Arolygiaeth Gofal Iechyd Cymru
Healthcare Inspectorate Wales

DRIVING IMPROVEMENT THROUGH INDEPENDENT AND OBJECTIVE REVIEW

Learning Disability Services

Thematic Report
2015-16

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Healthcare Inspectorate Wales (HIW) is the independent inspectorate and regulator of healthcare in Wales

Our purpose

To provide the public with independent and objective assurance of the quality, safety and effectiveness of healthcare services, making recommendations to healthcare organisations to promote improvements.

Our values

- **Patient-centred: we place patients, service users and public experience at the heart of what we do.**
- **Openness and honesty: in the way we report and in all our dealings with stakeholders.**
- **Collaboration: building effective partnerships internally and externally.**
- **Professionalism: maintaining high standards of delivery and constantly seeking to improve.**
- **Proportionality: ensuring efficiency, effectiveness and proportionality in our approach.**

Our Outcomes

Through our work we aim to:

Provide assurance:	**Provide independent assurance on the quality, safety, and effectiveness of healthcare by reporting openly and clearly on our inspections and investigations.**
Promote improvement:	**Encourage and support improvements in care through reporting and sharing good practice and areas where action is required.**
Strengthen the voice of patients:	**Place patient experience at the heart of our inspection and investigation processes.**
Influence policy and standards:	**Use our experience of service delivery to influence policy, standards and practice.**

1. Foreword

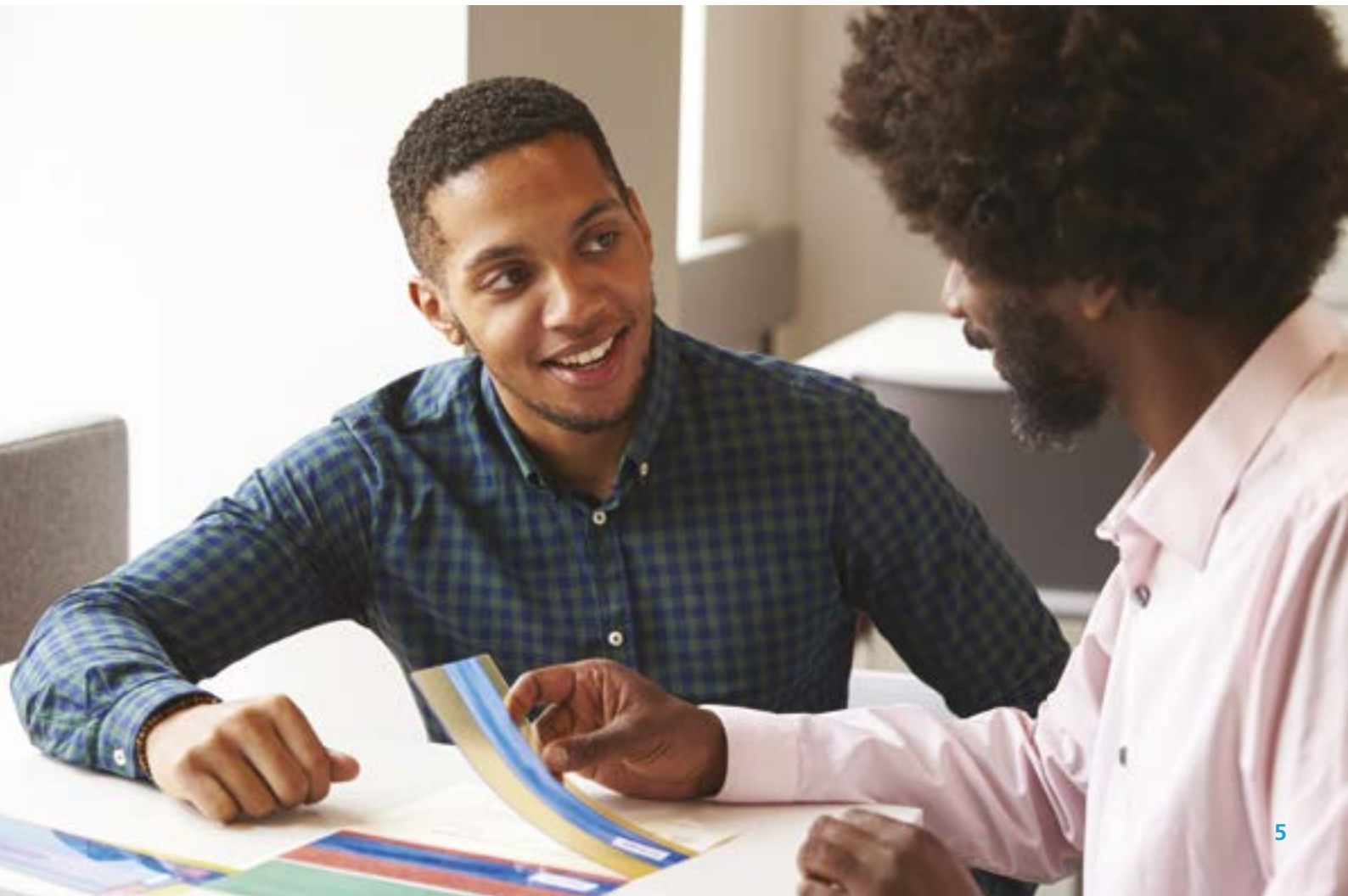
From July 2015 to July 2016 HIW undertook a thematic review of NHS health services for people with learning disabilities in Wales. The review included the following:

- A survey of all seven health boards in Wales.
- Detailed fieldwork alongside the Care and Social Services Inspectorate for Wales (CSSIW) in six community learning disability health teams from five different health boards.
- Inspections of community learning disability health teams in the two other health board areas.
- Inspections of NHS provided residential settings for people with learning disabilities, including assessment and treatment units.

This thematic report brings together and examines our findings across NHS learning disability services. It aims to identify common strengths and areas for improvement, and makes recommendations for health boards and policy makers. It also highlights good practice, to support improvement in the services provided to people with a learning disability in Wales.

Individual reports have been published for all inspections and can be found on HIW's website. In June 2016, we also published a joint report with the CSSIW of our joint inspection activity.

This report is available in alternative formats, including easy read.



2. Executive summary

HIW is responsible for inspecting NHS services to assess how well they meet the Health and Care Standards 2015. The Standards are at the core of HIW's approach, informing the judgements we make about the quality, safety and effectiveness of services provided to patients. This report provides the findings of our thematic review of NHS learning disability services during 2015/16.

HIW completed announced inspections to seven community learning disability health teams (one in each health board area). We also undertook unannounced inspections to 25 specialised NHS residential services for people with learning disabilities.

Overall, we found that people with learning disabilities were treated with dignity and respect by staff working with them. We saw that access to general healthcare services was good and patients were supported to manage their health conditions. People were registered with a local GP and had access to dental and optometry services. We saw the positive work of dedicated health liaison nurses who work mainly in acute hospitals to identify and respond effectively to the needs of people with a learning disability. We also saw health communication passports, (which help hospital staff to know about a person's individual needs and preferences), were in place for many people who are known to learning disability services.

However, in almost all areas we visited, staff told us of the lack of understanding of learning disabilities amongst general medical staff. We heard many examples where a person with a learning disability had been to hospital and their parent or carer had been asked to sign a consent form for their treatment, without any consideration of whether the person had the capacity to consent to the treatment themselves. Health boards must ensure their staff adequately protect the rights of people with learning disabilities.

Meaningful engagement to gain feedback on services was variable across health boards. We found that residential services in particular do not generally have a recognised system for seeking patient and relative feedback. Independent advocates can help people with learning disabilities to have a voice in providing feedback to services and making complaints where necessary. Health boards should ensure people have access to advocacy services so that they can have support where needed to uphold their rights.

When we inspected community learning disability health teams, our findings were mostly positive. We found:

- Staff made an effort to ensure people were involved in decisions about their care, where this was possible, even where verbal communication was limited. However, we noted that there was a lack of Speech and Language Therapy (SALT) in some areas to help people with their communication needs.
- Individuals received help that was well co-ordinated and met their needs.
- Staff faced significant challenges associated with the Continuing Healthcare (CHC) funding process which could lead to delays for people and their carers. However, staff worked hard to try to overcome these issues to provide people with consistent care.

- Timely and appropriate referrals by health staff working together to achieve shared outcomes for people.
- Patient records were of a good quality, but relevant information about a person was sometimes not all held in the same place and joint health and social care records were rare.
- Staff told us they received regular managerial and clinical supervision.

By contrast, we found that NHS residential services for people with learning disabilities required significant improvement in many areas. We found that whilst people usually received good individual care from staff who tried their best to care for patients, this was often not underpinned by good management and staffing arrangements. Our findings included:

- Environmental issues – maintenance jobs which had not been attended to, and uncleanliness and malodour in some settings.
- Patients and staff in a number of settings told us that meals were sometimes poor, there was sometimes little choice or variety and that food portions were small.
- A lack of communication aids which could help people to express themselves and enhance their understanding.
- Incomplete and inconsistent record keeping, with some information not dated, not contemporaneous and record entry of poor professional quality.
- Staffing issues – high staff turnover and high staff sickness; limited input from registered nurses; and managers did not always have the time required to devote to managing services. In some areas this led to a lack of effective leadership and governance.
- Staff were not always up-to-date with health boards' mandatory training, including the Mental Capacity Act 2005, Deprivation of Liberty Safeguards, cardiopulmonary resuscitation and safeguarding vulnerable adults.
- Senior health board managers did not always have oversight of these settings.

Health boards need to consider the purpose of their learning disability NHS residential settings and whether the care being provided at these establishments is purely healthcare. If not, health boards should consider whether a social model of care is more appropriate. We recommend that all people living in NHS residential settings have a thorough, multidisciplinary reassessment of their current needs for care and support.

We found that strategic planning for learning disability services as a whole could be improved. Most health boards did not have a system for monitoring the needs of their learning disability population, to support future planning and commissioning. Governance of learning disability services should also be strengthened, particularly in areas where one health board provides services to residents of another health board.

We also found that work was needed around succession planning and the sustainability of learning disability services. Many learning disability nurses are due to retire in the next few years, which will potentially leave services, and those who use them, without access to this well established specialist knowledge and experience.

We saw that there was not enough joint planning with local authorities to ensure that the right service provision was available for people in the area. This should improve in the future as the Social Services and Wellbeing (Wales) Act 2014 requires health boards to work with local authorities to jointly assess the needs of their population and to plan services to meet that need.

3. What we did

In 2015-16 HIW committed to conduct a joint piece of work with the Care and Social Services Inspectorate for Wales (CSSIW) in the area of learning disabilities.

In July 2015, HIW and CSSIW sent questionnaires to health boards and local authorities to find out how many people they know of in their areas have a learning disability. The responses showed that about a quarter of people who are living with a learning disability are receiving specific help from social services. This underlines the importance of health services understanding learning disabilities, so that all people, whether they are receiving help from social services or not, can receive the right support to manage their health and wellbeing.

To gain an overview of NHS learning disability services across Wales, our inspections looked at:

1. Community learning disability health teams.
2. NHS provided residential facilities for people with learning disabilities, including small residential settings and assessment and treatment units.

During the course of this work, HIW revisited the findings of our 2007 national review, which asked the following question:

> 'How well does the NHS in Wales commission and provide specialist learning disability services for young people and adults?'

That review set out 26 recommendations for improvement in learning disability services.

Community learning disability health teams

Community learning disability health teams are multidisciplinary teams usually comprising of learning disability nurses, occupational therapists, speech and language therapists, physiotherapists, psychologists and psychiatrists. The teams usually work closely with social services staff to undertake assessments and work with people who live in the community. The support people need and receive from health teams in the community is varied, and can range from support around sexuality and relationships for people with mild learning disabilities to specialist physiotherapy for people with profound and multiple learning disabilities.

Our inspections of community learning disability teams in five health board areas were conducted alongside inspectors from the CSSIW. The CSSIW considered how well care and support was provided to people with a learning disability from the local authority perspective. At the same time, HIW assessed the experience of people who received packages of care which were jointly funded by health and social care.

A stakeholder group was established which included All Wales People First; Mencap; Learning Disability Wales; Welsh Government; All Wales Forum of Parents and Carers; and the University of South Wales who train learning disability nurses and undertake research relating to the lives of people who have learning disabilities.

A national overview report of this work was published in June 2016 and can be accessed on our website.

HIW separately inspected the two other health board areas in order to gain a complete national view of community learning disability health services. Reports of these inspections can also be accessed on our website.

NHS provided residential care

HIW conducted inspections of NHS provided residential services in Wales, including:

1. Settings which were established after the closure of large institutions to accommodate people who had significant health needs, but who did not require traditional hospital accommodation.
2. Assessment and Treatment Units, which provide accommodation for people experiencing crisis or who need to undergo a period of assessment in order to identify what type of placement will best meet their needs.

Individual inspection reports were published for each of these settings on HIW's website.

HIW recognises its responsibility to protect the privacy and dignity of patients and does not identify individuals in any inspection reports. HIW recognised that some of the settings we inspected during this review accommodate a very small number of patients at any one time, sometimes on a long term basis. In naming a setting which accommodates a very small number of individuals, there is a risk that patients may be inadvertently identified by descriptions or information contained within an inspection report. It is HIW policy not to identify by name and/or address any setting which accommodates 5 or fewer patients at any one time but instead to refer to the setting by reference number and by health board in the published report. HIW does, however, expect settings to ensure the inspection report is made available to patients and their families, friends or advocates.

Methodology

Our inspections of community learning disability services were conducted by a minimum of two experienced inspectors, and were announced. Inspections of residential services were unannounced and we were accompanied by peer reviewers who were learning disability nurses.

During our inspections we reviewed documentation and information to establish how services were meeting the Health and Care Standards 2015. We gathered information from a number of sources including:

- Information held by HIW.
- Conversations with patients and carers.
- Interviews of the multidisciplinary staff team.
- Examination of a sample of patient records.
- Scrutiny of policies and procedures.

- Exploration of the arrangements in place with regard to clinical governance.
- A survey of all health boards in Wales.
- Meetings with strategic leads on learning disability services from the health boards.

Our inspections captured a snapshot of the standards of care within learning disability services at the time of the inspections.

We provided an overview of our main findings to representatives of the service at the feedback meeting held at the end of each of our inspections. Any urgent concerns emerging from inspections were brought to the attention of the health board in writing through HIW's immediate assurance process. Following the inspection, the service was sent a draft report with an improvement plan for them to complete. The improvement plan informed HIW of the actions being taken to address the issues identified. All improvement plans were evaluated by HIW to determine whether the service had taken, or proposed to take, sufficient action. Once the improvement plan was agreed, this was published alongside the inspection report.

4. What we found

Quality of the patient experience

Staying healthy

Overall, access to general healthcare was good. People received an annual health check with their GP and saw a dentist and optician when they needed to. People were helped to manage complex health conditions, such as epilepsy.

Standard 1.1 – Health promotion, protection and improvement

In 2007, we recommended that *"All people with learning disabilities receiving continuing care must be registered with a GP"*. In 2016 we found that access to general healthcare services for people with learning disabilities was generally good. In all the cases we tracked, both in the community and in residential services, the person with a learning disability was registered with the local GP. In some of the residential services we visited there was an arrangement whereby a local GP visited on a regular basis to support people with any routine issues. We also saw good liaison between local GP services and residential settings enabling prompt availability of medication for patients' physical health needs.

We found almost everyone in the cases we tracked, both in community and residential services, received an annual health check[1]. Some staff told us that the quality of the annual health check received by the individual was variable. In one area, learning disability nurses attended the annual health check where possible, to try to ensure the appointment was as effective as possible.

We saw that patients were supported to manage their complex health conditions, such as epilepsy, dementia and other physical health needs, which required clinical input.

In all residential settings we visited, people had regular appointments with a dentist and optician. Staff at one residential setting told us that where necessary a dentist attended the unit. In the community cases we tracked, we saw that people had a dentist and were encouraged to visit, sometimes with support from their learning disability nurse.

During our inspections of residential settings, we were not always able to clarify if patients had received relevant cancer screening. It is important that residential settings play their part in reducing health inequalities and support patients to access screening tests where appropriate.

[1] The Welsh annual health check for adults with learning disabilities was specifically introduced in Wales in April 2006 to promote early detection and treatment of health problems in people with learning disabilities.

Dignified care

People were generally treated with dignity and respect by staff working with them. Patients told us that staff were respectful and kind to them.

Standard 4.1 – Dignified care

Overall, we found that people were treated with dignity and respect. We saw a particularly strong value base in community learning disability teams, which was derived from the 'All Wales Strategy'[2] and focused on delivering a person centred approach. Patients told us that staff were respectful and kind to them.

At all the residential settings we visited, the staff team were knowledgeable about the patient group, with some staff having worked with the patients for many years. Staff tried their best to care for patients, often in difficult and challenging circumstances. Patients had access to their own bedrooms and received support to meet their personal hygiene needs where this was needed. We witnessed one occasion on which a patient's dignity and privacy was not respected. We saw a staff member providing personal care to a patient, having first propped open the door of the bathroom. This meant that the patient was in full view of anyone walking past. We raised this at the time and were assured this was an isolated incident. However, this highlights the importance of staff needing to remain vigilant to ensure they always consider the privacy and dignity of those they are supporting.

[2] In 1983, the Welsh Office published the 'All Wales Strategy for the Development of Services for Mentally Handicapped People'. The aim of the strategy was to enable people with learning disabilities to enjoy the full range of life opportunities and choices, to have positive identities and roles in their families and communities, to exercise choice and to develop independence, self-respect and self-fulfilment.

Timely care

People do not always receive timely care. This is because decisions about funding are sometimes not made quickly enough. Staff told us the Continuing Health Care process does not always work well for people with a learning disability.

Standard 5.1 – Timely access

In 2007, HIW's review found that there was often delay in establishing funding for placements, and that this could lead to *"conflict and dismay for service users and their carers"*. In 2016, we found there were still challenges relating to funding.

During our inspections of community services, we tracked a number of cases of people who received care packages funded by both the health board and the local authority. The system to determine whether joint funding is required, and if so in what proportion, is called Continuing Healthcare (CHC). Many staff teams told us of the difficulties they encounter in navigating the CHC process. We found that a lot of staff time was taken up undertaking assessments and reviews of need to establish the proportion of funding the person should receive from health and social care. Individuals and their families told us they do not mind who pays for their package of care, as long as the package meets their needs. We heard that as local authority budgets have been tightened, there has been an increase in referrals from colleagues in social services for an assessment of health need. This is leading to increased assessment time and decreased time for health staff to engage in therapeutic work.

On two separate occasions we heard that local community learning disability health services had refused to provide a service to a person who was placed in their area. This meant that the health staff from the person's home area had to travel long distances to ensure the person was provided with care, albeit this was not timely care. Health boards and policy makers should ensure that there is clear guidance to ensure people are always provided with appropriate and timely care, especially when they are placed outside of their home area.

Individual care

People usually had care plans which were based on their assessed need. However, these plans did not always help people to develop their life skills and to be as independent as possible. Activity plans for people in residential settings could be more stimulating.

There needs to be more training for general medical staff about the Mental Capacity Act 2005, so that when someone with a learning disability goes to hospital their capacity to consent to treatment is considered. The rights of people with learning disabilities must be adequately protected.

Meaningful engagement with people with learning disabilities and their carers to gain feedback on services was variable across health boards. NHS residential services do not seek feedback from people with a learning disability.

Health boards should consider the availability of advocacy to residential settings and ensure people have access to support where needed to uphold their rights.

Standard 6.1 – Care planning to promote independence

Patients usually had multidisciplinary assessments based on their individual needs and these were used to inform their ongoing and future care and treatment. We saw plans which included elements of Positive Behavioural Support[3], with preventative interventions in relation to health, well-being and behaviour. Patients usually had access to the right equipment to help them meet their needs. However, we did hear of instances when access to equipment was delayed due to funding disputes.

Where appropriate, we found patients had care and treatment plans as required under the Mental Health (Wales) Measure 2010[4]. However, staff had not always recorded whether efforts had been made to explain patients' care and treatment plans to them and whether patients agreed with the plans. Staff responsible for care and treatment plans must record the efforts made to explain these to patients, whether they have agreed them and if not, the reason, together with comments around this.

In residential settings, whilst we saw detailed care plans to address people's healthcare needs, we did not see plans to guide staff on how they could best support patients to develop their life skills to help them be as independent as possible. Some of the activities being offered to patients provided little opportunity for stimulation, and neither did they work on improving independent living skills. We also saw evidence that activity plans written in care planning documentation were not always being enacted to enhance quality of life of individuals.

[3] Positive Behavioural Support (PBS) is person centred model that applies evidence based interventions to improve an individual's communication and independence skills and thereby enhance their quality of life.

[4] The Mental Health (Wales) Measure 2010 is a law made by the Welsh Government which will help people with mental health problems in four different ways. http://gov.wales/topics/health/nhswales/mental-health-services/measure/?lang=en

It was positive to see that clear improvements had been made in the area of transition since HIW's review in 2007. The move from children's services to adult services can be a difficult and challenging time. Adult services operate differently to children's services. There are different eligibility criteria, different levels of intervention, and different levels of engagement with families and carers with issues of capacity to consider. In 2007, we reported *"[transition] is a concern that was consistently raised with us"* and that *"transition planning is not seen as a priority by many agencies"*. By contrast, during this review, people with learning disabilities and their families reported that transition had been a largely positive experience for them. All areas we inspected were aware of the challenges of transition and were working to improve the process for people and families.

Standard 6.2 – People's Rights

A recommendation from HIW's 2007 review was that *"the training needs of acute and primary care nursing and medical staff should be reviewed and training programmes to better equip them to understand and manage the needs of people with learning disabilities should be implemented."* It was disappointing that in almost all areas we visited in this review, staff told us of difficulties they had encountered with general medical staff. We were told of numerous examples where a person with a learning disability had received treatment in hospital and their parent or carer had been asked to sign a consent form for that treatment, without any consideration of the person's capacity to consent to their own treatment. It is clear that health boards need to do more to ensure all their staff are aware of the provisions of the Mental Capacity Act 2005 and to improve understanding of learning disability.

We found most, but not all, health boards had implemented the 1000+ Lives[5] guidance for improving general hospital care for people with learning disabilities. The 'care bundle' was designed to help health boards to be consistently alert to, and to respond to, the needs of people with learning disabilities, and their families and carers, when they access general hospital services. All health boards should ensure their staff are aware of this guidance.

During our inspections of residential services, we noted that as part of some patients' care and treatment, staff used the practice of seclusion[6]. Whilst we saw one setting where this was carried out in line with the health board's seclusion policy and closely monitored to ensure appropriate use, we also saw settings where seclusion practices were being used without any appropriate policy or safeguards in place. We found that there was a lack of understanding amongst staff at some units about what would constitute the practice of seclusion. Some staff classified the care and support they were providing as 'segregation' rather than 'seclusion'. This meant that appropriate risk assessments and safeguards to ensure the continued health and safety of staff and any patient being secluded had not been considered. Health boards should ensure that any practice of seclusion/segregation is reviewed and an appropriate policy developed to ensure that patients and members of staff are safeguarded.

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[5] http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/how%20to%20%2822%29%20learning%20disabilites%20care%20bundle%20web.pdf

This improvement guide was produced by **1000 Lives** Improvement, which is part of Public Health Wales, to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that people with learning disabilities receive.

[6] **Seclusion** is the supervised confinement of a patient in a room, which may be locked. Its sole aim is to contain severely disturbed behaviour which is likely to cause harm to others.

During our reviews of both community and residential services, we identified people who were subject to a Deprivation of Liberty Safeguard (DoLS)[7]. We identified that a significant number of people had emergency DoLS assessments in place, but were on a waiting list for a full assessment. There was a dramatic rise in the number of referrals for DoLS as a result of the 'Cheshire West'[8] legal judgement, which has impacted on the time taken for full assessments to take place. Health boards and local authorities need to work together to devise an effective response to this problem. The rights of people with learning disabilities must be adequately protected.

Standard 6.3 – Listening and learning from feedback

Meaningful engagement with people with learning disabilities and their families/carers to gain feedback on services was variable across health boards. Most community health teams had accessible questionnaires to support them in monitoring satisfaction with services, but in some cases these were new and not well established.

We found that residential services do not generally have a recognised system for seeking patient and relative feedback. Staff described informal and ad hoc ways of receiving feedback from patients and their relatives on their experiences of the care provided.

Patients should be enabled to communicate how they feel about various aspects of the service they receive. We were told in one area that the health board was looking to introduce a more formal way to regularly obtain feedback from patients and their families. This was to be an electronic based survey where questions could be presented in different formats, including the use of pictures and symbols. This was good practice and meant that people who had difficulty reading or difficulty understanding words would be helped so they could provide their views.

Independent advocates can help people with learning disabilities to have a voice in providing feedback to services and making complaints where necessary. In HIW's 2007 review, we identified that *"across Wales there is a lack of specifically trained advocates in the area of learning disabilities"*, and that *"where specific learning disability advocates are available, the service is reactive, often stretched and under-resourced"*. In this review, we found that access to statutory advocacy (Independent Mental Health Advocates (IMHAs) and Independent Mental Capacity Advocates (IMCAs)) was generally good. However, we found little provision for general independent advocacy which can help people to have support about a broader range of issues. In NHS residential services, we found that access to advocacy was limited. We saw reference to advocacy services in some places, but we did not see active involvement of advocates in any of the settings to promote people's rights. Health boards should consider the availability of advocacy to residential settings and should ensure people have access to support where needed to uphold their rights.

[7] The Deprivation of Liberty Safeguards (DoLS) came into force in England and Wales in April 2009 under amendments to the Mental Capacity Act 2005. They are designed to protect the rights of people who lack mental capacity and protect individuals from being deprived of their liberty unless it is in their best interests to protect them from harm, or to provide treatment, and there is no other less restrictive alternative.

[8] In March 2014, the Supreme Court handed down its judgments in the cases of P v Cheshire West and Chester Council and another and P and Q v Surrey County Council. These very significant judgements provided clarification on the definition of a deprivation of liberty.

Delivery of safe and effective care

Safe care

Staff in NHS residential settings were often expected to undertake housekeeping duties including cleaning, laundry and cooking as well as caring for the individuals using the service. This sometimes had an impact on the cleanliness of the environment. There were often outstanding maintenance issues which had not been attended to. Patients and staff in a number of settings told us that meals were sometimes poor.

In general, people's medication was managed safely and there were adequate processes for safeguarding adults across all the services we inspected.

Standard 2.1 – Managing risk and promoting health and safety

In our inspections of residential services, we found that there were often outstanding maintenance issues which had not been attended to. Some of these issues related to patient safety, for example fire safety procedures. We were told by staff in some services that it often took a long time for repairs to be carried out. For example, we were told it had taken approximately seven months to repair one of the patient toilets in one setting.

There was no emergency equipment (for patient collapse) available on site at many of the residential settings we inspected or the need for this equipment adequately assessed. This could present increased risks to patients, who may face a delay in getting the initial treatment they need.

Health boards need to ensure that settings are safe, well maintained and fit for purpose.

Standard 2.4 – Infection prevention and control and decontamination

We found that staff in residential settings were often expected to undertake housekeeping duties including cleaning, laundry and cooking as well as caring for the individuals using services. We found this sometimes had an impact on the cleanliness of the environment, and we noticed malodour in some settings. At one setting a housekeeper was employed which meant that registered nurses and health care support workers were able to concentrate on providing care and support to patients. Health boards should consider the scope of staff responsibilities to ensure the most appropriate use of their skills.

Standard 2.5 – Nutrition and hydration

We observed patients being supported with drinks to remain hydrated and to eat at the residential settings we inspected. However, we found the food on offer was variable in quality. Whilst in most settings we saw people receiving a nutritious meal, in others the food did not appear to be well balanced. Patients and staff in a number of settings told us that the provision of meals was sometimes poor, saying there was sometimes little choice or variety and that food portions were small.

Standard 2.6 – Medicines Management

In general, we found that people's medication was managed safely at the residential settings we inspected. Documentation had usually been completed accurately. We saw evidence of audits that had been done in most settings to ensure safe practice. In one setting we saw that GPs from the local surgery would write their prescription on to the in-patient Medicine Administration Record (MAR Chart). This maintained patient safeguards whilst streamlining the process for community and inpatient services. Medicines were usually stored in locked cupboards for safety. In some settings, we found that the temperature of the fridge was too high for stored medicines, or that the fridge temperature was not monitored. Staff need to ensure medicines are safely and correctly stored.

We observed the interaction between staff and patients during the administration of medication. Overall this was positive, but on one occasion we observed a nurse approach a patient and hand medication to a patient for them to take with very little exchange between the staff and patient, including not telling the patient what the medication was.

We saw easy read information leaflets were available in some settings to help patients understand their medicines and health conditions. Easy to understand information about medication should be available for all patients.

Standard 2.7 – Safeguarding adults at risk

There were adequate processes for safeguarding adults across all the services we inspected. In the community, we found that health teams usually reported any safeguarding concerns to the local authority rather than to the health board. It was therefore not always clear how the health board would be informed of issues of relevance to them. Senior nursing staff at residential settings showed a good knowledge of the process to follow should a safeguarding issue be identified.

Effective Care

Health communication passports were in place for many people known to learning disability services. This means that when a person with a passport is admitted to acute hospital, the general medical and nursing staff should be aware of important information about them.

We saw dedicated health liaison nurses who work mainly in acute hospitals to identify and respond effectively to the needs of people with a learning disability. These posts are not available in all health board areas.

Staff in community teams made an effort to ensure people were involved in decisions about their care, even where verbal communication was limited. We saw a lack of communication aids in residential settings, which could help people to express themselves and enhance their understanding.

Record keeping was of a variable quality. We saw good records which enabled the whole multidisciplinary team to have an accurate up to date picture of the person. We also saw incomplete and inconsistent record keeping by staff in some settings, with information not dated, not contemporaneous and of poor professional quality.

It was positive to see staff, particularly in some community teams, engaging in research and development work to improve the general health of people with learning disabilities.

Standard 3.1 – Safe and Clinically Effective Care

In 2007, HIW recommended that *"The effectiveness of good practice examples such as communication passports and Health Liaison Nurse posts should be fully evaluated and the results used to improve services across Wales."* It was positive to see that in 2016, health communication passports, which detail an individual's needs and preferences, were in place for many people who are known to learning disability services. This means that when a person is admitted to acute hospital, the general medical and nursing staff are provided with, and should be aware of, important information about the person. We heard that the health passport was often completed by the support provider. Whilst this is appropriate for people who live in a supported setting, health boards should consider the communication needs of those people who live with family, carers or by themselves. In residential services, we found that sometimes health passports were only available in electronic format. Settings should consider the availability of a hard copy of the passports in case a person needs to be admitted to hospital in an emergency.

It was also positive to see that some health boards employed dedicated health liaison nurses who work mainly in acute hospitals to identify and respond effectively to the needs of people with a learning disability. We saw excellent examples of this work in our community inspections, and the positive outcomes health liaison nurses had made to people's experience of hospital. In Betsi Cadwaladr University Health Board, we found there had been investment in a team of specialist health liaison staff including a dedicated liaison nurse for people with learning disabilities who needed mental health services. Wider health and social services colleagues all commented on the positive difference this team had made. In Aneurin Bevan University Health Board, we heard several specific examples of the positive differences that health liaison had made. For example, the health liaison nurse and community learning disability nurse had worked to coordinate input from a social worker, consultant in general health and a clinical psychologist. This ensured a person with a new diagnosis of cancer received the right support, information and advice to understand their diagnosis. It is positive that since our inspection, Abertawe Bro Morgannwg University Health Board has also introduced specific health liaison posts.

Where dedicated health liaison posts were not available, we saw community nursing staff worked hard to help people to access general health services. For example, in the Cardiff area we saw how nursing staff had helped women to access cervical screening and how they had built good relationships with other health providers such as audiology, optometry and dental services.

Standard 3.2 – Communicating effectively

In all community learning disability health teams we found staff made an effort to ensure people were involved in decisions about their care, where this was possible. We saw examples where health technology had helped to ensure people were involved in decisions about their care, even where verbal communication was limited. For example, we saw a tablet computer being used to help an individual in hospital who had limited verbal communication, to manage her anxieties and tell staff how she was feeling so that they could respond appropriately.

We found the patient groups being cared for in the residential settings had varying levels of verbal communication. Despite this, we saw a general lack of communication aids which could help people to express themselves and enhance their understanding. For example, we noted there were few pictures or pictorial signs in residential settings we inspected. Whilst the staff we saw were kind and considerate in the way they spoke with patients, in some settings there seemed to be an acceptance that there would be limited two-way communication between patients and staff. With an increased use of appropriate aids, communication may potentially be improved.

We saw bilingual (Welsh/English) signage on doors and we heard staff speaking in Welsh with patients, particularly in North Wales. In community teams, we found that the use of the Welsh language was variable. In most areas there was somebody in the team who spoke Welsh, but this did not appear to have been considered strategically. Health boards must ensure Welsh speakers are offered language services that meet their needs as a natural part of their care.

Standard 3.3 – Quality improvement, research and innovation

It was positive to see staff, particularly in some community teams, engaging in research and development work to improve the general health of people with learning disabilities. For example, in Aneurin Bevan University Health Board, we saw work on an education and research project for people with learning disabilities who have type 2 diabetes. The team had also been a pilot site for the Health Equalities Framework project which sought to measure the efficacy of health interventions. In Cardiff and Vale University Health Board, staff told us how they had introduced early screening of people with Down's Syndrome for dementia.

Standard 3.5 – Record keeping

In community teams, we found that records were of a good quality, but the organisation of records was variable. For instance, some teams had one record for an individual, with different sections for different health professionals. This meant that all the professionals working with the person could see an overall view of the holistic needs of the person. However, in other areas each health discipline had its own file, which meant that information was duplicated and there was a risk this could affect coordination of care. We heard that one of the biggest barriers to effective working in the community teams was the fact that there is no shared records management system across health and social care.

In residential services, we found records were of a variable quality. In one area, we saw a copy of the health board's record keeping policy in some of the patients' notes; records were well organised and held comprehensive detail of patients' assessed needs. We also saw clinical standards guidance was readily available. This was noteworthy practice. However, in some settings we saw incomplete and inconsistent record keeping by staff, with some information not dated, not contemporaneous and record entry of poor professional quality. We also saw some risk assessments which were out-of-date.

In one residential setting, we were particularly concerned to find that staff were not able to access patient records due to difficulties accessing the IT system where these records were stored. This meant that records were not available to staff to support their work and to ensure that service users' needs were being met effectively or safely.

Patient records were usually stored securely, but in some settings this could be improved as whilst there were lockable cabinets in place, keys were left in the filing cabinet doors. This meant that sensitive and personal records could potentially be accessed by unauthorised people.

Quality of management and leadership

Staff and resources

Community teams generally had a good multidisciplinary mix of staff. However, we saw there was a shortage of Speech and Language Therapists (SALT) in some areas.

There appeared to be enough staff working with the right skills to meet the needs of the patient group in most residential settings, but this needs to be reviewed as the needs of the patient group change. A number of settings had high staff turnover and high staff sickness, meaning that agency staff were used. At times we found managers were not supported and there was a lack of leadership and governance.

Staff were not always up-to-date with mandatory training. It is concerning that this included training on the Mental Capacity Act 2005, Deprivation of Liberty Safeguards, and safeguarding vulnerable adults.

We found that work was needed around succession planning and the sustainability of services, because a large cohort of learning disability nurses are due to retire in the next few years.

Standard 7.1 – Workforce

Health services should ensure there are enough staff with the right knowledge and skills available at the right time to meet need.

We found that in different parts of Wales, there were different pressures relating to availability of allied health professionals. For example, in one area there was a shortage of specialist physiotherapy provision, meaning that people with learning disabilities (generally those with more profound and multiple disabilities) did not have easy access to specialist help. In a number of areas, we heard about particular difficulties in accessing hydrotherapy provision. This was generally because there were not enough pools of the correct specification in the area to accommodate the needs of individuals.

It is notable that in our 2007 review, a lack of investment in speech and language therapy was identified. Our findings in this review identify that this still requires improvement in many areas. In one health board we found there was only one speech and language therapist employed to cover a large geographical area as they had struggled to recruit a second therapist. As a result of the shortage, they only concentrated on dysphagia (swallowing difficulties) rather than communication issues. Therefore, people in the area did not have any expert help with communication needs. It was noticeable that in the same area there was little easy read documentation, which would help people to understand written information, and that person centred plans were not in accessible format, which would help the person

to know what had been written about them. There also appeared to be a lack of speech and language therapy to aid communication in some residential settings.

Although there appeared to be enough staff working with the right skills to meet the needs of the patient group in most residential settings, acuity needs of patients must be considered to ensure there is the correct mix of staff. For example, in one setting we were told that one patient needed two staff members with them at all times, but we saw that there were a number of occasions when only two members of staff were on shift for the entire unit. We did see good practice in one setting which completed a weekly acuity return advising the health board on the health status of the patients and implications this had for the number of staff needed on the unit.

A number of settings had high staff turnover and high staff sickness. Most used health board bank staff as cover. Staff in one setting told us there had been occasions when bank staff did not have the sufficient specialist training required. We saw some dedicated staff teams, who would work overtime to cover unexpected sickness as a means of providing patients with a continuity of care from people they knew. Health boards need to consider staff teams that are frequently called upon to undertake overtime duties, as this has the potential to have a negative effect on their health and well-being. Health boards must make sure that bank staff used for specialist units have been adequately trained.

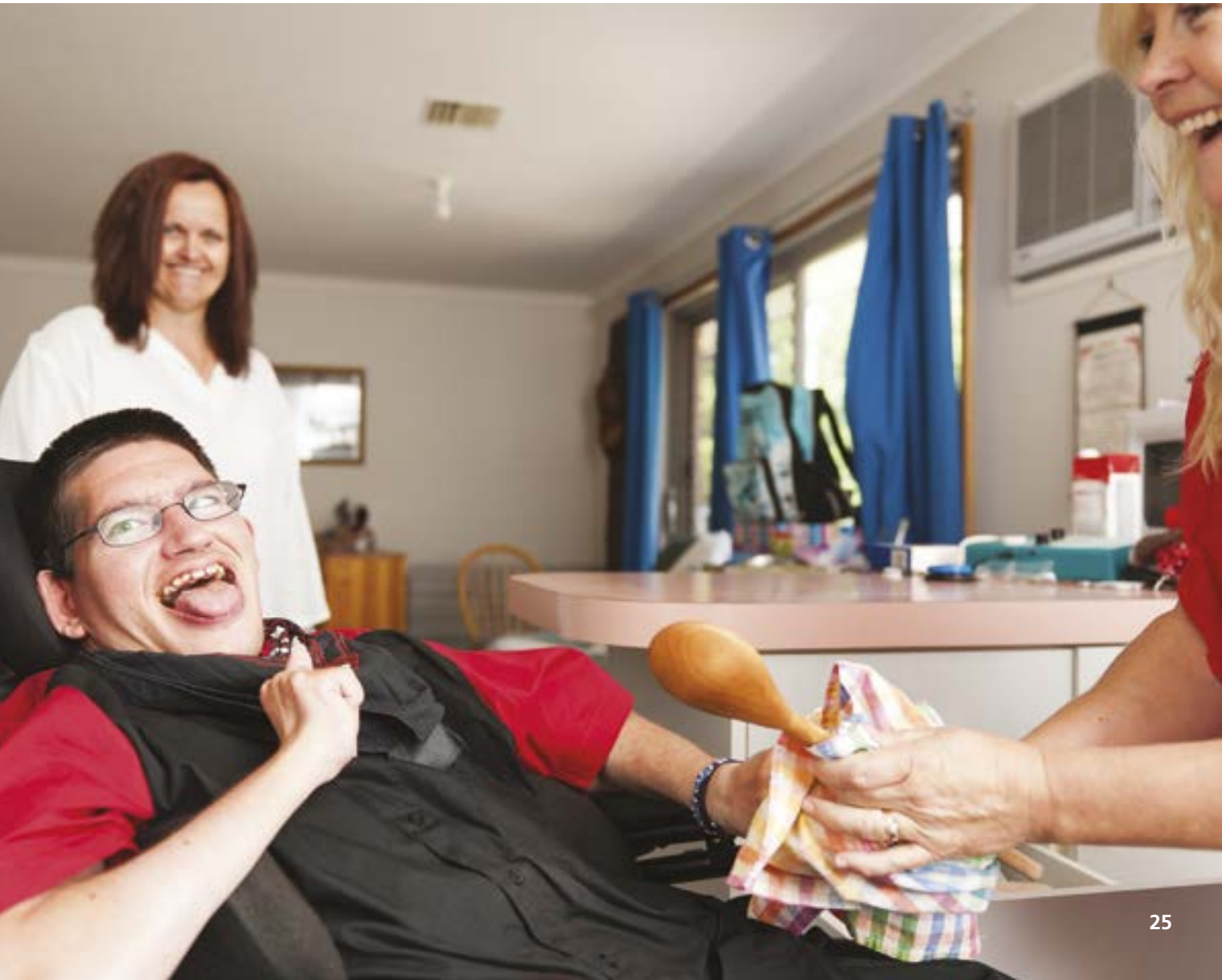
At times we found managers were not supported or they had a number of services to manage and therefore had limited time to devote to any one setting. Conversations with one manager indicated that protected management time had not been possible for some time due to low staffing levels. At another setting there was a distinct lack of leadership and accountability on the day we inspected, and support staff very clearly told us that there was nobody in charge. We found that in some settings there was also limited input from registered nurses.

A lack of leadership and governance on site can lead to poor practice going unchallenged and best practice or new developments not being applied. Health boards should ensure there are sufficient numbers of qualified staff to direct the complexity of the care being provided and lead the service at the same time.

We found that work was needed around succession planning and the sustainability of services, both in the community and in residential services. This is particularly because many learning disability nurses are due to retire in the next few years. Senior managers were aware of this issue, although some appeared to be more proactive than others at considering solutions, including arranging presentations to student nurses to encourage newly qualified staff to work within learning disability services. All health boards should consider this issue to ensure that people with learning disabilities continue to have a consistent service, provided by well trained staff.

We found in the majority of settings that staff were not up-to-date with all elements of health boards' mandatory training. It is concerning that this included training on the Mental Capacity Act 2005, Deprivation of Liberty Safeguards, cardiopulmonary resuscitation and safeguarding vulnerable adults. Some staff told us that they would like to attend more training tailored to their work in looking after patients with learning disabilities. We were concerned to find in some settings there was no formal system to monitor staff training, either at the service or by the wider management team, including whether mandatory training was up-to-date. Health boards must ensure that staff have the correct up-to-date training to provide safe and effective care.

We checked that staff received regular supervisions and annual appraisals of their work. Appraisals give staff the opportunity to receive feedback on their performance, to discuss training needs and indicate if any additional support was needed. Staff in community teams told us they received regular managerial and clinical supervision. In residential settings, this was usually more ad-hoc, or had been on an informal basis. Health boards must ensure that all staff have access to sufficient supervision to support them in their roles and that records are kept of supervision sessions. Health boards may also wish to consider the governance of the supervision and appraisal process to ensure that there is sufficient oversight by senior management.



Governance, leadership and accountability

Governance and leadership of learning disability services requires improvement. Most learning disability services sit within a merged learning disabilities and mental health directorate of the health board. Some staff held the perception that learning disability services are the 'poor relation' to mental health services in this structure, with less priority and focus. Health boards need to ensure they have sufficient oversight of the service they are providing or expect to receive for their patients.

We found that most health boards did not have a system for monitoring the needs of the learning disability population as a whole, to support future planning and commissioning.

Governance of NHS residential care was poor in most areas. It is concerning that senior health board managers did not always have oversight of these services. Health boards should question the purpose for providing long term residential care to people with learning disabilities, and whether social care is better placed to provide this care.

We considered the governance arrangements for learning disability services in the NHS. We found that most learning disability services sit within a merged learning disabilities and mental health directorate of the health board. In some health board areas staff told us they had the perception that learning disability services were the 'poor relation' with less priority and focus than on mental health services. In some areas, the merged learning disability and mental health directorate was new so the impact on learning disability services was unknown. However, overall, we found that governance and leadership of learning disability services could be improved.

Services in the geographical areas covered by Abertawe Bro Morgannwg University Health Board (ABMU), Cwm Taf University Health Board and Cardiff and Vale University Health Board are all provided by staff from ABMU. This creates an unusual situation whereby health boards have joint responsibility to people with a learning disability living in Cwm Taf and Cardiff and Vale.

We found that the governance arrangements of these services is under-developed and requires strengthening. ABMU learning disability services were undergoing a restructure at the time of this review, and it is essential the new management structure works with management in Cwm Taf and Cardiff and Vale University Health Boards to establish better governance of the services provided in those areas.

All three health boards need to ensure they have sufficient oversight of the service they are providing/expect to receive. Health boards, in conjunction with Welsh Government, should also consider whether the current arrangement is adequate, and provides sufficient safeguards as to the quality and level of service provided.

It is concerning that senior health board managers did not always have appropriate oversight of residential services, and in some areas only became aware of issues at these settings as a result of HIW's inspection. NHS residential settings were established for people who were not able to move to social care establishments at the time of their resettlement following the closure of long stay institutions in the 1980s and 1990s. Many of those people continue to live in in the same health settings to this date, with little consideration or ongoing assessment as to whether they are living in the most appropriate setting for them. For example, one setting we visited was originally set up as a place for people with challenging behaviour, but incidents of challenging behaviour were now a rare occurrence for current patients. Health boards should question the purpose of these settings.

Health boards also need to consider the type of care provided by staff at NHS residential settings. If staff are providing care and support, rather than purely healthcare, health boards need to consider if the services require registration with CSSIW. We note that one health board describes the care provided as "supported living", and should therefore consider what registration requirements apply.

Senior managers at Aneurin Bevan University Health Board have informed HIW that their Mental Health and Learning Disabilities Partnership Board has been working with relevant local authorities to explore, plan and deliver future service models which are best suited to the identified needs, preferences and wishes of individuals in receipt of learning disability residential services. This is positive and other health boards should also consider their residential provision for people with learning disabilities; ensuring they involve service users, their families and representatives.

In 2007, we found *"there was a general view that learning disability service planning was not being given a high priority"*. We examined health boards' Integrated Medium Term Plans (IMTPs)[9] as part of this review, and it was positive to see that some health boards had given specific consideration to learning disability services. Some health boards also had a joint commissioning plan in place or in development with local authorities in their area. However, there wasn't always a clear strategy as to how these plans would be implemented. For example, some health boards had identified that they had a growing population of older people with a learning disability. However, they had not moved on to considering what additional or different service provision might be required such as providing services for people with learning disabilities and dementia. We found that most health boards did not have a system for monitoring the needs of the learning disability population as a whole, to support future planning and commissioning. This meant that, in general, health boards did not have the depth of understanding of the current needs to be proactive in developing health services to meet future challenges. We found this was particularly true for people with additional needs such as challenging behaviour, people with learning disabilities who have offended or who are at risk of offending, and people with mental health conditions or older people with a learning disability.

[9] The NHS Finance (Wales) Act 2014 and associated NHS Wales Planning Framework require health boards to set out how resources will be used over a three year period. These plans are known as IMTPs.

5. Conclusions

Whilst positive improvement has been made for people with learning disabilities since our review in 2007, some significant challenges remain for the services providing and people receiving learning disability services.

Our findings show a real contrast between the good service provided by community health learning disability services and the sometimes poor service provided at some NHS residential services for people with learning disabilities. There appear to be challenges for health boards around staffing and management and leadership in these services, to ensure that patients and staff have the right level of support and that health board managers have sufficient oversight to ensure services are run safely. Health boards must review and reassess the people living in their residential services to ensure people are receiving the least restrictive care. They should consider if people require full time nursing care, and whether a move to social care would be appropriate. People should not be residing under a hospital model of care if this is not required.

It is positive that since 2007 there has been an increased use of hospital communication passports, and more health boards now employ learning disability nurses in health liaison roles. These measures have been shown to have a positive impact on the experience of people with learning disabilities using hospital services. However, it is disappointing that eleven years after the Mental Capacity Act 2005, people with learning disabilities are routinely not asked to consent to their own hospital treatment. It would appear that HIW's recommendation from 2007 that *"the training needs of acute and primary care nursing and medical staff should be reviewed and training programmes to better equip them to understand and manage the needs of people with learning disabilities should be implemented"* remains relevant.

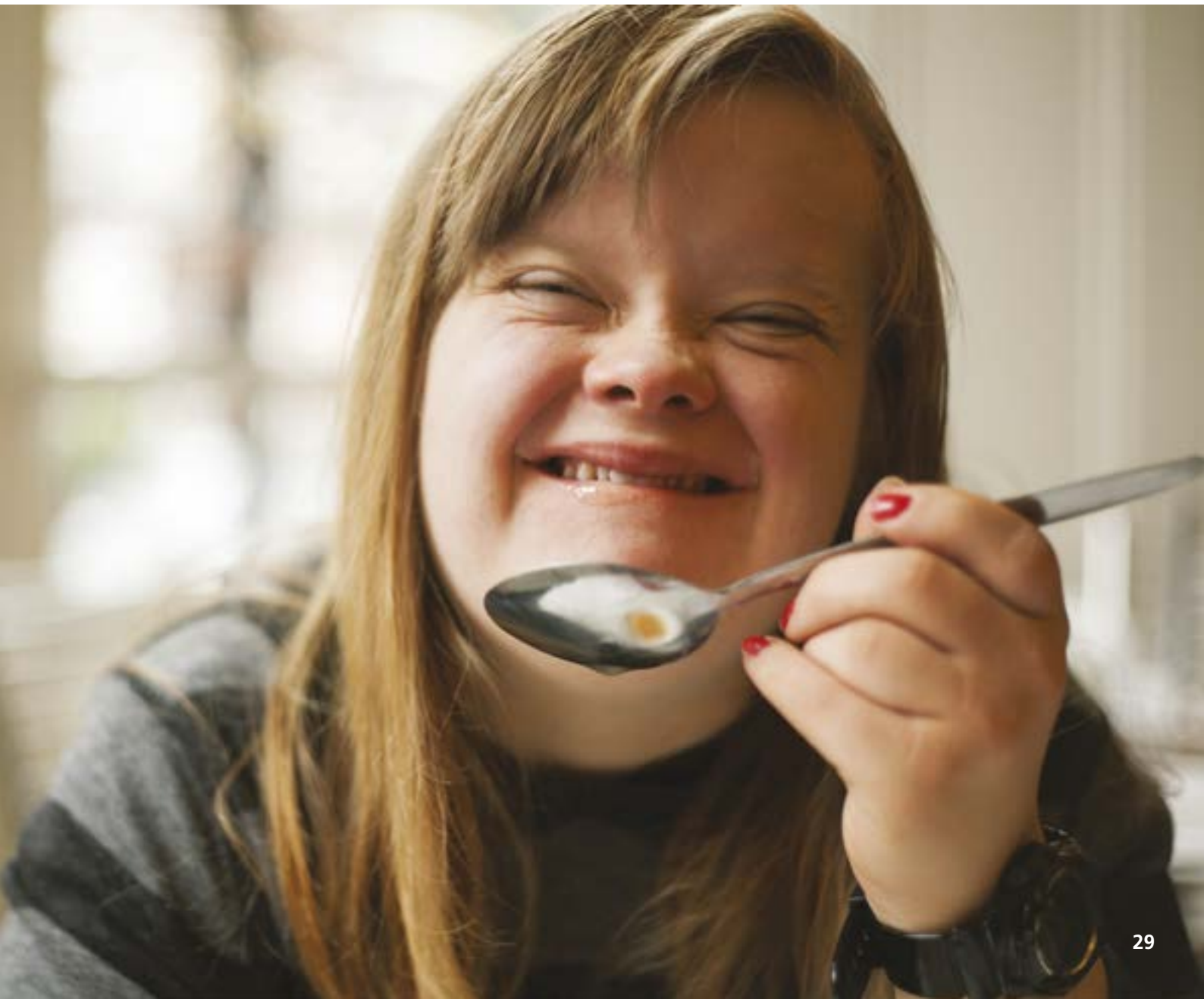
There is considerable complexity regarding the governance of learning disability services in some areas, particularly in areas where one health board provides the service to residents of another health board. Improved governance, strategic planning and leadership of learning disability services is required to ensure the services provided to people with learning disabilities meet required standards.

6. What next

HIW will be undertaking follow-up activity on recommendations that we have made during this review. This is to ensure that health boards are being vigilant in addressing these matters and taking all necessary action to ensure that people with learning disabilities are receiving safe, effective, person centred care.

HIW will liaise with Welsh Government and CSSIW to ensure that residential services are appropriately registered.

HIW will continue to promote the voice of the patient, to drive up standards in Wales and report openly on our findings.



Appendix A – Recommendations

As a result of the findings from our learning disability inspections in 2015-16, we have included the following overarching recommendations for health boards and policy makers to consider.

Recommendations	Health and Care Standard
Patient experience	
Health boards should continue to support patients to stay healthy, including ensuring people with learning disabilities have access to relevant cancer screening.	Standard 1.1
Health boards should consider how funding issues can be resolved quickly so that patients are able to have timely care, and access to appropriate equipment. Policy makers should consider whether there are any changes required to the continuing healthcare process to improve the experience of people with learning disabilities.	Standard 5.1
Health boards and policy makers need to ensure responsibilities are clear when a person is placed outside of their home area to ensure the person receives care in a timely way.	Standard 1; Standard 5.1
Patients should be involved in their care and treatment and discussions with patients about this should be recorded.	Standard 6.1
Patients should be supported to further develop their life skills to help them be as independent as possible.	Standard 6.1
Health boards should ensure that all staff are aware of the provisions of the Mental Capacity Act and how this relates to people with a learning disability, so that patients can be supported to make decisions about their treatment, including in wider healthcare areas.	Standard 6.2
Health boards should ensure that any practice of seclusion/segregation of patients is reviewed and an appropriate policy developed to ensure that patients and members of staff are safeguarded.	Standard 6.2

Recommendations	Health and Care Standard
Health boards should ensure that DoLS applications and dealt with in a timely way so that the rights of people with learning disabilities are adequately protected.	Standard 6.2
Health boards should ensure that patients have access to advocacy services, including availability of advocacy to residential settings to ensure patients can have support where needed to uphold their rights.	Standard 6.2
Health boards should ensure there are consistent systems for seeking patient and relative feedback on their experiences of the care provided across services. This information should be provided to patients in an accessible format to aid their understanding.	Standard 6.3; 3.2
Delivery of Safe and Effective Care	
Health boards should ensure environments are safe, well maintained and fit for purpose, including by ensuring: – Maintenance issues are addressed in a timely way – Availability of appropriate emergency equipment has been considered.	Standard 2.1
Health boards should consider how the cleanliness of services is maintained, including the most appropriate use of staff to do this.	Standard 2.4
Health boards must ensure that patients at residential units are encouraged to eat nutritious, varied, balanced meals.	Standard 2.5
Health boards must ensure that there are appropriate medicines management systems, including: • Ensuring medicines are appropriately stored. • Consideration has be given to the way this is administered to patients. • Information about medication is available for patients in a way that they can easily understand.	Standard 2.6
Health boards must ensure appropriate communication aids are available to assist patients in expressing themselves.	Standard 3.2

Recommendations	Health and Care Standard
Health boards must ensure Welsh speakers are offered language services that meet their needs as a natural part of their care.	Standard 3.2
Health boards should consider how record keeping can be improved including: • How information can be shared across health and social care. • Ensuring that records are contemporaneous and sufficiently detailed. • Kept securely and easily accessible to staff.	Standard 3.5
Quality of management and leadership	
Health boards should consider how SALT provision can be improved so that patients can be supported with communication needs, as well as eating and drinking.	Standard 7.1
Heath boards should carefully consider the dependency of patients and ensure that they have the right staff with the right skill mix to meet patient needs, including consideration of succession planning.	Standard 7.1
Health boards should ensure that staff receive up-to-date training to support them in their role.	Standard 7.1
Health boards need to demonstrate effective governance, leadership and accountability in learning disability services.	Standard 1
Where another health board provides the service, health boards should ensure responsibilities and delivery models are clear.	Standard 1