

This is the authors' accepted version of a manuscript due to appear in a forthcoming issue of *Journal of Applied Research in Intellectual Disabilities*

Postural care for people with intellectual disabilities and severely impaired motor function: a scoping review

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Acknowledgements: this work was supported by Public Health England. However, the findings and views reported in this paper are those of the authors and should not be attributed to Public Health England.

Conflicts of interest: none

Abstract

Background. Poor postural care can have severe and life threatening complications. This scoping review aims to map and summarise existing evidence regarding postural care for people with intellectual disabilities and severely impaired motor function.

Method. Studies were identified via electronic database searches (Medline, Cinahl, PsycINFO and Web of Science) covering January 1990 to March 2016, and email requests to researcher networks. Results were collated via descriptive numerical summary of studies and thematic analysis.

Results. 23 studies were identified and summarised narratively in relation to three themes: characteristics and prevalence; interventions; and service related issues. The evidence base is small with significant gaps. Lack of evidence for night time positioning equipment and 24-hour postural care needs to be addressed urgently.

Conclusion. Future research should be clearly directed towards ascertaining how best postural care interventions can be employed to help improve the health and quality of life of people with intellectual disabilities.

Keywords: postural care; intellectual disabilities; scoping review

Introduction

A postural management programme has been defined as: "... a planned approach encompassing all activities and interventions which impact on an individual's posture and function. Programmes are tailored specifically for each child and may include special seating, night-time support, standing supports, active exercise, orthotics, surgical interventions, and individual therapy sessions" (p.244 Gericke, 2006). More recently, postural care (the term adopted in this review to include all the individual components of a postural management programme outlined above) has been defined as a way of preserving and re-establishing body shape for people with movement difficulties (RCGP, 2012). The biomechanics of body shape distortion and the use of therapeutic positioning to prevent body shape distortion has recently been summarised (Hill and Goldsmith, 2010). Validated indices to measure symmetry have also been developed (Goldsmith et al., 1992) which increase sensitivity to the early signs of asymmetry, and indicate the therapeutic positioning needed to protect and restore body shape (Goldsmith and Goldsmith, 2013).

Poor postural care can have severe and life-threatening complications for people who have a limited ability to change position (Crawford and Stinson, 2015) and the wide ranging consequences of poor postural care have been summarised by the NHS Purchasing & Supply Agency (2009). For the musculoskeletal system, these may include contractures, loss of joint integrity (e.g. hip dislocation), decreased bone density, reduced range of joint motion and deformity (e.g. spinal scoliosis). For the neurological system, these may include problems with spasticity/muscle tone, reflexes, altered sensation and joint position sense, pain, and weakness. Digestion may be affected, with swallowing and choking being compromised by poor head to neck posture. Additional areas where problems may arise include: respiratory function; kidney/renal function; personal hygiene, ease of toileting and changing; functional ability (e.g. weight bearing, transfer and hand function); environment interaction (sensory perception, body aesthetics, learning, communication); and sleep pattern and

irritability. Positioning and posture also underpin the ability to function and access the environment (Crawford and Stinson, 2015).

Over the past 15 years, there has been increased awareness of the need to provide postural care over the entire 24-hour period. This usually involves: adaptive seating and/or moulded wheelchairs; night time positioning equipment (NTPE); moving and handling techniques; and advice and training across all settings that the person accesses (Crawford and Stinson, 2015). NTPE can be used during the substantial proportion of the day when the person is in bed and has been reported to be beneficial even for those with established body shape distortion (Goldsmith, 2000).

It has been proposed that most people who lack the ability to change their position would benefit from 24-hour body positioning (Crawford and Stinson, 2015) and that 24-hour postural care strategies should be considered in physical therapy programmes to prevent or delay the development of contractures or skeletal deformities in children and young people at risk of developing these (National Institute for Health & Care Excellence, 2012). However, disabled children generally are not being provided with the specialist equipment they require (such as seating and postural support systems), with provision of equipment being patchy at best (Centre for Economics and Business Research, 2014). It is widely accepted that the current systems that provide equipment and related services to children fail (CSED Consultant's Report, 2010).

The importance of the issue of postural care in relation to people with intellectual disabilities has been highlighted in a number of reports noting gaps in services and the need to provide postural care interventions to prevent postural deformities from developing (Michael, 2008, Mansell, 2010, RCGP, 2012, Heslop et al., 2013). Figures on how many people with intellectual disabilities require postural care are absent, although the number of people with profound and multiple learning disabilities (PMLD) can be used as an approximation. In 2014/15, 10,510 children in England had a Statement of Special Educational Needs (SEN) or an Education, Health and Care (EHC) Plan and were

identified as having a primary SEN associated with PMLD (Hatton et al., 2016). It has been estimated that in 2008, there were 16,036 adults with PMLD in England, with the numbers expected to rise by an average 1.8% annually to 2026 (Emerson, 2009).

No systematic reviews exist relating to postural care specifically for people with intellectual disabilities. Systematic reviews of systematic reviews point to limited evidence concerning postural care even when populations and interventions are broadly defined (Effgen and McEwen, 2008, Novak et al., 2013, Ryan, 2012). Systematic reviews, most commonly relating to people with cerebral palsy, have generally found insufficient high quality evidence for the effectiveness of a range of postural care interventions (Winfield et al., 2014, Bouwhuis et al., 2015, Legg et al., 2014, Katalinic et al., 2010, Prabhu et al., 2013, Kolman et al., 2015). However, limited evidence suggests that special-purpose adaptive seating systems may improve activities and participation for those with cerebral palsy (Gross Motor Functioning Classification System (GMFCS) IV and V) (Angsupaisal et al., 2015); there are indicative findings for an effect of bony surgery in stabilizing the hip in severe cerebral palsy (Bouwhuis et al., 2015); and hip surveillance involving standardised radiological screening of the hip even in children with no symptoms has been found to be effective in reducing hip dislocation in children with cerebral palsy (Novak et al., 2013, Gordon and Simkiss, 2006, Hägglund et al., 2014, Dobson et al., 2002).

For people with intellectual disabilities, the lack of evidence outlined above is compounded by issues that are likely to be more pertinent when providing postural care for this population. People with intellectual disabilities may have difficulties that make them less likely to be able to conform with a postural care programme. For example, NTPE is sometimes abandoned by users for a variety of reasons, such as difficulty sleeping (Hankinson and Morton, 2002), discomfort and temperature regulation, increased repositioning at night, and items being difficult to use and transport (Innocente, 2014). Sleep problems are common in adults and children with intellectual disabilities (c.f. van de Wouw et al., 2012, Priday et al., 2016) and likely to be a source of stress and sleep

deprivation for parents or carers. As such, the issue of abandonment due to sleep related issues may be more common in people with intellectual disabilities. Intellectual disabilities may also impact on the suitability of other postural care interventions, for example, cognitive impairment may reduce a patient's tolerance of bracing (Roberts and Tsirikos, 2016). Other issues raised in relation to intellectual disabilities include the need to address comfort in a specific adaptive seating system in children who also have severe communicative and cognitive impairments (Angsupaisal et al., 2015), and the need for studies of surgical interventions to assess pain expressed by the patients themselves especially for patients with intellectual disabilities (Boldingh et al., 2014).

In view of the issues outlined above, it cannot be assumed that research relating to people with cerebral palsy will apply equally to those with intellectual disabilities. In addition, whilst a proportion of participants in studies relating to cerebral palsy are likely to have an intellectual disability this information is rarely presented, and even allowing for a strong correlation between GMFCS level and intellectual functioning (Dalvand et al., 2012), it cannot be assumed that a child with a significant delay in motor function will also have an intellectual disability (Enkelaar et al., 2008). Conversely, only a minority (e.g. less than 25%; Cans et al., 1999) of those with intellectual disabilities requiring postural care will have cerebral palsy. Indeed, a number of specific conditions related to intellectual disabilities may result in the need for postural care (Imagama et al., 2013, Burns et al., 2003, Detweiler et al., 2013, Damasceno et al., 2014, Li et al., 2015, Takebayashi et al., 2006, Ager et al., 2006, Karmaniolou et al., 2015, Kerr et al., 2003, Butler et al., 2002, Laurier et al., 2015, de Lind van Wijngaarden et al., 2008).

In summary, due to the potential impact of intellectual disabilities on the implementation of postural care programmes and the unique issues involved, it is important to clearly delineate research specifically relating to postural care for people with intellectual disabilities. This scoping review maps and summarises existing evidence to address the question of what the state of

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evidence is with regards to postural care for people with intellectual disabilities, in order to identify gaps in the evidence base and provide a springboard for future research priorities.

Methodology

Scoping reviews are a relatively new methodology for which there is not yet a universal definition, definitive procedure or reporting guidelines (Pham et al., 2014). This scoping review employed an existing methodological framework (Arksey and O'Malley, 2005, Levac et al., 2010) which is the most frequently used scoping review methodology (Pham et al., 2014). It includes five stages: identifying the research question; identifying relevant studies; study selection; charting the data; collating, summarizing and reporting the results. As noted above, the research question was 'what is the state of evidence with regards to postural care for people with intellectual disabilities?'.

Identifying Relevant Studies

Electronic literature database searches were conducted in Medline, Cinahl and PsycINFO (all on EBSCO) and Web of Science (SCI-EXPANDED, SSCI and A&HCI) covering January 1990 to March 2016. Searches combined word and index terms relating to postural care and intellectual disabilities with the Boolean operator 'and'. An initial list of search terms was sent to two experts in postural care for comment and all suggested additional terms included. An example of a database specific set of search terms (Medline) is given Appendix One. The reference lists of articles meeting the inclusion criteria were searched. In addition, in March 2016 an email request for information on research relevant to the review was sent to members of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health Special Interest Research Group and the Intellectual Disability UK Research mailing list.

Study Selection

Inclusion Criteria

Articles were required to meet all the following criteria:

- Peer reviewed
- English Language full text
- Published from 1990 to March 2016
- Any research design
- Samples where 50% or more have intellectual disabilities or mixed samples where results are disaggregated for people with intellectual disabilities
- Presents results relating to postural care for people with intellectual disabilities who have severely impaired motor function.

Exclusion Criteria

- Reviews, letters, commentaries, editorials, meeting or conference abstracts
- Studies based on neonates (new born infants up to 28 days after birth)
- Studies on conditions where intellectual disabilities cannot be assumed (e.g. cerebral palsy) where results not disaggregated for people with intellectual disabilities
- In view of extremely specific issues related to postural care for people with relatively rare syndromes associated with intellectual disabilities (e.g. Williams-Beuren syndrome where mutation of the elastin gene leads to phenotypic changes in patients, including bone and joint dysfunctions (Damasceno et al., 2014)) studies relating only to people with relatively rare specific syndromes associated with intellectual disabilities were excluded (with the exception of Down syndrome which is the most common genetic cause of ID (Sherman et al., 2007))

- Postural issues in those who are ambulatory e.g. gait, postural balance/falls, mobility programmes, sleep position in those who are ambulatory
- Micro switch technology unless specifically related to postural care
- Medical genetics
- Research on wheelchairs not specifically related to postural care (e.g. benefits of powered wheelchairs, interventions to facilitate independent wheelchair use)
- Surgery relating to primary conditions rather than posture per se e.g. hip replacement due to osteoarthritis
- Studies relating to scale development (e.g. Fife et al., 1991) unless relevant data available from the use of the scale

Initially, titles and abstracts were used to exclude articles obviously not within the scope of the review (1st author). Those retained for further screening were those for which relevance could not be assessed without accessing the full text, or those that were potentially within scope. These studies were screened by two authors (1st and last author) and discussed until consensus was reached on whether or not they met the inclusion criteria. All relevant studies were included in the review regardless of methodological quality.

In view of the sometimes unclear distinction between research relating to people with cerebral palsy and research relating to people with intellectual disabilities, a pragmatic approach was taken in that articles published in specialist intellectual disability journals were judged to be related to intellectual disabilities.

Charting the data

The following data were extracted by one reviewer and entered into an Excel spreadsheet: first author; year; country; study focus; method; sample source; key sample features; sample size; age

range (mean (SD); median); sample living situation; % male; outcome measures (if applicable); and key findings. These data are summarised in Table 1.

Results were collated, summarised and reported via a descriptive numerical summary of included studies (e.g. number with particular research designs) and a thematic analysis (Levac et al., 2010). An iterative approach was taken in which a list of themes was identified via reading and re-reading the study summaries in Excel and these themes were allocated to overarching themes (Braun and Clarke, 2006). A descriptive narrative summary was used to present results.

Results

The process of identifying studies for inclusion is summarised in Fig. 1. Electronic database searches identified a total of 1,262 references (Medline 822, Cinahl 157, PsycINFO 192, AMED 91), with 1,026 remaining after removal of 236 duplicates. Following the first examination of articles, 149 remained for further consideration. After examination of full text articles and the addition of articles from other sources, 25 articles met the criteria for inclusion. These are summarised in Table 1. Each article presents information on a unique study, with the exception of one study which was described across two articles (Sewell et al., 2016, Sewell et al., 2015) and a further study also described across two articles (Neilson et al., 2000, Neilson et al., 2001), giving a total of 23 studies.

Figure One Here

Geographical Spread

Of the 23 studies, seven were conducted in the US, six in England, two in Scotland, one in England and Scotland and one in each of Australia, Canada, Germany, Italy, Japan, the Netherlands and Taiwan.

Methodological Design

The study designs included: retrospective cohort studies; single subject designs; cross-sectional surveys; within subjects quasi-experimental designs; case studies; case series; a mixed methods study consisting of an online survey and semi-structured interviews and focus groups; a qualitative focus group; a between subjects comparison of orthopaedic, functional, and cardiopulmonary measures in those who did and did not have scoliosis curves of $>45^\circ$; a retrospective review of surgery outcomes; and one study looking at postural alignment of patients and the relationship to 3D scans of the seating support surface.

Nine of the 23 studies had sample sizes of 10 or less. No study had a sample size of 100 or more.

Table 1 Here

Themes

In the following sections, we present a narrative summary of information identified in the 23 studies in relation to three themes (one study contributed to two themes): characteristics and prevalence of people with intellectual disabilities requiring postural care (4 studies); interventions (17 studies: surgery, behavioural, equipment, positioning and 'other'); and service related issues (3 studies).

Characteristics & prevalence of people with intellectual disabilities requiring postural care

Four studies included some information relating to the characteristics (including progression of postural related ill health) of people with intellectual disabilities requiring postural care, and prevalence of conditions related to postural issues. No studies on the number of people with intellectual disabilities requiring postural care were found. A study of 55 non-ambulatory, institutionalized adults with profound intellectual disabilities found conditions including scoliosis

(severity undefined) in 34/55 people (62%), contractures (23/55 people; 42%), and dislocation of hips (13/55 people; 24%) (Kozma and Mason, 2003). A more recent study of 99 adults with severe or profound intellectual and profound motor disabilities gives the percentage of those with spasticity (76%), deformations (72%; scoliosis 56%; hip 39%), contracture (32%), and decubitus/pressure area (20%) (van Timmeren et al., 2016). A comparison of patients with untreated scoliosis ($> 45^\circ$) to those with mild or no curves found they had more orthopaedic deformities involving the pelvis and hips and were more likely to need modified wheelchairs (Kalen et al., 1992). The authors suggest that the lack of difference found (e.g. on cardiopulmonary measures) to those with mild or no curves suggests careful consideration should be made before recommending a major surgical procedure, although it is acknowledged that it would have been better to compare those who have/have not had surgery for scoliosis.

One case study is presented of a male for whom severe scoliosis contributed to premature death (Waugh and Hill, 2009). X-rays demonstrate progress from symmetrical body shape at age 3 to severe scoliosis at age 23 shortly prior to death. The internal capacity of the thorax and abdomen reduced such that the right lung ceased to function. Body shape distortion caused: pain and discomfort; pelvic obliquity and rotation; disintegration of hips; respiratory failure; movement of digestive organs into the space reserved for lungs; and arrested peristaltic movement leading to faecal impaction.

Interventions

Most commonly, various interventions relating to postural care have been the focus of studies and these are described below in the categories of: surgery (3 studies); behavioural approaches (3 studies); equipment (7 studies); and positioning (3 studies). In addition, one study found that some participants benefitted from reduced muscle tone during relaxation training (Hegarty and Last, 1997).

Surgery. Three studies considered the outcomes of surgery. An early retrospective review of older children undergoing proximal femoral resection (where the femoral head and a portion of the femur are removed) for subluxation (partial dislocation) or dislocation of the hip found mixed results, with poor clinical results noted to be continued pre-operative pelvic obliquity, postoperative adduction contracture, and bony contact between the pelvis and the remaining proximal femur or its heterotopic ossification (bone tissue formation outside of the skeleton) (Perlmutter et al., 1993). Of the 13 patients in the study, 6 had a continued need for pain medication and all of these continued to demonstrate bony contact either by heterotopic ossification or by continued proximal femoral impingement onto the pelvis. The authors suggest that prevention of hip dislocation by very early treatment yields a more predictable and positive long-term outcome than their reported cases involving older children.

More recent studies have considered surgery for scoliosis. A study on radiological and clinical results after surgical correction of scoliosis by posterior-only (P; from the back of the spine) or combined anterior-posterior instrumented fusion (AP; from the front and back of the spine) in 57 patients with cerebral palsy (GMFCS IV or V) found good results, with an overall Cobb angle (a standard measurement to determine and track the progression of scoliosis) correction of 52% (54% in group P, 50% in group AP) (Beckmann et al., 2016). Major complications occurred in 23% (P) versus 46% (AP). Posterior instrumentation appeared to lead to comparable radiological results with shorter operations and shorter ICU and hospital stays than with combined surgery. However, a limitation was that preoperative pelvic obliquities differed between the two groups (group P 15°, group AP 26°). Preoperative deformities were severe (mean preoperative Cobb angle 94°) and the authors suggest that better results with fewer complications might be achieved if patients undergo surgery at an earlier stage.

One study considered the outcomes of spinal fusion for scoliosis in 34 children with cerebral palsy (GMFCS IV or V) in relation to activity and participation (Sewell et al., 2015) and carer assessed

quality of life (QoL) (Sewell et al., 2016). The study also compares outcomes to 36 younger children with significant scoliosis who did not undergo surgery and effectively had worsening scoliosis (as such, the groups were not strictly comparable). Spinal fusion was associated with an improvement in activity and participation and a decrease in spinal-related pain, whereas nonoperative treatment was associated with a small reduction in activity and participation and an increase in pain (Sewell et al., 2015). Spinal-related pain was the factor that correlated most with change in activity and participation in both groups. Similarly, spinal fusion was associated with an increase in QoL whereas nonoperative treatment was associated with a small decrease in carer-assessed QoL over 2 years (Sewell et al., 2016). Change in pain was the most significant factor affecting QoL changes. There was no difference in mobility, GMFCS level, feeding, or communication in either group.

Behavioural Approaches: Stimuli contingent on appropriate posture. Three studies with a total of seven participants used technology to provide stimuli contingent upon appropriate posture. In an early study, a switch activated by appropriate head and trunk position which turned on music was effective in increasing the duration of appropriate posture, although the average time in correct posture remained small (Domaracki et al., 1990). Similarly, one study adapted a Wii controller to turn on videos contingent on appropriate head posture and found that both participants significantly increased time spent with correct head posture (Shih et al., 2011). Finally, one study using pressure microswitches to establish choice responding prior to using stimuli (songs) contingent on appropriate head and trunk posture found that problem postures reduced to very low levels (Lancioni et al., 2015). It has been suggested that such methods could be used to maintain therapeutic posture without the need for constant one to one supervision thus extending 'therapy' time to a greater part of the day (Domaracki et al., 1990).

Equipment. Seven studies considered issues related to equipment. An early study looked at the effectiveness of a prototype seating harness for standard wheelchairs (Rennie and Flynn, 1992) with 10 adults. The prototype allowed significantly less movement than either a crutch strap or lap strap,

and all harnesses allowed less forward slide than when no harness was used. This was taken as an indication of the value of a harness, and the prototype harness in particular, in assisting the prevention of pressure sores and increasing disability resulting from poor posture.

A two phase study focused on the effects of a static versus a dynamic (motorized) prone stander on bone mineral density (phase I) and behaviour related to tasks and specific goals (phase II) in four preschool children with severe cerebral palsy (Gudjonsdottir and Stemmons Mercer, 2002). In phase I there were increases in bone mineral density in both children who used a dynamic stander and one of two children who used a static stander. In phase II there was little or no effect of type of stander on behaviour. It was noted that all tolerated the standing program well and often showed displeasure when the standing session was over.

One study looked at the relationship between postural head and neck alignment of patients and the configuration of the 'Seating Buggy' seating support surface measured using 3D scanning (Hatta et al., 2007). Seating was assessed as ill fitting in 10 out of the 21 participants. It was suggested that properly adjusted depth of thoracic support and distance of the lumbar support were related to satisfactory head-neck alignment and sitting balance.

One study looked at the impact of a malleable spinal brace (Soft Boston Orthosis) on measures of pulmonary mechanics (Leopando et al., 1999) with 12 young adults. Use of the orthosis did not significantly affect pulmonary mechanics or measurements of gas exchange. There was a trend toward increasing the work of breathing when the individuals were not wearing their orthoses, with the work of breathing being greatest in the sitting position without the orthosis. (It is noted that rigid braces can cause a decrease in vital capacity in young people with muscular dystrophy and scoliosis).

A survey matched the responses of 30 parents of a child with multiple and complex needs with those of the physiotherapist or occupational therapist involved in their seating in relation to perceptions of seating equipment (McDonald et al., 2007). Parents reported more 'dislikes' than therapists suggesting they had more experience of problems. Parents were particularly concerned with the ease of use and practical aspects of the seating system but this issue was not raised by therapists. Activity and participatory factors were not mentioned and the authors suggest that the child's activity, participation, environmental, and personal factors should be considered in addition to postural care when supplying children and their families with adaptive seating systems.

One study, which aimed to develop a model for evaluating the consequences of surgical and orthotic interventions for people with profound intellectual and multiple disabilities and their carers, reported benefits associated with moulded seats inserts for wheelchairs (Neilson et al., 2001). Whilst most of the 27 participants had used moulded inserts previously and received reconfigured inserts, patients benefited both physically and functionally with benefits in quality of life, sitting posture, feeding behaviour, and carer satisfaction with the results. Benefits in quality of life were less apparent for carers than for patients which may be because despite significant functional improvement, patients remained entirely dependent. When also including surgical and orthotic interventions, 62.5% of carers were satisfied with the wide ranging interventions (Neilson et al., 2000). Carers' satisfaction ratings in relation to 'posture' were 'good, very good or excellent' (n=13) & 'poor to fair' (n=3).

Finally, one recent study based on 13 qualitative case studies considers the comfort of children and young people with intellectual disabilities who were unable to verbalise when using positioning equipment (adaptive seating, standers and sleep systems) (Lyons et al., 2016). Facial and vocal expressions were predominant for detecting discomfort/comfort in most participants but whether discomfort from equipment was present sometimes remained unclear. Threats to comfort included the restrictive nature of some equipment, stretch procedures and positioning errors. Parents were

generally supportive of professionals using the equipment to achieve both health and educationally related goals but they also wanted periods of relaxation for their children with time out of restrictive equipment.

Positioning. Three studies considered issues specifically related to positioning. A study on the effects of positioning (supine, sitting, sidelying) on respiratory measures found that whilst results differed depending on the participant and outcome variables, oxygen saturation (SaO_2) was greater in sitting or sidelying than supine for 3/5 participants (Littleton et al., 2011). It is acknowledged that further research with a larger sample is needed to empirically link specific positions with improved respiratory efficiency.

One study examined the effects of positioning (wheelchair, sidelying, and "freestyle" on a mat without assistive equipment) on social-communicative interactions (McEwen, 1992). During structured interactions, adults initiated communication more when the 10 participants were in their wheelchair (small to medium effect size). Position did not affect students' communication during unstructured observations. The lowest functioning students ($n=5$) communicated more whilst in 'freestyle' (supine) during the structured observations (large effect size). The authors note that this latter finding was unexpected and further investigation is needed.

Finally, a case study of a girl with severe scoliosis who had been referred for surgery for rods in her spine is presented which illustrates pictorially scoliosis being improved and surgery being avoided following the adoption of night time positioning (Waugh and Hill, 2009).

Service related issues

One study looked at the views, understanding and training needs of members of a multidisciplinary team (MDT) who refer those with PMLD to 24-hour postural care (excluding physiotherapists who

provide 24-hour postural care) (Castle et al., 2014). Survey results indicated that around half of all the 57 MDT members who responded refer to the 24-hour postural care service. The vast majority did not have a specific assessment tool for identifying the postural needs of patients. Very few had received any training about the role and benefits of 24-hour postural care and nearly a third said they had no knowledge about the meaning and benefits of 24-hour postural care. The majority said that they would be happy to receive more training on 24-hour postural care with most favouring group training that included a checklist or screening tool to help identify 24-hour postural care needs. Results of qualitative interviews and focus groups with smaller numbers of people indicate that MDT members were not able to identify why individuals should be referred to the 24-hour postural care service and participants were unanimous in agreeing the need for further training specific to 24-hour postural care. Participants identified training to be important as it provides insight into the rationale for referrals and the essential clinical skills for recognising potential postural problems of patients with PMLD.

A survey looked at teacher and therapist views on postural care in a special school setting (Maher et al., 2011). The majority of the 18 participating teachers thought one or two position change(s) per day was optimal and cited fewer benefits of postural care than the 43 participating therapists. Reported barriers included unavailability of appropriate positioning equipment, education staff lacking the time and/or skills to carry out the programme and insufficient communication between education and therapy staff. Integration of postural care into the daily routine, provision of a written programme from therapy staff and increased communication between therapy and education staff were cited as facilitators. Overall, it is suggested that teachers would benefit from training with regards to postural care.

One study looked at the views of 11 professionals and carers from paediatric or learning disability services who were involved in the development and/or implementation of an integrated care pathway (ICP) for 24-hour postural care (Humphreys and Pountney, 2006). Team members felt that

the ICP had the effect of making members' interventions proactive rather than reactive. A training package for all carers that was put in place had been a keystone of the ICP and provoked enthusiasm from all members of the team. The training of respite carers was of concern due to the need to implement postural care across a wide range of settings. Overall, the perception was that the ICP had improved service delivery and would improve outcomes for children and adults with motor impairment, as one participant noted: "It's going to make untold difference to the whole of their lives. It sounds sort of visionary but . . ." (p237).

Discussion

Despite broad inclusion criteria, this review has identified only a small body of research relating to postural care for people with intellectual disabilities. Whilst a wide range of issues has been covered in the identified studies, few studies were found for each theme and overall sample sizes are small. Further, some studies have serious methodological limitations such as a lack of control of additional confounding factors which may have influenced outcomes. Overall, there were no RCTs or prospective studies.

There are significant gaps in the literature. Whilst there is some evidence to suggest that a substantial proportion of people with severe or profound intellectual disabilities are likely to have postural care needs, accurate data on this issue do not exist. Such data would be useful for those who need to plan services for this group.

Whilst this review has presented some small scale evidence regarding postural care interventions, of particular importance is the lack of evidence regarding NTPE and 24-hour postural care service provision. It has been suggested that effective 24-hour postural care can prevent deformity (Hill and Goldsmith, 2010, Crawford and Stinson, 2015) and thus avoid the negative health and quality of life implications associated with poor posture and avoid invasive interventions such as surgery for

scoliosis (Waugh and Hill, 2009) which is frequently associated with major complications (Beckmann et al., 2016). The lack of research evidence to support the efficacy of NTPE and 24-hour postural care needs to be addressed urgently, including a focus on the specific issues that may arise in relation to interventions involving people with intellectual disabilities.

There are a number of reasons for urgently addressing this gap in evidence. Firstly, a national survey of paediatric physiotherapists found that inability to obtain funding was the second most common reason cited for lack of access to NTPE despite potential benefit for an individual (NHS Purchasing & Supply Agency, 2009, Polak and Clift, 2007). Securing funding was noted to be very time consuming and lack of robust clinical efficacy data can make the justification for funding problematic (NHS Purchasing & Supply Agency, 2009). Indeed, in light of the lack of well-designed RCTs, the authors of a Cochrane review challenge the assumption that sleep positioning systems are a proven, effective treatment to reduce or prevent hip migration (Blake 2015). They also suggest that adverse effects appear underreported, perhaps because, in these instances, the equipment is usually abandoned.

There was a dearth of research on service related issues. Research is limited to studies on the perceptions of key stakeholders regarding postural care. No studies were found on how best to provide postural care services for this population. It is evident that across the UK, there are examples of innovations in practice that attempt to improve postural care for people with intellectual disabilities but peer reviewed research relating to these innovations is lacking. For example, in one area of England, a rise in critical incidents linked to poor postural care among patients living in supported living services was the impetus for developing a training package for all members of staff in the supported living service, leading to a tripling in referral rates (Mooney, 2014). Another area (Wakefield) has a clear postural care pathway, with referred children having a baseline measurement of postural symmetry, equipment being put in if needed and follow-up measurements being taken at least once a year (Snell, 2012). This approach, focused on early intervention and prevention, has been claimed to have cost benefits due to preventing the need for

surgical interventions. One area has set up two clinics to assess the posture of adults with profound and multiple learning disabilities, with regular reassessment and monitoring (Millett, 2015). A new occupational therapy 24-hour postural care service for people with learning disabilities in one city in the UK was evaluated after 12 months using a carer feedback questionnaire and found to have a positive impact on both clients and carers (Crawford and Curran, 2014). Finally, a one year postural care training programme for the workforce supporting the needs of children and young people with complex healthcare needs has also been described and evaluated (Hill, 2011). Closer links between researchers and those involved in such innovations in practice would help to build a more robust evidence base relating to postural care services.

Whilst the lack of evidence relating to people with intellectual disabilities partly reflects the lack of evidence regarding postural care for other populations, there are a number of additional potential reasons for the lack of robust research evidence concerning postural care for people with intellectual disabilities. First, people with intellectual disabilities are largely excluded from mainstream health and medical research (Feldman et al., 2013). Second, there are challenging ethical and logistical problems when conducting RCTs with people with intellectual disabilities (Oliver-Africano et al., 2010). Further, the population of people with intellectual disabilities who are likely to require postural care is a relatively small and scattered population across services where geographically there is no consistency in the provision (if any) of postural care services. Finally, behavioural issues may influence the participation of those with intellectual disabilities in studies of postural care. For example, it has been noted that assessment of pulmonary mechanics in individuals with severe cerebral palsy and marked cognitive impairment had never been reported, probably because of the difficulty of studying subjects who are unable to cooperate (Leopando et al., 1999). One study also excluded those with sensory defensiveness affecting tolerance for handling techniques (Littleton et al., 2011).

A further issue is the wide diversity of people with intellectual disabilities who may require postural care and the resultant diversity in needs. As noted in the introduction, there are varied specific syndromes associated with intellectual disability which may be associated with postural care needs and a limitation of this review is the exclusion of studies only relating to such syndromes. For example, in Prader-Willi syndrome (PWS), over two thirds of patients are affected by scoliosis at skeletal maturity (Odent et al., 2008), with scoliosis surgery frequently being necessary and associated with a high rate of complications (Accadbled et al., 2008). It has been suggested that in PWS, osteopenia, poor impulse control and defiant behaviours, and diminished pain sensitivity may complicate all aspects of orthopaedic nonsurgical and surgical management (Kroonen et al., 2006).

Similarly, as many as 40% of people with Rett syndrome have been reported to undergo corrective spinal surgery (Anderson et al., 2014) and children with Rett syndrome are very likely to undergo spinal fusion (Karmaniolou et al., 2015). Whilst positive outcomes of spinal surgery have been reported (Larsson et al., 2009, Downs et al., 2009, Kerr et al., 2003), it is associated with a high rate of postoperative major medical complications (Gabos et al., 2012). Further, for families of people with Rett syndrome, the decision to proceed with spinal fusion surgery can be associated with feelings of fear, obligation, relief and guilt (Marr et al., 2015). Little research has considered other aspects of postural care for people with Rett syndrome, with physiotherapy and bracing having been reported to be perceived as not reducing the progression of scoliosis (Ager et al., 2009). Future review work should consider the body of research on postural care for people with relatively rare syndromes associated with intellectual disabilities.

Recent research in the field of postural care has acknowledged the need to consider the degree of impairment of participants (Beckmann et al., 2016). Future research involving people with cerebral palsy should include information on the degree of intellectual impairment of participants in a standardized way. Future research should also address the question of whether early intervention could prevent or reduce asymmetry in people with intellectual disabilities. It is also unclear as to

what adjustments might need to be made to interventions for those with behavioural issues that limit their tolerance of postural care. Recent research has also gone beyond body structure to consider outcomes related to quality of life such as activity and participation (Sewell et al., 2016, Sewell et al., 2015). This is in line with the suggestion that focus in the use of postural care should consider the environment and participation in addition to body structure (Gough, 2009, McDonald et al., 2007).

Conclusion

The evidence base relating to postural care for people with intellectual disabilities and severely impaired motor function is small and lacking in studies that employ robust methodological designs. There are areas where there is a dearth of research which warrant urgent attention. Most notably, there is an urgent need for evidence relating to NTPE and 24-hour postural care. Further, despite examples of innovations in practice, there is no research on how best to provide postural care services for this population. Further research co-designed by families, postural care practitioners and academics is needed. Large scale survey work could identify the potential needs that exist for postural care and map the current picture of service provision relating to postural care for people with intellectual disabilities. Careful evaluation work, for example using realist evaluation (Wong et al., 2016), could investigate the impact on people and families of living in an area with a comprehensive postural care service versus areas without such a service. Longer-term cohort studies of young children with postural care needs could be employed to investigate the long-term impacts of early interventions. Health economic modelling could consider the costs and effectiveness of postural care as a whole, and also particular components of postural care. In view of the likely ethical problems of conducting RCTs in this area, quasi-experimental designs, and particularly natural experiments (Craig et al., 2012) may be more acceptable ethically. This might include implementation studies where the introduction of comprehensive postural care services is staggered. Research based on the suggestions above would begin to ascertain how best postural

care interventions can be employed to help improve the health and quality of life of people with intellectual disabilities.

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reporting standards for realist evaluations. *BMC Medicine*, 14, 96.

Appendix One: Example of database specific search terms (Medline)

TI (postur* N1 (care or manag* or support)) OR AB (postur* N1 (care or manag* or support)) OR TI ("body shape") OR AB ("body shape") OR TI (positioning) OR AB (positioning) OR TI ("lying posture") OR AB ("lying posture") OR TI ("adapt* seating") OR AB ("adapt* seating") OR TI ("supportive seating") OR AB ("supportive seating") OR TI ("seating system") OR AB ("seating system") OR TI ("sleep system") OR AB ("sleep system") OR TI ("therapeutic support") OR AB ("therapeutic support") OR TI ("night ortho*") OR AB ("night ortho*") OR TI ("chest distortion") OR AB ("chest distortion") OR TI (hip N2 (dislocation OR migration OR subluxation OR dysplasia)) OR AB (hip N2 (dislocation OR migration OR subluxation OR dysplasia)) OR TI (scoliosis) OR AB (scoliosis) OR TI ("respiratory function") OR AB ("respiratory function") OR TI (contracture) OR AB (contracture) TI ("standing frame") OR AB ("standing frame") OR TI (stander) OR AB (stander) OR TI (wheelchair) OR AB (wheelchair) OR TI ("hip surveillance") OR AB ("hip surveillance") OR (MM "Scoliosis/TH/SU/EP/NU/RH") OR (MM "Posture") OR (MM "Patient positioning") OR (MM "Wheelchairs") OR (MM "hip dislocation") OR (MM "Orthotic devices")

AND

TI (learning N1 (disab* or difficult* or handicap*)) OR TI (mental* N1 (retard* or disab* or deficien* or handicap*)) OR TI (intellectual* N1 (disab* or impair* or handicap*)) OR TI (development* N1 disab*) OR TI (multipl* N1 (handicap* or disab*)) OR TI (profound* N2 (disab* OR handicap*)) OR AB (profound* N2 (disab* OR handicap*)) OR TI ("intellectual function*") OR AB ("intellectual function*") OR TI ("Down* syndrome") OR TI ("intellectual development disorder") OR AB ("intellectual development disorder") OR (MH "Developmental Disabilities") OR (MH "Intellectual Disability+") OR (MH "mentally disabled persons") OR AB (learning N1 (disab* or difficult* or handicap*)) OR AB (mental* N1 (retard* or disab* or deficien* or handicap*)) OR AB (intellectual*

This is the authors' accepted version of a manuscript due to appear in a forthcoming issue of *Journal of Applied Research in Intellectual Disabilities*

N1 (disab* or impair* or handicap*)) OR AB (development* N1 disab*) OR AB (multipl* N1

(handicap* or disab*)) OR AB ("Down* syndrome")

Limiter: from 1990; English Language.

Figure One: Flowchart of Study Identification

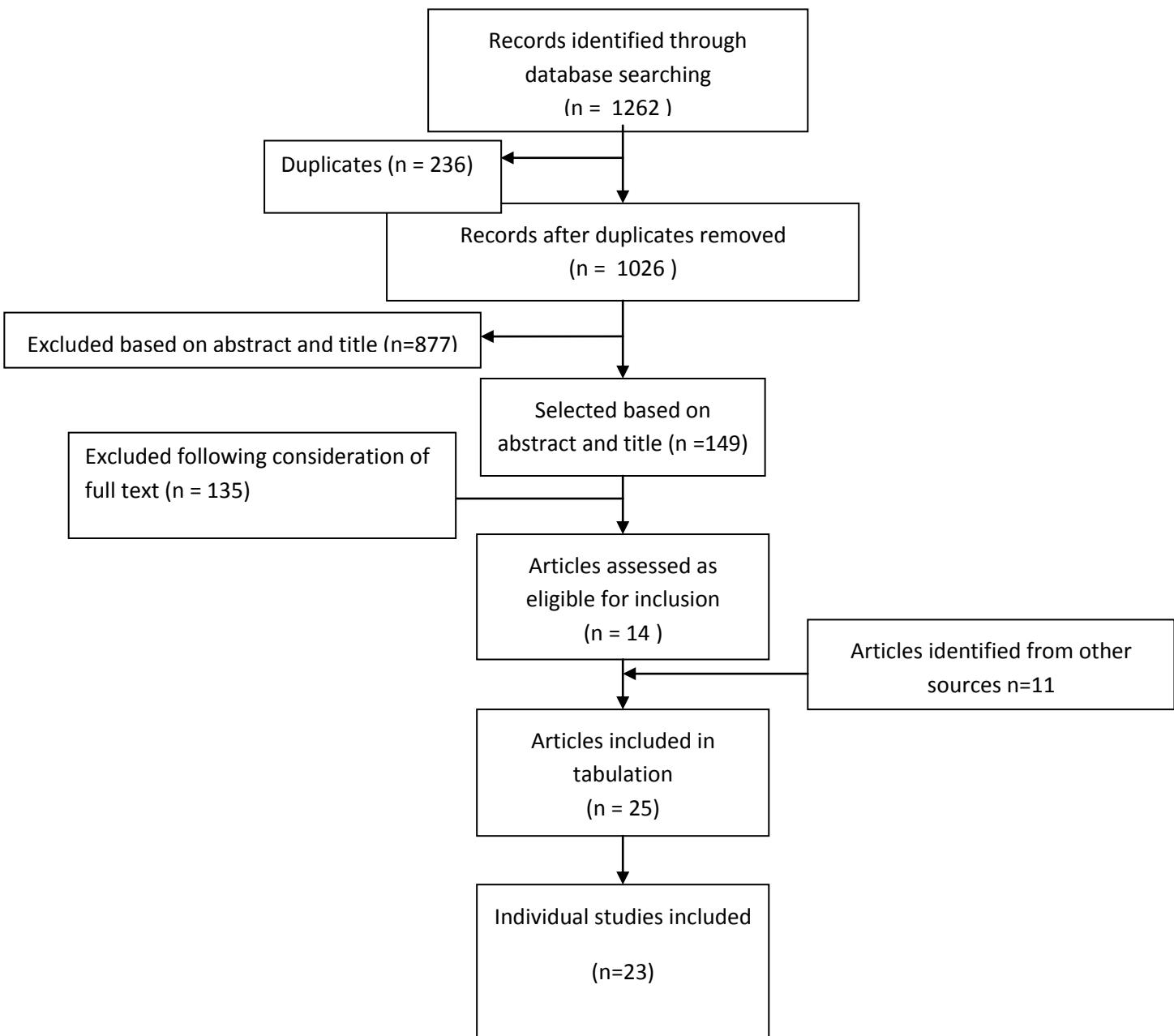


Table 1: Summary of studies relating to postural care for people with intellectual disabilities

Theme ¹	First author & year	Country	Study Focus	Study design	Key sample features	Sample size	Age range (mean (SD); median) yrs	% male	Key Findings
I (S)	Beckman 2016	Germany	Radiological & clinical results after posterior-only (P) or combined anterior-posterior instrumented fusion (AP) for correction of scoliosis	Retrospective cohort study	Severe CP (GMFCS IV or V). Moderate to severe ID: P 33/35 (94%); AP 16/22 (73%)	P 35; AP 22	P ns (15 (4); ns); AP ns (16.5 (7); ns)	A 46%; AP 50%	Preoperative deformities severe with mean Cobb angle 94°. Results good, with overall Cobb correction of 52% (54% P, 50% AP). Major complications in 23% (P) vs 46 % (AP). AP group had longer operations, greater blood loss & longer hospital stays & ICU stays. Correction of the main curve was similar at discharge (54% P, 50% AP)
S	Castle 2014 Phase I	England	Views, understanding & training needs of members of a multidisciplinary team (MDT)	Mixed methods Phase I: online survey	MDT members who may refer people with PMLD to the LD physiotherapy service for 24-hr postural care.	57	20-65 (ns (ns); ns). 42 aged 36-55	77%	50% refer to the 24-hour postural care service. The majority felt they had no (30.4%) or some (53.6%) knowledge about the meaning & benefits of 24-hour postural care. 82.5% did not have a specific assessment tool for identifying the postural needs of patients. 54.4% were not happy with the amount of training in 24-hour postural care they received & 75.4% said they would be happy to receive more training. 5.4% of respondents had received any training about the role & benefits of 24-hour postural care, while 78.9% believed this would benefit patients with PMLD. 68.4% favoured group training that included a checklist or screening tool to help identify 24-hour postural care needs
	Phase II	as above	as above	Phase II: semi-structured interviews & focus groups	Semi-structured interviews with 14 MDT professional participants representing all groups, & three profession-specific focus groups: SaLTs, CNs & psychiatrists	14 interviews; 3 focus groups (total n=16)	ns (from as above)	ns	Referrals were being made but MDT members were not able to identify why individuals should be referred to the 24-hour postural care service. Participants were unanimous in agreeing the need for further training specific to 24-hour postural care. Participants identified training to be important as it provides insight into the rationale for referrals & essential clinical skills for recognising potential postural problems of patients with PMLD
I (B)	Domaracki 1990	US	Effectiveness of biofeedback for improving head & trunk position	Single subject design	Children with severe to profound ID & multiple disabilities including visual impairment & problems with posture control	2	6 & 8	50%	Biofeedback (music) was effective in increasing the duration of appropriate posture. Average time in correct posture remained small even with intervention.
I (E)	Gudjonsdottir 2002 Phase I	US	Effects of a dynamic versus a static prone stander on bone mineral density (BMD)	Case series	Preschool children with severe CP & functioning below developmental age of 9 months, 2 with no mobility, 2 able to stand	4	4-5	75%	All tolerated the standing program well & often showed displeasure when the standing session was over. BMD increased in 2/2 children who used dynamic stander & 1/2 who used static stander, with increases in the lumbar spine, proximal femur, and/or distal femur
	Phase II	as above	Effects of a dynamic versus a static prone stander on behaviour	as above	as above	as above	as above	as above	Type of stander did not have an effect on Caroline Record of Individual Behavior (CRIB) measures for any subjects. Staff reported that the two subjects who stood in the dynamic standers in phase one were more content and calm while standing

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I (E)	Hatta 2007	Japan	Relationships between postural adaptation of patients & configuration of Seating Buggy's seating	Postural alignment of participant assessed & seating support surface measured using 3-D scanning	Profound CP, no independent mobility, all had ID (usually severe). Average period using the Seating Buggy 5.3 yrs.	21	17-54 (37.6 (ns); ns)	57%	Assessed fitting as appropriate or nearly appropriate for 11 & ill fitting for 10. Depth of thoracic support & the forward distance of lumbar support for those classed as ill-fitting were significantly reduced compared with that of those where appropriate or nearly appropriate fitting
I (O)	Hegarty 1997	England	Effects of relaxation training vs rest for people with severe/PMLD	Within subjects quasi-experimental	Severe or profound ID & physical or sensory handicaps; 6 non-ambulant, 4 ambulant with assistance	10	24-77 (ns (ns); ns)	30%	Relaxation training appeared to produce greater relaxation effects than rest. Postural measures (knee & elbow angles) improved during relaxation training for four people. Some clients with CP were able to reduce muscle tone during relaxation training
S	Humphreys 2006	England (North Devon)	Views of staff & carers on an integrated care pathway (ICP) for 24-hr postural management for children & adults	Qualitative focus groups	Members of postural management group who developed and/or implemented ICP. Parent (1), paediatric community physiotherapist (4), OT (3), community childrens' nurse (1), physiotherapy technical instructor (1), physiotherapist in community team for adult ID (1)	11	ns	ns	Team members felt the ICP made members' intervention proactive rather than reactive. The training package for all carers that was put in place had been a keystone of the ICP & provoked enthusiasm from all members of the team. The training of respite carers was of concern to all members of the team. The perception was that the ICP improved service delivery & will improve outcomes for children & adults with motor impairment
C	Kalen 1992	US	People with untreated scoliosis (> 45°) compared to those with mild or no curves	Between subjects comparison of those with & without scoliosis curves of >45°	56 out of total 62 adults with severe CP & profound ID (49), severe (6), moderate (6) & mild (1). Group I n=42 scoliosis <45°; group II n=12 scoliosis >45°	56	29-67 (39 (ns); ns)	42%	Patients in the scoliosis group had more orthopaedic deformities involving the pelvis & hips & needed modified wheelchairs more often than did those without curves. There were no differences in incidence of decubiti (pressure sores), highest functional level achieved, functional loss, oxygen saturation, or pulse
C	Kozma 2003	US	Medical conditions in non-ambulatory people with profound ID	Cross sectional survey	Non-ambulatory, institutionalized adults with profound intellectual disabilities	55	28-63 (ns)	47%	Conditions included scoliosis (62%), contractures (42%), dislocation of hips (24%)
I (B)	Lancioni 2015	Italy	Effect of technology-aided program on head & trunk forward bending (stimuli contingent on appropriate posture)	Single subject design	Moderate to severe ID, congenital encephalopathy with spastic tetraparesis or hip & legs impairments, spent day in a wheelchair when head & trunk tended to be bent forward	3	42, 37 & 23	67%	At baseline mean percentages of session time with presence of problem posture were above 80% for all participants, dropping to below 25% (first B ¹) & about or below 10% (second B ¹)
I (E)	Leopando 1999	Canada	Effect of Soft Boston Orthosis (SBO) on	Within subjects	Nonambulant, age < 25 yrs, spastic quadriparetic CP, no respiratory illness	12	5-23 (16.3 (4.8); ns)	33%	Use of the SBO did not significantly affect pulmonary mechanics or measurements of gas exchange. Work of breathing was greatest in the

Theme ¹	First author & year	Country	Study Focus	Study design	Key sample features	Sample size	Age range (mean (SD); median) yrs	% male	Key Findings
			pulmonary mechanics	quasi-experimental design	for at least 4 weeks prior to testing, prescribed SBO. All had severe or profound cognitive impairment				sitting position without the orthosis (1.2 dynes/cm), suggesting that the improved positioning achieved with the orthosis may decrease the work of breathing
I (P)	Littleton 2011	US	Effects of positioning (supine, sitting, sidelying) on respiratory measures	Single subject design	Adolescents & adults with CP (quadriplegia) & severe scoliosis, history of respiratory illnesses. All with ID. GMFCS V. No history of spinal stabilization surgery & not using spinal orthoses	5	17-37 (17, 22, 25, 26, 37)	60%	Preference for sitting or SL over supine differed depending on participant & outcome variables. SAO ₂ was greater in sitting or SL than supine for 3/5 participants. Further research with a larger sample is needed to empirically link specific positions with improved respiratory efficiency
I (E)	Lyons 2016	England & Scotland	Comfort when using adaptive positioning equipment	Qualitative case studies	Parents, teachers, therapists & key support staff of children & young people with physical and ID; do not use language; not all with CP but 11 GMFCS V, 2 GMFCS IV	13 children	4-19 (approx) (ns (ns); ns)	46%	Facial and vocal expressions were predominant for detecting discomfort/comfort in most participants but whether discomfort from equipment was present sometimes remained unclear. Threats to comfort include the restrictive nature of some equipment, stretch procedures & positioning errors. Distress was not ignored. All parents regularly attended to their child's needs during the night. Parents were generally supportive of professionals using equipment to achieve health and education related goals but also wanted periods of relaxation for their children with time out of restrictive equipment
S	Maher 2011	South Australia	Special school setting postural management: benefits, barriers & facilitators, suggestions for improvement	Cross sectional survey	Teachers, physiotherapists, occupational therapists & speech pathologists caring for children with CP aged 5-12 years, GMFCS level IV or V at special schools for children with significant intellectual & physical disabilities or special units within mainstream schools, for children with significant intellectual &/or physical disabilities.	61	ns	ns	More benefits were reported by therapists than teachers. Apart from 'comfort' & 'general health', no other benefits were named by more than 25% of teachers. 77% of teachers thought one or two position change(s) per day was optimal. Reported barriers included unavailability of appropriate positioning equipment, education staff lacking the time &/or skills to carry out the programme & insufficient communication between education & therapy staff. Integration of postural management into the daily routine, provision of a written programme from therapy staff & increased communication between therapy & education staff were cited as facilitators
I (E)	McDonald 2007	England	Parent & primary therapist perceptions of seating equipment for children with multiple & complex needs	Cross sectional survey	Parents of children with severe CP (with physical & learning disabilities) & occupational therapist or a physiotherapist who deals with the child's seating & positioning	30 pairs	ns	ns	Parents liked the chair for mainly environmental & personal factors (n=25), with body structures second (n=16). Therapists liked the chair for body structures (n=27) & environmental/personal factors (n=17). For dislikes, there were 60 replies from parents & 32 replies from therapists, suggesting that parents who had to use the chairs had more experience of problems. Parents were particularly concerned with the ease of use & practicalities of the seating system. These were not issues raised by the therapists. Activity & participatory factors were not mentioned.
I (P)	McEwan	US	Effects of assistive	Within	Children with profound ID attending	10	6- 12 (ns)	20%	During structured interactions, adults initiated communication more when

Theme ¹	First author & year	Country	Study Focus	Study design	Key sample features	Sample size	Age range (mean (SD); median) yrs	% male	Key Findings
	1992		positioning on social-communicative interactions with staff	subjects quasi-experimental design	special education classes, unable to sit independently, use assistive positioning equipment during school day, 9/10 CP.		(ns); ns		participants were in their wheelchair (small to medium effect size). Position did not effect students' communication during unstructured observations. Lowest functioning students communicated more whilst in 'freestyle' (supine) during the structured observations (large effect size). This latter finding was unexpected & further investigation is needed
I (E)	Neilson 2001	Scotland	Approaches for measuring the effects of special seating on people with profound & multiple disabilities & their carers	Within subjects quasi-experimental design	Adults with severe CP with profound ID, unable to walk, extremely poor or no postural stability with significant skeletal deformities. 8/9 had previously used molded seats & received replacement seats made to a new configuration	9	19-34 (22.7 (4.9); 20)	56%	Patients benefited both physically & functionally as a result of customized molded seating. Benefits were apparent in terms of patients' quality of life, sitting posture, feeding behavior, & carer satisfaction with the results. Benefits in quality of life were less apparent for carers than for patients.
	Neilson 2000	Scotland	Developing a model for evaluating the impact of surgical & orthotic intervention on the quality of life of people with PIMD & their carers	as above	Adults & children with PIMD referred for surgical, orthotic or wheelchair interventions over a one year period, 22 CP. 8 referred for surgical, 6 orthotic, 9 seating, 4 wheelchair interventions	27	2-55 (19 (ns); ns)	56%	On the whole, 62.5% of carers were satisfied with the wide ranging interventions. Carers satisfaction ratings in relation to 'posture' were 'good, very good or excellent' (13) & 'poor to fair' (3)
I (S)	Perlmutter 1993	US	Proximal femoral resection for subluxation or dislocation of the hip	Retrospective review	Older children undergoing proximal femoral resection. 11 CP spastic quadriplegia, 2 myelomeningocele, all non-ambulatory, all ID, all constant chronic pain due to subluxated or dislocated hips & difficulty with perineal hygiene due to limited hip passive motion	13	6.5-16.2 (11.7 (ns); ns) at surgery	ns	Resections were either at the level of the neck (9 hips) or in the subtrochanteric region (10 hips). The latter provided a better operative result. Hygiene care improved for 9/13. There were mixed results with poor clinical results noted to be continued pre-operative pelvic obliquity, postoperative adduction contracture, & bony contact between the pelvis & the remaining proximal femur or its heterotopic ossification. Patients with a satisfactory outcome did not demonstrate either pelvic obliquity or bony impingement at the pelvis. 6/13 patients had a continued need for pain medication & all of these continued to demonstrate bony contact
I (E)	Rennie 1992	Scotland	Effectiveness of a prototype seating harness for standard wheelchair	Within subjects quasi-experimental design	Adults who normally use a lap or crutch strap, very severe learning disabilities	10	17-54 (32.1 (ns); ns)	50%	All harnesses allowed less forward side than when no harness was used. The prototype allowed significantly less movement than either of the other harnesses
I (S)	Sewell 2015	England	Activity & participation after spinal fusion for scoliosis	Retrospective cohort study	Children with CP (GMFCS IV or V) & scoliosis Cobb angle >40°. i. Operative group 25/34 (75%) IQ < 70; ii. seating &/or brace group 21/36 (58%) IQ < 70. All non-walkers	i. 34; ii. 36	i. 10-17 (13.9 (ns); ns); ii. 8-17 (12.1 (ns); ns)	i. 59%; ii. 53%	Activities Scale for Kids performance version (ASKp) improved in all children who underwent surgery ($P<0.01$), mainly due to improved sitting balance and less pain. In the nonoperative group, 28 of the 36 children reported a reduction in the ASKp at 2 years ($P<0.01$). There was a reduction in the number of children experiencing pain in the operative group. There was an increase in the number of children experiencing pain in the nonoperative group. There was no difference in mobility, GMFCS level, feeding, or communication in either group

Theme ¹	First author & year	Country	Study Focus	Study design	Key sample features	Sample size	Age range (mean (SD); median) yrs	% male	Key Findings
	Sewell 2016	England	QoL after spinal fusion for scoliosis	as above	Children CP (GMFCS IV or V) & scoliosis Cobb angle >40°. i. Operative group 15/18 (83%) IQ < 70; ii. seating adaptations &/or bracing 7/15 (47%) IQ < 70. All non-walkers	i. 18; ii. 15	i. 10-16 (14 (ns); ns); ii. 8-16 (11 (ns); ns)	i. 50%; ii. 47%	Nonoperative treatment was associated with a small decrease in carer-assessed QoL over 2 years. Spinal fusion was associated with an increase in QoL. Change in pain was the most significant factor affecting QoL changes. There was no difference in mobility, GMFCS level, feeding, or communication in either group
I (B)	Shih 2011	Taiwan	Use of Wii Remote to maintain upright head posture via access to preferred stimulation (favourite videos)	Single subject design	Severe multiple disabilities with spastic quadriplegic CP, one with 'middle-level' ID, one profound ID. Problems with head posture but able to maintain normal (or upright) head posture in order to obtain preferred environmental stimulation	2	17 & 18	50%	Both participants significantly increased their time duration for maintaining upright head position (TDMUHP) to activate the control system in order to produce environmental stimulation during the intervention phases
C	van Timmeren 2016	Netherlands	Physical health problems in people with severe or profound intellectual & motor disabilities	Cross sectional survey	Adults with severe or profound ID (IQ <35), profound motor disability (fully wheelchair dependent), & impairments in vision &/or hearing	99	Male ns (47 (16); ns); female ns (45 (17); ns)	50%	Spasticity (76% (95% CI 67.6–84.4)), deformations (72% (95% CI 63.2–80.8); scoliosis 56%, hip 39%) contracture (32% (95% CI 22.8–41.2)), decubitus/pressure area (20% (95% CI 12.1–27.9))
C; I (P)	Waugh 2009	England	Postural care at night	Case studies	Case study i: male with severe scoliosis contributing to premature death; ii. female with severe scoliosis referred for surgery for rods in spine whose family adopted night time positioning	2	i. 3-23; ii. 9-11 yrs	50%	i. X-rays presented demonstrate progress from symmetrical body shape at age 3 to severe scoliosis at age 23 shortly prior to death. Internal capacity of thorax & abdomen reduced such that right lung ceased to function. Body shape distortion caused: pain & discomfort; pelvic obliquity & rotation; disintegration of hips; respiratory failure; movement of digestive organs into the space reserved for lungs; arrested peristaltic movement leading to faecal impaction. ii. Pictorial illustration of severe scoliosis being improved following night time positioning allowing for spinal rod surgery to be avoided

¹ I = intervention (S = surgery; B = behavioural; E = equipment; P = positioning' O = other); S = service related issues; C = characteristics of people with ID requiring postural care & prevalence.

Acronyms: CP cerebral palsy; ID intellectual disabilities; LD learning disabilities (common term for ID in UK); PMLD profound & multiple learning disabilities; PIMD profound intellectual & multiple disabilities; GMFCS gross motor functioning classification system; SaLT speech & language therapist; CN community nurse