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Care and Social Services Inspectorate Wales

National inspection of care and support for people with learning disabilities

Overview

June 2016

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1. Introduction

This report sets out the findings of the national inspection of care and support for adults with learning disabilities undertaken by Care and Social Services Inspectorate Wales (CSSIW), supported by Healthcare Inspectorate Wales (HIW), between July 2015 and February 2016. The purpose of the inspection was to assess the success of local authority social services in achieving outcomes that matter to people. It did this by assessing the efficiency, quality and safety of care and support provided to adult people with learning disabilities. Inspectors set out to consider factors that drive good outcomes for people as well as barriers to progress.

The three key questions for the inspection

1. How well does the local authority understand the need for care and support for people with learning disabilities, including support for carers and the development of preventative services, in its area?

2. How effective is the local authority in providing information, advice, assistance, assessment and care planning that achieves positive outcomes and which respects people with learning disabilities as full citizens, equal in status and value to other citizens of the same age?

3. To what extent have the arrangements for leadership and governance in the local authority delivered a clear vision for care and support for people with learning disabilities, aimed at improving outcomes, and which has the support and involvement of partners – including people with learning disabilities and carers?

The national inspection included detailed fieldwork in six local authorities and the corresponding health boards in Conwy, Gwynedd (both Betsi Cadwaladr University Health Board), Merthyr Tydfil (Abertawe Bro Morgannwg University Health Board commissioned by Cwm Taf University Health Board), Torfaen (Aneurin Bevan University Health Board), Pembrokeshire (Hywel Dda University Health Board) and Bridgend (Abertawe Bro Morgannwg University Health Board). Those inspection reports have been published separately on our website.

This overview report examines the findings of three main inspection activities. Firstly and most importantly, the evidence from the six individual inspections; secondly, the results of a thematic enquiry into services for people with learning disabilities that are regulated by CSSIW; and finally, the results of a national data and self assessment survey undertaken in all 22 local authorities in Wales and the local health boards. It identifies the most common strengths and areas for improvement, and concludes with the recommendations for practitioners, leaders and policy makers. It is designed to provide information to the public about the performance of local authority social services; and to support improvement in the care and support provided for people with learning disabilities.

Inspectors from Healthcare Inspectorate Wales (HIW) assessed how well health boards provide care and support for people with learning disabilities, including the efficacy of the partnership between social services and health. While their evidence informs the whole of the report, the specific findings for health services are outlined in the summary and included in the discussion of the findings for each of the key questions for the inspection in chapters 6 – 8.

We have worked closely with All Wales People First and the All Wales Forum of Parents and Carers throughout the national inspection, in an effort to engage productively with people and family carers who are affected by the issues discussed. Further detail about our engagement with people and with family carers can be found in chapter 4.

Alternative formats

This report and the six individual local authority inspection reports are available in easy read format on our website.

We worked closely with All Wales People First to develop a short film about the national inspection, which can be found on our website.

We also worked with Mencap, Learning Disability Wales, and the All-Wales Forum of Parents and Carers and their volunteers and members with learning disabilities as part of the outreach and engagement work for this report.

2. Summary

Introduction

The quality of care and support for many people with learning disabilities in Wales is largely dependent on the effectiveness of the front line social services and health staff who support them. For those who have family carers, it is the tenacity and assertiveness of their relatives that is also often crucial to the outcomes they achieve. Social services and health staff generally work well together at an individual and team level. Much more needs to be done, however, by leaders at all levels to support their staff by working in partnership with people with learning disabilities and family carers to shape care and support for the future.

There are examples where social services and health are thinking and planning together for the longer term and talking and listening to people about their ideas and plans. However, there are too many instances where this is not happening effectively on behalf of people with learning disabilities.

Understanding need

The pattern of care and support for people with learning disabilities still, to a large extent, rests on the legacy of the ‘All Wales Strategy’ which was introduced in 1983[1]. This is reflected not just in the focus on individual need and community based support, but also in the values held by people providing care and support, with an emphasis on a person centred approach which respects the rights of the person. This is positive and the success of the Strategy is a testament to what can be achieved by a coordinated effort, with funding, across central and local government, in partnership with health services and the independent and third sector in pursuit of a clear objective. The evidence from the inspection is that more needs to be done by local authorities, health boards and their partners to develop a better understanding of need and a new vision and direction for care and support for people with learning disabilities.

The framework provided by the Social Services and Well-being (Wales) Act 2014 undoubtedly offers scope to secure just such a sense of purpose. The challenge for all, including Welsh Government, is to ensure that people with learning disabilities, along with other people in need of care and support, have equal opportunity to benefit from the implementation of the Act.

The care and support provided for people with learning disabilities generally rests on an assessment of individual need. While most staff spoke of taking a ‘person centred’ approach to their work, the exact nature of the process varied considerably. In some places it was limited to a determined effort to use the

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[1] The principles of which were reiterated in subsequent guidance in 1994 and again in section 7 guidance on service principles and service responses in 2004.

standard approach to assessment and care planning to the best effect for the person. In others it amounted to a more sophisticated endeavour to deploy a more in-depth person centred approach, using trained facilitators and user friendly approaches to record the plan and review its impact. All the inspected authorities were attempting to use the information from individual assessments to better shape a preventative approach for the people concerned, i.e. one focussed on intervention that removes the need for high intensity, high cost support later on.

Only a minority, however, had successfully moved beyond individual planning to construct comprehensive and comprehensible assessments of the current and future care and support needs for people with learning disabilities in the local area. Those local authorities which had been more successful in developing an understanding of need were also those that had reached out systematically to people, family carers and partner organisations (including service providers) to engage them in conversation about the future. These were also the authorities that had moved beyond talk of change and started remodelling the pattern of care and support.

HIW inspectors found that on an individual level, people with learning disabilities received help that was well co-ordinated and anticipated their future needs. Health staff knew people well, and understood their needs. Person centred planning ensured the voice of the person was heard, and inspectors saw accessible, outcome focused goal planning.

There were examples of accessible plans which had clearly been created with people with learning disabilities and their carers; were specific to the individual; and which had been completed with input from health and social care professionals. Assessments of need were clear and there was evidence that this had led to timely, appropriate interventions which met people’s identified needs.

On a strategic level, there was a general understanding of the challenges facing health services for people with learning disabilities amongst senior leaders. In some areas there were also systems and structures in place which allowed some joint planning and commissioning work to take place. However, most health boards visited did not have a system in place for monitoring the needs and outcomes of the adult learning disability population as a whole. Inspectors could therefore not be assured that all health boards had the depth of understanding of current needs to be proactive in developing health services to meet current and future challenges.

Providing effective care and support

Multi-agency and multi-disciplinary work at the front line is underpinned by a very strong value base from most staff. People with learning disabilities were generally supported by people who wanted to listen, understand and help them as best as they possibly could. Inspectors found a range of different team structures in place in social services and health. These included multi-agency teams with co-located staff, virtual teams in which social workers and nurses worked flexibly in a variety of locations and a number of other arrangements. The evidence from the inspection is that while most staff would prefer to be co-located with their colleagues, the outcomes for people with learning disabilities are less dependent upon organisational structures than they are on the quality of practice, including team work, of individual professionals. Furthermore, where staff were well led and managed they were more likely to rise above any barriers – perceived or real – created by structures. Where they felt adrift from, or confused about, direction and purpose they were more likely to lose focus in their work with people. The lack of an effective shared records management system across health and social services also created a barrier to wholly effective joint working.

HIW inspectors saw that funding disputes caused delays for people and frustration for the front line staff providing services. While there was no evidence that this had a negative effect on outcomes for people, there was a considerable impact on staff, whose clinical time was increasingly spent completing funding assessments and managing the expectations of people with learning disabilities and their carers.

Inspectors looked in detail at the circumstances for 120 people with learning disabilities across Wales. In most of these examples people were safe and protected from abuse. There were some isolated examples where practice, particularly recording, required significant improvement and there were a small number of cases that were referred back to local authorities for assurance. Of more concern, however, were more widespread deficits with the leadership and governance of adult safeguarding. Quality assurance of adult protection was generally weak. Cross referencing of information across safeguarding, contract monitoring, complaints and Deprivation of Liberty Safeguards (DoLS) activity was the exception rather than the norm. In addition, the move to integrated safeguarding services across adult and children’s services in some local authorities – or plans to do so - had created confusion about lines of accountability and responsibility in the minds of some practitioners and managers. This may prove to be a short term difficulty and an integrated service should reap longer term benefits. The risk, however, is that the oversight of current practice is compromised and quality assurance is further weakened.

HIW inspectors found that most community health teams reported safeguarding concerns through the local authority rather than directly to the health board. Health boards could monitor trends and themes arising from these concerns via external multi-agency meetings, including Adult Safeguarding Boards. However, reporting processes and lines of accountability in respect of safeguarding were not always clear between community teams and health boards.

People with learning disabilities themselves spoke of concerns about their safety in the community – this was particularly the case for younger people and tended to focus on concerns about bullying, verbal abuse and a general anxiety about being unaccompanied in public places.

Inspectors were encouraged by the degree of familiarity with the concept of positive behavioural support for people with challenging behaviour. In some places this familiarity had resulted in high quality practice resulting in positive outcomes for people. In other places, staff are committed to the idea of positive behavioural support, but this is not always correctly and consistently applied. At times, the linked but distinct disciplines of person centred planning, positive behavioural support and active support were conflated to a confusing degree.

Staff generally worked hard with individuals to encourage and support them to speak up or to express their opinions in other ways. In the better performing local authorities, assessments, plans and reviews reflected the voice of the person. The provision of advocacy support to assist with this was variable, being more available in some places than others. Staff working in day services, in particular, tended to take a lead in facilitating group work with people that had a focus on speaking up and expressing choices. While this was a very positive feature, it was not always well supported by the wider organisation. HIW inspectors found that health staff were strong advocates for people with learning disabilities, particularly in promoting people's rights when using secondary (hospital) care.

Most adults with learning disabilities known to local authorities live at home with family carers (51%). The next highest number of people live in homes of their own with a tenancy and receive domiciliary support (36%) – arrangements that are usually referred to as supported living or supported accommodation. A further 1,000 people (11%) live in care homes that are registered and inspected by us. Those people who live in care homes mostly experience care and support that recognises their individuality, is focussed on outcomes and is regularly reviewed. The main area for improvement identified through inspections of care homes is in involving people with learning disabilities in their plans and reviews, focusing on opportunities for growth and development for people and then delivering aspirational and ambitious care plans. While we inspect the domiciliary care agencies that provide the care and support for supported accommodation schemes, we do not inspect the actual services where people live. Nevertheless the evidence from the national inspection is that while people living in supported accommodation generally receive a good service, some people do not experience positive outcomes even though their care plan might be quite aspirational and ambitious.

Arrangements to help younger people with learning disabilities make the transition to adulthood – an area where performance of many authorities has been criticised in the past – generally worked well. In the small number of examples considered in the inspection, good work by social workers and health staff had helped both the young person themselves and their family carers to prepare and plan for the transition.

Family carers for the people in the case sample, for the most part, spoke positively about the support they receive from social workers and health staff. There were some good examples of carers' assessments in the case sample. The feedback from family carers in focus groups was more mixed. Alongside positive comments about individual practitioners, there were concerns about delays with reviews of care plans, difficulty in making contact with care managers and a more general lack of engagement and consultation about planned changes to the pattern of services. Perhaps not surprisingly, those local authorities that lacked a clear sense of direction and strategic plan for their services were also the ones with a culture that could not readily access and accommodate the views of family carers.

Leading in partnership with people

This was the key area where inspectors found the need for the most significant improvement. Most of the 22 local authorities who responded to the national survey thought that their performance was good. However, in the majority of the six authorities subject to fieldwork, inspectors concluded that performance either required improvement or was poor. All authorities are dealing with the consequences of budgetary constraints with many making potentially unpopular decisions about the closure or reconfiguration of services. This is a difficult context for leaders at all levels. Nevertheless the inspection found strong evidence that the absence of clear, trusted and well established channels of communication with people, carers, providers and other stakeholders makes the job of leaders that much harder. HIW inspectors found that improvements were needed in communication between health board managers and staff to ensure that those at the front line felt valued in their roles and engaged with the health board's direction and priorities. When deficits in communication are coupled with a lack of commonly understood vision for the development of care and support - as it was in some local authorities and health boards – then leaders and managers face an uphill task in creating a positive service culture.

The partnership between health and social services is crucial to helping people with learning disabilities achieve good outcomes. In the recent past, that same partnership was central to the success of the resettlement of thousands of people from long stay hospitals into homes of their own. While the partnership continues to work fairly well at the front line, it is too often faltering at a strategic level. There were some positive features: work at an all Gwent level between health and social services had produced a Learning Disability Strategy 2012-17 which had produced some good outcomes for people; while the Western Bay Collaborative is addressing the strategic objective of providing services closer to home. Even in these positive examples, however, there were difficulties. These were linked to changes in management structures in both health and social services and the impact on the momentum for change. In all local authorities inspected, difficulties could be exacerbated by competing priorities for health services. In more than one local authority, senior staff in social services found it a challenge to establish who was responsible for what in health – and then to maintain a meaningful dialogue with them about plans and strategies.

3. Recommendations for practitioners, leaders and policy makers

Understanding need

1. Local authorities and health boards should together ensure that they plan resources, manage performance and value for money for care and support services for people with learning disabilities. This should include gathering relevant data and information with a view to planning service provision that can clearly demonstrate how it is meeting the needs of the current and future learning disability population.

2. Local authorities and health boards should together produce commissioning plans that reflect their population and needs assessments, and which promote best practice in the care and support of people with learning disabilities and their family carers.

3. Local authorities and health boards should each ensure that they talk and listen to people with learning disabilities and their family carers as, together, they set the vision and direction for care and support for people with learning disabilities.

Providing effective care and support

4. Local authorities should review their quality assurance arrangements for care and support planning with individuals – to ensure that plans are focused on outcomes for people, are regularly reviewed and involve the person themselves and, if agreed, their family carers wherever possible.

5. Local authorities and health boards should share best practice across their boundaries, e.g. in relation to positive behavioural support approaches for people with challenging behaviour, to ensure a more consistently good quality response for people with similar needs across Wales.

6. Local authorities and health boards should ensure that the lines of accountability and responsibility in relation to adult safeguarding are clear and understood by all those staff who have a part to play in protecting people with learning disabilities from abuse and neglect.

7. Health boards should consider how to strengthen the valuable health liaison work currently underway in primary and secondary care. In particular, health boards should consider how to ensure the principles of the Mental Capacity Act 2005 are truly understood and reflected in the actions of all staff within their organisation.

8. Health boards should work with local authorities to ensure that people are offered equipment that meets their needs in a timely way.

9. Policy makers should consider the Continuing Health Care process and its application for people with learning disabilities, to determine if any improvements to the process can be made. At the same time, health boards should work with local authorities to agree better ways of working so that the current process works as best as it can.

Leading in partnership with people

10. Policy makers, local health boards and local authorities should together talk and listen to people with learning disabilities, their family carers and service providers to develop a vision for care and support for people with learning disabilities in Wales that reflects the principles and opportunities offered by the Social Services and Well-being (Wales) Act.

11. Health boards and local authorities should ensure that their communication systems help staff on the front line to feel connected with the vision for care and support services. Health boards should work with local authorities to ensure there is effective communication and information sharing between health and local authority teams.

12. Clear guidance should be in place about the duty of care of health boards when placing people with learning disabilities out of county, and on those health boards receiving an individual from another area, to ensure people continue to get the help they need.

13. Health boards should consider the sustainability of their current workforce and any succession planning required to ensure people with learning disabilities experience continuity in the health care provided by community teams.

4. Context – Demography and data

We issued a survey to all 22 local authorities in Wales at the end of July 2015 and HIW issued a similar survey to the health boards. Both surveys were designed to collect data about the number of adults with learning disabilities known to local authorities and health services and where they live. Our survey also collected some basic information about other aspects of people's lives and (to a limited degree) the activities and expenditure of local authorities on services for people with a learning disability. The second part of the survey asked local authorities to consider the three key questions for the inspection and comment on what has driven progress and the barriers to further improvement. The findings from part 2 of the survey are reflected and referenced in chapters 6, 7 and 8.

While every effort was made to ensure that the returns were accurate and reliable, it should be noted that the data has not been subject to a formal quality assurance process by CSSIW and does not have the status of 'official statistics'.

As will be clear from the discussion that follows, the data returns strongly suggest some differences in the understanding of the terms used in health and social services – including 'learning disability'. While some of the apparent discrepancies may reflect some problems in the design of the survey, they also raise questions about the capacity of local authorities and their partners to deliver the detailed 'population assessments' that are required under the Social Services and Well-being (Wales) Act.

Population

The *Daffodil* web based system for predicting social care needs, developed for the Welsh Government,[2] provides an estimate of 58,000 adults with learning disabilities living in Wales. The responses to our survey suggest that just 12,641 or less than one quarter of this number of people are known to local authorities. The figure provided by the Daffodil system rests on a calculation of the likely prevalence rate for learning disability in a given population. It is possible that the estimated population figure of 58,000 includes those identified who have not subsequently needed any specialist support from social services. This issue will need further investigation by local authorities and health boards as they prepare their population assessments.

The chart below details the case status of the adults with learning disabilities known to local authorities. Totals for certain authorities are higher than the estimates given for the total number of known people. This suggests some

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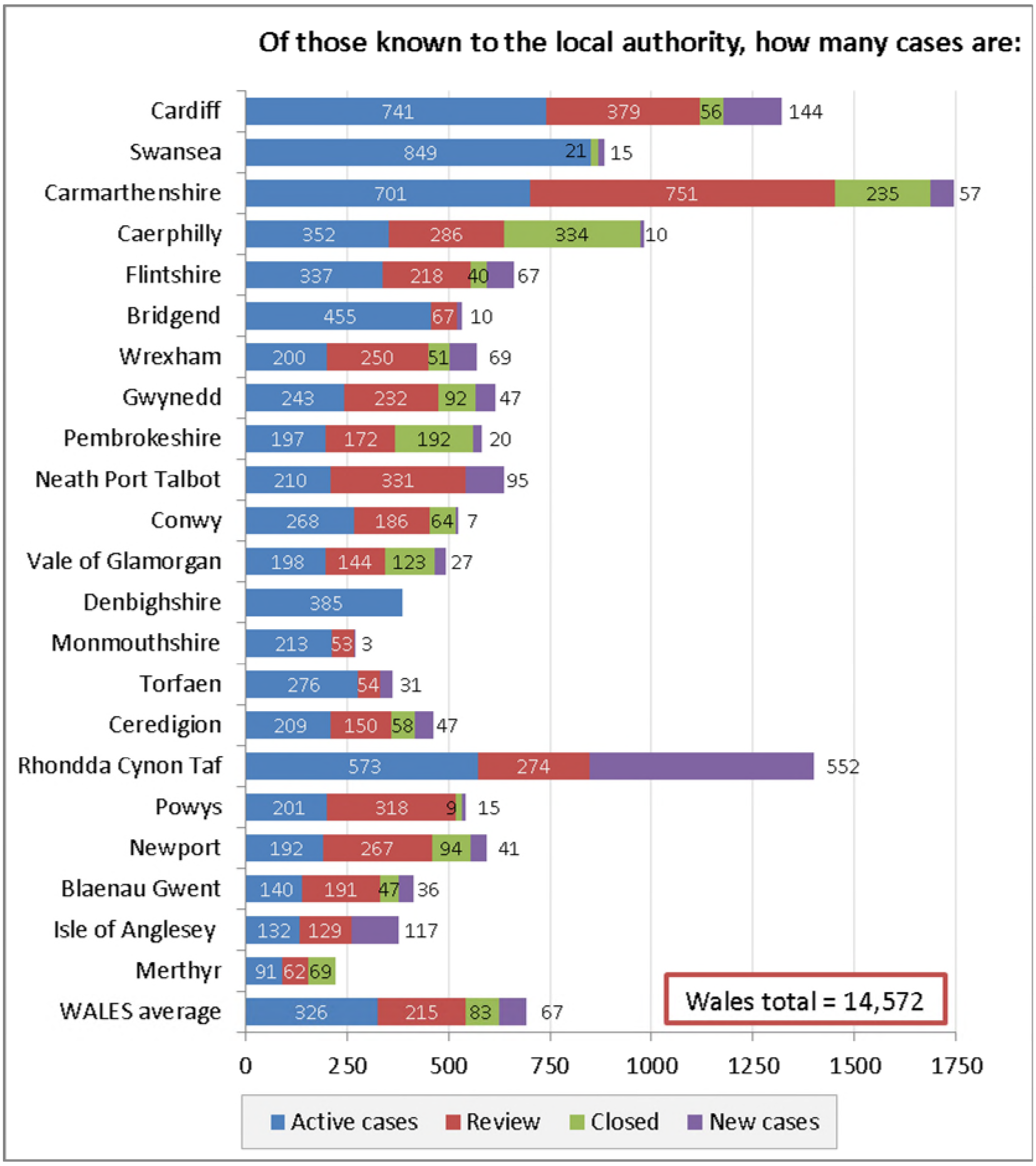
[2] http://www.daffodilcymru.org.uk/

double counting, e.g. a proportion of the active cases are also being counted as new cases.

Diagram 1



People with challenging behaviour

Both the local authority survey and HIW's survey of health boards asked about the number of people with challenging behaviour known to them. The surveys gave the same definition of challenging behaviour as a reference point. [3] Six out of the 22 local authorities in Wales did not answer this

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[3] *"Cultural abnormal behaviours of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary facilities."* Emerson, E (1995), cited in Emerson, E (2001, 2nd edition): Challenging Behaviour: Analysis and intervention in people with learning disabilities, Cambridge University Press.

question, citing a range of reasons, including that they did not collate information in this way. The total number of people with challenging behaviour recorded by the remaining 16 authorities was 1,342. The equivalent figure provided by the health boards was 952.

Where do people live?

A total of 4,824 adults who are known to local authorities live with family carers – a figure which illustrates the importance of relatives for many people with learning disabilities. It also highlights the extent to which those who provide care and support services (and plan for their development) need to take account of the contribution already made by carers.

Local authorities report that 3,344 adults live in homes of their own, with a tenancy and receive domiciliary support. This figure should encompass most of the arrangements that are usually termed ‘supported accommodation’ or ‘supported living.’

Of those people known to local authorities, just over 1,000 live in care homes that are registered to provide care for people with learning disabilities, while 143 people live in care homes where the main registration is for a category other than learning disability. Our routine inspections of regulated services during 2015-16 looked at any evidence in support of the three key questions for the national inspection. The findings are discussed in chapter 7.

Diagram 2

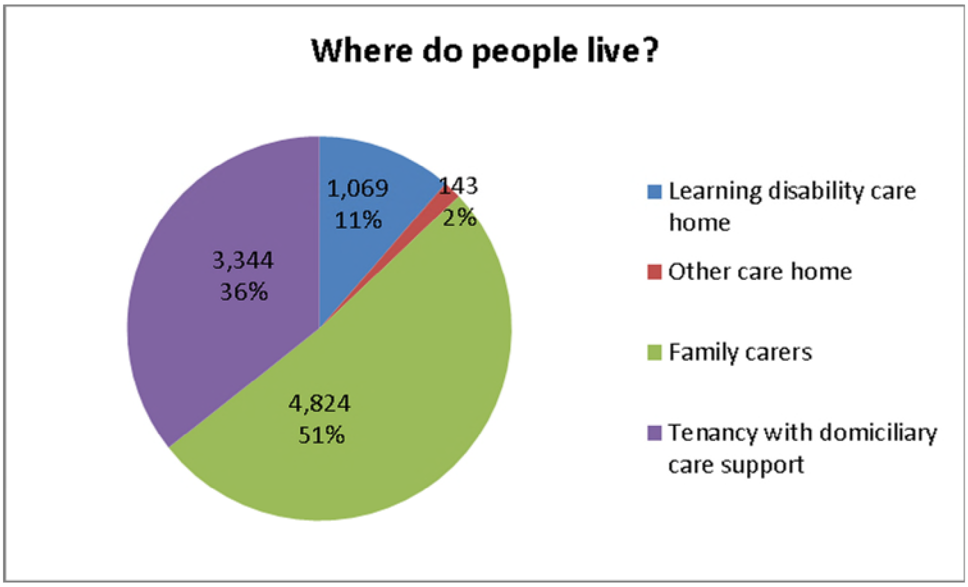
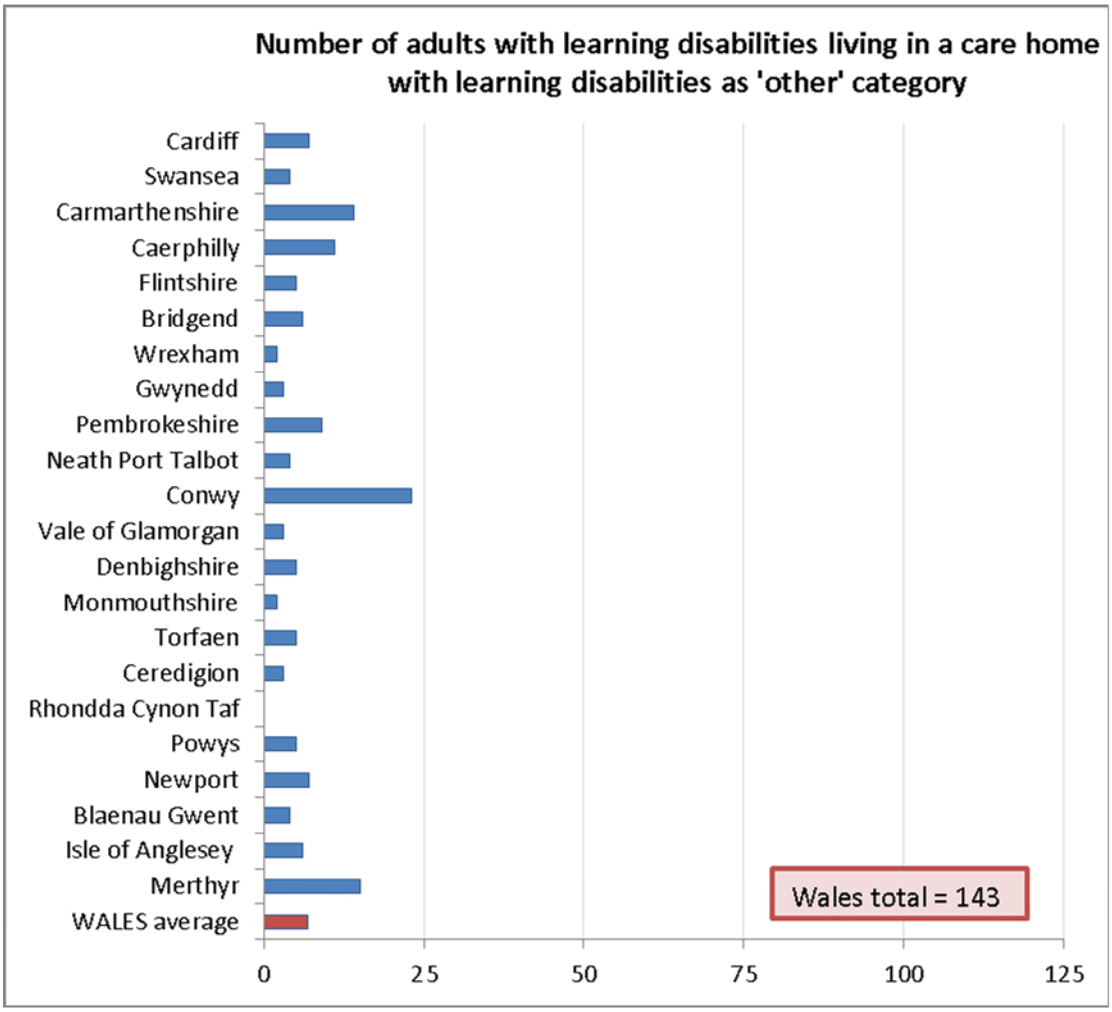
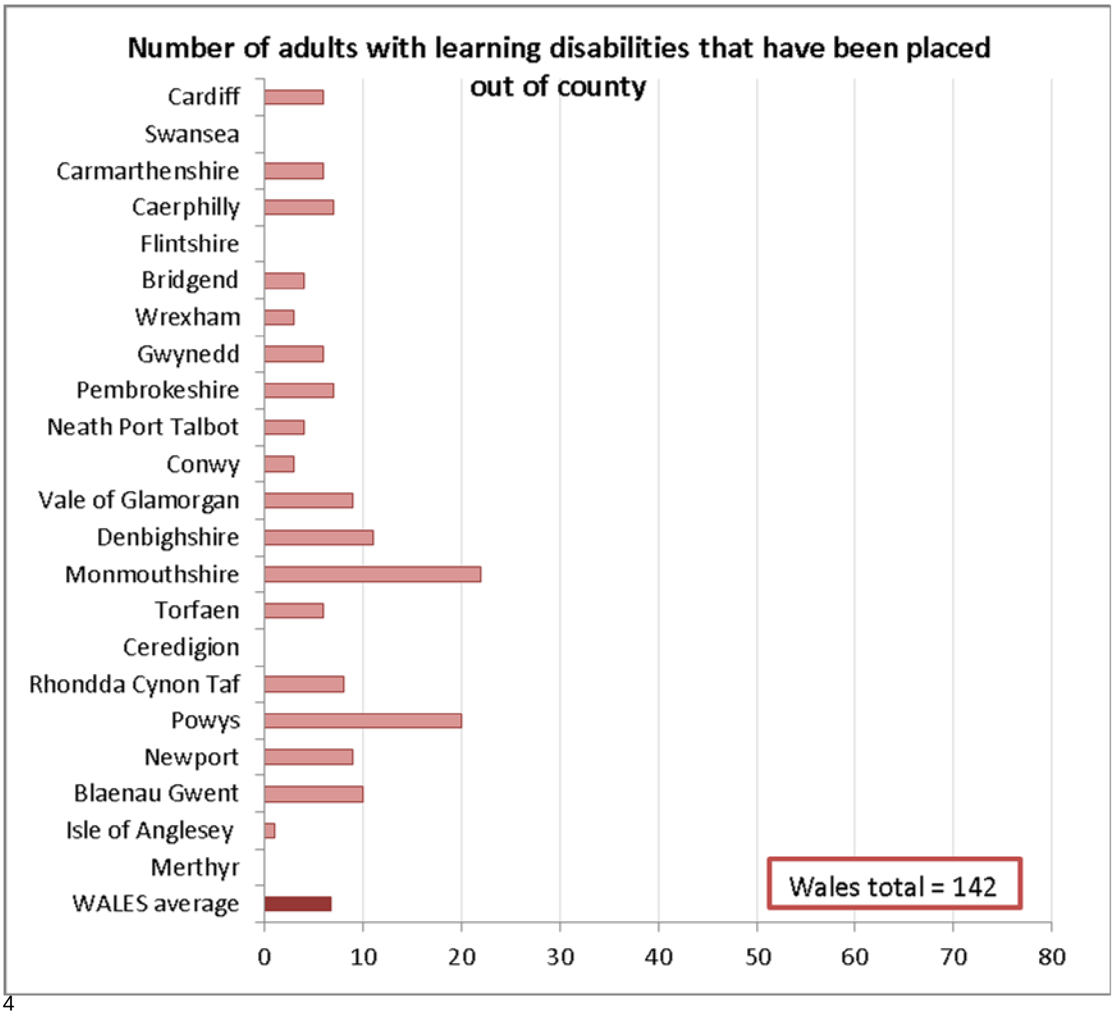


Diagram 3



The survey asked local authorities about the number of people who had been placed out of county (547), out of region (172) and out of country (142). This is an area of particular concern for practitioners, policy makers and people with learning disabilities themselves. While such placements might be entirely appropriate for some individuals (and may reflect their personal preference), the evidence from successive reviews and enquiries, i.e. the review of the care provided at Winterbourne private hospital, is that people generally achieve better outcomes closer to home and closer to those who are commissioning and paying for the service. It should be stressed that in a small country being placed ‘out of county’ may mean a placement even closer to home and family relatives. Also, for those living in the border counties in Wales a placement in England may be as ‘local’ as an in-county option. While the inspection did not consider in detail the reasons why people were placed out of county, the evidence from the fieldwork was that there was no correlation between lack of regular reviews and distance from the placing authority. Rather, where performance required improvement or was poor, then this was reflected across all locations.

Diagram 4



[4]

Health boards reported that as at 31 March 2015, 130 people with learning disabilities were living as inpatients in NHS provision. A further 53 people lived as inpatients in independent hospitals commissioned by the health board, while 97 people were compulsorily detained under the Mental Health Act 1983. Of those, 55 were detained out of their home county, i.e. in a different county from their ordinary place of residence or family home.

The use of day services

Our survey found that 5,582 adults use day services. This amounts to almost half of those people known to local authorities. Day services are neither registered, regulated nor routinely inspected by us or any other inspectorate or regulator. All the individual local authority inspections included visits, interviews and focus group activities that encompassed people who use day services of every description – including social enterprises and other opportunities and staff. The findings are discussed in chapter 6.

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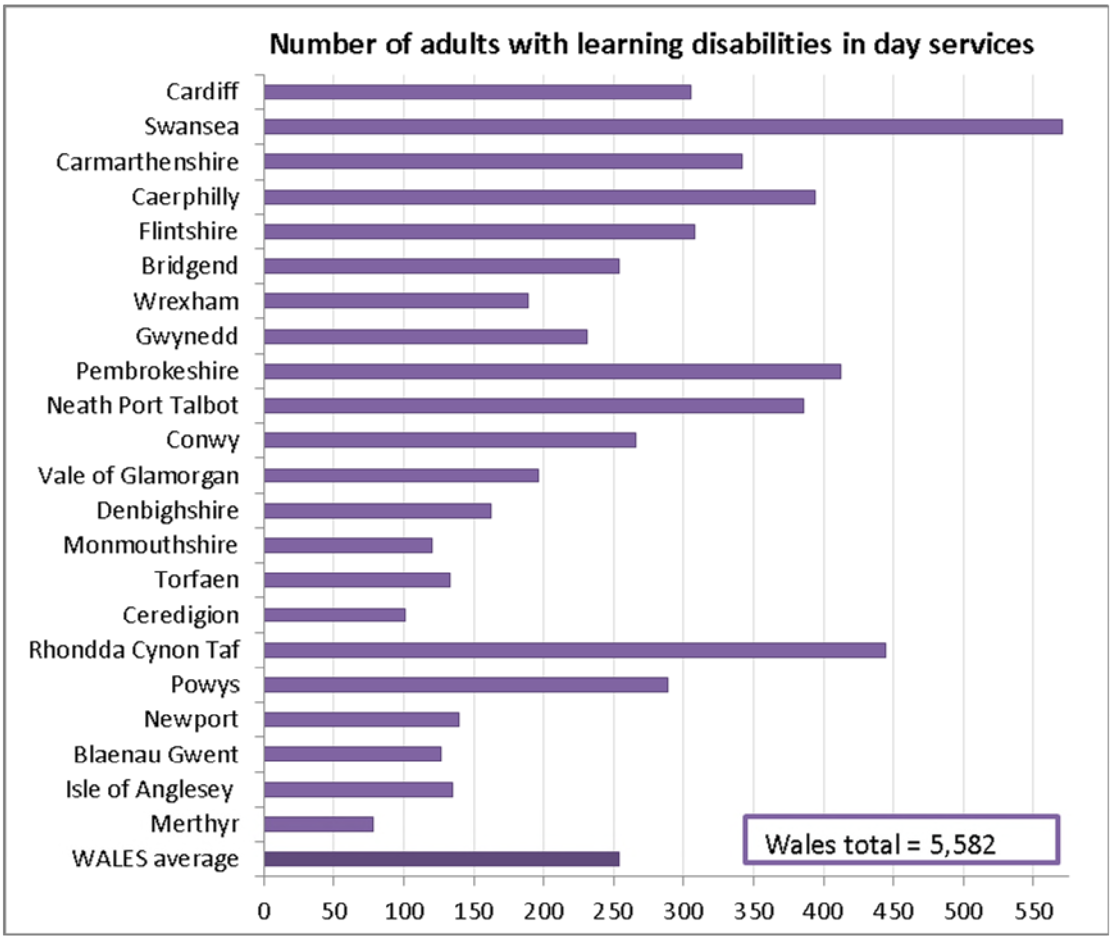
[4] The total of 142 people placed out of country amounts to just less than 1% of the total known to local authorities.

Diagram 5



What is the cost of care and support?

Our survey asked local authorities to estimate their expenditure per head for people with learning disabilities in the period April 2012 to March 2015. Four of the authorities included in the fieldwork spend above the Wales average figure while two (Gywnedd and Bridgend) spend slightly below the average amount. The inspection found no obvious correlation between the reported expenditure per head and the quality of care and support provided. In Pembrokeshire, for example, inspectors found the need for improvement “across the board” although the local authority had the highest expenditure per head in Wales in 2013-14 and in 2014-15.[5] Of course the amount spent matters, but the evidence from the national inspection suggests that how the money is spent matters more.

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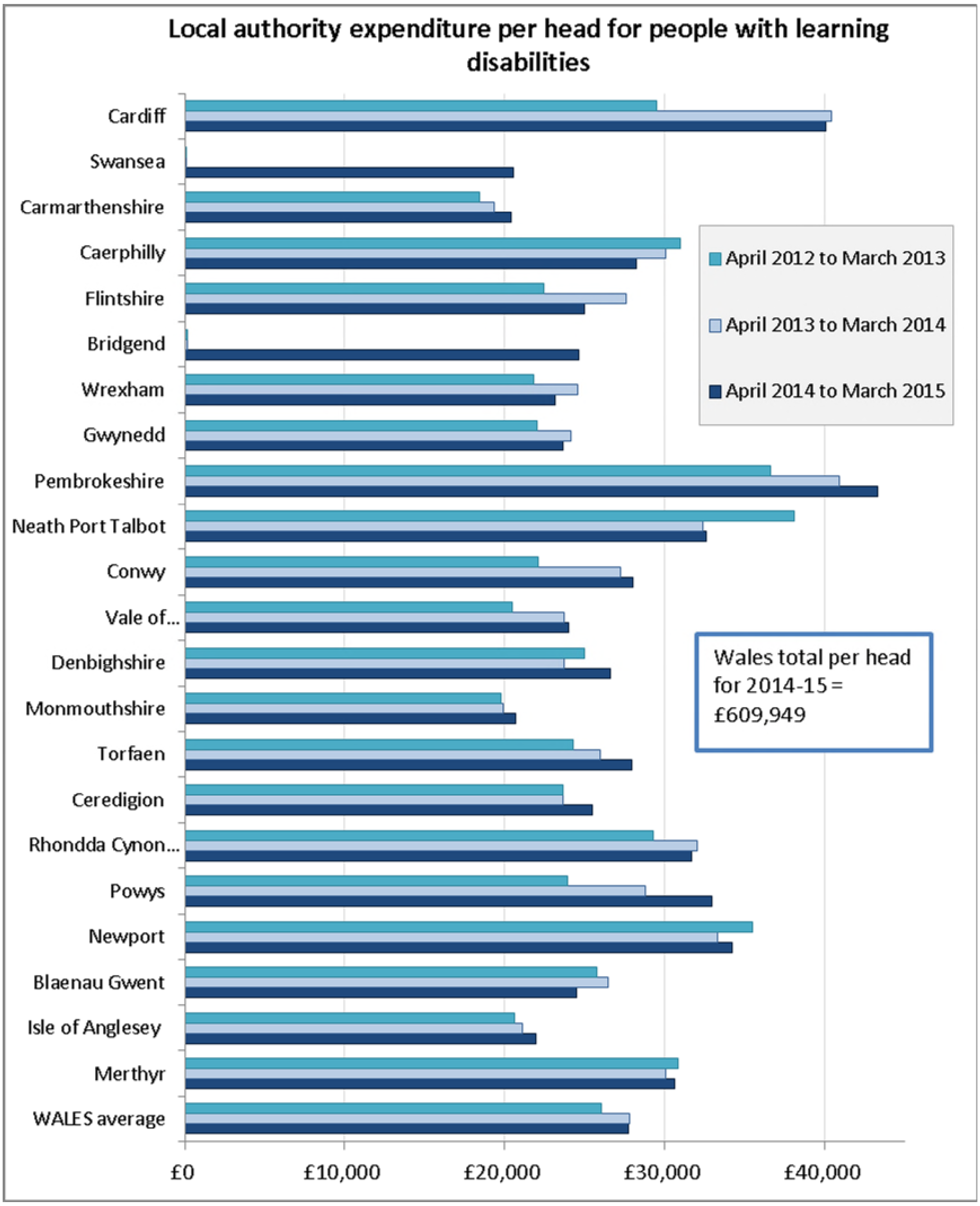
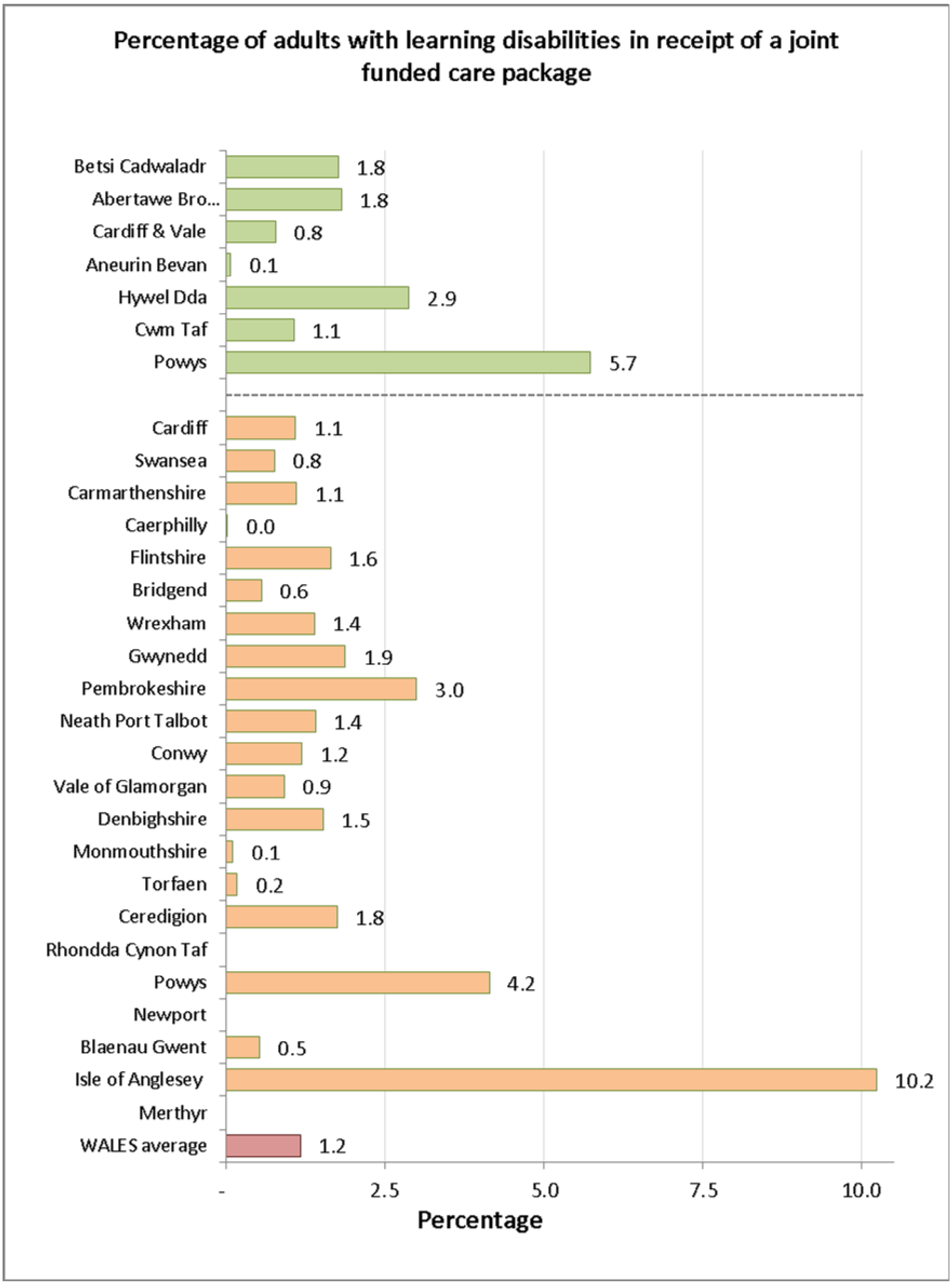
[5] *See page 5 in the CSSIW Pembrokeshire report.*

Diagram 6



Local authorities and health boards were asked about the total number of adults with learning disabilities in receipt of a joint local authority and NHS funded care package as at 31 March 2015. The Wales total provided by the local authorities amounted to 555, while the equivalent figure given by the health boards was 719. The discrepancy between the two figures may reflect genuine failings in the information systems, inconsistent application of the definition of learning disability or a combination of these and other factors. Diagram 7 shows that the Isle of Anglesey and Powys local authorities have a greater percentage of joint funded care packages for their ‘known’ populations than the other authorities in Wales, while those authorities in south east Wales have a noticeably low equivalent figure.

Diagram 7


Percentage of adults with learning disabilities in receipt of a joint funded care package
Betsi Cadwaladr 1.8
Abertawe Bro... 1.8
Cardiff & Vale 0.8
Aneurin Bevan 0.1
Hywel Dda 2.9
Cwm Taf 1.1
Powys 5.7
Cardiff 1.1
Swansea 0.8
Carmarthenshire 1.1
Caerphilly 0.0
Flintshire 1.6
Bridgend 0.6
Wrexham 1.4
Gwynedd 1.9
Pembrokeshire 3.0
Neath Port Talbot 1.4
Conwy 1.2
Vale of Glamorgan 0.9
Denbighshire 1.5
Monmouthshire 0.1
Torfaen 0.2
Ceredigion 1.8
Rhondda Cynon Taf
Powys 4.2
Newport
Blaenau Gwent 0.5
Isle of Anglesey 10.2
Merthyr
WALES average 1.2
-
2.5
5.0
7.5
10.0
Percentage

5. Listening to people - the work of All Wales People First and the All Wales Forum of Parents and Carers

On our behalf, both All Wales People First and the All Wales Forum of Parents and Carers carried out consultation sessions with their members to gather their views about the quality of care and support available to them. These sessions, which focused on two of the three key questions for the national inspection, were in addition to the individual meetings and focus groups held by inspectors during the fieldwork for the six individual inspections. All Wales People First and the Forum also helped with our preparation for two workshops with people with learning disabilities held at Learning Disability Wales' national conference in early November 2015, prior to the fieldwork for the first of the inspections.

The work of All Wales People First

All Wales People First consulted around 100 people through a combination of questionnaire and focus group activity. Not surprisingly, a wide range of views emerged, with most people focusing quite rightly on their individual experiences. Nevertheless, some common themes arose.

Understanding need

Most people spoke about their relationship with their care manager and other staff in response to this question, i.e. they focused on how well they thought people understood their individual need. Some people were positive about their care manager.

> "They will do it, it takes a bit of time, but she does what she said she'd do."
>
> "They are better than they used to be (for me)."

The majority of people were more negative and their concerns were largely about reliability (turning up on time); dependability (doing what is promised); and availability (having a care manager in the first place).

> "Don't always keep promises and sometimes when they don't they don't explain why not."
>
> "I used to see different social workers each time and I would have to explain from the start. I couldn't build a relationship, I didn't know them and they didn't know me. Now I've had the same one for the last two months, but the situation is the same because he hasn't seen me much. I feel nervous when I see him and my heart beats fast."

Staff who helped participants in focus groups in one local authority noted some common themes that, following an analysis of all the feedback, are equally relevant across all six authorities:

- people are not always sure if they have a social worker/ care manager or not;
- some people manage to build their own support networks that cover gaps left by formal care and support; and
- people without a social worker/care manager often don’t know or understand why they do not have one.

The Social Services and Well-being (Wales) Act is designed to support a wide spectrum of proportionate community-based services which people who have needs can use without having to rely on a complex assessment and care and support plan . It should also underpin arrangements in which people, irrespective of whether an individual has an eligible need, will have access to information, advice and assistance, as well as to a range of preventative and other services in the community. The evidence from our engagement with people is that, as the Act is implemented, careful attention will need to be given to how people with learning disabilities are helped to understand its implications and opportunities for them. Without this, there is a risk that the same set of circumstances for a person with a learning disability may be perceived quite differently, with the local authority seeing it as a positive example of co-produced, sustainable social services, and it being experienced as an isolating and confusing predicament by the person themselves. Finally, it should be stressed that the evidence from the national inspection is that many people already rely more on their families for support than they do on services.

Providing effective care and support

The focus groups concentrated their discussions on the quality of information, help and advice available to them; the extent to which local authority staff did what they said they were going to do; and the extent to which people were shown respect.

People commented on the quality of information about the help that might be available. There were concerns about the format of information – for example, too many words, small size of fonts and not enough pictures. This reinforces evidence from the fieldwork in which inspectors were also surprised to find a lack of readily available user-friendly information in some of the authorities.

Some younger people commented that the transitions process, with input while they were still at school, was a good way for them to learn about what might be available – particularly in terms of day time activities. Again, this supports the findings from the fieldwork, in which, for the most part, younger people in the case sample were relatively well served by the arrangements to help them make the transition to adulthood.

A greater and more powerfully expressed concern was about feelings of vulnerability and risk in the community.

“I get worried in council places – people laugh and I leave.”

“People in the community called me and my family names.”

“Sometimes the kerbs are too high for my wheelchair and the paths not wide enough so I worry I’ll tip into the road or if I go in the road get knocked down.”

While people said they would like to be less reliant on care and support services, a strong theme was that to achieve this they need local authorities, as corporate bodies, to take account of their needs in the way they design and manage other aspects of civil society, e.g. public transport, town centres, public safety.

A preventative approach to safety

In **Bridgend**, there has been a long standing relationship between the police and a local ‘People First’ group. People with learning disabilities have been involved in police training. Because of this, people in the focus group reported that they would not hesitate to contact the police on matters such as being exploited.

Design and location

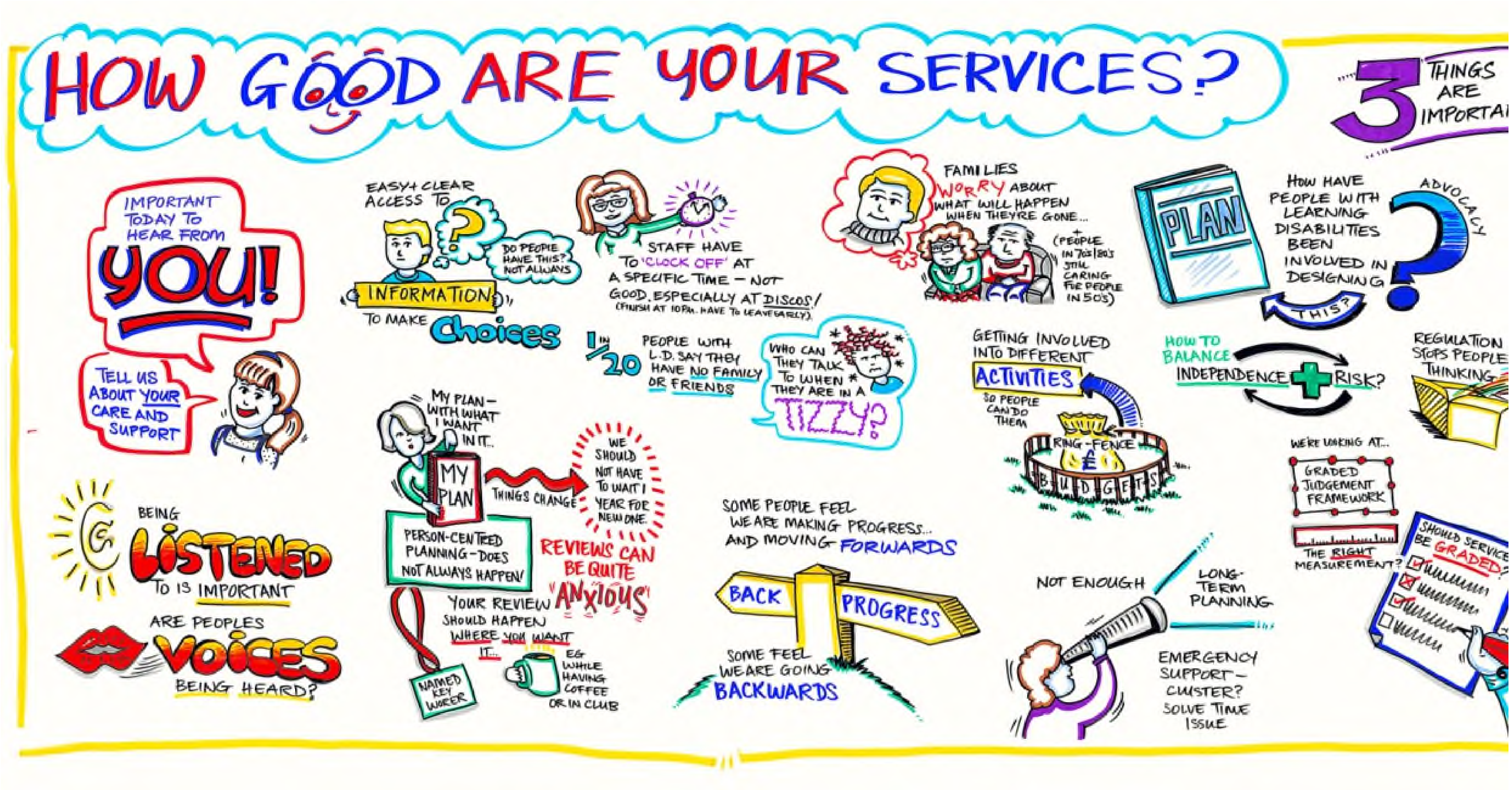
In **Torfaen**, one person commented: “Moving the council into the library was good - the librarians are helpful. They help read the leaflets.”

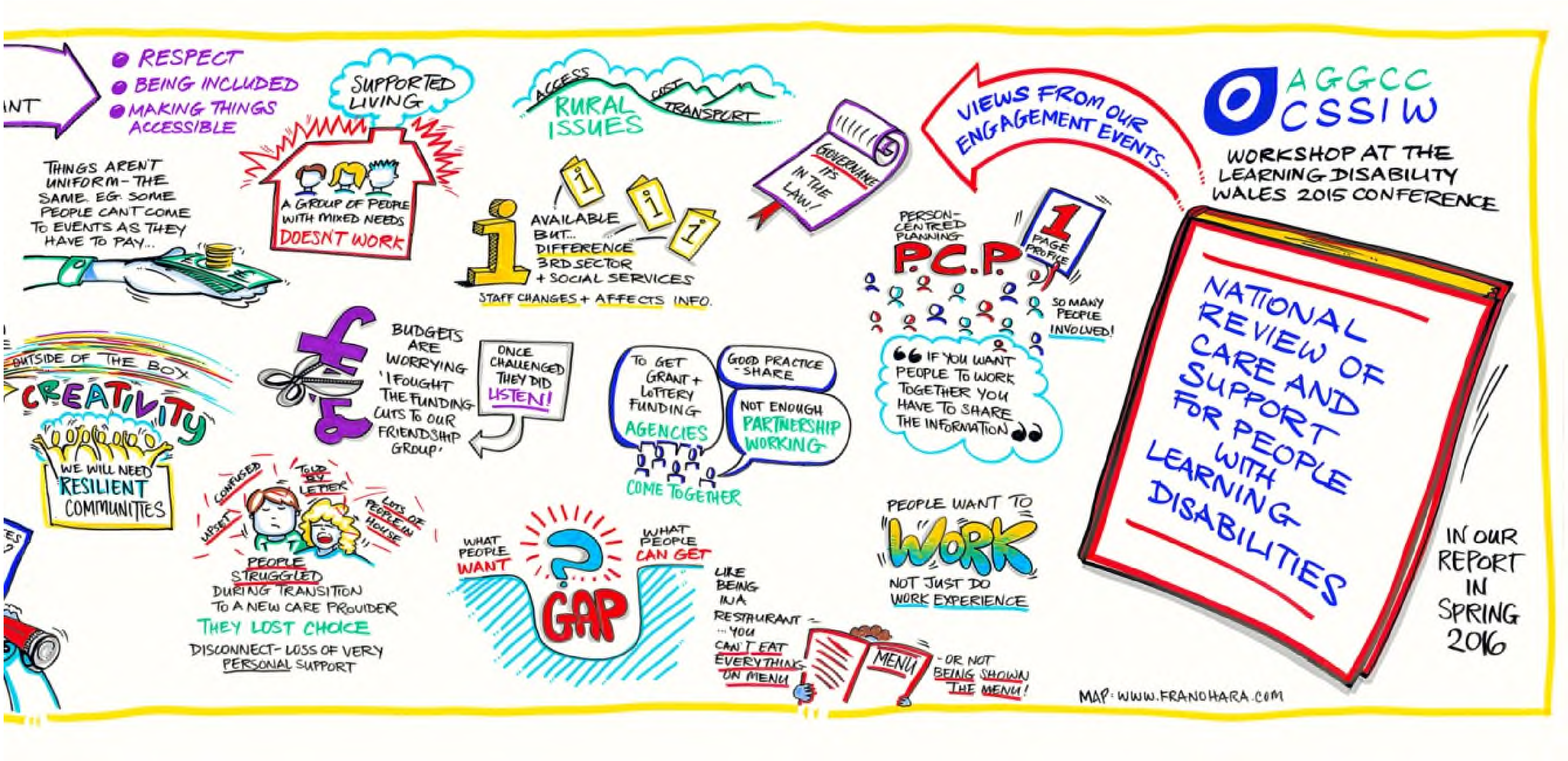
People were generally positive about the staff who supported them directly in residential supported living or day services. This supports the evidence from the fieldwork which found, for the most part, that staff at the front line aspired to a person centred approach that demonstrated respect for the rights of people.

“We feel like a team – even though we might argue, the staff support us to sort it out and we are all equal.”

“My support staff help me understand advice.”

Views about the help provided by care managers were more mixed. As the facilitator of one focus group put it: “There doesn’t seem to be a ‘corporate standard’. Members who were supported by a good social worker reported a good experience. People who were supported by a bad social worker reported a bad experience.”


HOW GOOD ARE YOUR SERVICES?
3 THINGS ARE IMPORTA
IMPORTANT TODAY TO HEAR FROM YOU!
TELL US ABOUT YOUR CARE AND SUPPORT
BEING LISTENED TO IS IMPORTANT
ARE PEOPLES VOICES BEING HEARD?
EASY+CLEAR ACCESS TO INFORMATION TO MAKE Choices
DO PEOPLE HAVE THIS? NOT ALWAYS
STAFF HAVE TO 'CLOCK OFF' AT A SPECIFIC TIME – NOT GOOD, ESPECIALLY AT DISCOS!
(FINISH AT 10PM. HAVE TO LEAVE EARLY).
1 IN 20 PEOPLE WITH L.D. SAY THEY HAVE NO FAMILY OR FRIENDS
WHO CAN THEY TALK TO WHEN THEY ARE IN A TIZZY?
MY PLAN – WITH WHAT I WANT IN IT...
MY PLAN
THINGS CHANGE
WE SHOULD NOT HAVE TO WAIT 1 YEAR FOR NEW ONE.
PERSON-CENTRED PLANNING – DOES NOT ALWAYS HAPPEN!
REVIEWS CAN BE QUITE 'ANXIOUS'
YOUR REVIEW SHOULD HAPPEN WHERE YOU WANT IT...
EG WHILE HAVING COFFEE OR IN CLUB
NAMED KEY WORKER
FAMILIES WORRY ABOUT WHAT WILL HAPPEN WHEN THEY'RE GONE...
+ (PEOPLE IN 70's/80's STILL CARING FOR PEOPLE IN 50's)
SOME PEOPLE FEEL WE ARE MAKING PROGRESS... AND MOVING FORWARDS
BACK
PROGRESS
SOME FEEL WE ARE GOING BACKWARDS
GETTING INVOLVED INTO DIFFERENT ACTIVITIES
SO PEOPLE CAN DO THEM
RING-FENCE
£
BUDGETS
NOT ENOUGH
LONG-TERM PLANNING
EMERGENCY SUPPORT – CLUSTER? SOLVE TIME ISSUE
PLAN
HOW HAVE PEOPLE WITH LEARNING DISABILITIES BEEN INVOLVED IN DESIGNING THIS?
ADVOCACY
HOW TO BALANCE INDEPENDENCE + RISK?
REGULATION STOPS PEOPLE THINKING
WE'RE LOOKING AT...
GRADED JUDGEMENT FRAMEWORK
THE RIGHT MEASUREMENT?
SHOULD SERVICE BE GRADED?



Visual map created by Scarlet Design, using feedback gathered at our workshop at the Learning Disability Wales 'Heart and Soul' conference 2015

The work of the All Wales Forum of Parents and Carers

The All Wales Forum of Parents and Carers supported us to in publicise and facilitate meetings with parents and carers in the six local authorities that were visited as part of the inspection. The evidence from these meetings has informed the detailed findings that are discussed later in this report. In addition, the Forum undertook independent consultation with groups of parents and carers across Wales during July and August 2015. The key issues that emerged from these meetings are outlined below. This feedback was used by the inspection teams to shape their approach to the individual inspections.

Friendships and relationships

People stressed the importance of involving family carers in the lives of their relatives who live outside of the family home in supported accommodation. They wanted those who provide support to people to make the person’s tenancy ‘real’ – with respect for the person’s rights as a tenant of their own home. Linked to this was the need to respect the right of the person to invite whom they wish to visit them at any time, including their family.

Community presence and value

Inspectors were encouraged to consider the extent to which people have the opportunity to mix with others outside of their normal living arrangements. Parents and carers stressed the importance of social interests, involvement in the local community and meaningful paid or voluntary work for people with learning disabilities.

Choice and opportunity

There was a focus on the experience of people living in supported accommodation schemes and the extent to which they have a genuine choice about where they live and with whom. Linked to this were concerns about the degree to which people can express their personal preferences about clothing and the furnishing of their accommodation. There was a concern about the language of service provision and the way in which information is communicated to people with learning disabilities. Parents and carers highlighted the important issue of spontaneity for people – wanting to see opportunities for people to do the unexpected and break out of set routines. They wanted to see their relatives having the opportunity to take managed risks underpinned by effective risk assessments.

Health care

The provision of effective health care for people with learning disabilities was a major consideration for parents and carers. Specific issues included the importance of annual health checks; the use of care bundles setting out key steps that should be taken when a person is admitted to hospital; and, importantly, the involvement of parents and carers in their relatives' annual health check.

Other issues

Parents and carers were also concerned about the provision of advocacy services; the extent to which staff respect the confidentiality of personal information (and the consequences of inappropriate disclosure); the degree to which their relative's well-being was promoted (including the importance of good quality care plans); and the quality of support to meet a person's spiritual and cultural needs.

Our inspection teams used the feedback gathered by both All Wales People First and the Forum to shape the approach to the fieldwork in the individual inspections. While the detailed work has informed the findings that are described in the following chapters, it is useful to highlight three cross cutting issues:

1. The quality and reliability of the relationship with staff (including care managers) is crucial to the achievement of positive outcomes for many people with learning disabilities.

2. The helping relationship should focus on promoting and supporting the rights of people with learning disabilities including their right to express and exercise choice.

3. The expression of choice should be underpinned by sound risk assessment and risk management so that people feel as safe as possible as they grasp new opportunities.

The familiarity of these findings does not negate their significance. They highlight once again the extent to which managers and leaders should focus on securing positive practice at the front line, in the way in which they commission and review care and support for people with learning disabilities.

6. Findings

Understanding need

How well does the authority understand the need for care and support for people with learning disabilities, including support for carers and the development of preventative services, in its area?

Expected outcomes

- People get help that is well coordinated and makes sense to them.
- Those who help people work well together, anticipate what people's might need in the future and jointly plan ahead to meet needs.
- People have a voice and are encouraged to express views and opinions.
- Service planning and commissioning is focused on the delivery of care and support that will maximise the rights, responsibilities and social value of people with learning disabilities.

Strengths

Good joint work between social services and health at the front line that is value driven and strives to focus on assessing and planning to meet the needs of individuals.

A positive culture for care and support characterised by attitudes and beliefs that reflect the legacy of the All Wales Strategy and subsequent section 7 guidance.

Areas for improvement

Reflecting the views and opinions of people with learning disabilities not just in the individual plan and reviews, but in developing an understanding of collective need and aspiration for the future.

Using the information from individual assessments and plans to help shape meaningful commissioning strategies for people with learning disabilities and their family carers.

The local authorities

Inspectors considered the experience of 120 adults with learning disabilities in some detail during the inspection fieldwork. In two thirds of these examples, inspectors found that people received help that was well coordinated by social services and its partners and which made sense to them. The co-location of health and social services staff in community teams is one factor that has driven progress in the more successful authorities, but variations on this approach can still be effective if they are underpinned by good leadership. Where outcomes were less positive for people they usually reflected a deficit in the oversight and quality assurance of the service. In addition, difficulties in one aspect of the work tended to reinforce and exacerbate difficulties in another, e.g. poor communication between health and social services staff is made worse if the agencies' respective IT systems are not readily compatible, but technical difficulties can then become an excuse for neglecting other ways of communicating and engaging with colleagues.

In **Torfaen**, the personal commitment, professionalism and skills of individual staff, including those at a senior level, have helped to create a service that has a strong value base and demonstrates a commitment to the voice of people with learning disabilities. The community learning disability team revealed good morale and team work, with mechanisms for appropriate challenge and support. They were positive about visible, approachable managers. Staff in the team receive regular supervision, support and learning opportunities. The local authority has given training on Person Centred Planning high priority for staff in a variety of services. Local authority staff have good access to training opportunities and much of this is extended to the wider social care workforce.

In **Pembrokeshire,** there were examples of good practice from individual practitioners, but these were not typical of the service as a whole. The content of case files examined by inspectors tended to be poorly formed, missing detail about the substance of care plans and, for the most part, lacked the views and opinions of the person concerned. Overall, there was a lack of focus on outcomes and some staff noted that they had not received training about an outcome focused approach. Both care management and external provider staff spoke of IT systems being a barrier to sharing information across health and social services. The social services record system was itself fragmented which meant that inspectors found it difficult, at times, to understand what had been done and when.

The legacy of the All Wales Strategy 1983 and subsequent policy guidance was strong, even in the poorer performing local authorities. This was reflected not just in the focus on individual need and community based support, but also in the values held by people providing care and support. There was an emphasis across all local authorities on a person centred approach which respects the rights of the person. However, there was significant variation in the level of success in turning a commitment to a person centred approach into meaningful plans for people that resulted in positive outcomes for them and which looked to the longer term future. This was only found in half of the cases examined by inspectors. It is important to note that, even in the better performing authorities, there were examples of less than effective care planning practice. The nature of the ‘person centred planning’ delivered for people varied considerably across and sometimes within authorities. A minority of people were helped to construct a plan with trained facilitators that was recorded and monitored in ways that put the person at the heart of the process. For the majority, the process, while reflecting a genuine desire to put the person at the centre of their plan, was less ambitious in application. For example, most people in the case sample had been encouraged to have a voice and express opinions about their circumstances and needs. However, there was considerably less success in using this information to construct plans that had real day to day impact for individuals. This is discussed further in the next chapter.

All the inspected authorities attempted to use the information from individual assessments to better shape a preventative approach for the people concerned. However, only a minority had successfully moved beyond individual planning to construct a comprehensive and comprehensible assessment of the current and future care and support needs for people with learning disabilities in the local area.

There were several common themes emerging from the national self assessment completed by all 22 authorities. The key factors that tended to drive progress were person centred planning; partnership working; and action arsing from commissioning plans. Barriers to progress included budgetary pressures (not just for social services but for health partners); staffing pressures; and the challenge of the sometimes conflicting needs of people with learning disabilities and their family carers.

In **Merthyr Tydfil**, most people receiving services had done so for many years and were well known to those who work with them. This personal knowledge was shared by people in senior manager positions and, in an informal way, had undoubtedly helped shape views about service development. In addition, the budget provision for services for people with learning disabilities in the authority is based on current and predicted costs of individual cases, with special attention to those coming through the process of transition from children’s to adult services. However, there is no formal vision or strategy for service development, based on an analysis of need. A learning disability commissioning strategy, produced in 2011, had not been effectively pursued.

In **Gwynedd,** inspectors noted a learning disability commissioning plan (2011-16) with reasonable analysis of current and projected need. However, in the past five years little work had been done to update this plan. Progress had been piecemeal rather than part of a determined and wide ranging improvement drive. Accommodation and development of community based options had been developed, but options for short term care and the partnership development of day services had not made similar progress. A new draft commissioning plan, produced shortly before the inspection fieldwork, had been developed without discussion with key stakeholders.

In **Bridgend,** good progress had been made against some of the objectives in the learning disability commissioning plan 2014-16 and, more generally, participation in the 'Western Bay Collaborative' formed the background for work to transform and remodel services locally, with a focus on greater independence and progression for people. The local authority has created new posts of community coordinators with the intention of further developing partnerships with the third sector.

Those local authorities which had been more successful in developing an understanding of need were also those that had reached out systematically to people, family carers and partner organisations (including service providers) to engage them in a conversation about the future. These were also the authorities that had managed to move beyond talk of change and begin remodelling the pattern of care and support for people with learning disabilities through the use of effective commissioning plans. However, the evidence from the inspection is that all local authorities, health boards and their partners need to do more to develop a better understanding of need and a new vision and direction for the care and support for people with learning disabilities. The framework provided by the Social Services and Well-being (Wales) Act 2014 undoubtedly offers the scope to secure just such a sense of purpose. The challenge for all, including Welsh Government, is to ensure that people with learning disabilities, along with other people in need of care and support, have equal opportunity to benefit from the implementation of the Act.

The health boards

HIW inspectors found that, overall, individuals in all the areas visited received help that was well co-ordinated and anticipated their future needs. Person centred goal planning was being used to varying degrees in all areas, and this ensured the voice of the person was heard. There were examples of accessible plans which had clearly been created with people with learning disabilities and their carers; were specific to the individual; and which had been completed with input from both health and social work professionals. In all areas visited, people had appropriate and clear assessments of need. There was evidence that assessments had led to timely, appropriate interventions which in general met peoples' identified needs.

In all health boards visited, people with learning disabilities and their families were encouraged to express their views about their individual care and support, and played an active role in planning the service they or their family member received on an individual level. In all areas, staff made an effort to ensure people were involved in decisions about their care, even where verbal communication was limited. In Aneurin Bevan University Health Board, inspectors were provided with specific excellent examples of how a health technology fund had helped people to express themselves.

In general, health staff in all areas were proactive in trying to meet people’s needs. There were examples of bespoke training for care staff in Positive Behavioural Support and the development of easy read information to support individuals in particular circumstances. Where there was a lack of service provision available, there were good examples of creative solutions to meet individual needs. For example, in Betsi Cadwaladr University Health Board inspectors heard about an individual for whom no suitable respite provision was available. Health and social care staff worked together to make a day services training flat available so that the person could have a break in a supported and familiar environment.

Inspectors found that staff were frequently engaged in preventative work for the benefit of people with learning disabilities, outside of their direct clinical work. There were examples of health teams being involved in innovative research to develop new ways of working. For example, in Aneurin Bevan University Health Board, inspectors saw work on an education and research project for people with learning disabilities who have type 2 Diabetes. Teams also supported people to use wider health services, such as annual health checks and regular blood tests (where needed) so as to avoid hospital admissions where possible.

Across all areas a particular focus had been placed on improving the transition pathway, for example by working with dedicated transition workers in the local authority to identify people who would need health support from their early teenage years. People with learning disabilities and their families mostly reported that transition had been a positive experience for them.

Unfortunately the proactivity on an individual and team level was not matched on a strategic planning level. Most health boards visited had no system in place for monitoring the needs and outcomes of the adult learning disability population as a whole, to support future planning and commissioning within health. This meant that, in general, health boards did not have the depth of understanding of current needs to be proactive in developing health services to meet current and future challenges facing the service. Inspectors identified particular challenges in service provision for people who had additional needs to those associated with their learning disability. These included challenges in meeting the needs of people with complex needs and challenging behaviour; people with learning disabilities who have offended or who are at risk of offending; and people with mental health conditions and older people with learning disabilities. A lack of management stability within learning disability directorates in many of the areas visited meant that health boards were not in a stable enough position to proactively plan. In those areas with stable management structures, there was more effective and proactive planning.

In Betsi Cadwaladr University Health Board, all of the cases reviewed by inspectors in Gwynedd showed staff had faced challenges in meeting individuals' complex needs and challenging behaviour through the current service provision, particularly in day services and respite. Lack of access to adequate and appropriate respite provision was an issue that was raised with inspectors in a number of the health boards inspected.

In half of the areas visited, concerns were raised with inspectors about individuals' access to community health teams when they are placed out of county (in a different health board area from their home). Inspectors heard that there were disagreements over which community learning disability team should provide care. The home health board thought the receiving health board should provide community services, but inspectors heard this did not always happen. Two cases particularly highlighted this issue in respect of people's psychiatric care. Additional difficulties were faced by people who had moved across the border into England.

There had also been a reduction in the provision of therapies and/or specialist learning disability therapies such as physiotherapy, hydrotherapy and speech and language therapy in some of the areas visited. This led to increased challenges for staff in meeting people's individual needs.

Some consideration of learning disability services was contained within some health board's Integrated Medium Term Plan. Some health boards also had a joint commissioning plan in place or in development. This was positive and indicated that learning disability services were included in some health boards' overall planning considerations. It also showed that some health boards were beginning to consider their obligations under the Social Services and Well-being (Wales) Act 2014 in respect of people with learning disabilities. However, there wasn't always a clear strategy as to how these plans would be implemented or how people's views would be incorporated at a strategic level. Inspectors concluded that, in general, health boards will need to improve their planning processes in order to effectively engage with their local authority colleagues and meet these obligations. Health boards should reflect on their services as a whole with relevant partners, gather the data necessary and devise plans which support service provision that will meet the needs of the learning disability population.

7. Providing effective care and support

How effective is the authority in providing information, advice, assistance, assessment and care planning that achieves positive outcomes and which respects people with learning disabilities as full citizens, equal in status and value to other citizens of the same age?

Expected outcomes

- People know and understand what care, support and opportunities are available and get the help they need, when they need it, in the way that they want it.
- People have a voice and are encouraged to express views and opinions.
- People receive an active offer in relation to their choice for communication, assessment and provision of care in the Welsh language.
- The help that people get is designed around individual circumstances and needs. It is provided in their language of need and they are involved in decisions that affect their life.
- People are safe and protected from abuse and neglect.
- People have good relationships with those that help them and they feel respected and valued by them.
- People who care for others feel supported and valued for the help that they give.

Strengths

Multi agency and multi disciplinary work with individuals.

Staff generally committed to hearing the voice of the person – very strong value base.

Creative and radical approaches to care and support for some people, including the use of supported accommodation.

Arrangements to help young people make the transition to adulthood.

Some good or excellent examples of positive behavioural support planning.

Some good or excellent examples of health liaison work between community services and primary and secondary health care, both through designated teams and by community health staff.

Areas for improvement

Better information for people, and engagement with them, about opportunities and options.

Leadership and governance of adult protection, including the collation and cross referencing of information to inform strategic planning.

Moving beyond to stability and safety for people to aspiration, ambition and outcomes for all.

Better understanding of positive behavioural support with more clarity and rigour in the way it is used with people.

A better strategic approach to the use and development of day services, built in partnership with people and their advocates.

Local authorities and health boards should work together and with policy makers to seek to improve the Continuing Health Care process.

The local authorities

Inspectors looked at the circumstances and outcomes for 120 people with learning disabilities in the case sample during the fieldwork in six local authorities. In parallel with this work, our inspections of 60 regulated services for people with learning disabilities, e.g. care homes, across the whole of Wales explored a range of issues linked to the key questions for the national inspection. Each local authority inspection also included meetings with individual people with learning disabilities; individual parents and carers; and separate focus groups for both.

Information and advice for people with learning disabilities was largely provided face to face by care managers and other staff providing care and support. While this can be the most effective approach for some individuals, it depends on the availability of staff and needs to be one part of a coherent approach to providing information and advice. In some places the local authority had been largely successful in establishing effective arrangements for information and advice.

In **Torfaen**, the authority’s general approach is to provide web based information. Managers within learning disability services, often working with People First, have taken steps to ensure that people and family carers get equal and effective access to information and advice; this includes the development of health passports and a handbook explaining how to stay safe and avoid abuse.

In **Conwy**, while many people will have been known to the authority for some time, people with learning disabilities, like others, can make use of the Conwy Access Team (Single Point of Access) and, if that team is not able to offer a solution through advice, information or signposting, the referral would be passed to the relevant team within the disability service. More specialist advice and assistance might come through some of the opportunities provided by Conwy Connect – an organisation focused on promoting rights of people with learning disabilities which brings together a range of stakeholders, including the local authority.

In other authorities, however, there was little information readily available to the public about care and support for people with learning disabilities. Overall, the evidence across the six inspected authorities was that much more needs to be done, not just to meet the needs of people now, but to fulfil the requirements of the Act.

In **Pembrokeshire**, there was no current user friendly information for people with learning disabilities about the work of the community team, or more generally about what the authority can do to support them.

In **Gwynedd**, there was limited information available about support and opportunities. Family carers in particular reported feeling disconnected from developments through lack of information about proposals.

In **Merthyr**, good work by care managers meant that they were a strong primary source of information and advice. But this was not supported by other forms of information – the health team had some leaflets, the social work team did not.

People with learning disabilities were generally supported at every level by staff who wanted to listen, understand and help them as best as they possibly could. People wanted to do a good job and in some examples had initiated and delivered creative and innovative care and support plans for people. Most of the people whose circumstances were reviewed by inspectors knew and understood what care and support was available and received the help they needed, when they needed it, in the way they wanted it. This is positive and reflects well on all the staff working in health and social care. It needs to be tempered, however, by the fact that a significant minority of people – about a third – were receiving help that required improvement or was poor.

Case examples[6]

Megan is a young person who has a severe learning disability, epilepsy and physical disabilities. She lives with family and receives additional care from a small team of support workers recruited and trained by her parents, who organise the care and support. While the assessment and care plan needed updating there was support from a social worker who had been allocated to the case in October 2015. A positive behavioural support plan is in place and there was support from an assistant psychologist. There was a clear costing available for the care and support provided which includes help from the Independent Living Fund, Direct Payments and a respite care package.

Gwen lived in a care home for older people for many years before it closed. Attention was given to meeting her needs in another service, including the involvement of the staff who had known her longest to plan for her future. The new placement is outside the local authority area though within the regional area. Advocacy was made available to help her make the necessary choices as she had no family.

Staff generally worked hard with individuals to encourage and support them to speak up or to express their opinions in other ways. In almost all of the inspected authorities' assessments, plans and reviews reflected the voice of the person. In only one authority – Pembrokeshire – did inspectors conclude that, in the majority of cases, practice required improvement or was poor. Inspectors saw examples of case files that contained 'alternative' methods of communication such as Makaton and Picture Exchange Communication. In other examples there were extensive efforts to reflect the voice of the person in plain language in their care plan. There were several good or excellent examples of people being supported by positive behavioural support plans, often underpinned by effective joint work between health and social services staff. At times the linked but distinct disciplines of person centred planning, active support and positive behavioural support were conflated to a confusing degree. The challenge for all authorities is to set up their quality assurance arrangements so that the best approaches are deployed for all the people for whom it would be helpful, rather than in a few examples of excellent practice.

There was a strong commitment to the idea of 'person centred planning' across all the inspected authorities. However, the nature and quality of the plan varied considerably. In most examples there was a strong and largely successful effort to construct a meaningful profile of an individual. In some examples this translated to a plan with specific and measurable objectives, focused on outcomes, that was likely to be effective in helping a person to develop new skills and relationships. In other examples, inspectors found a

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[6] All names have been changed in the case examples.

sense of ‘drift’ in planning for people.

Case examples

The assessments and reviews for Brian formed a good basis for the services provided. Brian’s views were taken into account by the social worker and provider staff who sought to enhance his experience and encourage positive change. There was a clear focus on maximising life opportunities, improving skills and functioning and not letting things just carry on as they were without exploring other options.

Chris is a middle aged man with profound needs living in a nursing home for older people that is also registered to provide a small number of places for people with learning disabilities. His carer is very happy with the placement and staff were clearly fond of Chris and provided him with a warm and caring environment. Inspectors were not able to identify a day to day plan for Chris’ care that conveyed a sense of enablement or progression (however small or incremental) either in writing or as explained by staff. When inspectors visited, Chris was asleep in front of the TV in a lounge at 11am. The total cost of this joint funded package with health was £1,223 per week.

Dianne receives 24 hour care and support in a care home. She has challenging behaviour and requires support with all aspects of daily living. There was a request for advice and support from the Positive Behavioural Intervention service in October 2014, but there was no record of this having been delivered. The last care plan was dated October 2014 and the last assessment was undertaken in October 2013. There was no information on file about the outcomes, costs, or value for money for Dianne’s joint funded package of care and support.

It is difficult to reach firm conclusions about the reasons for the variability in performance given the relatively small size of the case sample. Nevertheless, it appears that the reviews of care plans were less rigorous and ambitious where people were in relatively stable placements, either with their family carers or in supported living schemes or care homes. Reviews worked better where people needed to make a transition from one type of care and support to another, or where there were explicit concerns about vulnerability and safety.

In all authorities inspectors heard about pressures experienced by staff from the need to wait for applications for Continuing Health Care funding to be processed and, then, for disputes to be resolved. HIW inspectors encountered very similar feedback from staff in the health boards (discussed below).

Across all authorities there was evidence of a particular effort to improve the transition pathway for young people moving into adulthood. People with learning disabilities and their families mostly reported that transition had been a positive experience for them. Some local authorities used dedicated transition workers to identify people who would need health support from their early teenage years. In Bridgend, the local authority has commissioned a third sector organisation – Tros Gynnal Plant – to support children with disabilities through the transition process. In Torfaen transition planning routinely involved families and professionals in education, careers and the health service. In Gwynedd, reliable and consistent support and coordination from care managers through the transition process was well received by families.

In those authorities with a significant Welsh speaking population there was a good awareness of the need to make an ‘active offer’ to people about communicating in the Welsh language and promotion of the language across all services. In other authorities, where the Welsh speaking population was much smaller, there was reasonable awareness of the requirements of legislation and guidance, but less in the way of practical action. Providers in neighbouring authorities in North Wales reported very different outcomes from their efforts to recruit Welsh speaking staff. For those providing a service in Gwynedd this was much less of a problem but it was more of a difficulty for those working in Conwy. This illustrates the way in which local circumstances (including the availability and cost of transport) can impinge upon recruitment.

The overwhelming majority of people whose situations were reviewed by inspectors were safe and protected from abuse and neglect. There were, however, a handful of cases that inspectors referred back to the local authorities for attention. In most of these, the concerns were as much about the absence of clear recording of decisions and outcomes than they were about the quality of practice with the individuals in need of protection. There was room for improvement across all authorities in respect of the leadership and governance of adult protection. Quality assurance of adult protection was generally weak. Cross referencing information across safeguarding, contract monitoring, complaints and Deprivation of Liberty Safeguards (DoLS) activity was the exception rather than the norm. In addition, the move to integrated safeguarding services across adult and children’s services in some authorities – or plans to do so - had created confusion about lines of accountability and responsibility in the minds of some practitioners and managers. This may prove to be a short term difficulty pending the realisation of longer term benefits from an integrated service. The risk, however, is that the oversight of current practice is compromised and quality assurance is further weakened. People with learning disabilities themselves spoke of concerns about their safety in the community – this was particularly the case for younger people and tended to focus on concerns about bullying, verbal abuse and a general anxiety about being unaccompanied in public places.

As at 31 March 2015, the 22 local authorities in Wales reported that there were 354 people with a learning disability subject to a Deprivation of Liberty Safeguard. More significantly, all local authorities were experiencing a dramatic rise in the number of new referrals of people for DoLS. This is largely a consequence of the ‘Cheshire West’ judgement which gave clarity about the definition of a deprivation of liberty. In November 2015, for example, Conwy had over 400 people (not all with a learning disability) on its waiting list for an assessment in respect of a potential deprivation. In another example, Torfaen had prioritised a list of 124 people with a learning disability in supported accommodation for whom it needed to submit a court of protection application. All the inspected authorities were attempting to organise a response to the rise in demand with varying degrees of success. While there are no easy answers, an effective response will need to rest on a multi-faceted plan that includes the use of all available resources, including a prioritisation tool, and which shares experience, expertise and resources across local authority boundaries.

The experience of people with learning disabilities living in care homes

The data returns from local authorities suggest that there are just over 1,000 people with learning disabilities living in care homes where the primary registration category is for learning disability. Another 143 people live in care homes where the main registration is for a category other than learning disability. Our inspections of 60 care homes during 2015-16 considered the key questions for the national inspection with a particular focus on plans, reviews and safeguarding. The key findings were:

- almost all residents had a care plan in place with most plans demonstrating an effort to be ‘person centred’;
- not all plans contained sufficient information for providers to easily ensure that they are meeting needs effectively;
- the evidence for involving people in constructing and reviewing their plan was less strong – suggesting that the understanding of what it means to be ‘person centred’ is variable; and
- most staff reported receiving training in relation to safeguarding, the Mental Capacity Act and Deprivation of Liberty Safeguards.

The evidence is also that people generally had a range of activities available to them, but that the continued appropriateness of these is not always monitored well. Neither is there any widespread routine monitoring of the levels of participation of individuals. There was a good use of advocacy with some providers making determined efforts to publicise and promote its availability. It is of concern that a small number of services reported no use of independent advocacy for people.

The number of people with learning disabilities living, as tenants, in supported accommodation schemes (3,344) is far greater than those who live in care homes. While the agencies that provide the support to people in these schemes are registered and inspected by us as domiciliary care agencies, there is no routine inspection of the services themselves. The evidence from the national inspection is that people in supported accommodation schemes generally receive care and support that is focused on individual need and rests on a determined effort to hear the voice of the person. As noted previously, there were examples where care planning and review for people had been allowed to drift – this was not a problem confined to care homes. In addition, there were also individual examples where the reality of the 'tenancy' for people – including their capacity to choose their care provider - was, at the least, open to question. In a small minority of cases, inspectors also found that the necessary separation of responsibility for housing and for care and support was not in place. Where there are difficulties and concerns about the nature and legitimacy of the arrangements for people in supported accommodation schemes, they will only be solved through effective joint working between commissioners, providers, families, and the person themselves.

A well managed change

In the process of replacing two former group homes with supported accommodation, social services and health staff worked closely with residents and their advocates, their families and staff. Where necessary they undertook capacity assessments and options analysis to inform best interest decisions. They organised site visits to support an ethos of continuity of care and stability of the existing home environment.

Almost half of the people with learning disabilities known to local authorities make use of day services. Inspectors were struck by the extent to which day service staff provided a degree of personal continuity and consistency of approach for the people making use of the service. Inspectors also heard directly from people with learning disabilities about the extent to which day services provide the context for them to make and maintain friendships with their peers. Several authorities were involved or contemplating significant reorganisation of day services for people with learning disabilities. In two authorities – Pembrokeshire and Gwynedd – this raised strong and passionate opposition and concerns from some parents, carers and people using services. While inspectors did not examine either example in any detail, in both there were noticeable problems with the planning and management of communication about the proposals.

Family carers for the people in the case sample, for the most part, spoke positively about the support they receive from care managers and health staff. There were some good examples of carers' assessments in the case sample.

A number of carers, in several authorities, expressed considerable anxiety about the implications of the transfer of responsibility for Independent Living Fund monies to the local authority. While inspectors saw no evidence that any person had suffered financially from the changes, it was also clear that not all family carers had felt properly reassured by the information provided by staff about the changes. The feedback from family carers in focus groups was mixed. Alongside positive comments about individual practitioners, there were concerns about delays with reviews of care plans, difficulty in making contact with care managers and a more general lack of engagement and consultation about planned changes to the pattern of services. Perhaps not surprisingly, those authorities that lacked a clear sense of direction and strategic plan for their services were also the ones with a culture that could not readily access and accommodate the views of family carers.

The health boards

In the cases HIW tracked across all areas, inspectors found that health and social care staff worked well together in providing information, advice, assistance, assessment and care planning to people with learning disabilities. There were excellent examples of multi-disciplinary working to provide effective care and support to people with learning disabilities. Health teams were dedicated and had a strong value base which was rooted in the All Wales Strategy (1983). Teams were well established and this provided consistency for people. There was evidence of timely and appropriate referrals by health and social care staff working together on shared outcomes for people.

Overall, people with learning disabilities and their carers told inspectors they were very happy with the care and support they had received and confirmed they had received the help they needed, in the way they wanted it.

On an individual level people were encouraged to have a voice and express their views about their care and support. Meaningful engagement with people with learning disabilities and their carers to gain feedback on services was variable across health boards. Most health teams had accessible questionnaires to support them in monitoring satisfaction with services. In some cases obtaining feedback was a new process which had not yet been established. In others, the health team manager carried out regular audits of questionnaires in order to monitor people’s views and to consider making improvements.

Inspectors found joint working was especially successful where health and social services colleagues were co-located. Where teams were co-located, regular whole team meetings took place and the team was likely to work on team joint initiatives together. Where teams were located on different sites, joint working was not as effective.

Inspectors found that a significant barrier to joint working was the lack of an effective shared records management system across health and social care. Often health staff could not see the documents and records of local authority staff. This meant that there was no overall view of the holistic needs of the individual, which could be used by all the professionals working with that person. There was the risk that this could affect the coordination of care and understanding of a person's holistic needs.

Health teams worked effectively with the local authority and the health board's safeguarding team to resolve safeguarding concerns. Most community health teams reported safeguarding concerns through the local authority rather than directly to the health board. Health boards could monitor trends and themes arising from these concerns via external multi-agency meetings such as Adult Safeguarding Boards. However, reporting processes and lines of accountability in respect of safeguarding were not always clear from community teams to health boards.

Staff talked about the challenges and pressures placed on the team of increasing numbers of Continuing Health Care applications. Inspectors, however, did not see significant evidence of these funding disputes having detrimental effects on outcomes for people with learning disabilities. This is perhaps an indication of the commitment of frontline staff to maintain professionalism in handling ongoing frustrations, and to advocate for the focus to remain on the best interests of people with learning disabilities. However, inspectors found that staff were spending increasing amounts of time on funding applications, on assessments that were needed purely for this purpose rather than clinical need and in gathering evidence for processes that felt unclear to them.

Funding was also an issue in accessing specialist equipment. Whilst inspectors found good examples of innovative technology and equipment being used to help people communicate, there were also significant challenges and delays in the provision of equipment such as specialist chairs, which people needed for activities of daily living.

Staff also told inspectors about the challenges they faced in terms of engagement, understanding and sometimes attitude of primary and secondary health care colleagues. Understanding of the Mental Capacity Act 2005 was raised as a particular issue, with health staff in all health boards recalling instances where they had needed to advocate for an individual when doctors in hospital care had not understood their obligations in this respect.

Some health boards have 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. There were excellent examples of this work, which had made a significant difference to the patient experience for people with a learning disability. For example, in Aneurin Bevan University Health

Board the health liaison nurse, community nurse, social worker, consultant in general health, and the clinical psychologist worked together to ensure a person who had a new diagnosis of cancer was provided with the right information, advice and assistance. In Betsi Cadwaladr University Health Board there was investment in a team of specialist health liaison staff. Wider health and social services colleagues respected the work of this team and commented on the positive difference they had made to people's experiences of health care.

Health liaison teams explained how they also worked on health promotion and awareness, in particular promoting the use of hospital passports[7] and access for people to annual health checks with their GP. In Betsi Cadwaladr University Health Board, there was a designated mental health liaison nurse for learning disabilities and inspectors were provided with excellent examples of how this role, through staff training, the production of easy read materials and working directly with vulnerable patients, was improving the patient experience for people with learning disabilities who also had mental health needs.

Where dedicated health liaison posts were not available, for example in Abertawe Bro Morgannwg University Health Board, community nursing staff told us how they had worked with carers and secondary care medical staff to improve the secondary care pathway. Where there was a strategic commitment to improving links with primary and secondary care and where there were staff dedicated to improving these links, inspectors saw good outcomes for people with learning disabilities.

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[7] A hospital passport is a document which contains important information about a person with a learning disability so that hospital staff can know about them and their health needs when they are admitted to hospital.

8. Leading in partnership with people

To what extent have the arrangements for leadership and governance in the authority delivered a clear vision for care and support for people with learning disabilities, aimed at improving outcomes, and which has the support and involvement of partners – including people with learning disabilities and carers?

Expected outcomes

- People are helped to secure their rights and entitlements as citizens equal in status to people of the same age.
- Clear and trusted channels of communication are used to talk and listen to people with learning disabilities and their carers about objectives, plans and the use of resources.
- People are helped to understand how their views have been used to inform decisions, plans and activity what has changed as a result.
- The vision for care and support for people with learning disabilities specifies the intended impact on them in terms of outcomes and includes a longer term view with a focus on delivering sustainable social services.
- People experience care and support across health and social care that is well coordinated, cost effective and demonstrates effective partnerships between social services, health and the third sector.

Strengths

Leaders at all levels want to help people with learning disabilities to secure their rights and entitlements.

In some places, regional collaboration between local authorities and with health partners has produced plans that are having a positive impact for people with learning disabilities.

Those authorities that do better at engaging with people, family carers and with providers are also those that do better at creating a vision, plan and objectives that have an impact.

Areas for improvement

Developing a vision and plan for the future of care and support for people with learning disabilities in Wales, that is built in partnership with people with learning disabilities and family carers.

Making effective planning between health and social services for the longer term the norm rather than the exception across Wales.

Building more integrated services between health and social services.

Constructing systematic and meaningful approaches to listen and respond to the views and opinions of people with learning disabilities and family carers.

The local authorities

In all of the inspected local authorities there were leaders at all levels who demonstrated a desire and commitment to helping people with learning disability to secure their rights and entitlements. To a large degree this both reflected and supported the positive, value driven practice that was often found at the front line. The major deficit was in building on that desire and commitment to deliver a clear vision and plan for care and support for people with learning disabilities in partnership with health partners. In two authorities – Bridgend and Torfaen – significant progress had been made; in others, examples of innovative approaches to engagement and planning existed, but were not part of a coherent and overarching approach to planning, commissioning and delivery. Responsibility rests not just with senior leaders in local authorities, but equally with their peers in the relevant health boards.

In **Torfaen**, the Gwent Strategy for Adults with a Learning Disability 2012-17 is well established with nine agreed priorities. It is supported by a number of multi agency or stakeholder sub groups both regionally and in Torfaen which take forward its objectives.

In **Bridgend**, the Western Bay Collaborative is pursuing the strategic objective of providing ‘closer to home’ services. One project has been established and one further project is planned to open in the spring of 2016.

In **Conwy**, joint work with health colleagues in the North Wales Commissioning Hub had led to some progress with helping people placed ‘out of county’ to return closer to home. But there was not a strong sense of shared objectives, or a joint plan, over the longer term between health and social services. Senior leaders in the local authority reported several years of difficulty in securing consistent and reliable involvement from health colleagues in strategic planning.

In **Merthyr** there are formal partnerships in place between the local authority, its neighbour Rhondda Cynon Taf County Borough Council and Cym Taf University Health Board. Learning disability health services are commissioned, however, by Abertawe Bro Morgannwg University Health Board. The partnerships to date have not delivered any shared and detailed planning between health and social services to shape care and support for people with learning disabilities.

Even in the better performing local authorities, there was a degree of uncertainty about planning for the future. In Torfaen, plans to take forward the ‘Gwent Strategy’ beyond 2017 were under consideration in late 2016. In Bridgend, a timeframe for implementing a new model for the learning disability community support team has been delayed, by recent changes to the health board management structure, and the merger of the learning disability and mental health directorates..

Inspectors concluded that there is a pressing need to develop a new vision and model of care and support for people with learning disabilities that can be applied with some consistency across Wales. The Social Services and Well-being (Wales) Act – as noted earlier – offers a framework that can be used to both better identify need and to construct a sense of purpose and direction for the future. All partners, including policy makers, will need to work together to ensure the full potential of the Act is realised for people with learning disabilities and their family carers.

Those authorities that do better at engaging with people, with family carers and with providers are also those that do better at creating a vision, plan and objectives that work.

Conwy – Planning for the Future

Each year since 2011, the local authority has run two events designed to help parents, carers and their relatives think about and plan for their future accommodation needs. People with learning disabilities have the opportunity to attend a ‘Key to My Future’ event in the summer, while parents and carers can participate in a ‘Let’s Plan Together’ day in the autumn.

Staff involved were able to describe to inspectors the way in which the outcomes from these events link to the accommodation strategy and planning housing options. Care managers showed good familiarisation with ‘Planning for the Future’ and the way that it could help them in their work.

Conversely the absence of clear and trusted channels of communication with people, carers, providers and other stakeholders makes the job of leaders that much harder. In both Pembrokeshire and Gwynedd, for example, the plans for significant changes to day services as noted in the last chapter had raised vociferous and passionate opposition from some people with learning disabilities and family carers. In both examples it seemed highly likely that failings in communication and presentation of the proposals had contributed to a sense of grievance on the part of the people who would be most affected. All local authorities are, of course, dealing with the consequences of budgetary constraints with many making potentially unpopular decisions about the closure or reconfiguration of services. This is a difficult context for leaders at all levels. When this deficit is coupled with a lack of commonly understood vision for the development of care and support - as it was in some authorities - then leaders and managers faced an uphill task in creating a positive service culture.

The health boards

Overall, HIW found that the leadership and governance in learning disability health services were not delivering a clear vision for people with learning disabilities. Inspectors identified improvements that were needed in communication between health board management and frontline staff to ensure they felt valued in their roles and engaged with the health board's direction and priorities.

Two health boards visited had a current strategy specifically for learning disabilities. These were joint strategies between the health board and each of the local authorities in their areas. All other areas had no overall standalone plan or strategy for learning disability services as a whole. Plans around learning disability services were captured in Integrated Medium Term Plans and in some areas, where mental health and learning disability directorates had just merged, strategies were being developed and considered alongside mental health considerations. Inspectors were told that strategic planning was due to take place in some areas in the near future. However, some of these plans were vague and unclear, and inspectors were not assured that strategic joint working between health boards and local authorities would happen.

In all health board areas inspectors were told that the views of people who use services were already or would be taken into account within governance arrangements. There were some excellent examples of how people had been meaningfully engaged with developing joint strategies. However, inspectors found that clear, established and trusted methods of communication were generally, not yet in place. Most involvement for people who use services happened through the local authority and there were few formalised mechanisms within health services for consulting people on an ongoing basis.

There is a need for all health boards to actively engage with local authorities, third sector, staff on the ground, people with learning disabilities and their families and carers, in a more strategic way to set the direction for learning disability services to ensure they all move forward together.

Inspectors found that work was needed around succession planning and the sustainability of services. This is particularly important because many learning disability nurses are due to retire in the next few years. Senior managers were aware of this issue and some were more proactive than others at considering solutions, including arranging presentations to student nurses to promote their service. 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.

In all areas visited, learning disability services sat within the Mental Health and Learning Disabilities division of the health board. In some areas this was as a result of recent restructuring. There was a perception in many places visited that less importance and value was placed on learning disability services compared with mental health services. Within learning disability services generally, inspectors found clear governance processes were in place for community health teams. However, there were less clear governance arrangements in place for health board funded residential provision. As a result, HIW has brought forward an inspection programme of residential and inpatient provision.

9. Methodology

Teams of four inspectors from CSSIW visited six local authorities over two weeks for a total of 6 days between November 2015 and February 2016. HIW inspectors undertook work in the health boards at the same time and joined the CSSIW inspectors for joint inspection activity in the second week of each inspection.

The experience of 20 people with learning disabilities (and that of their family carers where relevant) was considered in detail in each inspection. Every inspection also looked in even greater detail at the circumstances and outcomes for eight of the people in the main sample – meeting the people concerned, interviewing staff and visiting some of the care and support services that those people received.

Discussion groups were held with people with learning disabilities; family carers; local authority staff; health board staff; and independent and third sector providers. Individual interviews were held with a wide range of staff in the local authority and local health board. During the second week of the inspection CSSIW and HIW inspectors listened to a joint presentation from health and social services about what had been achieved for people with learning disabilities. They then questioned senior managers from both organisations about the content of the presentation and, where necessary, other issues that had emerged during the inspection.

A range of advance information was supplied by each local authority prior to their inspection.

The fieldwork activity was supported by a data and self assessment survey of all local authorities and health boards and by a thematic probe in CSSIW's inspections of regulated provider services for people with learning disabilities.