The Winston Churchill Memorial Trust
Fellowship Report
Report By Anna Mae HendricK 2005

Subject title: Inclusion of children and adults within Mainstream education and the workplace

Report By Anna Mae HendricK
This report outlines the writer’s travels to Japan and America exploring best practise in Autism. The fellowship awarded the writer two weeks in Japan and two weeks in America. Due to circumstances the Winston Churchill Memorial Trust kindly allowed them to be split over a period of time.

Before elaborating on my travels the reader might find it helpful to know more about the writer and why this particular subject was chosen.

**The Writer**
My name is Anna Mae Hendrick and live in Helensburgh Scotland with my two children Christopher and Shaun; both my sons can best be described as rascals who just happen to have severe autism.

![Shaun and Christopher](image)

**Shaun and Christopher**

They are non-verbal and have many other difficulties that they face on a daily basis. Shortly after their diagnosis it became very apparent to me that there were no resources locally that they could access or indeed assist myself. As a result the Jigsaw Children’s Committee was formed. Initially it started as a small summer play scheme for children affected by disability but as the demand grew it developed and now provides support for approximately 50 children and their families. Areas of support are: -

- Short breaks throughout all school holidays and weekends
- After school clubs
- Sibling support
- Advocacy
- Training for children/parents staff
- Promoting awareness for inclusion
- Job opportunities
- Holidays
- Emergency respite
● Raising awareness

Funding is received through three main funders i.e.; Big Lottery Fund, BBC Children in need and the Local Authority. Other areas of support are through Local Community initiatives and the service users.

Funding is always an issue with any voluntary organisation who are always on the lookout for alternative supports. It was a result of a search of possible supporters to the group that I came across the Winston Churchill foundation. I quickly realised that this was something different and dreamed of the possibility of being accepted and being offered the lifetime opportunity of exploring alternatives to support the children and adults affected by autism within our local community. My dream was to look at best practises adopted by other countries. in particular what happens after eighteen when children leave school and how can they be best prepared especially those children affected by autism.

My application was accepted to travel to Japan and America and what a journey I have had.

Japan
My Journey November 2005

Keyaki-no-Sato

In 1985, the Welfare Corporation Keyaki-no-Sato was established at Kawagoe City in Saitama Prefecture 35 kilometres northwest of Tokyo. It was only the second such facility in Japan to specialize in caring for adults with autism. Founders of the corporation included Mrs. Hatsue Suda and 21 other parents of children with autism. Mrs. Suda is the current President of Keyaki-no-Sato and Vice President of the Autism Society of Japan. The first "Hatsukari-no-ie" (Hatsukari Home) was opened in 1985 to serve 50 persons with autism. Today, the organization has grown to include 8 facilities ranging from a "welfare" factory, a sheltered workshop, 4 group homes and the Saitama Support Centre for Persons with Autism and Developmental Disabilities. At present 90% of the 95 adults who are supported in these facilities have been diagnosed with autism.

Despite the great need for support services for adults with autism who face challenges in daily living, it took 7 years to incorporate Keyaki-no-Sato. The founders faced strong opposition from the local community. People were concerned that the proposed activities of Keyaki-no-Sato would jeopardize the area and decrease land values. The opposition movement received extensive coverage from the mass media. As a result, the local community and Japanese society at large had the opportunity to confront attitudes about
disability and come to terms with the rights of people with disabilities.

**Principles, Activities and Development of Keyaki-no-Sato**

The following principles guide the service providers in their aim to support adults with autism in the community:

1. Ensure that persons with autism live with human dignity, a sense of responsibility and with the opportunity to experience a range of life experiences.
2. Explore ways to support independent living in the local community, regardless of the severity of the disability.
3. View work as a core activity to promote participation in the community.
4. Promote the value of "independence as a group" in a way that persons with milder impairments help those with more severe impairments to work, cooperate and attain a measure of independence.

Support workers at Keyaki-no-Sato have been applying the principles successfully since Hatsukari-no-ie was opened in 1985. The original group of 6 or 7 adults with autism and 2 to 3 support staff found work cleaning markets, loading soft drinks in machines at factories, separating empty cans from other scrap metal at recycling companies, making miniature trains and making wooden carriers at a pallet manufacturing company.

Keyaki-no-Sato's innovative model of job coaching was in operation one year prior to the similar system established in the United States. The model enabled members of the community to understand autism while adults with autism learned the social rules.

My visit to Keyato was absolutely fascinating. I was met by Mrs Abe the Executive director and founder. A full board meeting had been convened with the other executives and I spent time speaking to them about the foundation, its hopes dreams aspirations and difficulties. They receive many visitors but surprisingly no one had ever visited them from Great Britain. Mrs Abe spoke warmly about her son and the difficulties they faced in his younger days. The business is similar to that of a social enterprise where all profits from the business is put back in to supporting the community/the charity.

The pallet factory was of special interest where I was warmly received with an impromptu highland fling. Each worker is assigned a task that is suited to there abilities. The factory is very industrious and immaculately clean. The workers are
employed at all stages of the making of the pallets. I was very careful in my observations to ensure I did not distract anyone from their tasks especially in the use of nail guns!!

As stated it took years to achieve the success of Keyaki. Each family cold called at least 3 companies each day over a two-year period. It also took personal commitment and each family donated the equivalent of £100,000.00 to make this project possible. The recycling and pottery enterprises are a tremendous success. The Centre also distributes its pottery to various outlets, the writer being one of them. I was particularly fascinated with the bakery where there was one support worker assigned to six young men and yet it ran like clockwork. The Centre has its own bakery shop within the village where I was treated to some of their wares. I found the centre awe inspiring and at a loss as to why it has not been visited before. Keyaki is an inspiration in itself. If there is any criticism or concern is that is some lack of thought for the future. The children or young men that started the project are now some years older and will continue to age. There seems to be very few signs of younger members joining the project. When I put this to Mrs Abe and others they were very reluctant to discuss preferring to focus on the here and now

My other slight concern where the living arrangements. All of which were very comfortable but they’re being no other peer group other than autism, which, in the writer’s opinion, could be somewhat restrictive.
My overall impression of Keyaki was a place of joy. The joy and peace was tangible. I could feel the respect everyone had for each other and visibly witnessed the support to help less able persons to be productive. The foreman was very diligent in his duties and took great delight in telling me about the social aspect inasmuch at the end of the week those wishing to all went out for a well earned drink. Pints were mentioned but I am sure this had been well rehearsed for his Scottish visitor as was the fling.

**Musashino-Higashi**

**Outline**
A Mrs Kiyo Kitahara founded Musashino-Higashi in 1964
The school consists of kindergartens, an elementary school, a junior high school and a specialised high school. The schools education system focuses on the integration of autistic and regular students. At present the total enrolment is 1710 of which 439 (26%) are autistic. Staff total 221 including 10 based at the Boston Higashi School Massachusetts, which was established as a branch in 1987. Musashino-Higashi is a private school.

Mrs Kitahara developed unique methods of teaching children affected by autism known as daily life therapy and mixed education, which are highly praised throughout the world.

The ultimate goal of daily life therapy is to promote social independence. For this goal to be reached, the individuality of each child must be thoroughly understood through observations of their daily development. Precisely planned training is directed toward overcoming developmental deficiencies. They must try to attain an independent life through their own efforts to overcome obstacles. A very structured programme.

My visit was at the time of the schools festival week and it gave me the opportunity to observe the children in a different setting. It also provided an opportunity to meet many parents. Mr Takamatsu, former Program Director of Boston Higashi now director of Program development at Musashino was my main contact and was extremely helpful.

The purpose of my visit was to establish their links with the community and how the daily life therapy helped the children prepare for adulthood and the workplace.
What I found was an acceptance by the children of each other and a Japanese sale of work (Parents association) that would shame any school in Britain.
The children presented a fashion show with some short stories. The finale concentrated on weddings and proposals. At times it was very difficult to determine who had autism and who did not. But it was moving to watch the children support the children who were somewhat unsure of what was going on. On speaking to the children throughout my visit I clearly got the impression from them that they saw nothing different with their school. A point that was repeated often that there was a waiting list of typical children wishing to access the schools educational programme. I was assured that any child with autism would be accepted so long as they were able to pay the school fees. There were no systems in place to help families who could not afford to pay the fees. The parents of the children had organised a sale of work and words fail me as to the extent of their sale. Each classroom was brimming with donations of the highest quality. One classroom could have been mistaken for a linen store. The children’s work was also on display, again of the highest quality. But on closer inspection/
discussions with the parents, I found that, although the school and families obviously had links with their local and wider retailers/communities, for such high quality donations, I was left with the distinct impression that the parents were so strong in their ties with each other because of the lack of acceptance by others. Some children on leaving school had secured employment mostly at banks but others were not so fortunate. They did consider Keyaki as an option but were not overly enthusiastic. Many parents believed in the opportunities for work at Keyaki but were reserved about their children attending full time.

**Gohongi Elementary School**

My travels continued and I had the opportunity to visit Gohongi Elementary School Yutenji. Gohongi School has one class for children affected by disability including autism (Yukinoki class). The head of the school Ms Nakamura greeted us very warmly and kindly introduced me to some parents. The school is very proud of its inclusion policy and the parents did not feel the need to look for an alternative placement.

It would appear that the teaching methods of Musashino-higashi Have spread and it was very evident that the class and school was well structured and using a total communication approach for the children affected by autism.

They also had facilities for one to one teaching and I was very impressed by their observation room for assessments. One room was in western style the other Japanese. It was explained that some of the children with autism found the Japanese style difficult the western style was much easier for them helping them to concentrate. It was heartening to see that children who were possibly not in a position to attend the Higashi school where receiving a well-rounded education in preparation for adulthood.

Japan has a lot to commend it in respect of its teaching methods and from what I saw of keyati-no-sato it saddens me that the Japanese government are not using this project as a pilot throughout the country. Keyati certainly has given the writer food for thought and seeing is believing. I certainly saw what is possible to achieve even with persons severely affected by autism and I absolutely believe it is possible to replicate. It is hoped that others will be convinced also. My journey to Japan would have been impossible if it were not for the wonderful Magokoro Yoshihira, My interpreter provided by the Japanese local government.
Boston Higashi

Having visited Japan and seen Musashino-Higashi it seemed the obvious choice to make comparisons with the Boston Higashi School and to research their emergence programme. Mr Jamie Marshall Division Director Emergence Program was my key contact. My visit also coincided with the YU Ai festival (Japanese Festival) and the family day at the residence.

Boston Higashi has an extensive employment education programme And have developed some very good relationships with the local community. They also have transition coordinators that work exclusively with the adult programmes that support the students after graduation. The student’s lives at the school are very structured and therefore very different from what they can expect in adulthood. The emergence programme was created to help bridge that gap. The programme focuses on employment outcomes/goals for young adult students aged between 19-22. The division mirrors the expectations to any other student after graduation (20/30 hours/week). Community connected academics provide students with intensive and relevant on site based learning in the community. The frameworks that are taught to these students are that of a 24 hr lifestyle incorporating academics, hobbies, domestic activities, exercise, employment and community involvement. The social and communication practises are taught in a way to allow them to be generalised post graduation.

I immensely enjoyed watching the children/ students take part in the Yu-ai festival and envied the sheer energy of their support workers at the school road race. My tour of the school and witnessing the achievements of the students was very rewarding and moving, but my main attention was focused on learning more of the emergence programme and seeing it in action. Similar to keyati in Japan the school had its own pottery workshop and the students took great pride in knowing that their products were being sold to various outlets. The students were well supported and each student was taking part at various levels according to their abilities.

I was very impressed with the schools vehicle valeting service and the director was keen to point out because of the student’s high standard, that there was a waiting list of clients eager to use the service. Again, like Keyati the valeting service was well thought out and regardless of the students ability or lack of expertise, there was
employment for all, even to the most basic i.e.: preparing rags for polishing. The students looked happy and content. All profits are used to enhance the student’s lives/opportunities. I also learnt that students also helped out at a local nursing home not only were the students gainfully employed, the elderly residents looked forward to seeing them.

But it was when I visited a local family restaurant that I found yet another hidden gem. This restaurant employed two students on a part time basis in their kitchen area (dishwashing). The students are severely affected by autism and at first any reader might, I would say wrongly, presume the mundane role of the task and was this achievement? I would argue YES.

They followed a pictorial timetable to know their task and were ably assisted by a young support worker from the emergence programme.

What I felt when I met these two young men was the sheer joy that same joy that I felt at keyati. It was obvious that they enjoyed their work and that their needs were being fulfilled. It was amusing and wonderful to see the young men check their timetable go upstairs to the bar area and manage to pull a pint of coke. On speaking to the support worker and asking whether she felt vulnerable on her own. I received a very decisive no. My reasons were that these were two very strapping young men who had access to all types of equipment including very large knives. But there was a true camaraderie in this restaurant, a tremendous sense of pride and achievement. The two young men were a vision to behold.

Again the parents of Boston Higashi, were very welcoming especially the president of the Parents association. The president’s son is in the emergence programme and although he does not have a paying job he works as a volunteer in a programme that distributes meals to senior citizens.

All the residential students have some sort of employment by their late teens.

There is much to commend the Boston emergence programme especially the transitions coordinators. Like keyati it gave the writer some powerful food for thought.
Federation for children with special needs

The Federation for children with special needs was founded in 1974 by parents who had fought for the passage of the Massachusetts special education law. They were initially supported by a group of 12 disability and parent advocacy organisations throughout the greater Boston area. Today the federation is an independent non-profit parent advocacy organisation that promotes quality education, accessible healthcare and public policy to protect the rights of children.

They are committed to listening to and learning from families and encouraging full participation in community life by all people especially those with disabilities.

Within the first year of their existence they received a federal grant which established the first pilot parent centre in the nation

My visit coincided with a training week for parents, which afforded plenty of opportunities to learn from them. I was also invited to take part in the sessions.

My main contact was Mr Richard J Robinson Executive Director.

The training seminars were very enlightening and very different to what the writer has accessed at home. Many of the training programmes parents’ access within Great Britain are about accessing information or learning about new developed strategies, The Federation training programme that I participated in was much
more about teaching/ empowering the parents with knowledge and skill to tackle the endless bureaucracy and systems engaged by the authorities. The parents pay for this training, which can cost well into hundreds of dollars. Training is certificated and it allows the parents to become trainers. This is an organisation that is well supported with literally hundreds of supporters/doners. They have a multitude of programmes covering every subject of needs of children and families. I learnt that the power of parents pulling and working together for those same goals can be truly awesome. The parents that I met were no different from those in Great Britain. They have the same needs and same expectations for their children. I was shocked to learn that they do not have a motability system like ours and transport for children is left to the parents. This subject was talked about at length and who knows the Federation may be the first Organisation in the USA to rectify this issue. I learnt a lot from the parents and was infected by their enthusiasm to learn and to make the system better for their children.

The New England School

The NES is a centre dedicated to providing children affected by autism and related disorders with a state of the art education and a uniquely individualised training programme.

The children are provided with educational, social and employment opportunities designed to eliminate their isolation from family and society.

They provide specialised training and support for all. They work with families and public educational institutions to ease the transition of the child with autism back into home and the community.

Their goal is to help each of their children to reach their individual human potential and to live a productive and independent life.

Again my visit was to explore alternative teaching measures out with the Higashi system. Unfortunately because of the high client profiles (some children from the United Arab Emirates (royalty)). Photographs were not allowed to be taken.

They have an extensive programme that runs for 365 days of the year. They cover every aspect in relation to children and families affected by autism. Many of the children attending the school have extreme challenging behaviour and it was reassuring to see the school use the CALM (safe, effective strategies for preventing and managing challenging behaviour) approach. CALM is also a strategy used by Great Britain’s National Autistic Society. Their training programme for their staff is to be envied, the majority of staff access masters in various subjects helping the children to develop.
The NES also uses the principles of Applied behaviour analysis in conjunction with its many other interventions/help systems. There were a number of interventions that were in existence that I had not seen before one was a protective sleeve that the teachers/support staff have with them at all times attached to a waist band. The sleeve is used when challenged by any child who is determined to bite. The staff member thereby being protected and also in a position not to react because of the pain inflicted. This therefore gives the opportunity to CALM the situation and redirect the child. The school also has quiet padded rooms. These rooms are again used when a child becomes distressed and aggressive.

However in order to protect the child and the misuse of these rooms the doors can only be activated by heat control from the supporter’s hand. If the palm of the hand is removed from the sensor at the door it is unlocked. Therefore the support worker has to remain in situ at all times until the child is ready to leave. I have an open mind about this intervention.

The school also encourages the children as they progress through The school to access work opportunities mainly confined within the school i.e.: café etc.

This school has the state of the art technology and very well supported. The pictorial evidence within the reception area of their supporters including the recent President Clinton is very evident. They are also in the process of further developing an equivalent emergence programme in the writer’s opinion similar to Boston Higashi. It will be interesting to see the developments and what can be learned from them.

**What did the writer learn?**

I have used my experiences since my return to enhance our own children’s lives at Jigsaw. In early 2006 a transitions day was held at a local hotel where over 50 persons attended from various parts of the community. The emphasis for the evening was inclusion. Pictures of our children were displayed throughout the area reminding every one attending these children are not just ours but part of their community. Open questions were raised such as, what is the community’s contribution, what about the work place, how do we support the children? Their children!!

I discussed my experiences and what I saw first hand. As yet we have not achieved that level of commitment but as a result of that evening a member of the Royal Naval Community fundraising board acquired a tailgate specialist mini bus for the group via the Variety club.
The group also received the employer of the year award 2006 from the local community for promoting inclusion in the workplace for all. The parents of Jigsaw and myself believe in inclusion, meaningful inclusion. I have seen at first hand what can be achieved and although photographic evidence is helpful nothing but nothing can replace the joy and peace that I felt at Keyati. I felt on fire and continue to do so and will do all that is in my power to enhance the lives of our children. My adventures in Japan and America have been life changing. My final thought is

“*It can be done they believed then so must we*”

With grateful thanks to the Winston Churchill Memorial Trust for a life changing experience.

Anna Hendrick
Parent of children affected by autism
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