

24 Hour Postural Care: The journey so far in the UK Sarah Clayton. Liz Goldsmith. Tess Ellis

Progress towards protecting body shape has evolved in the UK through the coming together of three strands of development:-

1. New and significant understanding of how and why the body distorts alongside nationally accredited training and equipment innovation.
2. Development of the social model of empowerment and personalisation.
3. Recognition of failure to protect body shape as a cause of premature death and the need for national guidance, indicators and accountability.

1) New and significant understanding of how and why the body distorts alongside nationally accredited training and equipment innovation.

Postural Care is gentle and respectful; it protects and restores body shape, muscle tone and quality of life. Success in the UK is emerging and systems to ensure national guidance, indicators and accountability are developing.

The story began 40 years ago.

1976

Fulford and Brown¹ first suggested that *"the 'squint' baby syndrome and the 'windswept' child syndrome in children with cerebral palsy are stages of the same syndrome and that in both the deformities are caused by the effect of gravity on an immobile growing child, rather than spasticity or muscle imbalance."*



¹ Fulford, GE. Brown, JK. *Position as a cause of deformity in children with cerebral palsy* Developmental Medicine and Child Neurology. 1976; (18): 305-14

In 1976 there was no valid or recognised method of measuring body symmetry and therefore the process of distortion was not understood. Neither the impact of pursuing function nor the effects on the body of long term positioning strategies were monitored. Pressure care to protect tissue viability was established but the need to protect skeletal structures and internal capacity of the abdomen and thorax along with resultant function of the vital organs was not recognised. Distortion of body shape was synonymous with disability and considered inevitable whilst servicing the problem became the foundation of an industry. In the future an ongoing journey towards protecting body shape will ensure a more appropriate use of vast expertise and resources.

1978

Positions were recommended in the light of current knowledge and available equipment in response to various short term issues. Without measuring body symmetry it was normal to persevere with positioning strategies that became dogma and were causing progressive distortion. e.g. *"It takes little more than a couple of years of being consistently supine to incapacitate these children for life".²* The benefits of side lying in the recovery position and alternate side lying in pressure care were well recognised.

1985

Early development of the idea that the family and those providing on-going support need specialist knowledge and skills along with recognition of the importance of pain recognition within the lives of those with complex disability. *"Physiotherapy is still sometimes seen as a separate entity "they go to physio twice a week" but ideally the physiotherapist is an advisor to carers on the daily management of the person, helping to draw up a 24 hour care plan, and advising on or obtaining the aids and equipment required".³*

1986

Further recognition of the need for the social model as well as a clinical care pathway ⁴. However the information provided reflects the prevailing dogma that supine lying was 'wrong'.

² Scrutton, D. *Developmental deformity and the profoundly retarded child*. p83-91. In Apley, J ed. *Care of the Handicapped Child*, A Festschrift for Ronald MacKeith. Clinics in Developmental Medicine No 67. Spastics International Medicinal Publications. 1978.

³ Goldsmith, E. Chapter 3.16 *Physical competence*. In *Caring for people with mental handicap a learning package for nurses*, Section 3 Developing Skills. English National Board for Nursing, Midwifery and Health Visiting. 1985.

⁴ Golding, R. Goldsmith, L. *The caring person's guide to handling the severely multiply handicapped*. Macmillan Education Limited. 1986 ISBN 0-333-38619-1



1992

Publication of an objective and statistically validated measurement technique to measure body symmetry⁵

1996

John Goldsmith invented Symmetrisleep – the first humane support for the lying posture.

1998

Original publication of an analysis of the time spent in different postures during the 24 hour period as well as the need for the individual to be supported in symmetrical positions⁶

2000

Publication of qualitative research⁷ that led to the understanding that families recognised benefits from the provision of lying support at night and that it is a highly complex intervention requiring extensive interpersonal skills in combination with clinical understanding.

2001

In the light of learning with families participating in the Mansfield Project clear safety considerations are identified with published acknowledgement that "*achieving a symmetrical supine sleeping position will have a significant beneficial impact in the long term*".⁸

The years that followed see a rapid accumulation of vast clinical experience which revolutionised both practice and understanding of the need for support. There was an emerging realisation that supported, symmetrical supine lying is the only position in which the body can be effectively protected and that safety planning needs to be completed by those who know the person best.

⁵ Goldsmith, L. Golding, RM. Garstang, RA. Macrae, AW. *A technique to measure windswept deformity*. *Physiotherapy*. 1992: (78) 4; 235-42.

⁶ Goldsmith, J. Goldsmith, L. *Physical management*. In Lacey, P. (Ed) *People with Profound and Multiple Learning Disabilities : A Collaborative Approach to Meeting Complex Needs*, David Fulton Publishers. 1998. 15- 28

⁷ Goldsmith, S (Clayton). *The Mansfield Project : postural care at night within a community setting* *Physiotherapy* 86, 10, 528-534, 2000

⁸ Goldsmith, J. Goldsmith, L. *Developing a service to provide postural care at night*. In Rennie, J ed. *Learning Disability, physical therapy, treatment and management. A collaborative approach*. Whurr Publishers. 2001



2004

Establishment of competence based and accredited qualifications with national recognition for those providing postural care⁹ along with measurement of body symmetry¹⁰ and the principles of de-rotation in the lying posture.¹¹

The course material covers:-

- ❶ Identification of Need: How and why the body distorts with identification of destructive postures and conversely the supportive symmetrical postures which protect body shape, muscle tone and quality of life.
- ❷ Pain and Consent: Analysis of pain and non-pain related behaviours, with development of a baseline score so that pain can be monitored / managed and the individual's consent identified and respected.
- ❸ Physical Assessment: Assessment of body shape and muscle tone to analyse risk / benefit of activities and strategies.
- ❹ Therapeutic Positioning at Night: Understanding of behavioural complexities, physical dangers and disturbances of sleep behaviour in those with movement impairment. Application of therapeutic positioning at night in a safe and humane manner.
- ❺ Achieving thermal comfort: The complexity of achieving thermal comfort when both reflex and behavioural components of thermal regulation may be compromised. Routine monitoring of core temperature and application of appropriate thermal care.
- ❻ Co-producing a Postural Care Plan: Consideration of the challenges faced by families and personal assistants and how support might be offered, including the use of postural care equipment effectively, safely and humanely.

2008

Publication of a person centred postural care pathway that identifies clear safety considerations, accredited training for care providers, use of objective and validated outcomes, family led variance reporting. Support for the lying posture is a fundamental part of a person's postural care and the equipment required sits alongside that needed for seating and standing.¹²

John Goldsmith invents award winning Simple Stuff Works support for the lying posture providing effective, secure de-rotation of body segments and solving thermoregulation, noise and hygiene issues.

⁹ <http://www.opencollnet.org.uk/qualifications/all-qualifications/postural-care>

¹⁰ <http://www.opencollnet.org.uk/qualifications/all-qualifications/measurement-of-body-symmetry>

¹¹ Goldsmith, J. et al. 2004. *Postural Care: Protecting Body Shape*. Accredited Course Text
<http://www.simplestuffworks.co.uk> ISBN 978-0-9935728-0-7

¹² Hill.(Clayton) S. Goldsmith, L. *Posture, mobility and comfort*. In Carnaby, S. Pawlyn, J. eds *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. Wiley Blackwell Publishing 2008



2010

Peer reviewed publication of the predictable patterns of body shape distortion outlining how the chest and spine respond to gravity over time. This includes a summary of the advantages of symmetrical supine lying and the pattern of rotational distortion caused by unsupported lying postures. *"The consequences of a failure to protect body shape are far-reaching and can be life threatening, with reduction of internal capacity of the abdomen and thorax compromising the function of vital organs."*¹³

Hip audit results for 2010 in Wakefield, an area of the UK with an established postural care pathway, indicate significant improvement in outcome for children

Hip dislocations in Wakefield: 1.

Hips dislocations in a neighbouring area with equivalent population but without established postural care pathway: 24.

*"In Wakefield we see the need for orthopaedic surgery as our failure"*¹⁴

The need to protect fragile structures from the downward force of gravity in sitting is acknowledged by use of tilt in space and reclined postures.¹⁵

2011

Simple Stuff Works system wins British Health Trades Association Independent Living Design Award¹⁶

Launch of the Mencap campaign supporting Postural Care.

*"Do you support someone with multiple disabilities or are you responsible for commissioning services for them? If the answer is yes, you need to know about postural care"*¹⁷

National Skills for Health Postural Care Project:

Recommendation 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..."*

Recommendation 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*

¹³ Hill (Clayton), S. and Goldsmith, J., *Biomechanics and prevention of body shape distortion*. The Tizard Learning Disability Review. 2010. Vol. 15, Issue 2, pgs. 15 – 29

¹⁴ Findings published. Carter, S. Tulwa, N. *Postural care in Wakefield: the story so far*. Elijah's Hope Postural Care Conference. Bristol 2015 Download <http://www.simplestuffworks.co.uk>

¹⁵ Carter, S. *Why does postural care work in Wakefield?* 2013. Download <http://www.simplestuffworks.co.uk>

¹⁶ <http://www.bhta.net/content/celebration-excellence-bhta-awards.html>

¹⁷ www.mencap.org.uk/posturalcare



*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.*¹⁸

2012

National recognition of the clinical efficacy of protection of body shape. ¹⁹

"The GDG (Guideline Development Group) consensus was that the movement and positional needs of the child or young person over a 24 hour period should be considered. In assessing the postural management programme account should be taken of sleeping and resting positions..." Page 69

"The GDG considered that training and support of family members or carers was key to successful postural management." Page 70

2013

The East Midlands Joint Children and Adults Efficiency Strategy Postural Care Project produced a number of Recommendations in Relation to the Winterbourne View Report and Safeguarding

- *"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"*²⁰

CIPOLD – established the link between a failure to protect body shape and resultant premature death. The difficulty of multiple co-morbidities is also identified.

Recommendation g:

"CCGs must ensure they are commissioning sufficient and sufficiently expert preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support"

Liz Goldsmith served on the Overview Panel consulting on deaths associated with postural issues.²¹

¹⁸ Hill (Clayton), S. *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. 2011. Download . <http://www.simplestuffworks.co.uk>

¹⁹ NICE Clinical Guideline: *Spasticity in children and young people with non-progressive brain disorders: management of spasticity and co-existing motor disorders and their early musculoskeletal complications.* NICE 2012

²⁰ Clayton, S. *Living local postural care project evaluation.* East Midlands SHA. 2013. Download <http://www.simplestuffworks.co.uk>

²¹ Heslop, P. et al. *The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) 2013* Norah Fry Research Centre. IHAL. University of Bristol. DoH. <http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>



2015

Trend identified between objective GIOBS data and respiratory complications²²

Simple Stuff Works system wins BHTA Best Established Product Award²³

Mainstream recognition within the nursing profession of the principles of postural care including the concept of chest rotation published in "At a Glance" series of text books²⁴

2016

Publication of an online eLearning course on 24 hour postural care provides universal access to the required skills, knowledge and values required to deliver effective protection of body shape. The course is accredited by Ofqual and certified as standard by the CPD Certification Service.²⁵

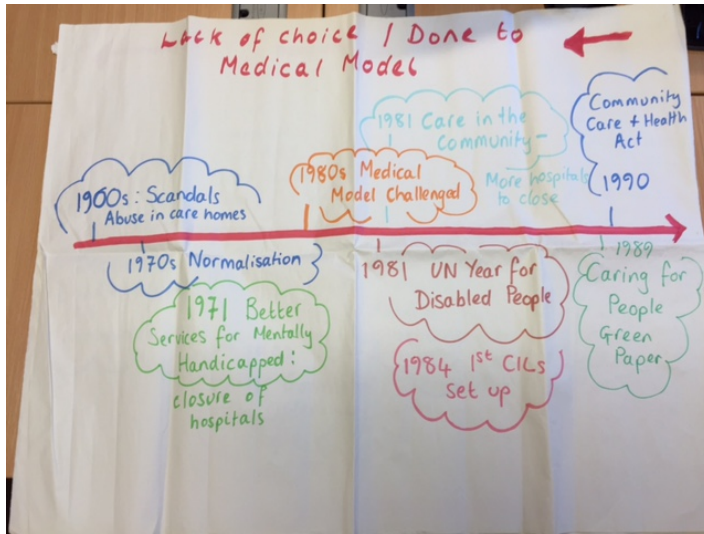
²² Birch, J. Clark, S. Turner, L. *The Liverpool postural care pathway*. Alder hey Hospital, Liverpool Community Physiotherapy Service. Findings presented at ACP Annual Conference 2015.

²³ <http://www.bhta.net/content/british-healthcare-awards-winners-making-difference-peoples'-lives.html-o>

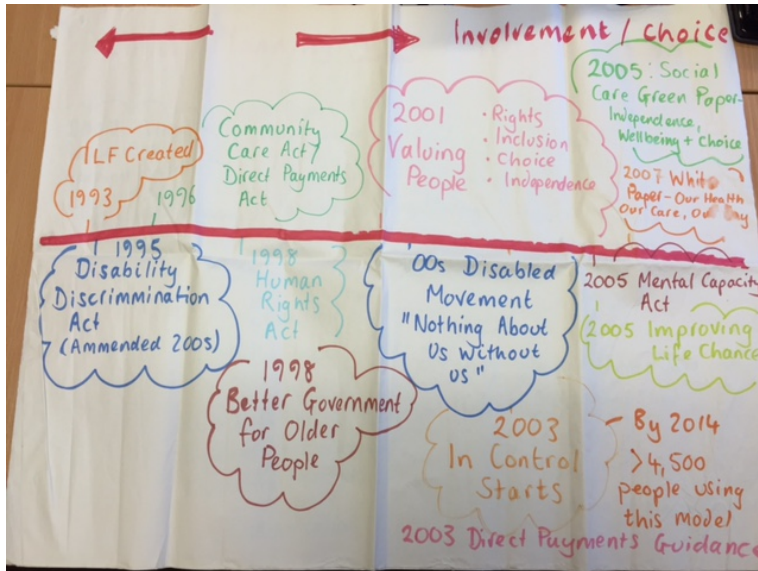
²⁴ Clayton, S. *Postural care*. In Gates, B. Fearn, D. Welch, J. eds *Learning Disability Nursing: At a Glance*. Wiley Blackwell. Sussex ISBN 978-1-118-50613-4 2015. p 100-101

²⁵ <http://biztrainingsolutions.co.uk/postural-care-awareness>

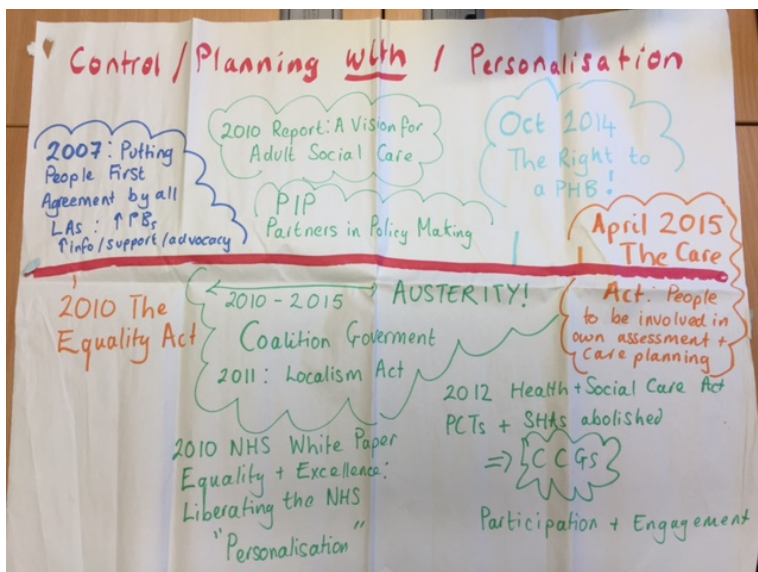
2) Development of the social model of empowerment in the UK



1900s - 1990



1993 - 2005



2007 - 2015



2016

The first family led postural care project is developed by PAMIS and sponsored by the Scottish Government to cover Scotland. Families complete Postural Care training²⁶ ²⁷and support each other in collaboration with healthcare professionals to provide postural care twenty four hours a day ²⁸

Family Leadership group “Changing our Lives” initiate a postural care campaign as a human rights issue.²⁹

²⁶ <http://biztrainingsolutions.co.uk/postural-care-awareness>

²⁷ <http://www.opencollnet.org.uk/qualifications/all-qualifications/postural-care>

²⁸ www.youtube.com/watch?v=Y6_7bNe5ZhU

²⁹ <http://www.changingourlives.org/got-my-back>

3) Recognition of failure to protect body shape as a cause of premature death and development of national guidance, indicators and accountability.

2006

A Learning Disabilities Indicator was included as an element of the Quality and Outcomes Framework (QOF) to identify numbers of people.³⁰

2007

Death by Indifference³¹

2008

Healthcare for All³²

"Overall, it appears that life expectancy is shortest for those with the greatest support needs and the most complex and/or multiple ('co-morbid') conditions. In Hollins³³ study for example, 52% of those who died also had respiratory disease compared to 15-17% in the general population. Early death in the learning disabilities group was significantly associated with cerebral palsy, incontinence, problems with mobility and residence in hospital."

"Early interventions are not undertaken to prevent postural deformities from developing. Many families receive no support or advice about how to manage the sleeping position of their child."

Recommends reasonable adjustments through QOF, Directed Enhanced Service (DES), Learning Disabilities Observatory and CIPOLD

2010

Health Action Planning and the need for GP involvement³⁴

European wide acknowledgement of the need for 24 hour postural care³⁵

³⁰ www.hscic.gov.uk/qof

³¹ <https://www.mencap.org.uk/DBIreprt> <https://www.mencap.org.uk/documents>

³² Michael, J. *Healthcare for All: report of the Independent Inquiry into Access for Healthcare for People with Learning Disabilities*. 2008.

³³ Hollins S, Attard MT, von Fraunhofer N, Sedgwick P. *Mortality in people with learning disability: risks, causes and death certification findings in London*. *Developmental Medicine and Child Neurology*. 1998; (40): 50-6

³⁴ Houghton, M. and Royal College of General Practitioners Learning Disabilities Group. *A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability*. 2010. Page 28

³⁵ 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



2012

Acknowledgement of the need to commission specific postural care services³⁶

2013

CIPOLD – established the link between a failure to protect body shape and resultant premature death. The difficulty of multiple co-morbidities is also identified.

Recommendation 9:

“CCGs must ensure they are commissioning sufficient and sufficiently expert preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support”

Liz Goldsmith served on the Overview Panel consulting on deaths associated with postural issues.

2015

Learning Disabilities Mortality Review (LeDer) Programme: IHAL
Public Health England

The first nation-wide review of all deaths of people with learning disability

“The LeDer Programme follows CIPOLD and aims to make improvements to the lives of people with learning disabilities by identifying issues that may have contributed to a person’s premature death”³⁷

2016

Learning Disability Mortality Review Programme Multiagency Review Panel for Themed Priority Deaths of Young People aged 18 – 24 years³⁸

A scoping review of postural care highlights an urgent need for research to establish best practice in *“preserving and re-establishing body shape for people with movement difficulties”* it also acknowledges that *“Validated indices to measure body symmetry have also been developed which increase sensitivity to the early signs of asymmetry and indicate the therapeutic positioning needed to protect and restore body shape.”³⁹*

³⁶ Improving Health and Lives: Learning Disabilities Observatory: *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence Based Commissioning Guide for Clinical Commissioning Groups (CCGs)* 2012

³⁷ <http://www.bristol.ac.uk/sps/leder/>

³⁸ <https://www.england.nhs.uk/2015/06/reduce-prem-mortality-ld>

<https://www.improvinghealthandlives.org.uk>

³⁹ Robertson J. Baines S. Emerson E. Hatton C. *Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review.* J Appl Res Intellect Disabil 2016 1 – 18
wileyonlinelibrary.com/journal/jar