SOUTHAMPTON CITY COUNCIL

NHS
Southampton City
Clinical Commissioning Group

Southampton City Policy Statement for Working with Children and Adults with Learning Disabilities whose Carers and/or Services are Challenged by their Behaviour

2014 - 2019

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1.0 Executive Summary

1.1 The Winterbourne View Final Report Transforming Care was released in November 2012. This followed an investigation into physical and psychological abuse suffered by people with learning disabilities and challenging behaviour at Winterbourne View private hospital. Transforming Care requires that by April 2014, each area will have a locally agreed joint plan to ensure high quality care and support services for all children, young people and adults with learning disabilities or autism and mental health conditions or behaviour described as challenging, in line with the model of good care set out within Transforming Care.

1.2 Good practice guidance on supporting people with learning disabilities, autism and those with behaviour which challenge emphasise:

- the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers;
- a focus on personalisation and prevention in social care;
- that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour
- that services/support should be provided locally where possible.

1.3 Southampton's Joint Challenging Behaviour Policy Statement and associated action plan is our response to this requirement. To deliver this, the Challenging Behaviour Local Implementation Group was formed, which has representatives across Southampton's statutory and voluntary sector.

1.4 The Challenging Behaviour Policy Statement identifies areas of development that will support commissioning intentions including ensuring systems are in place for preventative measures and early identification of those at risk, in order to avoid crisis. It also, ensures that those with the most complex needs, who are currently living within in-patient settings, are supported locally, with good quality provision.

1.5 In parallel to the work undertaken to refresh Southampton's Challenging Behaviour Policy Statement, Southampton's Autism Strategy Group have also been working to implement an action plan (2012-2015). There are obvious alignments within the work programmes due to the high incidence of co-morbidity of Autism/Learning Disabilities and Challenging Behaviour (20-30%). Southampton has made good progress in the area of Autism, which was reflected in the Autism Self Assessment Framework submission to Improving Health and Lives (IHAL) in September 2013.

1.6 This Policy Statement sets out our vision of how Southampton will respond to the needs of people with learning disabilities and behaviours that challenge, whilst meeting the needs of their carers.

1.7 The Challenging Behaviour includes members from Health and Social Care across children's and adults' services. Throughout the process we have engaged with stakeholders including service users and their families/carers, advocacy agencies, Solent NHS Trust, Southern Health Foundation Trust, Voluntary Sector agencies and Housing.

1.8 The Policy Statement provides the city with a clear direction of travel for the next five years in order to make necessary changes to support improvements in health and well-being for individuals who present behaviour that is challenging.

1.9 The key areas of priority within the Policy Statement include ensuring:

- safeguarding systems are proactive, rather than reactive;
- the safety of persons at risk by integrating strategies, policy systems and services within the framework of relevant legislation and promotion of human rights.
- that prevention occurs in the context of person-centred support and personalisation, empowering individuals to make choices and supporting them to manage risks.
- that the health and social care system have robust quality monitoring in place.
- that information systems are capable of identifying and recording people with challenging behaviour across health, education and social care systems.
- that there is comprehensive implementation across GP practices of annual physical health checks, with targeting of individuals at high risk, with access to expert opinion if needed.
- that the outcomes for young people who present challenges are improved through the development of the 0-25 SEND Service and associated pathway for transition.
- that plans are in place that meet the needs of people with learning disabilities who are ageing.

1.10 The key areas for improvement (service gaps) include the following themes and these have been informed through consultation with the Learning Disabilities Partnership Board:

- People living Out of Area
- The need to develop supported living services for individuals currently living in inpatient care and residential care facilities, by implementing the Complex LD Housing Business Case
- Reviewing how adults "at risk" due to challenging behaviour are monitored and supported through the Winterbourne at risk register, taking learning from children's services.

- ensuring access to meaningful activities
  - improving the vocational educational. opportunities for individuals and developing supported

employment for individuals “at risk” due to challenging behaviour.
- reviewing day activities available to “at risk” individuals.

- Healthcare
  - reviewing the role of the Community Learning Disability Team and the Intensive Support Team.
  - ensuring that all individuals at risk due to challenging behaviour have an annual health check, are supported to access all relevant screening programmes.
  - reviewing how GP’s are supported to assess, diagnose and treat individuals with highly complex needs, taking learning from children’s services.
  - reviewing all physical intervention approaches to ensure that individuals and cares are safe and well supported.

- Housing – supported by the Complex Housing Group
  - strengthening partnership work with housing providers to ensure that suitable accommodation is available, to prevent crisis, reduce admissions to inpatient services and prevent placement in residential care out of area.

- Carers/siblings & Respite and short breaks
  - ensuring that carers and family siblings are well supported, have access to appropriate training and respite care is available.

- Education
  - ensuring that children and young people at risk are supported and special schools work in partnership with families.
  - ensuring there is provision for further and lifelong education for people with behaviour that challenges.

- Transition
  - implementing 0 – 25 Services and ensuring that individuals and families have access to specialist knowledge and skills to assess and manage behaviour that challenges.

- Workforce Development
  - development and audit of a Good Practice Standards Checklist and developing a system wide workforce strategy.

1.11 The scope of the Policy Statement includes:

- Children from birth through to adults of all ages who have a Learning Disability and Challenging Behaviour and who live within the boundaries of the city. In addition, the health aspects of the project will extend to those who are registered with a Southampton GP regardless of their Ordinary Residence.
- Children or adults who are currently not resident within the city but for whom the LA or Southampton CCG are the responsible commissioner, for example those individuals placed in out of area placements.
- The parents and carers of those with LD and Challenging Behaviour who meet the criteria above/or who are at risk of this.

1.12 To support the change needed, the Challenging Behaviour Local Implementation Group (LIG), was formed in October 2012. This group is committed to a programme of action to transform health and care services and improve the quality of the care offered to children, young people and adults with learning disabilities or autism who have mental health conditions or behaviour that challenges to ensure better care outcomes for them and to improve their quality of life.

2.0 Background

2.1 The Policy Statement aims to understand and support differing communities to ensure that services are fit for purpose. It will be respectful of culture and work in the individual's best interest with individual human rights paramount.

2.2 The overall aim of the Policy Statement is for people with learning disabilities, who present challenges, to be able to lead fulfilling and purposeful lives within their local communities, optimising their health and wellbeing.

2.3 The way that support has been delivered has changed considerably over the years. Until the 1950s, it was generally accepted that people with learning disabilities could enjoy a better quality of life living with other disabled people in segregated institutions rather than in the community with their families.

2.4 In 1971 the Government produced a White Paper "Better Services for the Mentally Handicapped" which recommended that long-stay hospital settings for people with learning difficulties should gradually be replaced with support in the community.

2.5 Thirty years later in 2001 they published the White Paper Valuing People: A New Strategy for Learning Disability for the 21st Century which committed the Government to helping people with learning

disabilities to live “as normal a life” as possible, without unnecessary segregation from the community.

2.6 Community services were developed, in the form of Locally Based Hospital Units (LBHUs) and an increase in residential care (group homes). Additionally parents were better supported to care for their children into adulthood.

2.7 Southampton set up a programme of work in 2005-2008 to move people from LBHUs to individualised supported living schemes within the city. Investment was made by the Department of Health which supports capital investment in housing. This programme was driven nationally by the Department of Health, under Campus Re-provision standards. The investment improved the quality of life for those individuals. However, no additional funding was identified from the Department of Health to support the ongoing generations of people requiring bespoke housing to support their needs. It is expected health and social care organisations will work with a broader range of stakeholders to develop local services to support ongoing need.

2.8 In 2007 the Department of Health released the Mansell Report “Services for people with learning disabilities and challenging behaviour or mental health needs” which highlighted that the lack of development of appropriate services for people with Challenging Behaviour had led to an increase in the use of expensive placements away from the person’s home and not necessarily of good quality.

2.9 Client engagement from the Valuing People National Policy group also highlighted that people wanted more independence and choice. The City Council has introduced Personal Budgets and a person who is eligible for adult social care funding can have their personal budget as a direct payment (paid directly into a bank account) or as part direct payment and part directly provided services (a traditional care package managed by the Council). Unlike direct payments in the past, a personal budget can be used more flexibly to meet a person’s assessed needs. Southampton City Council and Clinical Commissioning Group (SCCCG) are implementing Personal Health Budgets from April 2014 which will be actively offered for those individuals meeting Continuing Health Care needs.

2.10 Think Local Act Personal (TLAP) is a national, cross-sector leadership partnership focussing on maintaining the impetus towards personalised, community-based social care and is driving forward these changes which SCCCG support.. SCCCG is a pilot area for implementation of personal health budgets, and we are encouraging individuals and their families who may have behaviours that challenge to take control of their support. This will provide better outcomes for this population.

2.11 The Mansell Report (2007) describes a positive style of commissioning, where local services are sought that really do address individual needs, and therefore give higher priority to funding services with more staff and more training and management input.

2.12 Preventing challenging behaviour is achieved through understanding the reasons for a person's distress, by recognising their vulnerability, anticipating their needs and designing care accordingly.

3.0 What is Behaviour That Challenges?

3.1 This Policy Statement is about the practice of supporting people with learning disabilities who present behavioural challenges. The terms, 'challenging behaviour' and 'learning disability', are often applied with wide variation and inconsistency. Challenging behaviour is a description of a set of problems, not a diagnosis in its own right.

3.2 Mencap defines a Learning Disability as reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone people for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

3.3 The Challenging Behaviour Foundation have identified that challenging behaviours are more common in people with a learning disability as compared to their peers without a learning disability.

3.4 The term 'challenging behaviour' has become distorted from its original meaning and has come to be misused as a diagnostic label. Severely problematic or socially unacceptable behaviour should be seen as a challenge to services rather than the person being stigmatised as being violent and aggressive. This Policy Statement seeks to respond to this challenge by promoting positive behavioural support, reducing the occurrence of damaging behaviour and maintaining people's access to a decent quality of life despite continuing behavioural difficulties.

3.5 This Policy Statement acknowledges the difficulty in defining and categorising behaviour which can be seen as subjective. There are differing understandings of the levels of challenging behaviour – for example an informal carer at home may classify behaviour at a different level than someone who is working in an inpatient setting. For the purposes of this document the following definitions around behaviour have been adopted:

- "We have defined Challenging Behaviour as culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is

likely to seriously limit use of, or result in the person being denied access to ordinary community facilities" (Emerson1995).

- The report “Challenging behaviour: a unified approach” (Royal College of Psychiatrists,: March 2007) proposes the adoption of a modified definition that builds on that of Emerson: “Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion”. This report indicates that a person with a learning disability may be expressing unhappiness in their current environment through their behaviour and that all behaviour has meaning or function and does not occur in isolation. It identifies that there are a number of underlying causes of behaviour that are a challenge to others.

3.6 One of the main functions of learning disability health teams in the UK is to work with people with a learning disability whose behaviour presents a challenge.

3.7 For the purpose of this document three categories of behaviour have been identified and it is acknowledged that this can be subjective to perception and experience:

1: **episodic behaviour** that challenges – mild behavioural difficulties that are not continuous.

2: **moderate behaviour** that challenges which is managed with the right support where the behaviour poses some challenge or risk to self or others.

3: severe behaviour that challenges and which poses a serious and constant challenge or risk to self or others.

3.8 Behaviour that Challenges is a demonstration of distress and an attempt by the person to communicate their unmet needs. It may result from an individual feeling threatened, fearful or anxious or be in response to a difficult situation, or a misinterpretation of the actions of other people. The behaviour can be in response to:

Environmental factors - for example:

- Over or under stimulating environments.
- Inappropriate supports.
- Poorly organised supports.
- Lack of understanding of support staff/carers.

Personal factors - for example:

- Mental ill health, autism, and syndromes with a risk of high behavioural support needs.
- Physical (for example pain).

- Emotional (for example bereavement).
- Communication difficulties.

3.9 The consequences of not addressing challenging behaviour can be far reaching and can include:

- Ineffective delivery of healthcare.
- An overreliance on anti-psychotic medication, seclusion and physical interventions (Restrictive Practice).
- An increase in physical injuries and psychological ill health among Clients, staff and families.
- Inability of an organisation to meet its legal duties to protect staff and vulnerable individuals.

3.10 This Policy Statement aims to improve the management of people who are at risk of behaviour that challenges whilst improving the approaches, skills and attitudes that minimise distress and meet needs. Practical strategies need to be developed to risk assess and manage behaviour that challenges.

3.11 Assessment and intervention must address the person, the environment and the interaction between the two as challenging behaviour is a product of an interaction between an individual and their environment. Historically challenging behaviour was managed by high levels of sedative medication and punitive approaches. These approaches are now discredited although a culture of blaming the individual is still present in services and society. Non-punitive approaches are now recognised as being best practice, rewarding and supporting positive behaviour.

4.0 Why changes need to be made

4.1 Historically individuals with learning disabilities who present challenges have often been excluded from some services or experienced restrictive or abusive care. These individuals have the same rights as others to an equitable service. This will be seen as inclusive services that provide a genuine choice of service options to people in their local community.

4.2 People with learning disabilities who present challenging behaviours are often marginalised, disempowered and excluded from mainstream society. Although long stay hospital provision has almost disappeared, there has been a growth in the provision of a range of residential and long stay care which can compromise the values of enabling people with learning disabilities to live ordinary, non- segregated lives.

4.3 In May 2011, The BBC Panorama programme – “Undercover Care: The Abuse Exposed”, showed disturbing scenes of people with a learning disability and autism being abused in a secure hospital at

Winterbourne View in Bristol. In October 2012 the BBC broadcast a follow up Panorama programme, "Winterbourne View - the hospital that stopped caring". Using undercover footage the programme revealed new evidence of poor training and false record-keeping.

4.4 The abuse revealed at Winterbourne View hospital was criminal. Staff whose job was to care for and help people instead routinely mistreated and abused them. Its management allowed a culture of abuse to flourish. Warning signs were not picked up or acted on by health or local authorities.. A key lesson is that when delivery of care is sub-standard, a person's distress can be exacerbated and perpetuated leaving staff unable to cope, and abusive practices can become the norm. The abuse at Winterbourne View Hospital had serious repercussions on the safety, wellbeing and dignity of patients.

4.5 In response to this the Local Government Association and NHS Commissioning Board (NHSCB) have established a joint improvement programme to provide leadership and support to transform services locally. This involves key partners including the Department of Health (DH), The Society of Local Authority Chief Executives and Senior Managers (SOLACE), the Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) and the Care Quality Commission (CQC) and will closely involve service providers, people with learning disabilities and autism and their families in their work. The Concordat aims are to:

- Ensure better care outcomes so that people have fulfilling and safe lives in local communities.
- Change and improve the quality of care and support for all people with learning disabilities or autism, who have mental health conditions or behaviour that challenges, and their carers.
- Transform the way services are commissioned and delivered, in a sustainable manner.
- Support local areas to work together to commission a range of personalised support, and
- Allow individuals a voice and a choice in how these services are designed and delivered.

4.6 For many people however, even the best hospital care will not be appropriate care. People with learning disabilities, which may include autism, will sometimes need hospital care but hospitals are not where people should live. Too many people with learning disabilities, which may include autism, are doing just that.

4.7 The Policy Statement identifies areas of development that will support our commissioning intentions including ensuring systems are in place for preventative measures and early identification in order to avoid crisis. The responses to the survey sent to families, carers, providers

and people whose behaviour challenges indicated that people want support before they reach a crisis point.

5.0 National Policy Drivers

5.1 General learning disabilities national priorities which underpin this Policy Statement are outlined in the overarching Strategy "Valuing People". However, there are a number of specific policy initiatives and key reports that have fundamentally influenced the development of this Policy Statement.

5.2 On an annual basis we have a requirement to undertake the Joint Health and Social Care Learning Disability Self-Assessment Framework. This is a single delivery monitoring tool that supports Clinical Commissioning Groups (CCGs), and Local Authorities (LAs), to assure NHS England, Department of Health and the Association of Directors of Adult Social Services on the following:

A. Key priorities:
- Winterbourne View Final Report
- Adult Social Care Outcomes Framework
- Public Health Outcomes Framework
- National Health Service Outcomes Framework
- Health Equalities Framework

B. Key levers for the improvement of health & social care services for people with learning disabilities:
- Equality Delivery System
- Safeguarding Adults at Risks requirements
- Health & Wellbeing Boards
- Consultation and co-production with people with learning disability and family carers

C. Progress Report on Six Lives and the provision of public services for people with learning disabilities.

5.3 This assessment has subsumed the previous LD Health Self-Assessment Framework (health led) and the Valuing People Annual Report (local authority led). It seeks to combine both previous reports, and local authorities are asked to the lead the return. There is a requirement to take our return the Health and Well being Board for sign off on an annual basis.

5.4 In December 2012 the Dept Health Final Report "Transforming care: A National response to Winterbourne View Hospital" was released. This draws firm conclusions about what went wrong:

a. No one commissioner had a lead or strong relationship with the hospital
b. Almost half of the patients were placed a long way away from their homes
c. For just under half of the patients the main reason for referral was crisis management suggesting a lack of local responsive services
d. People were staying for lengthy periods – with the average stay 19 months but some people were there for over 3 years
e. There was a very high number of physical restraints
f. Opportunities to pick up poor quality of care were repeatedly missed by multiple agencies
g. Routine healthcare checks were not being attended to
h. Patients had limited access to advocacy and complaints were not dealt with
i. There was a failure by commissioners to follow up on safeguarding concerns
j. There was a failure to monitor the assessment of individuals' needs or to promote their rehabilitation
k. The lack of any substantial evidence that people had meaningful activity to do in the day
l. Staff recruitment and training did not focus on experience in working with people with learning disabilities or autism and challenging behaviour. The training focused on restraint techniques

5.5 We recognise that there are some areas for improvement in Southampton and therefore our rationale for change will be based around our learning from the events at Winterbourne View. Whilst we have not found any evidence of abuse we acknowledge that we too have some of the above issues as follows:

a. We do have a number of people out of area and we are planning for their return. We are aware of blocks in the system around housing and have set up a Complex Housing Group which is working towards bespoke housing.
b. We recognise that our prevention and response to an individual's crisis could be better managed to enable the person to be well supported locally.
c. Currently not enough people in Southampton with a learning disability are accessing their Annual Health.
d. We need to maintain access to advocacy services and will be re-commissioning services in 2015.
e. We need to review the need for residential respite and develop more individual options – this review has commenced.
f. People need to be supported to access employment and community based services and have things to do during the day. A review of in house day support will be undertaken in 2014.

g. An autism training strategy and standard has been developed.

5.6 In 2007, Mencap released its report “Death by Indifference”, which revealed that people with learning disabilities were not being treated as well as other people by the NHS. This was followed by the independent Michael report the following year, which found that the NHS was failing to ensure equal access to care for people with learning disabilities.

5.7 On 5th December, 2013 the NHS launched a new guidance document ‘Meeting needs and reducing distress: Guidance for the prevention and management of clinically related challenging behaviour in NHS settings’. The purpose of this guidance is to provide practical strategies to prevent and minimise a person’s distress, meet their needs and ensure high quality care is delivered within a safe environment whilst in NHS settings.

5.8 The Care Act 2014 takes forward the Government’s commitments to reform social care legislation and with carers being treated as equal to the person they care for – putting them at the centre of the law and on the same legal footing.

5.9 An Independent Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) followed the “Death by Indifference” Report. This inquiry was tasked with investigating the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. In summary the findings were that the quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. Recommendations from the report are in Appendix 1.

5.10 The Five Good Communication Standards (Royal College of Speech and Language Therapists) 2013, outlines the standards as:

Standard 1: There is a detailed description of how best to communicate with individuals.
Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.
Standard 3: Staff value and use competently the best approaches to communication with each individual they support.
Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate.
Standard 5: Individuals are supported to understand and express their needs in relation to their health and wellbeing.

Everyone that supports an individual with a learning disability and or challenging behavior must work towards these standards.

6.0 Local Policy Drivers

6.1 TLAP (as mentioned within background) brings together people using social care and family carers with central and local government, major provider bodies, third sector, voluntary and other key sector groups. It is complemented by the support of many additional organisations and initiatives and links strongly to regional and local groups concerned to support personalisation.

6.2 Within Southampton these national drivers are being addressed through Southampton's Integrated Commissioning Unit, working jointly across health and social care.

6.3 Moving away from traditional models of care, services should now support service users to maintain their interests and ambitions and to have choice and control over key decisions in the care and support they receive. This ambitious shift in focus requires Providers to offer more innovative, flexible and responsive care which works with the individual, their carer and family to ensure needs are met in an individualised way.

6.4 This agenda presents real opportunities to improve commissioning practices and service provision but means commissioners and providers will face many practical challenges in order to build more responsive, personalised services that promote independence.

7.0 How Many People Present Challenges to Services?

7.1 Defining behaviour that challenges presents its own difficulties. It can be subjective to peoples' differing skills and tolerances. Behaviour can vary in intensity, duration and frequency and can be reactive to poor environmental management.

7.2 Behaviour that presents challenges is an area of immense clinical and social need. Between 10% and 15% of people who are supported in learning disability services show behaviours that are considered to cause a serious management problem, or would do without specific measures being in place (Emerson et al, 1997). These behaviours are generally seen as presenting a risk to the person (e.g. self injury, running off, eating inedible objects etc) or a risk to others (e.g. aggression, destroying furnishings, inappropriate sexual behaviour etc).

7.3 Prevalence rates for seriously challenging behaviours were comparable to those reported in the earlier studies, thus confirming previous findings. The prevalence of less serious challenging behaviour also has major clinical significance and emphasises the need for enhanced understanding and skills among personnel within primary and secondary tier health, education and social care services, and for strengthening the capacity of community teams to provide behavioural expertise.

7.4 Challenging behaviour (e.g. aggression, self-injury, destruction of environment) is a long-term, high-impact health problem in people with learning disabilities which is seen in about 10–15% of the population. It peaks at the ages of 20–50 and has severe impact on individuals and their social network as it can lead to exclusion and placements out of area. (UCL Policy Briefing Lessons for the Care of People with Learning Disabilities and Challenging Behaviour 2011).

7.5 Behaviour that presents challenges is the single most likely reason for someone to be placed in an out of city placement. A study undertaken in 2006 (Goodman et al) in the West Midlands showed that across two Strategic Health Authorities (total population 3.91 million), 623 adults were placed out of area at a cost of £35 million per year. 'Behaviour that presents challenges' and 'autism' were the main reasons given for the placements.

7.6 The number of people identified as challenging services is small in any given area. Estimates vary but it is likely that about 24 adults with a learning disability per 100,000 total population present a serious challenge at one time. The numbers of young people who challenge services and are in transition to adulthood are believed to be increasing and so will also need consideration. The length of time needed for support also varies but it is likely to be long term, and many people may present a serious challenge for much of the time or throughout their life. (Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (Revised Edition), DH (Ed Prof J Mansell) 2007).

7.7 However, this comparatively small number could increase substantially if learning disability services as a whole are not skilled at supporting people with less complex behaviour who, if supported inappropriately, have the potential to place greater demands on services. Commissioners therefore need to pay attention to ensuring a general level of service competency in working with people who challenge, as well as ensuring that there are specialist skills available for working with the smaller number of people whose behaviour challenges services significantly.

8.0 How Many People Who Present Challenges are from Southampton?

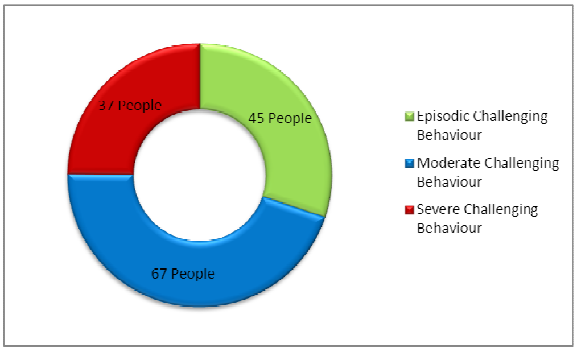
8.1 Public Health Southampton Intelligence Briefing Paper - Southampton Learning Disability Profile July 2012 details that "In England approximately 1.2 million people have learning disabilities (LD). This means that roughly 2% of the population has a learning disability although only 21% of this 1.2million were known to learning disability services." In Southampton the numbers of children and adults with a learning disability known to services is shown in the chart below, however the figures do not reflect the estimated 2% of Southampton's population of approximately 243,336

Table 1:

Number of People with a Learning Disability in Southampton (Dec 2013)		
0 -13 years		466
14 -17 years		187
18 - 19 years	31	
20 – 29 years	288	
30 – 39 years	185	
40 – 49 years	208	
50 – 59 years	175	
60 - 69 years	117	
70 - 79 years	39	
80 and over	13	
Total	**1056**	**653**

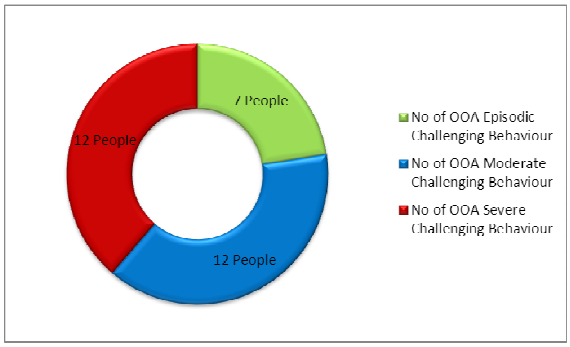
8.2 Emerson et al (1997) report that between 10% and 15% of people who are supported in learning disability services show behaviours that without specific measures would cause a serious management problem.

8.3 In Southampton 149 adults have been identified as having behaviour that challenges out of a total of 1056 known to services (i.e. 14%).This equates to 3% of the learning disability population of 4927. The following chart identifies the level of behaviour for these 149:

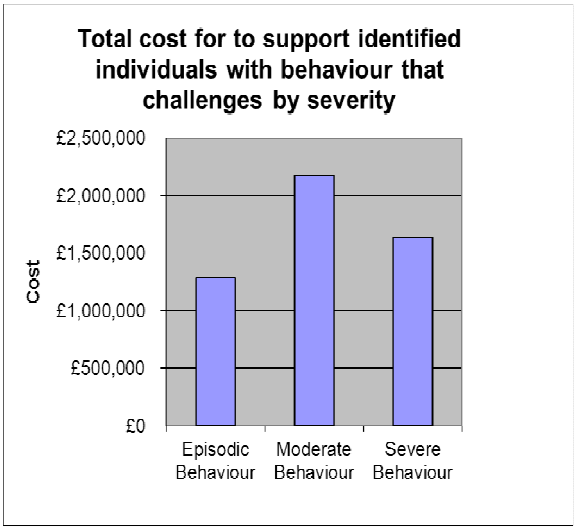


8.4 Goodman et al, (2006) identified “Behaviour that presents challenges is the single most likely reason for someone to be placed in an out of city placement”.

Out of the above 149 adults with challenging behaviour, 31 have been placed outside the city. The following chart identifies the level of the behaviour for these 31 adults:



8.5 The total cost to Southampton City Council and Southampton CCG to support the care of the 31 adults identified is £5,099,693 This can be broken down in the following ways:



8.6 We need a strategy to make sure that our community’s resources are used in the most effective ways to support people with a learning disability and their families locally now and in the future. To enable

this, people with learning disabilities who present challenges, need a co-coordinated approach to their support needs. This needs to be an evidenced based strategy based on research and best practice.

8.7 We need to have a multi-professional/multi-agency approach to service development and improvement, which comprises of a skilled responsive workforce that can meet the specific needs of people with learning disabilities who present challenges.

9.0 Safeguarding and Quality

9.1 SCC and health employees working across a broad range of teams and services have responsibility for implementing the Safeguarding Adults Multi-agency Policy, Procedures and Guidance and to ensure that the range of local Safeguarding Adults procedures is followed. Following training, practitioners and managers in a number of teams, and the Safeguarding in Provider Services team have responsibility for assessing, investigating and managing Safeguarding Adults concerns in partnership with other agencies.

9.2 Safeguarding Adults Multi Agency Policy has been developed by the four local safeguarding adults boards (4LSAB) covering Hampshire and the Isle of Wight to meet the requirements of No Secrets (2000), Department of Health and to support current good practice in adult safeguarding.

9.3 This Policy represents the commitment of organisations to work together to safeguard adults. Each local partnership is committed to adopting this Policy so that there is a consistent framework across Southampton, Hampshire, Isle of Wight, and Portsmouth in how adults are safeguarded from abuse, neglect and exploitation.

9.4 The report on the consultation on No Secrets (2000) found that prevention should be the foundation of safeguarding services. Our action plan details how this should lead to the services that people want to use, with the potential to prevent crises from developing.

9.5 Physical restraint of individuals is sometimes required to protect individuals, other service users and staff from injury and harm. Physical restraint must be viewed as a last resort with a greater emphasis place on diffusion strategies and techniques. Within the health, social and education system, staff are provided with varied training and skills to manage dangerous incidents. There is a need to review these approaches and standardise the approach so that staff and carers who work across settings are familiar and skilled. There is also a need to ensure that any restraint used is recorded, reported, reviewed and evaluated to ensure that the person is being supported in the best way possible.

9.6 In April 2014 the Department of Health released the Policy "Positive and Proactive Care: reducing the need for restrictive interventions". Increasing concerns about the inappropriate use of restrictive interventions across health and care settings led to this guidance. Across the full range of health and social care services delivered or commissioned by the NHS or local authorities in England, people who present with behaviour that challenges are at higher risk of being subjected to restrictive interventions. Many restrictive interventions place people who use services, and to a lesser degree, staff and those who provide support, at risk of physical and/or emotional harm. Appendix 2 outlines the key actions from this Policy.

9.7 One commonly used approach in Southampton and nationwide is the LaVigna Multi Element framework, which is widely used within positive behaviour support services. This framework looks at four intervention areas to reduce challenging behaviours and is intended to work as a long term group of interventions. The areas are:

- ecological strategies (to better meet the person's underlying needs and match the environment to these needs).
- positive programming strategies (to develop functional skills the person may then use instead of challenging behaviours to meet their needs).
- focused support strategies (to bring about rapid reduction in the severity and frequency of challenging behaviours).
- reactive strategies (to reduce the severity/impact of incidents as they occur).

9.1 Southampton's Integrated Commissioning Unit's (see below) ongoing monitoring with residential care providers ensures that the provision can demonstrate compassionate care and value based recruitment. The Quality Team runs quarterly forums for residential and domiciliary care providers where guest speakers share good practice.

9.2 In order to prevent people being detained against their will inappropriately, the 'Deprivation of Liberty Safeguards' (DoLS) came into force in 2009 and are an amendment to the Mental Capacity Act 2005. They apply in England and Wales only. The Mental Capacity Act allows restraint and restrictions to be used – but only if they are in a person's best interests. Extra safeguards are needed if the restrictions and restraint used will deprive a person of their liberty. These are called the Deprivation of Liberty Safeguards. The Deprivation of Liberty Safeguards can only be used if the person will be deprived of their liberty in a care home or hospital. In other settings the Court of Protection can be asked if a person can be deprived of their liberty. Care homes or hospitals must ask either a local authority or health body if they can deprive a person of their liberty. This is called requesting a standard authorisation. There are six assessments which have to take place before a standard authorisation can be given. If a

standard authorisation is given, one of the most important safeguards is that the person has someone appointed with legal powers to represent them. This is called the relevant person's representative and will usually be a family member or friend. Other safeguards include rights to challenge authorisations in the Court of Protection without cost and access to independent mental capacity advocates (IMCAs).

10.0 Local Commissioning Framework

10.1 Southampton's Integrated Commissioning Unit (ICU) is made up of two key partners - Southampton City Clinical Commissioning Group (SCCCG) and Southampton City Council (SCC).

10.2 The ICU commission in a more joined up way so that outcomes can be improved for residents in Southampton. Treating health, public health, social care, and other local authority functions such as housing, education and leisure, as a whole system rather than lots of individual services will improve outcomes, make it easier for people to understand and access services and make better use of our resources.

10.3 The ICU has made a strategic shift towards commissioning services which focus on better and more effective use of resources. There are three commissioning work streams:

- Prevention and Positive Lives.
- Supporting families.
- Integrated Care for Vulnerable People.

10.4 This third work stream (Integrated Care for Vulnerable People 2013 – 2015) aims to prevent or intervene early to avoid, reduce or delay the use of costly specialist services whilst promoting independence, choice and control in the community through integrated risk profiling and person centred planning processes. The high level outcomes are:

- More individuals have a personalised care plan and greater use of direct payments/personal health budgets, providing greater choice and control.
- Reduction in the use of acute services and residential care.
- Increased access to self-help/management information.
- More people using self management approaches.
- Reduction in delayed discharge /transfers of care.
- Greater mobilisation of community services focusing on person centred care.
- Fewer permanent admissions to nursing and residential homes.

10.5 Southampton's analysis of the needs of people with a learning disability is set out in detail in our draft overall Lifelong Disabilities Strategy. This

describes how needs are changing and increasing. Looking ahead, over the next ten years there will be increasing numbers of:

- young adults with a learning disability, including young adults with the most complex needs, with autism, profound and multiple learning disabilities and behaviours which challenge services.
- people living with older family carers.
- older people with a learning disability and therefore with an increased likelihood of dementia. People with a learning disability may develop dementia up to 30 years before the rest of the population.
- people with a learning disability from different cultures who may have a cultural model of disability.
- people for whom English is a second language.

10.6 Since September 2011 Southampton has been working as a Pathfinder, with families and professionals to develop a number of areas in response to the governments proposed Special education Needs & Disability (SEND) reforms, including:

- Development of an Education, Health & Care Plan (EHCP).
- Development of a Local Offer.
- The option for families to have more choice and control over their support through Personal budgets.
- Joint commissioning of services between the Council and SCCCG.

10.7 The ICU and our broader safeguarding function, driven by the Safeguarding Adults Multi Agency Policy (2013) have a role in improving the quality of provision for vulnerable people.

10.8 The strategic direction for the Council and SCCCG for improving health and social care for people with learning disabilities is through established pooled budgets, joint commissioning arrangements and the development of integrated care and support pathways. This will ensure early intervention and better integration across health, housing and social care.

10.9 We know that a number of changes have occurred within the city over the last five years. Our successes include:

- Developing an Intensive Support Team that supports people with behaviours that challenges in order to support them more effectively and prevent crisis/breakdown.
- Implementing better systems across the operational teams so that we joint work more effectively.
- Developing alternative forms of communication (e.g. the iPad system), that supports people to communicate using a range of apps, that enhances outcomes and access to primary and secondary health care services.

- Working with housing partners, so we can plan more effectively for future generations.
- Focusing advocacy services on those with more complex needs, so that equality of access to services is strengthened.
- Working in partnership with West Clinical Commissioning Group, and the Commissioning Support Unit, to commission more effectively assessment and treatment provision, for those that do require these services.
- Focusing on quality of provision, using the Francis Inquiry guidance, to ensure that we see services, assess their quality at the front end of service delivery, and work with providers to develop improvement plans where service delivery is not to the standard we require.
- Southampton's Multi Agency Resource panel (MARP) was set up to discuss the needs of complex children who required consideration outside the normal funding processes of each of the statutory services and an agreement of how such needs would be funded by each of the agencies. This prevented overlap of funding and joint responsibility and management of these children. It also provided a forum to anticipate needs and planning in order to reduce the need for crisis management. The MARP process updates the plans it agrees, including reviews of the placements that may be used for these young people for their continued appropriate use.

10.10 We know that there remain challenges for the system and therefore the Challenging Behaviour Local Implementation Group has been established. This is multi agency group that focuses on the Policy Statement requirement and action plan for the next five years. This group reports to the Learning Disability Partnership Board (LDPB), the Southampton Safeguarding Adults Board (SSAB), the Integrated Commissioning Board and the Health and Wellbeing Board (HWWB).

11.0 Our Vision, Objectives and Outcome

11.1 To support the change needed, the Challenging Behaviour Local Implementation Group (LIG), was formed in October 2012. This group identified the following Vision, Objectives and Outcomes to be achieved. The Group recognises that wider consultation with users, families and services is needed and that the policy and priorities may shift as a result.

- Each person will be regarded as a full and valued member of the community of their choice with the same rights as everyone else, and with respect to their diversity.
- Each person has the right to receive person centred services, which are flexible and responsive to changes in their circumstances, health and wellbeing.

- We will provide support and training to carers and families who are supporting people who they find challenging.
- We will ensure that services are delivered in the least restrictive manner and are able to respond to individual needs.
- We will strive to continually improve using the latest evidence to provide best treatment, care and support.
- We will work in partnership with individuals, their natural carers and across the full range of services (the voluntary sector, providers, GPs and the police) to ensure good quality integrated support.
- We want people with learning disabilities whose behaviour challenges services to be fully included in their local community with access to appropriate accommodation.
- We will ensure that we safeguard their wellbeing.
- We will work with commissioners to ensure that opportunities for short breaks tailored to individual needs are available to every family supporting a person whose behaviour presents a challenge at home.
- We will work with commissioners to look at reducing the reliance on specialist challenging behaviour homes to that of developing more individualised local solutions.

11.2 Objectives:

- There will be a competent and appropriate workforce and this will be evidenced and this includes providers and staff.
- Families will feel supported in a crisis.
- Strategies, policy systems and services will be integrated within the framework of relevant legislation to ensure that the promotion of human rights and the safety of persons at risk.
- People who are identified as at risk will have their services monitored.
- Person centred plans and advocacy will be available and plans will be monitored to ensure implementation.
- data collection on people who challenge services will be used to improve services.
- comprehensive implementation across GP practices of annual health checks with referral to specialist services where applicable.

11.3 Outcomes from the vision:

- An increase in people moving back to Southampton, if they choose to
- An increase in people with behaviours that challenge will be involved in meaningful activities based on their Person Centred Plan
- More people will be in work/exploring work options
- More people will be in supported living accommodation

12.0 Where We Are Now?

The Challenging Behaviour LIG has undertaken consultation with experts from a range of services and professionals to develop and map services against models of care that should be delivered under the Winterbourne View Report. These areas for development are detailed below:

Area for Development - People out of area A	
Current Position and Identified Gaps	• There are currently approximately 33 people with a learning disability with behaviour that challenges who are residing more than 10 miles out of Southampton. This is due to historic placement patterns due to lack of local provision. • There are currently five people identified that are receiving care and treatment within inpatient settings/medium secure units. • There are a further 18 people that have been identified that are at risk of needing bespoke arrangements to meet their needs. • Work is underway to identity the risks of maintaining the care for these individuals and plans put in place to mitigate concerns. Individuals and families will be fully involved in the development of these plans as appropriate. • All individuals (known to the CCG) have an allocated Continuing Health Care Case Manager who liaises with NHS England (Specialist Commissioning) regarding those within inpatient settings. • The level of planning for individuals varies and consistency across health and social care needs to be improved. Continuity concerns and crisis response time for distance placements are an issue.
Recommendations	A1. Undertake a review of the local (Winterbourne) register to improve risk management and implementation of care plans, preventing crisis and improve the planning and delivery of services locally. The review to take the learning from the existing Multi Agency Resource Panel process in place in local Childrens services. A2. Ensure Personal Health Budgets are used as appropriate

Area for Development - Access to meaningful activities B	
Current Position and Identified Gaps	• Person Centred Planning and Advocacy available to all with a learning disability through commissioned services. • There is a lack of services to support individuals who present challenging behaviour locally.

	• The skills of local day support staff are limited. • Individuals have very limited opportunities to work, or access education and leisure opportunities. • There are limited supported employment services, with access to job finding and job coaching expertise limited.
Recommendations	B1. Review of day support services to be undertaken in 2014. B2. Development of Supported Employment Strategy to ensure that expert skills are developed for individuals to access.(e.g. a range of employment opportunities to be explored for individuals including, job carving, micro firms, and cooperatives B3. LD Advocacy will be re-commissioned in 2014, to ensure that the needs of people with complex needs and behaviour that challenges are met within the city.

Area for Development - Health care for individuals at risk due to challenging behaviour *to include physical, mental, specialist roles (Prader Willi), support in a crisis – inpatient care.* **C**	
Current Position and Identified Gaps	• Too few people with a learning disability and behaviour that challenges are accessing their Annual Health Check (42% in 2012/2013) and that some behaviour may be as a result of a physical condition. • 74% of the LD population had their BMI recorded in the last two years and 36% of these are in the obese range and 0.6% in the underweight range. • 2.3% of adults with a LD are known to have coronary heart disease, 6% diabetes, 14% asthma, 2.6% dysphasia and 13% have epilepsy. • The health needs of individuals with a learning disability are gaining greater recognition in the Joint Strategic Needs Assessment (JSNA). • One LD Hospital Liaison Nurse at Southampton General Hospital covers the whole of the admissions for Hampshire. • The role of the Community LD Specialist Teams and the Intensive Support Team needs to be reviewed to ensure that health priorities are being met. • A subsequent skill mix review will be required to ensure that individuals who present challenges have access to specialist therapy e.g. Speech & Language Therapy and Psychology and specialist nurses as all behaviour is communicative in nature. • Improved access to telecare and telemedicine technology is needed to improve the assessment and support of individuals who present challenges. • A review of the need for inpatients care beds is required to inform future commissioning intensions. • A review of mental health provision needs to be made to ensure that all aspects of the “Greenlight toolkit”, which sets out best practice, have been adequately addressed locally. • Work needs to be undertaken to map out the current use and competence of staff deploying the range of physical restraint

	approaches being used • People have been placed in our area as they have a Southampton GP but they may not have any link or connection to the area. • Children's medical needs are mainly managed by Paediatricians however at transition this reverts to the GP who may not have the history or the expertise around genetic complexities.
Recommendations	C1. Annual Health Checks for people with Learning Disabilities are offered to those that may challenge services, and reasonable adjustments are made to support access and improved quality of the checks C2. Health Action Plans templates are widely available and used throughout services so that prevention/early intervention is across the system C3. Improve take up of Health Screening for people with a LD particularly Cervical and Bowel. Breast screening is more in line with the General Population. C4. Review access to expert physician support to assess, diagnose and treat individuals who have physical health causes for challenging behaviour C5. Review Joint Strategic Needs Assessment to ensure the health needs for LD citizens are recognised. C6. Review the role and function of the Intensive Support Team C7. Undertake a skill mix analysis of Community LD Specialist Team. C8. Improve access to telecare and telemedicine technology to support the assessment and care of individuals C9. Review the need for future LD inpatients bed provision for individuals who present challenges. C10. Undertake a review of the mental health needs for individuals with a LD to ensure that service pathways implement reasonable adjustments. In children's services ensure gap is bridged between LD and Children and Adolescent Mental Health Service (CAMHS). C11. Review the physical intervention approaches being used in the City and develop an improvement plan.

Area for Development – Housing **D**	
Current Position and Identified Gaps	• Many individuals with a learning disability who have complex needs are currently cared for in residential care settings. • Individuals with complex needs benefit from bespoke service designs to more appropriately support their physical, social and

	psychological needs. It is recognised that individuals' health and wellbeing can be more effectively supported if the person has control over who, where and how they live. • Many people with behaviours that challenge still do not live in supported housing and remain either in high cost residential care, hospital placements or at home with families who can find it difficult to support them. • Re-assessment as needs change (particularly in children) takes too long. • Access to stock is poor. • There are poor or no adaptations especially in private rented accommodation. • For adults there is a lack of accommodation in appropriate locations due to noise level needs.
Recommendations	D1. Bespoke housing is available for individuals who are placed out of area (and those that require Supported Living Services) D2. The Disabilities Housing Panel ensures that housing needs are met for people with challenging behaviours.

Area for Development - Carers/siblings & Respite and short breaks **E**

Current Position and Identified Gaps	• Southampton, Hampshire, IOW and Portsmouth (SHIP) launched an online Directory of Services in November 2013 which provides information and support for carers and siblings of people with autism. • Mencap's Carers' sub group operates in Southampton. • Carers are members of the Learning Disability Partnership Board. • Family Link service is commissioned by Southampton Council. • Greater attention needs to be made to ensure that siblings are also offered support and opportunities to develop. Often siblings are not recognised as carers and there would be benefit in recognising their careering role and the impact this has on their life. • A service review of residential respite for people with learning disabilities with a strong focus on the provision for people with behaviour that challenges is currently being undertaken. Only one adult with severe behaviour challenges is currently accessing the council's overnight residential respite service. The service does not cater for this group mainly due to compatibility issues. • There are 10 children/young people with severe behaviour accessing the service and 4 are out of area as local services are unable to meet their needs. • Emergency respite with appropriately skilled staff is available but this does not extend to the severe behaviour group • Review of Learning Disabilities Respite provision to widen opportunities for those with complex needs include use of personal budgets for respite provision
	E1. City wide services for Carers Strategy ensure that carers and siblings of individuals with learning disability who present challenges are recognised as a priority. E2. Learning Disabilities Respite provision to widen opportunities for those with behaviour that challenges, including the use of increased personalised approaches respite provision

Area for Development - Schools/education F	
Current Position and Identified Gaps	These are the areas that it is felt need to be explored to establish the current position: • MASH (Multi Agency Safeguarding Hub), operational for children. • Head Start bid successful pilot in Polygon can support wider learning • Early Help teams in place with strong liaison across city services • Person Centred Planning takes place in all Special Schools. • There are a number of children excluded from school due to physical aggression/verbal abuse. Southampton has a high rate of excluding nationally and is deemed to be a significant

	issue. • There are a small number of children placed out of area due to their behaviour. • The ability of parent/carers to follow behavioural interventions with adequate support and training from services needs to be addressed in order to ensure improved behavioural management. • In relation to transport, there is a requirement to consider the journey length and any trigger linked challenging behaviour, including opportunities to reduce this if necessary. Transport escorts do receive training regarding the management of challenging behaviour. • Children's emerging sexuality and associated behaviours requires further work in terms of scope/improvements to services • Mental health needs of children with learning disabilities requires wider support to ensure improved management • Joint work between school and home to support continuity of interventions • Behaviour accepted as being part of a individuals disability creating long standing repertoire of behaviours which become increasingly difficult to manage as an individual grows • The city has a small group of psychologists that offer training regarding conflict management based on Positive Support
Recommendations	F1. MASH/Early Help/Head Start to offer effective and efficient services to children and young people presenting with challenging behaviour. F2. Parents and carers will be better skilled to support the children they look after that display challenging behaviour F3. The least restrictive interventions are used within schools and a programme of Positive Behavioural Support is embedded to ensure better outcomes and reduction in challenging behaviours

Area for Development – Transition G	
Current Position and Identified Gaps	• Southampton has an established Transitional Operational Group (TOG) and Transition Multi – Agency Resource Panel (MARP). Young people, who are perceived as likely to need specialist adult services, receive a professional coordinated transition into adulthood. • The Council and providers use a range of communication systems which can cause operational issues for service planning. • The City is a Pathfinder Site for implementation of the SEND (Special Educational Needs and disabilities) reforms with the Children and Families Act 2014. The Children and Families Act

	becomes law on 1 September 2014. Preparing for Adulthood is a significant focus of the reforms. • The City is developing 0-25 SEND Service which will provide an integrated assessment and intervention service for children and young people 0 to 25 years of age, including statutory education, health and care assessment and plans. This service is due to be operational by April 2015 • Full time college courses are available but only for an average 3-4 days per week, with individuals unable to access structured activity for the rest of the week. Courses lack an employment focus and tend not to support a person to take up employment opportunities. • Employment prospects/opportunities are part of the assessment during the transition process, but very few are able to access paid work. • City Limits are working closely with colleges and SEN schools. • Families have a high expectation around the transition to adult services and are not always adequately prepared for what could be a lesser care package. • The Multi Agency Resource Panel (MARP) includes a transition planning meeting three times a year to which adult services are invited. They are then able to see which children are receiving care in children's services and have the opportunity to include them in financial planning. • The MARP process ends when adult responsibility takes over. This is not necessarily the same age for each young person. Young people who have statements of educational need will continue their *education* funding until their statement ends. If there is *social care funding*, this is handed to adult services at 18. *Child health services* provided as part of a statement of educational need will continue until a statement ends but continuing care health funding will pass to adult continuing care services if the adult criteria for continuing care are met. • Education, Health and Care (EHC) Plans will replace the current statementing and S139a processes from September 2014.. The EHC plan is intended to continue, with annual review; until the young person leaves education (up to the age of 25) This new structure has implications for MARP because of the change in ages that the new structure is intended to cover. There are also planned changes within the social care structure to accommodate the 0 – 25 age range. • In Southampton we are currently hosting the 'next steps' project funded by the National lottery to work with young people through transition. There are two workers based within Pathways team, one to work with children in care through the process of transition out of care. The other works with young people transitioning out of custody. • Southampton's Transition Strategy was developed in 2013.
Recommendations	G1. To support the Children and Families Bill 2013 implementation

	which will extend the special educational needs (SEN) system from birth to age 25. G2. Review MARP/TOG in light of the implementation of Childrens and Young Peoples Development Service 0-25 SEND Service, ensuing that the clinical, social and educational needs of individuals are met into adulthood. G3. Ensure that all transition plans will include person centred behaviour management plans which address the communicative functions of individuals.

Area for Development – Workforce **H**	
Current Position and Identified Gaps	• Children services are reviewing how professionals work together with the development of the role of the Lead Professional. There are some specific areas where there are capacity issues e.g. Speech and Language Therapists (SALT) where access for communication purposes is limited. • For adults, training is provided via a range of routes including: Voluntary Independent Providers (VIP). • Intensive Support Team provide training to carers and support staff. • Expertise and knowledge shared via the Quality Team. • Guest speakers available at the Provider Forums. • Dignity Forums ongoing supporting Core Principles. • Specific training can be agreed via flexible "one council" learning service.
Recommendations	H1. Southampton's workforce plan supporting people with challenging behaviour will be based on Positive and Proactive Care (2014) to provide a framework to radically transform culture, leadership and professional practice to deliver care and support which keeps people safe, and promotes recovery. H2. People supporting those with challenging behaviours will be able to communicate with individuals more effectively, using the Five Good Communication Standards (Royal College of Speech and Language Therapists 2013).

13.0 What Are We Going to Do Now?

13.1 The time frame covered by this Policy Statement is 2014 to 2019. The action plan covers a two year period but is a live document and will be updated as there transformation takes place.

13.2 The Challenging Behaviour Local Implementation Group (LIG), will have responsibility for the action plan.

14.0 Consultation on the draft Policy Statement

14.1 The draft Policy Statement was developed by a small group of learning disability clinicians and service managers who provide services to children and adults who present challenges.

14.2 Consultation has taken place in June 2014. See Appendix 3 for detail.

14.3 Following the consultation process the Policy Statement has been refreshed with final sign off by Health and Well being Board in July 2014.

14.4 The Challenging Behaviour Local Implementation Group will be ongoing with task and finish group/s dependent on themed areas, encompassing health, social care, children services, adult' services and cross sectors including education and housing. The Challenging Behaviour LIG will be seeking to set up formal strucures regarding groups August 2014. The Challenging Behaviour LIG will report to the Learning Disabilities Partnership Board, NHS England and the Health and Wellbeing Board.

Appendix 1

The key recommendations from the CIPOLD review of deaths

1	Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.
2	Reasonable Adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
3	NICE5 Guidelines to take into account multi-morbidity.
4	A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
5	Patient-held health records to be introduced and given to all patients, with learning disabilities, who have multiple health conditions.
6	Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
7	People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
8	Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.
9	Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
10	Mental Capacity Act advice to be easily available 24 hours a day.
11	The definition of Serious Medical Treatment and what this means in practice to be clarified.
12	Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
13	Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.
14	Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.
15	All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.
16	Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.
17	Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.
18	A National Learning Disability Mortality Review Body to be established.

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Norah Fry Research Centre University of Bristol 8 Priory Road Bristol BS8 1TZ Tel 0117 331 0973 Fax 0117 331 0978 Email ci-team@bristol.ac.uk

Appendix 2

Positive and Proactive Care: Reducing the Need for Restrictive Interventions - Key actions

Improving care

Staff must not deliberately restrain people in a way that impacts on their airway, breathing or circulation, such as face down restraint on any surface, not just on the floor.

If restrictive intervention is used it must not include the deliberate application of pain.

If a restrictive intervention has to be used, it must always represent the least restrictive option to meet the immediate need.

Staff must not use seclusion other than for people detained under the Mental Health Act 1983.

People who use services, families and carers must be involved in planning, reviewing and evaluating all aspects of care and support.

Individualised support plans, incorporating behaviour support plans, must be implemented for all people who use services who are known to be at risk of being exposed to restrictive interventions.

Leadership, assurance and accountability

A board level, or equivalent, lead must be identified for increasing the use of recovery-based approaches including, where appropriate, positive behavioural support planning, and reducing restrictive interventions Boards must maintain and be accountable for overarching restrictive intervention reduction programmes.

Executive boards (or equivalent) must approve the increased behavioural support planning and restrictive intervention reduction to be taught to their staff.

Governance structures and transparent polices around the use of restrictive interventions must be established by provider organisations

Providers must have clear local policy requirements and ensure these are available and accessible to users of services and carers.

Providers must report on the use of restrictive interventions to service commissioners, who will monitor and act in the event of concerns.

Boards must receive and develop actions plans in response to an annual audit of behaviour support plans.

Post-incident reviews and debriefs must be planned so that lessons are learned when incidents occur where restrictive interventions have had to be used.

Transparency

Providers must ensure that internal audit programmes include reviews of the quality, design and application of behaviour support plans, or their equivalents.

Accurate internal data must be gathered, aggregated and published by providers including progress against restrictive intervention reduction programmes and details of training and development in annual quality accounts or equivalent.

Service commissioners must be informed by providers about restrictive interventions used for those for whom they have responsibility.

Accurate internal data must be gathered, aggregated and reported by providers through mandatory reporting mechanisms where these apply, e.g. National Reporting and Learning Service (NRLS) and National Mental Health Minimum Data Set (NMHMDS).

Monitoring and oversight

Care Quality Commission's (CQC) monitoring and inspection against compliance with the regulation on use of restraint and its ratings of providers will be informed by this guidance.

CQC will review organisational progress against restrictive intervention reduction programmes.

CQC will scrutinise the quality of behaviour support plans which include the use of restrictive interventions.

Appendix 3

Challenging Behaviour Policy Statement Consultation: A report on the survey and consultations carried out in May, June and July 2014

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Partnership & Comme