Transforming care – what makes a difference?

This briefing paper sets out:

1. The background to meeting the needs of this group of children, young people and adults:
    - 1.1 What research tells us about meeting their needs
    - 1.2 A brief history of the Transforming Care (TC) programme.
2. What we know about the TC programme from
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1. Background

In the past children and adults with learning disabilities, especially those who displayed behaviour described as challenging, were segregated and institutionalised in long stay learning disability hospitals. In the 1970's following many scandals that exposed abusive practice, *Better Services for the Mentally Handicapped* (DH 1971) was published and there was a closure programme that aimed to move people out from institutional hospital care and into the community.

People who were considered more complex however, tended to end up in "campus" provision- often purpose built accommodation in hospital grounds – effectively still living in hospital. In 2006, in *Our Health, Our Care, Our Say*, the Department of Health made a commitment to close campuses by 2010, and with funding of £186m allocated in 2007, to move the people in campuses into personalised accommodation with the right support in the community. The Campus Closure programme was implemented through the *Valuing People Now* (2009) programme.

However, as the *Mansell Reports* (DH 1993, 2007) pointed out, despite knowing how to support these individuals, including children (*Don't Forget Us*, MHF 2007) the "system" continued to fail to adapt to meet the needs of individuals who display challenging behaviour – a typical approach continued to be to try and fit people in to what was already available, and when this failed to "put" people wherever there was a place that would take them. Coupled with a crisis management rather than an early intervention approach, often this resulted in out of area, high cost services that grouped people with complex needs and behaviour that challenges together. These services were often hospital, or "assessment and treatment" units (many privately run), where they stayed for many years at high cost and with little assessment, treatment or therapeutic input (*Transforming care: A national response to Winterbourne View Hospital* DH 2012).

1.1 Research – what do we know about meeting people's needs

Considerable research into the needs of individuals with learning disabilities who display behaviour described as challenging has established that:

- Relative to typically developing peers, children and adults with learning disabilities are at increased risk of displaying challenging behaviour. This is evidenced from an early stage (when children are under 5 years of age). Without effective support challenging behaviours tend to persist
- Challenging behaviour is best seen as a result of the complex interaction of personal, environmental, biological and developmental factors and should not be seen as a "diagnosis"
- Directly helping families of children and adults with learning disabilities is crucial to ensure that they can provide capable and supportive environments for individuals whose behaviours challenge and to ensure a good quality of life for all
- Many challenging behaviours, or the factors contributing to challenging behaviours, emerge early in the lives of children with learning disabilities; so, early intervention is crucial
- Such behaviour is often responded to in highly restrictive ways including the extensive use of physical intervention and chemical restraint
- Challenging behaviour is a significant risk factor both for abuse (often in the context of staff/carers not receiving the support they need to respond more appropriately) and exclusion from local communities into institutional care provision
- Challenging behaviours pose a significant risk to the emotional wellbeing and quality of life of family caregivers. The emotional wellbeing of caregivers can also in turn influence the way they support a family member with implications for the development of challenging behaviour
- The development of more humane and appropriate ways of responding to challenging behaviour requires the employment of personalised assessment strategies that seek to identify the function(s) the behaviour serves and the broader context within which it occurs
- Positive behaviour support is the best-evidenced approach to employing such assessment strategies and using the information they generate to put arrangements in place that both reduce the occurrence of challenging behaviour and promote a good quality of life for the individual
- Such personalised approaches will work most effectively in "capable environments" that are designed to minimise the likelihood of challenging behaviour being displayed
- With the right supports the vast majority of people whose behaviour is described as challenging can live full lives in community settings.

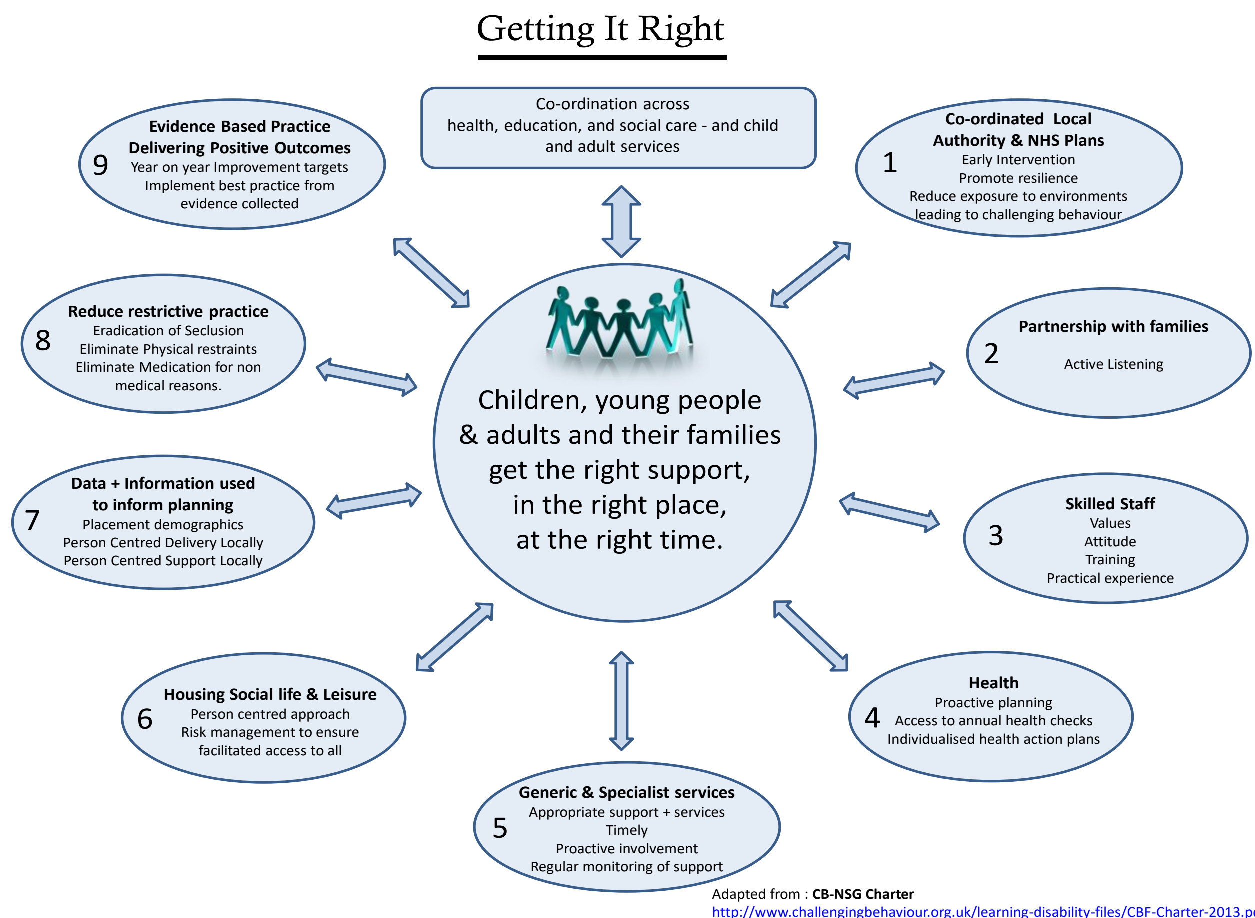
There is much recent and ongoing research that is relevant to the Transforming Care programme including:

- Prevention of challenging behaviour in residential settings (McGill et al, 2012-16, funded by NIHR SSCR)

- Transition from residential educational settings (McGill et al, 2016-18, funded by NIHR SSCR)
- Training staff in more empathic reactions (*Who's challenging who,* Hastings et al, 2015-17, funded by NIHR SSCR)
- Clinical and cost effectiveness of staff training in positive behaviour support (Hassiotis et al, 2012-17, funded by NIHR HTA)
- Early positive intervention with parents of children at risk of challenging behaviour (Gore et al, 2012-15, funded by Patricia Collen Memorial Trust)
- Increasing the quality of health service support for children with intellectual and developmental disabilities who display behaviour problems (Gore et al, 2015-19, funded by NIHR)
- Early Positive Approaches to Support (E-PAtS) for families of young children with intellectual disability: Feasibility study (Hastings et al, 2018-19, funded by NIHR PHR)
- Family based support to build capacity and resilience in family carers of adults with learning disabilities and challenging behaviours: Collaborative research (Cook et al, 2016-18, funded by NIHR RfPB)
- Early years' parenting and the behavioural development of children with an intellectual disability (Totsika et al, 2016-18, funded by the Baily Thomas Charitable Fund)

We know that it is possible to support children and adults with learning disabilities who display behaviour described as challenging well. We also know that many inter-related components need to be present in the system to enable this to happen- and that these are currently not all in place and working effectively.

In 2008, concerned at the lack of a strategic approach to meeting the needs of this group, the CBF convened a meeting of a range of senior stakeholders to ask if there was support to work together to make the system deliver better outcomes for children and adults with learning disabilities who display behaviour described as challenging. There was universal agreement and the Challenging Behaviour National Strategy group (CB NSG) was formed. CB NSG members co-produced a charter which set these component parts out:



The Transforming Care programme, as a result of abuse uncovered by Panorama at Winterbourne View Hospital in 2011, provided an opportunity to address these systemic issues as part of a co-ordinated, evidence based, change management programme. In 2012 CBF and Mencap produced an Out of Sight Report (http://www.challengingbehaviour.org.uk/learning-disability-files/Out-of-Sight-Report.pdf) that set out the systemic issues and the changes needed.

The Transforming Care Programme has consistently failed to meet its targets. It is entering its final year, and this paper has been produced to draw together what we know to enable an evidence based, informed discussion about what needs to happen next, and beyond March 2019.

1.2 Brief History of the Transforming Care programme and leadership

In May 2011, the BBC broadcast a Panorama investigation “Undercover care” which exposed, through secret filming, people with learning disabilities being abused by staff who were paid to support them in Winterbourne View, a private hospital run by Castlebeck Care (http://www.bbc.co.uk/news/uk-england-bristol-20078999 , documentary at: https://www.youtube.com/watch?v=m1b5M123Zdo). There was public shock and outrage, and a criminal investigation resulting in convictions and prison sentences. The scandal exposed significant systemic failures – people with learning disabilities were being channelled into inpatient services, often at high financial cost, which delivered poor outcomes and which, as the late Professor Mansell

put it, were being used as "dumping grounds which are damaging people". The Care Quality Commission carried out a Learning Disability Review (http://www.cqc.org.uk/sites/default/files/documents/cqc_ld_review_national_overview.pdf) of 150 similar services- and 48% failed to meet CQC's basic standards of care and welfare and safeguarding. The Government committed to action to address the systemic issues that were exposed, and published an interim report in June 2012, followed by a final report in December 2012 which had an accompanying Concordat with 63 actions (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf). This report committed a programme of action (and £2.86m) and to reviewing every person with a learning disability in an inpatient setting by **June 2013**, with everyone who was inappropriately placed to be moved out by **June 2014**.

In January 2013 the LGA-led Joint Improvement Programme was set up and tasked with delivery of the Transforming Care actions. Programme progress was slow and targets were missed. Two successive Programme Leads were appointed over the course of 18 months, but each resigned after a few months in post. There was a failure to meet the 2014 deadline.

A National Audit Office investigation (Report at: https://www.nao.org.uk/wp-content/uploads/2015/02/Care-services-for-people-with-learning-disabilities-and-challenging-behaviour.pdf) , a Public Accounts Committee inquiry (https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2015/care-learning-disabilities-16-17/) and a NHSE commissioned review by Sir Stephen Bubb (http://www.challengingbehaviour.org.uk/learning-disability-files/Transforming-Care---Time-for-Change.pdf) all highlighted lack of programme progress. In response, NHSE became more actively engaged and in October 2015 "Building the Right support" was published (https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf). This set out a 3 year plan to close 35-50% of inpatient beds for people with learning disabilities and develop the right support and services in the community, in line with the NHSE Service Model, by March 2019. A Delivery Board was set up which included NHSE, LGA, ADASS, the Department of Health and CQC. Despite significant efforts by many since 2011 to highlight the need to get the right support in place for children, the report did not include the DfE, Ofsted or ADCS and missed an important opportunity to commit to early intervention, prevention and a lifelong approach. 48 Transforming Care Partnerships (TCPs) were established as the mechanisms to drive change, and were tasked with developing plans to deliver the Building the Right Support commitments.

In March 2017, a follow up investigation from the National Audit Office concluded that "…the Department, and its programme partners are not yet on track to achieve value for money through the programme to close hospital beds for people with a learning disability". The recommendations from the report included addressing funding flows, workforce, data collection, community capacity and whether Care and Treatment Reviews (CTRs) lead to discharge into community provision.

In January 2018, Ray James (former ADASS representative on the Transforming Care Delivery Board) was appointed as the NHSE lead for Transforming Care. In March 2018 Ray set out in a letter that

NHS commissioners plan to decommission "just over 900 beds previously used by patients with a learning disability, autism or both" over the course of 2018/19, and to "publish more detailed, provider-level plans for bed closures in the spring of this year."

Since the start of Transforming Care there have been **six different ministers** with responsibility for social care (and the Transforming Care programme). The Ministerial responsibility for social care has been consistently demoted, from a Ministerial position in 2012 to part of a Junior Minister role in 2017, but in early 2018 the role was upgraded. Caroline Dinenage is the current Minister – she is Minister for Health and Social care.

2. What do we know about the impact of the TC programme?

2.1. What do we know from evaluations / investigations

BTRS NHSE evaluation

NHSE commissioned an evaluation of "Building the Right Support" (BTRS). The evaluation team developed a survey and will carry out in depth interviews with 10 sites. The survey was for "everyone who might have a view about their local TCP", but the response rate was very low- 232, with the majority from people employed in the learning disability field.

Key findings published so far are:

- Some people have moved out of Assessment and Treatment Units (ATUs) and live closer to family and friends
- Some TCPs are listening and planning with people and families
- New services are stopping people being sent into ATUs
- Some TCPs are improving their care and support so that people have better lives
- Having experts by experience have helped in Care Treatment Reviews
- Too many people are still stuck living in hospitals away from family and friends
- It is hard to recruit the right staff with the right skills and values
- TCPs can struggle to involve people and their families
- Finding the right houses and homes is difficult
- There has been slow progress in developing great services in local communities

NIHR survey of Directors of Social Care

Research interviewing Directors with responsibility for social care has been carried out – the work is being written up but is not yet published.

Evidence from families -Transforming Care: our stories

From September 2016, the National Autistic Society and Mencap, with the support of the Challenging Behaviour Foundation, interviewed the families of individuals in, or at risk of being in inpatient care. Thirteen families across England, of different ages and backgrounds and with very different needs were interviewed. They all shared similar concerns that their loved ones wellbeing was deteriorating and their needs were not being met. The resulting Transforming Care Our Stories report outlines serious failings of care including incorrectly supplying heavy doses of anti-psychotics when no psychosis was present, unnecessary use of restraint and a lack of staff trained in

autism. It also shows that the biggest challenge facing the families was the lack of appropriate services available in the local community.
The Transforming Care Children and Young People team commissioned the Council for Disabled Children, Barnardos, Kids and the Challenging Behaviour Foundation to hold focus groups and interviews with children and young people and their families about their experience of Transforming Care. This research is yet to be published.

Workforce evaluation
In 2016, HEE and the Royal College of Psychiatrists commissioned a report into the likely required NHS community workforce numbers as a result of Transforming Care. The work has been completed, and the reports written, but they are yet to be published.

National Audit Office (NAO) reports
In 2015 the NAO published its first report on the Transforming Care programme which was highly critical of the lack of progress which it described as "poor". The subsequent Public Accounts Committee made recommendations regarding initiating a closure programme, better commissioning, improving data collection and addressing funding flows.
In 2017, there was a follow up NAO investigation which concluded that although there was now a "solid basis for the programme" a number of unresolved complex challenges remain, namely: the funding flows, lack of evidence that the CTR process delivers the intended outcomes, lack of attention to workforce issues, continued issues with data collection and lack of development of community capacity.

Other NAO reports identify relevant issues for the programme, including their report on the social care workforce (nao report/the-adult-social-care-workforce-in-england), and the funding of social care (nao financial-sustainability-of-local-authorities-2018).

2.2 What do we know from data collections

There are a range of data sources that have the potential to be used for evidence of what is working and to identify priority areas to target input for maximum impact. It is important that these are brought together for a "complete picture" and analysed, but it is not clear who is doing this. The Transforming Care programme appears to focus only on inpatient numbers which are published- and it is difficult to see how this data is analysed to inform the programme.

Following the terrible revelations of institutional abuse at Winterbourne View, it was revealed that little to no data was held on people with learning disabilities. As a result, the Learning Disability Census, an existing annual data collection from providers that was due to come to an end, was reinstated. In January 2015, the Assuring Transformation dataset and Mental Health Services Data Sets (MHSDS) took over from the Learning Disability Census, as part of the Transforming Care programme emerging from the Building the Right support plan. As the Transforming Care programme nears its end in March 2019, it is hoped that the Mental Health Services Dataset will be developed to be the primary source of data.

The inpatient data tells us:
The numbers of people with learning disabilities in inpatient settings has not decreased significantly since the start of the TC programme, and the rate of decrease is slow.

- The number of children in inpatient setting has increased and has recently been higher from ever (240 as of February 2018) – this has more than doubled since March 2015, when the figure was 110.
- In March 2015, the average length of stay in an inpatient unit was 1,934 and in February this year was 1,972, showing an increase since the implementation of Building the Right support.

NHSE has stated that it plans to decommission just over 900 beds in the next 11 months. It is not clear if those individuals will move into community provision. If this is the case this will be a very significant and rapid increase in discharges given the rate of discharge over the last 7 years.

Data is no longer collected regarding:

- Restrictive intervention and adverse events

Data around restrictive intervention and adverse events is being collected in the Mental Health Services Data Set (MHSDS) but is not being published. As a result, there has not been any data published on this issue since December 2015 (the last Learning Disability Census). Importantly, this data should be broken down by age group, as the last Census showed that under-18s were the most likely age group to have experienced both adverse experiences and restrictive measures during the last three months.

- Use of antipsychotic medication and rapid tranquilisation

Data on use of antipsychotic medication and rapid tranquilisation was in the last Learning Disability Census (December 2005) but it is not being collected or published in the MHSDS. It is difficult to understand why this data is no longer considered important when NHS England has pledged to address the overmedication of people with a learning disability through the STOMP initiative, but will be unable to measure progress for this population without this data.

- Cost of in-patient placements

Data around the cost of in-patient placements was included in the Learning Disability Census in 2015 – however, it is not collected or published in the MHS dataset. It is important that this data is collected and published, to change commissioning practices, especially when considering cost versus outcomes for people in inpatient units and in the community.

In addition there are concerns about:

- Data submitted by independent providers

Independent providers are required to submit data on patients funded by the NHS to the MHS dataset. However, there is currently a lot of missing data in the collection.

- CTR information in Assuring Transformation data

Currently, it is unclear how many people who have had a CTR recommending discharge go on to be discharged. Though information on the number of CTRs, numbers of individuals with discharge plans and reasons for delayed discharge are published, it is important that this data relates to outcomes as well as processes. The CBF has suggested that the data reports how many people who had a CTR 6 months ago recommending discharge have been discharged and that it also shows how many people who had a CTR 12 months ago recommending discharge have been discharged. Data collection is a way to drive practice. Requiring collection of this information would encourage timely discharge.

- Number of people with a learning disability and/or autism in in-patient units

The Assuring Transformation dataset and the MHSDS dataset give very different figures for the number of people with a learning disability and/or autism in inpatient units. This issue was highlighted in the most recent NAO report on local services for people with a learning disability (2017): 'Programme partners need to develop a thorough understanding of why the two data sets have different patient numbers, in particular, why one shows a decrease in patient numbers and the other an increase. These two data sets should be reconciled'.

Children and young people data

In 2013 The Department of Health funded the Challenging Behaviour Foundation and the Council for Disabled Children to work in partnership on a three year project focussed on early intervention for children with learning disabilities whose behaviours challenge. This involved: convening a group of academic experts to review the data and the research evidence; focus groups with families to understand "what works" and; identification of best practice. The resulting publication "*Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge*" summarised the findings:

- Around 42,000 children in England have learning disabilities and display behaviours that challenge, a smaller number have severe learning disabilities;
- In addition to the children living in Assessment and Treatment Units, many children with statements for learning difficulties or ASD were boarding in residential special schools in 2014.
- The annual cost of keeping a child in an inpatient unit is £250,000. Children in residential schools are likely to go on to residential care as an adult. The annual service cost for an adult who displays severely challenging behaviour is £379,000
- Following a review of the evidence, the academic expert group recommended five components of better local support for children:
    - A person centred approach right from the start, involving a key worker or team around the child;
    - Early identification and rapid response;
    - Evidence based parenting support;
    - Local PBS services working across home and school;
    - Local crisis prevention approach.

The Transforming Care data collections identify high numbers of 19-24 year olds who are in inpatient services.

CQC data and information

CQC collect a significant amount of data and information through their regulation and inspection/registration roles.

CQC Ratings: The current CQC ratings for services for people with learning disabilities show that:

- Domiciliary care agencies and community social care have the highest proportion of services rated as good (90% and 87%) and Outstanding (both 5%).
- In residential homes 1% (37) of services are rated as inadequate.
- Ratings within adult social care services remain similar to the ratings reported in April 2017.
- In hospital services 70% of wards for people with learning disabilities are rated good and 84% of community services are rated good.
- There has been a slight increase in hospital services being rated good between April 2017 and April 2018.

Registration

There are three main areas in Registering the Right Support: opening a new specialist hospital or assessment and treatment unit; opening a new care home and change of type of activity (e.g. from hospital to care home, from care home to supported living).

The CQC have received applications in each of these three categories. Most have been considered by CQC as appropriate, but there are occasions when the CQC has refused the application. Reasons include the service being very large, or on a campus, or not required by commissioners; the location not being appropriate or the provider cannot demonstrate that they have sufficient or relevant skills; the environment is unsuitable or the provider cannot demonstrate that they will deliver person-centred care.

There needs to be clarity about what is meant by step-down and step-up, as well as emergency short term accommodation (to prevent an admission to hospital).

Inspection of services for people with learning disabilities

The CQC continues to look at how to improve the regulation and inspection of services for people with learning disabilities. In relation to improving assessment of hospital providers, the CQC are looking to use more observation to see how staff provide active support and care to people as detailed in their positive behaviour support plans.

The CQC recognises the importance of carers and families and are looking to increasing the use of experts by experience and increase the number of carers approached during inspections to understand more about people's experience of the support and care they receive.

In relation to physical interventions the CQC are reviewing how to strengthen our regulation of how staff in adult social care and hospital learning disability residential services providers use physical interventions.

The CQC are also looking at how it can make the best use of the data that they have to identify potential concerns early and inform when and how they inspect.

Safeguarding data

There is no central collection of data relating to safeguarding people with learning disabilities. Safeguarding Adults Reviews (formerly Serious Case Reviews) involving people with learning disabilities are not routinely collated to identify systemic issues and themes.

3. What do we know about the key areas of concern?

3.1 Funding flows

Immediately after the Winterbourne View scandal a range of people and organisations highlighted funding flows as one of the highest priorities to address the systemic issues. There are 3 main funding challenges relevant to Transforming Care:

- There is not enough funding available
- The funding that is available is spent on the wrong things (wrong type of service, crisis not early intervention etc)
- The funding is in the wrong part of the system and not accessible and needs to transfer from health to social care

This results in perverse funding incentives in the system – and children and adults do not get the right support in the right place at the right time.

Long term, chronic underfunding is blamed for many of the problems facing health and social care. 6 billion has been taken out of the system in the last 7 years (Housing, communities and local government committee, March 2019). Earlier this year, this committee consulted on how to fund social care sustainably for the long term ahead of the release of a government green paper.

Though money flow was identified as a fundamental, high priority area after Winterbourne View, funding issues have yet to be successfully addressed. Funding must move from NHSE specialist commissioning, to Clinical Commissioning Groups, to Local Authorities – but as yet there is no clear or quick process to do so.

The significant perverse incentives in the system include:

- The need for children's services to invest more funding in early intervention and prevention – increasing spending from children's budgets but with any financial savings likely to be to adult services budgets
- Short term, crisis management approaches – failure to provide additional resource until crisis is reached at which point options are limited and expensive (and are financed from a different source)
- Social care failures leading to crisis meaning people end up in inpatient services- which are funded by health and therefore provide a cost saving to social care
- Discharge from health provision to social care means a saving for health and a cost for social care

The 2015 Learning Disability Census (the last census carried out) (LDcensus-report-England 2015) confirmed that the average inpatient cost for NHSE provision was £3,449, and the average cost for private providers was £3,700. However, costs per week ranged from Under £1500 per week to over £6499 per week. Current costs are not collected or published in the new datasets.

Building the Right Support committed to "a new financial framework" to "underpin and enable transformation":

- NHSE Specialised commissioning budget for secure services to be aligned with Transforming Care Partnerships
- CCG's "encouraged" to pool budgets with Local Authorities (L.A's)
- People who have been inpatients for 5 years or more will have a "dowry" to contribute to "resettlement" costs. Dowries for people in NHSE commissioned places will be paid by NHSE to LAs, those in CCG commissioned places will have dowries paid by CCGs to LAs
- Transition costs (including temporary double running costs) will be met by £10m per year for 3 years transformation funding (for the 48 TCPs to bid for)
- £5m capital funding per year for 3 years will be available to the 48 TCPs to bid for

Financial flows in the system have been identified as a barrier to progress for over 6 years, highlighted in 2 National Audit Office reports and 2 Public Accounts Committee hearings. As yet this has not been resolved, but will need to be if the planned decommissioning of over 900 beds in the next 11 months takes place.

3.2 Community services

It is clear that for the objectives within Transforming Care to be met and sustained, a significant investment in the development of a range of robust and flexible community services is required. Community support and services are made up of people (in the right numbers with the right skills and expertise) and places (accommodation, short breaks, homes – individualised housing options). Generic support and services for this group should be accessible (with reasonable adjustments as required) in addition to specialist and/ or intensive support.

In 2014, the Transforming Care programme produced "Ensuring Quality Services" (ensuring-quality-services) which set out the range of support that should be available for children and young people with learning disabilities and/or autism and mental health needs. In 2015 a National Service Model (service-model) was produced which set out what every local area should have available, grouped under 9 "I" statements, and in 2017 NHSE published service model specifications model-service-spec-

In 2017 the NAO report highlighted the lack of development of community capacity by the programme. There is no source of information tracking the development of community provision against the Transforming Care Service Model. Evidence from families suggests that skilled and appropriate community support and services are lacking.

NHSE announced (March 2018) that 900 inpatient beds will close by March 2019, which will require a subsequent increase in community support.

There is no "standard offer" of access to specialist support for individuals with learning disabilities who display behaviour described as challenging, with great variation in what is available. The NHSE/ LGA/ ADASS Service Model (2015) sets out the range of local support and services that should be available in every area. It includes the statement "I can access specialist health and social care support in the community," but there is no data collected about the availability of such support. In addition, evidence suggests that key components of such support is in decline - The National Audit Office report on Transforming Care (2015) noted : 'Some specialist learning disabilities teams in the

community have been run down, which has contributed to delays in introducing appropriate care packages. This has also increased the risk of hospital admissions, and readmissions, and the pressures on hospital resources' (p36),

A survey of specialist behaviour support teams (Davison, McGill, Baker &Allen 2015) suggests a 30% decline, and a lack of availability of such support for children. As it is known that children with learning disabilities who display challenging behaviour are at greater risk of social exclusion, institutionalisation and abuse, this is of concern.

Provision for children

In 2013 The Department of Health funded the Challenging Behaviour Foundation and the Council for Disabled Children to work in partnership on a three year project focussed on early intervention for children with learning disabilities whose behaviours challenge. This involved: convening a group of academic experts to review the data and the research evidence; focus groups with families to understand "what works" and; identification of best practice. The resulting publication "*Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge*" summarised the findings. (see data section)

The evidence from the Early Intervention project led the Department of Health to commission Dame Christine Lenehan in 2016 to undertake a short strategic review in order to identify practical actions to be taken forward to better co-ordinate support. The resulting review "These are our children" published January 2017, focussed on the rights of children and made 11 recommendations for Government Departments, NHSE, Transforming Care Partnerships, Local Authorities, Professional bodies, ADCS, the LGA and others to take forward collectively. Recommendations include; a specific focus on 18-25s in residential provision, development of an effective model of care (particularly post ATU), better national and local coherence and implementation, plus further work on residential schools, workforce issues and financial incentives. The Government accepted the recommendations, with the caveat that implementation may be subject to resource constraints.

This was followed by a commission from the Department for Education for Dame Lenehan to review residential special school provision. The review "*Good intentions, Good Enough? The Lenehan review into Residential Special Schools*" was published in November 2016. The review identified that there are 334 residential special schools and colleges in the country with 4,878 children boarding and a further 1,268 boarding in post 16 specialist institutions. The report identified that 70% of all children in residential provision display challenging behaviour. For some this will be associated with autism, learning difficulties and communication difficulties and for others it will be associated with social, emotional and mental health needs. The report identified that these children require the most intensive support of any young people in the system, crossing the boundaries of education, health and care. The report set out a range of recommendations for the Department for Education, to improve leadership, standards and guidance. The Department for Education announced that it will be establishing a High Needs Board in order to take forward further action.

In March 2018, NHSE confirmed that between now and March 2019 "just over 900"inpatient beds for people with learning disabilities would be de-commissioned. It is important that a co-ordinated increase in commissioning community provision is aligned with this.

Any service (community or inpatient) should be in line with the NHSE service model, and NICE guidance. CQC consider the model as part of their review process for applications for registering new services. This addresses the issue of ensuring that new services are in line with the model, but it is known that some existing services (currently already registered) are not in line with the model of care.

Transforming Care aims to promote cultural change and although this is a laudable objective perhaps only now are we in a position to translate this into achievable objectives.

CETR's, although helpful, vary in their quality and capacity to bring an alternative response to crisis. ATU's continue to admit people with severe learning disability and or autism even when, in some cases, they have explicit admission criteria that states they should not admit. There is a failure to address, not just the decision-making, but to develop a coherent way of learning how to respond differently. When an ATU is the only alternative in a crisis it is a tragedy but if this happens a second time there is no higher level review to examine how a region is choosing to invest its resources.

It would help to have a metric that records how early identification of vulnerable people leads to more positive outcomes. For example, targeting young people approaching transition from school to adult services in time to develop a collaborative relationship with families is an obvious idea. This would mean identifying those who are vulnerable to challenging services in the future and to implement a thorough functional assessment (in keeping with NICE guidelines) and behaviour support plan, before a crisis happens. This could be recorded and reported.

There remains a lack of co-operation between child and adult services. It is known that certain combinations of need increase the chances for someone to develop behavioural repertoires that others find challenging. Once established, there will be a lifelong vulnerability requiring consistent, on-going planning to ensure the persons does not fall into crisis. Therefore, vulnerable young children will require support right through to adult services. It is imperative that no young person enters adult services without adequate preparation.

Families remain the biggest unused resource. With more thoughtful investment of support, information and collaborative learning, this could easily change.

An example of good practice is the new STOMP initiative in Sunderland which is proving successful in demonstrating that it is possible to reduce anti-psychotic medication for adults who had been prescribed them for their behavioural challenges, without any increase in behaviours of concern. This has been achieved through the co-ordinated work of a specialist PBS team, psychiatry and pharmacist. As one might expect, this takes time. In the mean-time there is a danger that some doctors are reducing medication without the necessary planning

3.3 Housing

Challenging Behaviour Foundation
www.challengingbehaviour.org.uk

(Independent overview of how the Transforming Care programme is progressing with housing -Alicia Woods.) There is no up to date data about housing need and delivery so conclusions are drawn from experiences of working with TCPs, conversations with national & local NHS housing leads and data from NHS monthly statistics https://digital.nhs.uk/catalogue/PUB30227)

The number of places in inpatient units seems to be increasing. In 2015/16, there were 4.8 places in these units per 100,000 of the general adult population – in 2017 this increased to 6.4 places per 100,000 population. Since March 2017, 100 people were discharged into the community but the population in inpatient units remains fairly static because of continuing admissions.

The only reliable figure available for housing need is in the housing guidance Building the Right Home, which states that at the time of publishing (December 2016), 2400 people required accommodation by March 2019. The majority of TCPs either have a housing plan or a draft one. According to the Transforming Care team, 38 of 48 TCPs have a housing plan, although that figure is likely to be higher and some of the housing plans have gaps in them.

Overview of delivery of housing for Transforming Care

1. **Transforming Care policy and guidance on housing** is good- national leadership is strong and now there are new posts with a regional focus. NHSE housing leads have an in depth understanding in terms of what housing is needed and are very clear about the need for person centred approaches to housing. However, the central TC team have no real authority over what TCP's do, and within TCP's there are some areas that are very strong on housing and other's that aren't.
2. **Availability and flexibility of capital** £20m capital was made available early on in programme but this has not been fully taken up (no figures available) because TCPs weren't ready and did not have robust plans in place. Even if it had been, it would not meet the housing needs of 2400 people and additional capital investment is needed.
   An additional challenge with take-up of capital is the necessary legal charge that NHSE has to place on properties, which makes any partial investment in these unattractive to a private investor, hence the capital only really works if used to fund a project in entirety.
   Where private investment (sometimes masked as social investment) is sought, a mix of the high returns needed on investment (6% or more) and investors wanting 20 year + agreements with service providers/Local authorities and lease agreements with housing providers. This creates high and unsustainable rents and requirements for contractual agreements that aren't do-able or sustainable. Meanwhile, more traditional housing associations have had to be more careful with their money and although they deliver affordable rents, they usually can't meet bespoke needs and their properties often aren't appropriate for the individuals still in hospitals for a variety of reasons. These different approaches to sourcing capital contribute to an inability to develop housing in a very planned and person-centred way.
3. **Some good housing has been developed**, mainly where commissioners and providers with experience of developing community solutions are working and already have the knowledge and contacts to deliver person centred approaches to housing. Because of the time required to develop bespoke solutions, it would be expected that examples of these are only coming to light at such a late stage of the programme.

Even where there is good commissioning, it has been difficult to make individual housing solutions work in a timely way. Commissioners and providers are unused to developing highly bespoke arrangements- it doesn't fit easily with commissioning and procurement practices.
Some of the challenges in securing individual property for bespoke needs come from approaching the care provider first and the care provider sourcing the accommodation. The specification for the accommodation is often very particular, which can be impossible to find in London and other high cost/sought after areas.
Despite the difficulties, there are some incredible stories emerging of people getting their own homes, being happy and defying everybody's expectations of them.

4. **Some institutional models are being developed** It seems that where there is less experience of developing community solutions, there has been a default to 'safe' models such as step down facilities – I have concern about some of these and whether they are just creating another layer of unnecessary service when people would fare better in bespoke solutions. LDE has challenged some of these developments publicly but it is too late once they are already at the stage of publicising a new scheme. It requires pressure and challenge from a place of authority and this does not seem to be happening.
5. **Uncertainty around funding for supported housing - t**he uncertainty around housing benefit for supported housing brought development to a standstill for some time- proposals have been made for the new funding model and in theory it should not affect much of the housing required through transforming care in the future. Whilst the sector waits for confirmation of policy, there is cautiousness in developing housing.
6. **Lack of understanding of community based solutions** There are still perceptions and a fear that individual housing solutions are unsafe for people with very challenging behaviour and therefore there is still a reluctance to develop them.
7. **Planning and commissioning needs to change** To deliver housing across a TCP requires an ability to both work strategically and in a person centred way to meet the needs of this particular group. TCPs need to be able to plan for the medium to long term and deliver solutions for people being discharged within weeks and months. No one housing solution will meet the needs of all people and a range of options are required, sometimes across a wider area than LA/CCG boundaries.
People also need housing that is not tied up with a support package and be able to remain in their homes if their support arrangements change- this requires a different practice from commissioning and procurement. TCPs are new partnerships, some of which are functioning well and some aren't but they are all relatively new with ever changing personnel and it is not easy to bring all those involved along to deliver housing in a timely way.
The delivery of housing will only be achieved with stronger partnership working between care providers and housing providers, as well as commissioners and local housing teams. Alliance approaches that bring housing providers to the table at an early stage to help commissioners develop a broad range of immediate and medium to long term solutions is required. At least one TCP is trialling an alliance approach but this is not on most TCPs radars and the regional TC housing leads are trying to do something to promote this approach.
8. **Housing requirements are not getting in to discharge plans** Where people are planning to move, they need housing built into discharge plans at an early stage and sometimes it is not until the person is considered 'fit for discharge' that housing is then thought about. There is a general lack of knowledge about housing and most levels in health and social care those

facilitating planning and discharge plans do not have the experience of confidence to create robust housing plans.

9. **People with mild learning disabilities, autism and offending behaviour** This group are the more difficult to discharge. People with mild or no learning disabilities, autism and offending behaviour have a whole different set of needs and vulnerabilities to most people that require housing under the TC programme, and hence additional complexity in terms of housing needs

3.4 Workforce

A workforce with the skills required, in sufficient numbers and located where they are needed, is crucial to getting the right support in the right place at the right time for children, young people and adults with learning disabilities who display behaviour described as challenging. Positive Behaviour Support (PBS) is the best-evidenced approach to employing assessment strategies and using the information they generate to put arrangements in place that both reduce the occurrence of challenging behaviour and promote a good quality of life for the individual. PBS is a multicomponent framework for developing an understanding of behaviour that challenges.

A workforce across education, health and social care settings with the right values, skills and capacity is crucial for the system transformation set out in Building the Right Support. The workforce includes: families and unpaid carers, education staff, health staff and social care staff –within children's and adult's services - and different organisations have workforce responsibility within the different parts of the system. A co-ordinated approach is required to recruit, train and support staff with the right skills and experience to meet the needs of children and adults with learning disabilities who display challenging behaviour.

A recent National Audit Office report (2018) Adult-social-care-workforce-england flagged the whole adult social care workforce as a concern: "The Department of Health and Social Care is not doing enough to support a sustainable social care workforce. The number of people working in care is not meeting the country's growing care demands and unmet care needs are increasing." If the aims of Building the Right Support are to be met and people with learning disabilities are supported within their local communities rather than in inpatient settings, there must be sufficient capacity and capability within the social care workforce.

The NICE clinical guideline (2015) on challenging behaviour (https://www.nice.org.uk/guidance/ng11) states that "Health and social care provider organisations should ensure that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of behaviour that challenges" and " Health and social care provider organisations should ensure that all interventions for behaviour that challenges are delivered by competent staff."

In 2016, a *Learning Disabilities Core Skills Education and Training Framework* was produced: (https://www.cppe.ac.uk/wizard/files/publications/leaflets/learning%20disabilities%20cstf.pdf

Every TCP should have a plan to deliver Building the Right Support, and this should include a plan to ensure an appropriately skilled workforce to meet the needs of children and adults with learning disabilities who display behaviour described as challenging. The workforce to deliver the

Transforming Care programme was identified as a risk by the National Audit Office (2017) as workforce plans are not timed to deliver a workforce within the community to support the number of people moving out of inpatients settings (as set out in Building the Right Support) by March 2019.

NICE guidance (2018) on the services to support children and adults with a learning disability who display behaviour described as challenging (https://www.nice.org.uk/guidance/ng93) includes workforce recommendations, including a lead commissioner with expertise who works across child and adults services with responsibility for this client group.

HEE has published a guide for Transforming Care Partnerships about the care roles needed to deliver Transforming Care : HEE Care Roles.pdf

In 2016, HEE and the Royal College of Psychiatrists commissioned a report into the likely required NHS community workforce numbers as a result of Transforming Care. The work has been completed but not yet published. This year Health Education England (HEE) released a draft health and care workforce strategy '*Facing the facts, shaping the future*' for consultation, and Skills for Care released a consultation about the adult social care workforce to feed into this. HEE's draft strategy noted that while numbers of staff in the NHS are increasing on the whole, numbers of Learning Disability Nurses are declining - there are 842 fewer learning disability nurses (36.5% decrease) than in 2012.

PBS Academy

Working as an informal collective of experts in Positive Behavioural Support, the PBS Academy (http://www.pbsacademy.org.uk) has worked with a variety of stakeholder groups (people with learning disability, direct support staff, family carers, commissioners, service providers) to develop and issue guidance and practical tools designed to increase understanding and improve the quality of PBS in the UK. The resources are all free to download and have been issued under a Creative Commons License so that they can be adapted and shared by others. The latest guidance available from the PBS Academy are Standards for PBS provider organisations/teams and for organisations/individuals offering training in PBS.

Partly following on from the work of the PBS Academy and others to generate interest in raising standards of PBS in the UK (through training, workforce development, and other means), a PBS Alliance is in the process of being established. This is being developed through the leadership of BILD, Ambitious about Autism, and the PBS Academy along with other partners. The stated core purpose is: "To develop a shared understanding of PBS, improve the quality of PBS training, support the implementation of PBS across the education, social care and health (including understanding of commissioners and regulators) in order to achieve our vision." The vision is in two parts: "People with learning disabilities and/or autism (and their families and carers) have a good quality of life, and The workforce is well trained, well led and well supported and has the skills necessary to meet the needs of the people they are supporting within community settings and schools". It is not yet clear how the PBS Alliance will develop and what impact it might have. However, the focus is very much on workforce skills.

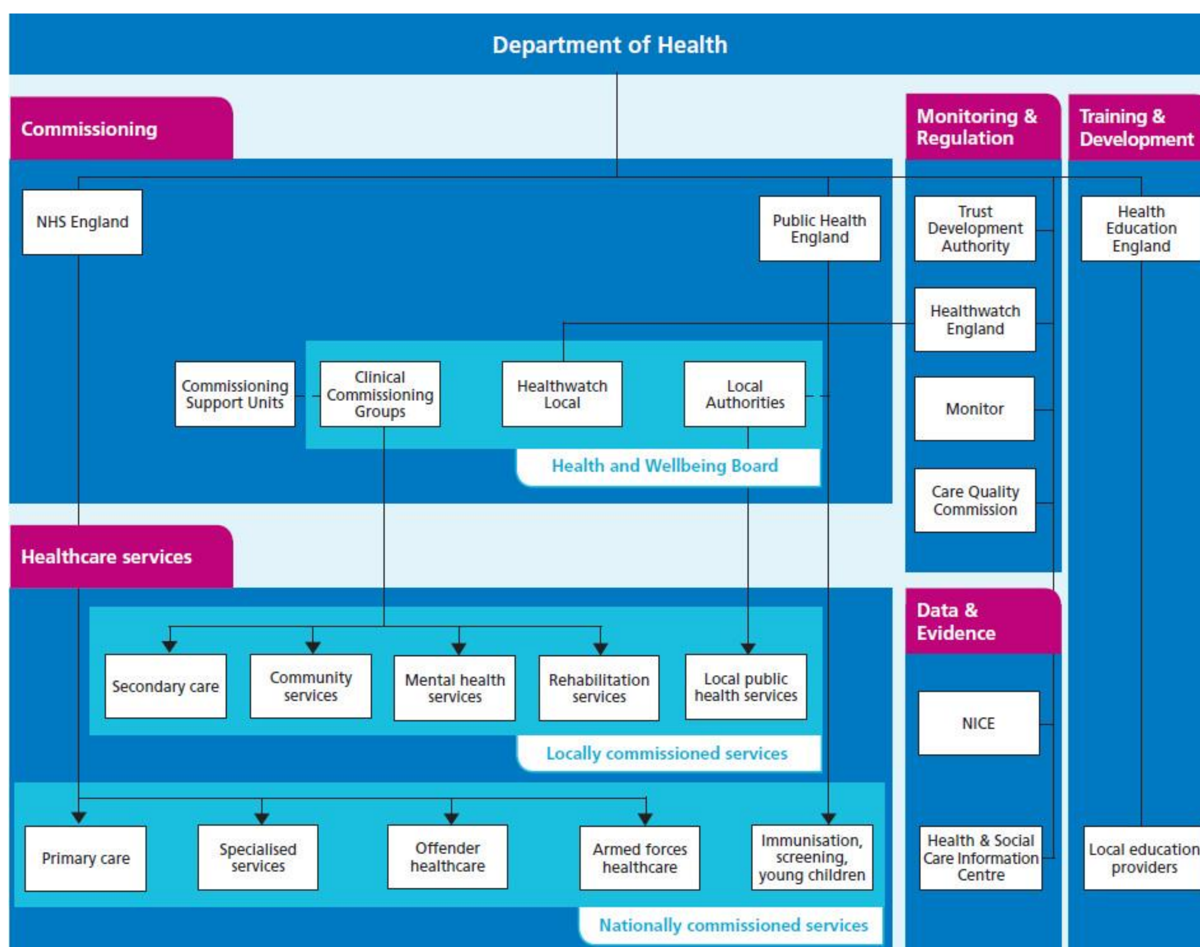
HEE children's workforce review

A specific piece of work has been commissioned to respond to the workforce recommendations in the Lenehan report. An Expert Advisory Group (EAG) was convened by the National Workforce Skills

Development Unit (NWSDU), Tavistock & Portman NHS Foundation Trust. The EAG comprised mainly professionals and met three times during January-March 2018 in order to advise HEE on the development of a workforce implementation plan, in response to the Lenehan Review recommendations 5 and 10. Tavistock and Portman engaged families as part of this review to seek their views on workforce issues. The draft report is out for consultation and is likely to be published in May 2018.

3.5 Leadership

The Transforming Care programme is a complex change management programme attempting to drive system change across multiple agencies including education, health and social care, for children and adults with learning disabilities who display behaviour described as challenging. Strong and co-ordinated leadership is required at a National, Regional, Local and Individual level - and within all components of the programme. For example, the health system has complex component parts (as described by HEE):



Social Care and Education are also complex systems. Strong leadership is essential to ensure that the Transforming Care objectives and commitments are visible, coherent and that there are clear lines of accountability.

Leadership has been defined as the art of motivating people to a common goal. For complex programmes such as Transforming Care leadership includes ensuring all organisations involved are working in a co-ordinated, collaborative and coherent way towards that goal, and are clear and transparent, maintain high standards, communicate effectively and work strongly together.

In January 2013, following the Transforming Care report (2012), the LGA-led 'Joint Improvement Programme' was set up and tasked with ensuring delivery of the actions. Programme progress was slow and targets were missed. In the first 18 months, two successive programme leads were appointed but each resigned after a few months in post. There was a failure to meet the June 2014 deadline to move people out of inappropriate inpatient provision and into community placements.

Since 2012, there have been many changes to the Government responsibility for this programme.

- From **May 2010 – September 2012** Paul Burstow appointed as Minister of State for Department of Health
- From **September 2012 – May 2015**, Norman Lamb was appointed *Minister of State for Care and Support*
- From **May 2015 – July 2016**, the role was rephrased to *Minister of State for Community and Social Care* and held by Alistair Burt
- In July 2016, the role was **downgraded** to *Parliamentary Under-Secretary of State for Community Health and Care* and held by David Mowat
- In **June 2017**, the role was **downgraded again** to a Junior Minster position - *Parliamentary Under-Secretary of State for Care and Mental Health*. It was held by Jackie Doyle-Price
- In January 2018, the role was **upgraded** to Minister of State for Social Care and is now held by Caroline Dinenage

Numerous reports were critical of the lack of progress of the programme (e.g. https://www.nao.org.uk/wp-content/uploads/2015/02/Care-services-for-people-with-learning-disabilities-and-challenging-behaviour.pdf https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/news/care-people-learning-disabilities-evidence-session/) http://www.challengingbehaviour.org.uk/cbf-articles/latest-news/bubb-report-published.html) In response, NHSE became more actively engaged and in October 2015 "Building the Right support" was published (https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf), a 3-year plan to close 35-50% of inpatient beds for people with a learning disability and develop the right support and services in the community by March 2019. A Delivery Board was set up which included NHSE, LGA, ADASS, the Department of Health and CQC, but did not include DfE, Ofsted or ADCS and missed an important opportunity to commit to early intervention, prevention and a lifelong approach. 48 Transforming Care Partnerships (TCPs) were established as the mechanisms to drive change, and were tasked with developing plans to deliver the Building the Right Support commitments.

In January 2018, NHSE appointed Ray James (former ADASS representative on the Delivery Board) to lead the Programme.

Leadership (individual, local, regional and national) is required from different parts of the system and from different stakeholders including:

- People with learning disabilities and their families
- Education
- Social Care
- Health
- Providers of services
- The workforce
- National Government
- Local Government
- Charities and voluntary groups

4. Opportunities / Frameworks for Driving change

a) NICE Guidance

There are now several national guideline documents for health and social care settings that have been developed through the rigour of the National Institute for Health and Care Excellence (NICE) process that are directly relevant to behaviours that challenge. Most directly relevant are the **clinical guideline on challenging behaviour (2015**), and **the service models guideline (2018**). Commissioners and providers are meant to use NICE guidelines to inform their work. Recommendations especially in the service models guideline are very relevant to the work of the NSG and closely aligned to Mansell report recommendations. Thus, there is a real opportunity to use NICE recommendations and the implementation of NICE guidance to influence change. A difficulty is that it is unclear whether/how these guidelines might apply to education settings. In essence, they do not apply in education settings – thus potentially hampering lifespan integrated support for people and their families.

Other NICE clinical guidance includes some reference to behaviours that challenge and recommendations include the use of functional assessment in particular (i.e., Autism adult and child guidelines). The 2016 Mental health/learning disability clinical guideline also includes recommendations consistent with challenging behaviour guidelines in terms of choice, independence, personalised approaches, and working in partnership with family carers as well as the need to offer support to family carers. Thus, a broader change in learning disability/autism services driven by a wider collection of NICE guidance could represent a significant opportunity for the NSG.

b) SEND reforms

The Children and Families Act 2014 brought in a number of changes to way the Special Educational Needs and Disability system operates. More detail is set out in the Code of Practice. The main changes included:

- Replacing the statement of special educational needs with Education, Health and Care plans (EHC plans) which cover young people from birth to age 25
- Enabling parents and young people to have control of a personal budget to buy additional support detailed in the plan.

- Local authorities must produce a 'local offer' of education, health and social care services it expects to be available in the area for children and young people up to 25 years

Further funding was announced in November 2017. (£29 for councils to support implementation, £9.7 million to establish local supported internship forums; and £4.6 million for Parent Carer Forums)

These changes provide a huge opportunity to put children and families at the centre of decision making about the support they need and to improve the way education, health and care work together to provide that support. However, introduction during a period of austerity means that many families have reported the loss of many services (such as short breaks) which used to provide local support and a focus on process by Local Authorities as they transition to the new system, rather than on improved family-centred planning and provision. If implemented as envisaged, the SEND reforms could transform the way support is planned and provided for children with learning disabilities whose behaviours challenge. However, current practice seems far removed from that vision.

c) The legal system

MHA review

The current review of the Mental Health Act could be significant for children and adults with learning disabilities who display behaviour described as challenging. Currently an individual meets the criteria for sectioning if they have a cognitive impairment and display behaviour which is a danger to themselves or others. All parts of the MHA framework that should provide protection for this client group have room for improvement, including the power imbalances in the system, how the Tribunal system works, and access to skilled advocacy.

Case law / legal challenges

CBF and Mencap have established a legal panel of lawyers with expertise in this area who are looking at potential strategic cases

d) Registration and Regulation

There is an opportunity to ensure that all regulators of services for this client group only register services that are in line with NICE guidance. There is work to do to address services already in existence that do not meet NICE guidelines.

e) Sustainability and Transformation Partnerships

In 2016 44 Sustainably and Transformation Partnerships of local NHS organisations and councils were formed (these do not align to the 48 Transforming Care Partnerships), and each produced a 5 year Sustainability and Transformation Plan setting out plans to improve health and social care.

f) NAO / PAC

The NAO could at any time decide to carry out a further investigation into the progress of the Transforming Care programme

g) Media

There is significant media interest regarding the Transforming Care programme, including individual stories, lack of progress towards targets, and the role of private providers.

Strategic influencing groups boards and committees

There are numerous national groups, committees and boards that are looking at elements of the system that need to change to deliver the Transforming Care objectives, including:

- Transforming Care (TC) Delivery Board
- TC Roundtable Stakeholder Group
- TC Children & Young People's (CYP) Board
- TC CYP delivery group
- NHSE Children with Complex Needs board
- DfE High Needs Board (to be established)
- NHSE Stopping the Over Medication of people with learning disabilities (STOMP)

Acknowledgements;

This briefing Paper has been complied with input and contributions for many CB NSG members – our thanks to those who provided information. It is intended as a summary overview of key issues in preparation for the discussions at the CB NSG meeting in April 2018.

A list of articles and reports referenced in this paper is being compiled and will follow