Transforming Care in Wales for people with learning disabilities and challenging behaviour- a draft action plan in response to the Winterbourne View abuse.

This report was produced at the request of the Welsh Government Learning Disability Advisory Group by the All Wales Challenging Behaviour Community of Practice. See appendix 1 for membership of the subgroup that produced the report.

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Introduction, Values and Vision
The abuse at Winterbourne View Hospital was both shocking and criminal. The review following the scandal highlighted a widespread failure to design, commission and provide services which give people the support they need close to home, and are in line with well established best practice.

The Department of Health Review: Final Report – *Transforming care: A national response to Winterbourne View Hospital* (DoH, 2012) lays out clear, timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging. The shared objective is for the health and care system to address past failings by listening to this very vulnerable group of people and their families, meeting their needs, and working together to commission the range of services and support which will enable them to lead fulfilling and safe lives in their communities. It sets out a commitment to work together, with individuals and families, and with the groups which represent them, to deliver real change, improve quality of care and ensure better outcomes. It also points out that the new health and care system brings a greater opportunity for people to work together more creatively to develop local innovative solutions.

The All Wales Challenging Behaviour Community of Practice (CB CoP) would caution the Welsh Government against complacency as, in the absence of a strategic pattern of service provision for people with learning disabilities and challenging behaviour, there is a real risk that the type of abuse seen in Winterbourne View could still occur in Wales, and may indeed already be happening. The key implications for Welsh social policy following the Winterbourne View abuse is the need to continue improving local service provision with the development of small-scale, community-based services that adopt Positive Behavioural Support (PBS) as their operational approach (see appendix 2 for a brief summary of PBS). When people with learning disabilities and challenging behaviour are given effective support locally to improve their quality of life, this obviates the need for them to be exported to very costly, institutional services such as Winterbourne View. Indeed, local alternatives can be both better quality and more cost effective. The CB CoP welcomes the Social Services and Well-being (Wales) Bill, which provides a platform that could help to achieve many of the recommendations in this document. However, clear directives and leadership is essential to establish joint commissioning of better quality local services for this particularly vulnerable group.

This report provides a high level summary and describes 6 short term and 19 long term key actions. CB CoP members wish to emphasise the need to follow through with identified work streams and a project management approach overseen by an improvement board with appropriate powers to implement the plan in practice (recommendation 19).

The vision and principles stated in the Welsh Government’s ‘Sustainable Social Services for Wales: A Framework for Action’ are equally applicable to people with learning disabilities and challenging behaviour as to any other Welsh citizen. At their heart is social integration and the requisite person-centred support to develop fully as participating members of the community. Achieving this is not easy for people with challenging behaviour, so a strategy is needed to help translate these values into action, through a comprehensive support structure underpinned by evidence-based best practice.
Figure 1 Recommended Structure of Optimum Service Provision in Wales for Children & Adults with Learning Disabilities & Challenging Behaviour

The diagram on the previous page outlines the desired hierarchical structure of services required to provide adults and children with learning disabilities and challenging behaviour the optimum quality of support. Underpinning the whole structure is Positive Behavioural Support (PBS) which is a person-centred approach delivered in a multi-disciplinary context. PBS is accepted internationally as evidence-based best practice (see appendix 2 for further information) and recommended in the Mansell Report (DoH, 2007) and in ‘Transforming care: a national response to Winterbourne View ‘ (DoH 2012).

Based on recently published prevalence rates (Lowe et al., 2007) extrapolated to the whole of Wales, it is estimated that around 3,480 people with learning disabilities will have a significant level of challenging behaviour: of these, around 2405 will show lesser to medium levels, while around 1075 will present with...
more demanding challenging behaviour. At any one time at the current level of service provision, around 80% are likely to be supported by learning disability community support teams and around 20% by specialist behavioural services. It is not possible to state precisely the number of people represented at the different levels in the diagram, as these data are not available and numbers will be influenced by the pattern of existing service provision.

The base of the triangle represents the majority of children and adults with challenging behaviour who currently live in family homes or other community settings (Lowe et al., 2007). At this level, all staff (e.g. residential and day service workers, teachers and classroom assistants, job coaches) should have an operational understanding of PBS, with additional support provided by learning disability community support teams and specialist outreach/peripatetic behavioural teams when necessary.

At the next level up, some adaptations to properties may be required. Attention may need to be given to: robustness of building fabric, location and furnishing of ordinary housing; locally-based specialist schools, some with residential facilities; bespoke day services, etc. Providers should come mainly from the Social Care and Education sectors in partnership with specialist NHS personnel and with additional support provided by learning disability community support teams and specialist outreach/peripatetic behavioural teams when necessary.

**All staff from this level onwards need to be highly skilled in achieving full implementation of PBS, and managed by skilled practice leaders.**

Assessment and treatment is best provided to most people in their natural environment. One of the key professional skills required at this level is the PBS model of Functional Assessment to ensure that treatment is person-centred and designed on the basis of comprehensive identification of the factors maintaining challenging behaviour. On occasion a small number of people will need admission to Acute Assessment & Treatment Units. Locally-based, small scale units, developed in partnership with specialist NHS personnel should provide short-stay therapeutic PBS interventions, to enable people to return to their usual homes. Members of the Challenging Behaviour Community of Practice have developed an outcome-based PBS model of assessment and treatment.

The apex of the triangle represents the very small proportions of people needing, low or medium secure settings, due to the dangers presented by their behaviour. The current pattern of service provision in Wales for this group is patchy, usually provided in institutional settings by private sector agencies, due to the fact that there are no NHS forensic facilities for people with learning disabilities in Wales. At this acute level, PBS continues as the model of choice, with intensive intervention from multi-disciplinary team members and mandatory involvement of external advocacy.

**Current problems and barriers to achieving quality services in Wales**

- The lack of appropriate services and accommodation in Wales results in people (particularly those in the upper sections of the triangle shown in the diagram) being placed out of their home area, in expensive institutional services. Many of these services claim to be specialist but some are of
dubious quality. Such ad hoc out of area placement with limited monitoring of placement quality was a direct cause of the Winterbourne View abuse. The continued use of such services drains already limited local Health and Social Care budgets and has deskillled local provider communities, including the NHS, therefore preventing the development of better alternatives. (Allen et al., 2007; DoH, 2004; 2007; NDTI, 2010; Care Quality Commission, 2012).

- Little or no effective joint commissioning, with a failure to base contracts on quality or service user outcomes.
- There is a disconnection between those commissioning out of area placements (inside and out of Wales) and those planning to repatriate these individuals. There is very limited joint working between Education, Health, Adult and Children’s Social Care Services.
- The lack of pooled budgets to develop more effective service structures.
- The current arrangements for Continuing Health Care (CHC) funding for people with learning disability and challenging behaviour.
- Lack of data regarding where people are currently placed and accurate comprehensive cost of placements.
- Restrictions on providers being creative and a culture of risk aversion.
- Lack of comprehensive PBS functional assessment of CB in people’s home environments, and patchy provision of specialist behavioural teams to enable this.
- Lack of skills in PBS across service sectors and inconsistency in the provision of training and managerial support.
- There is a misconception that developing local, resilient and skilled services will require significant new money. However, the reality is that a substantial amount of revenue funding is already in the system, but being spent inappropriately.
- The English Plan should lead to the English people currently placed in Wales rapidly returning home. This is likely to have a major impact on services in general, and a particularly destabilising effect on private sector services, potentially leading to financial collapse and closure.
ACTION PLAN

Short term Actions

1. The DoH plans for England contained in ‘Transforming care: a national response to Winterbourne View’ (DoH 2012) are impressive and in line with the recommendations in this Welsh Action plan. They should be endorsed by The Welsh Government.

2. The Mansell Report (DoH, 2007) has been formally adopted in England as part of the response to Winterbourne View and should be similarly endorsed in Wales.

3. Wales leads in many aspects of the development and implementation of PBS. The Welsh Government funded the development of a suite of award winning BTEC accredited e-learning courses in PBS, that are now well established and gaining an international reputation. The British Psychological Society is tasked with providing leadership to promote training in, and appropriate implementation of, Positive Behavioural Support across the full range of care settings as part of ‘Transforming care: a national response to Winterbourne View’, and is currently piloting these courses as their preferred solution. The Welsh Government should make these existing courses mandatory training for all staff who support people with learning disabilities and challenging behaviour in Wales.

4. The Welsh Government, through the auspices of the previous LDIAG, developed The Self Assessment Checklist for Monitoring Services for People with Learning Disability and Challenging Behaviour. Commissioners in Wales should be required to monitor services using this Checklist and submit the resulting Action Plans and report progress on an annual basis.

5. In South Wales, ABMU Health Board, LAs, social care providers and other CB CoP members have developed and piloted the ‘Evaluation Matrix for Challenging Behaviour Services: a service specification and evaluation tool for services for people with learning disabilities & challenging behaviour’. This is designed to evaluate service settings against gold-quality standards in line with the PBS model. This should be endorsed by the Welsh Government for use in the commissioning process and in evaluating existing service quality.

6. The current Closer to Home initiative, in South Wales, should be promoted by the Welsh Government as a key means of developing high quality services for people with learning disabilities.
**Long term Actions**

1. Establish a single active register of all children and adults with learning disabilities placed out of area, including out of Wales and out of county within Wales. This should be developed in partnership between Education, Health and Social Care. Currently, these data are extremely hard to access satisfactorily but are pivotal in planning around individual and locality need. The register should be reviewed annually to assess progress and demographic change. This could be achieved through collaboration with The Social Services Improvement Agency (SSIA).

2. Request evidence that transition plans are in place for children in residential schools in Wales and for Welsh children in England aged 14 or over. Establish mechanisms and standards for reviewing the quality of plans, including the extent and quality of user/carer involvement.

3. Request evidence that repatriation plans are in place for all adults with learning disabilities and challenging behaviour currently placed out of area within and outside of Wales.

4. Ensure user and carer involvement in the monitoring of services.

5. Establish mechanisms and standards for reviewing the quality of behavioural support plans, including the extent and quality of user/carer involvement.

6. Identify the location and ownership of all registered residential and NHS provision for children and adults with learning disabilities and challenging behaviour including those with a dual diagnosis of mental health. This could be done as part of the wider uses of the Self Assessment Checklist.

7. Consider the effect of the plans to repatriate all English service users on private sector providers in Wales, and develop contingency plans to ameliorate any deleterious effects.

8. Identify and develop the infrastructure needed in Wales for local, regional and national specialist accommodation, education and outreach services as described in the diagram on page 3.

9. Issue a clear directive to ensure joint commissioning between Health and Social Care, with Social Care as the lead agency, that clearly facilitates pooled budgets.
10. Issue a clear directive to Education, children’s and adult Social Services, and Health to collaborate in developing shared treatment approaches and improving the management of transition.

11. Develop an all-Wales accreditation system for all providers of services to children and adults with learning disabilities and challenging behaviour to improve and maintain a high quality of service provision.

12. Ensure the creation of an appropriately accredited and regulated workforce across Health and Social Care to provide a framework for delivering world-class services in Wales, by having staff with the right skills, at the right level and in the right place. This should be achieved via standardised training in Positive Behavioural Support, and to include Positive Behaviour Management, Active Support, inclusive communication, Person-Centred Planning, Autistic Spectrum Disorder, values, mental health, interactive training together with clear guidance on restrictive support practices. All these elements currently exist in Wales, but should be drawn together strategically as a work stream to establish a national training strategy for Wales.

13. For Acute Assessment and Treatment Units, specify a clear timescale for discharge after the decision to discharge has been made, and a national reporting system for delayed transfers of care.

14. Promote individual budgets and user/carer/provider involvement in creating Person Centred solutions.

15. Develop local and national systems for sharing best practice.

16. In line with the priority of reducing complexity and improving transparency, a clear comprehensive, straightforward policy statement on people with a learning disability should be produced as one document. It should clearly restate the values and vision referred to in this document and could be a parallel work stream of the LDAG so that it compliments rather than distracts from the required emphasis on action.

17. The Mencap campaign and whistle blowing helpline service should be supported by the Welsh Government and extended throughout Wales.

18. LDAG/CoP members to contribute to the establishment of the National Independent Safeguarding Board in Wales. There should be a clear statutory requirement for all organisations to report the use of any restrictive practices, including physical intervention and seclusion, to an external statutory regulatory body.

19. **Establish an Improvement and Implementation Board to develop the Plan.** The DoH led work in England is characterised by the emphasis on actions that are clearly allocated to groups and have a ‘project’ lead. There needs to be a similar focus on action in Wales. A project management...
approach to achieving practical actions needs to be adopted and led by the Welsh Government. Wales needs a high level cross-Governmental Improvement and Implementation Board to implement the Action plan by identifying work streams and formulate project task teams that have an identified project leader to achieve actions within specified timescales. Membership of the Improvement and Implementation Board could consist of senior representatives from Care and Social Services Inspectorate Wales, Healthcare Inspectorate Wales, Learning Disability Wales, Association of Directors of Social Services, Social Services Improvement Agency, NHS Wales Learning Disability, All Wales People First, All Wales Federation of Parents and Carers, Challenging Behaviour Community of Practice, academics/researchers and providers of education and children services. The Improvement and Implementation Board should be chaired at Ministerial level, as is the case in England.
Appendix 1. The All Wales Challenging Behaviour Community of Practice (CB CoP)

Deinstitutionalisation and person centred approaches have brought clear benefits for many people with learning disabilities. However, those people with challenging behaviour remain most at risk of experiencing social exclusion, inappropriate treatment, poor quality of life, abuse and institutionalisation. Wales is no exception in this respect. Although the 1983 All Wales Strategy led to development of community based services, people with challenging behaviour were often the last to benefit from deinstitutionalisation and are still likely to be placed ‘out of area’ in expensive and often poor quality services. Despite this concern, Wales is also fortunate to have many examples of people with challenging behaviour living valued lives in their local communities. This has been achieved through the support provided by families and skilled health and social care staff, many of whom have links with research centres in the Universities of Bangor and Cardiff. In addition, one of the most enduring legacies of the All Wales Strategy has been the development of a vibrant third sector, comprising a number of well-established ‘not for profit’ social care providers, who have worked in partnership with statutory agencies to drive up standards and achieve good quality of life outcomes for people who have challenging behaviour. However, good practice is not as widespread as it could be and there is a strong feeling that, in a relatively small country with devolved powers of decision making regarding health and social care, further improvements can be achieved.

In February 2010, the All Wales Challenging Behaviour Community of Practice (CB CoP) was launched with the aim of bringing interested, like-minded, people together to develop innovative ideas and approaches for improving the quality of life for people with intellectual disabilities and challenging behaviour. Etienne Wenger described a community of practice as a group of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly. They are defined by a shared domain of interest, in this case people with intellectual disabilities and challenging behaviour. A ‘community’ is only established when members engage in joint activities and discussions, help each other, and share information regarding their shared interest, building relationships that enable them to learn from each other. Members are ‘do-ers’ or ‘practitioners’ developing a shared repertoire of resources, experiences and tools, to address recurring problems—in short, a shared practice. (see www.ewenger.com for further information).

The CB CoP is, therefore, very much a product of its members’ commitment and hard work. With the support of the Welsh Government, there are currently over 300 members from a wide variety of backgrounds and organisations throughout Wales, including parents, health and social service professionals, commissioners and providers from all sectors. A key objective is to achieve change, driven by grass roots knowledge and experience. The response to Winterbourne View has been a constant theme at CB CoP meetings and, at the request of LDAG, a CB CoP subgroup produced this report in consultation with all CB CoP members.

Sub group members comprised:

- Steve Brown - Flintshire Social Services
- Jaki Bell - Betsi Cadwaladr UHB
• Jim Crowe - LDW
• Adrian Roper - LDW/ Cartrefi Cymru
• Gareth Matthews - Mirus (previously known as Opportunity Housing Trust)
• Tina Donovan - New Bridges
• Sharon Williams - Aneurin Bevan UHB
• Clare Trudgeon - Aneurin Bevan UHB
• Sam Williams - LDAG/ LDW
• Stephen Wade MBE - Director, Directorate of Learning Disability Services ABMUHB
• Dr. Edwin Jones - Directorate of Learning Disability Services ABMUHB
• Professor Kathy Lowe - Directorate of Learning Disability Services ABMUHB
Appendix 2 Positive Behavioural Support (PBS)

PBS can be defined as ‘…educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments. It blends best practices in behavioural technology, educational methods and ecological systems change with person centred values in order to achieve outcomes that are meaningful to the individual and to his or her family’. Preface p vii Bambara et al (2004)

Comprehensive detailed definitions of PBS can also be found in La Vigna et al 1989, Horner et al 1990, Carr et al 1990, and Allen 2009, 2011. In summary, PBS:

• Aims to understand the reasons for a person having challenging behaviour (functional assessment)
• Changes the environment reducing the need for the person to have to use challenging behaviour to get what they need (primary prevention)
• Respects and includes the person
• Improves the skills and quality of life of the person and those around them
• Keeps the person and those around them safe (secondary prevention and reactive strategies)
• Is an ethical approach based on contemporary values and avoids the use of punishment
• Is evidence based

PBS is a person-centred approach that focuses on primary prevention of challenging behaviour. That is, it effects behavioural change by improving a person’s quality of life, skill development and altering triggers for challenging behaviour (primary prevention). A lesser but integral element is to respond quickly to a person’s early signs of agitation by ‘switching’ off any missed triggers and the use of calming strategies such as distraction to prevent further escalation to ‘full blown’ challenging behaviour (secondary prevention). Should further escalation occur, reactive strategies that focus on maintaining distance and how to breakaway safely, are used. These include the use of physical intervention as a last resort, provided the techniques are ethical, i.e. avoid the use of pain or punishment and adopt the least restrictive approach (Allen, 2011).

Table 1 Core PBS strategies (based on Allen 2011)
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<th>Primary prevention</th>
<th>Secondary prevention</th>
<th>Reactive strategies</th>
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<td>Changing features of person’s physical environment</td>
<td>Stimulus change</td>
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<td>Altering programmatic environment</td>
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<td>Introducing total communication</td>
<td>Prompting to coping skills</td>
<td>Minimal Restraint</td>
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<td>Addressing internal setting events (mental &amp; physical health)</td>
<td>Not ignoring</td>
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<td>Improving carer confidence &amp; competence</td>
<td>Strategic capitulation</td>
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<td>Eliminating or modifying specific triggers for behaviour</td>
<td>Diversion to reinforcing activities</td>
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<td>Increasing rates of access to preferred reinforcers</td>
<td>Diversion to compelling activities</td>
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<td>Increasing the density of social contact</td>
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<td>Increasing rates of engagement</td>
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<td>Modifying demands</td>
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<td>Building behavioural momentum</td>
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<td>Teaching general skills</td>
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<td>Teaching functionally equivalent skills</td>
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<td>Teaching coping skills</td>
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There is a growing evidence base for the effectiveness of PBS, (e.g. Carr et al 2002, (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists 2007, Dunlap et al 2008) and Allen (2011) explores how the introduction of PBS can dramatically reduce the use of restrictive practices. However, the fundamental issue regarding the development of competent services for people with challenging behaviour is that it is not common to find PBS comprehensively understood or applied within existing services.

**Appendix 3 Summary of existing good practice re people with learning disabilities and challenging behaviour in Wales**
Considerable practical progress has been achieved by the ‘Closer to Home’ (C2H) partnership between Swansea, NPT, Bridgend LA’s and ABMUHB regarding joint innovative commissioning across health and social care in line with existing priorities for improved, cross boundary commissioning in Wales and the regional commissioning of specialist services. A range of tools such as model service specifications, contracts and processes have been established which are directly replicable across Wales. The work has been shared at the CoP and other forums— and interest has been expressed by several Welsh HB and LA’s. Lead contact Jock.Andrew@wales.nhs.uk

Similar initiatives are being developed in other areas e.g. in Aneurin Bevan LHB and the North Wales Service specification for the provision of support to people with learning disability who have complex needs and behaviour that challenges, developed in partnership with Betsi Cadwaladr UHB.

As a legacy of the 1980’s All Wales Strategy, Wales has a strong and vibrant range of third sector ‘not for profit’ providers of housing and social care for PWLD. These providers are values led and have embraced the PBS model. The service model is based on ‘ordinary’, community-based supported living homes for life, provided in partnership with registered social landlords. This is widely recognised as the most appropriate and cost effective type of provision. These third sector agencies provide a strong existing foundation for continued service improvement. Key contact jim.crowe@learningdisabilitywales.org.uk

Training in PBS. CoP members have key expertise in this area and have successfully engaged with the Care Council for Wales to produce new units on Positive Behavioural Support (PBS) and Active Support that have been placed on the UK wide Qualification and Credit Framework (QCF). A suite of award winning, accredited e-learning courses in PBS that were funded by the Welsh Government are available. There are over a 1,600 candidates already enrolled, with excellent feedback from candidates and relevant professionals. The courses provide a unique, high quality and cost-effective means of disseminating PBS. The British Psychological Society is piloting these courses to fulfil their responsibilities in line with the English concordat statement on P 12 that “The British Psychological Society (will) provide leadership to promote training in, and appropriate implementation of, Positive Behavioural Support across the full range of care settings”. Key contact edwin.jones@wales.nhs.uk

Wales has led the field in the development of Positive Behavioural Management as a key component of Positive Behavioural Support. This is a practical, ethical non aversive approach to reactive strategies. There are formal links with the British Institute of Learning Disabilities on these issues, and Welsh Guidance could easily be produced. Key contact Neil.kaye@wales.nhs.uk

It is also worth noting that University training in the theory and practice of the behaviour analysis skills underpinning PBS is also well-established in Wales, with postgraduate courses at the Universities of Bangor, Swansea, and South Wales. Most of the students on these courses are practitioners in health, social care, and education. Key contact r.hastings@bangor.ac.uk

Wales already has ‘The Self Assessment Checklist for monitoring services for people with LD&CB produced with the involvement of CoP members and published by LDAIG. This has been used successfully in some Welsh areas and feedback has been positive. The Service Specification and Evaluation Matrix for services for people with learning disabilities and challenging behaviour has been developed by CoP members and is used by several organisations. Lead contact Kathy.Lowe@wales.nhs.uk

The Winterbourne reports highlighted the lack of a clear model for assessment and treatment. Several CoP members provide NHS specialist ‘outreach’ behavioural support teams and or NHS assessment and treatment facilities and have a commitment to PBS in practice e.g. Betsi Cadwalladr, Aneurin Bevan, Hywel Dda, ABMUHB. Good practice has been exchanged in the CoP and an efficient PBS assessment tool, the Brief Behavioural Assessment Tool was developed and feedback has been extremely positive. Considerable work on a PBS evidence based model of NHS inpatient assessment & treatment has been undertaken by ABMUHB practitioners. This is known as the Assessment & Treatment Outcome Report (ATOR) with associated staff training etc. data is available regarding its positive outcomes. Lead contact Diane.Gray@wales.nhs.uk

The Access to Justice Guidebook produced by the Wales Criminal Justice Learning Disabilities Working group. Key contact Glyn.Jones2@wales.nhs.uk

There are other examples of good practice e.g. joined up transition approach between Health, Social Services and Education in Gwent and The Real Opportunities Project for young people 14+ in the same area. Community Connections service in West Wales.

CSSIW independent visitor scheme, a pilot project involving parents and carers and PWLD in inspections in East Wales Lead contact pauline_young@tiscali.co.uk

‘The real tenancy test’ produced by Cymorth and Learning Disability Wales

Transition work in Conwy, evaluated positively by CCNC and cited as good practice, in particularly the mature relationships in place with Education and Health. Key contact Ramona.Murray@conwy.gov.uk

Who’s Challenging Who?, which is a knowledge transfer partnership developed in Wales between Mencap Cymru and Bangor University. The project aims to improve learning disability services by helping social care staff develop positive attitudes towards challenging behaviour, and improve how they empathise with the people they support. Evaluation has shown good results in terms of positive changes in attitudes and empathy Contact: helpline.wales@mencap.org.uk
CB CoP members consider that the CoP provides an excellent model of good practice exchange that plays a key role in informing service development. A range of practical implementation tools and processes has been developed by CB CoP members that are of direct relevance. These include:

- 1st Actions checklist
- Self assessment checklist
- Evaluation matrix
- Brief Behavioural Assessment Tool
- Assessment and Treatment PBS model
- 3 stage training model
- Interactive training
- Positive monitoring
- Periodic Service Review
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