we had at Barrows Green in Cumbria. This large house, situated in beautiful grounds, is located in a very popular holiday area of the north west of England. We decided to change its function so that we would be able to provide holidays for intellectually handicapped children living at home. This we hoped would have a two-fold benefit: to the families by providing a short period of relief, and to the children by providing many new, exciting and stimulating experiences. The project is fun-orientated and children have the opportunity to take part in the many activities which are provided including camping, boating, horse riding and being with and playing with a multitude of animals. Over the years it has provided holidays for over 1,500 young people.

Barrows Green did one other important thing. It introduced us in a big way to families. We were humbled by what we found.



FAMILY SUPPORT SERVICES

From our contact at Barrows Green we quickly realised that many families were up against enormous odds. For many it was the first form of practical help, relief and assistance they had received. But we were only involved with their son or daughter for one or two weeks in the year. They needed so much more.

We wanted to develop a service to families that would be available to all families with an intellectually handicapped child in a well-defined and restricted geographical area. The services we would provide would be available to as many families as wished to be involved.

With the support and encouragement of Lancashire County Council Social Services Department we decided to base the first family support service in the Chorley area of Lancashire. So began in 1975 a real partnership with parents. Our first move was to contact as many families as we could where there was a known child with an intellectual handicap. Following a meeting of interested parents we then visited them all and talked to them on an individual basis about our hopes for the project, but more importantly, to find out what they wanted and what they felt should be provided. The project now provides a wide range of support services to families including holiday playschemes, parent workshops, toy library, respite care, information centre, developmental activity weekends and the services of volunteers. But underpinning all these services is the most important keystone — regular visits by our social workers to the families. It is through this regular visiting that we have gained the trust and confidence of families and have been able to keep closely in touch with their needs and their wishes about how the services should be developed in the future.

Following the success of the Chorley project, similar services were developed in Salford, Liverpool and Chester.

A fifth project in the South Ribble district of Lancashire will be started later this year. At the present time the division is helping over 400 families in the north west through these projects. When the South Ribble project gets under way that number will increase to 500.

FOSTERING SERVICES

Almost from the beginning of this journey we believed that no matter how good our residential services were it would be better for our children if we could place them with substitute families. When I visited the United States in 1975 I was privileged to visit the Macomb-Oakland Regional Center in Mount Clemens, Michigan. There I saw a wonderful fostering scheme where very handicapped young people and people with severe behaviour difficulties

were living happily and comfortably as part of a family. I revisited the programme in 1977 and 1979, and had those initial views very much reinforced.

I was determined that we would develop a similar scheme.

In 1979 we set up our first fostering project. We appointed a project leader and 3 social workers. We had identified several intellectually handicapped children in our residential service for whom we believed a family placement would be in their best interests.

The first placements were made in 1980. So began a most pleasant, stimulating and delightful period in the division's journey. In 1986 a second project was set up. We wanted to increase the overall numbers in placement and also to increase the rate at which placements were being made. We have now placed 75 children and young people. The oldest person in placement is 25, and 16 are aged over 20. Over the years we have sadly had 3 deaths and 2 breakdowns. The children placed have in the main been from our own residential services. But increasingly we are placing children from local authority and other voluntary residential services, and direct from hospitals. The children and young people placed with families have covered the widest range of needs and difficulties — from those who are medically fragile to those with serious behaviour difficulties. It would be hard to begin to describe the joy and pride we feel in our foster families, and in the children. The families are truly remarkable. And so are the children.

There is no doubt that the families have given an enormous amount to the young people placed with them. But it hasn't been one-way traffic. The young people in return have given as much back to the families as they have taken from them. The foster families would be the first to say that their lives have been enriched beyond measure by the addition of their foster son or daughter.

ADVOCACY SERVICE

This is the latest addition to the division's services and started in 1987. One of the most frightening concerns to any parent who has an intellectually disabled child is — "What will happen to my son or daughter when I die?"

The families we were involved with through our family support projects were saying this clearly to us. What they feared most was the fact that when they were no longer around, their sons and daughters would lose the best advocate they had. Who would look to the interests of their sons and daughters? Who would ensure that they were getting the services and the benefits to which they were entitled? Who would make sure that their wishes were being

respected? Who would ensure that they were not being abused? They turned to us for help.

Although we were a children's agency we were nevertheless very concerned indeed about the position of our families. We decided to offer a service which had two components. The first would be to act as trustees under the terms of a parent's Will, and administer any trust fund set up by the parent in favour of their son or daughter. The second service we would offer would be one of advocate. We would do the very best we could to ensure that their sons and daughters were getting those things to which they were entitled, and that their wishes were being respected.

This service is now just getting under way. We have a team of 3 social workers. Families are showing considerable enthusiasm for the service. It is a new venture in so many ways for us. Not the least being that we are making commitments and decisions for Barnardo's for perhaps the next 40, 50 or 60 years.

LESSONS

We have learnt so much over the years that they could be the subject of a paper in their own right. Maybe here I could offer some general themes.

Over-riding almost everything else is the lesson that for intellectually handicapped young people and their families wonderful things can and do happen. And they can be made to happen.

They happen when staff and agencies stay close to the people who use their services. When they listen, watch, consult and share with the people who use their services. They happen when there is love around. They happen because by being close to your people you know what services are needed and how to provide them.

They happen when staff and agencies really do believe in themselves — that they can and do change things. They happen when staff and agencies really believe in the people they are serving.

THE JOURNEY CONTINUES . . .

I hope our journey will be a long one yet. There will be more problems, difficulties, setbacks, hurts and heartaches as there have been in the past. But it will be a journey where we will continue to meet and work alongside fine people — wonderful families, young people and children. They, as others in the past, will continue to inspire us and drive us on. They will be people who will continue to bring us joy and fulfillment. Families, young people and children who it is a delight and a privilege to know and work with.

And that is something we should repay with interest every day.