

The MOVE Programme: Collaborative working to provide independent movement for children with physical disabilities and/or complex needs

Christine Shaw



Christine Shaw, MCSP (Member of the Chartered Society of Physiotherapists), is a physiotherapist who has worked in paediatrics in hospitals, clinics and the community for over 25 years. Before taking up the position of MOVE's

Development Manager she worked for Capability Scotland in a school for children with complex needs. Christine has been working with the MOVE Programme for the past eight years and is responsible for the professional development and expansion of the MOVE Programme throughout the UK and Europe – though her main target area is Scotland.

Summary

MOVE is a structured activity-based programme which uses the combined knowledge of education, therapy, social services and family to teach children with physical disabilities and/or complex needs the skills they will need to be able to sit, stand, walk and transfer to the best of their ability. It is a collaborative multi-agency approach in which team members from each discipline work towards the same goals and increased communication. Through this, MOVE can be used as an effective tool for inclusion and support for children / young people who have additional support needs and their families, whilst acting as a practical approach which can be incorporated into a school or organisation's day and the child's home life. The MOVE Programme is child-centred and aims to promote independence, leading to meaningful

participation in school, home and the community. The teaching of these functional skills is achieved through a top-down approach which focuses on activities that people are motivated to achieve, rather than on what they cannot do. The children on MOVE have a wide spectrum of disabilities and needs.

The central philosophy of MOVE is that movement is the foundation for learning, the aim of MOVE is then to offer movement opportunities to children with disabilities and so open up the world around them, transforming the world from inaccessible and hostile to accessible, interesting and full of opportunity and choice.

The development of the MOVE Programme in the UK is our priority. It is our aim to see MOVE accepted by all authorities, national education departments and health services as a programme to be automatically delivered to children and adults who have physical disabilities or complex needs. In order to do this it is imperative that we are able to raise awareness of our Programme to all those who would be able to benefit and for those who would be working with the Programme.

In my many years of working with people with special needs, MOVE has proved to not only give a better quality of life to its users, but also provides a much needed parent/child based regime, with a multi-agency team support.

Gail Evans, Senior Community Paediatric Physiotherapist, Dunfermline

April's Story

April, aged 14, has cerebral palsy and hydrocephaly. Before MOVE, she was completely dependent on her care team, and unable to even play with her friends. She had to crawl on the floor to move around, although most of her day was spent in a fully supportive chair. Unable to participate she became a passive observer of the world around her.

April's PE (Physical Education) teacher Maggie Roger started to think about what April might be able to achieve after she attended a MOVE course in 2000. During April's MOVE assessment, it was discovered that she was able to sit unaided on an ordinary chair for a short period of time. Her team and her mother were astounded! For the months to come the team focussed on helping April to sit for longer and longer periods and soon she was working on transferring from sitting to standing and vice versa. April is now able to get up and down from a chair and even from the floor unaided – usually to change the channel on the television or to rewind her favourite video!



April exploring the corridors at school

She is no longer crawling about on her knees. She is walking with confidence. For a while she walked in a gait trainer (a supportive piece of equipment), then between two people, finally holding onto a piece of cloth, and one day she took her first steps on her own. Her mum, Liz, explains what it was like to see her daughter walk for the first time, and the impact MOVE has had on April's life:

I could not believe my eyes... Here was our little girl, who everyone had

*said would never be able to do **anything** for herself and she was **walking** towards me. It was one of the happiest moments of my life!*

April now makes her way around the corridors of her school, nosing into activities in other classrooms! This of course has implications since there is such a strong link between sensory experience and cognitive development.

Through MOVE April knows that her body belongs to her, and her mind has followed. She is no longer the passive little girl who just lets things happen to her, but she realises that she has the right to make her own choices and she practises it regularly!



April enjoying playtime

In 2007 after much dedication, April graduated from the MOVE Programme. She is now included in all the class activities, as she was before, but now she is walking with the rest of the class out to play, she is eating her lunch in the canteen, she is tackling an entire flight of stairs at school and she is walking to the bus to go swimming. She is also showing the signs of being a typical teenager and refusing to walk at times when it doesn't suit her!

As a consequence of MOVE April's family is now focussing less on routine care and have much more quality time together doing family activities. April is now an active participant in her life and is a little girl who **can** do things.

MOVE's origins and target population

The MOVE Programme originated in California, USA, in the 1980s when teachers discovered that their severely disabled pupils were leaving school with less functional skills than when they had started. These children were not given the opportunity to practise these skills throughout the school day resulting in a regression in ability. MOVE was introduced in the UK in 1999 through The Disability Partnership (Registered Charity Number 1062307) and HRH The Prince of Wales' Advisory Group on Disability. In October 2007 MOVE Europe became the sole focus of the Charity.

The MOVE Programme is designed for anyone who has not learnt to sit, stand or walk by the age that they should have done. There is no child / young adult whose physical or learning disabilities are too severe for the MOVE Programme to be effective. There are however, some pre-existing conditions that might exclude a person from MOVE, for example brittle bones or severe orthopaedic difficulties. It is therefore important to have someone with a medical background, e.g. a therapist, on each MOVE team.

Nobody is too old to learn. Through a successful pilot project for the transition years (16-25) we have found that those who joined the MOVE Programme at an older age were also able to learn new skills and gain many benefits from their newly acquired independent movement. Therefore the Programme is now also open to adults.

The principles of the MOVE Programme

MOVE puts a structure and a framework around work that is already taking place. It seeks to bring services together and to encourage collaborative working at all levels. In this way MOVE gives equal worth to the input of every team member and is not a therapy technique that can only be carried out by professionals. The carers and the individuals themselves have the best knowledge of their needs. MOVE ensures that they are as fully involved as team members in developing the individual MOVE Programme. The structure used is based on six steps as follows:

The first step of the MOVE Programme is assessment. This is not a clinical or therapeutic assessment but an assessment of the child's everyday functional ability. This first meeting allows the whole team to be involved in assessment, with everyone's skills and knowledge about the child being recognized and listened to. We aim to identify what the child can already do in a variety of situations based on sitting, standing, walking and transferring. The parent or main carer is directed to a chart of ability levels in one of those skill areas and asked how well their child is able to function. The rest of the team then give their opinions and, following discussion, an agreement is reached. Very often the school team find that the child is doing things at home with mum that he does not do in school and vice versa!

Step two focuses on goal setting. This involves asking the child and family what is important to them. What would the child like to do that they cannot currently? What handling manoeuvres do the family find really difficult? The goals that are set are those of the family. The team listens to what is important for them and then educational and functional targets are developed accordingly. One of the reasons MOVE is so successful is that it is based on the child's goal, so there is motivation to learn. This is often not the case with therapy programmes. Examples of a child's goals are to be able to walk to the playground so that they can play with their friends, or to sit at a table so that they can enjoy a family meal. The Programme is also successful because it takes place in the child's own environment, helping to give the activities meaning and relevance for the child. Another reason is that each day the process gives the child many opportunities to practise a skill with all of the different team members and in different situations.

In steps three to six the team plans how to teach most effectively the skills required for the chosen activity, both in the child's natural daily timetable and at home. Because the whole team is involved there is a much greater buy-in which helps ensure that practice situations take place.

Our internal evidence has looked at a sample of the 2,500 children who have already benefitted from the MOVE Programme after they had been on it for over a year. We have monitored their ability to improve in 15 core skills including;

maintaining a sitting position, standing, and walking forward. The study has shown that 94% of the children looked at managed to either improve their ability or maintain their levels in each skill assessed. Of those children maintaining their skills, a number have degenerative conditions, therefore the fact that they were able to maintain these skills at all is an achievement in itself.

Why MOVE?

For those children / young adults using the MOVE Programme, the benefits do not only bring increased mobility, the skills learnt also bring health improvements, for example, muscles gain in strength, organs gain the freedom to function and there are improvements in breathing, circulation and digestion. MOVE also brings with it an improvement in learning and access to education as a child becomes more alert and able to participate. They gain a greater interest in learning and the world around them. Lastly the Programme also improves social inclusion and family life with a greater ability to communicate and interact with others.

The Move Programme can have a long-term involvement with each individual, tailoring work to changing needs as progress is made or if regressions occur due to the severity of their disabilities. Furthermore, MOVE provides:

- a framework which meets many aspects of the Every Child Matters Agenda
- physical development goals in individual Learning Profiles
- annual review targets
- transition profiles and care standards
- support for the Education (Additional Support for Learning) Act (Scotland) and The Children Act in England

The MOVE Programme also helps to strengthen a school/organisation's physical development provision for children and adults with complex physical needs. This has helped to improve OFSTED and JAR (Joint Area Review) reports for many of the participating schools, with comments including:

The MOVE Programme is a vital part of the whole school curriculum, which

brings physical education into every part of the school and every lesson... This increased independence enables pupils to move around as they wish without being dependent upon an adult.

Ofsted report, North Lincolnshire

Personal development is a major focus of the work of the school and is done well. Pupils are helped to develop their potential through the MOVE Programme, which enables them to make choices and travel independently.

Ofsted report, West Yorkshire

There are many examples of good, and sometimes outstanding individual programmes, including the MOVE Programme, a very successful and flexible activity-based movement programme.

Joint Area Review, Derbyshire
Children's Services Authority Area

MOVE's position to date

The MOVE Programme is already delivered through many local authorities and schools across the UK. Thirteen local authorities in the UK have embedded MOVE within the schools supporting children and their families. Several more have trained inter-disciplinary groups of staff and families with a view to continuing the development of MOVE.

The MOVE Programme is also being used in Austria, Denmark, Germany, Italy, Spain and Palestine and our partner organisation MOVE International is developing the Programme in the USA, Canada, New Zealand, China, Japan and Egypt.

What others say about MOVE

Since starting on the MOVE Programme we have had two children awaiting hip surgery who have been taken off the waiting list.

Phyllis Tulloch, Senior
Physiotherapist, Inverness

MOVE has helped Ami to realise her potential. Ami's goal was to go on a family holiday without equipment. We went to Florida and I took her buggy just in case. In the end it came in handy for carrying the bags, Ami didn't use it once.

Karen Al-Khina, Ami's mother, Kent

It's hard to describe the impact that seeing your disabled child moving independently, standing upright and engaging with the world around them can have on a parent who has been told that they will be on their back for their whole life.

Jan Wells, Head Teacher at Stanton
Vale School,

in Society Guardian, 10th January
2007

Jen enjoys her MOVE Programme – her whole body shape is maintaining. Her facial expressions and her pitched vocal sounds indicate to all who work with and know her how enriched her life is, and will continue to be, if MOVE is a steady, consistent and constant part of her life.

Professional Carer, Lincolnshire

For more information about MOVE and about their training opportunities:

Visit www.move-europe.org.uk or call 020 7403 6382