



POSTURE
POSITIVE

Postural care in the age of Covid-19

Produced by

Wright, R and Clayton, S
(2020)

Funded by

NHS England



NHS Improvement

With thanks to:


NHS England & NHS Improvement for the vision and funding to begin this project.

Particular recognition goes to the hard work and dedication of families and practitioners supporting people with learning disabilities and postural care needs. We acknowledge the hardship you have endured during 2020. Your passion for the people you love and support will see us through. Together we have skills and talents to bring about lasting change which improves the lives of people with learning disabilities.

© 2020 Born at the Right Time

Funding and competing interests, and data sharing This research was funded by NHS England and carried out by Rachel Wright, Founder of Born at the Right Time (Training provider Bridging the gap between practitioners and families), and Sarah Clayton, CEO of Simple Stuff Works (Training provider and equipment supplier). Data and technical processes are available from the authors.

Contents

	
Abstract	4
Literature	5
Method	6
Results	7
1. Monitoring outcomes	8
2. Reduction in service provision	9
3. Structure of the service	11
4. Adaptation to the crisis	13
5. Negative health impacts	15
Conclusion	19
Discussion	23
Where to go from here?	23
References	25
Appendices 1-4 The 4 initial qualitative surveys, Postural care in the age of Covid-19;	26
Appendix 5 Second survey	48
Appendix 6 Post-Covid-19 reflection tool Wright 2020	51

Abstract

The Posture Positive Project has been produced in partnership with colleagues from the learning disability nursing team at NHS England & NHS Improvement. to explore how the Covid-19 pandemic has impacted the provision and experiences of postural care services in England. Data was collected using four qualitative surveys targeting the following groups: people with learning disabilities (n=3); their families, carers and paid support staff (n=43); practitioners delivering postural care services (n=45); commissioners (n=0). A subsequent quantitative survey (n=53) focused on the ways practitioners and families feel connected and possible initiatives to improve postural care in the future.

Across the initial surveys five general themes emerged: **monitoring outcomes; reduction in service provision; structure of services; adaptation to the crisis; negative health impacts.**

It was found that families and practitioners were passionate about providing postural care but many families felt abandoned by the reduction in services brought about by Covid-19 restrictions. The changes brought about during the pandemic highlighted fault lines already present within the system and reduced provision significantly. Subsequently, the well-being of practitioners and families was negatively impacted with reported increases in the experience of pain and body shape changes for people with learning disabilities.

The second survey identified a preference for the continuation of virtual clinics and the most popular proposed initiatives were as follows: **one agreed funding stream for all postural care needs; annual postural care team meeting; postural care training for families and carers; library of short, upbeat, on-line videos; good and regular communication.**

It is proposed that improving the lives of people with learning disabilities through excellence in postural care requires a collective vision, commitment and action. Practical next steps are suggested with the launch of the Posture Positive Collective with an invitation to all those with an interest in improving postural care services to contribute and participate.

Literature

Postural care is defined by Mencap as ‘using the right equipment and positioning techniques to help protect and restore body shape’ ([Mencap, 2010](#)). People who find it difficult to move are at risk of developing changes in their body shape if the impact of gravity is not well understood by those around them.

These changes in body shape are highly predictable (Hill and Goldsmith, 2010) meaning that such changes are an avoidable secondary complication associated with having limited independent movement for both children and adults. Changes in body shape can have a life-limiting impact (Carter, 2017) as they may lead to distortion which affects breathing and increases the risk of chest infection – the most common cause of premature death for people with a Learning Disability in England (University of Bristol, 2019).

In May 2018 Public Health England (PHE) published guidance around Postural Care and People with Learning disabilities ([Public Health England, 2018](#)). There is an acknowledgement in this work that the evidence base for postural care provision is lacking, although the development of postural care in the UK has been documented ([Clayton et al, 2017](#)). The picture regarding evidence base has not dramatically changed in the last 2 years, however recent publications show growing interest in the field ([Casey et al, 2020](#)).

The approach taken by PHE is pragmatic. No-one disputes the reality of gravity and its impact on the soft structures of the body. With a growing

population of people with complex needs (Pinney, 2017) and limited movement, directly impacting their body 24-hours a day (Rodby-Bousquet et al, 2013) coupled with the predictability of body shape changes (Hill and Goldsmith, 2010) and in the absence of robust clinical evidence, the option whether to offer support or not to is no longer ethical. This stance is confirmed in the growing recommendations which identify 24-hour postural care provision as essential for those with complex needs ([Changing our lives, 2018](#); [Mansell, 2010](#); [Doukas et al, 2017](#); [Heslop et al, 2018](#) (CIPOLD); [NHS Improvement 2014](#); [NICE, 2020](#); [PAMIS, 2014](#); [Public Health England, 2018](#)

2020 brought with it the Covid-19 pandemic which has impacted health and social care provision around the world. A survey carried out in May 2020 by the National Executive Committee of Association of Chartered Physiotherapists for Adults with learning disabilities ([ACPPLD, 2020](#)) identified ways in which services for people with Learning Disabilities have adapted to living with Covid-19 in their communities. The results however were inconclusive as to how current provision will impact the lives of people with learning disabilities and their families.

Method

In understanding current provision and its impact, it is vital to seek the views of those delivering the service as well as those receiving postural care. Therefore, four surveys were created targeting the following groups:

- people with learning disabilities
- their families, carers and paid support staff (referred to as 'families' for the purpose of this report)
- practitioners delivering postural care services
- commissioners

Each survey was adapted to address the needs and perspective of respondents and deliberately written with a neutral tone to encourage open, unbiased comments. Surveys were shared on social media and via email and those who completed a survey were eligible to win a £100 gift card. All responses remained anonymous and participation was on an entirely voluntary basis.

The initial survey consisted of fifteen open questions exploring the demographics of respondents, their role in postural care, their experience of how provision has changed, the impact this has had on people and their hopes for improving postural care for the future. Each survey was tailored to the individual's perspective and expertise with an Easy Read version produced by an independent, external developer (see appendices 1-4).

Using the responses from the initial surveys a second, shorter, survey consisting of two questions was then created. The first question asked respondents to rate suggested changes to postural care provision and the second focused on preferred ways practitioners and families wanted to maintain connection amidst the current Covid-19 pandemic. This second survey was designed to elicit an understanding of possible creative ways families and practitioners saw postural care improving in the future (see appendix 5).

Results

From the four initial surveys (n=89), the majority of the responses came from practitioners (n=45) and families (n=41). There were three responses from individuals with a learning disability and no responses from commissioners.

Family responses represented a demographic from across England supporting people aged between 2-39 years. The majority of those receiving postural care were in school with only 11 being over the age of 18. All respondents had input from a physiotherapist (PT) or occupational therapist (OT), with nearly all (90%, n=36) having both. Families reported the person with a learning disability as predominantly having a high level of complexity with over 95% requiring more than three pieces of specialist postural care equipment. Practitioners from across England, serving individuals in every age bracket from infancy to the elderly responded to the survey. They represented education, health, social care and industry both working within public and private sectors.

Across all the initial (open question) surveys five general themes emerged:

1. **Monitoring outcomes**
2. **Reduction in service provision**
3. **Structure of the service**
4. **Adaptation to the crisis**
5. **Negative health impacts**



1. Monitoring outcomes

Families and practitioners advocated the importance of postural care. Many commented they were pleased this piece of work was taking place as postural care is vital for the health and well-being of people with learning disabilities yet is too frequently forgotten.

"[Postural care] is not a nice to have, it's essential."

– FAMILY

"We need to raise awareness of this silent killer."

– PRACTITIONER

The majority of families described why they were providing postural care;

- provide comfort (71%, n=29)
- maintain body shape (41%, n=17)
- enable function (27%, n=11).

Although many families found it harder to explain how they measured the success most respondents said they did so by visually noticing if a person's body shape is deteriorating or not (44%, n=18). By contrast, practitioners struggled to describe the key outcomes of postural care and ways of monitoring the success of interventions. Of those that did, some identified maintenance of function and visible signs of symmetry as key indicators.

Only 15% of practitioners reported using an objective measurement tool to monitor and review the success of interventions.

Nearly all families reported the use of more than three pieces of specialist postural care equipment (see Table 1).

Table 1: Reported use of specialist postural care equipment by families for people with learning disabilities

Specialist equipment	% Reported
Wheelchair	85
Stander	71
Supportive seating	59
Night-time positioning	54
Walker	43
Specialist bed	32
Splints (hand and leg)	17
Bath/Toilet	12
Specialist feeding/high chair	12
Lycra suit	5

According to these results, respondents were more likely to use a stander (which impacts posture for up to 1 hour a day) than night-time positioning equipment (which impacts posture for up to 12 hours a day).

Less than 30% of families reported using the triad of supportive seating, wheelchair and night time positioning which are the foundational of 24-hour postural care.

2. Reduction in service provision

Both families and practitioners noted that the Covid-19 pandemic had significantly affected equipment provision, provision of assessments and hands-on interventions. The most widespread disruption being within equipment provision (55%), postural care assessments (30%), alternative seating (38%), wheelchair services (36%) and hospital services such as orthotics, surgery and Botox.

Those services which did continue had minimal face to face contact and dramatically reduced capacity owing to rapidly changing practices in infection control and available space for social distancing.

Whether related to hospital discharge, supporting people in care homes, seating, night time positioning or active therapies such as hydrotherapy, only urgent cases were reported as being considered:

"Urgent referrals only due to risk of transmission, reduced input in care homes due to them not wanting visitors"

– PRACTITIONER

The general trend was that staff had significantly reduced or completely stopped face to face working and were now working remotely whilst providing virtual assessments. This was in part due to changes in practice but also because families no longer wanted practitioners in their homes with the increased risk this presented. Assessments and prescriptions for equipment were delayed in the

NHS although it was reported by a professional in industry that this wasn't always the case for privately funded equipment,

"NHS WCS (wheelchair service) closed. Self-funding clients using virtual tools on a frequent basis and face to face with appropriate PPE."

– PRACTITIONER

Across the board, capacity within teams was dramatically reduced because of:

- redeployment
- self-isolation
- remote working
- need for social distancing
- adapting to technology

Of the families questioned, nearly 70% reported not seeing anyone face to face. 60% confirmed physiotherapy input had been stopped and over 30% were no longer able to access wheelchair services or access an Occupational Therapist.

Some (n=12) families described physical changes to provision such as delays to equipment but even more (n=19) described feeling physically and emotionally abandoned by practitioners within postural care services:

66

"Everything stopped and we as parents had to take on every role - 24/7"

– FAMILY

"We were pretty much on our own!"

– FAMILY

Along with a sense of isolation, families felt instantly unsupported because of a sudden loss of contact:

"...generally, all aspects of my son's life has been impacted on and no one seems to want to help, we are in need of so much but there is no support there."

– FAMILY

"Families have felt isolated at times and forgotten about by some other services."

– PRACTITIONER

"Many specialists and therapists are difficult to contact due to them working from home or being redeployed throughout the nhs"

– FAMILY

One respondent reflected clearly the apparent disparity in the way different services adapted to Covid-19 restrictions:

"Some of the services have completely abandoned us, others are still good at communicating effectively."

– FAMILY

Families of adults with learning disabilities were twice as likely to feel abandoned when compared to families of children with learning disabilities.

As practitioners predominantly worked from home and stopped face to face contact, usual methods of contact were disrupted. These changes appeared to significantly alter the relationships practitioners had with families. Nearly half of practitioners felt changes in their working habits had no impact on their relationships with families while others felt the imposed distancing had negatively impacted connection with families (n=8).

However, over 40% of practitioners spoke of finding new, creative ways to connect with families and colleagues in the MDT. In contrast to those who saw no difference, these practitioners were upbeat and positive about improving relationships, listening to the family voice, increasing connection and empowering families by reducing barriers to engagement:

"I've found that there's a feeling that everyone is 'pulling together' in the pandemic to support the child... [it has] given us time to actually 'hear' the voice of the family... There's a feeling that we are all in this (the pandemic) together & we have found that common vulnerability which helps us to see each of us as human & takes away the barriers of who's teacher/parent/therapist."

– PRACTITIONER

"Yes, all appointments carried out virtually. Kept up to date via email and text rather than house visits"

– FAMILY

3. Structure of the service

30% of families felt the care at home (without the input of practitioners) was as good if not better than prior to Covid-19. In several cases this reflected their exasperation at services being poor prior to the pandemic,

"Postural care services poor prior to Covid but feels as if Covid has just delayed provision further and Covid used as reasons why services can't provide essential items."

– FAMILY

Although everyone recognised that the rapid and widespread changes thrust upon the service as a result of Covid-19 had a detrimental effect, there was a strong theme from both families and practitioners that this wasn't the full story. Rather they felt there was a long-standing problem underlying provision which had simply been exposed in recent months:

“

"Covid is a red herring! Postural care has needed to be changed for a long time and local practises vary considerably."

– PRACTITIONER

"The NHS service was appalling before and it's equally appalling now but they now blame Covid for this."

– PARENT

Families and practitioners both described a service focused on capacity of provision rather than individual and family's needs. Themes which came out of the data encompassed:

- Co-ordination
- Funding
- Coaching and empowering families

Co-ordination

As practitioners and families lost the usual ways of working and communicating within the MDT and with families, the lack of communication and co-ordination brought services to a spluttering stop for many.

"We took delivery of a new home chair for feeding during Covid lockdown. It was ordered with a rep from the company who came to home to assess and made video call to NHS OT. We've had it nearly 2 months and no one has come out to fit our child in the chair despite numerous emails. We haven't even had a reply to the emails. We are still waiting for NHS physiotherapist to return to working after they were redeployed at the start of Covid."

– FAMILY

"People with LD and their families need more co-ordinated approaches to their postural care plans; NHS services are at times fragmented across many different areas; these need to be somehow unified."

– PRACTITIONER

In order for co-ordinated care to be provided an existing infrastructure of collaboration between practitioners is essential alongside how well-trained care-givers in postural care:

"Two urgent needs were resolved...largely due to already-established close working dynamics within the service and it's providers...as well as the work that has previously been done by team clinicians to improve care-giver understanding of postural issues"

– PRACTITIONER

Coaching and empowering families

For many practitioners, suddenly no longer being able to work 'hands on' with clients, the importance of primary carers' knowledge, skills and capacity to provide postural care within the individual's normal environment was highlighted. The success of services was reported to be related to the extent to which services invested in training for families prior to Covid-19:

"Worked with carers to have equipment set up (this was always easier and probably done better where carers had had training or had previously worked with people who required similar support)."

– PRACTITIONER

"[Families have] improved education and independence with managing their postural care"

– PRACTITIONER

In some instances, training had not previously been seen as important but the Covid-19 crisis had put this in a new light. Both practitioners (25%) and families (20%) noticed that reduced practitioner involvement could lead to increased family empowerment, particularly if coupled with family training or coaching:

"...[I] have increased] my knowledge base and practical skills to enable better care without being completely reliant on other professionals."

– FAMILY

"...families have been empowered and proactive and have become more engaged with the service."

– PRACTITIONER

"We have had to learn more about the equipment our daughter uses and how to adjust this ourselves. We are more knowledgeable on how to do so now."

– FAMILY

Funding

Funding was a theme raised primarily by practitioners as a systemic issue which significantly impacts their ability to offer good quality provision (a finding reiterated in the second survey):

"It is a simple matter of understanding that funding and support for these people isn't a year to year exercise. Cheap product and service looks great on a spreadsheet. But if it doesn't work or go some way to help prevent destructive posture, it is nothing but a waste of money. You do not fix poor posture with mediocre service in 45 mins."

– PRACTITIONER

"It is confusing for a professional regarding which service does what, e.g. separate social care OT for home adaptations, school OT, early years OT & PT etc in a child development unit, wheelchairs service completely separate again. It's so disjointed & left to the family to navigate this."

– PRACTITIONER

“

"In those services that have embraced remote working it has been demonstrated that families can access specialist training and support in a more efficient and less intrusive way."

– PRACTITIONER

4. Adaptation to the crisis

In addition to upskilling and coaching families, most practitioners (80%) and many families (60%) identified other 'silver linings' which came about as the service adapted to the Covid-19 crisis. These included;

Benefits of on-line and virtual clinics

- 'Rallying' - a collective drive to adapt to meet needs
- Encouraging signs of resilience
- Benefits of on-line and virtual clinics

The biggest silver lining for families (and witnessed by practitioners) appeared to be spending more time with their children, not rushing around or travelling long distances for appointments. The joy of less time in the car was also expressed by practitioners. Many services started offering on-line or telephone access resulting in families reporting the relief of accessing appointments at home and practitioners being more contactable:

"This is actually better for many as saves having to make the trip into central London. We've found it easy to get hold of consultants and specialist nurses as necessary via email or what's app - even on weekends!"

– FAMILY

"Some families report that they have found the demands of a strict timetable positive."

– PRACTITIONER

In addition, practitioners noted the increased efficiency in virtual appointments as well as the benefit of seeing individuals in their own environment. This enabled practitioners to witness

families and individuals more relaxed and at home rather than distressed in a clinic environment. This in turn supported the development of therapies more suited to their environment and equipment available.

"The massive increase in time and preparation whilst using virtual sessions, making face to face session far more efficient and affective."

– PRACTITIONER

"I love seeing the children in their natural environment with parents fully present."

– PRACTITIONER

The change to on-line also brought about a change in the equity experienced by families and practitioners. One particular mother was exuberant at how, for the first time in her life, her daughter experienced true inclusion as the rest of the country experienced their 'normal life' and services were adapted to meet the needs of people in isolation:

"As businesses and services responded to the masses, who suddenly found themselves at home, my daughter was able to access a huge number of services and activities online, that had never existed before. Music therapy, sensory stories, sound journeys, dance classes, theatre shows, choir, all suddenly appeared online and we felt such comfort in knowing that everyone else was suddenly experiencing our norm."

– FAMILY

"Parent/therapist/schools relationships feel more equal."

– PRACTITIONER

"Team work and closer working relationships with other professionals and families as well as a better overview of a child's whole care package not just education."

– PRACTITIONER

'Rallying' - a collective drive to adapt to meet needs

Changes happened so quickly, sometimes by the day, and with guidance varying, a kind of camaraderie had developed. It was seen not just within the team but across the MDT and with families too. There was a strong theme from some practitioners supporting the concept of 'rallying' which perpetuated a more dynamic and flexible way of working:

"The rallying of staff to help out where ever needed including being retrained and redeployed. Being able to implement quick and new ways of working to ensure that children and young people still had access to our service."

– PRACTITIONER

"Keep going- just going to ensure service provision for the most vulnerable to ensure their needs are met and they are not forgotten over all the hype and hysteria of Covid 19. The team were/ are amazing to continue to work under difficult circumstances."

– PRACTITIONER

Encouraging signs of resilience

Across all the responses (practitioners, families and individuals) the theme of resilience shone through. The resilience of individual practitioners and families was recognised:

"People are more resilient and creative than you think and can survive in a world without healthcare professionals."

– PRACTITIONER

"I'm going to pat myself in the back and say I have provided great postural care to my son! Day and night, I have made sure he is sitting, standing or lying in the most optimal way for his health and comfort. Go me 🙌"

– PARENT

In addition, the ability of the networks of organisations providing postural care to change and adapt represented a broader example of systemic resilience. Practitioners demonstrated an ability to be flexible, collaborative and dynamic in their approach to communication with families, having a positive impact on practices. Despite the challenges, this perspective of shared responsibility and rallying in the face of adversity has, in places, stimulated shifts in practice and ways of working which would have previously taken months to implement:

“

"The inefficiencies of past practice had been accepted as inevitable because of resistance to change. The complete inability to deliver an acceptable postural care service under Covid 19 restrictions has forced changes which would have been thought to be impossible."

– PRACTITIONER

5. Negative health impacts

Practitioners

Many practitioners reported low morale and a feeling of disconnection in their work, both of which impacted their own mental health.

"Remote working and lack of physical presence of team members takes their toll mentally particularly."

– PRACTITIONER

"High stress levels to try to provide an effective service to those in greatest need within continually changing rules and many additional risk assessments."

– PRACTITIONER

"...negative impact on well-being and difficult to seek advice from colleagues"

– PRACTITIONER

Many missed the incidental conversations which happened at the kettle or passing in the corridor, some saying that lacking this kind of contact had hampered naturally occurring reflective practice and support from managers:

"...really missing the informal interactions, information exchanges and learning that happen in the office environment"

– PRACTITIONER

Families

Sadly, a strong theme throughout practitioner and family responses was carer burnout and fatigue. Families and practitioners reported carers' health deteriorating and having a knock-on effect with other family members:

"We are exhausted. There is no respite...We have been left heartbroken watching [daughter] go through so much pain with no professional willing to help. We feel alone and unsupported."

– FAMILY

"We did it all for 6 months and we ache and hurt as a result."

– FAMILY

"More work needed from me results in more stress, neglecting time with other children."

– FAMILY

"I phoned families weekly during lockdown, and they often felt very isolated and uncertain."

– PRACTITIONER

"Families are tired and stressed- the children have deteriorated."

– PRACTITIONER

Witnessing the impact of deterioration on loved ones also caused much anxiety and distress as the potential long-term implications became more apparent:

66

"...heart breaking to see. I've felt like I'm watching a car crash and there's nothing I can do and no one cares."

– FAMILY

"She will need spinal surgery or it will be too late to action and her spine will continue to deteriorate until it kills her."

– FAMILY

People with learning disabilities

The greatest impact, sadly remained with the most vulnerable – those with learning disabilities and postural care needs. Three individuals with learning disabilities shared their experience of their own postural care. These respondents had markedly less complex needs to those represented in the other parts of the survey. Yet all three described a decrease in healthcare provision where medical services, social interaction and respite had all been stopped, leaving a sense of abandonment. This in turn was reported as having a direct impact on health including mobility or overall physical health:

"I think I will once again become dependent on my wheel chair after working very hard to get out of it."

– PERSON WITH LEARNING DISABILITIES

Some families hoped Covid-19 would not negatively impact their loved one's health. However, over 60% identified a negative impact on the life of the person with a learning disability with a quarter specifically noticing a reduction in function.

Tragically, 7% (n=3) families reported loved ones being in more pain as a direct result of reduced provision. 40% of families and 27% practitioners reported worsening body shape:

"Hugely, negative impact on postures. Having to deal with changes that shouldn't have happened."

– PRACTITIONER

"We've seen a marked deterioration in her scoliosis and leg/hip discomfort and muscle tightness."

– FAMILY

"I'm really concerned about the deterioration in his spinal curve. I believe it's as a result of a sudden growth spurt and not being able to get any of his positioning equipment adjusted. I've been using rolled up towels to try and support him. Plus being at home all the time meant he missed out on the daily physio he would normally have at school. With the best will in the world it was impossible for me to replicate that."

– FAMILY

Nearly 80% of practitioners, like families, identified numerous ways individual's long- and short-term health was being negatively impacted as a result of inadequate postural care support. These included a third of individuals suffering noticeable body shape changes (deformity) with small numbers experiencing reduced functional movement and secondary health complications:

"[Family] told me the students were very bored, some showed signs of unhappiness."

– PRACTITIONER

"Lots of rapid progression of deformity"

– PRACTITIONER

"...postural deterioration and tissue problems"

– PRACTITIONER

The future remains bleak with nearly 70% of practitioners predicting that reductions in postural care provision in 2020 will have a significant, negative long-term impact on the body shape of individuals for years to come. The immense burden of care as a result of schools and day centres closing was seen to be the main reason carers were struggling but this insight deepened the respect practitioners had for the work families do:

"My admiration, support and sympathy (at risk of sounding patronising) for families and carers has deepened."

– PRACTITIONER

Second Survey Results

The second survey focused on two areas identified in the initial questionnaires.

- The ability for practitioners and families to feel connected
- Possible ways postural care could be improved in the future

When considering how practitioners and families connected, both groups identified a preference for the continuation of virtual clinics whilst just under a third of the respondents preferring the use of email to communicate (See Figures 1 and 2)

Figure 1: Family/Carers preferred communication

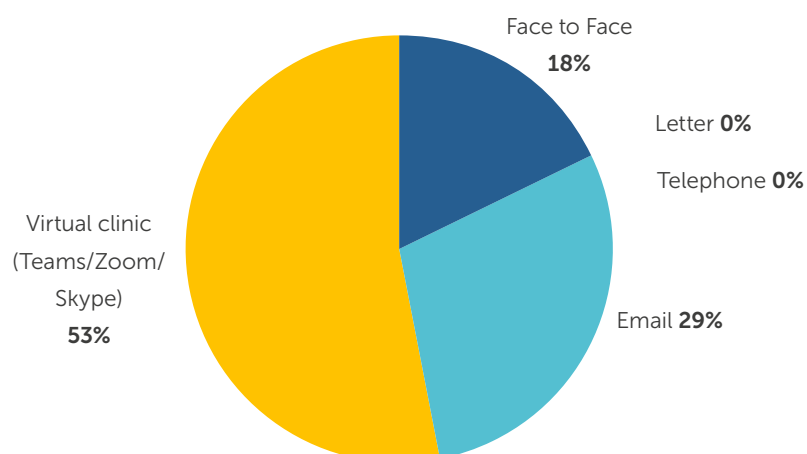
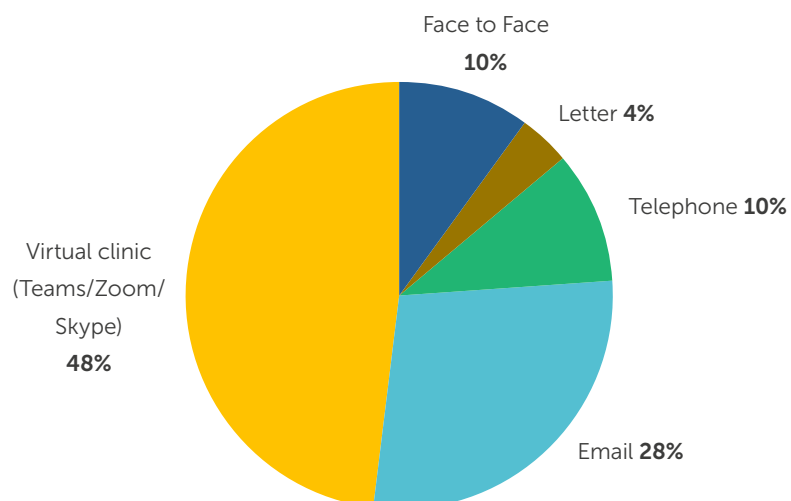


Figure 2: Practitioners preferred communication



Using the ideas and suggestions described by families and practitioners, the second survey described fifteen possible initiatives to improve postural care for people with learning disabilities. These included having a single point of contact for all postural care needs, an advice line to support families and agreed outcomes and targets (see appendix 5). Interestingly, families and practitioners both identified very similar top five new ways of working as shown in Tables 2 and 3.

Table 2: Practitioner: Top five suggested new ways of working (n=35)

	Suggested new ways of working	Highest ranked
1	Agreed funding stream/purse for all postural care needs	74% (n=26)
2	Annual postural care team meeting	54% (n=19)
3	Postural care training for families/carers	54% (n=19)
4	Library of short, upbeat, on-line films	54% (n=19)
5	Good, regular communication between practitioners and families/carers	43% (n=15)

Table 3: Family/Carers: Top five suggested new ways of working (n=18)

	Suggested new ways of working	Highest ranked
1	Annual postural care team meeting	72% (n=13)
2	Postural care training for families/carers	67% (n=12)
3	Agreed outcomes and targets for postural care	56% (n=10)
4	Library of short, upbeat, on-line films	50% (n=9)
5	Single point of contact practitioner for all postural care needs	44% (n=8)

When the results of the surveys are pooled the clear collective voice points towards co-ordinated funding, training, accessible information and co-productive working facilitated by good communication (see Table 3).

Table 4: Combined top five suggested new ways of working (n=53)

	Suggested new ways of working
1	Agreed funding stream/purse for all postural care needs
2	Annual postural care team meeting
3	Postural care training for families and carers
4	Library of short, upbeat, on-line videos
5	Good and regular communication

Conclusion

The strength of the data and emerging themes reflect the honest and open responses received from practitioners and families alike. The shift in service provision brought about by Covid-19 restrictions revealed deep fault lines within the system. As a consequence, the well-being of practitioners and families have been negatively impacted with reported increases in the experience of pain and body shape changes for people with learning disabilities.

It is disappointing that despite an externally produced Easy Read version, only three people with learning disabilities completed the survey. It is likely however, that this reflects the difficulties apparent in accessing the views of this population. It was noted that there were no responses from commissioners despite direct communication to reach this group. The results have to be interpreted in the light that there was little or no input from these two important groups. Despite this, there was very good numbers of responses from the families and practitioners, providing a sufficiently large body of data to distil firm themes. The themes of the results will be considered in turn:

Monitoring outcomes

Given the self-selecting nature of those completing the survey, it is unsurprising that the individuals, families and practitioners were all passionate and well educated about postural care. However, despite the bias in the sample, it is disconcerting that fewer than half of families responding reported the provision of 24-hour postural care.

The impact of gravity on a person's body with limited movement occurs 24/7. For twenty-four hours a day, gravity is slowly conspiring with the body's naturally occurring flexions and tightening's to, result in body shape changes, secondary health

issues and pain. Postural activities such as walkers, standers and hippotherapy give important postural changes, access to new experiences and potentially life-changing developments. However, given the time limitations of each of these activities, the fundamentals of successful postural care continue to occur in the (significantly less glamorous) timely provision of a well-assessed wheelchair, alternative seating and night-time positioning. Night-positioning alone can affect up to 12-hours of a person's time, protecting their body from harm. Careful consideration must be given to the therapeutic priorities of equipment and service provision.

The challenge for both practitioners and families alike appears to be the lack of robust, objective measurements which can inform and drive equipment and therapy provision. Despite Public Health England (2018) stipulating the importance of monitoring body shape changes to inform needs and provision, a mere 15% of practitioners reported using any objective means of monitoring.

Lack of 24-hour postural care, without clear outcomes and monitoring, creates gaping holes in the defence against the life-changing, negative impact of poor postural care.

Reduction in service

It is unsurprising that the dramatic and unparalleled changes in working practices reduced the capacity of services providing postural care needs. It is important to acknowledge that this reduction in service provision is due to the unprecedented situation and not individual practitioners. For families the resulting experience of abandonment at a time of crisis was palpable in almost every family's response. Families felt isolated and deserted by the practitioners and services commissioned to support them. Within the data there appeared to be two distinct groups of practitioners. Almost half seemingly accepted the loss of contact and predominantly waited for 'normal' services to resume whilst the other half gathered themselves to re-invent the ways in which they connected and communicated with families in order to adapt to greater, changing needs and environmental pressures.

Why some services and individual practitioners adapted more effectively to imposed change cannot be fully understood from the data. One key factor that did emerge was how families of adults were much more likely to feel abandoned than those with children. The role of the school, as a central body with multiple agencies involved, is unclear but could be an explanation for this variation in experiences.

Services have reduced capacity across the board, leaving families less supported. The way services have adapted to change has varied dramatically.

Structure of the service

As the pandemic affected all aspects of everyday life, fracture lines within a struggling postural care system were amplified with significant, potentially life-altering, ramifications. Services strained under significant external pressure while existing fragilities and failings emerged. Co-ordination, training and funding were the key themes which

emerged from the data in relation to postural care services.

The lack of commissioner input might simply be because the survey did not reach the right desks. However, there may be a more disconcerting connection between the lack of transparent and co-ordinated commissioning of postural care services. The issue of funding was raised by both families and practitioners alike. In the current provision model, a child with complex needs will have half a dozen specialist practitioners accessing a minimum of three funding streams to acquire all the necessary services, therapies and equipment needed for good 24-hour postural care. Without adequate communication between services, the burden of coordinating this provision lies with families.

There is an apparent disconnect in the way practitioners are commissioned to co-ordinate their efforts, fund equipment and educate families which results in a transactional, medical model of provision. Each practitioner has individual responsibilities within their own funding stream and associated hoops to jump through. The lack of overall co-ordination of these services to provide postural care for the whole 24-hours may be contributing to the piecemeal, disjointed services on offer. Despite the best efforts and dedication of hard-working, passionate, empathic practitioners, the system they exist within doesn't necessarily facilitate collaborative working with each other or with families.

The impact of Covid-19 highlighted existing failures and fragilities within postural care provision. Namely the way it coaches and empowers families, how it is co-ordinated and funded.

Adaptation to the crisis

The themes which emerged from the ways practitioners and families adapted to the Covid-19 pandemic is a testament to the hard work and dedication of everyone involved. It was universally agreed that no-one missed the time spent travelling in cars to appointments although the loss of physical contact had its own negative impact.

For both families and practitioners, changes in working practices resulted in reduced time spent rushing around, evidence of 'rallying' and resilience as well as showing the various ways families and practitioners adapted to life on-line. These changes are an indication that although the current service is stretched, the present state of flux might just be an ideal time to embrace wider reaching change.

Amidst a time of rapid transition, implementing transformation now might not only improve postural care but make it more sustainable and resilient in the future.

Negative health impacts

It is apparent that despite both families and practitioners reporting various ways they are endeavouring to provide good postural care in challenging circumstances there have been noticeable negative health impacts on everyone. Practitioners reported an impact on their mental health and families were noted by practitioners and themselves as having significant physical and emotional burnout as a direct result of diminishing support and exponential increases in caring demands.

As is often the case, those most significantly impacted are the people with postural care needs themselves. They were noted to have changes in body shape, tissue integrity and worsening pain.

When the term safeguarding is used in relation to postural care provision, it often has the intention

of highlighting an apparent inadequacy in a family's ability to deliver, and/or engage with, services, equipment and strategies. However, the principles of safeguarding assert the need for 'appropriate measures.' In terms of postural care services, this must therefore be applied to the funding, development, delivery and accountability of postural care services themselves.

In order for families to protect their loved ones, they must first have access to adequate equipment, the appropriate knowledge and competence, emotional and practical caring support, and access to relevant, objective outcome measures.

This research highlights that the current system of provision is inadequate, and this was corroborated by families and practitioners alike. Many of the families asserted that this has been the case long before the Covid-19 pandemic. Both practitioners and families are aware of the predictable, long-term consequences that are likely to come about if people are not protected.

Knowledge of the harm being done to individuals in combination with an inability to act leads to considerable distress on the part of families, care providers and health care practitioners. This distress was starkly evident within the responses to the survey and must be acknowledged. Previous work in this area ([Clayton 2013](#)) identified systemic safeguarding issues around knowledge and understanding of postural care, inadequate recognition of pain and distress, historical commissioning arrangements and a lack of objective outcomes:

It is vital that safeguarding is recognised as a collective responsibility that drives positive change rather than fuelling defensive attitudes, communication and reaction.

Safeguarding is crucial in postural care provision. It is the collective responsibility of the whole system to work together to protect individuals with learning disabilities from harm.

Second survey results

The results of the second survey are the clearest indication that both families and practitioners value some of the changes imposed by Covid-19, specifically the opportunity for on-line and virtual working. Furthermore, the results of the suggested 'new ways of working' question endorses findings highlighted by the first survey about the issues of co-ordination, funding, accessible information and training. It seems the voices of both families and practitioners are in unison about changes which would have a positive, lasting impact on the delivery of postural care.



Funding
Co-ordination
Co-production
Training
Accessible
Information

Discussion

Where to go from here?

The Posture Positive Project is founded on the principle that to imagine and develop excellence, it is essential to understand the experiences and impact postural care provision has upon everyone involved. After this, by working together, we can begin to dream, build and share what excellence looks like for people with learning disabilities who have postural care needs.

The intention of this project was to listen to the key voices involved in the provision of postural care for people with learning disabilities. It is proposed that improving the lives of people with learning disabilities through excellence in postural care requires the vision, commitment, skills and a collective voice.

Postural care provision needs to move away from a medical model of providing equipment and episodic regimes of therapy. Rather, it must begin to function within a self-management model reliant upon the empowerment of families through coaching, co-ordination, and co-production. The resulting effect would be two-fold; increasing the resilience of families and the systemic resilience of postural care provision.

Drawing on the insights and experiences of people with learning disabilities, their families and supporting practitioners, it is clear that 2020 could be a pivotal year for postural care provision. It is a time of imposed, dramatic change and a period of rapid transition which presents an opportunity for both strategic and grassroots transformations founded on the reality of lived experience, evidence-based practice, creativity and personalised care.

Any proposed initiatives must be positive, proactive and promote personalised care. The need for co-production, co-ordination and efficiency cannot be understated as the capacity within the system is limited. Despite this, there is a readiness for change that should not be overlooked. The Posture Positive Project proposes changes under the themes of standardisation and coordination and collaboration.

Standardisation

- Launch the Posture Positive Collective on [Facebook](#) and [Twitter](#) to provide on-line peer support for both families and practitioners.
- Launch the Posture Positive [YouTube](#) channel sharing excellence in practice, case studies, clinical evidence, care pathways and other resources.
- Develop standardised training for families/carers.
- Develop a Bronze, Silver and Gold award for services which demonstrate good standards in postural care which could include;
 - Provisions accommodating 24-hours of the day
 - Up to date care plans
 - Defined personalised outcomes
 - Training for families/practitioners
 - Use of standardised measuring tools
 - Annual reviews

- Promote the implementation of national guidance stipulating postural care outcomes and objective ways of monitoring success.

Co-ordination and collaboration

- Promote dialogue between families and practitioners through the Posture Positive Collective.
- Promote the use of reflective tools to improve co-production and co-ordination between the practitioners and families e.g. Post-Covid-19 Reflective Tool (Wright, 2020 – see Appendix 6).
- Pilot the impact of annual postural care reviews.
- Share the Posture Positive report with key individuals within Government, Social Care, Education and Health to support the case for a national funding strategy enabling postural care provision to be personalised and co-ordinated.



**The Posture
Positive Collective
will transform
postural care
provision to
improve the lives
of people of
learning
disabilities.**

Funding and competing interests, and data sharing This research was funded by NHS England and carried out by Rachel Wright, Founder of Born at the Right Time (Training provider Bridging the gap between practitioners and families), and Sarah Clayton, CEO of Simple Stuff Works (Training provider and equipment supplier). Data and technical processes are available from the authors.

References

- Carter, B (2017) [Poor posture in people with disabilities can be fatal](#). Accessed November 2020
- Casey, J, Rosenblad, A and Rodby-Bousquet, E (2020) [Postural asymmetries, pain, and ability to change position of children with cerebral palsy in sitting and supine: a cross-sectional study](#) Disability and Rehabilitation, DOI: 10.1080/09638288.2020.1834628 Accessed November 2020
- [Changing our Lives \(2018\) Postural care strategy](#). Accessed November 2020
- Clayton, S, Goldsmith, L, Ellis, T (2017) [24 Hour Postural Care: The journey so far in the UK](#). Accessed November 2020
- Clayton, S (2013) [Living Local Postural Care Project Evaluation](#). Accessed November 2020
- Doukas, T, Fergusson, A, Fullerton M, Grace, J (2017) [Supporting people with profound and multiple learning difficulties: Core and essential standards](#). Accessed November 2020
- Heslop, P, Blair, P, Fleming, P, Hoghton, M, Marriot, A, Russ, L (2018) [Confidential inquiry into premature deaths of people with learning disabilities \(CIPOLD\)](#) Accessed November 2020
- Hill, S and Goldsmith, L (2010) Biomechanics and prevention of body shape distortion. Tizard Journal
- Mansell J (2010) Raising Our Sights: services for adults with profound intellectual and multiple disabilities. Department of Health, London (Accessed November 2020)
- Mencap (2010) [Postural care: protecting and restoring body shape](#). Accessed September 2020
- National executive committee of Association of Chartered Physiotherapists for Adults with Learning Disabilities (2020) Survey exploring the role of Specialist Learning Disability Physiotherapy services during the COVID-19 pandemic.
- NHS Improvement (2014) [24-hour postural management for family carers](#). Accessed November 2020
- National Institute of Health and Care Excellence (2020) [Clinical Guideline: Spasticity in children and young people an overview](#). Accessed November 2020
- Pamis (2014) Postural care; [A guide to 24-hour postural management for families and carers](#). Accessed November 2020
- Pinney, A (2017) [Understanding the needs of disabled children with complex needs or life-limiting conditions. Council for disabled children](#) Accessed November 2020
- Public Health England (2018) [Making reasonable adjustments to postural care services](#) Accessed November 2020
- Rodby-Bousquet, E, Czuba, T, Hagglund, G, (2013). Postural asymmetries in young adults with cerebral palsy. Dev Med Child Neurol. 55(11):1009–1015
- Rolfe, G., Freshwater, D., Jasper, M. (2001) Critical reflection in nursing and the helping professions: a user's guide. Basingstoke: Palgrave Macmillan.
- University of Bristol (2019) [The Learning Disability Mortality Review \(LeDeR\) Programme Annual Report, 2018](#). Accessed September 2020

Appendices 1-4

The 4 initial qualitative surveys, Postural care in the age of Covid-19;

- Parent, family carer and paid support worker
- Practitioner
- Person with a Learning disability Easy Read version
- Commissioner





Postural care in the age of Covid; parent, family carer or paid support worker.

A people-focused project.

Postural care is 'using the right equipment and positioning techniques to help protect and restore body shape'⁽¹⁾. Changes in body shape can lead to negative consequences potentially causing premature death in people with a Learning Disability⁽²⁾.

A survey in May 2020⁽³⁾ identified various ways Covid-19 has impacted on people with Learning Disabilities. Further exploration funded by NHS England, is being carried out by Simple Stuff Works (experts in postural care) and Born at the Right Time (experts in communication and co-production).

Thank you for taking the time to complete the survey below, the results of which will be shared at an online event on the **23rd November 2020**. The survey is likely to take you about 15 minutes and must be submitted before **9th October 2020**. By supplying your email address at the end, you will be entered into a £100 Amazon voucher prize draw.

If you would like help completing this form there is an Easy read version* or you can email rachel@bornattherighttime.com to arrange to answer the questions over the phone.

*www.bornattherighttime.com/postural-care-project

1 Mencap (2010) Postural care: protecting and restoring body shape. <https://www.mencap.org.uk/sites/default/files/2016-11/Postural%20Care%20booklet.pdf> Accessed September 2020

2 University of Bristol (2019) The Learning Disability Mortality Review (LeDeR) Programme Annual Report, 2018. <http://www.bristol.ac.uk/sps/leder/resources/annual-reports/> Accessed September 2020

3 National executive committee of Association of Chartered Physiotherapists for [https://www.surveymonkey.com/create/?sm=C43osTS6Ur9xRIAUYyPBZ_2BaAdaawnocBXp75N5NQRTTU_3D#Adults with Learning Disabilities \(2020\) Survey exploring the role of Specialist Learning Disability Physiotherapy services during the COVID-19 pandemic](https://www.surveymonkey.com/create/?sm=C43osTS6Ur9xRIAUYyPBZ_2BaAdaawnocBXp75N5NQRTTU_3D#Adults%20with%20Learning%20Disabilities%20(2020)%20Survey%20exploring%20the%20role%20of%20Specialist%20Learning%20Disability%20Physiotherapy%20services%20during%20the%20COVID-19%20pandemic).

1. Completion of this survey is entirely voluntary. We want to understand how postural care is provided in order to support change. There are no anticipated risks to answering questions and it is hoped that the results of the survey will shape a project to support improving the lives of people with Learning Disabilities.

Identifiable data will be seen by the researchers only. All data will be stored securely in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and anonymised before reporting.

I give informed consent for the anonymised data I provide to be used for this project.

☐ Yes

About you

2. Where in the UK do you live?

3. How old is the person you care for with learning disabilities?
(If more than one person please complete individual forms)

4. What professionals help with the way they sit, stand, walk and sleep?

5. What equipment do they use to help with walking, sitting, standing or sleeping?

6. What keeps them busy?

School, College, Day Opportunity Centre, work etc

Changes to provision

7. Please list the postural care services that have changed for you since Covid-19.

This might be wheelchair services, hospital discharge and rehabilitation, operations, Botox, orthotics, night-time positioning or alternative seating provision for children or adults.

8. How have these services changed?

This might include the ability to see a professional face to face, urgent, non-urgent, referrals, assessments for new equipment, equipment handover, maintenance and adjustment, reviews and advocacy.

9. How have your relationships with therapists and services changed in the last 6-months (if they have at all)?

10. Please describe any great postural care you have seen or experienced in the past 6-months.

11. What good things have happened as a result of Covid-19 (if there are any)?

Impact on people

12. How have the changes to postural care services, as a result of Covid-19, impacted the person you care for?

13. How have the changes to postural care services, as a result of Covid-19, impacted you and your family/team?

14. Why do you think this has happened?

15. What do you think the long-term impact of 2020 will be on the postural care needs of the person you care for?

The future. Let's dream

16. Why do you provide postural care and how do you know if it is working?

17. If you had a magic wand, how would you like to see the Covid-19 pandemic change the way postural care is organised, provided and experienced by people?

18. Any other comments, insights or concerns around postural care in people with Learning Disabilities.

Congratulations – that is it.

You have finished. We really appreciate your help in this project.

Please provide your email address to be entered into a prize draw for a £100 Amazon voucher.

19. Enter into the £100 prize draw

Name

Email Address

20. I am happy to be contacted to discuss my answers further. (Be assured we will maintain your anonymity.)

☐ Yes

☐ No

If you have any questions or feedback, please email either **Rachel**
Rachel@bornattherighttime.com or **Sarah** *training@simplestuffworks.com*



Postural care in the age of Covid; Practitioner

A people-focused project.

Postural care is defined as 'using the right equipment and positioning techniques to help protect and restore body shape'⁽¹⁾. Changes in body shape can lead to negative consequences which cause premature death in people with a Learning Disability⁽²⁾.

A survey in May 2020⁽³⁾ identified various ways Covid-19 has impacted on people with Learning Disabilities. Further exploration funded by NHS England, is being carried out by Simple Stuff Works (experts in postural care) and Born at the Right Time (experts in communication and co-production).

Thank you for taking the time to complete the survey below the results of which will be shared at an online event on the **23rd November 2020**. The survey is likely to take you about 15 minutes and must be submitted before **9th October 2020**. By supplying your email address at the end, you will be entered into a £100 Amazon voucher prize draw.

1 Mencap (2010) Postural care: protecting and restoring body shape. <https://www.mencap.org.uk/sites/default/files/2016-11/Postural%20Care%20booklet.pdf> Accessed September 2020

2 The Learning Disability Mortality Review (LeDeR) Programme (2019). Annual Report, 2018. University of Bristol. <http://www.bristol.ac.uk/sps/leder/resources/annual-reports/> Accessed September 2020

3 National executive committee of Association of Chartered Physiotherapists for Adults with Learning Disabilities (2020)

1. Completion of this survey is on an entirely voluntary basis. The purpose of the project is to better understand how postural care is provided in order to support change. There are no anticipated risks to answering questions and it is hoped that the results of the survey will shape a project to support practitioners and families in improving postural care provision for people with Learning Disabilities.

Identifiable data will be seen by the researchers only. All data will be stored securely in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and anonymised before reporting.

I give informed consent for the anonymised data I provide to be used for this project.

☐ Yes

Demographics

2. Where in the UK do you work?

3. What ages are the people you serve?

4. What is the service/context in which you work and what is your role in providing postural care for people with learning disabilities?

Changes to provision

5. Please list the postural care services you provide that have been affected by Covid-19.

This might be wheelchair services, hospital discharge and rehabilitation, operations, Botox, orthotics, night-time positioning or alternative seating provision for children or adults.

6. How have these services changed since Covid-19?

This might include your ability to see a people face to face, remote working, referrals, urgent, non-urgent, assessments, equipment handover, reviews, capacity, training and advocacy.

7. Has your perspective and experience of the relationships between commissioners, therapists, families and individuals changed since Covid-19? And if so how?

8. What best practice have you been part of or seen during this time?

9. Describe any silver linings you have experienced (if there are any).

Impact on people.

10. How have the changes to working practice and provision, as a result of Covid-19, impacted you and your team?

11. How have the changes to working practice and provision, as a result of Covid-19, impacted people with learning disabilities and their families?

12. Why do you think this has happened?

13. What do you think the long-term impact of 2020 will be on people with learning disabilities, their postural care needs and long term health?

The Future. Let's dream.

14. What do you feel are the key outcomes for postural care services and how could they be monitored?

15. If you had a magic wand, how would you like to see the Covid-19 pandemic change the way postural care is organised, provided and experienced by people with Learning Disabilities and their families?

16. Any other comments, insights or concerns around postural care in people with Learning Disabilities.

Congratulations – that is it.

You have finished. We really appreciate your help in this project.

Please provide your email address to be entered into a prize draw for a £100 Amazon voucher.

17. Enter into the £100 Amazon voucher prize draw

Name

Email Address

18. I am happy to be contacted to discuss my answers further. (Be assured we will maintain your anonymity.)

☐ Yes

☐ No

If you have any questions, comments or feedback, please email either **Rachel** Rachel@bornattherighttime.com or **Sarah** training@simplestuffworks.com



BORN at the **RIGHT TIME**
Bridging the gap

NHS
England

Simple
Stuff
Works



Changes to your postural care



Easy read booklet

Who we are and what we do



We are 2 groups called **Born at the Right Time** and **Simple Stuff Works**. We help people with **disabilities** and their families and carers.



A disability is when your body or mind is different. You may need help or support to do everyday activities.



We want you to answer the questions on the yellow pages of this booklet. This is called a **survey**.



NHS England gave us money to do this survey. NHS is short for **National Health Service** which gives you free help with your health.

What our survey is about



Our survey is about **postural care**.



Postural care makes sure your body is in a good position and in good shape. Your carer might use equipment to move your body to a good position.



Good postural care is important and helps you stay healthy.



We hope our survey will help you and other people get good postural care.

How to answer our questions



There are **4** ways you can answer our questions. You can

Go to this website

<https://www.surveymonkey.co.uk/r/S993WYF>



Send an email to this address

rachel@bornattherighttime.com



Write in this booklet and sent it to us at this address

**157 Lifstan Way,
Southend-on-sea, SS1 2XG**



Call this telephone number

07891 979189



Your friends or family can help you answer our questions.



You don't have to answer our questions but if you do it will help us support people with disabilities.



We won't tell other people that you have answered our questions.

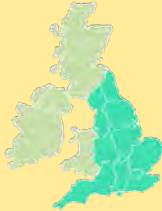


If you tell us your name and address or email address you might win £100 to spend at the online shop Amazon.

☐

Tick this box if you give **consent** for people to **read** and **use** your answers. To give consent means you say it is OK.

Our questions



1. Tell us where you live in the country.



2. Tell us who you live with.



3. Tell us how old you are.



4. Tell us who helps you to sit, stand, walk and sleep.

This might be people like your family, carers, physiotherapist or occupational therapist.

Empty box for response to question 4.



5. Tell us what helps you to sit, stand, walk and sleep.

This might be things like your wheelchair, walker or sleep system.

Empty box for response to question 5.

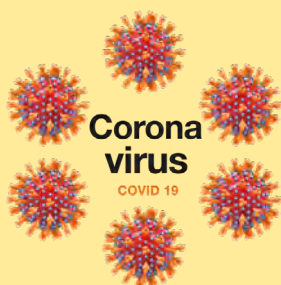


6. Tell us what keeps you busy.

This might be things like School, College, a Day Centre or work.

Empty box for response to question 6.

Our questions - changes to your postural care because of Coronavirus



Some care services changed this year because of **Coronavirus (COVID-19)**.



Coronavirus (COVID 19) is a new illness affecting people all over the world. It affects your lungs and breathing.



7. Tell us the parts of your postural care that changed because of COVID 19.

This might be things like your wheelchair services, hospital appointments, physiotherapy, or your sleep system.



8. Tell us how these parts of your postural care changed.

This might be things like how long you waited for care, how many people you saw, and where you saw them.



9. Tell us about any good changes to your postural care.

Our questions - how these changes made a difference to you



10. Tell us how these changes made a difference to you.

This might be things like more pain, you moved more or less, or the equipment you used to support your body.



11. Tell us why these changes made a difference to you.



12. Tell us if anything changed between you and the people who support you because of COVID 19.

This might be changes between you and your family, carers, therapists, or other services that support you.



13. Tell us how any changes to your postural care will affect you in the future. If there aren't any changes you don't need to answer this question.

Our questions - your future care



14. Tell us how you want your body to be supported and positioned.



15. Tell us anything else about yourself that might be helpful.

Thanks for answering our questions.

Try to win £100 to spend at the shop Amazon



If you tell us your name and address or email address you might win £100 to spend at the online shop Amazon.



Tell us your email address.



Tell us your name.



Tell us your address.

Your consent

☐

Tick this box if you give **consent** for us to **talk to you more** about your answers. To give your consent means you say it is OK.

Thank you to A2i for the words
www.a2i.co.uk (reference 32829)

The full version of this document is called
“Postural care provision for those with learning disabilities in
the age of Covid; a people-focused project..”

Appendix 5

Second survey





Just a quick one...

We have one final, very short, multiple choice question which we would love you to answer and we will enter you into a £20 prize draw for your inconvenience.

We promise not to ask you any more questions.

Using ideas given by families, carers and practitioners in the survey, we have written a list of things which might make help to improve postural care for people with learning disabilities.

1. What would benefit you (and other professionals like you) to provide good postural care?

	This would be amazing	This would be helpful	This already exists and is good	This wouldn't be very helpful	I wouldn't use this	This already exists and it isn't helpful
Postural care training for professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Postural care training for families/carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24-hour postural care advice line for families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24-hour postural care advice line for professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24-hour posture care-plan shared with all professionals/carer/support worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Library of short, upbeat, on-line films with advice and support from other parents and professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Single point of contact practitioner for all postural care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family/carer forum for peer support and share information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
On-line/virtual/video appointments to continue beyond Covid-19	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Remote access assessments with companies for equipment provision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Agreed funding stream/purse for all postural care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	This would be amazing	This would be helpful	This already exists and is good	This wouldn't be very helpful	I wouldn't use this	This already exists and it isn't helpful
Agreed outcomes/targets (ways and means) for the postural care of people with learning disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frequent contact with professionals to review and discuss issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Good, regular communication between professionals and families/carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annual postural care team meeting with the individual, family/carer and 1 therapist face to face - the rest attend on-line. This review would be made up of all the practitioners who deal with the person with learning disability's posture; social care and health OT's, physio, teachers, carer, family, wheelchair service and equipment providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

2. In order to maintain a level of connection with families at a time of lockdown/social distancing, what would be your preferred method of communication?

- ☐ Telephone
 ☐ Email
- ☐ Email
 ☐ Letter
- ☐ Virtual clinic (Teams/Zoom/Skype)
 ☐ Face to face
- ☐ Other (please specify)

Thank you for kick starting the **Posture Positive Project** in a what has been a very challenging 2020.

We hope you will join us on 23rd November to hear the views and experiences of families and professionals as we raise a determined and collective voice to influence where we go from here.

3. Complete to be entered into the a random draw for a £20 Amazon voucher.

Name

Email Address

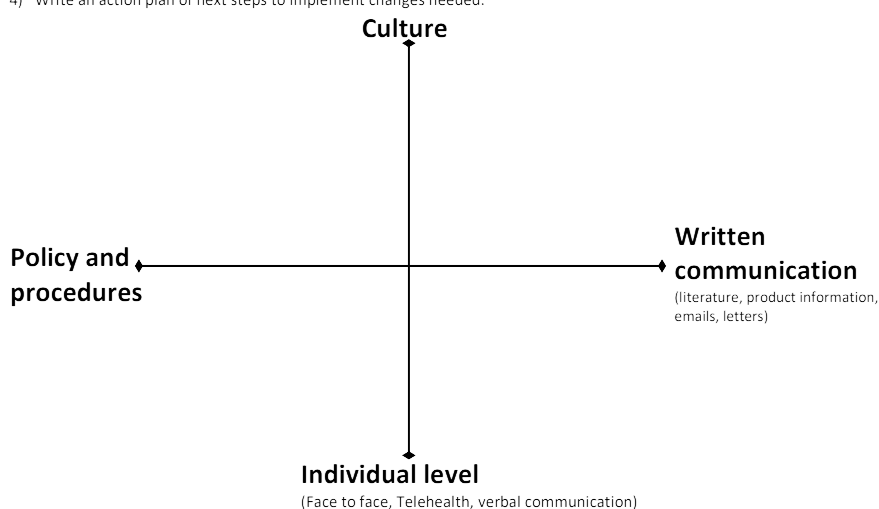
Appendix 6
**Post-Covid-19
reflection tool**
Wright 2020



Post-covid Reflection Tool (PoRT)

Actual and Aspirational Kite

- 1) In black, mark the level at which effective communication and co-production is incorporated into practice (using the table overleaf for associated **values** and **behaviours**).
- 2) In red, mark an **aspirational** level of communication and co-production post-covid with direct relation to what you aspire each aspect to be
- 3) Highlight the **behaviours** (on next page) which you can personally implement to help this happen (add more as required).
- 4) Write an action plan of next steps to implement changes needed.



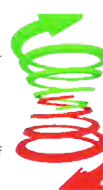
Trust Scale

Trust levels can be negative or positive. Each interaction is impacted by previous relationships, expectations and experience. Always consider how trust is hampering or fuelling co-production.



Empowerment Spiral

Throughout every aspect, consider whether actions, policies or culture is promoting or hindering the empowerment of all those involved.



© Born at the Right Time 2020

	Values	Behaviours
Culture	People and their voices are heard, valued and respected. Strengths and successes are emphasised. Adaptability and resilience is a cultural norm. Environments feel safe and positive for all. Openness and honesty is the norm. Individuals, relatives/carers and practitioners are equipped to participate in co-production. Power sharing nurtures reciprocal trust .	Time is allocated for communication and co-production from strategic thinking to individual care. Senior leaders champion and model effective communication and co-production. Individuals and relatives/carers are represented positively in private and public conversations. Responses are given in a way that acknowledges needs, resources and is always kind. Individuals, relatives/carers and practitioners are assumed to be competent. Accredited training is provided to ensure everyone understands and can participate in co-production. The use of one-page profiles by professionals to share with individuals and relatives/carers demonstrate people are at the heart of every decision made.
Policy and procedure	Collaboration with individuals and relatives/carers is the foundation of all policy and procedure development. Policies and procedures empower everyone by being clear, creative and flexible. Reciprocal dialogue underpins the production, review and implementation of policies and procedures.	Ideas and suggestions made by individuals and relatives/carers are encouraged and implemented. Participation by individuals and relatives/carers in creating policy and procedures is supported with appropriate reimbursements for time and expertise. Practitioners are empowered to use knowledge to support individuals and relatives/carers in a dynamic and creative way. Strategies help everyone to trouble-shoot, provide constructive feedback and manage complaints. Policies and procedures are clearly communicated in an accessible and functional way. Systems are accessible, policies and procedures are easy to understand and navigate.
Written communication	Transparency, accessibility and authenticity is at the heart of written communication Written communication reflects and values the reality of lived experience. Confidentiality is respected and protected. Written information nurtures trust and empowers practitioners, individuals and relatives/carers.	Clear information is given in a timely and constructive way describing well-defined responsibilities and expectations. Therapy or product benefits are explained in an accessible, robust, and concise way (Why not what). Individuals and relatives/carers are experts by experience and their views recorded as such. Clear guidance is given about next steps and timescales using clear, practical and helpful language. Information is accessible and only shared with permission. Information is produced and reviewed in collaboration with those who use and are affected by it. Alternatives to written communication are produced and used dependent upon need and assets.
Individual level	Partnership and collaboration is at the heart of meetings, conversations and decision making. Co-production and participation is actively encouraged with sufficient time and space given to facilitate it. Alternatives to face-to-face interactions available Mutual trust and empowerment is at the heart of every interaction.	Everyone is considered an equal partner with specialist skills and knowledge. Meetings and appointments are made with practitioners, individuals and relatives/carers needs and preferences and safety considered. Everyone is given sufficient resources to attend/participate and feedback in order to improve everyone's experience. Everyone respects differing opinions, uses preferred names and listens to understand. Personal values, perspectives and priorities are identified and respected by everyone. Everyone works together to develop shared goals with clear areas of responsibility for delivery. Individuals and relatives/carers are given options of preferred means of communication.

© Born at the Right Time 2020



	Current Practice limitations	Changes in cultural, practice or resources needed.	Action plan next steps
Telehealth Privacy, accessibility, wifi, relevance, costing, funding, infrastructure...			
Communication and co-production Trust, vulnerability, expectation of hope, reciprocal care, opportunity and expectation of co-production in the s			
Resilience and reimagining a service/practice Cultural norms, further changes which need to be made, potential resistance, who needs to be on-board, how can you co-produce with families			



Email :
admin@bornattherighttime.com

Website:
www.posturepositive.co.uk

Posture Positive Founded by:
Sarah Clayton and Rachel Wright