



JusticeforLB
Herb Audit Office

Report

by Sara Ryan
and George Julian

Actually improving care services for people with learning disabilities and challenging behaviour

Our vision is to get JusticeforLB and improve things for all other dudes.

Our campaign audit perspective helps people to hold Parliament and government to account and improve public services.



This report is dedicated to the memory of Tracey Taylor, My Life My Choice Champion and Trustee and JusticeforLB supporter.

The JusticeforLB campaign scrutinise public spending and performance for their supporters and is independent of Parliament and government. We have no Comptroller and Auditor General, no Officers of the House of Commons, and no employees to lead. We have no authority to certify accounts of government departments or other public sector bodies. We have no statutory authority to examine and report to Parliament on whether departments and the bodies they fund have used their resources efficiently, effectively, and with economy but that will not stop us. Our reports evaluate the value for money of public spending, nationally and locally. Our recommendations and reports on good practice could help government improve public services, and our work could lead to audited savings of a lot.



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Actually improving care services for people with learning disabilities and challenging behaviour

Report by Sara Ryan and George Julian

Ordered by no-one
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This report has been prepared under no sections of any acts for presentation to JusticeforLB supporters in accordance with our campaign value of transparency

Sara Ryan, PhD
George Julian, PhD
The Justice Shed

4 February 2015

LB FIGHTING FUND | £ Priceless

This report examines the challenge faced in delivering key commitments of the JusticeforLB campaign manifesto, the extent to which these have been achieved, and the barriers to achieving JusticeforLB and actually improving care services for people with learning disabilities.



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The JusticeforLB Herb Audit
Office study team consisted of:
Chris Hatton, George Julian
Sara Ryan, Paul Scarrott and
My Life My Choice under the
direction of a divine power of
optimism.

This report can be found on the
JusticeforLB website at
www.justiceforlb.org

For further information about
JusticeforLB please email us on
JusticeforLB@gmail.com

Or send us a tweet
[@JusticeforLB](https://twitter.com/JusticeforLB)

Key facts

581

days since LB died
in the 'care' of
Southern Health
NHS Trust

1 day

time between LB
dying and a briefing
about his mother's
blog being shared
with staff

1 billion

tears shed at the
pointlessness of it
all

170

blog posts shared by the campaign

8

events or meetings we've spoken at

15,388

tweets sent from the JusticeforLB account

8,010

miles travelled in pursuit of JusticeforLB

4

meetings with the Minister and Department of
Health representatives

21

media interviews given

15

extraordinary paragraphs in the letter sent to Sara
from the Southern Health NHS Trust CEO

£26,410.88

raised for the LB Fighting Fund

34

JusticeforLB films

72,578

words of feedback in response to our draft Private
Members Bill

1

Justice Quilt stitched with love

∞

number of promises broken (to infinity and beyond)

2

mentions in Hansard

£0

budget to conduct above

Summary

- 1** LB is short for Laughing Boy, the name used online for Connor Sparrowhawk. Connor was a fit and healthy young man, who loved buses, London, Eddie Stobart and speaking his mind. Connor had autism and epilepsy. Connor's mum, Sara, started a blog in 2011 to document their family life. It was a joyous and funny blog called [MyDaftLife](#).
- 2** On the 19 March 2013, after his behaviour had become difficult for his family and school to manage, Connor was admitted to hospital (Slade House Assessment and Treatment Unit run by [Southern Health NHS Foundation Trust](#)). He was 18 years old.
- 3** Connor's family visited him often and regularly raised concerns with the unit staff and management. After 107 days in the assessment and treatment unit, having received no assessment or treatment, Connor drowned in the bath on 4 July 2013.
- 4** The unit was fully staffed and had two spaces, so this was not an NHS resourcing issue. An independent investigation into Connor's death found it to be entirely preventable. This report was published on February 24 2014. Since then no actions have been taken by the Trust providing 'care' or by the commissioners who paid for the service, Oxfordshire County Council, to bring accountability.
- 5** The JusticeforLB campaign was established in February 2014 to work towards raising awareness of what happened to Connor, to improve things for other dudes, and to raise money to cover the families legal costs at inquest.

Scope of this report

6 We have focused on reporting progress towards achieving JusticeforLB, and other learning disabled people, over the past eleven months. The report examines:

- the campaign commitments (Part One)
- action against the commitments (Part Two)
- barriers and solutions to achieving JusticeforLB (Part Three).

7 Our methods are set out in Appendices One and Two.

Key findings

Understanding the scale of the challenge

8 Time and again we hit up against an absence of accountability and humanity. Trying to get accountability for the death of a young, learning disabled man has made visible a set of practices and processes that are simply wrong, unacceptable and inhumane.

9 Within weeks of Connor's death the first signs of cover up emerged. Initial concerns were raised when the unexpected and preventable death of a young man within a specialist hospital was recorded in the Southern Health NHS Foundation Trust [Board Papers of July 23 2013](#) (page 11) as 'natural causes'. This was before the post-mortem had been concluded.

10 Delay and prevarication has been present at every stage of the Justice journey. From providing copies of documents, to redacting entire pages of notes, to conducting staff disciplinary action, arranging staff interviews, to agreeing the final copy of the first Verita report, Southern Health NHS Foundation Trust have been obstructive. The impact of this delay is plainly evidence by the complete lack of accountability 20 months after Connor died.

11 Inertia or impotence? On the rare occasions where humanity or concern have been shown, it is nearly always accompanied by a shrug of the shoulders and wringing of hands. Whether this is due to inertia or impotence is not yet clear.

Putting in place delivery mechanisms for Justice

12 The challenge of taking action without resources. The campaign have found this particularly challenging. Continuous commitments has been necessary and the level of work involved is almost impossible to quantify. The Justice team recognise that we have to accept our limitations and ditch the notion of perfectionism.

13 Initial attempts to raise awareness. Learning disability is not an area that gains much media interest in the U.K. The campaign has used social media, effectively and relentlessly, to raise awareness. We have been supported by two key mainstream journalists ([Saba Salman](#) from the Guardian and [Phil Gayle and the BBC Radio Oxford](#) Team) in making people aware both of Connor's death, and the poor provision that many learning disabled people experience.

14 Action taken to maintain campaign momentum. Creative and innovative actions have kept momentum for the campaign going, to ensure that JusticeforLB does not fall off anyone's agenda. These actions include #107days of action, the Advent Calendar and 12 Days of Christmas. These activities involve considerable behind the scenes work and organisation, but have been effective and fun tools to maintain and develop people's interest.

15 Throughout the campaign we have documented action and kept records. The campaign has been able to draw on the support of an excellent archivist who has curated much of the social media attention around the campaign. Outputs are enormous and include numerous blogs, slideshares, films, an animation, a book chapter, artwork, stationery and music.

16 Attempts have been made from the start of the campaign to combine on and off line activism One of the central approaches of the campaign, has to seek to combine online and offline activity. We are aware that many disabled people do not have access to the internet, so we have always encouraged those online to share our messages offline. We have provided posters, flyers, films, postcards and information to help do this. Consequently the campaign has been successful in combining on and offline activism without too much difficulty. Postcards of Connor's artwork have been sold around the world and various artefacts have taken the campaign messages offline, including the Postcards of Awesome and the Justice Quilt.

17 We have learnt not to rely on official channels. The campaign has underlined how important it is not to rely on official channels for action. The recent [National Audit Office](#) report, the 2014 [Learning Disability Census](#) and the latest [Transforming Care for People with Learning Disabilities](#) report all clearly evidence that those with influence and power seem unable to do anything effectively, or efficiently. Additionally, it would appear that many organisations that were set up to support learning disabled people, and to campaign for change, have become nothing other than repetitive talking shops.

Impact of the JusticeforLB campaign so far

18 The reach of social media has been vast and has enabled us to spread the campaign messages globally. The campaign has used social media as it's principal mechanism for garnering support, sharing information and networking. It has ensured that we have reached a wide distribution of people, internationally, and it has also allowed for complete transparency of all our activity. Using a variety of media, include tweets, facebook messages, films, animations, presentations and photos, has allowed us to share our messages in several different ways.

19 People have told us that the JusticeforLB campaign has already had a positive impact on their lives. We have heard that we have strengthened the voice of learning disabled people; we have connected and brought people together; challenged inertia and routine thinking; highlighted inefficient wastes of learning disabled people's lives and of public money; we have changed the way people think; and perhaps most importantly right now, we have brought hope and belief to many.

Barriers to achieving Justice

20 It would appear that there is a complete lack of accountability. An unfortunate consequence of the reorganisation of the NHS appears to be that it has effectively left NHS Foundation Trusts largely unaccountable for their actions. While various organisations, including the CQC, Monitor, and NHS England have been tangentially involved in our pursuit of JusticeforLB, it seems that no-one has the power, authority, or will to stop Southern Health NHS Foundation Trust acting in contemptible ways.

21 We have unearthed a system struggling under the weight of inertia, characterised by impotence and hand wringing.

Partly as an outcome of the lack of accountability mentioned above, there is considerable impotence and (well intentioned) handwringing, which is clearly ineffective in terms of action.

22 The ultimate barrier appears to be that learning disabled people are seen as less than human.

Perhaps the most core barrier to achieving JusticeforLB and other learning disabled dudes, is that learning disabled people are not seen to be fully human. This positioning means that people's human rights are dismissed in practice, allowing barbaric practices to continue.

23 An ever-present threat to achieving JusticeforLB is that the impossibly slow progress may have such a negative impact on Connor's family that they are no longer able to campaign.

Given the repeated actions of Southern Health NHS Foundation Trust it is unclear whether this is in fact a tactic employed deliberately. The length of time taken by any of the relevant organisations to do things, together with the almost structured delay in the process of gaining accountability is wearing, distressing and difficult.

Recommendations for achieving Justice

24 The buck has to stop somewhere. It is crucially important that new routes for accountability are established. Transparent information about the circumstances of a learning disabled person's experience in hospital is required to support this. Currently there is no automatic right to an independent investigation when someone dies in a secure setting, yet our campaign has identified numerous examples of obstructions and prevarications so far (see 9 above for the first within weeks of Connor's death). We cannot trust NHS Trusts to conduct rigorous investigations into the deaths of patients who are so evidently held in low regard.

25 Move existing money to those who need it most. There are several instances where money could be moved from existing arrangements to make for more equitable experiences for all parties. Firstly, bereaved families should be entitled to funding for legal representation at inquests. This is only fair as publicly funded bodies draw on the public purse for their representation. Secondly, the colossal sums of money spent on inpatient services for learning disabled people should be reallocated to community support (see the [National Audit Office](#) report for more on this). Thirdly, charities that are funded to improve the lives of learning disabled people (or other groups) must act on behalf of those people. The current overlap between provider and campaigner is toxic and adds to the system inertia. It is time to stop the talk, and move to action.

26 There is a need to simplify things and truly embrace transparency. One suggestion we have is that when someone dies in a secure setting, families should be offered the equivalent of a family liaison officer to help them negotiate the terrain ahead. Another is that NHS and local authorities should stop hiding behind structure and process, quit using jargon, increase their easy read materials and transparency, and get back to the level of human.

27 We have three recommendations that relate to the law and legal recourse. Efforts should be made to support learning disabled people and their families to better understand the existing law and how it can be used to stop some of the current atrocities from happening. We would like to see corporate manslaughter charges being brought more often, where appropriate, rather than the current reluctance and apathy. Finally, we would like to see the provisions within the LBBill become law

28 The coming of age of candour? Our evidence fails to give us any confidence that NHS Trusts will operate within a duty of candour, without significant changes to existing cultures, structures and processes. Candour is about openness, honesty and transparency, such rare commodities in our pursuit for JusticeforLB. One recommendation is for CQC inspections to examine the role that legal experts play in preparing organisations for conforming to a Duty of Candour; they might also examine how staff have been coached and supported to perform for an inspection too. Finally attention should be paid to how relatives of deceased people are treated.

Conclusion

29 It's possible! We believe that the JusticeforLB campaign demonstrates that a considerable amount can be achieved if you strip away layers of tired bureaucracy, hierarchy and vested interests and just get on with it. In a genuinely collective way.

Part One

Campaign commitments

Where the campaign came from

1.1 On 4 July 2013 Connor Sparrowhawk, known online as LB died an entirely preventable death in the 'care' of Southern Health NHS Foundation Trust. His mother, who had been blogging about life with Connor for a number of years, was immediately contacted by one of her Twitter followers, a human rights barrister who put Sara in touch with INQUEST. The family were advised that they would need legal representation at the inquest and would need to take action immediately.

1.2 An independent report was commissioned (after a fight with the Trust about the requirement for it) from Verita. The final report was [published on February 24 2014](#). It found that Connor's death was preventable and was the outcome of poor leadership and epilepsy care.

1.3 The Southern Health NHS Foundation Trust delayed publication of this report that day until past 6pm, generating a collective outrage on Twitter. This day really marks the start of the JusticeforLB campaign, which has two primary aims, to raise awareness and to raise funds to support the funding of legal representation at the inquest.

The Connor Manifesto

1.4 In March 2014 the then CEO of NHS England, David Nicholson, [met with Sara and Rich](#). Sir David was two weeks shy of retiring, so Jane Cummings, Chief Nursing Officer for England joined the meeting, to provide continuity. One of the outcomes of the meeting was that Sara agreed to send NHS England what JusticeforLB would look like. This was known as [The Connor Manifesto](#).

1.5 The Connor Manifesto was structured around three sets of actions. The first directly relate to Justice for what happened to LB. They include staff referrals to their professional bodies; a corporate manslaughter prosecution; and meaningful involvement in the inquest and other investigations so those responsible can be held to account in public.

1.6 The second set of actions relate to Southern Health NHS Foundation Trust, Oxfordshire County Council and the Clinical Commissioning Group. They seek an explanation as to how such poor services could be commissioned; reassurance this will not happen again; and an independent investigation into the other 'natural cause' deaths in Southern Health learning disability and mental health provision over the past 10 years.

1.7 The third and final set of actions relate to securing justice for all learning disabled dudes. This includes changing the law to include an automatic right to an independent investigation with every death in a 'secure' setting; improved CQC inspections and a critical lens to examine what '(un)acceptable' practice looks like for dudes like LB; prevention of the misuse of the Mental Capacity Act as a tool to distance families and isolate dudes. It also calls for the NHS to make provision for learning disabled people a complete and integral part of health and care services and for proper informed debate about the status of learning disabled adults as full citizens in the UK.

Campaign values and principles

1.8 It has been important to those involved with the JusticeforLB campaign that we live by our values, and what we hope for all learning disabled people. To that end, learning disabled people were the start of, and central to everything we have done throughout our campaign.

1.9 Another campaign value central to all our activity is transparency. Throughout the campaign we have recorded all our actions online, for anyone to access and join. We have crowd-sourced contributions throughout, seeking the wisdom of the crowd, not assuming that we know best.

1.10 We are non prescriptive in how people engage with our campaign, or contribute to bringing Justice. We have embraced a personalised approach, welcoming contributions in whatever form they reach us. It is important to us that we collectively work to improve things.

1.11 On a related note, we have embraced the art of asking for help. When we have needed skills that we do not personally have, we have asked our network, and time and again people have stepped forward to help us.

1.12 Perhaps the most important principle is that we are explicit and open about our own agenda (see 1.4 to 1.7) and that we have no vested interests.

Part Two

Action taken to forward campaign commitment

Putting in place effective delivery mechanisms for Justice

2.1 The 107 days that Connor spent in the unit in 2013 were marked in 2014 by [people adopting days for a range of different actions](#). These activities related to sport, music, academia, blogging, art, politics, fundraising, hairdressing and transport. It was an explosion of joy, love and commitment. A post was [shared on the blog daily](#) outlining who had adopted the day and what they were using it for. The #107days campaign [started on Day 1](#) with [Postcards of Awesome](#), where learning disabled people and their family and friends were invited to send a postcard outlining what was awesome about them. The action ended on Day 107 with hundreds of people changing their profile pictures on social media to Connor for the day and [sharing what the campaign had meant to them](#).

2.2 The idea for a Private Members Bill emerged 4 days after #107days in a [tweet](#), and accompanying [blog post from Mark Neary](#). The [draft #LBBill](#) calls for the law to be changed to ensure that disabled people are fully included in their local community. It seeks to ensure that the default position for a disabled person is living in their own home, or a home of their choosing, and to move the impetus to the State to provide evidence of why they should be moved elsewhere. This should stop the current situation where family members, friends and advocates have to fight to overturn decisions and get disabled people out of hospital. An initial draft of the Bill was launched in November 2013, clauses were discussed daily through the [12 Days of Christmas](#), and JusticeforLB supporters arranged local events to discuss the bill. We have received over 150 pages of [feedback on the blog](#) and in the [Facebook group](#), and the Bill is currently in the second stage of drafting.

2.3 Advent 2014 was celebrated with a virtual advent calendar that comprised of daily treats. The advent calendar was shared on the [JusticeforLB blog](#) and by email. Treats included photos of LB, interviews with his brothers and sister, the unforgettable [Santa Baby trio](#), [Rebecca Lawthom's Inaugural Lecture](#) and getting [up close and personal with the Justice Quilt](#).

2.4 Academic activity related to the JusticeforLB campaign so far includes a number of funding applications, conference presentations and workshops, some early discussions about a substantial grant application, and a book chapter in *Disability and Social Media* (In Press) called *#107days: a transformative, subversive or accidental exercise in effective action?*

2.5 The Justice Quilt, is a crowd-sourced people's artwork that includes contributions from across the world. JusticeforLB supporters, and craftivists, stitched patches in memory of Connor and a team of four stitchers led by Janet Read, stitched them all together. The [Justice Quilt](#), a remarkable symbol of activism, love and resistance, featured in the Embroiders' Guild [Embroidery Magazine](#) in January 2015, and begins its tour of the UK later this month at [Newman University](#), Birmingham (from 12-27 February). The second leg will see the Quilt displayed at the [People's History Museum](#) in Manchester from 1-22 April.

Seemingly ineffective, or excruciatingly slow, delivery mechanisms for Justice

2.6 The first Verita report (see 1.2) was published almost a year ago and as far as we are aware no-one has been held accountable, despite these independent investigators finding Connor's death to be preventable.

2.7 Various investigations are ongoing. A second, broader investigation by Verita will examine the state of learning disability provision at the time Connor was admitted to hospital. Mazars are conducting an investigation into the response to all deaths in Southern Health NHS Foundation Trust's learning disability and mental health provision since 2011. Two staff have been referred to their disciplinary bodies, one by the Trust and one by Connor's family, and staff disciplinary action still continues.

2.8 The Police and the Health and Safety Executive both have ongoing investigations. Two Pre-Inquest Review Meetings have been held and an inquest with a jury has been agreed. The tentative date for the inquest to take place is in early October 2015, over two years since Connor died.

Part Three

Impact, barriers and solutions to achieving JusticeforLB

Social media reach of the campaign so far

3.1 The JusticeforLB campaign relies heavily on social media as a mechanism for sharing our messages and raising awareness. We have compiled some headline statistics about the usage and engagement on our various social media platforms.

3.2 The [JusticeforLB Twitter account](#) has 2,235 followers and has shared 15,388 tweets. Many people also use the #JusticeforLB and #LBBill hashtags to chat about the campaign.

3.3 The [JusticeforLB Facebook page](#) has been in existence since March 2014. It has 1,901 likes and the average post on the page is seen by 1,030 people. There is also a very active [LBBill Facebook group](#) which was established in November 2014 and has 1,002 members.

3.4 The [JusticeforLB](#) and [LBBill](#) YouTube channels have 34 videos currently available on them. These films are promotional and educational and designed to bring the campaign alive to a wide range of people. The films have been viewed a total of 6,299 times (5,500 views of the main campaign channel and 799 views of the LBBill easy-read films).

3.5 The [JusticeforLB SlideShare account](#) was established in December 2014 to help us share our presentations with a wider audience. So far in just two months there have been 7,277 views of the 9 presentations uploaded. Presentations include overviews of the Postcards of Awesome (see 2.1), introductions to the Justice Quilt (see 2.5), visual testimony of why we need the LBBill (see 2.2) and a keynote lecture given by Prof Chris Hatton during advent (see 2.3).

3.6 The JusticeforLB blogs can be found in three places, [#107days](#) of action, [LBBill](#), and [JusticeforLB](#). The combined total of blog activity so far consists of 170 blog posts, an average of 15 a month. The blogs have been viewed 109,450 times by 47,073 visitors. They have also accrued 568 comments, yet more evidence that people are actively engaging with the campaign.

Blog	#107days	LBBill	JusticeforLB	Total
Established	Mar 2014	Nov 2014	Dec 2014	
Posts	119	26	25	170
Views	76,467	27,721	5,262	109,450
Visitors	33,309	11,718	2,046	47,073
Comments	394	123	51	568

3.7 The geographical reach of the JusticeforLB campaign has been considerable. We have seen people engaging online in almost all continents, and we have seen offline activity take place in numerous places outside of the U.K. including America, Australia, Canada, France, Ireland, Singapore and New Zealand.

3.8 It is important to acknowledge that it would appear a lot of the effectiveness of the social media action was in part due to the existing presence of key campaign supporters on social media platforms. Sara had been blogging about life with Connor for years, and had been active on Twitter and Facebook before the campaign was needed.

Impact of the campaign so far

3.9 Paul Scarrott, a Trustee and Champion at My Life My Choice, had this to say about the campaign:

‘Connor’s story is so important to me and my friends because it affects us directly as well as personally; none of us want to die or see our friends dying in the appalling way that Connor did. The JusticeforLB campaign has helped strengthen our voice and helped us to highlight the terrible waste of life and public money that surrounds some of the so-called ‘care services’ for people with learning disabilities’.

3.10 Frances, a parent of a young learning disabled dude, [said this](#) about the campaign on Day 107:

‘I had experienced my own child’s traumatic time in a unit and felt I may have hypercritical in my observations when visiting the unit, powerful places, but never in a million years did I think that a young dude with known epilepsy could drown in a bath in a hospital.

Through the campaign and the journeys blogged it is so obvious that parents are not listened to for whatever reason, Your blogging is changing this, empowering parents to join forces and gain strength when fighting for the support needed for loved ones, it shows where the real expertise lies... you may be an accidental campaigner in such tragically sad circumstances but I feel you will have made a significant impact and helped save lives of other young dudes’.

3.11 Care Services Minister Norman Lamb recently said this about our campaign, in an Adult Autism Strategy discussion in the Houses of Parliament ([Hansard, January 13 2015](#)):

‘I, too, pay tribute to the campaigning of JusticeforLB’

3.12 Chris Hatton, a Professor at Lancaster University, had this to say:

‘The #JusticeforLB campaign has, in the best possible way, put a rocket up my, er, existence. It has challenged me in ways that are both encouraging and uncomfortable, confronting me with realities both unutterably grim and extraordinarily beautiful. It has given me an opportunity to connect with a huge range of people who I should have been connected with in the first place and to learn so much. It is changing how I think and what I do (slowly, too slowly), and it is teaching me to speak the truth as I see it’.

3.13 Sam Sly, who works to support learning disabled people to leave hospital, [said this](#) at the end of 107days:

‘It has blown me away that such a horrendous event as the preventable death of a young, vibrant man has brought so many people from different walks of life together in such a passionate and loving way. These people and this campaign has had more impact on changing crap use of ATUs than years of waiting for the system people to change it! But to me the most important thing about the campaign is seeing other families who have been in the same situation as Sara or are still in living hell with their child in an ATU get strength, come forward and grow in confidence about shouting from the rooftops that it is not acceptable and they are not putting up with crap anymore!’

3.14 Steve Broach, Human Rights Barrister and key instigator of the LBBill, said this:

‘I don’t think there’s ever been a campaign for justice quite like JusticeforLB. It has brought people together in the most incredible way. Through the relentless tide of system failure and inertia it has offered hope and a belief that things can get better. What a legacy it would be for LB if real change actually, finally happened.’

Barriers to achieving Justice

3.15 There are several obvious barriers to achieving JusticeforLB, not least the simple fact that no one person, or organisation, would appear to be ultimately responsible. An unfortunate consequence of NHS restructuring is that it has created a pack of toothless tigers with NHS Foundation Trusts roaming around largely unaccountable for their actions. Despite, several of the key organisations being tangentially involved in the pursuit for JusticeforLB (namely the Care Quality Commission, Monitor, and NHS England) the only conclusion we are left to draw is that no-one has the power, authority or will to stop Southern Health NHS Foundation Trust acting in contemptible ways.

3.16 This lack of accountability, or regard for humanity on the behalf of Southern Health NHS Foundation Trust, reveals a system struggling under the weight of inertia, staffed largely by well-meaning, but ultimately impotent, hand wringers. While this should not be dismissed entirely, humanity and empathy is to be welcomed, it ultimately will not lead to action or accountability.

3.17 It would appear that the ultimate barrier to achieving JusticeforLB and other learning disabled dudes, is that learning disabled people seen as less than human. This positioning, as discussed in Prof Rebecca Lawthom's inaugural lecture (see 2.3), means that people's human rights are dismissed in practice, enabling barbaric practices to prevail.

3.18 One final barrier to achieving JusticeforLB that is ever present, is the impact of the excruciatingly slow progress, the damage it does to Connor's family, and the potential threat that it will have such a negative impact that they are no longer able to campaign. If this were to happen then JusticeforLB supporters would step up and continue to campaign on their behalf, however the negative impact on their health should not be underestimated. The repeated inhumane actions, and structured delay, of Southern Health NHS Foundation Trust suggest that a culture of learning disabled people not being fully human extends to their family members too.

Recommendations for achieving Justice

3.19 It is perhaps unsurprising that the first of our recommendations for achieving JusticeforLB, and for all learning disabled people, is to address the accountability barrier. It is essential that new routes for accountability are established. There is little point in independent investigations being conducted, finding a death to be entirely preventable, and nothing happening as a consequence. It is inefficient, ineffective, distressing and insulting.

3.20 In the optimistic spirit of the JusticeforLB campaign, we will suspend the limitations of a lack of accountability, and our second recommendation is for more independent investigations. We believe that there should be an automatic right to an independent investigation when someone dies in a secure setting.

3.21 We would recommend that all families bereaved when their learning disabled relative is held within a secure setting, should be [offered a family liaison officer](#), to help them navigate the terrain ahead. This person must be genuinely independent of the responsible organisation or commissioners.

3.22 It is also our recommendation when someone dies in the care of a publicly funded organisation that bereaved families are entitled to funding for legal representation at inquests. This is the only way in which anything close to parity can be established.

3.23 We would like to see the NHS and local authorities emerge from the candour shadows, and stop hiding behind process and structure. It would be helpful if meaningful, jargon free, accessible and open records were kept. One extract from the latest [Southern Health NHS Foundation Trust Board Papers](#) illustrates this need:

‘9. Learning Disabilities – Latest Commissioning Position

9.1. Mark Brooks, Chief Finance Officer, updated the Committee on the meeting that he and Katrina Percy had attended with the Trust’s commissioners for Learning Disabilities in Oxfordshire and representatives from Monitor.
REDACTED’

It is impossible to see how any learning disabled person, or their family members or advocates, could make informed decisions and choices or understand the latest commissioning position for services likely to affect them, on the basis of such levels of secrecy and redaction.

3.24 We would like to see efforts made to support learning disabled people and their families better understand existing law and their legal rights. It is apparent from the feedback received to the initial draft of the LBBill that people are currently significantly misinformed about their basic human rights. We would also like to see the provisions within the LBBill become law.

3.25 We consider that it is time now to change the law to facilitate the moving of money within the system. The LBBill calls for learning disabled people to live in their local community; to date lack of funds have been blamed for this not happening. The recent [National Audit Office](#) report revealed that inpatient learning disability services cost £557 million per year. This is money which could be reinvested in community-based support (and would add almost 11% to the current social care budget for adults with learning disabilities of £5.3 billion).

3.26 The 2014 [Learning Disability Census](#) reported that the average fee for a person in an inpatient unit was £3,426 per week (or £178,152 per person per year). For everyone in inpatient units, this adds up to well over half a billion pounds per year (£557 million). One particularly innovative suggestion collected during our audit, an excellent example of thought diversity, was that commissioning could be better achieved using the [booking.com](#) website. First, it only allows a maximum stay of 30 nights. Second, a week's stay in a Deluxe King Room at the Savoy Hotel, London would be cheaper at £3,314 per week.

3.27 The JusticeforLB campaign has shown us what can be achieved in less than a year, where there are no vested interests, and people are connected and enabled to bring about change themselves. To that end we are struggling to see the value provided by charities that are funded to improve the lives of learning disabled people (or other groups) but have a toxic overlap between provider and campaigner. We consider this is adding to the system inertia.

3.28 On 27 November 2014 a statutory Duty of Candour came into place for the NHS in England. This is a legal duty to be open and honest with patients, or their families, when things go wrong that can cause harm. Our evidence fails to give us any confidence that NHS Trusts will operate within a duty of candour, without significant changes to existing cultures, structures and processes. We recommend that CQC inspections include examination of the role legal experts play in preparing organisations for conforming to a Duty of Candour. They might also examine how staff have been coached and supported to perform for an inspection. Examining how family members of deceased patients are treated may reveal something about the culture of the leadership.

Appendix One

Our audit approach

1 This report examined the JusticeforLB campaign's progress towards the aims of the campaign. These focused on three areas outlined in The Connor Manifesto (see 1.4 to 1.7). We examined:

- the extent to which we understood the challenges we faced in gaining #JusticeforLB;
- performance against the campaign aims, detailed in The Connor Manifesto; and
- the barriers to gaining #JusticeforLB and improving things for all other learning disabled dudes.

2 We applied an analytical framework with evaluative criteria to determine measure of success. We drew on crowd-sourced responses to the campaign shared via social media and in real life.

3 We held no focus groups and interviewed no officials, policy makers or care staff. We did ask a completely biased selection of JusticeforLB supporters to share what the campaign had meant to them (see 3.8 to 3.10). Our evidence base is described in Appendix Two.

Appendix Two

Our evidence base

1 We reached our non-independent conclusions, after analysing the range of evidence which we gathered from across our social media platforms between March 2014 to January 2015. Our audit approach is outlined in Appendix One.

2 You can see all our evidence yourself on the following social media platforms:

JusticeforLB blog: <http://justiceforlb.org/>

#107days of action blog: <http://107daysofaction.wordpress.com/>

Sara's MyDaftLife blog: <https://mydaftlife.wordpress.com>

LBBill blog: <https://lbbill.wordpress.com/>

JusticeforLB Twitter: <https://twitter.com/justiceforlb>

JusticeforLB SlideShare: <http://www.slideshare.net/JusticeforLB>

JusticeforLB Facebook: <https://www.facebook.com/JusticeforLB>

LBBill Facebook Group:

<https://www.facebook.com/groups/894280943919818/>

Appendix Three

Leadership and responsibilities for achieving Justice

1 None

Appendix Four

Our accounts

1 Money In

LB Fighting Fund (fundraising – ring fenced) £26,410.88
LBBill Donation £1,000 (anonymous private donor)
Donation from Housing & Support Alliance towards initial LBBill Easy Read materials

2 Money Out

Donation to JusticeforNico £1,000
Payment to CHANGE for LBBill Easy Read materials £1,000
LBBill Mailchimp subscription \$60

3 Donations in kind

Love, time and skills by the bucket load.

Cost of travel, overnight accommodation, web domains and biscuits for the Justice Shed met by the JusticeforLB supporter incurring the cost.

Cost of PO Box for the Justice Quilt patches met by Janet Read.



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