Living Local Postural Care
Project Evaluation

This is one of five projects within the 'Living Local' Programme and part of the East Midlands Joint Children and Adults Services Efficiency Strategy. This Programme is within both Health and Social Care which is targeted at delivering better and more personalised outcomes for young adults (aged 14-25) and adults with complex health needs to enable them to live closer to home and have better, more fulfilling lives. 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 in relation to the Winterbourne View Report and Safeguarding

Safeguarding principles	How does this relate to postural care?
Prevention	• Protecting body shape reduces the need for complex care provision enabling people to be supported closer to home • A clear postural care plan should be in place as early as possible • The use of objective and validated outcome measures is imperative if comparisons of progress are to be made as the child or young person grows • Best practice indicates that hip dislocation is avoidable and chest rotation can be restored. Data should be collected and shared in order to demonstrate progress towards improved outcomes
Improving the Quality and Safety of Care	• The first circle of support, when appropriately trained, are the only people able to decide if a person is safe to use a particular piece of positioning equipment at any given time • Only they can combine specialist knowledge with an encyclopaedic understanding of the individual
Accountability and Responsibility for Quality of Care	• A postural care pathway should be in place with a clear focus on efficacy as well as efficiency • Any person on this care pathway should be made aware of this and a copy of the pathway should be made available in an accessible format • People within an individual's first circle of support should know who should be doing what and when • Outcomes should include measurement of body symmetry, hip status, posture analysis and pain profiling • Robust pain monitoring and relief systems should be in place, particularly for those who do not communicate in traditional ways • Postural care should be included in the Annual Health Check and as part of a person's Health Action Plan
Equality and Inclusion	• The more complex a person's body shape becomes the greater the risk that they will become socially isolated and vulnerable to abuse • Protection of body shape must be viewed as part of a holistic approach to supporting individuals to live fulfilled, pain free lives within their local community close to the people that love them
Accredited Training	• Exposing families to unregulated activities described as training poses a safeguarding and liability risk • Accredited training facilitates partnership working and the development of helping relationships • Training should be quality assured and nationally accredited in order that those undertaking it can be confident of its content and that assessment is robust

How did the project come about?

Following the scandal exposed by the BBC at Winterbourne View a serious case review identified that the best place to care for people with learning disabilities is within their homes and communities where they are known and valued.

It is recognised that the more complex a person's care becomes the more limited their choices are in relation to where they can live, who they live with and who supports them. The further a person lives from those that love them the more likely they are to become victims of abuse or neglect. The following comment is taken from 'The Biomechanics of Body Shape Distortion Commentary" written by Janet Cobb and Alison Giraud Saunders in 2010.[1]

"The consequences of a failure to protect body shape are serious and can be life threatening. First, distorted body shape affects many of a person's choices: where they live, where and how they spend their days, the activities they can enjoy, how they move about (both indoors and out), where they are able to go to the toilet and get changed. People with badly distorted body shape will have fewer choices and require more complicated equipment and much more of the time and energy of their supporters will be taken up with managing the complexities of their care."

A key finding of the report into the abuse and neglect of people living at Winterbourne View was that individuals should receive personalised services that meet their needs. The provision of postural care in a person and family centred manner with clear and objective outcome measures is a good example of how personalised care can be delivered to meet an individual's complex needs.

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[2]. At the same time many NHS services are stretched to capacity and are unable to respond to rapidly changing demographics[3] and new demands on healthcare provision. The Confidential Inquiry into Premature Death of People with Learning Disabilities, due to report in March 2013, was commissioned due to the well-recognised differences in outcome between individuals who have a learning disability and those who do not. Raising Our Sights recommended the development of dysphagia services, recognition of pain and distress in people who are unable to communicate in traditional ways and postural care services to support the needs of people with complex and continuing healthcare needs[4].

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 Their

[1] Cobb, J. and Giraud-Saunders, A., Commentary on 'Biomechanics and Prevention of Body Shape Distortion', *The Tizard Learning Disability Review,* Vol. 15, Issue 2, pgs. 30 - 32 , 2010

[2] Michaels, Sir. J. 'Healthcare for All, Independent inquiry into access to healthcare for people with learning disabilities' July 2008.

[3] Emerson, E. 'Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England' June 2009

[4] Mansell, J., "Raising Our Sights: services for adults with profound intellectual and multiple disabilities" Page 24. Tizard Centre, University of Kent. March 2010

Families[5]. 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[6]

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

Individuals 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[7]. 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 chronic disabling conditions and premature death for the children, young people and adults involved.

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. Glover and Ayub[8] 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. It is imperative therefore that the risks posed by body shape distortion are well understood by all those supporting individuals with multiple disabilities.

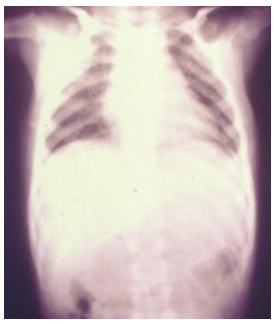
[5] World Health Organisation Regional Office for Europe. "Better health, better lives: children and young people with intellectual disabilities and their families: Ensure good quality mental and physical health care" EUR/51298/17/PP/5. Page 3. October 2010

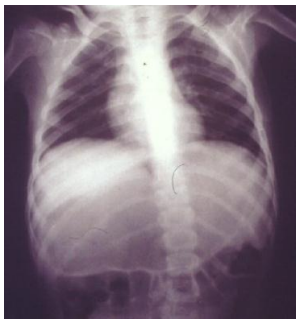
[6] www.mencap.org.uk/posturalcare

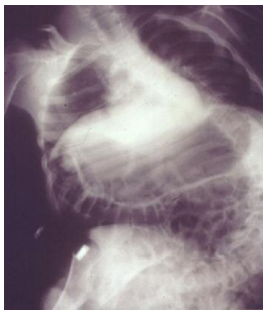
[7] Hill, S. and Goldsmith, J., 'Biomechanics and Prevention of Body Shape Distortion', *The Tizard Learning Disability Review,* Vol. 15, Issue 2, pgs. 15 – 29, 2010

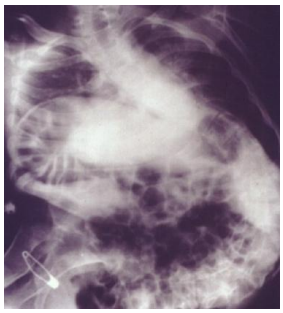
[8] Gyles Glover, G. Ayub, M: "How people with learning disabilities die." Improving Health and Lives: Learning Disabilities Observatory. Supported by Department of Health. June 2010

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 1


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 the understanding of families as well as health and social care practitioners in order that the avoidable nature of body shape distortion be acknowledged and understood. It is only with this understanding that outcomes relating to body shape distortion for people with complex healthcare needs will improve.

Sir Jonathan Michael's inquiry Healthcare for All 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 practitioners coming into contact with families that include children and young people with mobility problems are competent to provide safe and accurate advice, support or signposting to the relevant service in relation to postural care.

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[9]. Whilst this project did not address issues

[9] Department of Health: "Understanding Personal Health Budgets." Spring 2012

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 social enterprise working to develop accredited protection of body shape training for people with movement difficulties, such as children with cerebral palsy. They provide quality assured, accredited training in both therapeutic positioning and validated, non-invasive measurement of body symmetry. For a number of years now the organisation has worked with family leadership groups such as Partners in Policymaking and is 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. In 2010 they were shortlisted for an Accolade Award for Most Effective Practice in Workforce Development across Partner Agencies. Postural Care CIC provided the quality assured and externally accredited training undertaken during the project and were responsible for this evaluation.

What did we do?

The project brief contained the following aims

- To deliver interventions that build levels of knowledge and expertise in applying postural care techniques to ensure that people with complex needs receive the support they need to protect their body shape 24 hours per day
- To challenge assumptions that distortion of body shape is inevitable for people with multiple disabilities
- To 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

At the beginning of the project two introductory sessions for therapists were held in Leicester and Mansfield in order to recruit support and give an opportunity for service providers to have a preview of what would be taught in order to allay any anxiety. Postural Care CIC shared the course content and offered a further 6 training sessions, at no cost to the project, for therapists in order that they would be able to feel confident to play an active part in the courses later in the year. It was felt that this would support practitioners to develop working relationships with others attending the course without appearing to be undermined by an external agency. Throughout the courses the objective was to develop good, open partnership working and it was imperative therefore to remain sensitive to the fact that any dissemination of new information could be perceived as critical of current practice.

Between November 2012 and January 2013 Postural Care CIC delivered 5 accredited postural care courses at Level 2 (Appendix 1). The Postural Care Award is recognised nationally at Level 2 and is included on the Qualification Credit Framework (QCF). The content of each course included: Identification of need; recognition of pain and consent; understanding how and why the body changes shape; understanding the principles of 24 hour postural care; achieving thermal comfort and delivering postural care in a person centred way.

What happened?

A total of 186 learners were registered for the level 2 Awareness course, of these a total of 159 submitted evidence which has been verified as meeting the course requirements. This equates to a pass rate of 85.5%. These learners will be receiving their certificates during March 2013. 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…	Excellent %	Good %	Acceptable %	Poor %
The course content	89	11	-	-
The presentations and information	93	7	-	-
Information and resources	88	12	-	-
The venue and refreshments	74.5	24.5	1	-
Were your needs met?	82	16	2	-

The comments below are a representative selection from the learner's feedback. A recurring theme was that even experienced practitioners 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, young people and adults at risk of body shape distortion.

Which part of the training did you find most useful?

- All of it - have learnt so much and have taken away with me so much new knowledge
- All of it - resources were really excellent
- Working at the table with group and looking at different postures. This course is excellent
- To actually understand which way bodies are distorted to understand how to assist with postural care
- How it can change people's shape, how to review the posture and it has given me motivation to try and use this
- Thermal care/ safety checklist/ pain.non pain - EVERYTHING!
- Practical parts, things which can be used during daytime at school. Learning theory behind practice and understanding the importance. The whole course is fantastic
- All of it very applicable, wish it had been part of my LD nurse training course in 1985-88
- All of it really, but really enjoyed the films and practical elements
- Just learning how people's body shape can be improved so easily & how to do this in practice
- I found the group work useful as we could collate information to get the best answers, and how passionate the tutors were had an effect to want to make a change
- I have learnt an awful lot in 2 days! Thoroughly enjoyed all of it. Explanations were thorough, various teaching techniques used to keep everyone involved. Your enthusiasm (all 3 of you) radiates and inspires. Thanks!

What could be improved?

- Having a practical part to practice measuring on each other would have been useful. Seeing equipment and have a play
- Slower pace as a lot of info in a short space of time
- A lot of information in 2 days
- Having longer to discuss equipment available for postural care. Maybe some examples
- I thought the pace was good but a lot of people wanted to talk a lot, so maybe more time to share experiences
- Nothing - unless you know where we can get our hands on funds or make people realise how important this is
- Information on how we can put postural care into place. ie funding and support for parents/carers
- Opportunities for more practical practice
- Needs to be given to Paediatricians to pass on to orthopods, spinal surgeons, etc

Is there anything we can do to support you in the future?

- More training please - I would like to train others, maybe speak at one of my parent partnership meetings or at a new cerebral palsy forum in Lincoln
- As a student nurse I think this should be a compulsory course for every Learning Disabilities student
- Continue to run these open access courses
- Consider increasing awareness amongst parents/families in this area, to offer sessions to introduce topic eg at schools
- Send any new information on funding/help by email
- Yes - I will be in touch re more input for our OT's and how to promote better posture in the county
- Information on further courses. Contact numbers for related support
- Information re equipment - costs etc. Support in educating staff in workplace. Support in outcome measurement. Collaboration in audit/research re:postural care
- We are hoping to get this in our service and pass information and knowledge on to others & hopefully get this training for staff within our service
- More training

Self-assessment of skills relating to postural care

The self-assessment was completed before and after the course. The skills audits were used to develop a skills profile of the average course attendee (Charts 1 and 2) as well as being consolidated for all the learners as a group who completed both audits (Charts 3 and 4).

The self-assessment audit is based on a skill set of 30 items with the increasing size of the line / 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

Without exception learners identified an increased confidence in their skills in relation to postural care. The self-assessment process is not an independently verified measure of competence however it does give a reasonably good indication of how individuals feel about each of the necessary skills.

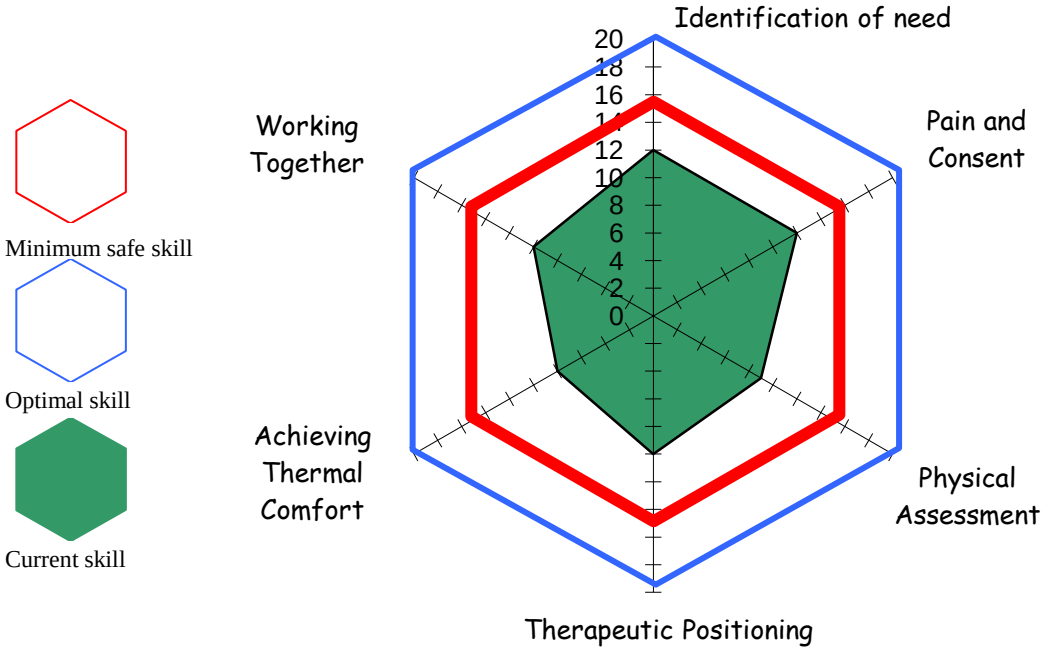


Chart 1 Average of 125 Postural Care Self-Assessment Audits Pre Course

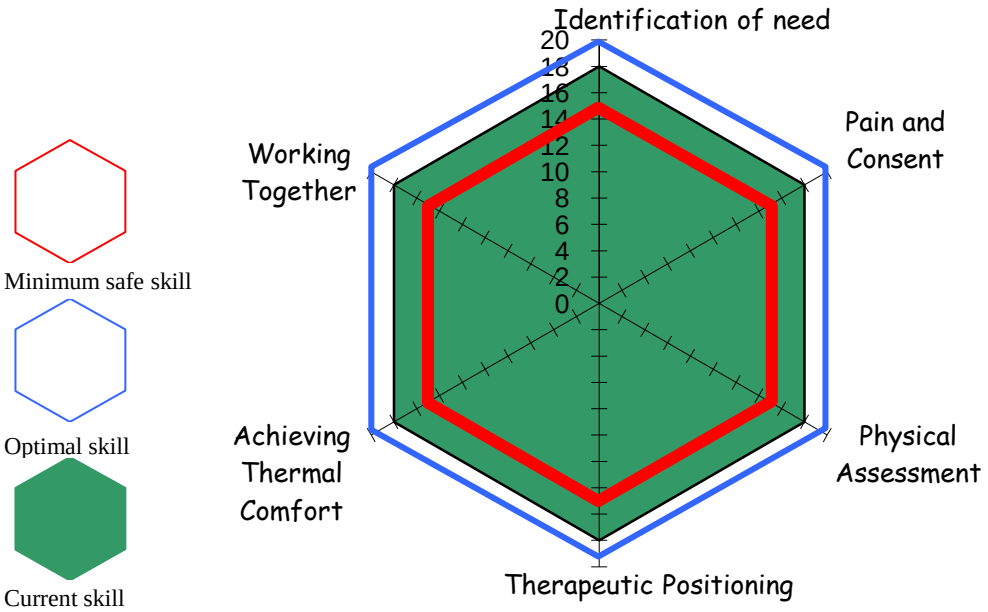


Chart 2 Average of 125 Postural Care Self-Assessment Audits Post Course

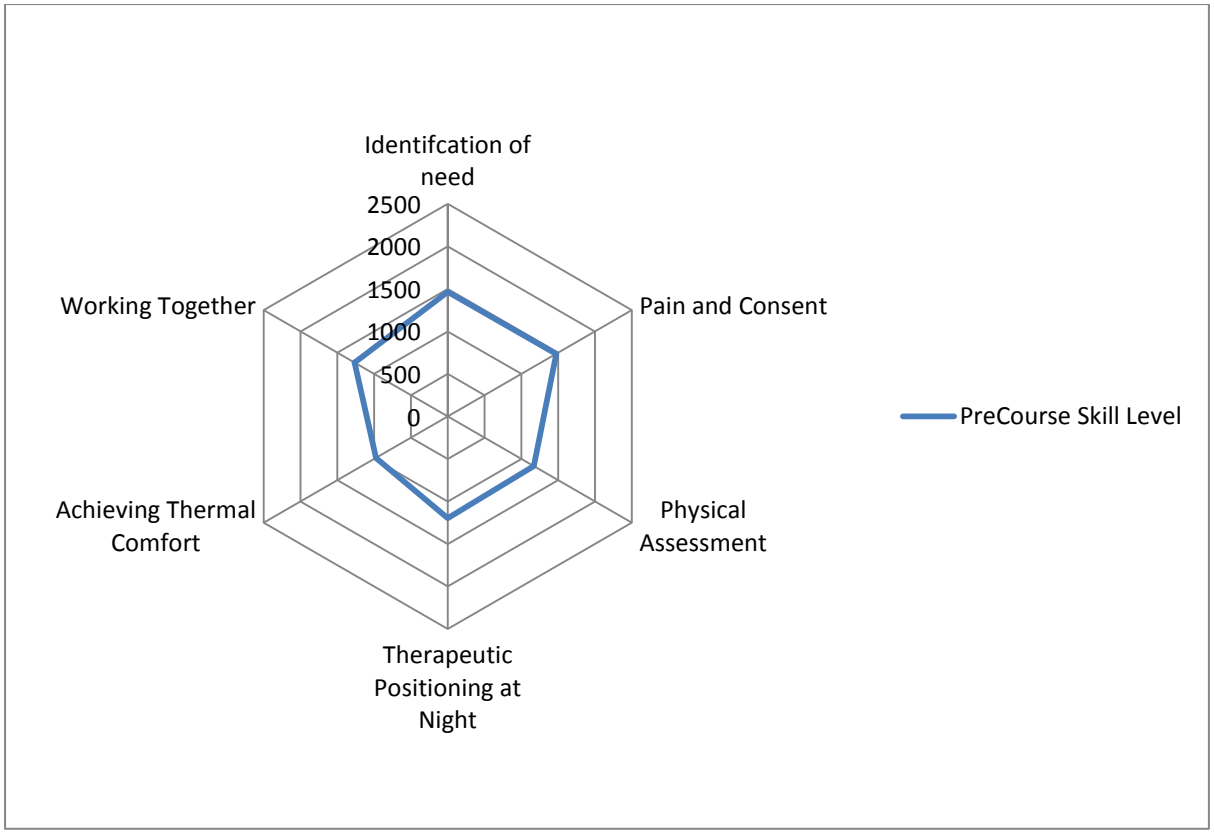


Chart 3 Pre Course Self Assessed Skill Level East Midlands 2012

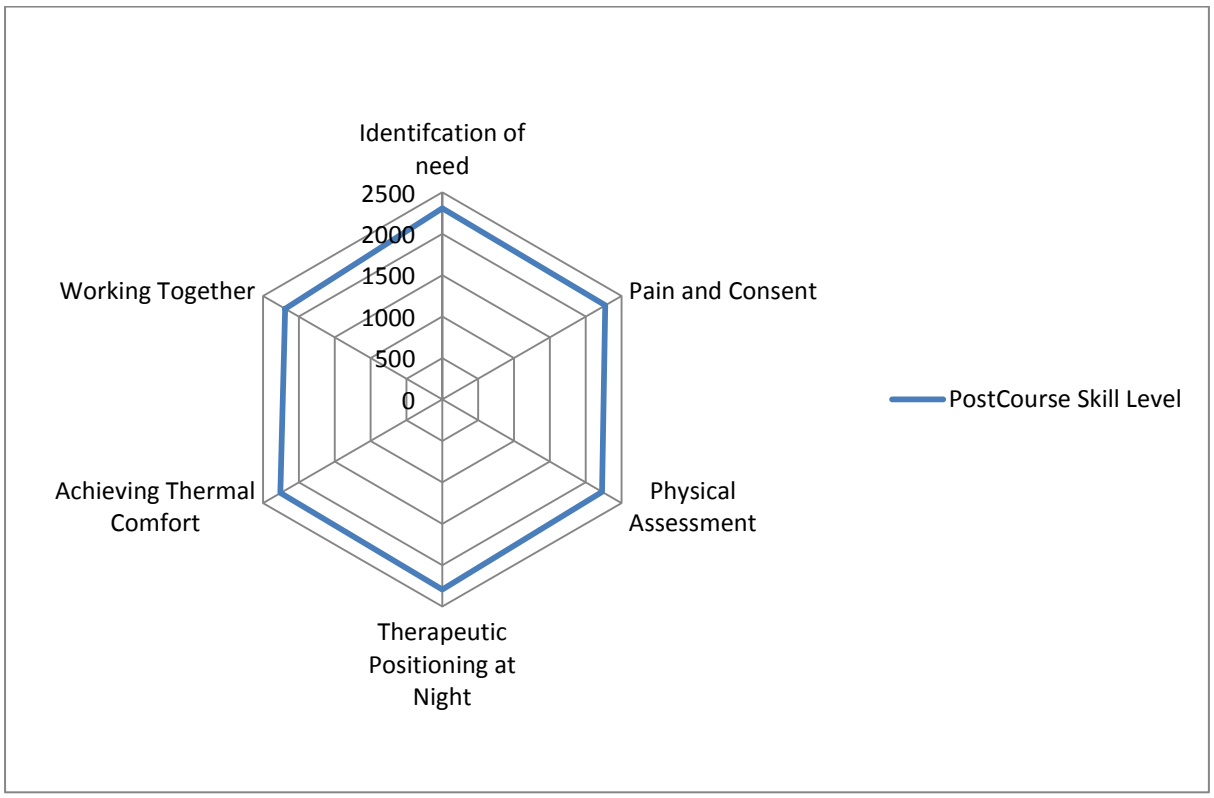


Chart 4 Post Course Self Assessed Skill Level East Midlands 2012

What did we learn during the training process?

The self-assessed skills audits reflect a gap in knowledge and awareness of both health and social care practitioners attending the courses. Whilst there were a number of well-informed therapists poor general awareness of postural care is an issue that needs to be addressed in order that those who need support are easily identified and intervention provided in a safe and effective manner.

Whilst knowledge of postural care was limited there existed an impressive and comprehensive understanding of the support needs of people with complex disability. The Safety Planning, Helping Relationship (Appendix 2) and Impact of Body Shape Distortion (Appendix 3) group exercises reflected a broad, compassionate and person centred value base. This person centred philosophy would provide an excellent foundation from which postural care provision could be developed.

The need to widen the gateway to information and provision is clear, the possibility of task sharing with other health and social care practitioners should be considered. This approach has been adopted in fields similar to postural care such as the Trusted Assessor Role.

Recognition of Postural Care provision as a Safeguarding Issue

Changes in body shape are increasingly recognised as an avoidable secondary complication for individuals who find it hard to move. This shift in our understanding requires a similar change in the way we design and deliver services. Following the abuse at Winterbourne View a Serious Case Review highlighted a number of key implications for service providers. These findings should be considered in relation to postural care and are summarised at the beginning of this evaluation.

Recognising Pain and Distress

As part of the course learners were asked to think about a person they know well who does not communicate using words. They then completed an adapted version of the Paediatric Pain Profile developed by Dr Anne Hunt. The average pain score from 157 participants was 10.80 'On a Good Day' but when thinking of the same individual 'On a Bad Day' the average was 27.15. Dr Hunt's original research stated that a pain score of 14 could be considered to indicate 'moderate to severe pain'. The highest score given 'On a Good Day' was 42, and 'On a Bad Day' was 54: the highest possible score is 60.

During the courses the following were repeatedly cited as causes for increased pain: body shape distortion; periods of illness; ill-fitting or inappropriate equipment; lack of changes in position; active interventions such as stretching and the use of standing frames.

The recognition of interventions carried out in the name of therapy that cause pain and distress is not new. In 2003 the NSPCC report '"It doesn't happen to disabled children; Child protection and disabled children[10]" acknowledged that "We still come across situations where child care professionals do not believe anyone would abuse a disabled child; where the child's pain and

[10] NSPCC 'It Doesn't Happen to Disabled Children' Child Protection and Disabled Children. Report of the National Working Group on Child Protection and Disability. 2003

distress is not recognised; where abusive practices are seen to be necessary because of a child's impairment." There is an urgent need to investigate these findings more closely.

Listening to people

It became clear during the course of the training that the vast majority of practitioners present acknowledged that they did not have a full understanding of how and why the body changes shape with the exception of some therapists. This lack of awareness makes the job of advocating for an individual at risk of body shape distortion almost impossible. If health and social care practitioners are unaware of the avoidable nature of body shape distortion then family carers are at an even greater disadvantage. There is a need for open and honest communication in order that people have a true understanding of current service provision, this communication is obscured at present by a lack of awareness, defensive attitudes from some practitioners, the use of medical jargon that may not be understood and a lack of reliable outcome measures.

In terms of safeguarding we must consider the risks faced by individuals if those supporting them do not have the knowledge or language to highlight concerns or to hold service providers to account. It is imperative that accessible tools such as the adapted pain profile are available, are used regularly as part of on-going support and monitoring systems and that family carers or personal assistants are valued and recognised as having a wealth of knowledge about the person they love or support.

Further barriers to change lie in the historical commissioning of services. Traditionally services responsible for postural care provision lack robust objective outcome measures, in part due to underlying sense of inevitability – why measure something you cannot prevent? Validated measurement of body symmetry, available since 1992, provides invaluable data and should form part of an individual's annual health check and health action plan as a method of improving the general healthcare and physical health of those at risk of body shape distortion.

There is a need to anxiously examine service provision with a focus on outcome – a shift from measuring efficiency to measuring efficacy. Assumptions have been made that a 'good' service can be identified through examination of service delivery – how quickly people are seen, how often they are seen, how quickly equipment is provided. Whilst some of this is important the key to knowing whether the service is effective is to measure the effect that it has on the people that access it – is body shape being protected? If we do not know the answer to this we may be tempted, in the light of growing demands on services, to do more of the same, to have more therapists so that we can be more efficient – but are we any more effective?

Listening to people must also include listening to the experiences of other service providers. Comparison of body symmetry data allows areas of good practice to stand out, Wakefield for example where, in 2010 at the time of the Mencap campaign there were no children or young people aged between 0-19 who have hip dislocation. How does this figure compare to services in the East Midlands? What do they do in Wakefield to achieve such success? Paediatric therapy services in Lincolnshire have a CQUIN relating to standardised and validated measurement of body symmetry – awareness of this is growing amongst family support networks and needs to be

reflected across the region. In contrast the use of non-validated measures is logically indefensible and would not occur in other fields of service provision.

In conclusion

Protection of a person's body shape reduces the risk that they will experience secondary problems in relation to both their health and social care. There is currently a lack of awareness amongst many health and social care practitioners of the principles of postural care and protection of body shape. The more distorted a person's body shape the more likely they will be to need specialist support which may not be close to their home or community. There is a need to listen to people that access services, to their pain and distress as well as to what their body is telling us about how effective our interventions have been. Partnership working and the formation of helping relationships between those providing services and those providing hands on care and support is essential. Further training is needed to drive awareness of postural care and service development across the region.

Useful links

Postural Care CIC www.posturalcareskills.com

Postural Care elearning www.debramooreassociates.com

Skills for Health www.skillsforhealth.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 Postural Care Campaign www.mencap.org.uk/posturalcare

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

Appendices

1. Postural Care Level 2 Award
2. The Helping Relationship Group Work
3. The Impact of Body Shape Distortion Group Work

Unit title:	Postural Care Awareness
Level:	Two
Credit value:	3
GLH:	24
OCNWMR unit code:	PT1/2/NQ/016
QCF unit reference number:	K/503/6042

This unit has 6 learning outcomes.

LEARNING OUTCOMES	**ASSESSMENT CRITERIA**
The learner will:	**The learner can:**
1. Understand the need for postural care.	1.1. Describe risk factors within an individual's posture and movement. 1.2. Identify organs in the body from x ray. 1.3. Describe factors relating to posture and movement that will affect an individual's health, social and psychological wellbeing.
2. Be able to identify pain and non-pain related behaviour in individuals who are unable to communicate.	2.1. Carry out an assessment of pain and non- pain related behaviour. 2.2. Score and interpret an assessment of pain and non-pain related behaviour.
3. Be able to distinguish between destructive and supportive postures.	3.1. Assess postures using a Posture Analysis checklist that identifies destructive and supportive postures. 3.2. Predict potential distortion caused by habitual postures.
4. Understand how to apply 24 hour positioning safely and humanely.	4.1. Describe patterns of sleep. 4.2. Identify environmental factors necessary for good positioning. 4.3. Identify risk factors for 24 hour positioning. 4.4. Carry out safety planning for 24 hour positioning.

LEARNING OUTCOMES	ASSESSMENT CRITERIA
The learner will:	**The learner can:**
5. Understand the principles of achieving thermal comfort for people needing postural care.	5.1. Describe the implications of having disturbed heat regulatory reflexes. 5.2. Describe the problems associated with inability to apply heat seeking and heat avoidance behaviour. 5.3. Describe potential solutions to achieve thermal comfort.
6. Understand external factors affecting the provision of postural care.	6.1. Describe external factors that may affect the provision of postural care.

Assessment information

Guidance:
This grid gives details of the assessment activities to be used with the unit attached. Please refer to the OCNWMR Assessment Definitions document for definitions of each activity and the expectations for assessment practice and evidence for verification.

The assessment activities for this unit are indicated in the table below:
Key: P = Prescribed – this assessment method *must* be used to assess the unit.
O = Optional – this assessment method *could* be used to assess the unit.

Case study	**O**	**Project**	**O**
Written question & answer/test/exam	**O**	**Role play/simulation**	**O**
Essay		**Practical demonstration**	**O**
Report	**O**	**Group discussion**	
Oral question and answer	**O**	**Performance/exhibition**	
Written description	**O**	**Production of artefact**	
Reflective log/diary		**Practice file**	**O**

Purpose and aim of the unit	Promote awareness of the risks and benefits of protection of body shape. Encourage the safe and considered use of therapeutic positioning in order to minimise risks to all involved.
Unit review date (01/11/2011)	01/11/16
Details of relationship between the unit and the relevant NOS or other professional standards or curricula (if appropriate)	N/A
Specific requirements about the way the unit must be assessed (if appropriate)	N/A
Guidance for developing assessment arrangements for the unit (if appropriate)	N/A
Support for the unit from a SSC or other appropriate body (if required)	Skills for Health
Sector Subject Area (SSA)	1.3
Owning body	OCNWMR
Date from which unit will be available for learners	01/11/11
Availability for use	Restricted – open to a defined group of AOs to award credit

EMP Learning Outcome 6: The Helping Relationship

"There is a certain kind of helping relationship in which one person helps another to make increasingly good decisions" Carl Rogers

What works?	What doesn't work?
Being treated as an individual	Being judgemental
Good communication	Not doing what you say you are going to do
Trust	Changes of personnel / poor handover
Empowering people	Lack of understanding of the other person's circumstances
Negotiation and compromise	Being unkind / spiteful / hurting people
Non judgemental	Misusing power/ enjoying power over others
Empathy / walk a mile in my shoes	Being Bloody minded / Enjoying a fight
Consistency	Being useless and drinking someone's coffee
Active listening	Lack of communication
Watching the person with empathy if they cannot talk / Pain Profiling	Not being efficient
Honesty	Not being trustworthy / not trusting others
Giving time	Not having the right knowledge
Being available / contactable	Not being up to date
Having knowledge and experience	Unrealistic expectations
Having appropriate boundaries	Telling people what to do
Having defined responsibilities	Demanding "compliance"
Defined goals	Not giving time / taking up time for nothing
Choice / supporting the family's choice	Power imbalance / one has all the power / the other does all the work
Appropriate confidentiality	
Being open	Not getting back to people/ not returning phone calls
Being realistic	
Treating the family as experts	Having no control
Acknowledging each other's expertise	False promises
Being realistic	Criticising / treating people like children
Working together to solve problems	Pushing services onto families
Partnership working / including as a team	Patronising people / belittling them
Natural rapport / liking each other	Disciplinarian approach / dictating
Acknowledging when things are not right	Service led / institutional abuse
Moving on / passing responsibility to someone else if things are not right	Inappropriate language
	Not being adaptable
Respecting the family's priorities / understanding needs of the rest of family	Typecasting people / condemning them / making sure a bad reputation is perpetuated
Forgiving / making a fresh start	Assuming superiority over others
Suggesting / informing / not imposing	Being negative / depressing / pitying
Practical help	Not helping / adding to difficulties
Kindness / common sense / humour	Not making an attempt to learn what it feels like to be that person
Gentleness / Love	

Physical, Social and Psychological Impact of Body Shape Distortion

Learning Outcome 1 AC1.3

Physical Impact

Body shape distortion may have an impact on the following:-
Pain and distress: Breathing: Need for medication and complications of multiple medications Digestion: Infections: Constipation: Loss of field of vision: Weight loss – dysphagia – swallowing Malnourishment/starvation: Pressure areas/sores: Risk of drooling: Immobility: Abnormal muscle tone/spasm: Low immune system: Bowel problems: Reflux / vomiting: Heart function affected: Circulation: Bone density: Hip dislocations / chest distortion / contractures /scoliosis: Sleep deprivation: Unable to go through puberty: Loss of sexual function

Social Impact

Body shape distortion may have an impact on the following:
Loss of dignity: need for large equipment: Reduced access: Stress – person, PA's, family: Need for much more time for personal care time: opportunity for all other activities reduced Communication problems: Reduced physical contact – reduced intimacy: Breaking of relationships: Expense of care increased, poverty: Less life enhancing opportunities / relaxation / enjoyment: Loss of independence: Dependent on others: Need for benefits increased: Loss of spontaneity for all the group: More exclusion & restrictions: Life becomes small: Risk of abuse and brutality increased: Privacy reduced and yet no time to be alone: People in your life who are uninvited, maybe unwanted: Stereotyped and de-humanised: Opportunity to love, care: Providing priceless life lessons, what is important: Sense of proportion: Sense of spirituality: Sharing rare gifts: Understanding of mortality: Gratitude for blessings

Psychological Impact

Body shape distortion may have an impact on psychological wellbeing in the following ways:-
Loneliness: Fear: Lack of motivation: low self- esteem: Loss of identity: Grief: Loss: Depression Worry about other people's perceptions: Justification of your affection: Unconditional love: Fear of the future: fear of other people: defenceless: Assumptions of role of carer: Exhaustion & sleep deprivation: Physical & emotional exhaustion: Anxiety: Distress: Terrified of daily routines: Isolated: Living in fear: Defenceless: Loss of friendships: Loss of human contact: Feeling worthless: Opportunity to share unique gifts if valued