

**Supplementary written evidence submitted by the Challenging Behaviour Foundation
(ADL0013)**

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Executive Summary - Key areas for recommendations

1. Investing in and developing good community services

Providing **good community services** is the key to Transforming Care and must be the top priority. We urge the Committee to recommend:

- That the government prioritises the development of a clear **housing** strategy that has sufficient resources attached to meet the needs of people with learning disabilities
- Investment in robust specialist community health services to support people in the community that avoid relying on in-patient care
- That the government publishes its strategy for addressing the findings in reports by the **National Audit Office** (2015, 2017) and Building the Right Support interim **evaluation** as soon as possible, which includes measuring **outcomes** for individuals.
- Sensible **funding flows** that incentivise discharge and disincentivise admission are urgently identified and implemented.
- **Data collection and publication** on local areas' community capacity is implemented so that resources can be better targeted.
- Initiatives to provide targeted **external support** to local areas from individuals with specialist expertise are introduced, building on learning from hospital closures.
- Items 2-5 (below) are implemented

2. National leadership

The Transforming Care initiative will only succeed if the national leaders responsible for it are experienced, knowledgeable and committed. We urge the Committee to recommend:

- That DHSC appoints a senior official (with appropriate expertise) who is accountable for co-ordinating and leading the work, working across Government and with ALBs, voluntary organisations, and with people and families with lived experience.
- That DHSC seeks (and publishes) assurance from NHSE that the new **part-time** Learning Disability Director post-holder has sufficient knowledge, skills, time and resources to demonstrate that Transforming Care will continue to be a priority for NHSE.
- Publication of the detailed BTRS cross government strategic plan (with SMART targets) that is evidence based, costed, resourced and includes a timescale for delivery of outcomes by XXXX (date)

3. Early Intervention

Early intervention is fundamental in preventing admission and must be prioritised and embedded within local community health and social care support and services. This is linked to investment in local community support (1 above).

4. Commissioning

Commissioning is a key function under Transforming Care, linked to investment in community support (1 above) yet commissioners have no professional body or standards and are not regulated. We urge the Committee to recommend that the role of

commissioners is formalised to ensure they work to a set of standards and professional practice guidance, and that relevant NICE guidance is implemented to ensure a lifelong approach (which will address the transition issues).¹

5. Workforce

There is insufficient capacity and capability in the workforce currently, which was identified by the NAO in 2017.² The Government must publish a detailed workforce strategy that includes short and long-term targets and addresses the deficiencies in the broad spectrum of staff supporting children, young people and adults with learning disabilities and autistic people. This includes all staff from support workers to consultant clinicians and clinical directors. It should build on the lessons from the Oliver McGowan training pilots and includes tiered training.

Specific intervention is needed to ensure individuals are discharged. We urge the Committee to recommend that the government follows up on its commitment to implement specialist discharge staff, and that these staff be based on the Intervenor model piloted for Children and Young People.

A new initiative- External Specialist Support

The External Support Group (ESG) is an initiative set up by the CBF that brings together a number of individuals with significant practical experience in supporting individuals with complex needs in community settings- including developing individualised packages of support – and maintaining that support to provide good outcomes for individuals. Areas of experience in the group include families, experience in clinical/medical practice; commissioning; inspection and regulation; research and evidence; advocacy; the third sector; family support. The group members are motivated to help improve the quality of life and care provision for individuals inappropriately 'stuck' in hospital placements as well as influence systematic change and improve practice in the long term (micro and macro systems). The ESG will focus on practical *doing with*, not *doing for*, local teams and will adopt an investment approach- investing additional capacity and enhancing existing skills leaving a sustainable legacy. By working in partnership to achieve change at an individual level, the group will model and influence best practice and enhance ways of working to build more robust systems of support for the broader population of people with complex needs at risk of hospital placement.

6. Care and Treatment provision

¹ NICE Guidance [NG11], *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges* (May, 2015). Available online: (<https://www.nice.org.uk/guidance/ng11>)

And

NICE Guidance [NG93], *Learning disabilities and behaviour that challenges: service design and delivery* (March, 2018). Available online: (<https://www.nice.org.uk/guidance/ng93/chapter/Recommendations>)

² National Audit Office, *Local support for people with a learning disabilities* (March, 2017). Available online: (<https://www.nao.org.uk/report/local-support-for-people-with-a-learning-disability/>).

Urgent action is needed to improve the treatment of individuals in in-patient settings. Restrictive interventions are harmful and their use must be drastically reduced. We urge the Committee to recommend:

- The Minister of State for Social Care immediately addresses the issue of inadequate data collection (e.g. continued lack of reporting from providers of Restrictive Interventions; data collection on distance from home etc.).
- The Minister provides a report on the range of data collected for the Transforming Care programme, its analysis and evidence of how it is used to inform the BTRS Delivery plan.

[1] Introduction

In February 2021, the Challenging Behaviour Foundation (CBF) worked with Mencap, Rightful Lives and Learning Disability England (LDE) to submit a [Transforming Care evidence paper to the Health and Social Care Committee](#) to aid with their ongoing inquiry into the treatment of people with learning disabilities and autistic people.³ Following this, on 9th February CBF, Mencap, Rightful Lives and LDE all provided oral evidence to the committee. On 13th April Dr Ken Courtenay, Dr Theresa Joyce and Sir Norman Lamb provided further oral evidence to the committee.

On the 27th April 2021, the Committee heard oral evidence from Helen Whately MP, Minister of State for Social Care; Claire Murdoch, National Mental Health Director for NHSE and Roger Banks, National Clinical Director for Learning Disabilities and Autism for NHSE. The CBF have produced this paper in response. It offers an evidence-based reply to some of the statements made by the witnesses during the Committee session on the 27th April 2021 and where relevant, offers appropriate evidence-based recommendations. Several appendices are included with further information. We hope this document will assist the Committee in their review of current policy and inform their report and recommendations.

We would happy to discuss any of the items in this paper in more detail. Please do not hesitate to get in in contact with Mary Spence on mary@thecbf.org.uk

[2] National Strategy

[2.1] Making & Keeping Promises

Claire Murdoch assured the committee that ‘Simon Stevens is absolutely clear...that we have to deliver on our promises for 2023/24 and that not delivering is not an option’. However, similar promises have been made in the past and subsequently broken. For instance, Simon Stevens announced a ‘transition map’ into community services and the beginnings of a closure programme in the [Public Accounts Committee hearing on services for people with intellectual disabilities and challenging behaviour on 9th February 2015](#).⁴ Stevens stated that the NHS had the intention and the power to begin a programme of closures for inadequate services, using CTRs to evaluate care being provided, from which NHS and CQC have the powers “to make the decisions about whether these facilities will continue to be funded”. This has not materialised. Furthermore, two days after Claire Murdoch made her statement on delivering on promises during the evidence session, it was publicly announced that Simon Stevens would be stepping down from his role, ‘as planned’. There needs to be reassurance that once Simon Stephens has left NHSE this issue remains a priority.

We recommend the Committee requests a transition plan that outlines this.

Helen Whately indicated that she was open to ‘radical’ ideas to address the current failure of the Transforming Care programme and the negative impact this has on autistic people and individuals with learning disabilities. However, the solutions needed are not radical. They are well known and have been for almost a decade. To transform care, all parts of the “system” need to work in a co-ordinated way to focus on delivering good outcomes. To make this happen, knowledgeable and specialist leadership nationally and regionally is required to develop a comprehensive and cohesive, thought-through plan, that includes an implementation programme that is delivered locally, and supported and monitored. Report after report has made the same recommendations. We need:

³Written evidence submitted by the Challenging Behaviour Foundation, Mencap, Rightful Lives and Learning Disability England (ADL0001). Available online: (<https://committees.parliament.uk/writtenevidence/22342/pdf/>)

⁴Public Accounts Committee, *Oral evidence: Care services for people with learning disabilities and challenging behaviour (HC 973)*. Available online: (<https://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/public-accounts-committee/care-for-people-with-learning-disabilities/oral/18031.html>)

- 1) targeted and sufficient investment to ensure the right community support is in place, including the right housing
- 2) to prioritise prevention and deliver early intervention support
- 3) to build capacity and capability in all parts of the workforce
- 4) to remove perverse financial (and other) incentives and provide adequate funding
- 5) to work in partnership with families and individuals
- 6) to address and improve poor commissioning
- 7) robust inspection and scrutiny of services by inspectors who know what they're looking for
- 8) a cross governmental strategy for Transforming Care with clear leadership, expertise, resources and accountability

[2.2] National Leadership

We continue to have concerns over the National Learning Disability Director role. It has been over four months since Ray James left the Learning Disability Director post – and the NHS was well aware his tenure would end in December 2020. The fact that the post has been vacant for so long, with no information being shared on recruitment or on the restructuring of the role is concerning.

We were told during the evidence session that an appointment has been made – yet no details were forthcoming over who this person is or their expertise and skills that equips them for the role. While we were told that the Director role becoming part-time rather than full-time is not a 'downgrade', we have not been given the information needed to justify faith in the effectiveness of this part-time role.

No information is available regarding the details of new senior roles being created to support the Director, nor how the individuals appointed will also be sufficiently qualified or held accountable. Likewise more information on how 'integrated working with Mental Health' will operate in practice is required.

We would urge the Committee to request a staff chart that is transparent and demonstrates that Transforming Care will continue to be a priority for the NHS and be staffed accordingly.

[3] Community services

[3.1] What does good community care look like?

As the Committee is already aware, providing good community care and services is the key to transforming care. The Minister, despite presumably being aware of the 10-year transforming care programme to deliver good community support, requested clarity over what good community care looks like. It is of significant concern that she is apparently unaware of the considerable evidence available.

Appendix I contains a diagram explaining exactly what good community support means.

Appendix II contains documentation clearly showing what good support looks like, along with NICE guidelines.

Further, there are numerous examples of best practice. We know how to support people well. See Appendix III for a case study of this.

We urge the Committee to recommend that the government clearly demonstrates how it has analysed and utilised previous report recommendations to develop its proposals, and how those proposals will enable people with learning disabilities to be well-supported in the community.

[3.2] Developing Good Community Services with a focus on Early Intervention

When asked about community services, Claire Murdoch replied that they are 'busy building 24/7 crisis alternatives. Through the NHS Long Term Plan, £17m was invested in 2019/2020 and £131m will be invested in 2023/24. Virtually all of that new investment is there to fund the likes of crisis provision, key workers for children and young people, intensive community support, respite.'

We are alarmed by the continued crisis management approach and the lack of focus on early intervention. For example, keyworkers are often only allocated to children and young people who reach crisis. Keyworkers need to be allocated as early as possible to prevent deterioration to crisis-point. Additionally, children need peer support before they are allocated a keyworker. Crisis provision does not work in isolation, and there needs to be investment in early intervention if we are to avoid so many families reaching breaking point.

Positive Behaviour Support (PBS) is the best evidenced approach for supporting people with learning disabilities whose behaviours challenge, as recommended by NICE, the Department of Health, NHSE and the DfE [Guidance 'Reducing the need for restraint and restrictive intervention'](#) (June, 2019).⁵

We know that if we invest in PBS and whole family support from an early age there is less risk of challenging behaviour or restrictive practices occurring, and therefore less risk of triggering a pathway to admission to ATUs. For more on this “well trodden path”, please refer to the CBF and Council for Disabled Children (CDC)'s [Paving the Way paper](#).⁶

Families need early support from specialists, emotional support and the right information at the right time in a form that is right for them. Alongside the benefits to the person and their family, early intervention reduces the need for more costly later interventions (such as crisis interventions or institutionalised care). The annual cost of keeping a child in an inpatient unit is £250,000, and the annual service cost for an adult who displays severely challenging behaviour is £379,000.⁷ The cost savings of localised evidence-based early intervention have already been shown. A financial review found that The Bristol Positive Behavioural Support Service produced savings of £1.8 million in just four years.⁸

Drastic action is needed in order to see the words of policy become reality. The gap between Government policy and outcomes for children with learning disabilities whose behaviours can challenge is stark and has been further exacerbated by the pandemic ([see The CBF's New Normal reports for evidence of this](#)).⁹ Without a specific focus on this group, outcomes are likely to worsen rather than improve, at significant cost to the health and wellbeing of children and families and significant financial cost to the state.

Early intervention does not just apply to children- providing timely support to all individuals when it is needed can prevent deterioration and crisis. We are concerned that current early intervention projects are typically only pilots or only have short term funding, and therefore cease after a few years. To develop sustainable early intervention, investments in this area need to be considered as part of a long-term plan, and funding should not disappear after a couple of years. This long-term, reliable funding is crucial to enable long-term planning and deliver clear, successful pathways. It is possible to commission and provide good local services for children, young people and adults with learning disabilities whose behaviours challenge – and it is cost effective to do so

For more information on the importance of Early Intervention, please see our Early Intervention Briefing Paper (submitted alongside this evidence report), our initial submission to the HSCC and the [CBF and Council For Disabled Children Early Intervention Paper](#).

⁵ DfE, *Reducing the need for restraint and restrictive intervention* (June 2019). Available online: (<https://www.gov.uk/government/publications/reducing-the-need-for-restraint-and-restrictive-intervention>)

⁶ The Challenging Behaviour Foundation and Council for Disabled Children, *Paving the Way*. Available online: (<https://pavingtheway.works/project/wp-content/uploads/2016/02/pavingthewayreport.pdf>).

⁷ The Challenging Behaviour Foundation, *Early Intervention for Children with Learning Disabilities whose behaviours challenge* (Nov., 2014).

⁸ The Challenging Behaviour Foundation and Council for Disabled Children, *Paving the Way*.

⁹ More information on the The CBF and SF-DARIN New Normal Project can be found on the CBF website. (<https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/changing-poor-practice/new-normal/>).

We urge the Committee to recommend that the government prioritises early intervention and invests long term funding into early intervention and community service provision.

[3.3] Housing

Every month, NHS Digital publishes the causes of delayed discharge. Every month, for the last twelve months, the most common specified reason for delayed discharge has been ‘Lack of suitable housing provision’.¹⁰

Moreover, this issue had hindered the progress of the Transforming Care since its inception. At each anniversary of the programme:

Year	Most common reason for delayed discharge	Percentage of discharges it has delayed
March 2015	Lack of suitable housing provision	29%
March 2016	Lack of suitable housing provision	42%
March 2017	Lack of suitable housing provision	39%
March 2018	Lack of suitable housing provision	40%
March 2019	Lack of suitable housing provision	38%
March 2020	Lack of suitable housing provision	34%
March 2021	Lack of suitable housing provision	47%

The Minister agreed that ‘we need a strategic approach to make sure [housing] is improved’, yet despite the longevity of this issue, the government has yet to put forward a strategy. Too often when questioned on housing, the government points to its new Community Discharge Grant. This is intended to cover double-running costs while an individual transitions from inpatient services back into the community. In response to a letter to Sir Chris Wormald that the CBF co-authored with Mencap and Rightful lives, David Nuttal made clear that the grant is ‘designed to address issues with accessing housing’ i.e. it will not provide the necessary *additional* resources urgently needed to develop the housing element of the Building the Right Support model.

We urge the Committee to recommend the government prioritises the development of a housing strategy that has sufficient resources attached to meet the needs of people with learning disabilities.

[3.4] Funding Community Services

Providing sufficient long-term, ring-fenced and joined-up funding for community services is urgently needed. The Minister indicated that this is one of the pieces of work that the Delivery Board is currently doing. It is unclear why this work has not already been completed as the issues in this area are well known:

- In its [2015 report](#), the National Audit Office identified that the absence of a ‘mechanism for pooling resources to build sufficient capacity in the community’ was a barrier to meeting the Winterbourne View Concordat commitments.¹¹

¹⁰ NHS Digital, Learning Disabilities Services Statistics. (<https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>).

¹¹ National Audit Office, *Care service for people with learning disabilities and challenging behaviour: executive summary* (2015). Available online: (<https://www.nao.org.uk/wp->

- In its [2017 report](#), the National Audit Office stated that money is not yet being released from mental health hospitals quickly enough to help pay for extra community support; not enough community accommodation is being put in place to enable people to leave hospital and there has been little progress in achieving other programme objectives (e.g. workforce developments, hospital care closer to home).¹²
- The [interim independent evaluation](#) of Building the Right Support (BTRS) published in 2018 made several recommendations related to investing in community service, including increasing preventative support, more investment in the workforce, increasing the supply of accessible housing, and pooling or aligning budgets across health and social care.¹³

In 2013, NHSE spent £557m on inpatient care for patients who were autistic and/or had learning disabilities. A more up-to-date figure is not readily available, but we have yet to see the government commit resources anywhere near this figure to community services.

We understand that the approximate £20m per year allocated for the Community Discharge Fund does not represent the total investment in community services but it does highlight the backwards, reactive approach to Transforming Care that has hindered the programme since its inception: money is being committed and made available for *discharge* before it is being made available to develop the community services for an individual to be discharged into. We are concerned that the Community Discharge Grant is just another short-term, attention grabbing sound-bite that masks the lack of a genuine commitment to a long-term, preventative approach to community services. Further delay is inexcusable.

We urge the Committee to recommend that the government publishes its strategy for implementing the recommendations from NAO reports and the BTRS evaluation as soon as possible, which includes measuring outcomes for individuals. Sensible funding flows that incentivise discharge and disincentivise admission are urgently needed. Early Intervention is fundamental in preventing admission in the first place and must be protected from further cuts.

[4] Care and Treatment Provided

[4.1] Restrictive Interventions

There is no clear evidence of a reduction in restrictive interventions according to data in the NHS Digital Mental Health Services Data Set.

Data reported in the [MHSDS data set](#) shows a high number of incidents of restrictive interventions experienced by children, young people and adults with learning disabilities and/or autism in inpatient services.

- The total number of reported restrictive interventions in January 2021 was **3,970**
- In the latest MHSDS data, figures on use of restrictive interventions were only provided for 1 out of 17 independent inpatient providers and approximately half of NHSE inpatient providers. Providers must be held to account for lack of recording and reporting.
- Within January 2021 there were 920 reported restrictive interventions against children and young people under 18 in inpatient settings

content/uploads/2015/02/Care-services-for-people-with-learning-disabilities-and-challenging-behaviour-summary.pdf).

¹² National Audit Office, Local Support for People with a Learning Disability: Report by the Comptroller and Auditor General (2017). Available online: (<https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf>).

¹³ *Evaluation of Building the Right Support: summary of findings to date and recommendations arising* (Oct., 2018). Available online: https://www.strategyunitwm.nhs.uk/sites/default/files/2019-01/1%20Short%20Summary%20of%20Recommendations_0.pdf).

- This included at least 70 incidents of prone restraint.¹⁴

We suggest the Committee request that the Minister immediately addresses the issue of continued lack of reporting from providers to enable better understanding of the current situation. What is required is:

- **An understanding of the extent of the use of restrictive practices**
- **A plan to address its use that is resourced, and measures and reports outcomes**

The panel's commitment to action in response to recommendations in CQC's *'Out of Sight'* report and the Sheila Hollins review (their full responses have yet to be publicly published) did not provide reassurance that the restrictive intervention against children and young people who are autistic and/or have learning disabilities is being sufficiently addressed. We know that children and young people are being restrained and secluded in schools and other education and social care settings, as well as inpatient hospitals. Please see appendix IV for more information.

We are not convinced that current proposals in the Mental Health Act (MHA) white paper will reduce use of restrictive intervention (and is limited by the fact that it will only apply to individuals detained under the MHA). We have highlighted this in our response to the MHA white paper consultation, and again below.

Though 'Least restriction' is one of the MHA's key principles, there are limited proposals around tackling the shocking levels of restrictive interventions used against people with learning disabilities and autistic people in inpatient units. MHA reform is an opportunity to set out clear legal prohibitions against the use of restraint, further to the requirements brought in by the Use of Force Act 2018. By embedding prohibitions directly into the MHA, policymakers could set out much stricter frameworks than those set out in good practice guidance (which often isn't followed), by legislating, for instance, that there must be no planned prone restraint and that restraint should only ever be used as a last resort after less restrictive options have been tried.

The White Paper says: *'There may also be a need to strengthen the existing text on restrictions within the Code of Practice and the CQC's role in monitoring its implementation.'* This does not seem ambitious enough or specific enough to tackle this deeply shocking issue.

Care and Treatment plans and reviews must be made statutory, so that important recommendations around reducing restrictive interventions are enacted. All uses of restrictive intervention or seclusion should be recorded, including events preceding incidents in order to learn from incidents and minimise frequency and duration going forward, and to provide a record of accountability when things go wrong. There must be requirements to record what plans are in place reduce the restrictions, the evidence these plans have been carried out, and that recording is accurate - this is important to ensure that any restraint is in line with the 'least restriction' principle. In the Care and Treatment Plan it should be recorded with transparency why whatever restrictive intervention used is the 'least restrictive' (for instance, as there isn't a psychologist available to do a functional assessment, or that the unit is short staffed) and how this is being addressed to prevent continued use of restraint going forward.

There is a need to identify who is accountable for addressing this issue. The Minister could take responsibility for reducing restrictive interventions for children, young people and adults with learning disabilities and autism across health, education and social care settings including ensuring

- **Care and Treatment plans and reviews are made statutory, so that important recommendations around reducing restrictive interventions are enacted.**

¹⁴ Learning Disability Services Monthly Statistics: MHSDS January 2021 (Apr., 2021). (<https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-march-2021-mhsds-january-2021-fina>)

- **Rigorous reporting of restrictive interventions including events preceding incidents in order to learn from incidents and minimise frequency and duration going forward, and to provide a record of accountability when things go wrong**

[4.2] Culture & Training

When questioned about how to change practice culture and improve the training of staff working with people with learning disabilities, the Minister answered that there will be ‘a programme of work to drive culture change’ and that ‘Oliver McGowan mandatory training pilots will be evaluated to ensure effectiveness’.

We welcome the Oliver McGowan mandatory training pilots, but it is vital that the quality of the training developed and the implementation strategy are robust and consider outcomes for individuals.

We urge the Committee to recommend that the Oliver McGowan mandatory training is robustly evaluated and reviewed to assess whether the training is contributing to practice improvements, *specifically* delivering better outcomes for people with learning disabilities and autistic people, *and* gives a commitment to continue to further develop and deliver long term workforce training in learning disability and autism.

We are concerned that the Oliver McGowan training is being incorrectly treated as a ‘catch-all’ solution. For example, the training is designed with limited consideration of trauma, despite trauma being a key issue for children and their families navigating the system. Findings in the CBF report [‘Broken: the psychological trauma suffered by family carers of children and adults and the support required’](#) support views reflected by families elsewhere- that information and support is hard to find, and that the lack of support can be traumatising. 71% of families identified ‘trying to find a way through the complicated education, health and social care system’ as a risk factor for experiencing family trauma.¹⁵

We recommend that the Oliver McGowan training includes (or is supplemented by additional training that includes) risk factors for trauma to ensure professionals adopt a trauma-informed approach.

We are concerned that ‘changing practice culture’ is a wider issue than workforce – and even the workforce challenges cannot be addressed by the Oliver McGowan training alone. Other elements, such as the sharing of best practice, will enable cultural changes. For examples of good practice, please refer to our [Paving the Way report](#).

A key issue is the lack of learning disability and autism expertise of professionals in senior management positions. For example, members of the External Support Group (formerly known as the Doing Group) have raised concerns that in some areas the leads responsible for the person they are supporting, including the clinical lead, the NHS regional team lead, and the NHS England’s National Mental Health Director lack specialist learning disability and autism experience and training. This lack of training for individuals in senior posts is alarming because these professionals hold significant influence over care decisions and are best placed to drive cultural change. Training will be insufficient if not coupled with strong practice leadership.

We recommend that professionals who hold senior managerial positions within learning disability and autism directorates are required to evidence their expertise in learning disabilities and autism both prior to appointment and as part of their continuous professional development.

A similar issue exists in clinical psychology and psychiatry, where learning disability training remains an optional addition to the curriculum. The [‘Good Practice Guidelines for UK Clinical Psychology](#)

¹⁵ The Challenging Behaviour Foundation, *Broken: the psychological trauma suffered by family carers of children and adults and the support required* (Dec., 2020). Available online: (<https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/brokencbfinalreportstrand1jan21.pdf>).

[Training Providers for the Training and Consolidation of Clinical Practice in Relation to Adults with Learning Disabilities](#)' clearly outline how to ensure that all clinical psychologists are well-equipped to work with adults with learning disabilities.¹⁶

We recommend that this knowledge is embedded in the core curriculum for these professions. Furthermore, in recognition of [the trauma experienced by families navigating the system](#), we recommend that professional bodies ensure that their workforce is trauma aware and trauma informed to comply with legal frameworks.

Therefore we recommend that all professionals who may work with individuals who are autistic and/or have learning disabilities, are provided with trauma-informed training in learning disabilities and autism as part of their mandatory training.

Although we welcome the plans to make the Oliver McGowan training mandatory across all health and social care settings, we are alarmed by the lack of consideration for the rest of the system. There should be training in learning disabilities and autism across education, health and social care.

It is vital that culture and working practices are reformed across the whole system if we are to avoid the "well-trodden path" of individuals ending up in ATUs. Concerningly, many teachers currently do not receive appropriate training. Reports repeatedly highlight the lack of training for staff across settings e.g. [These are our Children](#) (Lenehan, 2017).¹⁷ Without training for staff, families are left unsupported, and so children with behaviour that challenges are set on a path to poor outcomes, including admission to ATUs.

Furthermore, we are concerned that the Oliver McGowan training "[will not and cannot include training in specific interventions, treatments or approaches](#)."¹⁸ There is robust evidence that behavioural interventions are most effective when delivered in the early years. However, health visitors and families surveyed in a recent study highlighted the lack of training around challenging behaviour for early years professionals.¹⁹ If early years staff are not sufficiently trained, we are concerned that families will not be supported to develop proactive strategies in the early years. This lack of early intervention limits families' ability to support their child to lead as independent a life as possible with the least use of restrictive interventions possible. Without an understanding of positive behaviour support and challenging behaviour in the early years and within schools, we will continue to see the significant use of restrictive practices at school, leading to crisis, exclusion, expulsion, and the eventual submission of the individual to institutionalised care settings such as ATUs.²⁰

We recommend that health visitors, teachers and other professionals supporting individuals with learning disabilities and their families are provided with appropriate, evidence-based training on learning disabilities, autism, challenging behaviour, person centred care, positive

¹⁶ The British Psychological Society, *Good Practice Guidelines for UK Clinical Psychology Training Providers for the Training and Consolidation of Clinical Practice in Relation to Adults with Learning Disabilities* (Apr., 2012). Available online: (<https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Good%20Practice%20Guidelines%20for%20UK%20Clinical%20Psych%20Training%20Providers%20for%20the%20Training%20%26%20Consolidation%20of%20CP%20in%20Relation%20to%20Adults%20with%20LD.pdf>).

¹⁷ Christine Lenehan, *These are our Children* (Jan., 2017). Available online: (<https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Good%20Practice%20Guidelines%20for%20UK%20Clinical%20Psych%20Training%20Providers%20for%20the%20Training%20%26%20Consolidation%20of%20CP%20in%20Relation%20to%20Adults%20with%20LD.pdf>).

¹⁸ Health Education England, *The Oliver McGowan mandatory training in Learning Disability and Autism* (<https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism>).

¹⁹ The Challenging Behaviour Foundation, *Institute of Health Visitors report* (in press).

²⁰ PABSS and the Challenging Behaviour Foundation, *Reducing Restrictive Intervention of Children and Young People* (Jan., 2019). Available online: (<https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/reducingrestrictiveinterventionofchildrenandyoungpeoplereport.pdf>)

behaviour support, and proactive and reactive strategies, and that the [NICE guidance](#) is implemented.

[4.3] Supporting Discharge

The Minister has stated that the government will be putting in place specialist staff to support discharge based on the Children's Intervenor model. It is imperative that unlike these Senior Children's intervenor pilots, funding for these specialist staff is long-term and ring-fenced. There should be the dual aims of effecting change on both the individual level, and the system-wide.

A new initiative- External Specialist Support

The External Support Group (ESG) is an initiative set up by the CBF that brings together a number of individuals with significant practical experience in supporting individuals with complex needs in community settings- including developing individualised packages of support – and maintaining that support to provide good outcomes for individuals. Areas of experience in the group include families, experience in clinical/medical practice; commissioning; inspection and regulation; research and evidence; advocacy; the third sector; family support. The group members are motivated to help improve the quality of life and care provision for individuals inappropriately 'stuck' in hospital placements as well as influence systematic change and improve practice in the long term (micro and macro systems). The ESG will focus on practical *doing with*, not *doing for*, local teams and will adopt an investment approach- investing additional capacity and enhancing existing skills leaving a sustainable legacy. By working in partnership to achieve change at an individual level, the group will model and influence best practice and enhance ways of working to build more robust systems of support for the broader population of people with complex needs at risk of hospital placement.

We recommend the specialist discharge staff initiative is developed in-line with the ESG model. Please see Appendix VI for more information.

[5] Commissioning

[5.1] Training and Oversight

The Minister has indicated that work is underway to improve the training and skills of Commissioners as well as improving oversight in line with the recommendations of CQC's [Out of Sight, Out of Mind](#) report and the Sheila Hollins review into seclusion. The government have yet to publicly respond to either of these reports and as we understand it, we aren't expecting a statement until the weeks commencing either the 17th or the 24th May.

It is vital that the recommendations from these reports are implemented in full.

Serious concerns have been raised about commissioning, with Commissioners continuing to fund unsuitable community placements and unsuitable placements in inpatient units. Commissioning is a key function for Transforming Care- yet commissioners have no professional body or standards and are not regulated. (For example, see CQC Out of Sight report recommendations around the need for better commissioning). "Specialist commissioning" is often neither specialist nor commissioning- it is purchasing what is available often by people with little or no learning disability or autism experience. There seems to be little or no accountability for commissioners who fail to develop community solutions and who fund places in inadequate services or the wrong model of care. Commissioners should be subject to financial audits to ensure they spend public funds that deliver good outcomes and do not cause harm.

[5.2] Provider Collaboratives

As the Committee will be aware, there are numerous concerns over the Provider Collaboratives initiative. Claire Murdoch is due to write to the Committee on this issue. We would like to see a timescale for this letter.

The key questions that we recommend that this letter should answer are those that have already been put to Simon Stevens and Liz Durrant:

- What safeguards are in place to address the current culture within the NHS of its specialist commissioners “buying what’s available” rather than commissioning what is actually needed? If the Provider Collaboratives are an attempt to address this - what process is in place to ensure that large private providers (highly motivated to be part of these initiatives to increase their market share) do not use this as an opportunity to develop the types of services they want to deliver, rather than what is needed?
- How will provider collaboratives ensure that small (often single person) local services to meet people's needs are developed (rather than congregate services that are administratively and financially convenient for providers)?
- What safeguards are in place to ensure that only providers with the right skills, expertise and experience, including delivery of good outcomes for individuals are recruited?
- How (and when) will you measure success of the collaboratives (in terms of peoples experiences rather than from the service providers perspectives)?

In addition:

1. It is difficult to find clear transparent information about the Provider Collaboratives (what they are, what benefits they aim to deliver, how their performance will be evaluated and by whom, a list of them and their members etc)- where can this be found?
2. What is the process to recruit providers to the collaboratives? What criteria have to be met, what is the “term of office” and what is the selection process?
3. Does the recent announcement by NHSE that CCGs will be disbanded mean that Provider Collaboratives will replace them?
4. What steps are being taken to include care providers in collaboratives in order to ensure that community placements have a care focus rather than a medical focus?
5. How will small care providers be incentivised and supported to be involved in collaboratives especially where they are values-led and not-for-profit?
6. How does the provider collaborative initiative align with the Joint Strategic Needs Assessment within an area, and other initiatives such as the “local offer” and the Service Model to ensure there is a focus on early support – the right support in the right place at the right time to meet local needs - rather than the services that service providers want to set up?
7. How do providers join a collaborative – are they invited, is it an open recruitment process? (e.g. if one is established already- and an organisation want to join?) Likewise, is there a process to remove a provider and on what grounds?
8. How are people with lived experience (including family carers) supported to be engaged meaningfully in the process- where within the governance structures are there opportunities to be fully engaged and have a meaningful say and what is in place to ensure that there is a range of lived experience and broad representation?
9. What funds are made available to the collaboratives and where can this information be accessed, including sums allocated to individual providers?

Furthermore, more information is needed on ‘Pathway Panels’. As we understand it, it is these panels, **not** Provider Collaboratives that will include individuals with lived experience. As we understand it, the Provider Collaboratives are progressing without the Pathway Panels even being set up and there is no assurance that those individuals will have the balance of power in that group; there is no information easily available about the panels, and no indication of how the members with lived experience will have the breadth of experience and knowledge across the wide spectrum of needs of the learning disabled and autistic population- and the range of support and services they need. It is therefore disingenuous to suggest that Provider Collaboratives are the answer to the need for good community-based services that include individuals with lived experience.

[5.3] Transforming Care Partnerships (TCPs) and out-of-area placements

During the session on 27th April, the Minister responded to questions raised regarding out-of-area placements for people with learning disabilities by stating that “*TCPs should be taking action if too*

many people are being placed out of area". We have a number of outstanding questions regarding this answer provided by the Minister.

Firstly, we would like some clarity on how many is "too many" - is there a government-set target which TCPs must aim for? What monitoring occurs for placements made, according to each TCP? In [MHSDS data](#), the distance to treatment for 15% of people is over 50km, while worryingly the distance for 27% of people is 'Unknown'.²¹ We have no available break-down of data on distance from home by TCP and no analysis of the reasons for out of area placements.

We would urge the Committee to recommend that data collection on distance from home is improved by requiring Commissioners to submit this information to the monthly Assuring Transformation data collection.

There are also questions regarding the mechanisms through which TCPs are able to challenge out-of-area placements. What are the processes that TCPs must follow when an out-of-area placement is made, and what are their routes to "take action" on this? What remit do they have for challenging these placements when treatment is provided in a TCP different to that of the person's origin area? If TCPs are to be the vehicle through which out-of-area placements are to be challenged, then we would like more clarity on how this challenge operates.

[5.4] Maghull development

Despite Claire Murdoch's reassurances during the evidence session that "*only people with the most complex needs and care will be given a bed and the target length of stay will be no longer than 18 months and intensive therapy will be provided*" and that "*We're working closely with CQC to make sure it does meet the model of care*" there are still serious concerns about the Maghull development, and we do not believe it is in line with best practice.

In building the proposed 40 bed unit and closing the Specialist Learning Disability Site in Whalley (also run by Mersey Care), like is being replaced for like. Sir Stephen Bubb in the 2014 report [Winterbourne View - Time for Change](#) highlighted that '**we must not close down one set of institutions only for another to appear**'.²² In supporting the new 40 bed unit for people with learning disabilities there is a risk that the government is doing exactly this.

Ian Trenholme/ CQC confirmed in correspondence in March 2021 that "*any application received will be considered against our Right Support, Right Care, Right Culture guidance. The service would be required to demonstrate how it meets this guidance as well as its compliance with other regulations and national policy.*"

The [CQC's registration guidance](#) states that '*We will only register, and favourably rate, services that allow people's dignity and privacy to be maintained and that facilitate person-centred care. This must be in line with current best practice guidance and **not be developed as new campus or congregate settings**. In our experience of registering and inspecting these types of service, the larger a service is, the harder the provider will need to work to clearly demonstrate it delivers high-quality, person-centred care.....It is unlikely that services that are not similar to ordinary residential accommodation will be registered.*'²³

It is hard to understand how a target length of stay of 18 months (likely longer) in a 40 person institution conforms to CQC's guidance, national policy or best practice. It is vital the Committee scrutinizes government support for the Maghull development against national policy.

²¹ Learning Disability Services Monthly Statistics: MHSDS January 2021 (Apr., 2021). (<https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-march-2021-mhds-january-2021-fina>)

²² Stephen Bubb, *Winterbourne View- time for change* (2014). Available online: (<https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>)

²³ CQC, *Right Support, Right Care, Right Culture* (Oct., 2020)

[5.5] BTRS Delivery Board

After a considerable length of time, a new governance structure has finally been set up comprising of the Building the Right Support Delivery Board chaired by the Minister of State for Social Care, an Advisory Group of people with lived experience and a Stakeholder Update Forum. However, each group meets for one hour, just 4 times a year which is an insufficient amount of time to address the delivery of transforming care. There has been no strategy published as of yet and the limited information that is available identifies the same broad headings that have been discussed for years (e.g. transition, workforce, financial flows) without any information about action, resources or implementation. There is no evidence that any different action is being taken or that there will be any different approach to that which has failed to deliver for the last 10 years. There needs to be a focus on building community capacity, moving away from inpatient services and more focus on children and early intervention.

We recommend that the governance structure is addressed as a matter of urgency with the publication of a detailed strategy focussed on building community capacity. There should be more time and resources committed to monitoring the delivery of transforming care.

[5.6] Regulation

The Minister suggested that the CQC will be taking a tougher stance, closing down more services and not registering services if they don't look like they're going to fit with the model of care. This directly conflicts with the proposal to commit Government funding to a new 40 person institution on a segregated site (see point 5.4 above)

At the APPG on Transforming Care in November 2020, representatives from the CQC stressed that how 'tough' they can be on inpatient service providers is limited by the lack of alternative community provision and emphasised the importance of good community services in preventing admissions in the first place.

In order to improve safeguarding and regulation, we urge the Committee to recommend that the recommendations from Glynis Murphy's independent review are implemented in full (see Appendix V),

Recent CQC consultations suggest that the CQC is looking to move away from regular on-site inspections. Site-visits are an important aspect of the inspection process and are an essential safeguard against the development of closed cultures. This is particularly important for people with learning disabilities and/or autism and behaviours that challenge as they are at risk of inappropriate admission to inpatient units; often a long distance from home and where it is known that there is a risk of harmful restrictive interventions. Other regulatory approaches are not robust enough to offer the same level of protection as site visits, especially unannounced or out of hours site visits. We disagree with the CQC's Transitional Regulatory Approach proposal to limit on-site inspections to sites where the CQC already has information that people may not be receiving good care. This reactive approach intervenes too late: individuals may have already been harmed and the CQC will have failed in its role to protect the rights of vulnerable people.

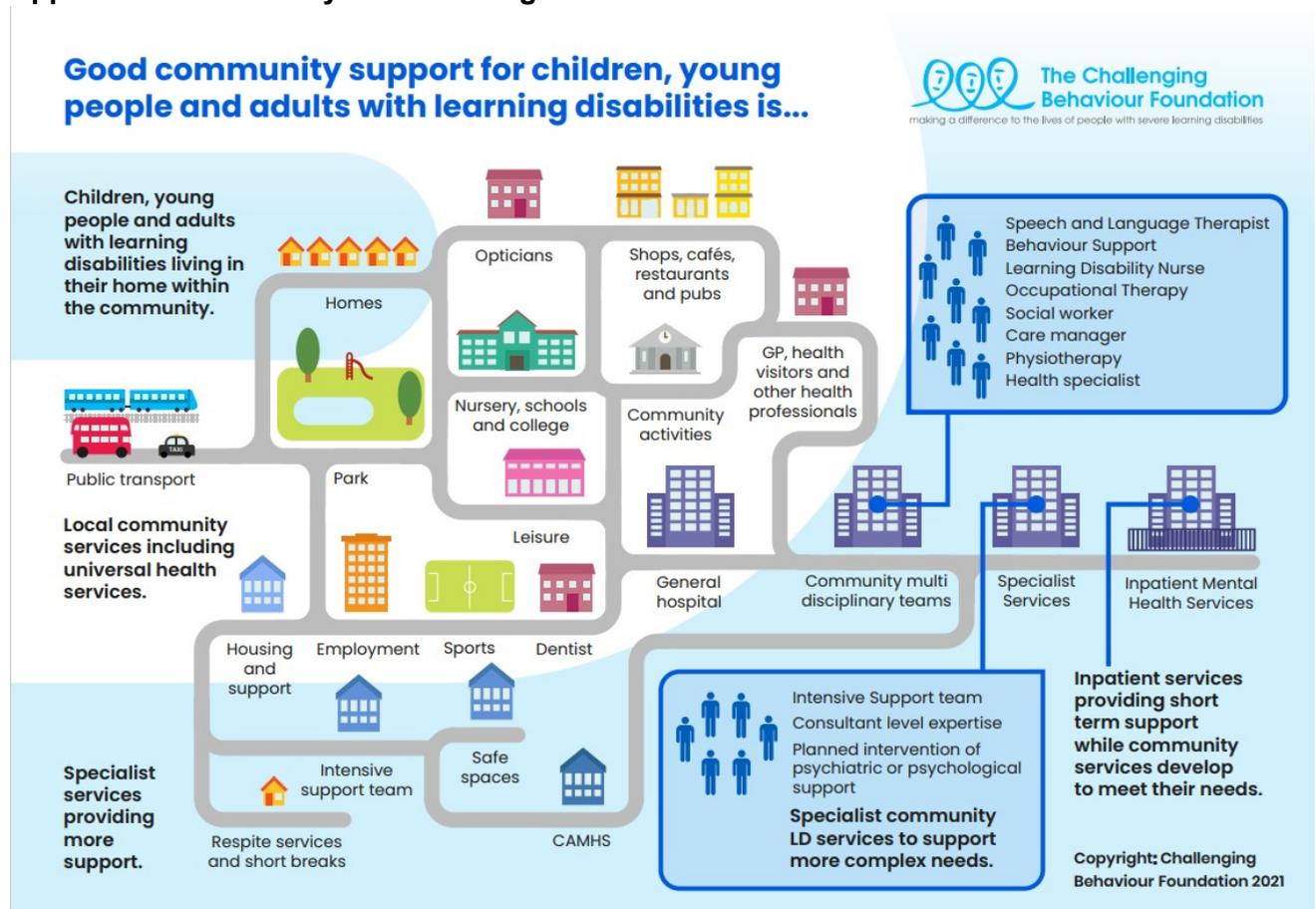
As illustrated by the Maghull site above, we are very concerned that the CQC are continuing to register services that don't fit with the right model of care.

The recommendations from the CQC *Out of Sight* report; the Glynis Murphy review of Whorlton Hall and the JCHR report on the detention of young people who are autistic and/or have learning disabilities must be implemented in full. The government must outline how it plans to implement and resource these recommendations.

Appendices

- Appendix I- Community Services diagram
- Appendix II- Reports detailing good community support
- Appendix III- Case Study of good practice
- Appendix IV- Restraint of children and young people
- Appendix V- Recommendations from the Glynis Murphy independent review into Whorlton Hall
- Appendix VI- External Support Group logic model

Appendix I- Community Services diagram



Appendix II- Reports detailing good community support

NICE Guidance and quality standards

NICE Guidance [NG11], *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges* (May, 2015). Available online: (<https://www.nice.org.uk/guidance/ng11>)

NICE Guidance [NG93], *Learning disabilities and behaviour that challenges: service design and delivery* (March, 2018). Available online: (<https://www.nice.org.uk/guidance/ng93/chapter/Recommendations>)

NICE Quality Standards [QS101]: *Learning disability: behaviour that challenges* (October, 2015). Available online: (<https://www.nice.org.uk/guidance/qs101>)

Reports and research

Jim Mansell, *Services for people with learning disabilities and challenging behaviour or mental health needs* (1993), Revised (2007).

NHS, *Developing support and services for children and young people with a learning disability, autism of both* (September, 2017). Available online: (<https://www.england.nhs.uk/wp-content/uploads/2017/09/developing-support-services-children-young-people-with-learning-disability-1.pdf>).

NHSE, *Building the Right Support* (October, 2015). Available online: (<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>)

NHS and LGA, *Ensuring Quality Services*. Available online: (<https://www.local.gov.uk/sites/default/files/documents/ensuring-quality-services-701.pdf>)

From Families

Transforming Care: Our Stories. Learning from families' experiences to transform care for people on the autism spectrum, with a learning disability or both
[transformingcareourstories.pdf](#) (challengingbehaviour.org.uk)

Paving The Way –examples of what works/ good support in the community for children and young people. [What works? - Paving the Way](#)

Everybody Matters Film: [Everybody Matters Film. Driving Change. The Challenging Behaviour Foundation, UK](#)

Appendix III- Case study of good practice

Josh lived in his family home with his siblings until July 2012 when his self-injurious behaviour increased and as a result he was sent to an assessment and treatment unit 260 miles away. We reluctantly agreed to this, because we were told it was for a 6-month assessment period to give everyone an understanding of the support and services he needed. Nearly three years later Josh was still in the same unit.

This experience has been heart breaking for the whole family. Josh continually asked for us at the unit and when he can't see us he can become anxious and self-injures. Josh's mother, step-father or I travelled to visit him every other weekend which was financially draining and took us away from our respective families and other children. Josh barely saw his siblings or extended family who all missed him dearly.

The unit completed their assessment years ago. Josh's self-injury reduced and a clear discharge plan specifying the support required was drawn up. It took a public campaign before Cornwall committed to develop the services required to bring Josh home, and even then there were repeated delays.

Josh has been living in his new home in Cornwall, with a bespoke care package, since early November 2015.

The long list of medication he was on in the inpatient unit has finally ceased - it has taken 2 years to get him off the medication. Now that he is off - it has improved his ability to forward plan, his appetite, physical health, his self-esteem, outlook on life - he's more confident each day, it's easier for him to cope, he's not distressed as much, he sleeps better and is eating better. I had never realised what an impact all that medication had.

He is now living the life he should be living. Josh has reached the 18 milestone. It has been a very long road but he has come out the other end. We can look forward. He can live the life he wants and has a human right to.

Appendix IV- Restraint of children and young people

A 2019 report by the Children's Commissioner *Far Less Than They Deserve* shows widespread mistreatment of vulnerable children and young people in Assessment and Treatment Units, including restraint and seclusion.

A joint report by CBF and PABSS, published January 2019 [Reducing Restrictive Intervention of Children and Young People'](#) (2019), found evidence of hundreds of children injured through the use of restraint, seclusion and other restrictive practices in both mainstream and special schools, suggesting that staff do not have the skills and expertise they need to meet children's needs using evidence-based approaches.

88.2 % reported their child or young person had experienced physical restraint. 91% of children and young people who had been restrained or secluded experienced a negative emotional impact, and 58% were physically injured during restraint or seclusion. The emotional impact on children and young people who had experienced restraint reported in the survey included anxiety, signs of depression, and meltdowns.

This can be avoided through the use of Positive Behaviour Support – the best evidenced approach for supporting people with learning disabilities whose behaviours challenge, as recommended by NICE, the Department of Health, NHSE and the DfE Guidance ['Reducing the need for restraint and restrictive intervention'](#) (June, 2019)

Lack of the right support for children and young people early on can lead to behaviour escalating, exclusions from school and use of restraint. As well as this being traumatic and damaging in itself, it can begin a pathway into inpatient units.

Appendix V- Recommendations from the Glynis Murphy independent review into Whorlton Hall

- Not rating services as good or outstanding if there is evidence of frequent use of restraint, seclusion or segregation
- Using information already gathered on services to create a list of 'red flags' for a service at risk of abuse or restrictive practices
- More flexible inspections when there is a risk identified/continuous Requires Improvement rating i.e. longer and more thorough inspections; reduced need for overwhelming evidence allowing inspectors to go in earlier where there is a concern.
- More inspections in the evenings and at the weekends including unannounced inspections
- No longer allowing the registration or expansion of isolated services
- Taking abuse seriously when it is uncovered and improving reaction to whistleblowing and complaints by recognising that this is probably the 'tip of the iceberg'
- Services should not be rated as 'Good' or 'Outstanding' if they cannot show how they support whistleblowing and reporting of concerns.
- Trialling of the Group Home Culture Scale tool, to evaluate whether it helps inspectors determine which settings have closed cultures.
- Trialling of the Quality of Life tool to gauge whether it helps CQC move from evaluating process, towards evaluating more relevant service user outcomes.
- Development of guidelines for when evidence of the quality of care should be gathered from overt or covert surveillance.

Appendix VI- External Support Group Logic Model

Context, Assumptions and Aims:

Context: After the Winterbourne View Hospital scandal in 2011, the Transforming Care programme aimed to reduce the number of inpatients with learning disabilities and autism and develop appropriate and robust community support, but has consistently failed to meet its own targets. Admissions remain too high, there are concerns about the quality of inpatient support, assessment and treatment and the average length of stay remains at over 5 years. Transformation requires all parts of the system to work in a co-ordinated way to invest in the right support in the right place at the right time, but there remain too many perverse incentives and complex issues including capability and capacity in the workforce.

Assumptions: There is no simple "quick fix". Access to the skilled support and expertise required is difficult to locate. There are systemic issues to overcome that require additional input. Local areas would benefit from access to external support and expertise to identify solutions and ways to implement them via a supportive model. There may be resistance to change and historical and political issues to confront.

Aim: To provide support and expertise to local areas and practitioners to:

- enhance and develop their knowledge and skills
- improve the quality of life and care provision for individuals with learning disabilities whose behaviour challenges who are inappropriately 'stuck' in hospital
- influence and drive system changes to improve practice to avoid such situations over the long term.

