



## Bristol Health and Wellbeing Board

Title of Report:	Building Rights - Independent Review of Services for Autistic People and people with Learning Difficulties
Author (including organisation):	Hugh Evans, Executive Director, People
Date of Board meeting:	28th July 2021
Purpose:	Decision / oversight and assurance / information and discussion (delete as appropriate)

### 1. Executive Summary

- 1.1 Commissioned by Bristol City Council, in consultation with the Keeping Bristol Safe Partnership, and produced by Sir Stephen Bubb, who led the NHS England review into the Winterbourne View scandal (published 2014), this independent review (*Building Rights: a review of Bristol's policies and actions for people with learning disabilities and autistic people*) makes three key recommendations to help services and systems become more aware and have a better understanding of the challenges faced by autistic people and people with learning disabilities. These are set out below.
- 1.2 Sir Stephen recommended the following, in direct response to the experiences of the three families featured in his review:
  - Establish a Charter of Rights
  - Establish a simple and effective 'right to challenge', for people who feel marginalised by, and powerless within the system
  - Establish an independent commissioner for autistic people and people with learning disabilities.
- 1.3 Bristol City Council welcomes the findings of the *Building Rights* report, and fully accepts the recommendations.

### 2. Purpose of the Paper

This report aims to inform the Health and Wellbeing Board about Sir Stephen Bubb's independent review and seeks the board's support for the actions and the approach we need to take as a city to honour its recommendations.

The council is developing a plan to implement the recommendations in Sir Stephen's report. This will be a joint effort between Bristol City Council, NHS and other statutory, independent and voluntary / community sector partners, to be delivered through the Healthier Together Mental Health, Learning Disabilities and Autism transformation programme.

### 3. Background and evidence base

- 3.1 One of the reasons this report was commissioned in 2019 was because it was necessary to establish how aware local agencies across Bristol are about the

experiences of autistic people and people with learning disabilities, and to understand how we can progress our ambition to create a city that is welcoming for all. The recommendations in this report will help us to work towards this aim.

### 3.2 Some progress has been made since the report was commissioned.

- A new multi-agency **children's Autism Diagnosis Hub** has been implemented.
- The **We Work for Everyone** campaign has commenced, which specifically targets autistic people and people with a learning disability to support them to find and maintain paid employment.
- Following a recent selection process, Bristol is to be an MHCLG-funded **Changing Futures** pilot area. This will provide a start to the much-needed work to address the needs of some of the most complex individuals inside and outside the system.

### 3.3 We want to robustly challenge the iniquitous social experiences that people with learning disabilities and autistic people have.

- People with learning disabilities die on average 20 years younger than the general population and only 37% of people with a learning disability live beyond the age of 65.
- There is markedly increased premature mortality in autistic people owing to a multitude of medical conditions.
- Individuals with high-functioning autism are at higher risk of suicide.
- 74% of autistic adults report that they experience difficulties in accessing health care, and 88% felt that health professionals failed to understand their health needs.
- 70% of autistic people have a mental health condition (NICE): 40% have two or more.
- In 2015, autistic people made up 38% of the number in mental health hospitals, now it is 57%. (1,165 autistic people). The average length of stay is 5.6 years and the average distance from home is over sixty miles.
- 72% of people of working age with mild learning disabilities are not in employment.
- Only 22% of autistic adults are in any kind of employment. (ONS, Feb 2021)
- Many people in the prison population have a learning disability.
- It is estimated that autistic people are up to seven times more likely than the general population to be involved in the criminal justice system, as a victim, a witness, or a defendant.
- (UK Parliament, January 2020)
- Disabled women were over five times more likely to have experienced sexual assault in the last year.
- The lowest proportion of home ownership is among those with learning disabilities, and people with learning disabilities and their families are more likely to live in poverty.
- 29.5% of people who are homeless have probable learning disabilities.
- Nearly two-thirds of children with autism between the ages of 6 and 15 have been bullied.

### 3.4 The adverse experiences of people with learning difficulties and autism cover the gamut of social experience: people consigned from childhood to 'assessment and treatment' institutions; people who are sometimes able to function with minimal support but who can slip into situations where they are exploited and abused; people who are overlooked and never get a chance to vote, go to work, socialise, or benefit from all of

the basics of citizenship that most of us take for granted. A disproportionate number become subject to the criminal justice system both as victims and perpetrators. Stark health inequalities are apparent.

- 3.5 This is about equity, human rights, social justice and citizenship. People with learning disabilities and autistic people experience some of the starkest social disadvantage of all citizens. Our social structures are simply not geared up to cater for people with diverse needs.
- 3.6 Sir Stephen Bubb states that despite our best efforts as individual organisations, the approaches we employ to support people with learning disabilities and autistic people are disjointed and offer incomplete solutions. At best, we manage crisis situations and perceived problems, but we often do this through services that control people, rather than through approaches that enable and empower.
- 3.7 The council is working up a framework to implement the recommendations in Sir Stephen's report. This will be joint effort between Bristol City Council, NHS and other statutory, independent and voluntary / community sector partners, to be delivered through the Healthier Together Mental Health, Learning Disabilities and Autism transformation programme. Work will include the following.
  - An audit of the situation as is, and the creation of a strong and long-term lived experience approach, through which we will actively develop working relationships with people with learning disabilities, autistic people, their families and support organisations in order to co-produce plans
  - The development of a systemic approach to complex needs through Changing Futures (funding permitting)
  - A dialogue with progressive and ambitious service providers to develop a procurement specification to encourage the 'best in class' services to come and build capacity in Bristol, North Somerset and South Gloucestershire
  - A dialogue with the fledgeling Integrated Care Partnerships to encourage the development of supportive community-based approaches to enable people to partake meaningfully in their local communities
  - Continued work with housing, employment support, and neighbourhood development programmes to ensure that there are better opportunities for people to partake in the activities of everyday life.

## 4. Community/stakeholder engagement

- 4.1 Consultation is taking place with the Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group

## 5. Recommendations

- 5.1 That the Health and Wellbeing Board support the actions and the approach we need to take as a city to honour the recommendations in *Building Rights: a review of Bristol's policies and actions for people with learning disabilities and autistic people*, the recently published independent review of services to help Bristol become a more welcoming and inclusive place for autistic people and people with learning disabilities. Building Rights was written by Sir Stephen Bubb, who led the NHS England review into the Winterbourne View scandal, published in 2014.
- 5.2 The council is developing a plan to implement the recommendations in Sir Stephen's report. This will be joint effort between Bristol City Council, NHS and other statutory,

independent and voluntary / community sector partners, to be delivered through the Healthier Together Mental Health, Learning Disabilities and Autism transformation programme.

## **6. City Benefits**

- 6.1 This approach aligns with Bristol City Council's One City Plan and its aim to make Bristol a fair and sustainable city. Particularly in relation to the Health and Wellbeing theme to ensure everyone in Bristol will have the opportunity to live a life in which they are mentally and physically healthy and addressing health inequalities.
- 6.2 This work also aligns with Bristol City Council's Equalities and Inclusion Policy (2018-2023) in terms of valuing diversity, tackling harassment, in particular the objectives:
- E03. To provide inclusive services which actively address inequality and exclusion and enable all of Bristol's citizens to realise their potential and live safely.
  - E04. To achieve a measurable increase in the extent to which communities facing inequality can share in and contribute to the city's success.
- 6.3 Public sector equality duties are entirely relevant to these proposals as we are seeking to eliminate discrimination and harassment and address the inequalities and disadvantage faced by people with learning disabilities and autistic people. Many people who have learning disabilities and autistic people also face multiple disadvantages and may have other protected characteristics (e.g. related to race, age, sexual orientation) and this is also being considered. Equalities Impact assessments will need to be undertaken for all agreed proposals and people with lived experience involved in co-producing any changes or plans.

## **7. Financial and Legal Implications**

This report provides an overview of Sir Stephen Bubb's review. Activity that develops as a product of the review will require financial and legal involvement, and this will be detailed in subsequent reports.

## **8. Appendices**

- Building Rights - powerpoint slides
- Building Rights – Report of Sir Stephen Bubb