

South East London Transforming Care Programme



November 2017

Content

- Context - how it all began
- Programme scope – who is in the ‘Transforming Care cohort’?
- What does this mean for ‘providers’, CCGs and local authorities?
- The South East London TCP Programme
- A family’s experience
- What worked well and what didn’t
- What next?

Context –how it all began...

Context



2011



2012

Context

- Winterbourne View scandal sparked a national debate about not just that hospital, which was closed, but about the way in which the health and care system, and society as a whole, treats people with learning disabilities
- The scandal did not happen in a vacuum – another example of how the NHS, and society as a whole, has repeatedly failed this group of people
- 2012 – six workers from Winterbourne View given prison sentences

2012 Winterbourne View Concordat

- ✓ Department of Health
- ✓ Local Government Association
- ✓ Directors of Adult Social Services
- ✓ Royal Colleges
- ✓ Voluntary sector organisations and others...

Context

- 30 September 2013 and 30 September 2014, 923 people were transferred out of inpatient care
- Over the same period – 1,306 people admitted to inpatient care.
- Consistently – more people admitted to hospital than discharged.

‘Transforming Care’

- ✓ People with learning disability and/ OR autism who present behaviour that challenges
- ✓ Commitment to reduce the number of inpatients – by half, by April 2019
- ✓ NHS England, LGA, ADASS, HEE, Skills for Care, CQC
- ✓ Delivery support – NHS England’s ‘Learning Disabilities programme’
- ✓ Monitoring through NHS England assurance process
- ✓ Focus on prevention as much as discharging people; work on a sub-regional footprint through the ‘Transforming Care Partnership’

**Programme scope – who is in the
‘Transforming Care cohort’?**

‘Transforming Care cohort’

Individuals with a learning disability and/ or autism, who present behaviour that challenges and are in an inpatient setting or have needs such that they require that level of support.

‘Learning disability’

Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a significantly reduced ability to cope independently (impaired adaptive and / or social functioning), and;
- which is apparent before adulthood is reached and has a lasting effect on development.

Used by the Department of Health, developed through the Valuing People initiative.

Learning disability is different from a specific learning difficulty, such as dyslexia, or a mental health condition.

‘Autism Spectrum Disorder / Condition’

“A lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them”.

Three main areas of difficulty (‘triad of impairments’):

1. social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice);
2. social interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own);
3. social imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine).

A spectrum condition - while all people with autism share certain difficulties, their condition will affect them in different ways

Around 50% of people with autism also have an LD.

‘Behaviour that challenges’

“Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and / or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion”

‘Behaviour that challenges’ is not a diagnosis and does not in itself imply any understanding as to the causes of the behaviour. The behaviour may be a way for someone to let people know what they want or how they feel, or to try and control what is going on around them, or be a response to physical or mental distress.

National

In England...

- Approx. 1.2M people with LD
- Approx. 650k people with autism
- Approx. 24,000 people who present severely challenging behaviour
- **Approx. 2,500 people in inpatient beds**

South east London

- Total population of 1.9M
- Approx. 35k people with LD
- Approx. 17k with autism

Inpatient numbers : currently 39 adults in CCG-commissioned beds; about 48 adults and 4 children and young people in beds commissioned by NHS England Specialised Commissioning

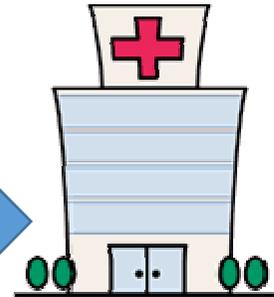
- Approx. average cost of inpatient bed/ day - £500
- Average annual cost/ patient: £180k
- **For 87 people this is nearly £16M**

Pathway



Oxleas
NHS
South London
and Maudsley
NHS Foundation Trust

**Community
Mental Health
Team**



**MH Hospital/
Assessment &
Treatment Unit**

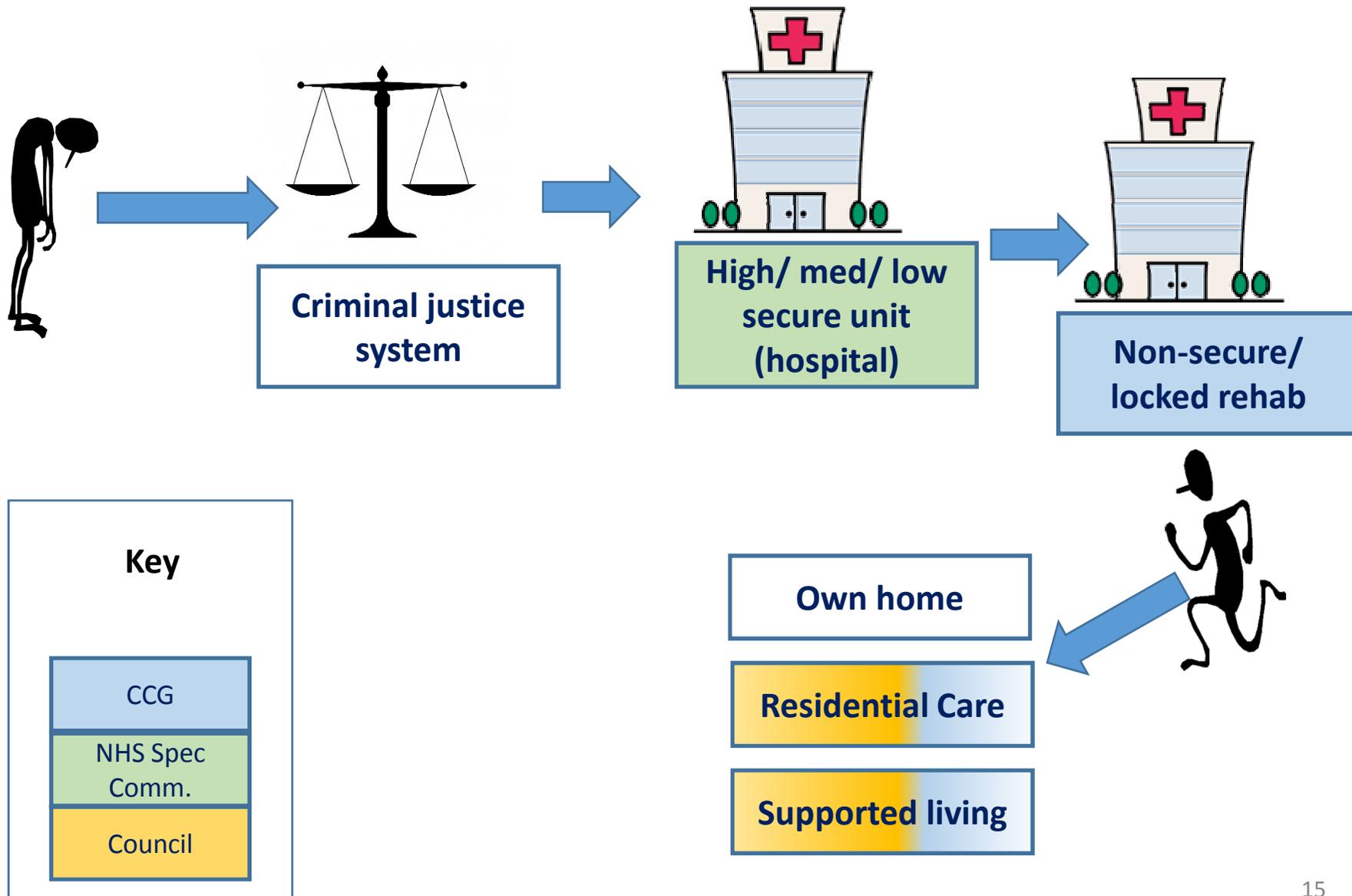


Key

CCG
NHS Spec Comm.
Council

Own home
Residential Care
Supported living

Forensic pathway



Who pays?

- Help at home ('domiciliary/ home' care) – local councils
- Residential care – councils and CCGs
- Supported living – councils and CCGs
- Mental health services in the community, e.g. CMHTs; CLDTs; outreach/ out of hours support – CCGs
- Mental health inpatient beds (adults) – CCGs
- Mental health inpatient beds (children and young people) – NHS England Specialised Commissioning
- Mental health 'forensic' inpatient beds - NHS England Specialised Commissioning
- Mental health community forensic services – CCGs and NHS England Specialised Commissioning.

**What does this mean for providers,
CCGs and councils?**

National agenda and programme

Discharging people

- Specific guidance on and monitoring of local delivery
- Care and Treatment Reviews/ Care, Treatment & Education Reviews (CTRs/ CETRs)
- 'Dynamic Registers'
- Assuring Transformation dataset on NHS Digital
- Close monitoring of inpatient numbers and lengths of stay

Prevention

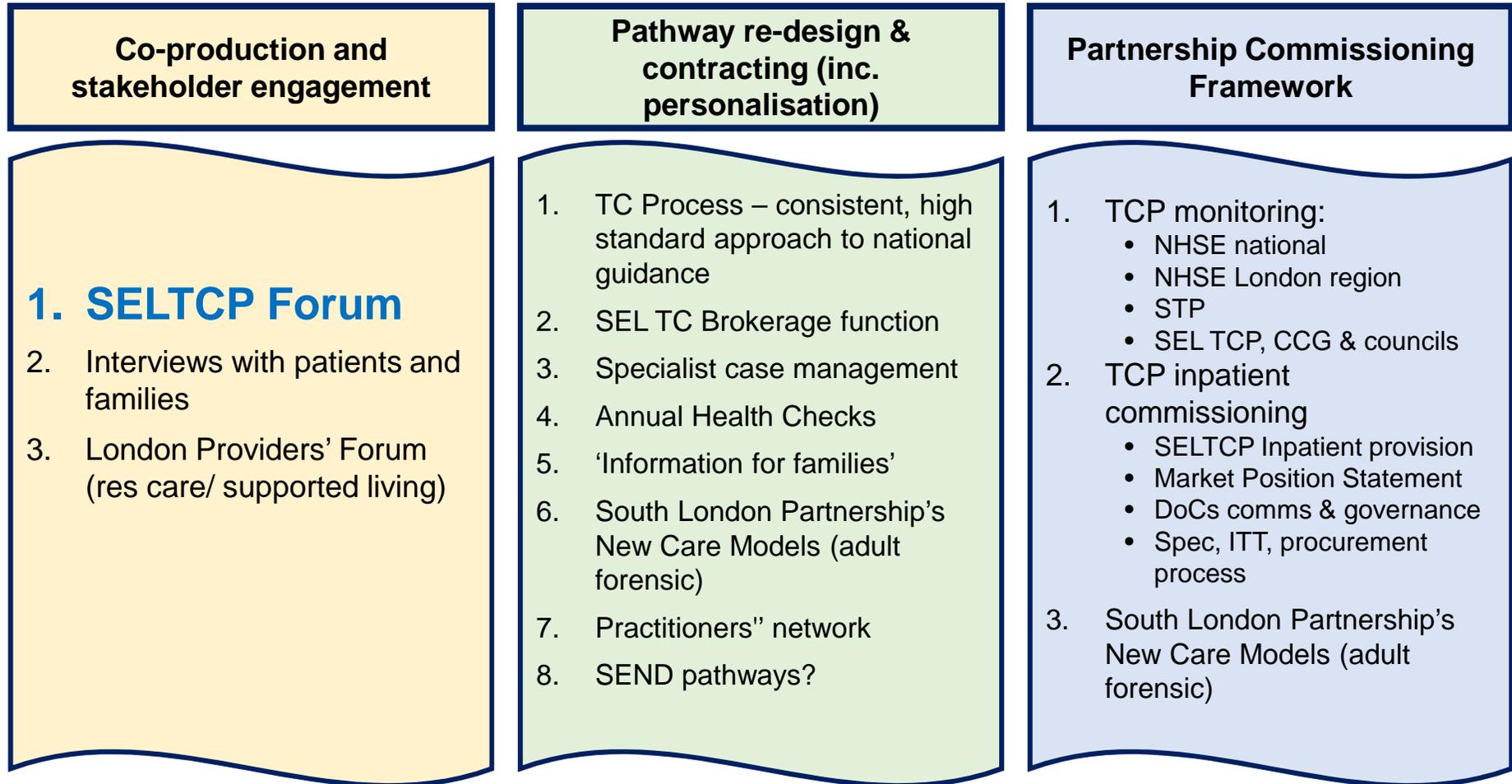
- Very broad agenda which covers a range of initiatives...
- Review of community services
- Housing
- Intensive outreach services
- Personal budgets/ personal health budgets
- Workforce
- Annual health checks for people with learning disabilities
- More...

How we respond to the national agenda

- Very close monitoring of 'Transforming Care cohort'
- Hospitals need to **identify** everyone in an inpatient bed (mainstream mental health as well as specialist learning disability unit) with learning disability OR autism
- Must be clear on the **diagnosis** – not just for reporting but ensuring people are on the right pathway – show evidence of this
- **Understand** the purpose and mechanics of 'Care and Treatment Reviews'/ 'Care Education and Treatment Reviews' – supplements CPA; timescales within which they must be done; who need to be involved; purpose of the CTR/ CETR
- <https://www.england.nhs.uk/learning-disabilities/care/ctr/>
- Work closely with commissioners in CCGs to provide information on this cohort – NHS England monitor CCGs on their performance
- Understand the national plan and vision as described in 'Building the Right Support'

The South East London Transforming Care Programme

South East London Transforming Care Programme - plan



@ssinghlondon

A family's experience

Alice M

Son experienced crisis in adolescence.

Difficult to explain to services (initially GP) what was wrong and son did'ent engage.

High achieving academically but stopped attending school and stopped talking

Needed a diagnosis 'of something' to access services.

CAHMS made a home visit and said 'he is behaving like someone who is autistic – Asperger Syndrome but he will have to engage for a diagnosis and we cannot make any more home visits.

Cycle of visits to A&E around meltdowns and distress.

Eventually sectioned for assessment to the Bethlem AMHU

Didn't speak, didn't engage until low level bullying led to an altercation and was then discharged with an Asperger Syndrome diagnosis a number of days later. Asked if to wanted to stay on the ward but could not see why – did'ent accept diagnosis.

Wouldn't return home, went to live with relatives but crises that no-one else understood meant he would have to leave sometimes within days – 6 months like this.

We asked for another Assessment under the MHA – he passed it but would not leave the Assessment Suite or see me.

He then entered Care aged 17.5, chose not to share and is now 20. We haven't seen him for circa 3 years.

What worked well and what didn't

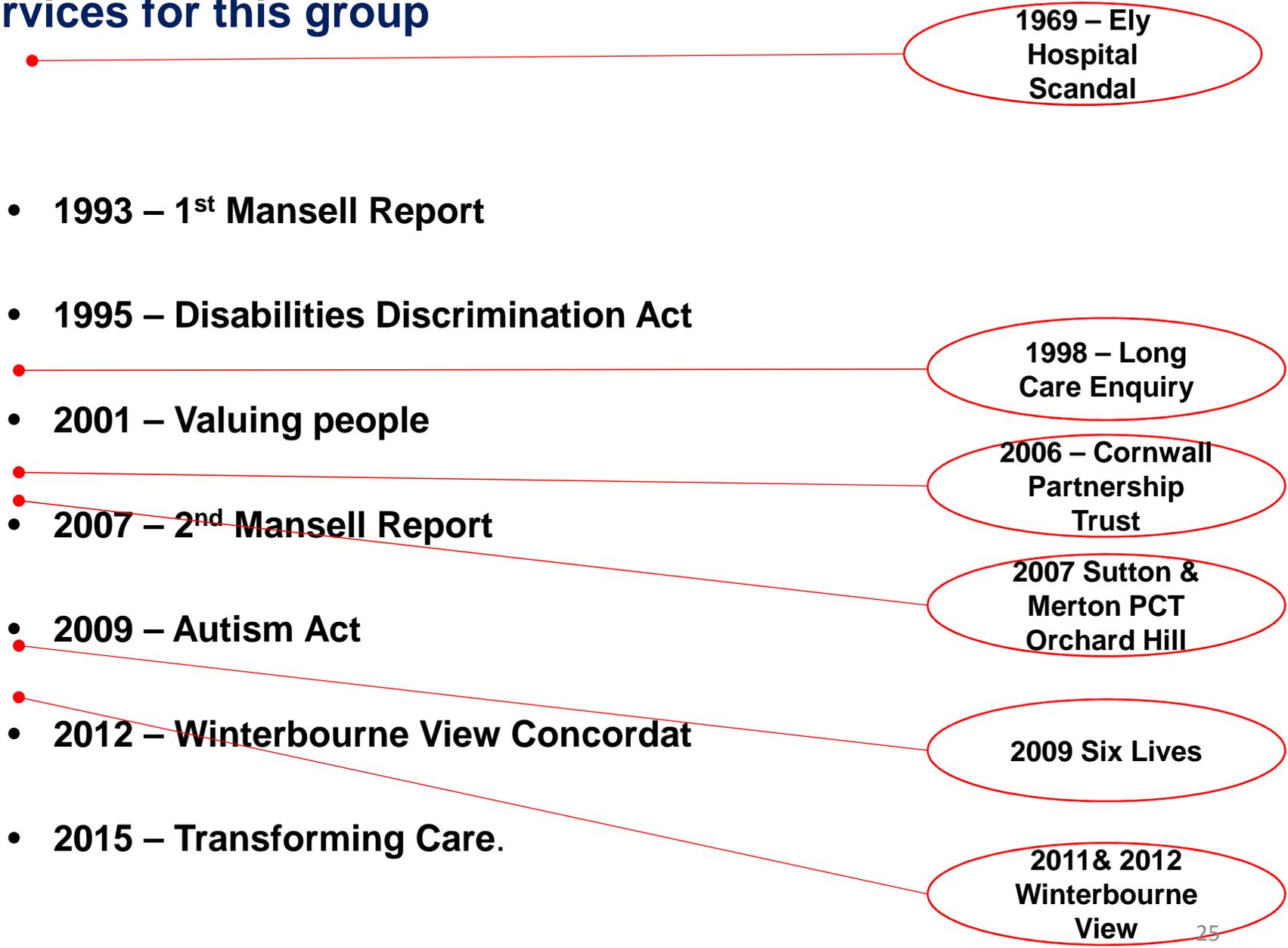
What made problems much more acute

- Late diagnosis
- Not fitting neatly into any service
- The long term consequences of missed opportunities – should never need to enter a AMHU or Care system. Very restrictive, very traumatising.

Not all, some things worked well:

- Experienced CAMHS clinician made home visit
- Being able to go to a local inpatient bed
- Social Care have helped with a different range of strategies – a bit 'hit and miss' though but it does show the value of not working on deficits model just focussing on enabling (but knowing he is autistic is essential)

National policies have not delivered consistently good services for this group



Questions/ discussion

More information

National policies and initiatives

1993 – 1st Mansell Report, the key good practice guidance document for those with responsibility for supporting people with learning disabilities or autism and behaviour that challenges.

1995 – Disabilities Discrimination Act, made it unlawful to discriminate against people in respect of their [disabilities](#) in relation to employment, the provision of goods and services, education and transport. (Superseded by the Equalities Act)

2001 – Valuing people, strategy to improve lives of people with LD. Included a five year programme of work.

2007 – 2nd Mansell Report, updated 1st report in the light of Valuing People

2009 – Autism Act, first ever disability-specific law. Duties on Government to produce strategy and guidance for adults with Autism

2012 – Winterbourne View Concordat, agreement across health, social care and voluntary sector to programme of change to transform health and care services for people with LD and/ or autism and closure of inpatient services

2015 – Transforming Care.

Service failures

- **Ely Hospital Scandal 1969 – Systematic physical abuse**

Web link to committee <http://www.sochealth.co.uk/national-health-service/democracy-involvement-and-accountability-in-health/complaints-regulation-and-enquiries/report-of-the-committee-of-inquiry-into-allegations-of-ill-treatment-of-patients-and-other-irregularities-at-the-ely-hospital-cardiff-1969/>

(The first major care scandal in the NHS)

- **Long Care Enquiry 1998 – Physical and sexual abuse**

Web link to inquiry report: <http://www.hampshiresab.org.uk/learning-from-experience-database/serious-case-reviews/long-care-inquiry-buckinghamshire/>

- **Cornwall Partnership Trust 2006 – Physical and psychological abuse**

Web link to inquiry report: http://image.guardian.co.uk/sys-files/Society/documents/2006/07/04/CORNWALLFINALREPORT_embargoed5July.pdf

Service failures

- **Sutton and Merton PCT Orchard Hill Hospital 2007 – Physical and sexual abuse**

Web link to enquiry

report: http://webarchive.nationalarchives.gov.uk/20060502043818/http://healthcarecommission.org.uk/db/documents/Sutton_and_Merton_inv_Main_Tag.pdf

- **Six Lives – Investigations by the Health Ombudsman, made at the request of Mencap, of the deaths of six people with LD whilst in NHS or local authority care.**

Weblink to report:

http://www.ombudsman.org.uk/data/assets/pdf_file/0013/1408/six-lives-part1-overview.pdf

Key documents

Building the Right Support (NHS England, ADASS, LGA) -

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

Building the Right Support, National Service Model (NHS England, ADASS,

LGA) - <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

Winterbourne View: Time for Change – the challenge ahead -

https://www.acevo.org.uk/sites/default/files/ACEVO_report_TCA_final_web.pdf

NHS England website -

<https://www.england.nhs.uk/learningdisabilities/care/>