

A One Year Postural Care Training Programme for the Workforce Supporting the Needs of those with Complex and Continuing Healthcare Needs: Project Evaluation

Skills for Health (SfH) has been working in partnership with Postural Care CIC on a project to deliver a one year training programme for the workforce supporting the needs of children and young people with complex healthcare needs. This evaluation will outline the background to the project, how the work was carried out and the key findings and recommendations of those involved.

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Recommendations:

1. Quality assured and accredited postural care training should be available locally for families and mandatory for cross agency workers within the children's workforce; contributing to the essential, intensive cross agency support for individuals and families that need it most.
2. Services providing postural care should be accountable for the structure and quality of the information, training and support available locally to families. The role of a Postural Care Facilitator should be established.
3. Development of national standards for the training, advice and support available to families is needed.
4. The Postural Care Awareness Unit should be accredited nationally and included on the Qualifications and Credit Framework (QCF); this will be completed by May 2011.
5. Alterations in critical dimensions of the chest are associated with reduced internal capacity of the abdomen and thorax and contribute to secondary complications such as reflux and digestive problems, dysphagia, aspiration and respiratory infection; therefore measurement and monitoring of the Goldsmith Indices of Body Symmetry should be provided by therapy services to all children and their families.
6. Therapy services should make data regards efficacy of provision available for comparison with other services.
7. The Goldsmith Indices of Body Symmetry provides invaluable information that should be shared during Transition and subsequently included within the annual health check.
8. All families of children and young people at risk of body shape distortion should receive quality assured training and advice with regards to how to protect their children. Accredited training should be available for those who wish to undertake it
9. Family networks should be encouraged as a vehicle to disseminate knowledge and support associated with child and family centred postural care as well as self determined equipment provision.
10. Professionals need to recognise the vast levels of skill, experience and dedication demonstrated by families and include them to co-produce effective services.
11. The success of this project as evidenced by participant feedback should be recognised and used as a foundation for comparison with other approaches as well as future training development.
12. Providers need to explore the potential for new ways of working across the workforce that considers an integrated approach based on lifelong need, collaborative working across agencies, participation, consultation and inclusion rather than professional role.
13. Providers of services should be aware that individuals and their families will be becoming increasingly aware of the avoidable nature of body shape distortion.
14. Postural care as a mainstream aspect of service provision should become core business.

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How did the project come about?

A review exploring stakeholder's opinions of the key children and young people's health workforce priorities was carried out by Skills for Health between November 2008 and April 2009 as part of Stage 1 of a work programme agreed between SfH and the Children's Workforce Development Council (CWDC).

Following data analysis stakeholders were invited to suggest priority area work options for project development and an Advisory Group was convened to evaluate proposed options. Following a meeting of this group one of the selected work areas for development was Postural Care (Protection of Body Shape) aimed at families and Allied Health Professionals supporting children and young people with complex healthcare needs. This work development option was proposed by Janet Cobb, manager of the UK Health and Learning Disability Network

Why was this project needed?

Many individuals with complex and continuing healthcare needs, including the new generation of young people dependent on medical technology, have their health needs unmet by current mainstream, community based NHS services. At the same time many NHS services are stretched to capacity and are unable to respond to changing demographics and new demands on healthcare provision such as the development of dysphagia services, recognition of pain and distress in people who are unable to communicate in traditional ways, postural care (protection of body shape) or the needs of people and families living with medical technology.

What little research is available (Kirk 1999) indicates that many individuals and their families feel isolated and unsupported. No Ordinary Life (Mencap 2001) also provides an indication of the lack of support experienced by many families caring for children and adults with complex and continuing healthcare needs.

This project addresses one of these issues, the availability of specialist services in relation to postural care and protection of body shape, as identified by Mansell 2010 and the European Declaration on the Health of Children and Young People with intellectual Disabilities and the Families (WHO 2010). Postural care is likely to remain an important subject on the health agenda as awareness increases and its benefits are realised.

A lack of investment in family carers and equipment supply has led to the dangerous perception that changes in body shape are inevitable for individuals who have movement difficulties. Changes in body shape have become synonymous with a population who may be described as having complex and continuing healthcare needs associated with disability.

However, advances in understanding and recent work in relation to postural care have shown that body shape distortion may be considered a secondary complication associated with limited mobility.

Due to the often complex nature of health and social care needs for children with multiple disabilities, families frequently come into contact with a large number of professionals from different support agencies. It is important that those working with children across all of these agencies can identify children and young people at risk of body shape distortion and know how best to signpost families in order to initiate appropriate support and intervention.

Children with complex healthcare needs or multiple disabilities are most at risk in terms of body shape distortion, the predictable patterns of which are well understood (Hill and Goldsmith 2010). These changes in body shape, particularly chest distortion, have a high financial cost associated with them, for example in terms of need for increasingly complicated equipment or surgical intervention as well as a high emotional and physical cost associated with premature death for the children and young people involved.

Secondary complications associated with a failure to protect body shape are acknowledged within the NHS Pasa Buyers Guide to Night Time Positioning, published June 2009:

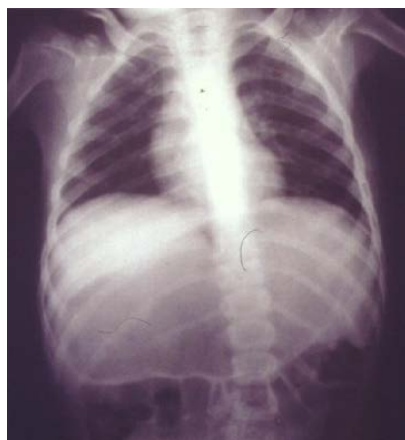
- *"The musculoskeletal system (contractures, loss of joint integrity, e.g. hip dislocation, decreased bone density, reduced range of joint motion and deformity, e.g. spinal scoliosis)*
- *The neurological system (spasticity/muscle tone, primitive reflexes, altered sensation and joint position sense, pain, weakness)*
- *Respiratory function*
- *Digestion (including swallowing and choking, both of which are compromised by poor head and neck posture) and kidney/renal function*
- *Personal hygiene, ease of toileting and changing*
- *Functional ability*
- *Environment interaction (sensory perception, body aesthetics, learning, communication)*
- *Sleep pattern and irritability"*

Premature death of people with learning disabilities including those with complex and continuing healthcare needs is sufficiently well recognised that it has become the subject of a confidential inquiry. "How people with learning disabilities die" (Glover and Ayub 2010) found that "Two causes of death stood out because they affected a lot of people with most sorts of learning disabilities and they might be preventable. They were: Problems caused by solids or liquids in the lungs or windpipe; Epilepsy or convulsions." Changes in chest shape can exacerbate existing difficulties with swallowing and may increase the risk of respiratory infection.

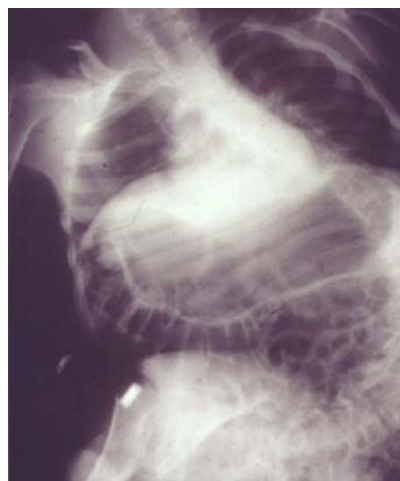
The following series of X-Rays shows how devastating changes in body shape can be over time. X-Ray 1 is of a little boy at the age of 3; he had a diagnosis of Cerebral Palsy and could move himself around on the floor whilst lying on his back. X-Ray 2 is of the same little boy at the age of 10, his chest is beginning to rotate in an anti-clockwise direction, measurement of the critical dimensions of his chest would reveal this to those supporting him and indicate the need for simple preventative strategies to be introduced at the time to maintain body symmetry. In the absence of such postural care, X-Ray three is of the same person, now a young man of 17 years old, the growth spurt of puberty has accelerated the distortion of his chest and his internal organs have been affected by his deteriorating body shape. X-Ray 4 was taken shortly before this young man passed away at the age of 23. Changes in body shape can in themselves become life limiting.



X-Ray 1: Age 3



X-Ray 2: Age 10



X-Ray 3: Age 17



X-Ray 4: Age 23

The principles of postural care are very simple. As there are 24 hours in a day there are 8,760 hours in a year. A child or young person that attends school will be there for a total of 1,140 hours, this leaves 7,620 hours of the year with their family. If a child or young person goes to bed at 9pm and gets up at 7am they will spend a total of 3,640 hours in bed. On average a child will spend three times longer in bed than they will in school. If we fail to support children and young people well in bed the effects of destructive lying postures can be devastating.

The project aimed to impact directly on outcomes for children and young people, significantly improving the lives of some of the most vulnerable children and young people and their families. Conservative protection and restoration of body shape using therapeutic positioning is a relatively new and exciting development, the project is ground breaking in terms of the techniques being taught and its use of objective outcomes for children in relation to physical therapeutic intervention.

At present there is a worrying lack of provision in some parts of the UK and of general awareness of the risks associated with changes in body shape within the children's workforce. Outcomes for children can only improve once the issue has been clearly identified and acknowledged.

Sir Jonathan Michael's inquiry Healthcare for All (Michael 2008) found *"a gap in services for children with profound disabilities and complex needs who have musculoskeletal problems. Early interventions are not undertaken to prevent postural (distortions) from developing."* It is imperative that professionals coming into contact with families that include children with mobility problems are competent to provide safe and accurate advice, support or signposting to the relevant service in relation to postural care.

The QIPP Agenda and Outcome Based Commissioning Strategies are calling on public health teams to reassess their current practices. The provision of Postural Care training upholds the current NHS guidance on improving efficiency and productivity within NHS workstreams.

Quality

- Improvement in quality of life – reduces need for invasive and expensive interventions including surgical procedures, reduces need for complex equipment, aids and adaptations
- Improved quality of service provision – responsive, objectively monitored using validated non-invasive measurement of body shape
- Improved accountability for service providers with the use of accredited training

Innovation

- Accredited training designed for health and social care professionals as well as the first circle of support – parents, family members and personal assistants
- Use of validated, non-invasive outcome measurement – Goldsmith Indices of Body Symmetry. (Goldsmith et al 1992)
- International uptake of training – for example accredited courses are now available in Australia and Canada.

Productivity

- Measurement of body symmetry supports evidence based service provision
- Improving and widening access to therapeutic positioning training supports active therapy service provision during the day
- Self-management reduces demands on service providers in relation to day to day contact
- Bureaucracy involved in service centred equipment acquisition currently inflates prices for equipment to the extent that the system is unsustainable – evidence of this in children’s service within ‘It’s not too much to ask’ and Audit commission report ‘Fully Equipped’
- Accredited training and audited skills acquisition in combination with validated non-invasive outcome measures allow comparison of service providers and will drive service improvement

Prevention

- Protecting body shape prevents secondary complications for the patient
- Prevention of costly intervention including surgery, inpatient stays, intensive physiotherapy associated with multilevel surgery, complex equipment, aids and adaptations, alternative feeding methods, potential reduction in respiratory infections and medication costs associated with controlling muscle tone.

Accredited and quality assured training in combination with supporting families to choose the equipment and strategies that best suit their needs have a significant role to play in coming years with the introduction of Personal Health Budgets (PHBs). Whilst this project did not address issues specifically relating to PHBs it did generate much discussion when considering how to meet the growing demand for postural care services and equipment in the current financial climate.

Who was involved?

Postural Care CIC is a Community Interest Company (denoting not for profit) working to develop and provide protection of body shape training for people with movement difficulties, such as children with cerebral palsy. The Company provide quality assured, accredited training in both therapeutic positioning and validated, non-invasive measurement of body symmetry. For a number of years now they have worked with family leadership organisations such as Partners in Policymaking and are committed to supporting the development of a robust knowledge base within this field. Postural Care CIC advocates joint training of multiagency workers alongside families wherever possible to support the understanding of roles and responsibilities of others in a constructive way. Postural Care CIC provided the training undertaken during the project and have been responsible for this evaluation. External evaluation would have been preferable but was not possible due to the prohibitive costs involved. As part of the follow up to this work a Randomised Controlled Trial application has been submitted in partnership with the University of Warwick which will provide further independent evaluation.

SfH is the Sector Skills Council for the health sector across the United Kingdom. Its role covers all healthcare employers – including those in the National Health Service, independent and voluntary sectors. SfH is part of a UK network of Sector Skills Councils covering 85% of the UK economy. Its strategic aim is to develop a skilled, flexible and productive workforce for the whole health sector in all UK nations, to raise the quality of health and healthcare for the public, patients and service users.

SfH's specific aims are to:

- Develop and manage national workforce competences
- Profile the UK workforce
- Improve workforce skills
- Influence education and training supply
- Work with our partners.

CWDC lead children and young people's workforce reform in England, improving chances for children and young people throughout the country. The common core, one strand of CWDC work, describes the skills and knowledge that everyone who works with children and young people (including volunteers) is expected to have. The six areas of expertise offer a single framework to underpin, multi-agency and integrated working, professional standards, training and qualifications across the children's workforce. There are six aspects of the common core: effective communication and engagement; child and young person development; safeguarding and promoting the welfare of Children and Young People; supporting transitions; multi agency and integrated working and information sharing. Each aspect of the Common Core was relevant to the project and reference was made to these areas during the training.

8 Primary Care Trusts (PCTs) were originally involved in the project although one had to drop out shortly after the start of the project due to personal issues and work commitments of the healthcare professional involved.

The seven PCTs that completed the project were: Cornwall and Isles of Scilly; Derby; Knowsley; Lincoln; Trafford; Wakefield and Wandsworth. Case Studies were completed from each of the areas detailing the existing therapy service, the backgrounds of the Awareness course learners, quotes from participants, the impact locally and plans for the future. Appendix 1

What did we do?

The project aims

- Raise awareness of the risks associated with a failure to protect body shape and to develop the concept that distortion of body shape is an avoidable secondary complication associated with mobility problems
- Demonstrate that training family carers alongside professionals can be mutually beneficial
- Introduce the standardised, validated and reliable Goldsmith Indices of Body Symmetry as an objective outcome measure for therapeutic intervention
- Support cross agency working in relation to the development and provision of postural care within each of the PCTs
- Raise awareness of the key CWDC Children and Young People's workforce development programme, the Common Core Refresh and the development of qualification frameworks relevant to the workforce.

One individual from each participating PCT trained to become a licensed postural care trainer. This is an accredited course at Level 3 and equates to 90 hours of study time. Each postural care trainer then cascaded postural care awareness training to a further 10 individuals, this course was also accredited but at Level 2 with an equivalent of 30 hours study time. In order to achieve their accreditation all participants had to complete an evidence portfolio. The accredited units used are available from Postural Care CIC for those who wish to have details of content and depth of the training undertaken.

At the beginning of the project introductory information sessions were held in each of the PCTs and the licensed trainers encouraged young people and their families to attend to find out more. As a result each of the PCT pilot sites recruited at least one family carer on to the Level 2 awareness course to be trained alongside multiagency workers.

The training offered is accredited and quality assured through the Open College Network West Midlands Region and was mapped to SfH competences. Development of the course in line with these competences is ongoing as part of the process by which the unit will become available as a National Award at Level 2 within inclusion on the QCF.





What did it cost?

The project was funded by Skills for Health with match funding from each of the participating PCTs with a total cost of £50k. Each PCT has been considering developing sustainability plans and cost savings and return on investment will vary owing to local variations, for example one PCT has a dedicated postural care manager with no clinical caseload, another charged for the awareness sessions.

What happened?

The Awareness courses were held in the summer of 2010. A total of 65 learners were registered for the level 2 Awareness course, work commitments led to a number of interested people being unable to attend and so overall we were just short of the predicted 70 learners. Each course participant completed a feedback form at the end of the two day course, the overall results of which are collated below.

Overall Rating Table

How did you rate...				
The course content	96%		2%	2%
The presentations and speakers	98%	2%		
The venue and refreshments	85%	13%		2%
Information and resources	92%	6%	2%	
Were your needs met?	94%	4%	2%	

The comments below are a representative selection from the learner's feedback. A recurring theme was that even experienced professionals and parents described the information as new to them. Many of the participants that took part commented that they felt that the information should be available to all those working with children and young people at risk of body shape distortion. Many were shocked that they had not been made aware of the risks and avoidable nature of distortion of body shape.

Which part of the training did you find most useful?

- *Being able to look at my child and make a better assessment of his postural needs*
- *The interaction from all present was very positive and good to hear from different professionals*
- *The theory component was fantastic but the practical brought everything together*
- *It was all really useful – I liked the mix of professions, agencies, parents*
- *All parts of the training have raised my awareness and helped me to see how things can be changed for the better*
- *Everything on the course will prove useful to me. It is something I now feel confident to discuss with families and implement*
- *All of it, particularly the photos of the changes as they were very powerful. It was useful seeing a child measured*
- *Having a parent on the course*
- *The simple information and things you can do to put things right*
- *The way postural care can change a person's quality of life with minimum intervention*
- *Learning about the huge impact lying symmetrical can benefit a person inside and out*
- *Thought the whole 2 days were enlightening and thought provoking. I have gained lots of knowledge and skills to use at home. Met new friends!*
- *Overall knowledge around implications and impact poor postural care has on quality of life and access to learning*
- *All the training was very useful in helping me to understand the importance of the body functions and how postural care is an absolute must*

What could be improved?

- *Some additional time – felt a bit rushed on occasions*
- *As a non-medical professional I struggled a bit with medical terms but the list in the pack helped and tutors did recognise and accommodate for this*
- *More of it. I'd like to do another 2 days (even if it was doing the same thing again!)*
- *On occasions terminology was a little too high but when asked to explain this was done well*

Do you have any other comments about this training or future activities?

- *Everyone who works with children should do this training*
- *Would recommend that everyone who works in a healthcare environment with children needing postural support attend this programme and that all parents have access to this information from the word go!!*
- *Having a mix of parents and professionals – complements well and helps*
- *I feel it was absolutely the correct decision for a senior manager in school to have an understanding of postural care to ensure an holistic approach with all the needs of the child at the centre of any intervention – including education*
- *I found this training a complete learning curve which I found absolutely fascinating. I feel that everyone should be made aware of the importance of postural care i.e. GP, medical staff, etc so that everyone concerned can get together and discuss each child's/persons requirements/needs this is as important as every other special need a child/person may have. Postural care is as important as wearing your splints!*
- *I think all healthcare professionals should do this training along with parents*
- *I think it should be rolled out further to meet what is surely a great need out there*

The following is an example of a self assessment tool on a skill set of 30 items with the increasing size of the green shaded area representing increasing confidence using a four point scale:-

4★★★★ I feel confident that I am fully aware of this issue and can relate it to life situations

3★★★ I feel confident that I am aware of this issue

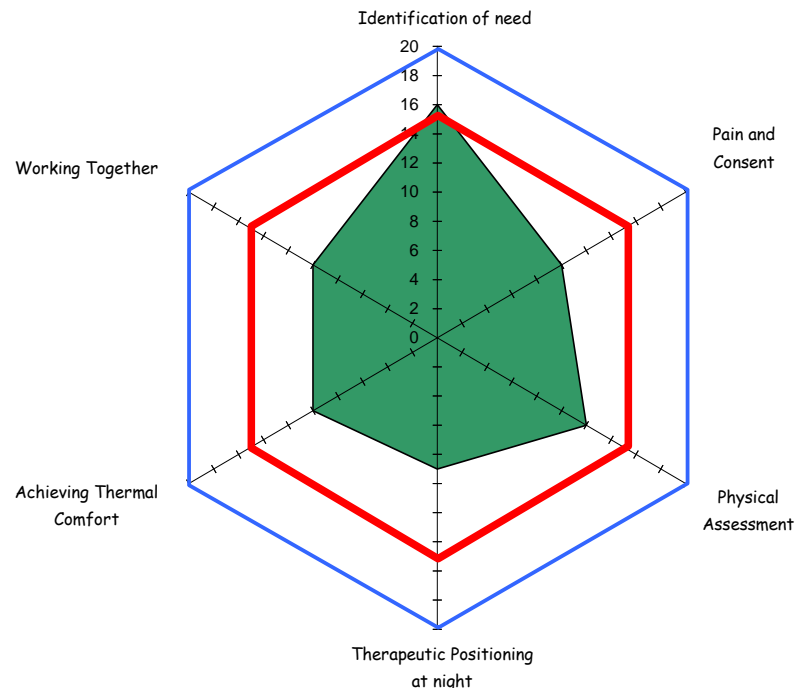
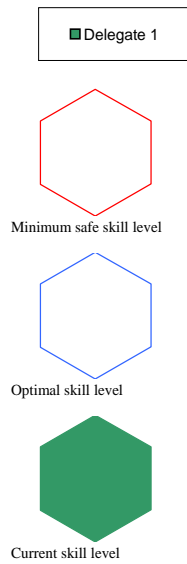
2★★ I feel I need further guidance with this issue

1★ I need to learn about this

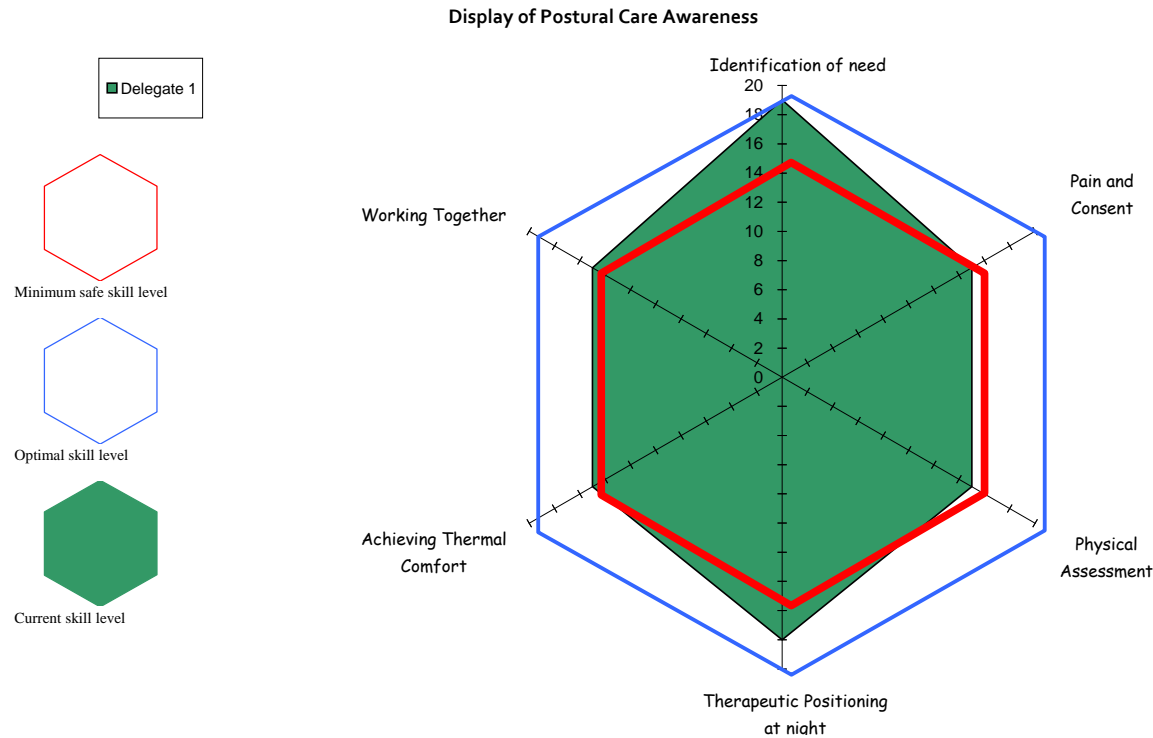
The assessment was completed before and after the initial two day face to face training had taken place and was reported both for individuals and consolidated for the learners as a group. Without exception Awareness Unit learners identified an increased confidence in their skills in relation to postural care.

PRE-COURSE SKILL LEVEL

Display of Postural Care Awareness



POST-COURSE SKILL LEVEL



Tutor comment. Delegate 1 - they were pleased with their audit results. We did discuss further support they may like to have to fully understand the physical assessment tools used and we agreed this also related to the therapeutic positioning too. They were going to go away and reflect on the course material and are now happy.

What did we learn?

Established provision of postural care was varied between each PCT. This ranged from a lack of provision of night time positioning equipment for any child apart from those prepared to self fund to an established care pathway with dedicated equipment funding, managerial support and sign up from the local paediatric orthopaedic surgeon.

A common theme throughout the project was that those training to become licensed postural care trainers were not recognised as needing time dedicated to the project and did not experience any reduction in caseload. The expectations of the dominant inherited culture are that children and young people will be provided with hands-on therapy. The prevalence of body shape distortion within the adult population would indicate that this approach has been unsuccessful in the past despite the best efforts of all involved.

There is potential for conflict as families learn of the benefits of self management alongside hands-on therapeutic intervention particularly where resources are scarce. The minority negative feedback in the overall rating table reflected a disappointment in the ability of services to provide intensive ongoing hands-on therapy and a reluctance to consider alternative options. Supporting families to understand the lack of success of previous interventions in relation to protection of body shape and to inspire them to implement a new approach is challenging and requires high levels of sensitivity, skilled communication and tenacity.

The considerable extra work generated by the project was often carried out during the participants own time and reflects a passion and commitment to the project and to the families each of these professionals support. Cornwall PCT has recognised that the transition between existing provision and support of self management requires development of a new role; this has had a hugely positive impact on the work in Cornwall. This has lead many involved in the project to conclude that there is a need for the role of a Postural Care Facilitator (Appendix 2) to be established. The following Risks and Benefits of the project were identified by those training to become licensed postural care trainers.

Benefit Identified	Evidence for this benefit
1. Provides a focus on child centres outcomes	<p>Increased numbers of children and young people being measured provided information on critical dimensions of the chest as well as symmetry of structure and movement of the pelvis and legs, any progress, improvements or deterioration is now recorded</p> <p>Use of Anatomical Measuring Instrument (AMI) being monitored and recorded</p>
2. Identification of areas for development	<p>Highlighting key areas for development including new ways of working, new roles, care pathways, post project intentions and the use of validated, objective outcome measures relating specifically to body symmetry</p>
3. Inter-professional working and raised awareness across agencies encouraging partnership working with families	<p>Awareness trainees were from a variety of sectors and professions, for example health, social care, and education</p> <p>Traditional barriers between those providing and those accessing services were naturally overcome through joint experience and collaborative working during the face to face training, this continued for example during the development of learner evidence portfolios and follow up of the children involved</p> <p>Inter-professional activity, for example promotion sessions to other health professionals, interagency activity is being recorded along with development of family stories</p>

<p>4. Involves families</p>	<p>Family participants on awareness training sessions, evidence of follow up activity with families, development of local case studies, recording of family stories and experiences, recording of quotes from feedback, encouraging families to participate in service design and delivery</p> <p>Development of educated, skilled family support networks and development of shared collective experience and problem solving</p>
<p>5. Increases knowledge and awareness of postural care and body shape distortion</p>	<p>Numbers taking accredited training (65 registered, 60 accredited at time of going to print), number of qualified trainers</p> <p>Follow up presentations, demonstrations, anticipated increase in referrals received, social media hits for example DVD requests, You Tube hits and Facebook hits and inclusion in local family and service newsletters</p>
<p>6. Health benefits for children and young people</p>	<p>Production of new local family stories, records and feedback alongside use of existing family stories demonstrating protection and in some cases restoration of body shape, muscle tone and quality of life</p> <p>Support for families to maintain behavioural change in intimate and emotive aspects of family life inspired by the positive experiences of their peer group</p>
<p>7. Potential to reduce costs</p>	<p>Production of local family stories with costings, potential reduction in secondary complications and the need for intervention. The potential cost savings has generated sufficient interest in this approach that a proposal for a clinical trial of the care pathway has been submitted</p>

8. Major service benefits through links into adults services and continuity of care	Potential for involvement or raised awareness of links with adult services, family stories, transition support activity, participation of professionals from adult services in accredited training sessions, development of new, improved care pathways
9. Getting a pathway, evidence base and basis for protocols	Development of local service case studies to support care pathway development as well as competence development in line with new pathways Potential for child and family centred commissioning which may link to PHBs
10. Develop evidence base	Record application and identify improvements – maintain records and log. Local data collection and evaluation. Development of family stories
11. Broader engagement in understanding children's health needs across other sectors, not just health	Cross sector and family involvement during all Awareness courses
12. Potential for income generation through delivery of awareness training	Future potential for delivery of accredited training locally to generate income and to support service development
13. Qualification development	Training to be included on the QCF from May 2011
14. Raised awareness of common core of knowledge and skills across children's workforce	Raised awareness of common core, all Awareness trainees receiving updated common core refresh information

Risk Identified	Risk reduction action
1. Potential for negative effect if postural care information is given without full support and monitoring eg producing body shape distortion, aspiration etc	The training is accredited and quality assured but does not replace the essential advisory role of therapists and other healthcare professionals. The training supports a partnership approach between clinician and family. Clinicians are governed by their own code of conduct. Tutors sign up to a license agreement regards the use of the training materials and are accountable for their own practice. Awareness training is for skills and knowledge only – it does not allow an individual to practice but enables signposting and problem recognition
2. Increase in workload	Local agreement needs to be made with line management for individuals completing this training. Postural Care CIC will support the recognition that investment in training families increases their self reliance and reduces their ongoing dependence on services, of particular significance in relation to potential changes in service delivery and the introduction of PHBs. An increase in the self reliance and success of the majority of families will free up resources for those that are less able to self manage
3. Perception of pushing a product.	No marketing within project e.g no sales reps at sessions but trainers have the opportunity to invite in reps as wanted and to provide information in line with local policy and practices. Commercial products including towels, cushions, hippos etc as well as specialised equipment were indispensable to demonstrate the allocation of biomechanically correct supportive forces. The Anatomical Measuring Instrument is the tool necessary to carry out the validated Goldsmith Indices of Body Symmetry
4. Confusion between 2 companies and separation between project pilot and product.	As above. The project was about training only and any product use is dependent on the trainer approach. Invitation by trainers of any companies to support training could be developed as required

5. Lack of dedicated time to support project	This was subject to local agreement with managers. Support available from Postural Care CIC e.g. to help with outcomes achievement
6. Professional disadvantage because of current role, ie non-therapist felt they may have more to learn	There are therapist and nurse tutor trainers with each having different skills and knowledge offering a range of benefits over the project duration. Postural Care CIC support is available to help bridge any perceived gaps. Mutual support from tutor colleagues was available as required
7. Failure to deliver across agencies	Recruitment to Awareness sessions across agencies and to include families has been successful for the project overall
8. Perceived fear that the training will not be sustainable	Evidence and success stories from project. Local sustainability plans in agreement with local management

The following areas were identified as requiring development but were outside the remit of the project. Areas looking to develop postural care services would be advised to consider these carefully.

1. Funding for equipment
2. Funding battles between agencies and with out of borough Health Authorities
3. ICT – technology sometimes disparate between PCT and NHS thus causing difficulties recording and reporting information
4. Long term sustainability

Project Output / Outcome / Conclusions and Recommendations

Output	Outcome / Impact	Conclusion	Recommendation
7 licensed postural care trainers	<p>Potential for locally available training provision</p> <p>Recognition of current gaps in service provision.</p> <p>Increased awareness of the CWDC Common Core</p>	<p>Gaps remain in service provision in relation to postural care. However with appropriate tools, training and support health and social care professionals are more than willing and capable of providing quality assured and accredited training</p> <p>This project demonstrates that families are capable and willing to participate in training</p> <p>Existing gaps in service provision do not exist because of staff complacency but because there is little expectation that body shape can be protected</p> <p>Training supply within the participating PCTs has been improved</p>	<ol style="list-style-type: none"> 1. Quality assured and accredited postural care training should be available locally for families and mandatory for cross agency workers within the children’s workforce; contributing to the essential, intensive cross agency support for individuals and families that need it most. 2. Services providing postural care should be accountable for the structure and quality of the information and training available locally to families. The role of a Postural Care Facilitator should be established. 3. Development of national standards for the training, advice and support available to families is needed.

<p>60 Awareness Unit learners completed accreditation (92% of those registered)</p>	<p>Increased awareness of concepts and issues around protecting body shape as identified as a gap in the original stakeholder review.</p> <p>Better cross agency understanding of the risks associated with failure to protect body shape</p>	<p>Increased awareness of the issues and concepts surrounding protection of body shape is essential to drive service improvement and to raise expectations for children and young people.</p> <p>Many who attended did not realise the avoidable nature of body shape distortion and so did not necessarily see the need for service development</p> <p>Training professionals from different agencies alongside families contributes to the breakdown of perceived divisions and contributes to the essential , intensive cross agency support for individuals and families that need it most</p>	<p>4. The Postural Care Awareness Unit should be accredited nationally and included on the Qualifications and Credit Framework (QCF); this will be completed by May 2011.</p>
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<p>Each of the participating PCTs is now using the Goldsmith Indices of Body Symmetry as an objective outcome measure for children and young people at risk of body shape distortion</p>	<p>Robust evidence base for intervention</p> <p>Improvement can be monitored and any deterioration related to concerns regards current interventions</p> <p>Evidence base for ongoing equipment supply</p>	<p>Collation of data in relation to measurement of body symmetry is essential to drive service improvement and reform with the expectation that body symmetry will be protected throughout childhood</p> <p>Periods during which children are particularly at risk such as during the growth spurt of puberty will be highlighted for individuals and their families so that resource implications can be predicted and met</p>	<p>5. Alterations in critical dimensions of the chest are associated with reduced internal capacity of the abdomen and thorax and contribute to secondary complications such as reflux and digestive problems, dysphagia, aspiration and respiratory infection; therefore measurement and monitoring of the Goldsmith Indices of Body Symmetry should be provided by therapy services to all children and their families.</p> <p>6. Therapy services should make data regards efficacy of provision available for comparison with other services</p> <p>7. The Goldsmith Indices of Body Symmetry provides invaluable information that should be shared during Transition and subsequently included within the annual health check</p>
<p>Increased confidence as evidenced by skills self assessment</p>	<p>People are more likely to participate confidently in partnership working, both across agencies and between agencies and families</p>	<p>It is possible to deliver accessible training to professionals from a range of backgrounds alongside families that use services in order to increase confidence and competence</p>	<p>8. All families of children and young people at risk of body shape distortion should receive quality assured training and advice with regards to how to protect their children. Accredited training should be available for those who wish to undertake it</p> <p>9. Family networks should be encouraged as a vehicle to disseminate knowledge and support associated with child and family centred postural care as well as self determined equipment provision</p> <p>10. Professionals need to recognise the vast levels of skill, experience and dedication demonstrated by families and include them to co-produce effective services</p>
<p>Good overall feedback</p>	<p>Increased likelihood of generating future</p>	<p>Postural care courses do not need to be exclusively the realm of the medic – with a</p>	<p>11. The success of this project as evidenced by participant feedback should be recognised and used</p>

<p>from participants</p>	<p>attendance, particularly amongst families if the course was felt to be worthwhile</p>	<p>range of teaching methods, visual and kinaesthetic teaching aids and well differentiated materials, protection of body shape can be made accessible to all</p>	<p>as a foundation for comparison with other approaches as well future training development</p>
<p>Short listing of the project for a national social care Accolade Award 2010</p>	<p>Recognition of the cross agency nature of the project – Most Effective Practice in Workforce Development Across Partner Agencies</p> <p>Raised awareness of the issues and concepts to a wider audience</p> <p>Increased credibility of those working to support families to combat avoidable body shape distortion</p>	<p>Raised awareness and credibility of this work has led to three major developments:</p> <p>The formation by Mencap of a Postural Care Action Group to continue to raise awareness nationally and to support families to gain access to training</p> <p>Funding through Mencap for a short film highlighting some of the important issues and challenges faced by families</p> <p>Submission of a randomised controlled trial of the postural care pathway used during the course by the Clinical Trials Unit at Warwick with input from Child Health, Medical Statistics, Health Economics, Consultant Paediatric Orthopaedic Surgeon and the Foundation for People with Learning Disabilities</p>	<ol style="list-style-type: none"> 12. Providers need to explore the potential for new ways of working across the workforce that considers an integrated approach based on lifelong need, collaborative working across agencies, participation, consultation and inclusion rather than professional role 13. Providers of services should be aware that individuals and their families will be becoming increasingly aware of the avoidable nature of body shape distortion 14. Postural care as a mainstream aspect of service provision should become core business

What has happened within the participating PCTs since the project ended?

There have been a number of developments within the participating PCTs since the project came to an end. In Cornwall a further 48 learners from school and short break settings have been registered for the Awareness Course. In Lincolnshire all paediatric physiotherapists and occupational therapists, a total of 29, have been registered to become qualified in measurement of body symmetry using the Goldsmith Indices as well as being provided with the equipment required to carry out the measures. A one day introductory session has also been undertaken with all staff and interested parents at one of the special schools in Lincoln. Wakefield are training three of their therapists using the Advanced Unit as well as supporting 8 parents and staff at a local school to complete the Awareness Unit. The licensed trainers from Trafford and Knowsley have provided support for the training of physiotherapists working out of Alder Hey hospital and in the Liverpool area, a total of 23, for both the Awareness and the Measurement Units.

At a National level raised awareness and credibility of this work has led to three major developments:

- The formation by Mencap of a Postural Care Action Group to continue to raise awareness nationally and to support families to gain access to training.
- Funding through Mencap for a short film highlighting some of the important issues and challenges faced by families.
- Submission of a randomised controlled trial of the postural care pathway used during the course by the Clinical Trials Unit at Warwick with input from Child Health, Medical Statistics, Health Economics, Consultant Paediatric Orthopaedic Surgeon and the Foundation for People with Learning Disabilities

Postural Care CIC will continue to support this pioneering work through the management of the licensed trainer network and the UK Postural Care Network. They will also continue to develop course and standardisation material in partnership with the Open College Network West Midlands Region.

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Useful links

Postural Care CIC www.posturalcareskills.com

Skills for Health www.skillsforhealth.org.uk

Children's Workforce Development Council www.cwdcouncil.org.uk

UK Health and Learning Disability Network www.networks.nhs.uk/nhs-networks/uk-health-and-learning-disability-network

Foundation for People with Learning Disabilities www.cwdcouncil.org.uk

Mencap www.mencap.org.uk

Confidential Inquiry into Premature Death of People with Learning Disabilities <http://www.bris.ac.uk/cipold/confidential-inquiry/why/>

Raising Our Sights http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Personal Health Budgets <http://www.dh.gov.uk/en/Healthcare/Personalhealthbudgets/index.htm>

Appendix 1 – Participating PCT Case Studies, Compiled by Pam Truman, Skills for Health

Cornwall and Isles of Scilly PCT

Rosie Yarnall, Paediatric Postural Management Advisor, is employed by Cornwall and Isles of Scilly Community Health Services. This is a relatively new role and has been developed as part of the Paediatric Therapy service redesign, which is currently taking place in Cornwall.

Her post sits within the Paediatric Community Nursing team and is focused on developing a paediatric postural management service, Countywide, working alongside therapists, nurses, other health professional, families and carers. As part of this service development, with funding and backing from her commissioners, Rosie has taken part in the Postural Care Skills pilot.

Awareness Training delivery

The postural care awareness training was delivered to a mixture of family carers, volunteers and trained staff together. Feedback from all participants was extremely positive with the practical sessions being rated particularly highly.

Quotes

“It was refreshing to have parents, professionals from social services and people from the voluntary sector attending. The input from parents was great ...they really kept me grounded. I would recommend that someone in every care location has this knowledge, someone who can cascade the knowledge to other staff. Everyone with a physical disability deserves to be given the opportunity to prevent/correct body shape distortion. This would make a huge difference to their general health and wellbeing.” Karen Whiteside Paediatric Practice Educator Home Care Team

“I wish I had come to this course five years ago. My eyes have been opened.” Awareness training participant

“Postural care should be part of every child’s care plan, to be talked about regularly and openly.” Awareness training participant

“The whole experience has been extremely positive. It has provided me with a blue print for training families, carers and support staff. The participants of the postural awareness training have been absolutely thrilled with the training they received and the assessment tools they took away with them. I am already been asked when the next training will take place. The profile of family centred postural care has been raised throughout Cornwall but there is still a long way to go.” Rosie Yarnall Postural Management Advisor and pilot lead in Cornwall

Knock on effects

'As part of my evaluation of the training I received during the pilot study, I felt I needed to extend my teaching skills further. I have just completed the Preparing to Teach in the Life Long Learning Sector (PTLLS) certificate, which I feel compliments the skills I have already learnt.'

The health commissioners and managers, have been very supportive and kept a close watching brief on the whole of the project. They are keen to use postural care skills within the QIPP framework for children's services.

The profile of postural care has been raised across the services and it is hoped that further Postural Care Awareness training will be rolled out in the near future. However, consistent funding streams, for further training, have not yet been identified.

Other services in Cornwall are becoming interested in this training, including adult learning disabilities services.

Plans and hopes for the future

- To roll out postural care awareness training across the whole of the county
- To work with families, carers and other agencies, to provide postural care training, where possible.
- To ensure Professional Care organisations working for the health services are trained in Postural Care Awareness, using this as the baseline competency for care staff working with children in Cornwall & Isles of Scilly
- To work with health commissioners and review the use of Postural Care skills training within the QIPP framework & consider how it fits within CQC
- To extend this work into educational settings

Derby City PCT

NHS Derby City is the local primary care trust (PCT) for Derby and is responsible for health care across the whole of the city. The PCT commissions a wide range of services to ensure that the right health services and support are available for the people of Derby. The PCT boundaries match those of Derby City Council and the two organisations work closely together.

The PCT serves over 280,000 people registered with 34 GP practices in and employs over 1,400 staff including health visitors, district and school nurses; therapists, chiropodists, dietitians, public health practitioners and staff in Children's and Specialist Services, as well as staff in sexual health services, accountants, managers and support staff.

The pilot project lead in Derby PCT is a lead nurse working within the Integrated Disabled Children's Services team, part of Children's Services providing nursing services to The Light House, which provides a residential respite service for children with challenging behaviour and/or children with complex needs.

The nurse lead manages a team consisting of ten registered nurses, one night care assistant and one house keeper.

The PCT funded the pilot agreed through the lead physiotherapist.

The nurse lead is the only nurse training to become a licensed postural care trainer across the pilot sites. She is dual trained as a Registered Nurse Learning Disabilities and a Children's Nurse and has a lot of experience working with children with disabilities and with complex health care needs. She has worked in postural care and in the acute trust within the palliative care team before taking the lead nurse role at the Light House earlier this year.

Awareness Training delivery

The postural care awareness training participants included a parent and sibling, nurses and physiotherapists with a total of eight recruited to the training, two under the proposed number.

Quotes

"All of it has helped" Awareness training participant

"Everyone who works with children should do this training" Awareness training participant

Perceived Benefits of being a nurse taking part in the pilot

Provides direct nursing support to children as part of a residential respite service

As care includes overnight support for children it has been easy to apply learning from project, for example, night time positioning

It has been easy to direct others delivering care at the Light House so that learning is spread across the team delivering care for children across a 24 hour service.

Input of specific knowledge and skills based on nursing experience

Three day training session – could influence training in nurse related aspects, for example pain control and thermal control

Perceived Disadvantages of being a nurse taking part in the pilot

Terminology during the three day training session was sometimes physiotherapist related so not always easy to understand

Plans and hopes for the future

To implement plans based on learning from project ensuring appropriate postural care and sleeping system support is provided to children receiving respite care at the Light House particularly at night.

To raise awareness of parents of children receiving respite care over night through the eight awareness session trainees. Fifty to sixty children use the service each night with each child receiving approximately 3 nights respite care a month. Over a year this will target a significant number of families.

Over time to roll out to all families with children with complex needs.

Personal development opportunities perhaps seeking a role with a higher postural care component to it.

To quantify and provide evidence of benefits offered to children and families within the Light House.

To focus on one child from awareness session learning focusing on providing an evidence basis, for example, using AMI measurement and producing a case study working with and including child's parent.

Aim to replicate with other children in the Light House with other awareness session participants.

Plans to discuss learning from project with line manager drawing up plans to extend across the city and county.

NHS Knowsley

NHS Knowsley provides primary health care services for its local people through its own staff and through contracts with local GPs, Dentists, Pharmacies and Opticians

It works in close partnership with Knowsley Council's Directorate of Wellbeing Services, incorporating social care, leisure and culture in a partnership called Knowsley Health & Wellbeing.

NHS Knowsley provided the match funding for the pilot project.

The project lead's role is a Clinical Specialist Physiotherapist, Pre School, a role that sits in the integrated targeted and specialist paediatric team. The team consists of physiotherapists, occupational therapists, speech and language therapists and community nurses.

Awareness Training delivery

Following the initial awareness information day thirty one attendees of eleven professions attendees expressed an interest in becoming learners, of which eight went on to take the awareness training. The information day posed the question of how we could make postural care blossom in Knowsley.

Awareness training participants were four community nurses, an assistant practitioner, a mum, and two teaching assistants supporting children with additional educational needs. three community nurses, a physiotherapist...

All participants rated all aspects of the training at the highest level describing the training as excellent, informative and useful. The theory was excellent and the practical brought it all together. Participants thought as many people as possible should be targeted and trained.

The project lead has extended awareness raising beyond the eight learners through:-

Making a presentation about the postural care work to the Knowsley Learning Disability Partnership Board who requested more information about postural care in the borough. The Board aims to ensure people with learning disabilities in the borough have better quality lives. The meeting at which the presentation was made included self advocates, carers, private and voluntary sector partners and health and social care staff.

Talking on the accredited Simply Sleep course to a wide variety of attendees

Training therapy staff on hip migration and hip X Rays.

The introduction of an hour long weekly measuring club to improve knowledge and skills.

Delivery of awareness of postural care to all paediatric therapists

Delivery of three taster measuring sessions at each group supervision session to introduce all staff to using the Goldsmith Indices as an outcome measure

Has been requested to deliver awareness session to a group of commissioners

Distribution of DVDs to specialist nurses and advised who to share DVD information with.

Has met with workforce development about developing the role for Assistant Practitioner in postural care in the future with plans to put forward a business case to secure funding to take this forward.

Quotes

“It has been a privilege to make so many aware of the importance of postural management and assist in its implementation from families at the centre to all involved with children to help protect body shape”

Jane Nurney, Clinical Specialist Physiotherapist, Pre School and pilot project lead.

“Although I’m not involved in the project I want to say that I think it is brilliant. The training that I came to was very thorough and what I liked particularly was the service user involvement.”

Ruth Ball Occupational Therapist at The Lifehouse

“I feel the information Jane provided was extremely relevant and enhanced the training for everyone.” Jane Rossiter, Senior Portage Worker Integrated Children’s Disability Service

“I found the postural care awareness sessions very insightful. It was really useful as a refresher on postural care especially the 24 hour management of it, but also gave me a greater appreciation of how night time postural management can be of huge benefit to older children with greater deformities and how it can help to reduce these. I have found completing joint assessments with the children useful especially with children with more complex issues as it helps to discuss and problem solve these to achieve the best position for the child. I have also found it beneficial to do the measuring jointly as a learning exercise I think it works well when completing this on a child. I think it is also good that we have an outcome measure so that we can monitor and record changes to a child’s posture. I think this also links in really well with the current work we are completing for the paediatric therapy team on night time postural management.” Michelle Bamford, Senior Paediatric Occupational Therapist St Helen’s Hospital

“Great to see comprehensive evaluation. I have heard good feedback from other professionals. I think the next phase is to perhaps look at how we embed this with the acute trusts and with other community providers, schools etc “ Assistant Director, Commissioning for Children

“From the point of view of Knowsley Learning Disability Partnership Board, we were extremely interested in your project and wanted to have further discussions involving Department for Children and Family Services and commissioners regarding the possible expansion of this work into adult services creating consistency of care from childhood through transition and into adulthood. As you will recall we were especially interested in your own evaluation – including reduced hospital visits/admissions, reducing related health problems and improving people’s lives. We hope that this may show postural care as an area where we can invest to save – not only improving lives but managing resources more effectively.” Stuart Sheridan, Learning Disability Partnership Board Project Officer

“I thought that the course was really interesting and informative. Looking at it from a mums point has made me a lot more aware of the way Elliott is not only sleeping but also just general laying. I am very glad that I went on the course as he has slight curvature and I am able to act on it now rather than it getting worse”. Danielle ,Mum

“I found it very inspirational, motivating and informative, I was delighted to hear that you were leading on bringing this very much needed work to Knowsley.” Johanna Lee, Clinical Lead Nurse Learning Disabilities, Health and Well Being, NHS Knowsley

“I do feel you have started the work appropriately in Children’s services and it MUST now continue through to adult services, your recent session at the LD Partnership board again was very informative and well received by adult services. And of course the chair of the board commented that she and the board will be interested in this work progressing to adult services and hopes a cohort of staff in adult services to work together to see how this can be taken forward. I most certainly will be interested in this.....

Recommendations:

- Primary and Acute adult care therapy services are also aware of postural care and implement it into their way of working, as the DOH rightly so want all people with LD’s to use mainstream health care services. So we do hope that they will be inclusive in taking this much worthy work forward.

Very best wishes in the future with postural care and we look forward in adult services to continuing to work in partnership with you.” Johanna Lee, Clinical Lead Nurse Learning Disabilities, Health and Well Being, NHS Knowsley

“I thought the training day at the wild flower centre was really good. It was nice to get some insight from parents and carers testimonies/presentations.

It has informed our service in terms of looking at the information parents and carers are getting and it has made me think about how I discuss postural care needs with my families. It was also useful to speak with other professionals across children’s and adult services about what their plans are and how we can all promote good postural care with our families”. Stuart Clark, Senior Physiotherapist – now training to become a licensed postural care trainer, Community Paediatric Physiotherapy, Alder Hey Children's Hospital

“I feel I now have increased knowledge of postural management and the importance of 24 hour management, which has often been forgotten due to time, lack of understanding and compliance. However, the importance had now been reinforced and increased understanding and awareness has led me to think about the children on my case load and the possible benefits to them and systems that could be put in place with these children.

Also the simple system which is easier for parents to use and monitor, without them being daunted by the complexity of the equipment or feel it is too much to complete on top of other things, and too much to move etc in the middle of the night. I have found the system easier to use and deal with and therefore easier to explain to parents and get them on board to use it, and understand the importance of night time positioning.

The training and information given has also allowed greater understanding to support the families and support them through the process in a gradual approach rather than backing away or giving limited support due to being used at night when we are not present. It has become a team approach with the parents and area of discussion rather than being forgotten or overlooked.

Hugely beneficial to have someone on the team with skills in the area and increased understanding and links to others, so provide support and guidance if felt it is an area to look at with a child on caseload and someone to discuss this with. Also good to have the skills in team regarding measurement and having an objective measure for the child, family and team to have support regarding why beneficial, which perhaps having had or had access to within the team.

Overall have felt beneficial to the children known to the service, their families and an asset to the team to have and support.” Rebecca Mann, Senior Paediatric Occupational Therapist, St Helens Hospital

"I'm in the process of applying to get on the 4 day posture management course for adults and children with complex disabilities. I'm definitely looking at night time position more in each assessment I do. I have not applied for any sleep systems yet but have had some success using pillows. I'm giving out guidelines with pictures for night time positioning and a brief explanation of why 24 hour posture management is so important. I've found that the staff in supported accommodation have really embraced making changes and I think this is because they understand the logic behind it". Specialist Physiotherapist

"We always find the postural care training and information really useful and informative especially in relation to sleep training. I've seen it twice now and the information and especially the photos of before and after intervention still amaze me". Karen Rigby, Preschool support worker

"I am really pleased I attended the training/information days as it has given me a greater insight and knowledge in how vital postural care management is for our patients and continuous management throughout their lives to identify changes in their posture to address them as soon as possible to prevent further problems". Les Roberts, Therapy Assistant

Plans for the future

Plans for the future include:-

An evaluation of sleep systems and making training on all sleep systems available to the team.

Running more level two awareness courses rolling out the training to education and portage and any other groups who have expressed an interest in postural care.

Training of more parents and anyone who works with children.

Further personal development to include AMI training.

Continue to roll out and improve measuring skills in the team promoting increased use of AMI.

The development of a baseline measurements database.

Further development of the measurement database recording measurements for all assessed children so that recommendation of sleep system provision is based on need.

Establishment of links with adult learning disabilities to roll out postural care to adults services.

Exploring the potential for cross PCT postural care training with the licensed postural care trainer in Trafford.

Developing an assistant practitioner role in postural care management with plans to put forward a business case to secure funding to take this forward.

Leading on setting up a night time postural management pathway and using the pathway to identify need, set up night time postural management clinics, carrying out appropriate interventions and reviewing.

Extending the Night time postural management pathway to include the physiotherapist from adult learning disabilities and the Social services OT's from both Knowsley and St.Helen's.

CWDC - Common Core of Knowledge and Skills

Effective communication and engagement with children, young people and families

Communications skills have been essential for training programme delivery for the project pilot. Training has been delivered to a range of interested parties from parents and colleagues to Board level and communications skills have been adapted accordingly to suit the audience.

The Learning Disability Partnership Board, for example, has specific guidelines for speakers to assist those invited to attend the board meetings to facilitate ease of communication. This is supported with guidelines for written information, an easy word list, guidelines to produce accessible information for a general audience of people with learning disability and a checklist.

Other supporting communication tools used to support the project includes records completion, data base formation and the development of a pathway.

Child and young person development

The project lead works in a preschool environment which includes assessment of babies. Use of the AMI is to enable early identification, intervention and prevention so a knowledge of normal milestones development is essential. A knowledge of behavioural development is essential so that the use of the AMI kit and follow up action is linked to development and also individualised for each child. A child with autism, for example, may take longer to be introduced to a new method of measurement than a child who does not have autism. All assessments and interventions must be paced in line with the child's needs and adapted accordingly, although the earlier the intervention can be done the better.

Safeguarding and promoting the welfare of the child or young person.

All staff are given regular training to the level appropriate for their role.

Supporting Transitions

Strong relationships have been developed with the adult learning disabilities team to take forward learning and initiatives from the project that bridge the transition gap between children's and adults services for individuals with learning disabilities. Postural care is being rolled out to the adult services to ensure continuity of care and maintenance of postural care management standards.

Is there an example here or if not could a hypothetical example be included? No example, comments sound very positive for stage we are at! I am meeting with commissioner for Learning disability next week.

Relationships with local special schools are also strong with cross agency assessments to improve outcomes for the child and facilitate an holistic approach to assessment and intervention.

Multi agency and integrated working

The team is an integrated targeted and specialist paediatric team consisting of physiotherapists, occupational therapists, speech and language therapists and community nurses. There are strong cross agency links between health and education and the team regularly works with other professionals, for example, the child development centre at St. Helens.

Information Sharing

Information sharing through records has extended. Records were shared between occupational therapists and physiotherapists but this has been extended to speech and language therapists and nurses in the special schools. Information leaflets are produced for sharing with signed consent from parents who have signed up to information sharing.

NHS Lincolnshire PCT

NHS Lincolnshire merges the former three primary care trusts serving Lincolnshire known as East Lincolnshire PCT, West Lincolnshire PCT and Lincolnshire South West teaching PCT.

Lincolnshire PCT is one of the largest in the country responsible for the whole of Lincolnshire covering an area of 2,350 square miles, with a total population of 715,000 and 102 GP practices.

The pilot project lead is a Clinical Advisor Children's Occupational Therapist who works in the Family and Healthy Lifestyles Directorate in Children's Therapy Services team. The team consists of Occupational Therapists, Physiotherapists and Speech and Language Therapists and are managed by the Clinical Team Lead Specialist Services.

The Clinical Advisor Children's Occupational Therapist is one of three advisors, the other two being in Physiotherapy and Speech and Language Therapy. The three work alongside three geographical leads each of whom has responsibility for one of three geographical areas within the county.

Awareness Training delivery

The postural care awareness training participants included a parent, an early years support worker, a class teacher for children with additional needs and her teaching assistant, another teaching assistant from a main stream school who works one to one supporting a child, three therapy assistants, an occupational therapist from the children with disabilities team and a residential care officer.

Feedback from the participants was overwhelmingly positive. Feedback indicated 100% highest rating given for training content, presentation and speaker, information and resources and meeting personal needs. Participants reported raised awareness of the need for postural care and increased confidence. The practical sessions were felt to be particularly useful. 80% of participants reported nothing could be done to improve the awareness training whilst 20% thought that extra practical time using the positioning equipment would have been helpful. 80% were keen to put the training into practice.

Most feedback supported the need for more training so there are plans for follow up sessions which include a practical element.

Plans and hopes for the future

The pilot project lead has successfully completed a business case and bid for funding for the entire children's clinical workforce to complete the Goldsmith's two day measurement training. This will ensure all the physiotherapists, occupational therapists and therapists, a team of at least twenty eight staff, are trained in the use of the Goldsmith's measurement indices and tools. The intention is to embed the indices as a measure to establish a baseline and to monitor progress and improvements.

One of the trainees has changed roles and moved to Lincoln County Hospital as a paediatric physiotherapist and links with her will be maintained to extend into the acute sector.

Implementation plans are currently being drawn up for outcomes measurement working towards the Goldsmith's indices as an outcome measure in order to measure the effectiveness of interventions by re-measurement and comparison with baseline data in order to assess improvement and/or ensure maintenance.

Selection of children for measurement is to be determined and consideration given to universal or targeted measurement but it is hoped all children currently seen by physiotherapists, occupational therapists and speech and language therapists will be included.

The postural care lead hopes that the next stage will involve rolling out postural care awareness training to all staff working with children with additional needs. It is hoped that subsequent raised awareness will trigger an interest in postural care that will encourage follow up and signposting and enable practitioners to engage with parents in need of postural care support for their children.

Tissue viability nurse will be targeted because of the number of enquiries about pressure problems in children that are caused by postural problems. Rolling out awareness would highlight the need for postural care to be included as part of the assessment process facilitating appropriate intervention.

Raising awareness sessions for parents are also to be planned to enable parents to better understand the benefits of postural care and to help them support their children's postural care needs and to facilitate improvement in outcomes for the child. For example, a child with cerebral palsy returning to school after the holidays may be stiffer with reduced mobility owing to lack of intervention over the holiday period. The same child using a postural care sleep system and postural care tools over the same period will return to school without any deterioration because the parents can continue to support the postural care interventions introduced in the school. The potential for transformation and improved outcomes is significant if parents' understanding can be enhanced through provision of relevant information, support and trust.

Trafford PCT

THIS Trust jointly manages Trafford Children and Young People's Services (CYPS), which has responsibility for health, social care and education for the 53,000 children and young people in the borough and works alongside other partners such as the local authority and Trafford Healthcare Trust and the voluntary and community sector.

The aim of CYPS is to improve quality of life outcomes by bringing different agencies and services together to provide an integrated service for children, young people and their families, by:

- Joint commissioning arrangements
- Joint governance and management
- Operating a single integrated service delivery process
- Setting up a number of multi-agency services and teams

The pilot project lead in Trafford PCT is a Highly Specialist Physiotherapist who works in the Trafford Children's Therapy Services team within CYPS. The multi-agency team works across the Trafford community caring for children and young people with special and complex needs and their families. Postural care fits well within the remit of this service.

The PCT funded the pilot.

Awareness Training delivery

The postural care awareness training participants included parents, physiotherapists, occupational therapists, a manager from a respite care home, a nurse from transitional adult services and a head teacher from a Specialist School.

There was a charge to attend the training so that a nice venue with food could be provided. This contributed to a really good atmosphere and a feeling that the participants were taking part in something special.

Feedback highlighted that the participants found the practical sessions particularly enjoyable with many indicating that the exercise using the hip straps was particularly insightful.

Quotes

“Our intention of getting involved in the project was to raise standards of quality and care in Trafford. for children with complex needs” Sue Winnington Team Leader

“By the end of the year postural care will be here to stay and part of all therapists’ interventions”. Ingrid Stanfield Highly Specialist Physiotherapist and project lead

“It was particularly useful to gain overall knowledge around the implications and impact poor postural care has on the quality of life and access to learning”. Awareness training participant

“All the training was very useful in helping me to understand the importance of the body functions and how postural care is an absolute must”. Awareness training participant

“Wearing straps on the body gave a real insight into how a child with high muscle tone would feel – a really good practical exercise to do”. Awareness training participant

“I feel it was absolutely the correct decision for a senior manager in school to have an understanding of postural care to ensure an holistic approach with all the needs of the child at the centre of any intervention – including education”.

Head Teacher of a Special School and Awareness training participant

“I found this training a complete learning curve which I found absolutely fascinating. I feel that everyone should be made aware of the importance of postural care i.e. GP, medical staff etc so that everyone concerned can get together to discuss each child/persons requirements/needs. This is as important as every other special need a child/person may have. Postural care is as important as wearing your splints. There should be lots more courses/meetings to reinforce the importance to everyone concerns and further it more”. Michelle, Mum and Awareness training participant

Perceived Benefits of the project

Increase in knowledge and training of Therapy team staff.

A project audit of participants has indicated trainees have improved knowledge and Skills for Health Improved quality of service delivery to clients

The course and training is far reaching having provided the tools to measure outcomes against specific criteria

Completion of case studies will enable development of a long term reflective view

The project has helped to raise the profile of postural care and the Therapy Services team within the PCT and CYPs

It has provided an opportunity for the team to work and learn together thereby strengthening team bonds

Facilitated further improvements in integrated working

Helped to blend knowledge between different professionals, for example, physiotherapists and occupational therapists

Deadlines helped the participants stick with the project which has helped to drive the issues and reduced likelihood of other pressures influencing work.

Postural care is very much a core subject and this has been reinforced by the project.

It has encouraged a whole team approach and whole team sharing of knowledge and skills.

It works across all children and all children's services.

Perceived cost savings by providing training in-house through qualified postural care trainer within service.

Increased networking opportunities.

Provides an opportunity to introduce a new evidence based initiative that improves outcomes for children and increases value added contribution of the team to overall children's services.

Helps to build the portfolio of the team and justify value.

Offers clear criteria on which to base decisions for children and families

Plans and hopes for the future

Plans to hold a follow up day for awareness training participants as part of ongoing audit and to find out how participants used learning.

Aims to influence commissioners through the Task and Finish group looking at equipment costs and funding across services to provide postural night time management. The project will help define what a child needs, his/her individual package of care based on need.

Hopes to influence newly commissioned services and new commissioning pathways.

All of the therapists, occupational therapists and physiotherapists, will complete a two day awareness course so all of the team have the same knowledge and skills.

Working towards income generation around Trafford, possibly extending this within the North West Region.

Link and network with other qualified postural care trainers.

Extend awareness training across other disciplines, health, education, voluntary sector.

Plan to deliver one hour introductory presentation session followed by two day awareness training as follow up for interested parties

For the first year to rely on current project lead and qualified postural care trainer but to consider training other band 7 therapists from different specialisms within the team to become qualified postural care trainers.

Looking to develop clear assessment criteria for relevant interventions, for example, the introduction of sleep systems.

The North West is the only Region that has two PCT participants completing the postural care trainer qualification so may consider linking with the other PCT trainer as it might be useful to combine knowledge and learning, if only for delivery of the first set of training. One person delivery over a two day training course is not good for either the trainer or trainees so lining with another trainer could offer variation for the participants and provide support for the trainer.

Considering the potential to undertake Postural Care's one day measuring training with subsequent input to and benefits for the service.

Wakefield Children's Therapy Services

Mid Yorkshire Hospitals NHS Trust provides paediatric physiotherapy services to children and young people across the whole of the Wakefield Metropolitan District and also Occupational Therapy at the west side of the area. Wakefield District PCT provides Occupational Therapy services to children and young people at the East side of the area. This input also covers schools, inc. special schools that lie within each of those geographical areas. Both these therapy services are integrated across the two therapy specialities and are co-located but with separate management and professional accountabilities.

The pilot project lead is a physiotherapist therefore working for the acute trust. Wakefield District PCT provided match funding for the pilot.

Postural care management has been developed across both sides of the Wakefield district since 2005 following the submission of a business case to invest in paediatric therapies and to support 24 hour postural management equipment.

A small postural care work group from a combined team of physiotherapists and occupational therapists has met every two months since 2005 to take the work forward. The team has worked on all areas of postural care significantly developing uptake across the Wakefield District.

Awareness Training delivery

Awareness training participants included parents and attendees from respite care from both health and social services, education, therapy assistants from paediatrics and adult learning disabilities and a nurse from the childrens complex care needs team.

All participants rated the training very highly finding it all useful, applicable and enjoyable. Feedback indicated that the practical applications and demonstrations were particularly helpful,

Quotes

"I would recommend that everyone who works in a healthcare environment with children needing postural support attends this programme. That all parents have access to this information from the word go." Awareness training participant

"I found the course fantastic. All of it was really useful. It was a real eye-opener to the danger of bad postural sleeping," Awareness training participant.

"The course was fantastic! I am using it all the time at work and keep on telling everyone else about it and why it needs to be done. It's such a simple thing and so easy to do, it is absolutely brilliant. We could really do with some photos....." Allison Morris, Deputy Manager Rosegarth Respite Care Unit

“Historically health professionals have not always been good at including users and the project has been invaluable for promoting parent and user involvement.” Physiotherapist

“As the Wakefield District were already using postural care concepts we had done various pieces of work to support this provision. My task was so much easier then as I had to correlate our existing evidence and carry on and develop it further. We now have a wealth of evidence, resources and contacts to keep on pushing our boundaries and promoting the cause even further. I have thoroughly enjoyed being a part of this project and would like to thank Skills for Health for giving us all this opportunity.” Suzanne Carter, Specialist Physiotherapist in Paediatrics and Project Lead

“This pilot has helped us further develop the service of Postural Care for the families in Wakefield. We have been able to look at our current provision , evaluate our progress and identify potential areas for expansion . It is fantastic that we have been able to get the involvement of parents and a wider range of professionals eg respite centres, ward and schools. It has strengthened these interagency relationships and enabled us ‘bed in’ the knowledge more widely. We know that this will be hugely beneficial to our children and young people, as the skills and understanding of the ‘Team around the Child’ are strengthened. Who knows what influences may impact on us in the future. However we cannot go back, knowledge is not wasted, skills can be utilised and parents have the awareness necessary to change the futures for their children for the better.” Jan Kelly, Clinical Manager Paediatric Physiotherapy

Impact

For professionals:

Lack of awareness within the paediatric therapy team is unacceptable. There is now enough evidence available supporting the need for 24 hour postural care for even the most junior of staff to access. Professionals must become more adept at identifying the children at risk of body shape distortion from an early age. All staff must have funded access to accredited and quality assured training to ensure this.

Professional knowledge gained from this training must be used to provide quantitative data/outcome measures to enlist the support of senior managers and commissioners in order to gain support for further funding for equipment and further training and to support any workforce redesign requirements for service delivery.

For the family;

Families must be empowered to protect and care for their child’s posture whilst they remain symmetrical being given the knowledge and skills required to ensure their child stays straight whilst they grow and understand preventative measures that can be taken.

The best way to ensure this is to provide parents access to accredited and quality assured training, particularly crucial for parents with personal health budgets. Providing the family with knowledge and skills promotes professional/family partnership working and supports the participation agenda. Additionally parents groups may have access to alternative

sources of funding. Groups of parents together can provide a wealth of experience, ideas and support.

For the School:

Schools must also be given the knowledge to understand and embrace the concept of postural care. Partnerships between the therapy team and special schools are good. Collaborative working can be enhanced further by raising postural care awareness in the schools through training enabling school staff to identify the postural care needs of the children attending the school.

Ideal opportunities exist to promote accredited and quality assured training, for example on INSET days. In Wakefield the specialist teachers in the ACCESS team would be ideal targets for training which may then open up postural care as one of the topics required for the non-teaching support staff within the Wakefield area.

Respite Care:

Rosegarth offers an excellent respite service to children in the Wakefield District. It was surprising therefore to find that staff were unaware that a child had been using a sleep system at home.

Knowledge and communication is crucial. With knowledge of postural care the staff would recognise a child at risk of body shape distortion and would liaise with the family to ensure needs based assessment and intervention. An empowered family ensure delivery of their child's postural care needs whilst in respite.

Accredited and quality assured postural care training is therefore also needed for staff providing respite care.

Plans and hopes for the future

Visions of potential for service redesign with a dedicated postural care post adding value to service provision for children and young people with complex healthcare needs.

The awareness training participants were targeted and selected based on current good working relationships and a proposed plan for roll out in trainees areas.

The plan is to roll out into respite care and to the community nursing teams focusing on teams who can support parents.

Some of the awareness trainees are already taking the concept into their workplace.

One of the attendees, a nurse from the adult nursing team is interested in taking the next level course. Another of the attendees, a therapy assistant from the adult learning disabilities service, is interested in taking the next level course.

To develop a standard training package.

To deliver training to physiotherapy team.

To work with adult nursing services to help take steps to reduce transition barriers and risks created particularly for children with complex needs who are moving into adult services.

Kingsland School has requested the course can be run with parents so plan to deliver training to parents with access to funding from parent network groups.

Plans to roll out locally and regionally.

To develop relevant partnerships to take the work forward and to include plans for funding of equipment.

Wandsworth PCT

Linden Lodge School

Linden Lodge School is a specialist sensory and physical college providing education and support for pupils aged three to nineteen with a visual impairment or multi-disabled visual impairment that affects access to learning and for pupils with profound and multiple learning difficulties. Pupils attend as day pupils or as weekly boarders and come from about 28 Local Authorities throughout southern England, attending as day pupils or as weekly boarders.

The Therapy Team

Linden Lodge school buys in therapy and health services from Wandsworth PCT, who provided match funding for the project.

The Therapy team consists of paediatric physiotherapists, one of whom is the project lead, speech and language therapists, occupational therapists and multi therapy assistants. The therapy assistants posts are part funded by the school, the remaining posts by Health. The team work with education staff from the school and a team of nurses and residential officers.

The Therapy Services Clinical team Leader profiled services needed in the school and found that needs did not match provision but as an estimated 70% of pupils are out of borough there have been conflicts over service funding provision and issues around how to recoup costs from out of borough authorities.

As the school has residential pupils the project offered an opportunity to demonstrate benefits of overnight postural care and sleep systems. Five sleep systems were provided to facilitate intervention and evaluation.

Awareness Training delivery

The postural care awareness training participants included five parents, one occupational therapist, two paediatric physiotherapists, a nurse, a learning support assistant and a residential care worker.

For the Postural Care Workshop feedback was elicited via the use of an Evaluation form at the end of the 2 day Basic Awareness course.

10 of our 11 participants were very positive regarding all aspects of the course, although for the professionals (OT & PT in particular), their needs would have been more fully met had the practical element of the course been greater.

The Dissatisfied Participant:

Of 11 participants only one was very dissatisfied (& angry) with the course content & did not feel her needs were met. Ms X's dissatisfaction with the course was clearly evident in her body language & lack of participation throughout the 2 days, although as she began to join in over the final hours of the last day, we had hoped she may have shifted. Her feedback form however, confirmed she remained very unhappy with the course & this was noted immediately prior to participants leaving.

Identifying the Problem:

In an attempt to take remedial action promptly, a frank discussion with Ms X took place on site to establish more precisely the nature of her discontent. Her main issue was that 2 whole days were spent discussing aspects & theory of postural care that she felt, could adequately be covered in 2 hours; & insufficient time was spent covering the practical aspects of actually what to do for her particular child. She also felt the course content had been misrepresented & perhaps would have benefited from clearly stating the aims of the course to avoid disappointment such as her own.

Analysis:

Pre-course information was uniform for all participants. As Ms X was the only individual of 11 to feel the course was misrepresented, it may be considered that her interpretation was the problem rather than the pre-course information itself. Influencing factors may have included unmet cultural expectations; her frustration at her expectations not being met in terms of therapy being 'done to' her child may have manifested as anger.

Remedial Action:

Having identified the issues, possible ways forward were discussed directly with Ms X immediately. This included a joint home visit with Ms X's child's school physio to assess for an agreed Postural Care Plan. Ms X consented this would be an appropriate strategy; School physio was agreeable to the planned joint home visit, however Ms X was unresponsive with post-course email contact to finalise an appointment time. One further email was sent in an attempt to engage Ms X; there was no response. As the School physio has opportunity for more regular informal contact, I suggested that she may enquire if she would like a joint visit at some point.

Quotes

"This training was very new to me; I was at the novice stage, not quite an expert. However, all components extremely relevant."

"The general atmosphere, Very friendly & easy to feel comfortable to join in."

"Thermal regulation - talking about temperature control, core temperature & the effects of not being able to control your temperature."

"Identifying destructive postures & pain & non-pain related behaviours."

"Actually teach how to do this - hands on- to actually help the kids."

"Simply thank you for a fab course and enlightenment and going away with far greater knowledge!"

Plans for the future

The provision of five sleep systems enabled the project lead to trial the systems and compile evidence which has highlighted very significantly improved outcomes for the children, with quite extraordinarily successful results for one child in particular. These case studies will provide compelling evidence to secure home borough funding.

Based on the evidence two boroughs have already agreed funding.

Plans for the future are based on extending the sleep system provision and building up a wider evidence base to secure further funding so that more children can benefit from having a sleep system.

The lead plans to work with other Health Authorities to promote the benefits of postural care including sleep systems liaising with Postural Care CIC where necessary.

Further parent workshops are also planned.

CWDC - Common Core of Knowledge and Skills

Effective communication and engagement with children, young people and families

Highly developed communication skills and systems are required to maximise communication with the children and young people within the school and with their families, who are often out of borough.

Many communication modes are used with the children ranging from simple systems such as switches and go talks to augmented assisted communication devices. Differentiated signing, MAKATON, is used by the Speech and Language Therapists and a tutor runs courses. All staff are encouraged to use MAKATON or a toned down version to develop better communications skills when working with the children and young people.

Objects of reference are used and there are several sensory rooms and a Smart chair system with rails around the school for pupils' training.

Each child has a multi therapy programme folder that travels with him/her. The initial concept was to link this with education, for example, mobility and functional vision assessments but the folder has retained a health focus in practice with the school "G" drive providing cross agency information.

The school believes that education and support is based on partnerships between the school and the family. Parents and guardians are kept fully informed of their child's

progress by several methods, including weekly home school diary, frequent use of email, telephone calls, two formalised telephone contact days a year, school reports, fortnightly

Newsflash and a termly Newsletter. Further communication opportunities are offered by open days, school entertainments and social events where parents can meet the staff informally. Additionally there are annual reviews which the Therapy team attend.

Child and young person development

The school accommodates children and young people aged three to nineteen. All of the therapists' work is acknowledges each child's development stage working on a team approach that enables each child to reach his/her full potential on an individualised basis.

A new pupil is assessed and development plans put into place in accordance with assessed developmental stages.

Safeguarding and promoting the welfare of the child or young person.

All staff are given regular training to the level appropriate for their role. There are regular safeguarding meetings and all children's supervision includes safeguarding elements.

Both the school and the PCT have specified Safeguarding leads known to staff to enable appropriate signposting and so that concerns can be raised and issues followed up.

Supporting Transitions

This area is one that the Therapy team acknowledged as an area that needed improvement. Young people leaving the school move to a variety of settings for example local authority, specialised college, parents and support homes and transition has historically been ad hoc.

In order to improve transition one of the occupational therapists has developed a care pathway to determine how improvements can be made.

Multi agency and integrated working

Multi agency and integrated working, particularly between health and education, is key to working within the school ensuring each child and young person receives the best support available. The school would not be able to function without this and links to the wider medical support are also essential to optimise outcomes. Paediatric consultants, orthopaedic surgeons and tertiary hospital staff both in and out of borough work with the team within the school as needed. Some of the children also have Social Workers. There are currently two looked after children within the school. The wider team also includes music therapists and play workers.

The Principal's vision is of a One Stop service provision for all pupils.

Information Sharing

The therapy team liaise regularly with both internal multi agency school staff and out of borough therapy teams who take over care of the child out of term times. Each child has a multi therapy programme folder which travels with him/her. Parental consent is obtained to ensure information in the multi therapy programme folder is shared.

The school "G" drive IT system is available for all staff to access and there are several systems available for sharing information with families as referred to in the communication section.

Appendix 2 – Postural Care Leader Role

POSTURAL CARE LEADER

A Postural Care Leader may come from a variety of backgrounds. They would need to have extensive experience in a personal and/or professional capacity of protecting body shape by the provision of postural care and to be qualified to deliver postural care training. A Postural Care Facilitator's remit would be cradle to grave and accountable for -

- Development, implementation and monitoring of a 24 hour multi-agency, person centred postural care pathway "It's My Life!" which is divided into 5 steps:-.

Step 1

- a) Identification of need
- b) Identification of stakeholders and building relationships

Step 2

- a) Baseline measures of body symmetry
- b) Making a plan

Step 3

Empowerment of individuals, families and relevant multi agency supporters through accredited and quality assured training

Step 4

Establishing Individualised equipment acquisition in accordance with all established health and safety regulations

Step 5

Ongoing support, measurement, keeping in touch and recording results

Variance Reporting

Throughout this process variation reporting will be facilitated to be led by the person, family and first circle of support.

- Support the development of links to family leadership groups to enhance knowledge and self- help regarding protection of body shape
- Support the development of links to enhance knowledge and support from health and social care professionals
- Raise awareness of the need to provide postural care and signpost the route to protecting body shape