



Report to Healthier Communities & Adult Social Care Scrutiny Committee 19 September 2011

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Report of: Miranda Plowden (Director of Commissioning, Communities) and Eddie Sherwood (Director of Care and Support, Communities)

Subject: Six Lives

Author of Report: Ed Sexton (Commissioning Officer – Learning Disabilities, Sheffield City Council) and Heather Burns (Disability Strategy and Specification Manager, NHS Sheffield/ Commissioning Manager – Learning Disabilities, Sheffield City Council)

Summary:

The *Six Lives* report was published in March 2009 by the Health and Parliamentary Ombudsman and Local Government Ombudsman. The report covered an investigation into the avoidable and shocking deaths of people with learning disability in NHS secondary care hospitals.

Six Lives reinforced the recommendations of Sir Jonathan Michael in a previous report, *Healthcare for All*, about the serious health inequality faced by people with learning disability, who typically die 10 years younger of preventable health conditions unrelated to their learning disability.

The Ombudsmen recommended that all NHS and social care organisations in England should “review urgently and report accordingly to those responsible for the governance of those organisations within 12 months of the publication of the report” on:

- **A review of the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas.**
- **A review of the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities**

This paper identifies work that has progressed in Sheffield between NHS Sheffield, Sheffield Teaching Hospitals, Sheffield Health and Social Care Trust and the Local Authority on the recommendations of the Ombudsmen since the publication of *Six Lives*. This includes a focus on:

- Involving people and developing a strong evidence base
- Analysis of hospital admissions data
- Preventative screening
- COPD (breathing problems)
- Postural care
- Epilepsy
- Dental
- Sensory impairments (vision / hearing)
- Mental Health
- Annual health checks by GPs

There remains a focus on the recommendations of the Ombudsmen aimed at improving the access of learning disabled people to all mainstream, primary and secondary health services.

This paper has been brought to the Scrutiny Committee to highlight the work that is being undertaken and to seek guidance on future priorities.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	
Informing the development of new policy	
Statutory consultation	
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Community Assembly request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	X
Other	

The Scrutiny Committee is being asked to:

1. Provide a steer on current and future activity to meet the Ombudsman's recommendations.
2. Provide a view on how the health inequality agenda for people with a learning disability is kept high on the Health and Wellbeing agenda.
3. Comment on the role of the Scrutiny Committee in overseeing and scrutinising the wider determinants of ill health in relation to this population
4. Ensure that differential impacts on this population due to the inequalities that they face are always considered when decisions affecting cuts to council and other services are discussed.

5. Recognise that the social exclusion that this population and their carers experience leads to further inequalities in health and their wider life opportunities, and to act as champions themselves to improve the lives of their learning disabled constituents.

Background Papers:

Six Lives: the provision of public services to people with learning disabilities, Parliamentary and Health Service Ombudsman Report (2008-9)

'Six Lives' progress report, Department of Health (2010)

Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities, Sir Jonathan Michael (2008)

Death by Indifference, Mencap (2007)

Healthy Ambitions, Strategic Health Authority (2008)

Valuing People Now, Department of Health (2009)

How people with learning disabilities die, The Learning Disabilities Observatory (IHaL) (2010)

Raising our sights: services for adults with profound intellectual and multiple disabilities, Professor Jim Mansell (2010)

The Government's response to 'Raising our sights: services for adults with profound intellectual and multiple disabilities', Department of Health (2011)

Category of Report: OPEN

Report of the Director of Commissioning – Miranda Plowden and the Director of Care and Support, Eddie Sherwood

Report on Six Lives

1. Introduction/Context

The Scrutiny Committee has been asked to receive this report to give it an opportunity to consider the work that has been undertaken in Sheffield to meet the recommendations of the Health Ombudsman and Local Authority Ombudsman in the report, *Six Lives*. The Scrutiny Committee is asked to consider the impact of the *Six Lives* report and the implications of things going wrong in health settings within Sheffield.

This paper aims to inform the Scrutiny Committee about the agenda around equalities and inclusion. Although this clearly affects health there is also a City Council responsibility around *Six Lives*.

A programme of work is underway to review and improve the effectiveness of health systems and services in Sheffield. This is informed by the Ombudsmen's

recommendations, although much of the work was already underway or planned through existing health priorities. The Scrutiny Committee is asked to comment on this work and make recommendations for future activity.

2. Main body of report, matters for consideration, etc

Six Lives report was published in March 2009 by Ann Abraham, Health and Parliamentary Ombudsman, and Jerry White, Local Government Ombudsman. The report covered an investigation into the avoidable and shocking deaths of people with learning disability in NHS secondary care hospitals.

The Ombudsmen recommended that all NHS and social care organisations in England should “review urgently and report accordingly to those responsible for the governance of those organisations within 12 months of the publication on the recommendations listed above in the introduction.

Six Lives found evidence of some serious and distressing failures in service across both health and social care. Investigations found poor services and actions in relation to a number of the NHS bodies and local councils involved. In some cases there had been service failure for disability related reasons or the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

Six Lives reinforced the recommendations of Sir Jonathan Michael in a previous report, *Healthcare for All*, about the serious health inequality faced by people with learning disability, who typically die 10 years younger of preventable health conditions unrelated to their learning disability.

This paper identifies work that has progressed in Sheffield between NHS Sheffield, Sheffield Teaching Hospitals, Sheffield Health and Social Care Trust and the Local Authority on the recommendations of the Ombudsmen since the publication of *Six Lives*.

There remains a focus on the recommendations of the Ombudsmen aimed at improving the access of learning disabled people to all mainstream, primary and secondary health services.

The work that is being done in Sheffield has been noted for exemplary practice on a number of areas relating to improving access to health care and referenced in national publications over the last four years.

Evidence

The local review that has been carried out in relation to health services and systems is informed by a strong evidence base generated through the completion for the last three years of the Yorkshire and Humber SHA annual Self Assessment Framework, an information gathering exercise on the performance of local health services. Additionally, Sheffield is in the enviable position of having the ability to interrogate evidence available through the

Sheffield Case Register on the health and other needs of the learning disabled population in Sheffield, a longitudinal study of the population for over 30 years.

Involving people

A key priority for Sheffield is to listen to what people with a learning disability and their families say about health services and systems. There has been investment of time and resources into improving communication channels.

The monthly People's Parliament provides a forum for people with a learning disability to discuss issues and question decision-makers. The Parliament has elected its own MPP for Health, which has proved to be an effective representative role.

The Learning Disability Partnership Board, and its working groups, has continued to improve accessibility to people, although there is further work to be done to support people to understand complex agendas. Family carers feel that health services in Sheffield are particularly good at involving people with a learning disability in projects and at listening to them and their family carers.

Self assessment

As stated above, the Yorkshire and Humber SHA Annual Health Self Assessment Framework (SAF) provides a mechanism for routinely monitoring and evaluating the effectiveness of health systems and services.

Sheffield involves a range of stakeholders in its self assessment, including people with a learning disability and families. The SAF assesses four key priorities:

1. Closure of long stay hospitals and resettlement of residents.
2. Addressing health inequalities and aiming for people with a learning disability to receive as good health services as everyone else.
3. Making sure people with a learning disability are safe in health services
4. Making sure the improvements in health services described in *Valuing People Now* are being carried out

The self assessment is rigorously evaluated and validated by the Strategic Health Authority.. Sheffield was the only area in the region to achieve green ratings in all four priority targets last year, and has maintained its position in this year's ratings.

Joint Strategic Needs Assessment (JSNA) and Sheffield Case Register

Sheffield has excellent information about the learning disabled population, helped by the maintenance of the Learning Disability Case Register. The JSNA is continuing to develop intelligence further.

NHS Sheffield was approached as one of only 6 PCTs in the country to be a partner in the national Learning Disability Public Health Observatory (PHO) to help understand better the health needs of this population and areas of best practice. As part of the Learning Disability Partnership Board, this connects all organisations with the work of the national PHO.

Sheffield has a national reputation in the area of data and research. Maintaining resources to support the JSNA and Case Register are important priorities.

The number of people with a learning disability is increasing and set to rise further over the next decade. A key increase is among young people with complex needs reaching adulthood, including significant numbers from BME communities. There is a 255 overall increase in the population over the last 10 years, and a rise of 120% within this of young people with profound and multiple impairments.

The Learning Disability Partnership Board has addressed these priorities over the past two years with the development of strategies for challenging behaviour dementia, autism and profound intellectual and multiple disability.

Specific work is taking place with people with the most complex needs. This has involved targeted clinical input into day services where people with profound intellectual and multiple disabilities and complex needs are supported. It has focussed on postural care, management of respiratory disorders and intensive interaction. The work on intensive interaction has led to positive outcomes for individuals supported through the project as staff are better able to meet people's needs, through an improved response to their communication.

The review into health systems and services that the Ombudsmen called for was aided by the ability of Sheffield to identify what contact learning disabled people have with Sheffield Teaching Hospitals either as in patients or outpatients through linkage of the Sheffield case register with the STH Patient Admission System.

Evidence on learning disability and morbidity has been used to inform the JSNA and is being interrogated for a national study by the PHO, as mentioned above.

Analysis of a range of such data sources has in part influenced a preventative programme of work that has been introduced around:

- **Access to and awareness of bowel screening**
Staff, family and paid carers have received public health training on recognising the symptoms of bowel cancer.
- **Cervical screening**
The NHS Sheffield Cervical Screening Service now generates lists of eligible women, which is cross referenced with the Sheffield Learning Disability Case Register. The Screening Administrator flags to GP's women with learning disability and identifies the need for double appointments and other reasonable adjustments. The practice then produces the invitation to screen list. The Screening Service also contacts the person's home, to encourage uptake, and may visit some homes to meet with families and individuals to reassure and support. Cervical Screeners have had learning disability training.
- **Eye care and vision work**
The Sheffield Teaching Hospitals (STH) Ophthalmology service works with the lead officer for eye care and vision and delivers outreach sessions for people with learning disabilities and their families to promote access. This work builds on positive earlier work recognised nationally through the SeeAbility project with local ophthalmologists led by Pauline Hargreaves (Pauline.hargreaves@sheffield.gov.uk).

- **Training for hospital Staff**
There has been a comprehensive programme of learning disability awareness training for hospital staff supported by a nationally recognised e-learning programme.
- **Dentistry**
A partnership between NHS Sheffield, Sheffield Health and Social Care Trust and Sheffield University Dental Public Health consultants, has led to research which is just being published into the dental needs of learning disabled people.
- **Annual Health Checks**
Sheffield continues strongly to encourage GP practices to sign up to the Directed Enhanced Service (DES) contract, whereby patients with a learning disability are offered annual health checks. There was an increase in health checks in the last annual returns, from 729 to 979, with 59% of eligible people receiving one. Plans are in place to target practices not yet signed up to the DES and support the completion of the health checks.

Health and social care integrated approaches

Sheffield City Council and NHS Sheffield have been working together on shared priorities, including enhanced monitoring of organisations delivering care and support to people. The health and wellbeing needs of people with higher support needs are a key priority.

Examples of joint activity over recent months are:

- Close work with the Care Quality Commission (CQC) and other partners to prioritise inspections
- The development of a joint contract monitoring tool for care homes
- A contracts focus on providers previously joint-funded
- A shared approach to monitoring continuing healthcare packages of support
- Alignment of commissioning priorities

3. What does this mean for the people of Sheffield?

The JSNA cites national evidence that people with a learning disability are 58 times more likely to die before the age of 50 than the general population from associated congenital conditions, but also from preventable secondary health conditions. They are also significantly more likely to suffer additional health problems, with life expectancy 10 years shorter than the rest of the population.

Improving access to health services and health outcomes for people with a learning disability in Sheffield strongly aligns with local authority priorities. It is consistent with the *Better Health and Wellbeing* strategic outcome and contributes to the principles of prevention and fairness set out in *Future Shape*.

The issues are important to the people of Sheffield from the perspective of equality and human rights legislation, to ensure that the most disadvantaged population in the city has equal rights and opportunities to access health

services and the necessary support to enable them to do so. Work to support access to good quality health services for people with a learning disability contributes to Sheffield's wider intentions to reduce health inequalities.

The local learning disability population is increasing – by 14% between 2004 and 2009. The biggest factor was a 38% increase in the number of young adults (aged 20 – 29). This trend is set to continue in the next decade and is influenced by more children with complex disabilities surviving into adulthood. Between 2009 and 2012, the number of children with a learning disability is expected to rise by 6.3%, with the highest increases amongst children on the Autistic Spectrum Disorder; with Profound intellectual and Multiple Learning Disabilities; or with Speech, Language and Communication needs.

The number of people with a learning disability from black and minority ethnic (BME) communities increased by 80% between 1998 and 2008. The Pakistani community accounts for 45% of all people with a learning disability from BME communities. As with the learning disability population as a whole, there is an increasing trend in young people with complex needs from BME communities.

There are implications for Sheffield if its systems to protect its learning disabled population fail.

4. Recommendation

The Scrutiny Committee is asked to:

1. Consider the work that is being undertaken around improving access to health services for people with a learning disability, to provide a view on its relevance to the Ombudsmen's recommendations and to provide a steer on current and future activity to meet the Ombudsman's recommendations.
2. Ensure that the needs of this population are not overlooked in relation to the move from PCT commissioning to GP commissioning and to help to ensure that the Health and Wellbeing Board maintains a watching brief on this work.
3. Provide a view on how the health inequality agenda for people with a learning disability is kept high on the Health and Wellbeing agenda.
4. Comment on the role of the Scrutiny Committee in overseeing and scrutinising the wider determinants of ill health in relation to this population
5. Ensure that differential impacts on this population due to the inequalities that they face are always considered when decisions affecting cuts to council and other services are discussed.
6. Recognise that the social exclusion that this population and their carers experience leads to further inequalities in health and their wider life opportunities, and to act as champions themselves to improve the lives of their learning disabled constituents.