
Introduction

We were a young couple living in London in 1965, when our fourth child, a boy we named Barry, was born. He was a sweet baby, always smiling, never crying but he developed very slowly and missed all the expected milestones. Our GP. told me, “you Mothers are always looking for something to worry about. You shouldn’t complain he is too good!” But Barry was too good and I knew something was wrong.

When he was twelve months old he developed a hernia and was admitted to Great Ormond Street Hospital for an operation, expecting to be discharged the next day, but at last the doctors there realised that something was amiss and started doing numerous tests and investigations to find out what was wrong.

They kept him in hospital for six weeks and eventually the Consultant solemnly announced – “Don’t worry, it’s not fatal. Just take him home and hope for the best!” There was no clear diagnosis, although the doctors said that the slow development was probably due to a virus infection, I had had early on in the pregnancy.

We went through several years with Barry suffering from bronchitis, constant running nose, slow development (he got his first tooth when he was 18 months old) and he never ever learned to chew properly. But with all the problems, he was a very beautiful and cute little boy, forever happy and sweet and beloved by everyone.

After several years and lots of medical appointments and research, we finally accepted Barry was what was then termed ‘mentally deficient.’ It was a terrible title for such a sweet baby but that was the terminology at that time. There was no cure or medicine that could reverse the condition, but we spent many, many long hours waiting in doctors’ surgeries and hospital corridors, seeking for a magic cure, hoping against hope that hope that a miracle would occur and Barry would eventually recover.

He struggled to speak clearly and refused to chew and seemed to spend most of his life on anti-biotics. When he was five years old a local psychologist made a quick assessment and announced decisively that Barry would never read or write and we should send

him to a local Council special school for mentally handicapped children. We visited the school but were horrified at the thought of our sweet little child spending his days there. The school had few facilities and did not provide more than a 'baby sitting' service and not a very good one at that.

When Barry was ten years old he could read a little and entranced everyone who met him with his gorgeous smile and with his head of curly blond hair and he melted everyone's heart. But there was very little progress and we were at a standstill as to how to proceed to educate him.

He had many physical problems and numerous operations. I have lost count of the number of times he was in hospital. He actually thrived on it and enjoyed it more each time. It was uncanny how quickly he learned symptoms of most illnesses and could describe in detail what ailed him and everyone else in the ward.

One day I borrowed a library book, aptly titled, "What to do with your Brain Injured Child." That book changed the direction of our lives. It was written by an American Doctor, Dr. Glenn Doman who described a method of stimulating the brain by a full time programme of exercises and a very effective educational system which had amazing results. We were entranced and did a lot of research to find out about this system, which was developed in Philadelphia, USA. This was the very first time we had seen any information on how we could possibly help our child and we made an appointment to take Barry to Philadelphia. There was a year long waiting list but just a few weeks later we were lucky to be given an earlier appointment as there was a cancellation.

Philadelphia

We went to America with great hopes and learned about this innovative treatment, called Patterning, which involved scores of volunteers working with Barry eight hours a day, seven days a week. It was a colossal undertaking, especially with other children to care for. We could not do this alone and needed a lot of help and one day I bravely knocked on the door of wonderful neighbour, and told her what we needed and why. She immediately offered to arrange teams of volunteers to come every day to do the program with Barry.

I wrote an article about Patterning which was printed in the local newspaper, letting people know about it, in the hope that people would come forward to help us. In those days, it took a lot of courage to publicise that you had a child with a disability. “Mental handicap,” as it was then called, was not something spoken about in polite society but I was happy to sign my name to the article as we needed help and the only way to get that help was to ask for it.

This was the start of a mammoth undertaking. We had great help from the local community, neighbours and friends and we transformed our home into a gymnasium and resource centre. There was an enormous outpouring of interest and in a few short weeks we had enough volunteers to start the programme in earnest.

Patterning

We had groups of three people, four times a day, so we were busy all day long with people coming and going and soon we had over one hundred volunteers a week. Barry loved all the attention and was the star of the district with lots of visitors popping in to see what was happening at the “circus.”

The basic programme was a patterning exercise with three people moving Barry’s arms and legs in a crawling action, on a padded table top. This took five minutes four times a day. In between was the most popular part, called SIR – Suspended Inverted Rotation, where Barry was strapped upside down on a pulley, attached by soft ankle straps, made to measure by a kind local suitcase manufacturer. It was intended to increase the blood supply to the brain since oxygen is carried round the body in the blood and increased oxygen to the brain improves intelligence and development.

We swung Barry upside down and round and round and once he got used to it, enjoyed the fun. Everyone had a good time and there was lots of laughter and singing and amazingly we managed to do the full programme most days. This SIR transformed our ‘gym’ and the neighbours’ children loved to come in to have a turn.

The rest of the programme was a series of exercises, rolling over, sensory integration, reading and an interesting intelligence

programme that kept us all busy. This daily programme took eight hours a day, every single day of the year. There was an enormous out-pouring of help and interest and numerous calls from people who heard about the programme, asking for information about it as they wanted to know if this system could help their own child.

We did a Reading Programme with Barry which was very effective and consisted of showing Barry flash cards quickly at every mealtime until he had a repertoire of several hundred words. At the same time our youngest child was still in his high chair and even though we didn't purposely try to teach him, he quickly started reading and got off to an amazing start and could read fluently by the time he was three.

We continued this programme for three years and Barry's physical strength improved enormously, he was no longer a weak little boy who fell over at the slightest shove. He developed strong muscles and lungs and looked the picture of health. The little boy, who doctors said would never read or write, learned to read quite well and had amazingly good general knowledge. Barry once said, "I wonder if the bees have already pollinated the roses." When I showed him a picture illustrating a story, he asked me, "Is it fiction or non-fiction?"

One day I was trying to tell him about the moon covering part of the sun, not thinking that he actually knew what I was talking about. I was amazed when he said, "Oh, you mean an eclipse!" And this was from a ten year old, whom a year previously, did not know what the word 'weather' meant.

We adapted the original programme we had learned about in Philadelphia and kept on refining it, with great success. We taught Barry about cars, insects, animals, birds, trees, maps, geography and whilst he was learning all this, our volunteers learnt too and we all had a great time with this educational programme. We became the 'experts' in London and taught the method to many others as well.

When Barry finished the three year programme he was accepted in a primary school even though he was older than the others. He was small and looked a few years younger than his actual age, so

the difference between him and the other children was not so noticeable. He made good progress academically and socially.

Long Treks

Barry was usually brought home by one of the teachers, but one day he missed his lift and did not arrive home. The school was closed and in those pre-mobile phone days, we could not reach his usual driver. We frantically telephoned the police, who told us to come into the Police station to report him as 'missing.' I was on the point of leaving the house and when Barry suddenly arrived! He had walked all the way home himself – a walk of about 2 hours.

Little did we know that that was the first of hundreds and hundreds of times where he went missing. As the years passed, Barry's disappearances became frequent events. He was often missing overnight, and for several days at a time. The longest time he was missing was ten days, during which time we were desperate with worry and did not know where to turn. I cannot count the nights I stood by the window looking out to see if he was arriving home.

During this time, after Barry finished the patterning program, he again deteriorated physically and was frequently ill. He was in and out of hospital many times and became very knowledgeable about medical matters and it was uncanny how he knew in detail symptoms of a variety of 'conditions.'

He had numerous operations and could describe to us in graphic detail the numerous heart attacks, amputations and deaths he 'observed' in the wards. He enjoyed every minute of it and we decided the best 'job' for him would be to be hospital porter transporting people to and from the operating theatre or to the mortuary!

Accident

When Barry was fifteen years old, he flew over his bike, landing flat on his stomach and came home in pain, looking pale and ill. He had ruptured his spleen and needed emergency surgery. He had a long difficult recuperation period during which time he needed high dosages of penicillin, to which he later became allergic and

suffered numerous attacks of unbearable itchiness and felt as if insects were crawling all over him.

Barry spent several long stretches in different hospitals, all in an effort to get to the bottom of his various problems. He had developed a variety of unusual fetishes and habits and we gradually realised that from being a sweet little child with a learning disability, his mental health issues became of paramount concern.

After that we searched for alternative options for Barry and during that period I was persuaded to allow him to take driving lessons. He had driving lessons for several years but eventually at the third driving test, he actually passed. He read and understood The Highway Code and it was a great celebration when he received his driving license. Remember, this was a boy whom the doctors had predicted would never read or write.

He had several cars, which he crashed one after the other, each time miraculously escaping injury. He even drove his brother in law in a London black taxi, which we had bought for him, all the way to Bangor, in Wales with their holiday luggage and miraculously arrived there and back in one piece. I personally was afraid of going with him in the car as on one occasion, he drove so close to a bus that the mirror right next to me was knocked off by the bus. I was so afraid that I never went out with him in the car again.

We began to look around for a 'job' for Barry and had the idea of him becoming a bread salesman. We applied for a grant and he received an Award of £1,000 from the Prince of Wales Trust for Innovation and Enterprise and we bought him an electric 'float.' He built up quite a successful business. We did the administration, keeping accounts & computerised the lists of orders and customers and kept track of deliveries.



Barry used to knock on neighbours doors asking if they wanted bread delivered each morning. They gave their orders and Barry bought the bread from a local baker. He collected the bread early in the morning and delivered it to the addresses on his list and then collected the money at the end of the week.

During these years, Barry still ran away frequently, and we often got irate telephone calls from people waiting for their bread delivery whilst Barry had parked the float, full of bread in a nearby street and gone off on a 'trip' that could last a few days. We were left with soothing unhappy customers, retrieving the bread and arranging for it to be delivered by a local mini-cab service! In spite of this the "business" grew but it was becoming increasingly difficult for Barry to manage the deliveries and after a few years the 'business' closed down. It could have been a successful enterprise and I wonder why no one else provides a bread delivery service.

Barry remains learning disabled and still has many difficulties, he now happily lives with his sister and her family and is well known and has many friends in the local community.

We are often asked whether it was worth all the effort we put into his education and development. The answer is a resounding YES. He can travel alone all around the city (and often does), he enjoys his life and has an amazing memory, remembering the names of each of the numerous doctors, dentists and therapist who have treated him over the years.

But most of all, the information and experience gained from educating him helped me to help hundreds of other children. I

have made educational programmes for numerous children, and later with the help of one of our other sons we opened The National Light & Sound Therapy Centre where we continue to treat and help children with autism and a range of other difficulties.

We also set up a Registered Charity for children and adults with learning disabilities which developed from a small parent group into a large organisation which now manages two Registered Residential Homes and several Supported Housing projects. The Charity expanded and now also runs a Day Centre in North London and helps many hundreds of children and adults each year.

From the experience gained over the years, I have put together some suggestions and recommendations for parents of Special Needs children. You will find some of these on our Blog on our website. Some of the ideas may be useful for your own child or for teachers. I hope others will benefit from the knowledge I have gathered over the last twenty five years.

The world has moved on in that time, and it is no longer a stigma to have a child with a disability but I remain convinced that parents are able to do a great deal to help their child by constant repetition, a regulated program and with love and laughter.

The National Light & Sound Therapy Centre

During the years when we were busy with the Patterning Programme and later the Charity, one of our elder sons became very interested in researching therapies and medical interventions that could help his brother and other children with disabilities. Entirely self-taught, he became quite an expert and people used to come to him for advice in a range of health and medical issues.

In 1992, he heard about a new treatment called Auditory Integration Training (AIT), developed by Dr. Guy Berard from Annecy, France. It just so happened that his wife is French and off she went to learn about this innovative two week treatment that was reported as having significant impact on children on the autistic spectrum and children with speech and communication difficulties.

Very soon after we received a telephone call from a journalist, Colin Brennan, who had an autistic son and having heard about Dr. Berard's treatment, decided to find out more about it and interviewed Dr. Berard in preparation for an article that had been commissioned by the News of the World Sunday Magazine. He had read the book "The miracle of Georgie" written about the miraculous cure of a young American girl called Georgie and told her story very beautifully in a two page colour spread in the middle of the magazine. Colin asked Dr. Berard if he could give him a contact in London, who would be able to answer any questions about the treatment that he was expecting to receive. Dr. Berard told him that he had just trained a young French lady who lived in London and gave him our telephone number. We agreed that our telephone number should appear at the end of the article, anticipating a few enquiries about the treatment. In the event, we received over one thousand calls within the first six weeks. We were totally unprepared but saw the great potential to help many children. We had a trained therapist, we had bought Dr. Berard's audiokinotron and all the equipment we needed and we had over a thousand potential clients.

We rented a few rooms nearby and started producing information packs to send out to the many enquirers and within a few weeks began treating children with AIT. We called ourselves the Light & Sound Therapy Centre and became a Limited Company in 1992. As children began arriving from all over the United Kingdom we renamed the Centre, the National Light & Sound Therapy Centre. Children came from all over the UK and from all over the world. We could have called ourselves the International Light & Sound Therapy Centre, but decided not to change the name again.

We followed Dr. Berard's methods word for word, and our results matched his exactly. Out of one hundred children approximately a quarter made no progress, another quarter had a minor improvement, a further quarter made good progress and the remaining children made major improvements. This was a major breakthrough, particularly in children who were on the autistic spectrum and were non-verbal.

During the first three years we researched and varied the programme in an effort to improve on Dr. Berard's results. We felt that 25% major improvement wasn't good enough and we aimed to

give children a better chance. We firstly introduced Light Therapy which enhanced the original AIT and within a few short months we saw that the success rate had improved. We then added a third therapy we called Sound Modulation, basing the therapy on the work of Dr. Tomatis, another French ear, nose and throat specialist who used slightly different methods than Dr. Berard. Dr. Tomatis had noted that the audiograms of people with good voices had a certain pattern that could be recognised as being on a curve. We used this information to change the way the sounds from the Kinetron are heard and we immediately saw that the rate of success improved again, in particular with regard to speech. This was very useful and we decided to continue to use the combination of these three treatments and called it AIT PLUS. We had successfully increased the success rate to 46-47% which was a great advance on the original figures. We told Dr. Berard about this and he was very supportive of our work. To our knowledge no one else uses this combined treatment and we were very excited to have developed the original therapy so successfully.

As the years went by, we expanded the Centre and sent two other staff members to France to be trained by Dr. Berard. Now in 2016 we have treated well over one thousand children and continue to offer AIT PLUS, educational advice and support and behaviour management techniques for parents of children with a wide range of difficulties.

This booklet is an effort to put together our recommendations and suggestions and we hope it will benefit you and your child. We are available by email on info@lightandsound.org.uk if you have any queries or comments and we would love to hear if any of our ideas help your child.

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