

A Trade in People:

The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder



Mark Brown, Elaine James and Chris Hatton

Series Editor: Hannah Morgan

CeDR Briefing Paper 2017:1



Centre for Disability Research

Brown,M, James, E. and Hatton, C (2017) **A Trade in People: The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder** Lancaster: Centre for Disability Research.

The Centre for Disability Research (CeDR) is a specialist research grouping that promotes and conducts high quality interdisciplinary research and research-led teaching about disability. CeDR publishes a range of working, briefing and position papers as well as research reports, summaries and other resources

Series Editor: Hannah Morgan, Director, CeDR, Lancaster University

Introduction

On the 31st of May 2011 the BBC programme [Panorama's Undercover Care: The Abuse Exposed](#) was broadcast. It would lead to the prosecution and conviction of 11 members of staff, the closure of Winterbourne View Hospital and a flurry of activity on the part of government to try and establish why it had happened and how it could be prevented from happening in the future.

To this end the government conducted an inquiry that would lead to the publication of [Transforming Care: A National Response to Winterbourne View Hospital](#) which was jointly published with a [Concordat: Programme of Action](#) setting out the steps that government and key stakeholders would take to ensure that anything like the scandal at Winterbourne View would never happen again.

However, Transforming Care and its accompanying Concordat also set out to tackle the existence and the role of the hospitals themselves, and the emerging realisation that many of the people who were in them, shouldn't be, or were in them for far too long.

Specifically, the Concordat set the community a number of objectives that the government expected to be achieved by 1 June 2014. These objectives included a review of hospital placements, the establishment of registers of people with challenging behaviour, the drafting and implementation of local plans, national leadership driving change at a local level, a life-course approach with planning beginning in childhood, and improved quality, safety and regulation. Over 50 organisations signed up to the Concordat and within it the different sectors committed themselves to different objectives.

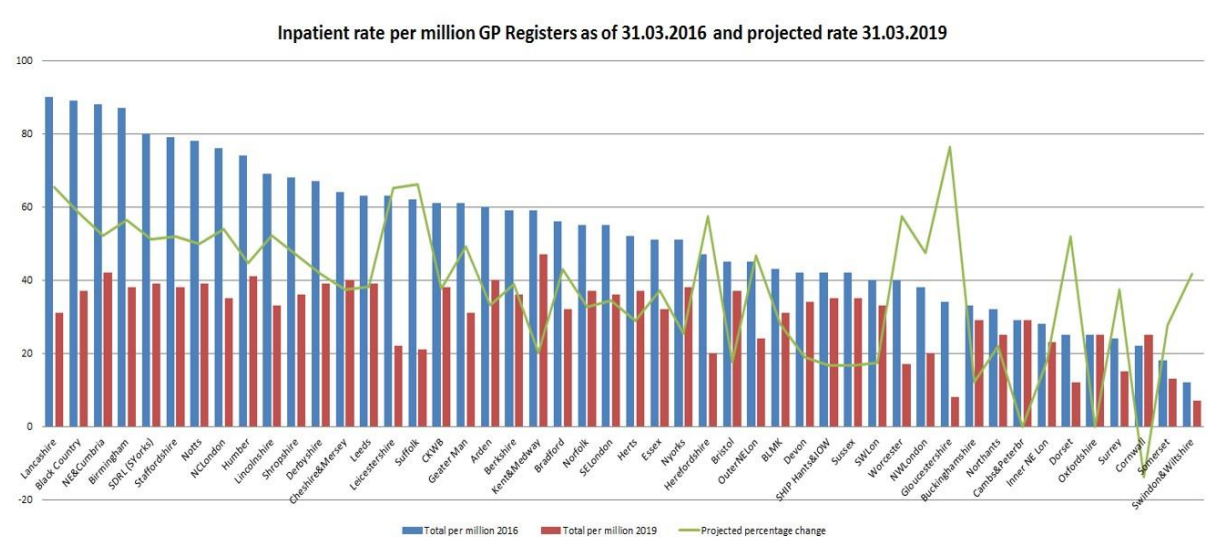
Whilst some of the Concordat's objectives were met, the overarching objective of getting people out of hospitals and back into their communities was missed. As a result a new inquiry was launched with a focus on the way in which services were being commissioned under the Chair of Sir Stephen Bubb. In 2014 the inquiry published [Winterbourne View - Time for Change](#) or The First Bubb Report as it would come to be known. The report argued that there were a number of reasons why more progress hadn't been made, the most significant of which being:

It is that we make it too hard for stakeholders across the system to make change happen, and too easy to continue with the status quo. And we do not give enough power or support to the people most eager and best placed to make things change - starting with people with learning disabilities and/or autism themselves and their families

Winterbourne View - Time for Change, p.9

The report then went on to make 11 recommendations, the majority of which were incorporated in some form or another into [Building the right support](#). Published in October 2015, the purpose of *Building the right support* was to develop community services and infrastructure that would allow for the closure of inpatient provision. Central to it was the establishment of 48 Transforming Care Partnerships, made up of Clinical Commissioning Groups (CCG), Local Authorities and other local stakeholders and a new National Service Model that was intended to be used as guidance for what should be in place by no later than March 2019. In addition to this *Building the right support* set rigorous targets for the reduction in inpatient bed use that they expect local areas to achieve, namely a 45-65% reduction in capacity for CCG Beds and a 25-40% reduction in the number of NHS Commissioned Beds. The objective is that this would lead to a reduction in the number of people using inpatient provision from 2,600 to 1,300 - 1,700 by March 2019.

In order to make comparisons between areas. NHS England uses the number of inpatients as a proportion of a million people registered with GPs in the Transforming Care Partnership.



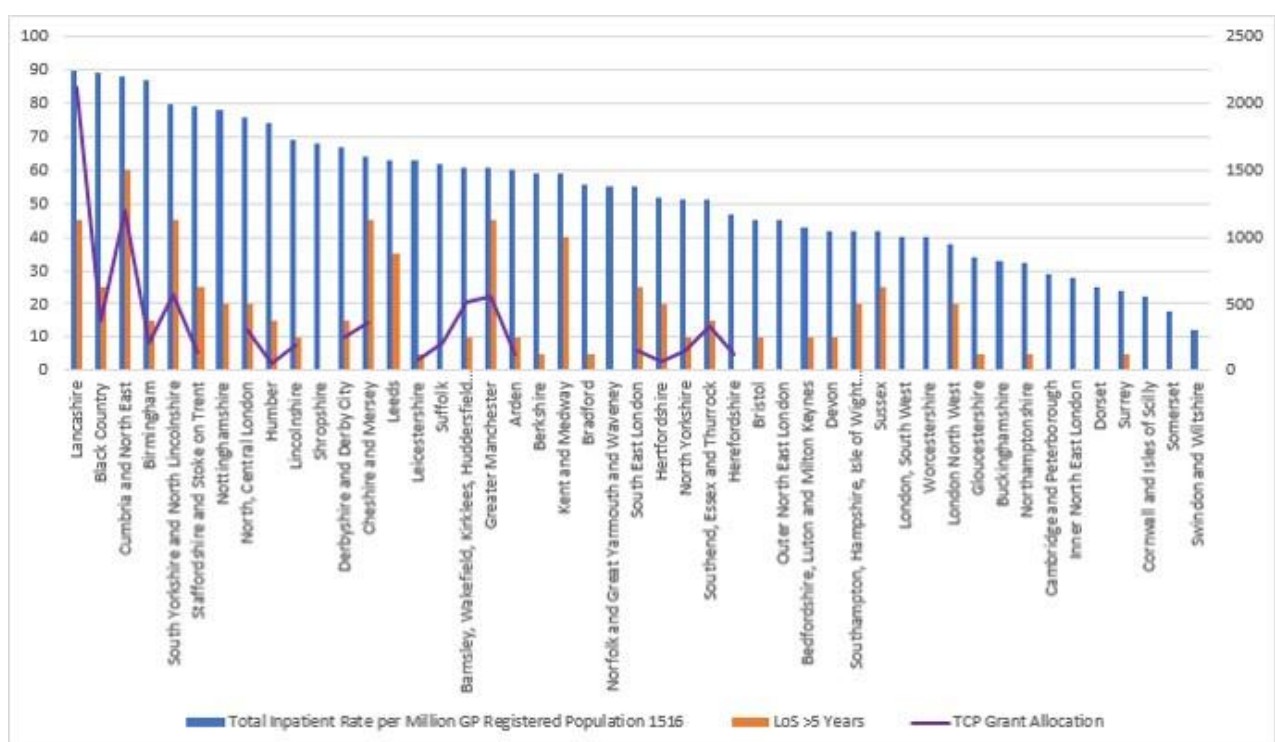
Graph 1 Inpatient rates and projected percentage change from 2016 to 2019

Graph 1 shows the inpatient rate per million people registered with GPs for the individual Transforming Care Partnerships. The column in blue is the rate at the beginning of *Transforming Care Building the Right Support*, the column in red is its expected target in 2019, and the green line is the percentage that the rate is expected to change within an area.

There are also expected to be reductions in the distances that people have to travel and in the average length of stay. In implementing *Building the Right Support* the government places a significant emphasis on getting people who have been in inpatient provision for more than five years home and they established a

dowry to support the costs of resettling people as they stepped down from hospital with individual, personalised support plans. In addition to this Partnerships were invited to develop Transforming Care Plans (TCP) and put in bids for Transformation funding to build and develop new models of support.

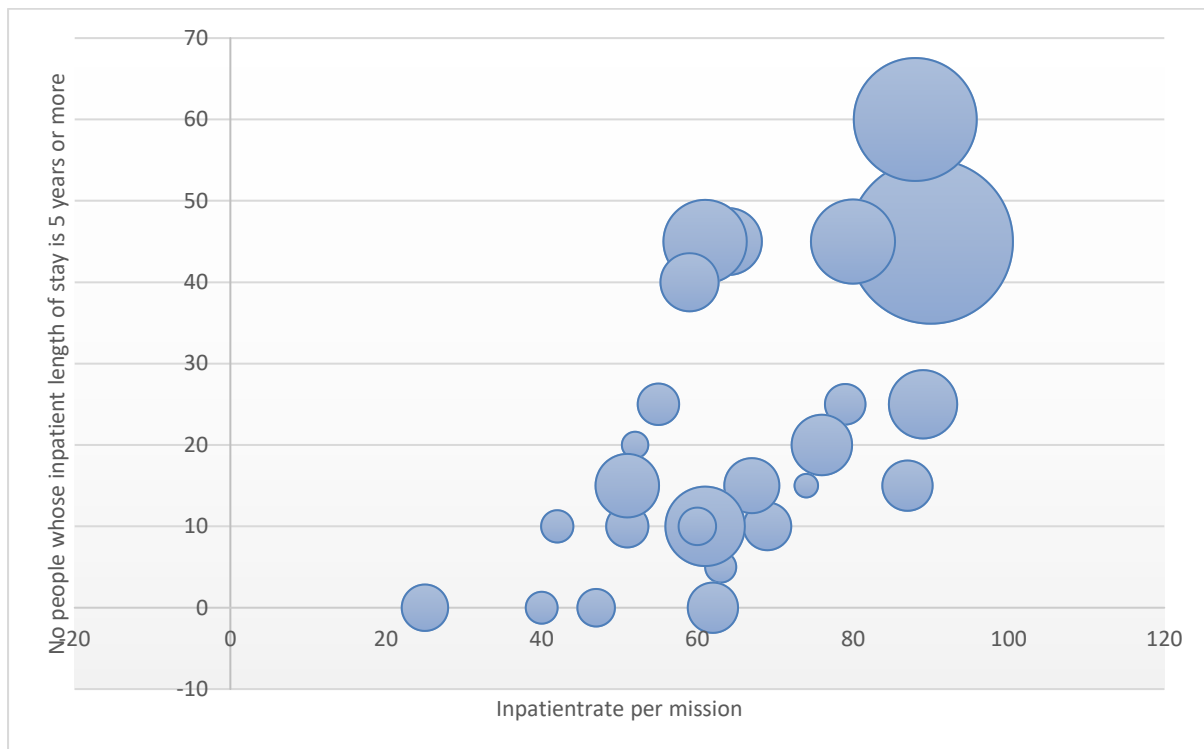
In Graph 2 we show the inpatient rate per million people registered with a GP with the percentage of the inpatient population that have been detained for over 5 years. In addition to this the purple line and the column on the right shows the amount of TCP Grant allocation that an area has received in its 2016 TCP grant allocation. A proportion of the funding was held for TCP's in the South to bid for.



Graph 2 - Inpatient Rate, Length of Stay and Transformation Grant Allocation.

The grant funding was part of the £30 million in Transformation Funding. As Graphs 2 and 3 shows it appears to have been allocated to areas where higher proportions of the inpatient population have been detained for over 5 years. The size of the “bubble” in graph 3 represents the value of the Transformation Funding grant to the Transforming Care Partnership from NHS England.

Looking at the two graphs together we can see that many areas are being expected to achieve significant reductions in the number of people who are inpatients. However, most areas have not been selected by NHS England to receive transformation funding to support them in achieving those targets. Time will tell how realistic an expectation this proves to be and it is this kind of ambiguity that underpins the reason for carrying out this work.



Graph 3 - Bubble chart showing the relationship between inpatient rate, number of people whose length of stay is greater than 5 years adjusted for the size of Transforming Care Grant

As part of our campaign to support the rights of people with learning disabilities and/or ASD to live in their own homes, and in order to ensure that we are able to keep track of the progress of *Transforming Care Building the Right Support*, [Seven Days of Action](#) submitted a Freedom of Information (FOI) Request to NHS England for the financial appendices to the 48 Transforming Care Plans. These provided us with a comprehensive, although in some cases patchy, breakdown of current and future spending plans. In addition to this the following data has been used to develop an overview of the way in which the inpatient healthcare system is operating:

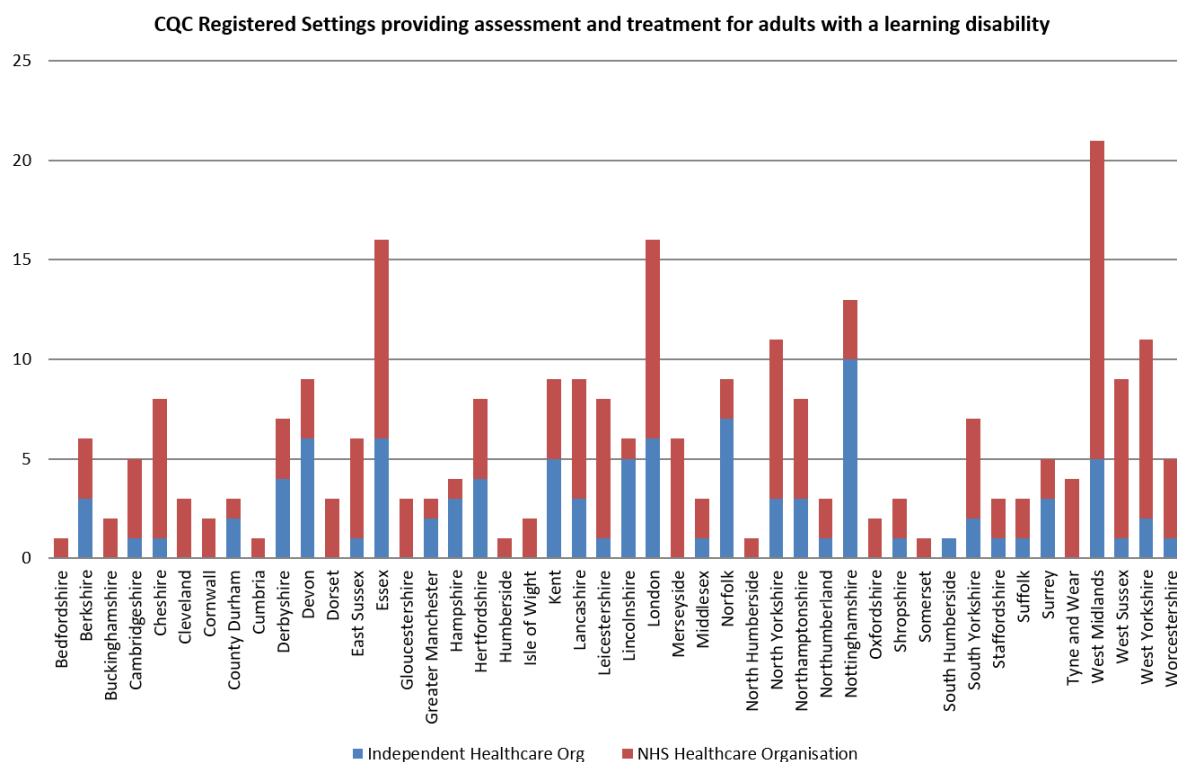
- Office of National Statistics (ONS) (2016). Clinical Commissioning Group Mid-Year Population Estimates
<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/clinicalcommissioninggroupmidyearpopulationestimates>
- Care Quality Commission (CQC) database of registered providers extract, provided under FOI
- NHS Digital Assuring Transforming Care
<http://www.content.digital.nhs.uk/catalogue/PUB22555>

- UK House Price Index (UKHPI) data published by Land Registry © Crown copyright 2016 - April 2016 Release Date 14 June 2016, updated 5 July 2016 <https://www.gov.uk/government/statistical-data-sets/uk-house-price-index-data-downloads-april-2016>
- Endole: Business Information Company Check <https://www.endole.co.uk>
- Companies House UK Government <https://beta.companieshouse.gov.uk/>

When we started looking at the data it was clear that there are greater numbers of Transforming Care Partnerships (TCPs) with very high or very low rates of inpatient provision than can be explained by the prevalence of learning disability within the different TCP populations and that factors other than the occurrence of learning disability and ASD were playing a role in affecting the probability of somebody being placed in an in-patient setting. The question we explore in this report is what might those factors be?

The in-patient healthcare economy for people with learning disabilities and/or autistic spectrum disorder

In total in 2015/16 £477.4 million was spent on keeping approximately 2,500 people with learning disabilities in hospital in Assessment and Treatment Units (ATUs). Of those beds 1,170 of those places were provided by the NHS and 1,290 or 52% of those places were provided by the independent sector. In 2010 the percentage of beds in the independent sector was 33% having risen from 20% in 2006. Over the last 10 years the landscape of the inpatient healthcare economy has gone from one that was dominated by NHS provision to one in which the independent sector is now playing the greater role.



Graph 4 - Number by location and provider type of units registered with the Care Quality Commission to provide assessment and treatment to learning disabled people

The independent sector beds were spread across 96 units registered with Companies House and 38 provider organisations. Ten of those units had dual registration with the Charities Commission.

Figure 1: Location of ATUs in England

NHS in orange, independent providers in purple



In 2015-16 we estimate that the value of the Inpatient Healthcare Market to the “independent” sector is in the region of £284 million. Most of that provision operates on a for profit basis and our sons and daughters are its currency. On average a person who has been in hospital for 5 years will generate £950,000 in income for an independent sector organisation, although significantly higher levels of income are possible.

One of the characteristics of the independent sector and its effect on the inpatient economy is that whilst Transforming Care Partnerships have responsibility for commissioning in-patient beds they have had relatively little control over where independent beds or independent residential provision is located, as this quote from the Southampton, Hampshire, Isle of Wight and Portsmouth (SHIP) Transforming Care Partnership illustrates.

The SHIP TCP is a nett importer of people with a learning disability. A review of Residential Care commissioned beds identified less than 50% of available capacity was purchased by local Health and Social Care Commissioners with the remainder from out of area teams such as London Boroughs and neighbouring counties. Portsmouth is a nett importer of people with a learning disability plus a nett exporter of in-patients as there are no beds on Portsea island. This is a similar picture in the Southampton area. The Isle of Wight has no locked rehab, low or medium secure provision, it has one assessment treatment bed on Osborne Ward, Sevenacres.

[Southampton, Hampshire, Isle of Wight and Portsmouth Transforming Care Plan](#)
p.22

So whilst many other forms of NHS provision have been planned and developed around an area’s demographic characteristics the development of inpatient provision for people with learning disabilities and ASD has been shaped by a number of other factors. Some are historical, others appear to be driven by more prosaic economic factors like the cost of developing and running provision. Irrespective of the reason, the uneven spread of provision has led to the development of what is effectively a “market” of people with a learning disability which the growth of the independent sector has intensified.

Northamptonshire is another partnership area that illustrates this phenomenon, as the following quote from their Transforming Care Plan illustrates.

Northamptonshire is a County with several large providers and this this has created an ‘importer’ concern. An example of this is Gretton Homes who support up to 59 people who have Prader Willi syndrome and, whilst many placements are funded from other areas, it causes a significant strain on our local specialist

services. In addition, we have two local independent hospitals; St Andrews and St Matthews. St Andrews is a large provider of services for people with learning disabilities. This hospital is in the process of expanding with a new 100 bed service for people with autism which is a significant concern for the CCGs from an economical and value based perspective.

[Northamptonshire Transforming Care Plan](#) p.24

There appear to be two different issues in play in both of these quotes - firstly the movement of people into an area because of the availability of learning disability provision, which means that this will effectively become their home authority. The second is the pull effect of having large independent providers of in-patient provision in the area.

According to 2015 figures St Andrews provides beds to over 100 people with learning disabilities who are from outside of the partnership area.

County	Number of People
Cornwall/Devon	5
Bristol /Somerset/ Dorset	8
Hants/Reading/Ascot/Chiltern	7
Sussex/Kent	14
London Boroughs	8
Oxford/Milton Keynes/Herts	7
Gloucester/Hereford/Worcestershire/Shropshire	12
Warwick/Coventry	5
Birmingham	14
Derby/ Notts / Leicester	5
Staffs/Telford	7
Lincoln	3
Lancashire	1
Yorkshire	2
Cumbria	1
Teeside	1

Table 1: Home Local Authority of people living in St Andrews 2015

It is evident that the decisions of independent providers to commission provision in certain areas has a significant effect on the patterns of provision across the country and the ability of local commissioners to purchase beds in their locality. St Andrews is probably the most powerful example of this and their ability to “attract” inpatients from across the length and breadth of the country is having a significant effect on local inpatient rates.

Inpatient rates

As previously mentioned, in order to make comparisons between Transforming Care Partnership areas NHS England uses a statistic called inpatient rate per million people registered with their GP to measure the inpatient rate for a given Transforming Care Partnership. We wanted to see what specific factors might be affecting inpatient rates so as a first step we tested for correlations between a number of different factors.

Pearson Correlation (Parametric)		inpatient rate per million GP popn 2015/16	Number of inpatients resident for 5 or more years	Number of CQC registered inpatient settings	House Price Index 1/4/2016	Rate per million risk register packages of care	million children & young people packages of	million former inpatients packages of care
Total inpatient rate per million GP popn 2015/16	Pearson	1	.617**	.419**	-.440**	.375**	-.122	.080
	Sig. (2-tailed)		.000	.003	.002	.009	.414	.594
	N	47	47	47	47	47	47	47
Number of inpatients resident for 5 or more years	Pearson	.617**	1	.499**	-.310*	.364*	.044	-.027
	Sig. (2-tailed)	.000		.000	.034	.012	.768	.858
	N	47	47	47	47	47	47	47
Number of CQC registered inpatient settings	Pearson	.419**	.499**	1	-.155	.155	.048	-.180
	Sig. (2-tailed)	.003	.000		.299	.300	.749	.225
	N	47	47	47	47	47	47	47
House Price Index 1/4/2016	Pearson	-.440**	-.310*	-.155	1	-.393**	.203	-.153
	Sig. (2-tailed)	.002	.034	.299		.006	.170	.303
	N	47	47	47	47	47	47	47
Rate per million risk register packages of care	Pearson	.375**	.364*	.155	-.393**	1	-.056	.113
	Sig. (2-tailed)	.009	.012	.300	.006		.706	.451
	N	47	47	47	47	47	47	47
Rate per million children & young people packages of care	Pearson	-.122	.044	.048	.203	-.056	1	-.017
	Sig. (2-tailed)	.414	.768	.749	.170	.706		.909
	N	47	47	47	47	47	47	47
Rate per million former inpatients packages of care CHC/117	Pearson	.080	-.027	-.180	-.153	.113	-.017	1
	Sig. (2-tailed)	.594	.858	.225	.303	.451	.909	
	N	47	47	47	47	47	47	47
**. Correlation is significant at the 0.01 level (2-tailed).								
*. Correlation is significant at the 0.05 level (2-tailed).								

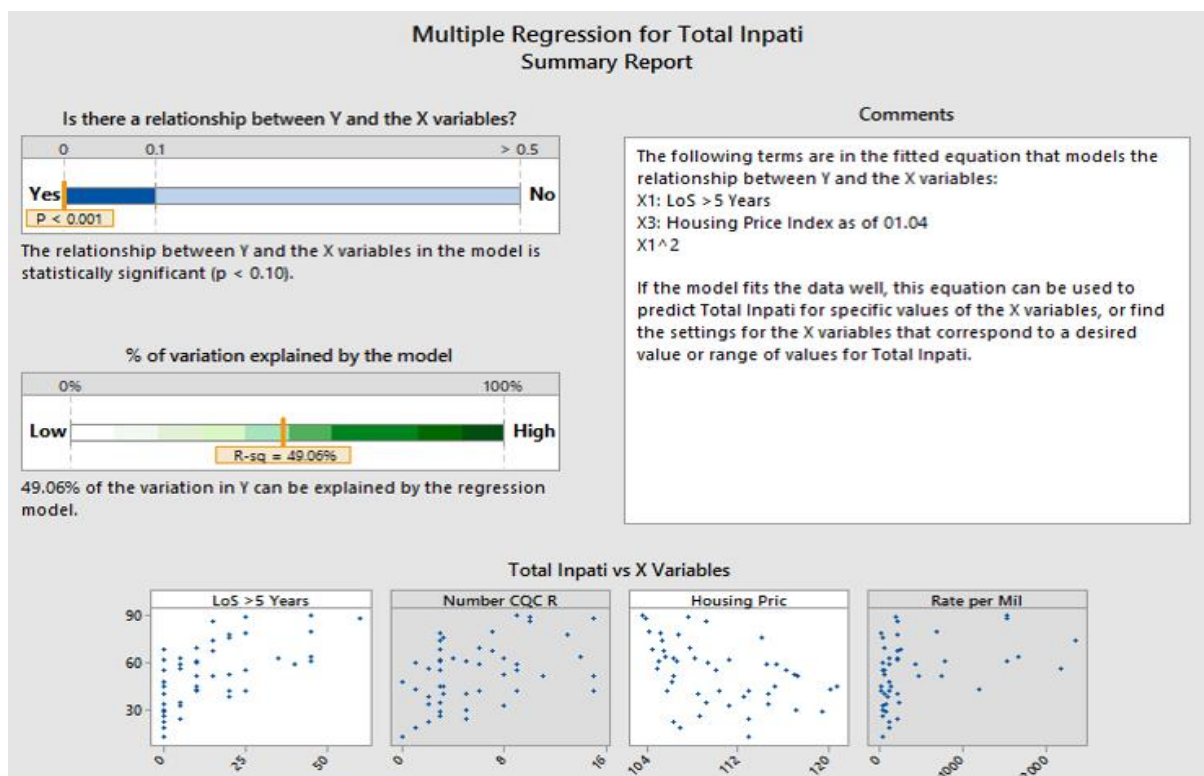
Table 2 - Pearson correlations

As Table 2 shows, the inpatient rate per million GP registered population shows correlations (high-lighted in yellow or tan) between the number of inpatients resident for 5 years or more, the number of CQC registered inpatient settings, the rate per million risk register packages of care and an inverse correlation with the UK House Price Index, which means that if the inpatient rate is high house prices are likely to be low. This is interesting but it is simply a statistical correlation which tells us that there is some sort of relationship but it doesn't tell us anything about the effect that the different variables might be having on each other, so we went on to carry out a regression analysis. In a regression analysis we modelled the possible effect that the different independent variables might be having on the dependent variable.

In our first analysis, our dependent variable was inpatient rate per million people registered with their GP, the independent variables were those that had indicated a correlation, namely:

- Inpatients resident for more than 5 years
- The number of CQC registered in-patient settings
- House Price Index, and
- Rate per million people on TCP risk registers

Our regression analysis showed that the independent variables that showed the strongest associations with the inpatient rate per million people registered with their GP were length of stay greater than 5 years and the House Price Index, and that in combination they were able to explain 49.06% of the variation in the dependent variable.



Interestingly, length of stay had the strongest association with inpatient rates. Our analysis goes some way in supporting narrative plans submitted by the 48 Transforming Care Partnerships. This indicates that economic factors such as the cost of housing may be important in shaping patterns of inpatient provision. Arguably, these may be affecting the decisions of “healthcare entrepreneurs” to establish provision in areas with relatively low infrastructure costs. This is important because it means that decisions about patterns of inpatient provision are being driven by economic factors rather than clinical need.

These indications are in line with the 2012 IHAL report¹ (Glover and Olsen 2012) which reviewed a significant number of characteristics of inpatient provision, one of which was the extent to which Strategic Health Authorities (SHA) “imported” or “exported” patients. The restructuring of the health service means that direct comparisons are problematic. However, the report is clear that the movement of patients across authorities is widespread. The table below shows the extent to which SHAs were involved in placing people out of area.

Table 21. Geography of placement – Where patients from each Strategic Health Authority area are placed.

Where A&T patients are placed (%s by row)		Strategic Health Authority location of placement											Total
		North East	North West	Yorkshire/ Humber	East Midlands	West Midlands	East of England	London	South East Coast	South Central	South West	Other/ Unknown	
Commissioning PCT/SHA	North East	93%		1%	1%	1%	4%		1%				135
	North West	15%	81%	1%	1%							1%	79
	Yorkshire/ Humber	18%		61%	13%		5%		1%			1%	92
	East Midlands	8%		13%	66%	1%	11%		1%				80
	West Midlands	5%		1%	4%	80%	9%					2%	176
	East of England	3%		1%	1%	1%	93%	1%		1%			160
	London	6%	1%		2%		34%	39%	4%	6%		6%	93
	South East Coast	2%					29%		34%	32%		2%	41
	South Central	3%	1%		6%		15%	1%	6%	64%	3%	1%	72
	South West	4%			1%	6%	25%			14%	42%	7%	69
	Other and unknown	12%	1%	8%	3%	14%	28%	4%	1%	4%	4%	21%	347
Total		17%	5%	7%	7%	15%	26%	4%	2%	7%	3%	7%	1,344
Where all in-patients are placed (%s by row)		Strategic Health Authority location of placement											Total
		North East	North West	Yorkshire/ Humber	East Midlands	West Midlands	East of England	London	South East Coast	South Central	South West	Other/ Unknown	
Commissioning PCT/SHA	North East	93%		2%	2%	1%	2%		0%			0%	294
	North West	7%	89%	0%	2%	1%						1%	300
	Yorkshire/ Humber	13%	10%	66%	8%		2%		0%			1%	240
	East Midlands	2%		4%	89%	1%	3%		1%			1%	389
	West Midlands	3%		0%	8%	79%	4%				0%	5%	428
	East of England	1%		3%	3%	1%	91%	1%		0%			334
	London	4%	1%	1%	11%		25%	25%	24%	4%	1%	5%	174
	South East Coast	1%			4%		9%		76%	9%	1%	1%	147
	South Central	1%	0%		6%		7%	0%	3%	80%	1%	1%	219
	South West	2%			11%	2%	8%			7%	63%	7%	225
	Other and unknown	11%	3%	8%	9%	11%	22%	2%	4%	1%	3%	26%	892
Total		13%	9%	7%	16%	12%	17%	2%	5%	6%	5%	8%	3,642

Glover and Olsen 2012, p.53

From here we can see that in 2010 93% of the people in ATUs in the old North East SHA were placed within area whereas only 39% of people from London are placed within London based ATUs. It also shows that 25% of London commissioned placements are commissioned in the East of England, 11% in the East Midlands and 24% on the South East Coast. We do not currently have access to more recent figures. But it does support our argument for the existence of a “trade” in people with learning disabilities and ASD that is increasingly being shaped by the decisions of healthcare entrepreneurs.

Length of Stay

We also looked at the factors that might be associated with length of stay, where the length of stay is greater than 5 years. The initial Pearson correlation analysis shown above in Table 2 indicated that there was a strong positive correlation between the number of inpatients who had been resident for more than 5 years

^{1 1} Glover, G & Olson, V (2012). Assessment and Treatment Settings and Other Specialist Inpatient Care for People with Learning Disabilities in the Count-Me-In surveys, 2006 to 2010

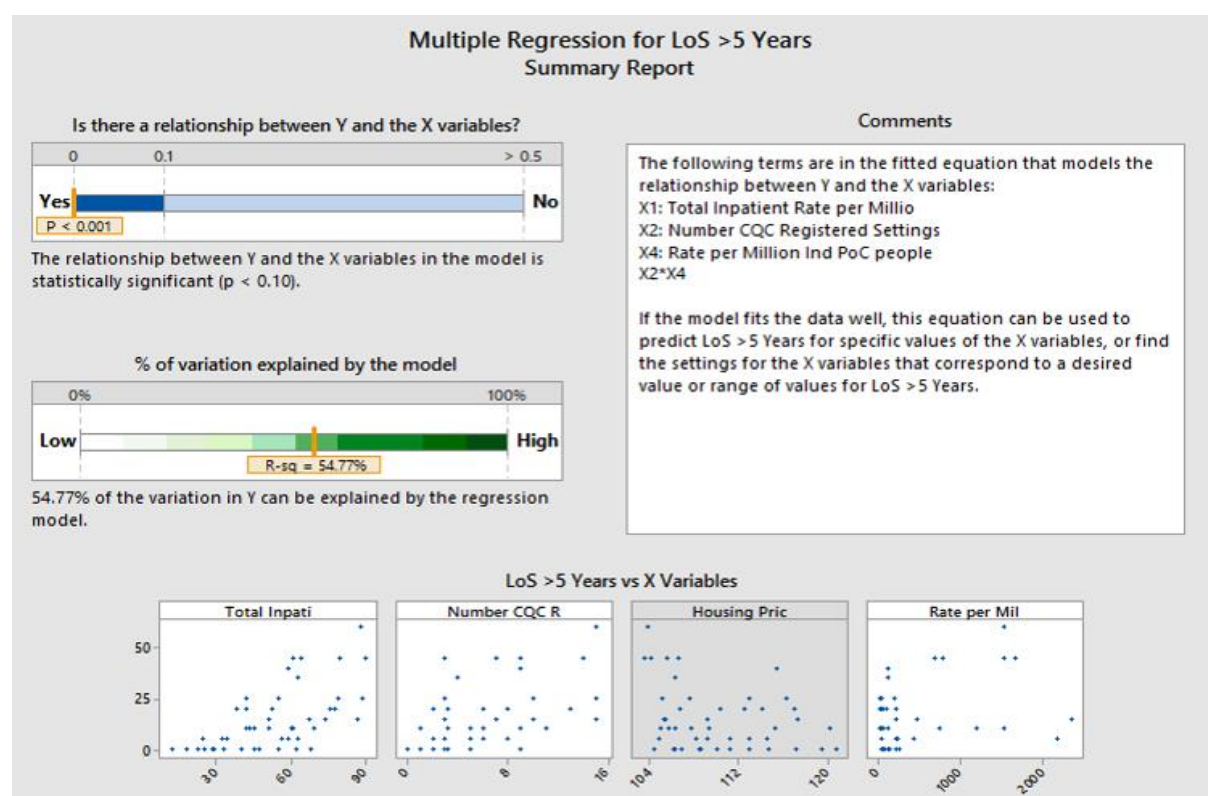
and the inpatient rate, a moderate correlation between length of stay and the number of CQC registered settings that there are in an area and a weaker inverse correlation with the UKHPI.

In order to look at these relationships in more detail, we ran a regression analysis with length of stay greater than five years as the dependent variable and the following independent variables:

- Inpatient rate per million people registered with the GP
- Number of CQC registered inpatient settings
- UK House Price Index
- Rate per million risk register packages of care, and
- Rate per million former inpatients receiving funded community support (s117/CHC)

The analysis indicated that the number of people with a length of stay of longer than five years is most strongly associated with inpatient rates and the number of CQC registered settings and that between them they explain 47.28% of the variance in the number of people within a partnership who have been in inpatient provision for over five years.

By including the rate or numbers of former inpatients who are receiving packages of care then the amount of variance that the model explains rises to 54.7%.



So according to our model these three independent variables explain almost 55% of the variation in the length of stay greater than five years across partnerships:

- Total inpatient rate per million people registered with their GP
- The number of CQC registered settings and
- The number of Section 117/CHC packages of care

The impact of the number of S117/CHC packages of care raises some interesting issues.

S.117 and Responsible Commissioners

Section 117 Packages of Care are packages of care that according to Section 117 of the Mental Health Act must be put in place following somebody's return to the community. According to the information that we received as part of our Freedom of Information request, Transforming Care Partnerships were forecasting a spend of £1,478 million on "individual community support packages for former inpatients and those at risk of admission" for section 117/CHC aftercare packages for 2015/16. The levels of spending involved go some way to explain why many of our families cite arguments about who pays for aftercare as one of the reasons that they have struggled to get their sons and daughters home.

In 2013 the government issued [new guidance](#) which stated that the commissioner responsible for paying for S.117 aftercare would be determined by the location of where the individual is registered with their GP. This meant that once a patient had registered with a GP in the location of the hospital in which they were being detained, the financial responsibility for the cost of their aftercare support became the responsibility of the CCG in which the GP was located and given that the longer somebody is in hospital the more likely they will be to have registered with a local GP, the more likely the hospital would come to be seen as a person's home partnership.

This would often create a disincentive to discharge and perversely an incentive to export people out of area, because "originating" authorities would know that once individuals had registered with a GP they were effectively able to wash their hands of any financial responsibility for the individual.

For some local authorities and CCG commissioners this has meant that they have had to fund disproportionately high numbers of people through Mental Health Section 117 aftercare. For example, in the financial appendix the Norfolk partnership Transforming Care Plan stated that it was providing 300 packages of care and support, costing local CCG commissioners a total of almost £23 million. Other commissioners have simply been unable to discharge patients, which would in turn make it difficult for partnerships to reduce their inpatient admission rates.

This data is supported by the experience of the solicitors Browne Jacobson who list the following effects of the guidance on their [website](#):

- *delaying the discharge of medically fit patients from hospital whilst disputes over aftercare responsibilities are resolved*
- *the creation of a disincentive to the commissioning of appropriate local services for fear that patients with complex needs would be placed 'out of area' by other CCGs, and thus become the responsibility of the receiving CCG where such services are located as soon as the patient registers with a GP there*
- *the failure to encourage joined up commissioning, as the patient's responsible local authority would often remain the same whereas the responsible CCG would shift around depending on where the patient had registered with a GP at any given time*

Recognising the impact that this guidance was having the government amended the [Responsible Commissioner Guidance in April 2016](#). Now a person's home CCG remains liable for their S.117 aftercare even if they leave hospital but decide to live in the area in which the hospital is located. However, the change in guidance is not retrospective, so it won't have any effect on the significant number of people who were detained in inpatient provision prior to April 2016.

The experiences of people with learning disabilities and/or autistic spectrum disorder

Research data and information on the views and experiences of the people with learning disabilities who are detained in inpatient provision is difficult to obtain. The 2012 Institute of Health and Lives report, *Assessment and Treatment Units and Other Specialist Inpatient Care for People with Learning Disabilities in the Count-Me-In surveys, 2006 to 2010*, identified five different types of adverse experience that patients were likely to have to endure, seclusion, accidents, assaults, restraint and self-harm (Glover & Olson 2012):

- 7% of patients experienced seclusion - this appeared to be restricted to a minority of providers;
- 22% experienced at least one accident;
- 35% suffered an assault;
- 41% were subject to hands-on restraint; and
- 27% self-harmed.

Glover and Olsen 2012, p. iv

The report also established that patients detained within the independent sector were 30% more likely to experience an assault and 60% more likely to be restrained than inpatients in NHS Units.

The stories of families involved in the Seven Days of Action campaigns give us some insight into the harsher reality of what this kind of data may mean. Names have been changed and the family members have given permission for their words to be used.

One morning, he was made to attend a meeting with other patients. There were several patients, along with support staff, in a small lounge area. He tolerated this for a while, but then asked to leave. A support worker told him that he couldn't leave, so my son, in a panic, struck the support worker. This same worker retaliated by grabbing him, forcing his arm up behind his back, and manhandling him out of the room.

When I went to visit later, I noticed that my son's arm was badly swollen and asked about this. I was told by a nurse that his arm must be swollen because he had struck the support worker. The nurse did not tell me that he had been in any way restrained. I repeated my concerns later, on leaving and was assured he would be observed. Still no mention of a restraint. The next morning the manager rang me and said she was organising for him to go to A&E because his arm was still swollen. An x-ray revealed that his humerus was badly broken and that the break was compatible with someone having their arm forced up behind their back. This

bone is one of the thickest bones in the human body and therefore quite difficult to break.

<https://www.sevendaysofaction.net/>

Glover and Olsen's report also recognised that an out of area placement was significantly associated with independent provision.

The impact on families

One of the factors that made us want to do this piece of work was that we could see the impact that the inpatient healthcare economy was having on people's lives. Repeatedly we would hear of people who had to go into inpatient provision because of a lack of local available support or of people who were still being detained simply because there wasn't anywhere for them to be able to return to or who had struggled to maintain relationships and contact because of distance. We asked some of our families to share their experiences of these themes.

Distance

Jane

When Richard was 18 we as a family tried everything we could to find an appropriate home for him as near to us as possible. Unfortunately there was nothing. We ended up searching the country far and wide. At this point our knowledge was minimal and basically did what we were told to do.

We found a home for Richard in Dorset. Miles from us, a three hour drive each way but at the time, we were grateful to have found it. Visits over the years were only monthly. Work commitments and the distance were a real issue. It usually involved us staying down there at a B&B in order to spend time with him. This went on for ten years. This had a huge effect on our family. Richard missed out on seeing his nieces and nephews. Only having limited visits from mum and dad which he loved but caused him great stress. The anxiety of knowing we were coming was hard for him to deal with and often unsettled him for days. Then when we arrived he had difficulty in adjusting to it. Then the reverse anxiety of us having to leave. It was a huge stress.

The home was bought out by a new company and many changes made. Staff left, new (inexperienced) staff were brought in and things slid downhill for Richard very rapidly. He had a lot of meltdowns and became extremely depressed. Unfortunately due to not seeing him very regularly we failed to see this ourselves and were only really aware when things got too bad.

Richard was taken to a nearby high security hospital and sectioned.

I always felt that if I was able to have seen him several times a week (normal life) I could of been more aware and maybe prevented the awful outcome. Distance was such an issue. We didn't have a normal relationship and caused us all so much stress.

After four months he was moved to an ATU in Stoke on Trent, even further away. I felt overwhelmed with guilt. Felt it was all my fault. If he had lived near me, none of this would have happened.

Carol

When our son was in the ATU, it was only an hour's drive, but that was still an hour too far, and with the motorway madness, the journey often took double the time. We know we were lucky compared to many, but it meant every visit had to be planned and orchestrated. We couldn't just pop in, and he couldn't keep in touch with the mates and his previous workers. It was like he went away, and has never come back. He's been out of the ATU for nearly two years, but he's still too far from his original family home and everything he knew for the first 22 years of his life.

Lyn

It was a 600 mile round trip to St Andrews to visit my daughter, it did not affect family life as she is an adult, but it took its toll on me her 65 year old mother. As she became physically ill (huge abscess on her back which involved a week in hospital and surgery to remove it, and increasing weight causing type 2 diabetes on top of already being a renal transplant patient) I decided to visit her more often for prolonged periods.

Money

Jane

My LA have always told me it was lack of provisions that meant we had to look further afield for homes. They never said it was money. But surely this just means they weren't investing in any provisions locally. Again they encouraged me to search country wide for suitable homes. I was never told of any other options and my lack of knowledge and naivety trusted the powers that be. If it wasn't for the groups on facebook which lead me to be put in touch with the right people and with the tremendous support and help I received I don't know I would have done it.

Anne

It seems the LA was using the cheapest option when considering a care provider which resulted in the lack of experience and breakdown in care after eight weeks

Carol

I don't think it has directly, as it wasn't that we identified a home for him that people said, that's too expensive. Of course indirectly it has. This is due to the lack of good local support and that has been due to lack of funding.

Diane

The LA had used this as an excuse for ten years. If he had stayed in his area he would have had great services and care. Where he is, it's in the middle of nowhere.... ...the best care and support is back in his borough. He asked to come back home for so many years and no one listened to him but now he's been groomed and scared to say what he wants. I haven't seen him for six weeks and I feel I am losing him and he can't say that he misses me as a mum

Local Support

Jane

There is no local support. My LA were absolutely shocking. No help at all. They put every obstacle in my way. Options were never offered or even talked about. When I did find suitable homes they took so long to decide on whether they thought they were viable, that we lost out to others. It felt like they deliberately stalled and held out as long as they could so as not to have to pay.

Richard's ATU said after three months of him being there, all he needed was a home. He was off section 13 months. 13 months of battling with my LA to provide what he needed.

Richard living with me at home was never an option. It wasn't what he wanted and I would not have been unable to cope as now on my own as my marriage broke down. Besides, he's a man now. Will be 30 this year. Why should he have to live with mum?

I truly believe that had I not named and shamed my LA in my petition against them, and without the local press coverage, I think I'd still be fighting now.

Carol

This has hugely affected his ability to stay close, and it ruined our son's life and ours for many years. When we asked for support when he was at home, it didn't come. When we hit crisis, the local support didn't exist so he was shipped off. When he was ready for discharge, there was nothing local so he's further away than we'd like, but it was the only option at the time. We miss him every day, it's like a void that no matter how busy we are, it's never filled. I live for the times we see him - how sad does that sound, (and I'm not a needy, clingy Mum, honestly ;-)) - we never really relax. Every time the phone goes from his house, I am anxious. It's mostly good calls - he's got great support workers, and they know him well now, so my anxiety is out of proportion, but I can't change this. His sister's life also changed forever the day he was admitted - she wrote to her cousin "This

was the worst day of my life, and the hardest thing my Mum and Dad have ever had to do." (Leaving him at the ATU.) God how I wish we hadn't.

Conclusion

Our data indicates that inpatient rates are being influenced by the decisions of healthcare entrepreneurs to locate in areas where house prices are lower and that once there, the length of their stay in hospital will be influenced by the care infrastructure that is in place. Namely the numbers of people who are inpatients, the number of CQC registered settings and the number of s117/CHC packages of care.

If considered in conjunction with the experiences of people with learning disabilities and their families and the content of a number of the Transforming Care Plans, it is clear to us that the way in which the healthcare economy has been encouraged to develop by recent governments turns people into commodities and liabilities. For local authorities and CCGs they are liabilities that they have often sought to export to other areas and for independent hospitals they are a commodity and source of millions of pounds of income and profit.

The impact of this has been exacerbated by the appalling [2013-2016 Responsible Commissioner Guidance](#) which intensified the pre-existing tendency for authorities to move people out of their area to "importer" regions and play hard ball when it came to getting them back.

The consequence for people and their families is a struggle to maintain relationships and any semblance of an ordinary family life and that rather than simply having to deal with the emotional and behavioural crisis, they end up having to fight a system where the bottom line isn't somebody's clinical need, it's profit. We believe that by allowing this industry to develop in this way the government has been complicit in the development of a system that fundamentally undermines the human rights to of people with learning disabilities and/or ASD and their families. Our findings suggest that there may be systematic and institutionalised breaches of both Article 5 of the European Convention on Human Rights Article 5, the right to liberty and Article 8, the right to a private and family life taking place. For far too many families the right to a private and family life has been torn from them in the fight for their loved one's liberty.

My life has just been fighting to free my son and get him back near his family and siblings. It's a very sad case. What they have done to my autistic son, who should never have been locked up. I hope he can be free and get his life back and start living again.

In this report we argue that, the way in which the in-patient healthcare economy for people with learning disabilities and/or Autistic Spectrum Disorders (ASD) operates, has a significant effect on people's ability to maintain links with their home communities and their ability to maintain relationships that are integral to their long term well-being and play a fundamental role in their right to an ordinary life.



CENTRE FOR DISABILITY RESEARCH

<http://wp.lancs.ac.uk/cedr>