

# The early years of the Down's Syndrome Association

by Shirley Quemby

Before our much-wanted first child, Roger, was born, in October 1971 (when I was over 30 and had already experienced miscarriages) I was aware I could give birth to what was then still called a 'mongol' baby. I had heard a speaker on Woman's Hour talking about teaching her own child before she began attending their village school.

Despite the general view that babies and children with Down's syndrome could not learn, I was determined to teach Roger everything that typical babies achieved, helped by local families with young children.

My brother lived nearby. Outside their daughter's school my sister-in-law met Felicity Stafford. Felicity's daughter Jenny, who was two and a half, had Down's syndrome. They had recently moved from Birmingham where they knew Rex Brinkworth, founder of the then Down's Babies Association (later to become the Down's Children's Association and today, the Down's Syndrome Association).

We obtained Rex's publications, which included advice on vitamins and minerals to combat low absorption, but more importantly, practical advice and ideas of ways to encourage Roger to develop his physical and cognitive skills. Rex gave us a programme of exercises and activities designed to encourage young babies and children with Down's syndrome to reach their full potential.

Rex's message, that babies with Down's syndrome could learn and develop well, contrary to the low expectations of the world in general, many medical professionals and even some parents, was hugely newsworthy at the time. Rex was on national TV; magazines published articles by Felicity; and I was interviewed on BBC Radio London.

We started the first Down's Babies Association branch in Cheam in June 1973 as there was no local support for new parents. Parents came from across South East England, officers were appointed. We held open days for families and a regular



*Roger pictured with his sisters, Oct 1975*

newsletter began. Isabel Gordon, a member of The National Council of Women in Epsom, joined us and ran the branch for ten years while our children were little. Regular talks were given by Isabel and Felicity to students, health visitors and other organisations.

Our daughter was born just before Roger's second birthday and he took great interest in teaching her. By the time his second sister was born, 17 months later, I was teaching Roger to read with flash cards. He progressed enthusiastically and his speech improved. Being the eldest, Roger enjoyed playing school teacher!

In February 1976 the BBC made a TV film for its Open Door series. A doctor and parent in Southend who were helping new parents with Rex's advice on early stimulation were in this film as were Felicity, Jenny and ourselves. Jenny was cheered ascending her school climbing frame!

Newsletters by Robert Stafford, Isabel Gordon and Elisabeth Blackwell (mother of Rebecca, born 1970) included invaluable ideas. Clear drawings filled the pages of every edition showing active babies and simple toys, providing

welcome advice to parents working alone at home. Each newsletter also included contact details of members who were ready to help any new parents seeking friendly advice or a local group.

For our half-yearly open meetings, school or church halls were hired by DBA volunteers. Speakers provided guidance on education, health and other aspects of developing independence, even how to teach the 'pincer grip'. Dr Janet Carr OBE, who had been researching a cohort of babies with Down's syndrome since 1964, advised on behaviour.

Members created smaller local parent groups to share this challenging - yet rewarding - childhood. Most groups were represented at branch committee meetings so the branch founders came to know parents across the south east leading to half-yearly meetings being set up in their areas.

Friends raised funds for postage, printing and hire of halls. Stalls were held at fêtes to publicise the Association and change the public's perceptions of children who had Down's syndrome. Although attitudes and language were slow to change, donations came in.

In 1975 an international Special Education Conference was held at Kent University. Our branch displayed a screen of photographs at the event and the delegates from Norway and Japan requested translations of Rex Brinkworth's ground-breaking work.

By 1978 the branch office had moved to The Old Rectory beside Carshalton Ponds. Committee meetings were held here for which Isabel wrote the minutes for ten years then I produced them until 2016.

Down's Children's Association meetings were held at the Quinborne Centre in Birmingham, led by Rex, who delivered detailed practical information for parents who wanted to support their child to develop. By 1978 more branches were founded, all spreading Rex's vital message and guidance; that babies and children with Down's syndrome could learn and, as Rex stressed, will go on learning.

Felicity's son was dyslexic. Jean Shergold, the teacher who helped him, then took an interest in Jenny and the children of other local members, concentrating on the needs of each one. When a child became bored, to maintain interest in practising for the lesson she would move the coloured pencil and paper to the floor - to add fun to the task! Probably the two



*Roger pictured with his sisters, Nov 1976*

lessons learnt by all parents, then and now, is to make learning fun and to teach visually as far as possible.

Jean continued to be involved with the branch. As children who had Down's syndrome were accepted into mainstream reception classes, we were called in to advise teachers. Jean and I gave talks during lunch breaks. We noted their problems then wrote the first information sheet for teachers incorporating advice to help the worried, sometimes even frightened, teachers who were going to have a child who had Down's syndrome in their class for the first time. It was published by the Down's Children's Association as a booklet, credited to myself and Jean.

An immense debt is owed to Rex Brinkworth MBE and his small team in Birmingham enhanced by Felicity Gresser (formerly Stafford) and her team in Cheam and DSA volunteers across the country.