

Pecyn Dogfen Gyhoeddus



Swyddog Cyswllt:
Maureen Potter 01352 702322
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At: Cyng Carol Ellis (Cadeirydd)

Y Cynghorwyr: Mike Allport, Marion Bateman, Jean Davies, Andy Dunbobbin, Gladys Healey, Cindy Hinds, Kevin Hughes, Rita Johnson, Mike Lowe, Dave Mackie, Hilary McGuill, Ian Smith, Martin White a David Wisinger

28 Medi 2018

Annwyl Gynghorydd,

Fe'ch gwahoddir i fynychu cyfarfod Pwyllgor Trosolwg a Chraffu Gofal Cymdeithasol ac Iechyd a fydd yn cael ei gynnal am 10.00 am Dydd Iau, 4ydd Hydref, 2018 yn Ystafell Bwyllgor Delyn, Neuadd y Sir, Yr Wyddgrug CH7 6NA i ystyried yr eitemau canlynol

R H A G L E N

1 YMDDIHEURIADAU

Pwrpas: I dderbyn unrhyw ymddiheuriadau.

2 DATGAN CYSYLLTIAD (GAN GYNNWYS DATGANIADAU CHWIPIO)

Pwrpas: I dderbyn unrhyw ddatganiad o gysylltiad a chynghori'r Aelodau yn unol a hynny.

3 COFNODION (Tudalennau 3 - 20)

Pwrpas: Cadarnhau cofnodion y cyfarfodydd ar y cyd â'r Pwyllgor Trosolwg a Chraffu Gofal Cymdeithasol ac Iechyd ar 24 Mai, a cofnodion y cyfarfod ar 14 Mehefin 2018 fel cofnod cywir.

4 MENTER GYMDEITHASOL DOUBLE CLICK - ADRODDIAD CYNNYDD (Tudalennau 21 - 52)

Adroddiad Prif Swyddog (Gwasanaethau Cymdeithasol) - Aelod y Cabinet dros y Gwasanaethau Cymdeithasol

Pwrpas: Rhoi gwybod i aelodau am gynnydd cliciwch ddwywaith ers ei sefydlu fel Cwmni Cymdeithasol

5 **STRATEGAETH ANABLEDD DYSGU GOGLEDD CYMRU** (Tudalennau 53 - 152)

Adroddiad Prif Swyddog (Gwasanaethau Cymdeithasol) - Aelod y Cabinet dros y Gwasanaethau Cymdeithasol

Pwrpas: I dderbyn adroddiad ar y Strategaeth Anabledd Dysgu

6 **CYNNYDD I DDARPARWYR** (Tudalennau 153 - 318)

Adroddiad Prif Swyddog (Gwasanaethau Cymdeithasol) - Aelod y Cabinet dros y Gwasanaethau Cymdeithasol

Pwrpas: I dderbyn adroddiad ar y cynnydd i ddarparwyr

7 **YMWELIADAU ROTA**

Pwrpas: I dderbyn adroddiad llafar gan Aelodau'r Pwyllgor

8 **RHAGLEN GWAITH I'R DYFODOL** (Tudalennau 319 - 324)

Adroddiad Hwylusydd Pwyllgor Trosolwg a Chraffu Iechyd a Gofal Cymdeithasol - Not Applicable

Pwrpas: Ystyried Rhaglen Gwaith i'r Dyfodol y Pwyllgor Trosolwg a Chraffu Gofal Cymdeithasol ac Iechyd

Yn gywir



Robert Robins
Rheolwr Gwasanaethau Democraidaidd

Eitem ar gyfer y Rhaglen 3

**JOINT EDUCATION & YOUTH AND SOCIAL & HEALTH CARE
OVERVIEW & SCRUTINY COMMITTEE
24 MAY 2018**

Minutes of the meeting of the Joint Education & Youth and Social & Health Care Overview & Scrutiny Committee of Flintshire County Council held at County Hall, Mold on Thursday, 24 May 2018

PRESENT:

Councillors: Janet Axworthy, Marion Bateman, Sian Braun, Geoff Collett, Paul Cunningham, Carol Ellis, David Healey, Gladys Healey, Patrick Heesom, Cindy Hinds, Dave Hughes, Kevin Hughes, Tudor Jones, Mike Lowe, Dave Mackie, Hilary McGuill, Martin White, David Williams and David Wisinger

CO-OPTED MEMBERS: Lynn Bartlett, David Hytch, and Rebecca Stark

APOLOGIES: Interim Chief Officer (Education and Youth)

SUBSTITUTIONS: Councillor Mike Reeve (for Andy Dunbobbin)

CONTRIBUTORS:

Councillor Christine Jones, Cabinet Member for Social Services; Councillor Ian Roberts, Cabinet Member for Education and Youth, Chief Officer (Social Services); Senior Manager Safeguarding and Commissioning; Senior Manager Children and Workforce; Senior Manager Inclusion and Progression; Senior Manager Integrated Youth Provision; Early Years and Family Support Manager; Safeguarding Unit Service Manager, Family Support Manager and Planning and Development Officer

ATTENDANCE:

Education and Youth Overview & Scrutiny Facilitator and Committee Officer

1. APPOINTMENT OF CHAIR FOR THE MEETING

The Education & Youth Facilitator sought nominations for a Chair for the meeting.

RESOLVED

That Councillor David Healey be appointed as Chairman for the meeting.

2. DECLARATIONS OF INTEREST

Councillor Sian Braun declared a personal interest in Agenda Item 9 – Childcare Offer for Wales, Flintshire due to her accessing this service.

3. CORPORATE PARENTING STRATEGY

The Chief Officer (Social Services) introduced a report to endorse a refreshed Corporate Parenting Strategy for Flintshire. He advised that the report outlined the ongoing work being undertaken to form a new Corporate Parenting Strategy within the context of the Social Services and Well-being (Wales) Act 2014 and national developments relating to Corporate Parenting.

The Planning and Development Officer provided background information and reported on the main considerations, as detailed in the report, concerning progress in developing Flintshire's Corporate Parenting Strategy. He explained that the Strategy would be in place for at least 5 years to ensure consistency and make a positive difference for looked after children and care leavers. He referred to the draft Corporate Parenting Strategy 2018-2023 which had been provided to the Committee for endorsement.

Councillor Hilary McGuill asked if the text in the Strategy could be amended to read as if it were addressing a child. The Planning and Development Officer agreed to amend the text accordingly.

Councillor Kevin Hughes asked if the Strategy could be amended to reflect, where a looked after child was placed in foster care, consideration would be given to placing them with foster parents who had the same religious beliefs or ethnicity. The Senior Manager Children and Workforce explained that this was already taken into consideration and agreed to include it within the Strategy.

Following a suggestion by Councillor Carol Ellis, the Committee recommended that a short presentation on Corporate Parenting be given at a future meeting of the County Council and also to the Chief Officer Team. The Senior Manager Children and Workforce suggested that young people be invited to shape the presentation to provide Members with real life examples.

Mrs. Rebecca Stark suggested that personal examples from young people showing how the Strategy had worked for them be added to the final Strategy.

Councillor Janet Axworthy suggested that the title of the Strategy be changed to 'Looking After You: Corporate Parenting Strategy'.

In response to a suggestion from Councillor Cindy Hinds and the further comments made by the Committee around the Pride of Flintshire event, the Senior Manager Children and Workforce suggested that he e-mail all Members with a brief overview of the Pride of Flintshire event and also to invite contributions from Members.

Mr. David Hytch asked if co-opted Members of the Education & Youth Overview & Scrutiny Committee could be included in the e-mail and also be invited to attend the Pride of Flintshire event in September.

RESOLVED:

- (a) That the proposed actions to publish a new Corporate Parenting Strategy, taking into account the proposed amendments suggested by Members, be endorsed;
- (b) That the proposed action for all Flintshire County Council staff to be responsible for delivering the Strategy be endorse;
- (c) That the proposed action to develop and implement a cross-portfolio action plan to deliver on the statements outline in the Strategy, be endorsed; and
- (d) That Corporate Parenting be raised at a future County Council meeting and Chief Officer Team, with the involvement of young people.

4. EDUCATIONAL ATTAINMENT OF LOOKED AFTER CHILDREN IN FLINTSHIRE

The Senior Manager – Inclusion and Progression introduced a report on the Annual Education Attainment of Looked After Children. She advised that the report outlined the academic attainment of Flintshire’s Looked After Children for the academic year 2016-2017. The data related to the Looked After Children cohort identified in line with the definition ‘A child of statutory school age, i.e. between 5 and 16 years, who was looked after during the academic year 2016-17, for at least one year prior to 31 August 2017’. The Senior Manager explained that for the purpose of the report, children looked after under Short/Breaks/Respite Care were not included in the statistical analysis. The data had been grouped into four age groups corresponding to the National Curriculum Key Stages. The Senior Manager reported on the main points as detailed in the report.

Mrs. Lynne Bartlett asked if the educational attainment of children who had previously been looked after was monitored. The Senior Manager – Inclusion and Progression said that once this data had been defined it could be collated.

Councillor Hilary McGuill raised concerns around the number of Looked After Children in Education who were leaving school without qualifications and asked how this was being addressed. The Senior Manager – Inclusion and Progression reported on the various initiatives being used to engage with young people to encourage them to continue with their education. She commented on the challenges and emotional difficulties experienced by some young people in their early years which could also impact on their performance throughout their education. Councillor Hilary McGuill suggested that looked after children who had gained success through educational settings, be invited to speak to looked after children who were feeling disaffected by education for one reason or another.

In response to a question around mental health and the possible shortage of psychologists in North Wales, the Chair advised that Marilyn Wells, CAMHS Service Manager, and Andrew Gralton, Assistant Director of Children's Services would be attending the meeting of the Social & Health Overview & Scrutiny Committee to be held on 14 June 2018, to discuss the CAMHS.

Councillor Gladys Healey expressed concerns around the schools admission policy and said that some parents experienced difficulty in enrolling their child into a local school. She also commented on the increasing number of parents who elected to have their child educated at home. In response to the concerns Councillor Ian Roberts explained that there were various reasons why some children were not able to attend their parent's choice of school. He also advised that there were no boundaries for school admissions. Councillor Roberts reported that there was a national increase in the number of parents who chose to have their child educated at home. The Senior Manager – Inclusion and Progression reported that the Welsh Government was undertaking work to look at the increasing trend for home tuition and the reasons why parents opted for this service.

Councillor Carol Ellis commented on the emotional and physical difficulties experienced by some young people during their upbringing and said that their achievements were commendable as a result of the problems they had overcome. In response to a question from Councillor Ellis on the support available to Looked After Children in school, the Senior Manager – Inclusion and Progression, explained that there were substantial support systems in place in schools and referred to the post of a designated Looked After Children teacher in schools and the wider counselling services which were available.

Councillor David Williams referred to the range of vocational courses available to young people as an alternative pathway to higher education and career opportunities.

Councillor Cindy Hinds commented on the issue of bullying of young people via social media and asked how this was being addressed in schools. The Senior Manager – Inclusion and Progression, said this problem was taken seriously by schools and spoke of the work undertaken to provide guidance and support to schools on how to deal with it.

The Committee recommended that a report on School Admissions be submitted to a future meeting of the Education & Youth Overview & Scrutiny Committee.

RESOLVED:

- (a) That Members actively engage as Corporate Parents for Looked After Children, promoting awareness and challenging provision within Flintshire educational settings;

- (b) That Members actively encourage all educational staff to promote the educational welfare of Looked After Children within Flintshire establishments at a 'whole school level'; and
- (c) That a report on School Admissions be submitted to a future meeting of the Education & Youth Overview & Scrutiny Committee.

5. SAFEGUARDING OF CHILDREN AND CHILD PROTECTION

The Senior Manager Safeguarding and Commissioning introduced a report to provide information on the Children's Safeguarding provision and Child Protection process within the County boundaries. She explained that the report provided key statistical and performance related information about children at risk for whom the Authority had significant safeguarding responsibilities.

The Senior Manager Safeguarding and Commissioning referred to the main considerations, as detailed in the report, around Children's safeguarding, Education and Youth, and Social Services priorities for the safeguarding of children, and corporate safeguarding.

In response to a question by Councillor Tudor Jones concerning whether the targets for review of children on the Child Protection Register were met, the Safeguarding Unit Service Manager explained that the Authority had robustly achieved all its targets for review of children on the register in line with the All Wales Child Protection Procedures.

Councillor Kevin Hughes asked if information was available on the ages of children on the child protection list and also whether there was any correlation between the ages and the categories of risk. The Safeguarding Unit Service Manager said that the data on ages of children was available and could be shared. She also said that the data could be broken down to see if there was any correlation between the ages and the categories of risk.

Councillor Hilary McGuill raised concerns regarding the safeguarding of children in the vicinity of school premises at the end of the school day. In response the Safeguarding Unit Service Manager referred to the work of the Corporate Safeguarding Panel and advised that representatives from both Education Services and the Police attended the Panel and commented on the partnership work which took place around areas of shared concern. Councillor McGuill suggested that the Police be asked to monitor 'hot spots' in areas of concern to prevent children and young people from harm and to deter anti-social behaviour.

Councillor Patrick Heesom commented on the lack of provision of youth services for young people in Flintshire which he said had created a 'dire' social need.

RESOLVED:

- (a) That the information in relation to the Safeguarding of Children and Child Protections for the period 1st April 2017 to 31st March 2018, be noted; and
- (b) That due regard be taken to the partnership working taking place across portfolio areas to protect children and young people from harm.

6. ADDITIONAL LEARNING NEEDS AND EDUCATION TRIBUNAL (WALES) ACT 2018

The Senior Manager – Inclusion and Progression introduced a report to update on implementation plans arising from the Additional Learning Needs Bill Legislation. She provided background information and reported on the main considerations, as detailed in the report.

During discussion Officers responded to the questions raised by Councillor Tudor Jones regarding the care and support provided to young people with Additional Learning Needs (ALN) from the age of 18.

The Senior Manager – Inclusion and Progression reported that it would be reasonable to anticipate that the increase in age range from 19 to 25 and the broadening of the legislative cover, would result in a larger number of Individual Development Plans. The revised legislation also provided for the responsibility for the commissioning and funding of Post 16 specialist provision to transfer from Welsh Government (WG) to Local Authorities; the mechanism for this was yet to be defined.

It was suggested that a further report on what Flintshire was doing for care leavers could be provided to a future meeting of both the Education & Youth Overview & Scrutiny and Social & Health Care Overview & Scrutiny Committees.

RESOLVED

- (a) That the report be noted; and
- (b) That an update report on local and regional implementation plans arising from the legislation be submitted to a future meeting of both Education & Youth Overview & Scrutiny and Social & Health Care Overview & Scrutiny Committees

7. FLINTSHIRE EARLY HELP HUB

The Senior Manager Integrated Youth Provision, introduced a report to provide an overview of the operation and effectiveness of the Early Help Hub. She provided background information and invited the Senior Manager Children and Workforce to present the report.

The Senior Manager Children and Workforce explained that the Hub offered families advice and assistance when previously referrals would not have been actioned and there was a high risk of a repeat referral back to Children's Services with more complex need being defined. He reported on the development of the Early Help Hub which could be summarised into the following phases:

- Design
- Soft launch
- Implementation

Members spoke in support of the excellent work which had been undertaken on the Early Help Hub and congratulated officers on their achievements. Members also spoke in support of the collaborative work which had been undertaken to design and develop the Hub with multi-partner agencies, citing the North Wales Police and Public Service Board as an example.

Mrs. Rebecca Stark commented on the need for funding to be continued in the future and asked how the profile of the Early Help Hub could be raised to ensure the Welsh Government, other authorities and organisations/bodies, were aware of the work and the positive outcomes being achieved in Flintshire.

RESOLVED

- (a) That the Committee congratulate officers on the work which had been undertaken on the Early Help Hub;
- (b) That the ongoing work and commitment to the Early Help Hub as part of a wider programme to support families experiencing trauma aligned to Adverse Childhood Experiences (ACE's) be supported; and
- (c) That the Committee support the collection of data and evidence to demonstrate the need for continued Families First funding from Welsh Government.

8. CHILDCARE OFFER FOR WALES, FLINTSHIRE

The Chief Officer (Social Services) introduced a report on the rollout of free childcare provision and advised that the report provided an update on the funded Childcare Offer for Wales in Flintshire. He invited the Early Years and Family Support Manager to present the report.

The Early Years and Family Support Manager reported on progress in developing and delivering the Childcare Offer for Wales in Flintshire and referred to the main considerations as detailed in the report.

Councillor Martin White congratulated officers on the excellent work which had been undertaken to roll out the Childcare Offer in Flintshire.

RESOLVED:

- (a) That the progress made to full roll out of the Childcare Offer in Flintshire be endorsed; and
- (b) That the proposed cross-country delivery plan be endorsed.

9. ATTENDANCE BY MEMBERS OF THE PRESS AND PUBLIC

There were no members of the press or public in attendance

(The meeting started at 2.00 pm and ended at 5.05 pm)

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Chairman

SOCIAL & HEALTH CARE OVERVIEW & SCRUTINY COMMITTEE
14 JUNE 2018

Minutes of the meeting of the Social & Health Care Overview & Scrutiny Committee of Flintshire County Council held in the Delyn Committee Room, County Hall, Mold on Thursday, 14 June 2018

PRESENT: Councillor Gladys Healey (Vice Chair in the Chair)

Councillors: Mike Allport, Marion Bateman, Jean Davies, Cindy Hinds, Kevin Hughes, Rita Johnson, Mike Lowe, Dave Mackie, Hilary McGuill, Martin White, Ian Smith and David Wisinger

SUBSTITUTION: Councillor David Healey (for Andy Dunbobbin)

APOLOGIES: Councillor Carol Ellis

CONTRIBUTORS: Councillor Christine Jones, Cabinet Member for Social Services; Chief Officer (Social Services); and Senior Manager - Safeguarding and Commissioning

Representatives of Betsi Cadwaladr University Health Board

Rob Smith, Area Director East

Lesley Singleton, Assistant Director of Strategy & Partnership Mental Health & Learning Disabilities

Jane Bryant, Area Nurse Director

Steve Forsyth, Area Nurse

Dr. Gareth Bowdler, Area Medical Director East

Andy Roach, Director of Mental Health & Learning Disabilities

Representatives of Welsh Ambulance Services NHS Trust

Richard Lee, Director of Operations, Welsh Ambulance Service

Andy Long, Area Manager for North Wales, Welsh Ambulance Service

Children and Mental Health Services (CAMHS)

Andrew Grafton, Assistant Director of Children's Services

Marilyn Wells, Service Manager

IN ATTENDANCE: Social & Health Care Overview & Scrutiny Facilitator and Democratic Services Officer

10. MINUTES

The minutes of the meeting held on 10 May 2018 were received.

Matters Arising

In response to a query from Councillor Ian Smith, the Chief Officer (Social Services) agreed to provide an explanatory list of the acronyms used in the reports submitted to Committee.

RESOLVED:

That the minutes be approved as a correct record and signed by the Chair.

11. DECLARATIONS OF INTEREST

Councillor Dave Mackie declared a personal interest as a representative of the Community Health Council.

Councillor Gladys Healey also declared an interest as a representative of the Community Health Council

12. BETSI CADWALADR UNIVERSITY HEALTH BOARD

The Chair welcomed Rob Smith, Area Director East, Lesley Singleton, Assistant Director of Strategy & Partnership Mental Health & Learning Disabilities, Jane Bryant, Area Nurse Director, and Dr. Gareth Bowdler, Area Medical Director East, to the meeting,

The Chair invited the Officers to provide a general update on Primary Care and Community Services. Jane Bryant gave an update on the range of nursing and community services available to support people who wished to be cared for at home. She reported on the support provided to patients who were discharged from hospital to enable them to receive care and treatment at home and remain in their community.

Dr. Gareth Bowdler provided an update on Primary Care services and commented on the improved terms and conditions for employing GPs which it was expected would assist the offer of work for GPs in Flintshire to address recruitment shortage.

The Chair thanked Officers for their update and invited Members to raise questions.

Councillor Rita Johnson referred to the closure of Flint hospital and the loss of beds and asked if Holywell Community Hospital had the capacity to meet demand. Jane Bryant confirmed that occupancy levels were high, however, the Matron worked with Glan Clwyd Hospital and GP's to ensure best access and use of community beds in Holywell Community Hospital. The increased focus on treating patients at home in and out of hours was a key area to progress.

Councillor Hilary McGuill commented on the staffing of Minor Injury Units (MIUs). She felt that in some cases staff did not have the right

competencies/confidence to undertake treatments e.g. stitches or administering intravenous drips, which resulted in patients needing to visit Accident and Emergency departments in hospital. Councillor McGuill suggested that nursing staff could rotate between main A&E departments and MIUs units to maintain skills. Councillor McGuill also suggested that patients may be reluctant to be discharged from hospital because they may not have access to prompt diagnostic testing as they had as in-patients.

Dr. Gareth Bowdler agreed that there was a need to ensure nursing staff within MIU units had the right proficiencies and skills and this was an area of development which was a high priority. Rob Smith referred to the review of urgent care provision currently taking place across Flintshire and Wrexham which was looking at improvements including closer links between GP's, Accident & Emergency Departments and MIUs. Consideration was being given to integrating and rotating primary care and Accident & Emergency and MIU staff. Dr. Bowdler acknowledged that there was room for improvement in discharge planning with one of the key concepts being that discharge planning should start as soon as a patient was admitted. Regarding diagnostic testing, Dr. Bowdler advised that work was ongoing to facilitate diagnostic testing and to ensure that patients had appointments booked before being discharged where possible.

In response to a question from Councillor Ian Smith regarding replacement of fluorescent lighting with LED lighting at the MIU in Mold, Rob Smith agreed to make enquiries with the estate office and provide a response.

Councillor Kevin Hughes commented that he had experienced an 8 hour waiting time at Wrexham hospital Accident and Emergency Department and said that whilst he had received excellent service better communications at A&E Departments would alleviate frustration for patients and enable them to understand the reasons for delay. Councillor Hughes also commented on smoking outside the hospital entrance and asked what could be done to improve signage and promote education on the health risks. Councillor Hughes congratulated staff at Wrexham hospital A&E department on the excellent work they do.

Rob Smith said an 8 hour wait was not acceptable and referred to the national target of 4 hours which should be delivered in most cases. He explained that BCUHB worked closely with hospitals to reduce the pressure on A&E departments and agreed to make further enquiries regarding the issue of communication and report back to the Committee. He agreed with the comment that it would be helpful if patients were regularly updated if a long delay occurred. Referring to the issue of smoking, Mr. Smith commented that this was an on-going problem and improvements seemed to have only a short term impact. However, he would raise any specific concerns Members had around smoking outside the entrances to the Maelor Hospital with the hospital again.

Councillor Marion Bateman said she had been advised that the X-Ray department at Mold Hospital only treated children over 5 years old and asked if

BCUHB were looking to change the provision to include younger children. Dr. Gareth Bowdler advised that the service available depended on the skill set of the individual member of staff on duty at the time rather than the patient's age.

Referring to the recruitment of GPs the Chair asked if it was stipulated in their contract that they had to practice for a minimum of 2 years in Wales. Dr. Gareth Bowdler advised that GPs on a training course received a golden 'hello' to enable them to set up practice in Wales for a couple of years following their training.

The Chair thanked Officers for their attendance and detailed answers to Members questions.

RESOLVED

- (a) That the update on Primary Care and Community Services be noted; and
- (b) That Officers from BCUHB be thanked for their attendance and input

13. WELSH AMBULANCE SERVICES

The Chair welcomed Andrew Long, Area Manager North, and Richard Lee, Director of Operations, Welsh Ambulance Services NHS Trust, and invited them to give a presentation on ambulance performance in the Betsi Cadwaladr University Health Board area.

Andrew Long advised that the purpose of the presentation was to explain the transformation which had been taking place in ambulance services in Wales, highlight some of the positive developments, and explain where further work needed to be done. He said it was also an opportunity to share the Welsh Ambulance Services experiences of implementing the Clinical Response Model to date, highlight what had been learnt along the way, and put the introduction of the Clinical /response Model in the context of wider organisational and system change. The main points of the presentation were as follows:

- NHS Wales and Welsh Ambulance Services NHS Trust
- conditions for change – our operating environment
- designing ambulance into unscheduled care
- what did we do?
- moving from red to amber response
- what does the future look like for WAST and our staff and patients?
- frequent callers
- hear and treat
- clinical desk effectiveness and clinical desk in Police
- performance, response and demand
- Hospital lost hours
- a new way forward

Councillor Marion Bateman commented on the issue of repeat calls to the ambulance services by individuals who did not require urgent or necessary medical treatment. She referred to a scheme in England whereby individuals were given a 'buddy' number to contact in the first instance to assess the call and avoid the request for an ambulance to attend if not necessary. Richard Lee referred to the Frequent Callers initiative to deal with repeat callers to the Ambulance Service and cited as an example a patient who had phoned emergency services 600 times in a year and who was in need of support but not medical treatment. He commented on the alternative options to be considered before an ambulance was despatched if urgent medical treatment was not needed and cited referral to a GP, a visit from a community nurse, support from the third sector or provision of alternative transport, as examples. He reported on the success in reducing the number of ambulance call-outs and advised that the control rooms prevented approximately 2,000 unnecessary ambulance call-outs a month. He also referred to the 'Come to See me' initiative which involved sending the 'right' NHS service to treat a patient.

Commenting on ambulance response times, Members were informed that less than 20 calls to the ambulance service were red emergencies. The target for red calls was 7 minutes and 59 seconds which could include community first responders arriving within that time. Officers took the opportunity to emphasise the importance of large buildings such as County Hall being equipped with a defibrillator which can save lives and costs less than £1,000.

Officers referred to the increase in the training of advanced paramedic practitioners to provide additional skills to the service and advised that funding was currently being secured to provide an advanced practitioner at Dobbshill Ambulance base. Councillor McGuill commented that whilst one practitioner was a step in the right direction there was still a need for more staff. The officer agreed that there was a need to develop the service and that an education programme was in place to enable paramedics to undertake additional learning and there was enthusiasm amongst paramedics to take-up the programme.

Councillor Ian Smith queried the cross border arrangements with England. Andy Long explained that the Welsh Ambulance Services NHS Trust had good cross border arrangements with the Countess of Chester Hospital and said that the approach going forward was to take less people to hospital and to treat more people at home and assist people to leave hospital if they were well enough.

Councillor Kevin Hughes asked if there had been an increase in assaults on staff. Officers responded that there were no increases in the number of assaults, however, as activities had increased some staff wear body cameras. Officers explained that the Welsh Ambulance Services NHS Trust had a zero tolerance approach to violence and abusive behaviour towards staff and had well-being strategies and other initiatives and skills in place to protect and support staff.

Councillor Hilary McGuill asked if the link falls service provided by the North Wales Fire Service was still in operation. Rob Smith responded that BCUHB had tasked the Community Asset Team in North Wales for this as they were responsible for the service. The issue of funding was raised and discussion took place around the challenges to be met concerning nursing and care homes and the need to work collaboratively with the Health Board to seek an alternative to a request for the ambulance service to respond to falls.

In response to a further question from Councillor McGuill concerning the role of the falls assistant and how it would be delivered in the future, Officers explained that the role of the falls assistant would continue and would be delivered in each geographical area in an appropriate way, for example in rural areas a volunteer system may be more appropriate. Councillor McGuill referred to an initiative where homes are provided with a lifting cushion which can be used in the event of a fall.

The Chair thanked Andrew Long and Richard Lee for their attendance and detailed answers to Members questions.

RESOLVED:

That the presentation be noted.

14. REGIONAL MENTAL HEALTH STRATEGY

The Chair invited Lesley Singleton, Head of Strategy and Partnerships for Mental Health, to introduce the report. Lesley Singleton presented the North Wales Mental Health Strategy 'Together for Mental Health' which was a 5 year plan for Betsi Cadwaladr University Health Board (BCUHB) to develop mental health services and work with partners, including the Council, to improve services for the citizens of North Wales. She emphasised that the Strategy had been developed focusing on a person's outcome approach and said that on the past the traditional model to Mental Health had not been what people wanted or needed. The emphasis was on keeping people in their own bed with services wrapped around and ensuring that communities align to supporting emotional wellbeing.

The Chair thanked Lesley Singleton for presenting the Strategy and invited questions.

Councillor Kevin Hughes commented on the issue of medication and expressed concerns that medication prescribed to young people may cause them to become addicted in the future. Lesley Singleton acknowledged the concerns and referred to the need to have an understanding of what outcomes people wanted and to tailor interventions around individual need. Andrew Grafton, Assistant Director of Children's Services, gave an assurance that any medication given was considered necessary and was regularly reviewed. He said that one of the challenges was that people were looking for a "magic" intervention. He reassured the Committee that the service was delivered by a group of highly trained medical professionals and reviewed appropriately.

Councillor Hilary McGuill asked if a person could refer into the system without going through a GP. She commented that a GP did not necessarily understand the needs of the individual and that on occasions the housing teams also did not understand the individual's needs. Lesley Singleton referred to the Crisis Hub which had been established in Wrexham and said that BCUHB were in discussion with Flintshire County Council regarding establishing a similar service in Flintshire. She referred to the PARABL talking therapies partnership that worked across North Wales and said it was possible to self-refer to that.

In response to a question from Councillor David Healey, Lesley Singleton confirmed that BCUHB were looking to roll out the crisis hub initiative in Flintshire for one day a week.

The Chair commented on the stigma attached to mental health and mental health issues in the workplace. Lesley Singleton added that the stigma of Mental Health in the workplace remained a problem but some positive examples were starting to develop. She advised that the charity Awyr Las was promoting an 'I can' campaign around mental health to challenge the stigma of mental Health with the emphasis on giving people an opportunity to start a "difficult" conversation. She said it was also about the opportunity to get employers to start to think about mental health first aid and support to help employees get back into the workplace.

RESOLVED:

That the North Wales Together for Mental Health Strategy be noted.

15. SOCIAL SERVICES ANNUAL REPORT

The Chief Officer (Social Services) explained that the purpose of the Social Services Annual Report was to set out the improvement journey and evaluate Social Services' performance in providing services to people that promote their wellbeing and support them to achieve their personal outcomes.

The Chief Officer reported on the main considerations, as detailed in the report, and drew attention to the improvement priorities identified for 2018/19 which were also outlined in the draft Social Services Annual Report for 2017/18.

Councillor Kevin Hughes congratulated the Chief Officer and his team on the content of the report and their hard work.

RESOLVED:

- (a) That the draft Social Services Annual Report for 2017/18 be endorsed; and
- (b) That the Chief Officer (Social Services) and his team be congratulated on the work undertaken.

16. YEAR-END COUNCIL PLAN MONITORING REPORT 2017/18

The Chief Officer (Social Services) introduced the Year-end Council Plan Monitoring Report 2017/18. He explained that the report presented the monitoring of progress at the end of year for the Council Plan priority 'Supportive Council' which was relevant to the Committee.

The Chief Officer provided background information and advised that the monitoring report for the 2017/18 Council Plan was a positive report, with 83% of activities being assessed as having made good progress, and 74% having achieved the desired outcome. Performance Indicators showed good progress with 56% meeting or near to period target. Risks were also being successfully managed with the majority being assessed as moderate (63%), minor (8%) or insignificant (6%).

The Chief Officer reported that the following performance indicators showed a red status for current performance against target for the Committee:

- Percentage of care homes that have achieved bronze standard who have also achieved silver standard for Progress for providers

Referring to the above indicator the Chief Officer explained that the target had been overly ambitious as the actual performance was exemplary with the Council taking forward sector leading progress with the achievement of the bronze award in 10 homes. He continued that the approach had been shortlisted in the biannual Care Accolade awards taking place in September 2018.

- Percentage of employees who have completed the level 1 e-learning training package to meet the requirements of the Domestic Abuse and Sexual Violence National Training Framework

The Chief Officer advised that an action plan was produced for each performance indicator which showed a Red status which would look in detail at what steps could be taken to mitigate future underperformance and whether the indicator should be carried forward to the 2018/19 Council Plan.

The Chief Officer advised that the following major risks had been identified and progress against the risks in the Council Plan were included in the appendix to the report.

- demand outstrips supply for residential nursing home care home bed availability
- knowledge and awareness of safeguarding not sufficiently developed in all portfolios
- failure to implement safeguarding training may impact on cases not being recognised at an early stage

Referring to indicator 1.4.2.1 on page 186, Councillor Hilary McGuill asked if a copy of the national data referred to in the report could be provided to the Committee. The Chief Officer agreed to provide the information. Indicator 1.5.1.2. page 188.

The Chair congratulated the Chief Officer (Social Services) and his team on the performance achieved.

RESOLVED:

That the report be noted.

17. ROTA VISITS

Following a request from Councillor Hilary McGuill, the Social & Health Care Overview & Scrutiny Facilitator agreed to chase up the schedule of future rota visits.

18. FORWARD WORK PROGRAMME

The Facilitator presented the Forward Work Programme and advised that the next meeting of the Committee was to be held on 4 October 2018.

In response to a request from Councillor Hilary McGuill the Facilitator agreed to write to BCUHB and the Welsh Ambulance NHS Trust to request an update on the issues raised at the meeting.

RESOLVED:

- (a) That the Forward Work Programme be updated accordingly; and
- (b) That the Facilitator, in consultation with the Chair of the Committee, be authorised to vary the Forward Work Programme between meetings, as the need arises.

19. MEMBERS OF THE PUBLIC AND PRESS IN ATTENDANCE

There was one member of the press in attendance and no members of the public.

(The meeting started at 2.00 pm and ended at 4.25 pm)

.....
Chair

Mae'r dudalen hon yn wag yn bwrpasol

Eitem ar gyfer y Rhaglen 4



SOCIAL AND HEALTH CARE OVERVIEW AND SCRUTINY COMMITTEE

| | |
|------------------------|--|
| Date of Meeting | Thursday 4 October 2018 |
| Report Subject | Double Click Social Enterprise – Progress Report |
| Cabinet Member | Cabinet member for Social Services |
| Report Author | Chief Officer for Social Services |
| Type of Report | Operational – Progress Report |

EXECUTIVE SUMMARY

This report is presented to Overview and Scrutiny Committee as a Progress Report on Double Click Design and Print which is over 2 years old as a Social Enterprise.

Double Click has progressed greatly as a fully independent Social Enterprise, offering increased employment and training opportunities for all staff including people with mental health issues.

Double Click has secured significant external lottery funding and as a result have purchased state of the art equipment that support the development of the business.

RECOMMENDATIONS

| | |
|---|--|
| 1 | Committee members recognise the progress achieved after 2 years. |
| 2 | Committee members continue to support and promote Double Click as a social enterprise. |

REPORT DETAILS

| 1.00 | EXPLAINING DOUBLE CLICK AS A SOCIAL ENTERPRISE |
|------|---|
| 1.01 | Double Click used to be restricted to employing support workers where the requirements for the post were prescribed. As a result of moving to a social enterprise Double Click can now employ people with a range of skills. They have, for example, just employed a graphic designer/trainer who can share her skills with trainees and improve the products. They have also introduced an internship post to increase the skills in the graphic design area. |
| 1.02 | A payment system used in business has also been set up to make it easier for customers to pay by card. Pay Pal is now linked, which, in addition to the practical advantage, actually makes Double Click more business-like. Volunteers are now paid expenses, reflecting their commitment. |
| 1.03 | <u>Partnerships</u> – Double Click are now forging ahead with partners to further enhance the experiences of trainees/volunteers. They now have close business ties with training organisations/local companies. They have a full order book and are designing for the likes of BCUHB, NEWydd, NEWCIS Flying Start, to name but a few. |
| 1.04 | <p><u>Training</u> – Double Click can now be more flexible/creative in their training. There are 3 levels of learning at Double Click.</p> <ul style="list-style-type: none"> • Level 1 - We offer an online video training course where the Trainee can learn at their own pace and practice using the software while taking part on the course. A few course available are: InDesign, photoshop, Illustrator, Excel and wordpress. • Level 2 - We teach how to put the newly acquired skills into action. We offer one to one support and give guidance and help to finely tune their skills and knowledge. • Level 3 - We are looking to develop the trainee and hopefully get an accreditation at Double Click in conjunction with a college or University. We are also looking into Open University sponsorship for our Trainees. |
| 1.05 | <u>Grant funding</u> – As a social enterprise, Double Click are able to apply for grants to promote their businesses and fund developments. As an example, they have received National Lottery funding for computer equipment, something not previously open to them. |
| 1.06 | Double Click are still able to benefit from expertise within Flintshire County Council in areas such as Safeguarding/Mental Health Knowledge/Health and Safety. They have access to all Social Service mandatory training available. |
| 1.07 | People with relevant skills and background can be brought onto the Board of Directors. Double Click currently have a Flintshire County Council Councillor, a person with a finance background, a person with Mental Health background and two advisors from Flintshire County Council and Social Firms Wales. This brings a range and balance of contributions. They are now looking to expand/increase number of Directors, bringing |

| | |
|------|---|
| | additional expertise/knowledge. |
| 1.08 | Double Click hosted the Cabinet Secretary for Economy and Transport, Ken Skates who visited on the 24 th September 2018. The Cabinet Security recognised the great progress made by Double Click as Social Enterprise which he described as model for other sectors in the principality. |

| | |
|-------------|---|
| 2.00 | RESOURCE IMPLICATIONS |
| 2.01 | Cost – Flintshire County Council contribute £110,000 to Double Click. This amount has not increased over past 2 years, so is effectively a cost reduction, taking inflation and other factors into account. |

| | |
|-------------|---|
| 3.00 | CONSULTATIONS REQUIRED / CARRIED OUT |
| 3.01 | n/a |

| | |
|-------------|--|
| 4.00 | RISK MANAGEMENT |
| 4.01 | Risk that Double Click would be unable to implement a successful development plan, and achieve business outcomes and orders. This is mitigated by effective leadership from the management team and governance by a robust board with involvement with business and community leaders, including from the council. |

| | |
|-------------|--|
| 5.00 | APPENDICES |
| 5.01 | Appendix 1 - Double Click Report 17-18 |
| 5.02 | Appendix 2 - Mindful Autumn |
| 5.03 | Appendix 3 - Mindful Autumn - Welsh |

| | |
|-------------|--|
| 6.00 | LIST OF ACCESSIBLE BACKGROUND DOCUMENTS |
| 6.01 | <p>Double Click Promotional Pack</p> <p>Contact Officer: Jo Taylor, Service Manager, Disability, Progression and Recovery – Adult Services Telephone: 01352 701341 E-mail: jo.taylor@flintshire.gov.uk</p> |

| | |
|-------------|--------------------------|
| 7.00 | GLOSSARY OF TERMS |
| 7.01 | None. |



double click
DESIGN & PRINT
Supporting Mental Health

DOUBLE CLICK DESIGN & PRINT CIC REPORT

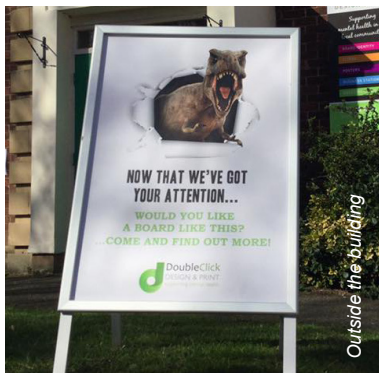
supporting mental health in the community
January 2017-18



Sponsored event



Certificate awarded



Outside the building

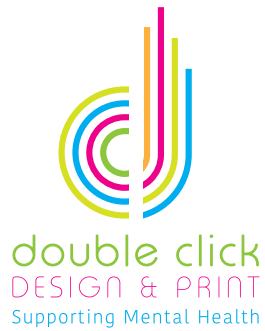


Lunchtime walk with staff and trainees.

Working for and with the community!

DESIGNS THAT INSPIRE THE MIND AND MAKE A DIFFERENCE.

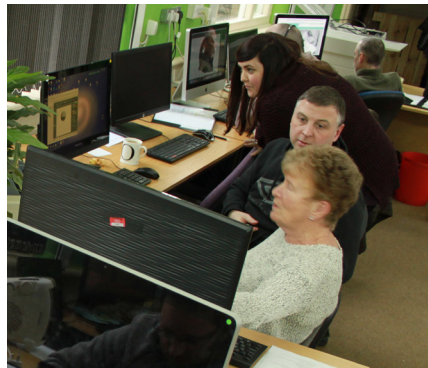
DESIGNS THAT INSPIRE THE MIND
AND MAKE A DIFFERENCE.



2017-18 Year report

Double Click is a design and print enterprise based in Shotton. Its income is generated by providing training and development opportunities to people who have experienced or continue to experience mental health problems.

Double Click's products include the design and printing of leaflets, brochures, flyers and general business stationery, as well as website design.



| | |
|--------------------------|----|
| Contents | 1 |
| Products and Services | 2 |
| Double Click Structure | 3 |
| Profit & Loss accounts | 4 |
| Balance Sheet | 5 |
| How are we doing? | 6 |
| What's going on | 7 |
| Training and Development | 8 |
| 3 Clear steps | 9 |
| Courses now available | 10 |
| Outcomes | 11 |
| Branding and The Team | 12 |



Products and Services

Two sources of income for Double Click.

In January 2016 Double Click Design was transformed from a Flintshire County Council Service, supporting people with mental health problems to become a new Social Firm, a business with a social conscience.

Printing service

The core part of Double Click's product portfolio is the design and production of newsletters, business cards, documents, flyers, leaflets and pull-up banners. The aim is to extend this portfolio in the near future to include a full range of digital services. Customers for our products and services currently include the Local Authority and Businesses and it is intended that this customer base will be expanded through the development of a wider marketing strategy. We will be building on our strengths as a business with a social conscience and taking pride in our personalised 1-1 customer service. Looking to the long term, we realise customer loyalty is extremely important to Double Click and this will remain a significant focus in our developing marketing strategy.

Training placements

Double Click provides training placements for people with mental health issues. It is intended to enable these individuals to further develop their work related skills in an environment which, whilst business orientated, is able to adequately support the volunteers, trainees and employees according to any additional needs. Our training programmes are now up and running with online learning from "Learn Direct" proving to be a highly successful way for delivering a coherent programme of learning. This method of learning ensures that all trainees taking part can learn at their own speed whilst receiving regular feedback on their progress. On completion, further 1-1 specific training is provided by our graphic design tutor. A portfolio of work compiled by the trainee demonstrates their competence and would assist them in future interviews.

As well as developing graphic/printing skills we also give the trainees opportunities to acquire confidence by being involved in day to day administration and customer care. Support in managing cash flow, petty cash and visiting the bank is also an important feature of Double Click's office based training.

Double Click Structure

A closer look at Double Click

22 TRAINEES

Here at Double Click we have 22 people who are all engaged at different levels of learning. The content of training packages is negotiated and agreed with each trainee. Everyone's particular situation is assessed and their learning is sensitively managed by the staff.

5 STAFF

Andrew Lloyd-Jones General Manager
Sue Davies Support Worker/Admin
Heather Jones Graphic Designer
Claire Doughty Trainer & Designer
Sian Jones Graphic Designer

2 VOLUNTEERS

Our volunteers are essential to the success of Double Click. The responsibility that comes with the title of volunteer is regularly acknowledged. Their impact on contributing to the success of Double Click is recognised through feedback.

4 DIRECTORS

Sumnadipa Chair
Paul Cunningham Flintshire Councillor
Anne Rowlands Finance Director
Andrew Lloyd-Jones General Manager

What is a Social Firm?

A Social Firm is a not-for-private-profit business where the social mission is to create employment, work experience, training and volunteering opportunities within a supportive and inclusive environment for people who face significant barriers to employment – in particular, people with a disability.

Mission

Designs that inspire the mind and make a difference.

At Double Click, our mission is to give each of our customers the best professional service possible at an affordable price. We believe in giving individual attention to each customer, building a solid and lasting relationship based on trust and customer satisfaction.

Opening

Monday-Friday 9am - 4pm for customers

Tuesday-Friday 10am - 4pm for trainees



DOUBLE CLICK DESIGN AND PRINT CIC
PROFIT AND LOSS ACCOUNT
FOR THE YEAR TO 31 MARCH 2017

| Turnover | <i>(12 month period)</i> 2017 | <i>(3 month period)</i> 2016 |
|---|--------------------------------------|-------------------------------------|
| | £ | £ |
| Turnover | | |
| Sales | 15,657 | 4,189 |
| Cost of sales - materials | 8,632 | 569 |
| Gross profit | 7,025 | 3,620 |
| Expenses | | |
| Staff costs | | |
| Salaries | 52,907 | 5,571 |
| Consultancy | - | 3,180 |
| Seconded staff | 19,263 | 6,832 |
| Volunteer travel | 383 | - |
| | 72,553 | 15,583 |
| Rent & service charges | 6,552 | 1,867 |
| Utilities | 1,266 | 177 |
| Cleaning | 324 | - |
| Repairs | 725 | - |
| IT | 391 | 400 |
| Website | 790 | 112 |
| Accountancy | 1,000 | 500 |
| Insurance | 606 | - |
| Postage | 88 | - |
| Sundry | 824 | 75 |
| Depreciation | 878 | - |
| Amortisation | (878) | - |
| | 85,119 | 18,714 |
| | (78,094) | (15,094) |
| Other income | | |
| Flintshire County Council <i>(Training & Development)</i> | 117,440 | 14,652 |
| Compensation - bank | - | 450 |
| Net profit | 39,346 | 8 |
| Corporation tax | (7,869) | - |
| Retained profit | 31,477 | 8 |

DOUBLE CLICK DESIGN AND PRINT CIC
BALANCE SHEET
AS AT 31 MARCH 2017

Intangible fixed assets

| | |
|--------------------------------|---------------|
| | Goodwill £ |
| Cost At 01.04.16 & 31.03.17 | 1 |

5. Tangible fixed assets

| | Equipment £ | Total £ |
|-----------------|----------------|------------|
| Cost | | |
| At 01.04.16 | - | - |
| Additions | 3,512 | 3,512 |
| At 31.03.17 | 3,512 | 3,512 |
| Depreciation | | |
| At 01.04.16 | - | - |
| Charge for year | 878 | 878 |
| At 31.03.17 | 878 | 878 |
| Net book value | | |
| At 31.03.17 | 2,634 | 2,634 |
| At 31.03.16 | - | - |

Debtors

| | 2017 £ | 2016 £ |
|---------------|-----------|-----------|
| Trade debtors | 865 | 801 |

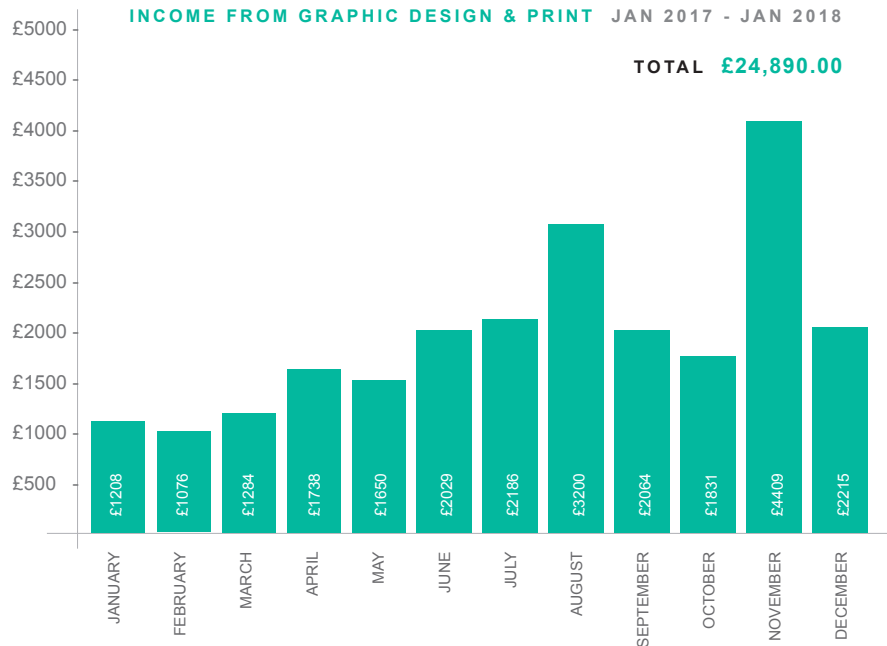
Creditors: amounts falling due within one year

| | 2017 £ | 2016 £ |
|----------------------------------|-----------|-----------|
| Trade creditors | 4,854 | 7,869 |
| Corporation tax | 7,869 | - |
| Other taxation & social security | 2,887 | 135 |
| Other creditors | 2,520 | 2,938 |
| Accruals and deferred income | 6,940 | 13,380 |
| | 25,070 | 24,322 |

How are we doing? JAN 2017 - JAN 2018 INCOME

Customers:

The high rate of return customers is a clear message that we are doing a good job. Our loyal customer base is the backbone of Double Click and this we value greatly.



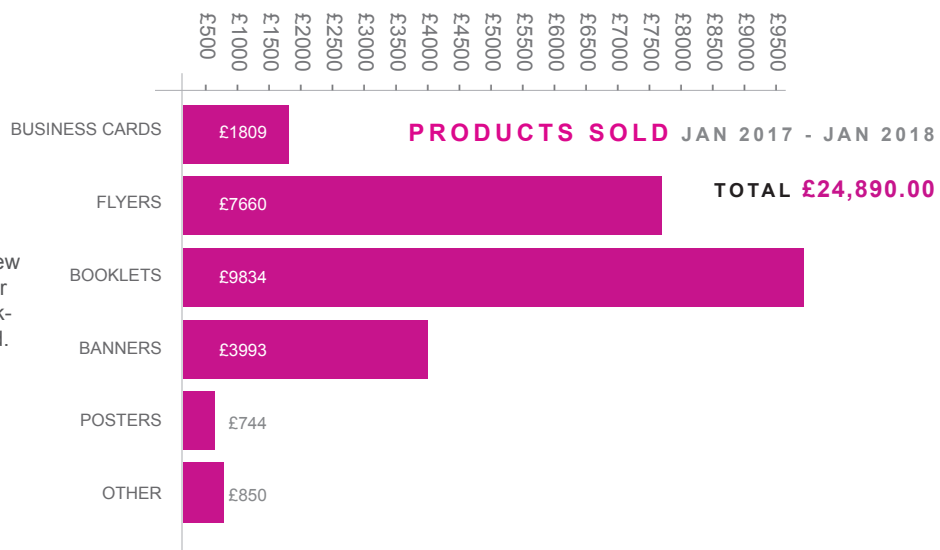
Materials:

Cost of materials is an element of Double Click that is constantly changing. A number of paper merchants have announced price increases in 2017. Increases of between 6% and 9% are anticipated for 2018.



Outside Printers:

We have outsourced 147 jobs and spent £6008.00 but this has given Double Click an opportunity to offer more to our clients. Our Graphic Design department has made this possible.



Products sold:

The products we are now offering the customer has increased again with the new Product Guide but it is clear to see that Flyers and Booklets are still in high demand.

Double Click News

A summary of our year

- Our Learn Direct courses have yet again been a big hit with our trainees, the confidence that comes with completing the certificate and creating a designed product for their portfolio proves very satisfying.
- Purchased, 2 new computers this year along with new software. Software subscription is now one of our major expenditures but the need to keep up with the latest software is paramount.
- Sian graduated in her Graphic Design and Multimedia Degree course at Glyndwr University in November. She is now a paid member of staff here at Double Click.
- A further development of our branding has created a fresh, modern look.
- Unfortunately in 2017 Double Click was broken into, damage to the building and computers created an opportunity to review our security. New window shutters, outside security lighting and a new alarm have been installed.
- New interior daylight lighting has created a more design-friendly environment.
- As a Social Firm Double Click has flexibility in terms of who we employ. We have, for example, just employed a consultant web trainer who can share his skills with trainees and staff to improve our digital products. Neil brings with him a wealth of commercial knowledge and technical ability.
- Sponsorship of 20 x A2 posters at the Diversity Festival in Mold organised by Rainbow Biz. This is something we will certainly be doing again, a fabulous way to get our name in the local community.
- Paypal: We are now able to accept card payments via Paypal.
- Folding Machine purchased: This new product has been a big help with offering a quick turnaround to our customers.
- We attended the Glyndwr University conference: (World Mental Health Day) 10th Oct.
- We have put together a new training and development information pack. The new look to our logo has been incorporated,
- New signage outside the building, along with new "A boards." This has proven to be an effective way to attract new customers.
- Due to the closure of FLVC print room, we will be offering a 20% discount on all jobs from FLVC Members and to all charities.
- One of our trainees, Hilda, has now become a volunteer.
- 19 attended our Christmas Meal at Jemoleys in Penyffordd. Jemoleys is a long standing customer of Double Click. We are presently creating a website for them.
- We can now offer customers recycled paper /envelopes and clear compostable packaging.



Trainees

Training and development

We have 22 Trainees who are all at different levels of development. The Learn Direct course has proved extremely successful in developing our trainees' skills in all aspects of graphic design. It allows each individual to learn at their own pace, followed by 1-1 tuition and support from a member of staff qualified in graphic design. Each trainee has their own development programme and personal portfolio of work which is regularly updated with the trainee's progress.

“ All staff are supportive, helpful and understanding and have welcomed me to participate in projects which are beneficial to my ongoing training and personal development ”

Dave/Trainee

“ I like hand-making cards... I find the interaction with people to be very rewarding ”

Hilda/Volunteer



Support is offered throughout the trainee's learning, this is something that all staff are involved with.



Staff and trainees working together is a vital part of Double Click's daily programme of activities.

“ I have completed a Learn Direct course in Indesign & Photoshop in a non-stressful, non-pressurised environment. ”

Wayne/Trainee



World Mental Health Day at Glyndwr University

“ The Double Click experience I feel is not to be underestimated, from being here for approximately a year, the culture and environment the team has created is one which naturally comes across as non-judgemental, relaxed, welcoming, friendly, positively supporting, empathetic and understanding, and this I feel every time I walk through the door. ”

Alan/Trainee

Training & Development

3 Clear Steps For the new Trainee, Looking to make a next step!

A page from our New Training & Development Guide

INTRODUCTION TO DOUBLE CLICK...

STEP 1...

Referral from Social Services to Double Click



Initial contact will be made with Jacqueline Vaughan-Thomas. To discuss whether Double Click is the right choice for you.

A meeting will then be arranged with Jacqueline, and Andy the manager of Double Click, for you to discuss the possibilities of potential training and development.

Once accepted you will be invited to spend some time at Double Click discussing your personal development programme with one of our trainers.

Step 2...

Personal Development Plan

What would you like to achieve whilst at Double Click?

We will discuss your strengths and aspirations, and then create a package of training tailored to you. This will be linked to your outcome reports.

A personalised development plan will be created for you, and together we will decide what courses and training would be suitable.

Step 3...

Training Available

Here at Double Click we have various training opportunities available.

We purchase Learn Direct Courses for trainees eager to learn more about specific software, including graphic design software such as Adobe InDesign, Adobe Photoshop and Adobe Illustrator to web design software Dreamweaver and desk top publishing software like Excel.

We can train you in packaging, folding, trimming, quality control, office related skills, book keeping, cash and receipts.

Courses now available

All the information you need in one pack!

A page from our New Training & Development Guide

Level 1...

Online Training

You will learn and practice at your own pace from an online, in-depth video training course. You will have your own individual log in details, and if you wish, you may also continue the course at home providing you have the suitable software.

The Courses that have been taken so far are: InDesign, Photoshop, Dreamweaver and Excel. We offer one-to-one ongoing help and support throughout the course.

Level 2...

At this level you will decide which avenue of further progression you would like to take. Then you will learn how to put your newly acquired skills to the test.

We will offer you one-to-one support and give you guidance and help as you fine tune your new skills and knowledge through the various options available.

HOW ARE WE GOING TO PROGRESS FURTHER?

Level 3...

Are you equipped with relevant skills to progress into further education?

We will continue to research potential courses available.

We are looking to develop the trainees and hopefully get an accreditation at Double Click in conjunction with a college or university.

Office Based Learning...

This will be mainly given by Sue.

Sue can help you follow guidelines and learn table work by learning how to fold, trim and package artwork ready for our clients, also filing, financial procedures, photocopying, recording skills etc.

Outcomes 2017

Trainees' outcomes

Trainees' success at Double Click

18

Learn Direct completed courses

This year we have introduced a new on-line learning course which has been well received. It has proved to be highly enjoyable while also instructive. A certificate of completion is awarded to the trainee at the end.

22

Trainees engaged with Double click

Trainees have developed their skills in graphics with 1-1 tutorials and by being involved with real jobs from paying customers. This high level of engagement comes from a learning process that encourages further development.

3

Office based learning

Three trainees have now undertaken an introduction to office based skills. This covers all the basic requirements for understanding petty cash, cash flow and the banking system within Double Click.

2

Table-Top Work

An important feature of Double Click, table-top work, allows trainees who are not involved with the computer side of the business to be part of the team. Trainees learn to cut, fold and package products for sale.

6

Moved on

3 gained employment, 2 left for College and University and 1 progressed to become a Volunteer.

2

Volunteers

Our Volunteers are Ben and Hilda. After a number of years as a trainee, Ben is now one of our valued Volunteers. Hilda has a skill in organising the table work and getting trainees actively involved.

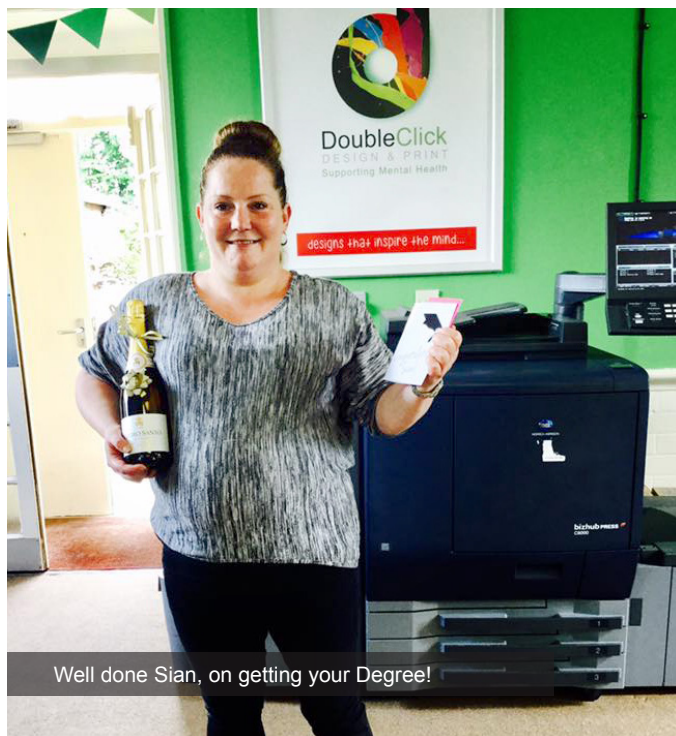
3-1

Staff to trainee ratio

On any given day at Double Click we will have 6-9 trainees on the premises. It is important that we offer design and computer support to our trainees, their development is of key importance.

Reasons to Celebrate

Certificates, Degrees & a new look!



Our New logo!

The Double Click branding has now been updated, it's brighter and more contemporary.

It's consistent use across all our marketing products, such as on our signage and product guide, means that Double Click is a more recognised local business and this has generated increased sales and interest to the Social Firm.

Our mission statement

Designs that inspire the mind and make a difference ...

is now being used in conjunction with our branding. This phrase was developed in collaboration with the trainees.



Product guides have been given to FLVC with a 20% discount sticker attached to the front. Local charities are also given the same discount.

Meet the team



Andrew Lloyd-Jones
General Manager



Sue Davies
Support Worker/
Administration



Heather Wilde
Graphic Designer



Claire Doughty
Trainer & Designer



Sian Jones
Graphic Designer

Our board of Directors are:



Sumnadipa
Chair



Paul Cunningham
Flintshire Councillor



Anne Rowlands
Finance Director



Andrew Lloyd-Jones
General Manager

Unit 36, The Lodge, Deeside Enterprise Centre, Shotton, Deeside CH5 1PP

t. 01244 846411 e. doubleclick.design@yahoo.com www.dcdesignprint.co.uk

DESIGNS THAT INSPIRE THE MIND AND MAKE A DIFFERENCE.

Tudalen 40

Mindful

Autumn
2018

One Step at a Time

My name is Danielle Humphreys, for many years I have experienced long standing enduring mental health difficulties namely severe social anxiety, PTSD and depressive disorder. I had very poor self-esteem and strongly believed that I was not good at anything (despite being a talented florist).

Over the years I have really struggled, with no support. My recovery journey began about 3 years ago when I went on a 12 week self-esteem course. I found it extremely difficult and the biggest achievement was being in the room with other people. I was then referred to the Flintshire Community Living team, this referral totally changed my life.

I was appointed a support worker who did exposure techniques with me and built up my confidence, she introduced me to Flintshire wellbeing brochure and together we looked at which courses I'd like to go on. The first one I attended was 'dealing with difficult situations' run by Unllias. I went on this without my support worker and was struck by debilitating anxiety, I wasn't even

able to introduce myself and had zero confidence.

The people facilitating the course were really kind and supportive and made me feel more comfortable and I managed to stay the day even with a small contribution at the end. There were some leaflets there about the 'speaking out' project I didn't know what it entailed but I filled it in.

From the wellbeing brochure I also went on a 3 week confidence course with the SAFE project. SAFE was something very special to me and I attended various courses which helped increase my confidence and assertiveness. I went onto become a volunteer for SAFE.

So where am I now? Well, I don't see the psychiatrist anymore as I am doing well. I am part of the Unllias 'Speaking Out' service and carer involvement project and through this I attend the regular project meeting. I am also part of the MINDFUL editorial group. Last November I did an intensive Train the Trainer course and now I co-facilitate with Unllias. I facilitate my own flower workshop in the wellbeing brochure and other



mental health organisations within Flintshire.

Once a week I demonstrate flower arranging or encaustic art at the craft consortium. I also volunteer regularly at the local animal rescue.

I used to be scared of everyone and everything, but I'm not now. I still experience anxiety every day but I no longer let it limit me anymore.

It maybe difficult to try new things but it's worth setting measurable goals to give things a go. Don't set too high expectations of yourself, and take one step at a time to reach your goals.

article by *Danielle Humphreys*

Could You Reduce Your Water Bill?



Contact us today to find out about the range of tariffs we offer which could help reduce your water bill. These include:

HelpU

Our HelpU scheme will cap your water and sewerage bill at £197.37 and is available to customers where the total household income is £15,000 a year or less.

WaterSure Wales

Our WaterSure Wales scheme is available to our customers who have a water meter fitted. It helps households on a low income with either a large family or a family member with a certain medical condition. Your annual charges will be capped at £319.95.

Water Direct

Our Water Direct scheme takes away the hassle of paying your bills. It allows those customers who receive certain benefits and are currently in arrears to pay directly through their benefits. If you sign up we will even reduce your bill by £25!

Customer Assistance Fund

If you have arrears with us, our Customer Assistance Fund could help. This scheme not only helps you pay your ongoing current charges, but helps you pay off your arrears at the same time. If you commit to a payment plan for 6 months we will pay off half of your arrears, if you then pay for a further 6 months we will pay off the remaining balance of your arrears.

Contact us now and you could soon start benefitting from the help we can give you.

Call

0800 0520145, Opening hour 8am -8pm (Monday – Friday) and 8.30am – 1.30pm on Saturday.

Email

water.enquiries@dwrcymru.com

Online

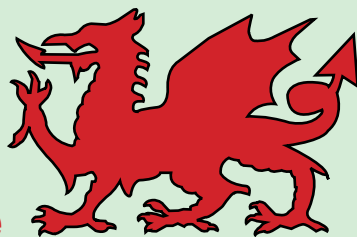
dwrcymru.com/money

If your organisation seeks and implements ways to maximise income, provides financial assistance or gives practical support and advice to clients, please contact us to become a trusted partner and receive our free training or awareness session. To find out more please contact Tracey.jones@dwrcymru.com



WELSH CONVERSATION GROUP

Meet every Wednesday at 12.30pm
at Deeside Enterprise Centre
Rowley's Drive
Shotton



Everyone Welcome

First Session
5th September
to
Final Session
19th December

Next Steps Volunteering Course

“Going out and volunteering sounds simple, but many people don’t volunteer because they don’t know where to start”. It was this simple sentence that formed the idea for the Next Steps Volunteering Course. Next Steps found that many people wanted to volunteer, but didn’t know where they could volunteer, if they could volunteer, or if they had the skills and confidence.

There are many benefits to volunteering, including making a difference to the lives of others, increasing confidence and self esteem, gaining new

skills, knowledge and experience and meeting new people and making new friends.

The accredited course looks at all this, and more, over a 6 week period. The course looks at what a voluntary organisation is, your skills and interests and which volunteering role would suit you. It is also gives you the tools to look after your own health and wellbeing whilst volunteering, with sessions on Dealing with Difficult Situations, Wellness Tools and Communication. The course also includes a visit to FLVC (Flintshire Local Voluntary Centre) in Corlan, Mold, to meet the team and find out more about the wide variety of volunteering roles available.

The course is now in its 4th run, with all 8 set to complete the course in August. 17 people

have completed the course, with 9 people going on to volunteer, 1 returning to college to study for their A-Levels and, 3 people going on to paid work. One volunteer has said “I gained back my confidence and have been able to become a volunteer. My overall experience volunteering has been excellent. I have renewed my skills and I enjoy supporting people, teaching them new skills and it’s nice when you see them smile”



Drop In to Flint!

Hi, I’m Pat and every Friday you’ll find me at the Flint Drop-in. I did not go out for almost 2 years and felt isolated, but now I cannot wait for Fridays to come around.

The Drop-in is a social hub where I feel I belong, it is my time to unwind and join the rest of the gang, everyone is very welcoming and it’s just a great place to be yourself.

There are many activities on offer such as table tennis, bowls, scrabble, bingo, board games and painting. There really is something for everyone, including those less mobile such as myself.

Of course, should you prefer, you can just drop in for a chat.

Refreshments are provided, such as tea, coffee, cakes, toast and crumpets and often someone is playing a guitar in the background which is very relaxing.

Please do come and try the Drop-in at Flint. You will be made to feel welcome by staff, volunteers and service users alike and Did I mention the cake?!



Theatr Clwyd Opportunities

As part of Flintshire's plan to encourage Partnership working with third sector organisations, Communities and existing resources I went along to a meeting with Annie Dayson who is Theatr Clwyds Arts and Wellbeing Manager. She made the group feel very welcome and we each gave an overview of the service we provided. It was clear to see that Annie felt strong about creating a good working relationship and came up with a number of options for us to tap into. I came away from the meeting feeling that we were going to help provide lots of new opportunities for the people we support. It was agreed that a few of us would meet again and be introduced to other members of her team who could help with

some of the activities we had discussed.

I passed on contact details to both Next Steps and Social Links and both teams made arrangements to meet up. Next Steps are very excited to be working in partnership with Theatr Clwyd for volunteering opportunities. Theatr Clwyd are currently re-developing their volunteering programme and are hopeful that this should be available in the autumn. We are looking forward to being able to offer the people we work with unique volunteering opportunities to gain experience and new skills both front of house and backstage. Social Links are now organising a bi-monthly gathering at the theatre to see a stage production or a film. They are organising a back stage tour so that the group have the exciting opportunity to see what happens behind the scenes

and also to meet some cast members.

The theatre group has become increasingly popular and is a brilliant way for people to try something new, rekindle a hobby and socialise while meeting new people.

They are now planning to book their Christmas night out at the Pantomime on Thursday 13th December. The tickets to see Dick Whittington are £21 each, if anyone would like to come along please contact Laura at Social Links for more information on

01244 810185.



article by
Joceline Vaughn-Thomas

.....

Growing Places Open Day 2018



A fantastic time
was had by all!

Tudalen 44

North Wales Suicide and Self –Harm Prevention Strategic Plan

Each year in Wales between 300 and 350 people die from suicide – this is about three times the number of people killed in road accidents. In 2015 the Welsh Government published a document called Talk to Me 2 which sets out strategic aims and objectives to reduce and prevent suicide and self-harm in Wales over the period 2015-2020.

The 6 objectives are set out as follows:

1. To further improve awareness, knowledge and understanding of suicide and self -harm amongst the public, individuals who frequently come into contact with people at risk of suicide and self -harm and professionals in North wales.
2. To deliver appropriate responses to personal crises, early intervention and management of suicide and self- harm.
3. To provide information and support for those bereaved or affected by suicide and self-harm.
4. To support the media in responsible reporting and portrayal of suicide and self –harm.
5. To reduce access to the means of suicide.
6. To continue to promote and support learning, information and monitoring systems and research to improve understanding of suicide and self-harm in North Wales and guide action.



In response to these objectives, an action plan has been developed by a sub group of the North Wales and Powys Suicide and Self Harm Prevention Group. This is a multi-agency working group made up of representatives from the NHS, Local Authorities, Police, Network Rail, HM Coroner and Third sector organisations. Feedback from the Strategy Launch which was held on 21st February 2018 was given consideration and incorporated into the delivery plan.

The sub-group has been meeting regularly to put actions in place to meet the objectives. The aim is for further sub-groups to be established for each Objective, which can then feed in to the health board's LITs (Local Implementation Teams). The Chair, Dr Gwenllian Parry, will be arranging separate meetings outside the main meeting to discuss progress made by each sub-group from September this year.

Each Objective has multiple tasks involved but here as an example is an overview of the work being undertaken for Objective 1. The Objective is "To Develop a training framework for the training of professionals and individuals who come into contact with people at risk of suicide and self -harm including the general public". The sub-group have agreed that this should include the use of Recovery Education Programmes (such as the Flintshire Learning for Recovery and Wellbeing Programme) being developed throughout North Wales, to deliver training to carers or anyone affected by mental health issues. Other partners should be involved, such as schools, universities and other educational establishments. Generally there should be a focus on better information being made available for the general public on Suicide and Self-Harm. Also the aim is to promote Health and Social Care employees awareness and improve their knowledge of where to go for emotional support within their own workplace.

A copy of the Action Plan is available at www.nhs.uk or Search for North Wales Suicide and Self-Harm Strategic Plan.



KIM INSPIRE

Mental Health Support to Women.
Contact: **01352 872189**
www.kim-inspire.org.uk
KIM4HIM men-only service



C.A.L.L

Community Advice and Listening Line
Free and confidential mental health
help line covering the whole of Wales.
Contact: **0800132737**
www.callhelpline.org.uk



Advocacy Service North East Wales

Provides an independent, confidential
and free advocacy service for people
experiencing mental health problems
living in Flintshire and Wrexham.
Contact: **01352 759332**
www.asnew.org.uk



Hafal

Hafal supports the carers of people with
a serious mental illness and also pro-
vides more intensive support to carers
and families at times of crisis.

Contact:

Karen Jones or Janet Fletcher
01244 834923
www.hafal.org



CAB (Citizens' Advice Bureau)

Provides free, confidential advice
and information on social welfare
and law.

08444 772020
www.flintshirecab.org.uk

Flintshire NEW Mind

Information and support for mental
wellbeing

Contact: **01352974430**
enquiries@newmind.org.uk
www.newmind.org.uk

Speaking Out Flintshire

Contact: **01745 827903**
www.unllais.co.uk

Round the Clock Support

116123 From any phone

www.Dewis.Cymru
Cael dewis a chymryd rheolaeth



www.Dewis.Wales
Have choice and take control

The Dewis Cymru website is THE place to go
if you want information or advice about your
well-being – or want to know how you can help
somebody else. www.dewis.wales

Drop-in information

MONDAY

Hope Church Hall

1:30pm to 3:30pm

TUESDAY

Mold, Chapel Art Centre, Tyddyn Street

10:30am to 12:30pm

WEDNESDAY

Rivertown United Reformed Church
Chester Road West, Shotton

10:30am to 12:30pm

**New
times**

FRIDAY

St Mary's Church Hall, Flint.

10:30am to 12:30pm

SATURDAY

C.A.B Offices in Connah's Quay

10:30am to 12:30pm

Mold Mind Drop-in at Wellbeing Centre,
23b Chester Street Mold

1:00pm to 4:00pm

All Welcome

Community Mental Health Teams (CMHT) Primary Care Tiers 1 & 2

Mold and Flintshire: Pwll-Glas: **01352 750252**

Deeside: Aston House: **01244 834921**

Mindful Newsletter is available on request
please contact:

Double Click Design on **01244 846411**
email: doubleclick.design@yahoo.com



Mindful

Hydref
2018

Un Cam Ar y Tro

Fy enw i yw Danielle Humphreys, ers blynyddoedd lawer rwyf wedi bod yn dioddef ag anawsterau iechyd meddwl hirbarhaol, yn bennaf, pryder cymdeithasol difrifol, PTSD ac anhwylder iselder. Roedd gen i hunanhyder isel iawn ac roeddwn yn credu'n gryf nad oeddwn i'n dda ar unrhyw beth (er gwaethaf bod yn flodwraig dalentog).

Dros y blynyddoedd rwyf wir wedi cael traferth ymdopi, heb unrhyw gefnogaeth. Dechreuodd fy siwrnai adfer tua 3 blynedd yn ôl pan es i ar gwrs hunanhyder 12 wythnos. Roeddwn yn ei weld yn hynod o anodd a'r llwyddiant mwyaf oedd bod yn yr ystafell gyda phobl eraill. Cefais wedyn fy atgyfeirio at dîm byw yn y gymuned Sir y Fflint, mae'r atgyfeiriad hwn wedi newid fy mywyd yn llwyr.

Cefais weithiwr cefnogi i weithio gyda mi a buom yn gwneud technegau amlygu ac adeiladu fy hyder, fe'm cyflwynodd i lyfryn lles Sir y Fflint a gyda'n gilydd fe edrychom edrych ar ba gysiau yr hoffwn eu gwneud. Yr un cyntaf yr es arno oedd 'delio â sefyllfaoedd

anodd' a oedd yn cael ei gynnal gan Unllais. Es ar y cwrs hwn heb fy ngweithiwr cefnogi a chefais fy nharo gan or-bryder difrifol. Fedrwn i ddim hyd yn oed cyflwyno fy hun a doedd gen i ddim hyder o gwbl.

Roedd y bobl a oedd yn hwyluso'r cwrs yn wirioneddol garedig a chefnogol ac yn gwneud i mi deimlo'n fwy cyfforddus a llwyddais i aros trwy'r dydd, gan hyd yn oed wneud cyfraniad bach ar y diwedd.

Roedd yna daflenni yno am y prosiect 'siarad allan', doedd gen i ddim syniad beth oedd o, ond fe lenwais y daflen.

O'r llyfryn lles, fe es i hefyd ar gwrs hyder 3 wythnos gyda'r prosiect SAFE. Roedd SAFE yn rhywbeth arbennig iawn i mi a mynychais amryw gysiau a helpodd i gynyddu fy hyder a'm pendantrwydd. Es yn fy mlaen i ddod yn wirfoddolwr ar gyfer SAFE.

Felly lle'r ydw i rŵan? Wel, dydw i ddim yn gweld y seiciatrydd bellach gan fy mod yn gwneud yn dda. Rydw i'n rhan o wasanaeth 'siarad allan' Unllais a'r prosiect cyfranogiad gofawyr, a thrwy hyn, rwy'n mynychu'r cyfarfod prosiect rheolaidd ac rwyf hefyd yn rhan o grŵp golygyddol MINDFUL. Fis Tachwedd diwethaf, fe wnes i gwrs hyfforddi'r hyfforddwr dwys, es erbyn hyn rydw i'n cyd-hwyluso



gydag Unllais. Rwy'n hwyluso fy ngweithdy blodau fy hun yn y llyfryn lles a sefydliadau iechyd meddwl eraill yn Sir y Fflint.

Unwaith yr wythnos, rwy'n dangos sut i drefnu blodau neu gelf annisgwyl yn y consortiwm crefftau. Rwyf hefyd yn gwirfoddoli'n rheolaidd yn y ganolfan achub anifeiliaid lleol.

Roeddwn i'n arfer bod ofn pawb a phopeth, ond dydw i ddim yn awr, rwy'n dal i ddioddef o or-bryder bob dydd ond dydw i ddim yn gadael iddo fy nghyfyngu mwyach.

Efallai ei bod hi'n anodd rhoi cynnig ar bethau newydd ond mae'n werth pennu nodau mesuradwy i roi cynnig ar bethau, peidiwch â gosod disgwyliadau rhy uchel ar gyfer eich hun, cymerwch un cam ar y tro i gyrraedd eich nodau.

Erthygl gan *Danielle Humphreys*

A Allech Chi Gostwng Eich Mesur Dŵr?



Cysylltwch â ni heddiw i ffeindio allan am yr amrywiaeth o dariffs rydym yn cynnig a allai helpu lleihau eich bil dŵr. Mae rhain yn cynnwys:

HelpU

Gallai ein cynllun HelpU arbed hyd at £190 ar eich bil dŵr a charthffosiaeth ac mae ar gael i'r cwsmeriaid hynny sydd a chyfanswm incwm cartref o £15,000 y flwyddyn neu lai.

WaterSure Cymru

Mae ein cynllun WaterSure Cymru ar gael i'n cwsmeriaid sydd a mesurydd dŵr. Mae'n helpu cartrefi ar incwm isel ac sy'n cynnwys teulu mawr, neu aelod o'r teulu sydd a chyflwr meddygol penodol. Bydd cap o £308 ar eich taliadau blyneddol.

Water Direct

Mae ein cynllun Water Direct yn cael gwared ar y drafferth o dalu eich biliau. Mae'n galluogi'r cwsmeriaid hynny sy'n derbyn budd-daliadau penodol ac sydd ar hyn o bryd mewn ôl-ddyled i dalu yn uniongyrchol drwy eu budd-daliadau. Os byddwch yn cofrestru byddwn yn hyd yn oed yn lleihau eich bil trwy £25!

Cronfa Cymorth i Gwsmeriaid

Os oes gennych ol-ddyledion gyda ni, gall cwsmeriaid sydd eisoes ag ôl-ddyledion gael help gan ein Cronfa Cymorth i Gwsmeriaid. Mae'r cynllun hwn nid yn unig yn eich helpu i dalu eich costau cyfredol parhaus, ond yn eich helpu i dalu cyfran sylweddol o'ch ôl-ddyledion ar yr un pryd. Os byddwch yn ymrwymo i gynllun taliadau am 6 mis, byddwn yn talu hannereich ôl-ddyledion, ac os byddwch yn talu am 6 mis arall, byddwn yn talu gweddill eich ôl-ddyledion.

Cysylltwch â ni nawr fel y gallwch dechrau manteisio o'r cymorth gallwn eich cynnig.

Ffoniwch:

0800 0520145, oriau agor 8am – 8pm (Llun-Gwener) a 8.30 am – 1.30 pm ar ddydd Sadwrn.

e-bost:

water.enquiries@dwrcymru.com

ar-lein:

dwrcymru.com/money

Os yw eich sefydliad yn ceisio ac yn gweithredu ffyrdd o wneud y mwyaf o incwm, yn darparu cymorth ariannol neu yn rhoi cymorth a chyingor ymarferol i gleientiaid, cysylltwch â ni i ddog yn bartner dibynadwy ac yn derbyn ein hyfforddiant am ddim neu sesiwn ymwybyddiaeth. I gael gwybod mwy, cysylltwch â Tracey.jones@dwrcymru.com

GRŴP SGWRSIO CYMRAEG

Cyfarfod bob Dydd Mercher am 12.30pm yng Nghanolfan Fenter Glannau Dyfrdwy Rowley's Drive, Shotton, CH5 1TP

Croeso i bawb!



**sesiwn cyntaf
Medi 5ed
to
Sesiwn olaf
Rhagfyr 19fed**

Cwrs Gwirfoddoli Next Steps

“Mae mynd allan a gwirfoddoli'n swnio'n syml, ond nid yw llawer o bobl yn gwirfoddoli oherwydd nad ydynt yn gwybod ble i ddechrau”. Y frawddeg syml hon ffurfiodd y syniad ar gyfer Cwrs Gwirfoddoli Next Steps. Canfu Next Steps fod llawer o bobl eisiau gwirfoddoli, ond nid oeddent yn gwybod lle gallent wirfoddoli, pe gallent wirfoddoli, neu a oedd ganddynt y sgiliau a'r hyder i wneud hynny.

Mae yna lawer o fanteision i wirfoddoli, gan gynnwys gwneud gwahaniaeth i fywydau pobl eraill, cynyddu hyder a hunan-barch, ennill

sgiliau, gwybodaeth a phrofiad newydd a chwrdd â phobl newydd a gwneud ffrindiau newydd.

Mae'r cwrs achrededig yn edrych ar hyn oll, a mwy, dros gyfnod o 6 wythnos. Mae'r cwrs yn edrych ar beth yw mudiad gwirfoddol, eich sgiliau a'ch diddordebau, a pha rôl wirfoddoli fyddai'n addas i chi. Mae hefyd yn rhoi'r offer ichi i ofalu am eich iechyd a'ch lles eich hun wrth wirfoddoli, gyda sesiynau ar Ymdrin â Sefyllfaoedd Anodd, Offer Lles a Chyfathrebu. Mae'r cwrs hefyd yn cynnwys ymweliad â Chanolfan Wirfoddoli Lleol Sir y Fflint yn Corlan, Yr Wyddgrug, i gwrdd â'r tîm a darganfod mwy am yr amrywiaeth eang o rolau gwirfoddoli sydd ar gael.

Mae'r cwrs bellach yn ei bedwaredd cylch, gyda'r 8 yn

barod i gwblhau'r cwrs ym mis Awst. Mae 17 o bobl wedi cwblhau'r cwrs, gyda 9 o bobl yn mynd ymlaen i wirfoddoli, 1 yn dychwelyd i'r coleg i astudio ar gyfer eu Lefel A, a 3 o bobl wedi mynd ymlaen i waith taledig.

Dywedodd un gwirfoddolwr “Rwyf wedi ennill fy hyder yn ôl ac wedi gallu dod yn wirfoddolwr. Mae fy mhrofiad cyffredinol o wirfoddoli wedi bod yn rhagorol. Rwyf wedi adnewyddu fy sgiliau ac rwy'n mwynhau cefnogi pobl, dysgu sgiliau newydd iddynt ac mae'n braf pan fyddwch chi'n eu gweld yn gwenu”.



Galw'ch Heibio yn y Fflint!

Helo, Pat dw i, a phob dydd Gwener fe welwch fi yn y Ganolfan Galw Heibio yn y Fflint. Wnes i ddim gadael y tŷ am bron i 2 flynedd ac roeddwn yn teimlo'n unig, ond rŵan fedra i ddim aros nes i bob dydd Gwener ddod.

Mae'r Ganolfan Galw Heibio yn lle cymdeithasol lle rwy'n teimlo fy mod yn perthyn, dyma fy amser i ymlacio ac ymuno â gweddiill y gang, mae pawb yn groesawgar iawn ac mae'n lle gwych i fod yn chi eich hun.

Mae yna lawer o weithgareddau ar gael megis tenis bwrdd, bowlio, sgrabl, bingo, gemau bwrdd a phaentio.

Mewn gwirionedd mae rhywbeth i bawb, gan gynnwys y rhai sydd llai abl yn gorfforol fel fi.

Wrth gwrs, os yw'n well gennych, gallwch alw heibio i gael sgwrs yn unig. Darperir lluniaeth, fel te, coffi, cacennau, tost a chrwmpedi ac yn aml mae rhywun yn chwarae gitâr yn y cefndir sy'n eich ymlacio'n llwyr.

Dylech alw draw a rhoi cynnig ar Galw Heibio yn y Fflint. Fe gewch groeso gan staff, gwirfoddolwyr a defnyddwyr gwasanaeth fel ei gilydd a.....

Wnes i sôn wrthy ch am y cacennau?!



Cyfleoedd Theatr Clwyd

Fel rhan o gynllun Sir y Fflint i annog gweithio mewn partneriaeth â sefydliadau'r trydydd sector, cymunedau ac adnoddau presennol, es i gyfarfod ag Annie Dayson, sef Rheolwr Celfyddydau a Lles Theatr Clwyd. Rhoddodd groeso i'r grŵp ac fe roddom i gyd drosolwg o'r Gwasanaeth a ddarparwyd gennym. Roedd yn amlwg gweld bod Annie yn teimlo'n gryf ynglŷn â chreu perthynas waith dda a chafwyd nifer o opsiynau i ni ymuno â nhw. Es i ffwrdd o'r cyfarfod yn teimlo ein bod ni'n mynd i helpu i ddarparu llawer o gyfleoedd newydd i'r bobl yr ydym yn eu cefnogi. Cytunwyd y byddai rhai ohonom yn cyfarfod eto ac yn cael ein cyflwyno i aelodau eraill

o'i thîm a allai helpu gyda rhai o'r gweithgareddau yr oeddem wedi'u trafod.

Trosglwyddais y manylion cyswllt i Next Steps a'r Social Links a gwnaed y ddau dîm drefniadau i gyfarfod. Mae Next Steps yn hapus iawn o fod yn gweithio mewn partneriaeth â Theatr Clwyd am gyfleoedd gwirfoddoli yn Theatr. Mae Theatr Clwyd ar hyn o bryd gan ail-ddatblygu eu rhaglen wirfoddoli ac maent yn obeithiol y dylai hyn fod ar gael yn yr hydref. Rydym yn edrych ymlaen at allu cynnig cyfleoedd gwirfoddoli unigryw i'r bobl yr ydym ni'n gweithio gyda nhw i ennill profiad a sgiliau newydd yn y blaen tŷ a'r cefn llwyfan. Mae Social Links rŵan yn trefnu ymgasgliad bob dau fis yn y Theatr i weld cynhyrchiad llwyfan neu ffilm yn y sinema. Maent yn trefnu taith gefn llwyfan er mwyn i'r grŵp gael y cyfle cyffrous i weld beth sy'n

digwydd y tu ôl i'r llen a'r cyfle i gwrdd â rhai aelodau o'r cast. Mae'r grŵp theatr wedi dod yn gynyddol boblogaidd ac mae'n ffordd wych i bobl roi cynnig ar rywbeth newydd, adfywio hobi a chymdeithasu wrth gwrdd â phobl newydd.

Maent bellach yn bwriadu archebu eu noson Nadolig allan yn y Pantomeim ar ddydd Iau 13 Rhagfyr. Mae'r tocynnau i weld Dick Whittington yn £21 yr un os hoffai unrhyw un ddod draw cysylltwch â Laura yn Social Links am fwy o wybodaeth.

01244 810185.



Erthygl gan
Jacqueline Vaughn-Thomas

Diwrnod Agored Growing Places 2018



Cafodd pawb
amser gwych!

Cynllun Strategol Atal Hunanladdiad a Hunan-Niweidio Gogledd Cymru

Bob blwyddyn yng Nghymru mae rhwng 300 a 350 o bobl yn marw o hunanladdiad - mae hyn tua thair gwaith y nifer o bobl a laddwyd mewn damweiniau ffordd. Yn 2015 cyhoeddodd Llywodraeth Cymru ddogfen o'r enw Siarad â Mi 2 sy'n nodi nodau ac amcanion strategol i leihau ac atal hunanladdiad a hunan-niweidio yng Nghymru dros y cyfnod 2015-2020.

Nodir y 6 amcan fel a ganlyn:

1. Amcan 1: Gwella ymhellach ymwybyddiaeth, gwybodaeth a dealltwriaeth am hunanladdiad a hunan-niwed ymhlith y cyhoedd, unigolion sy'n dod i gysylltiad yn aml â phobl sydd mewn perygl o gyflawni hunanladdiad a hunan-niwed a gweithwyr proffesiynol yng Ngogledd Cymru.
2. Darparu ymatebion priodol i argyfyngau personol, ymyriadau cynnar a rheolaeth ar hunanladdiad a hunan-niwed.
3. Gwybodaeth a chymorth i'r rhai sydd wedi cael profedigaeth neu yr effeithiwyd arnynt o ganlyniad i hunanladdiad a hunan-niwed.
4. Rhoi cymorth i'r cyfryngau fod yn gyfrifol wrth bortreadu ac adrodd ar hunanladdiad ac ymddygiad hunanladdol.
5. Lleihau mynediad at bethau y gellir eu defnyddio i gyflawni hunanladdiad.
6. Parhau i hybu a chefnogi dysgu, systemau gwybodaeth a monitro ac ymchwil i wella ein dealltwriaeth am hunanladdiad a hunan-niwed yng Ngogledd Cymru ac arwain camau gweithredu.

Mewn ymateb i'r amcanion hyn, mae is-grŵp o Grŵp Atal Hunanladdiad a Hunan-niwed Gogledd Cymru a Phowys wedi datblygu cynllun gweithredu. Gweithgor aml-asantiaeth yw hwn

sy'n cynnwys cynrychiolwyr o'r GIG, Awdurdodau Lleol, yr Heddlu, Network Rail, Crwner EM a sefydliadau'r Trydydd Sector. Rhoddwyd ystyriaeth i'r adborth o'r Lansiad Strategaeth a gynhaliwyd ar 21 Chwefror 2018 a'i ymgorffori yn y cynllun cyflawni.

Mae'r is-grŵp wedi bod yn cwrdd yn rheolaidd i roi camau ar waith i fodloni'r amcanion. Y nod yw sefydlu is-grwpiau pellach ar gyfer pob Amcan, a all wedyn fwydo i Dimau Gweithredu Lleol y bwrdd iechyd.

Bydd y Cadeirydd Dr Gwenllïan Parry yn trefnu cyfarfodydd ar wahân y tu allan i'r prif gyfarfod i drafod cynnydd a wnaed gan bob is-grŵp o fis Medi eleni.

Mae gan bob Amcan dasgau lluosog yn gysylltiedig â nhw, ond dyma enghraifft fel trosolwg o'r gwaith sy'n cael ei wneud ar gyfer Amcan 1. Yr Amcan yw "Datblygu fframwaith hyfforddi ar gyfer hyfforddi gweithwyr proffesiynol ac unigolion sy'n dod i gysylltiad â phobl sydd mewn perygl o hunanladdiad a hunan-niweidio gan gynnwys y cyhoedd". Mae'r is-grŵp wedi cytuno y dylai hyn gynnwys defnyddio Rhaglenni Addysg Adferiad (megis Rhaglen Dysgu ar gyfer Adfer a Lles Sir y Fflint) sy'n cael eu datblygu ledled Gogledd Cymru, i ddarparu hyfforddiant i ofalwyr neu unrhyw un sy'n cael ei heffeithio gan faterion iechyd meddwl. Dylai partneriaid eraill fod yn gysylltiedig, fel ysgolion, prifysgolion a sefydliadau addysgol eraill. Yn gyffredinol, dylai fod ffocws ar sicrhau bod gwybodaeth well ar gael i'r cyhoedd ar Hunanladdiad a Hunan-niwed. Y nod hefyd yw hybu ymwybyddiaeth gweithwyr lechyd a Gofal Cymdeithasol a gwella eu gwybodaeth o ble i fynd am gefnogaeth emosiynol yn eu gweithle eu hunain.

Mae copi o'r Cynllun Gweithredu ar gael yn www.nhs.uk neu Chwiliwch am Gynllun Strategol Atal Hunanladdiad a Hunan-niweidio Gogledd Cymru.





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Tudalen 52

Gwybodaeth Canolfannau galw heibio

DYDD LLUN

Neuadd Eglwys yr Hôb

1:30pm tan 3:30pm

DYDD MAWRTH

Canolfan Gelf y Capel, yr Wyddgrug,
Stryd Tyddyn

10:30am tan 12:30pm

DYDD MERCHER

Eglwys Ddiwygiedig Unedig Rivertown
Chester Road West, Shotton

10:30am tan 12:30pm

Amser
Newydd

DYDD GWENER

Neuadd Eglwys y Santes Fair, Fflint.

10:30am tan 12:30pm

DYDD SADWRN

Swyddfeydd Canolfan Cyngor ar Bopeth
yng Nghei Connah

10:30am tan 12:30pm

Canolfan Galw Heibio Mind yr Wyddgrug
yn y Ganolfan Les,

23b Stryd Caer, yr Wyddgrug

1:00pm tan 4:00pm

Croeso i Bawb

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ar ran

Cyngor Sir y Fflint



Eitem ar gyfer y Rhaglen 5



SOCIAL & HEALTH CARE OVERVIEW SCRUTINY COMMITTEE

| | |
|------------------------|--|
| Date of Meeting | Thursday 4 October 2018 |
| Report Subject | North Wales Learning Disability Strategy |
| Cabinet Member | Cabinet Member for Social Services |
| Report Author | Chief Officer, Social Services |
| Type of Report | Strategic |

EXECUTIVE SUMMARY

The Learning Disability Strategy sets out the vision for health and social services for people with learning disabilities in North Wales. It includes information about the needs of the population and what matters to them, what we want to see change and how we will put the strategy into action. Many people have been involved in writing the strategy including people with learning disabilities; parents/carers; local authority and health staff from children's and adults' services across the region; and, third and independent sector providers of learning disability services. The strategy is due to go to the Regional Partnership Board for approval in November after which it will go through the approval processes of the six local authorities and the health board.

RECOMMENDATIONS

| | |
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| 1 | To consider and comment on the North Wales Learning Disability Strategy. |
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REPORT DETAILS

| 1.00 | EXPLAINING THE NORTH WALES LEARNING DISABILITY STRATEGY |
|------|--|
| 1.01 | The Social Services and Well-being (Wales) Act 2014 includes a statutory duty for Regional Partnership Boards to prioritise the development of services in relation to people with learning disabilities. This is a priority in the North Wales Regional Plan (Area Plan) produced by the Regional Partnership Board. |
| 1.02 | The North Wales Learning Disability Strategy will set out how we will work towards integrated learning disability services in North Wales. It is being developed jointly by Betsi Cadwaladr University Health Board (BCUHB) and the six North Wales councils. |
| 1.03 | <p>Our vision for North Wales is that people with learning disabilities will have a better quality of life; living locally where they feel 'safe and well', where they are valued and included in their communities and have access to effective personal support that promotes independence, choice and control. The strategy is based around what people have told us matters to them:</p> <ul style="list-style-type: none"> • having a good place to live • having something meaningful to do • friends, family and relationships • being safe • being healthy • having the right support <p>Within each of these areas we include: the needs of people with profound and multiple learning disabilities; and, support through changes in life from early years to ageing well, including the needs of older carers and the transition from children's to adult's services. We are committed to strengthening Welsh language services and providing an active offer through the Mwy na geiriau/More than just words framework.</p> |
| 1.04 | The strategy includes information about what we know about the population, current services and what we want to see change. Some of the key findings of the needs assessment are that there around 810 children with a severe or profound learning difficulty and 2,900 adults with learning disabilities receiving services in North Wales. The number of people with learning disabilities needing support is increasing and people with learning disabilities are living longer. These trends are likely to continue. There are also an increasing number of older carers (including parents and family) providing care and support for people with learning disabilities. People with learning disabilities tend to experience worse health, have greater need of health care and are more at risk of dying early compared to the general population. There are likely to be more young people with complex needs needing support. |
| 1.05 | To achieve our vision and provide services based on what matters to people (a good place to live, something meaningful to do and so on) we have planned five work packages that will set out <i>how</i> we will change things in order to achieve good lives for people with learning disabilities. The work packages will take an asset-based approach to build on the skills, networks and community resources that people with learning disabilities already have. They will be co-produced with people with learning disabilities and their |

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| | parents/carers so we share power and responsibility for making the changes. We will also work closely with staff in the six local authorities and the health board to improve communication and understanding of the reasonable adjustments that people with learning disabilities may need to access health care and other public services. The key to achieving our vision will be to work with local communities to make sure people with learning disabilities are truly valued and included in their communities. |
| 1.06 | <p>The five work packages proposed are:</p> <ul style="list-style-type: none"> • Integrated structures: making sure health and social services work better together to support people with learning disabilities. • Workforce development: making sure staff know how to communicate well with people with learning disabilities in Welsh or English and can make changes to support them well. This will help people get the health care they need. • Commissioning and procurement: work with other organisations to make sure we have the types of housing and support people need. • Community and culture change: work with the local community to make sure people with learning disabilities can access lots of different activities and meet new people if they want to. Help more people with learning disabilities to get paid jobs. • Assistive technology: Find ways to use technology like alarms and mobile phones to help people be more independent. |

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| 2.00 | RESOURCE IMPLICATIONS |
| 2.01 | Putting the strategy into action has staff and financial resource implications for the six local authorities and BCUHB. The aim of the strategy to improve the way we use our resources but there is likely to be a need for additional resources initially to manage the project and to deliver the work packages. These resource implications will be prepared in detail as part of the development of the five work packages. We have submitted a bid to the Welsh Government transformation fund to ask for support with these additional costs. |

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| 3.00 | CONSULTATIONS REQUIRED / CARRIED OUT |
| 3.01 | <p>The strategy was based initially on findings from the consultation carried out as part of the population assessment and regional plan. In addition we consulted using:</p> <ul style="list-style-type: none"> • An online questionnaire and easy read questionnaire circulated widely to staff, partner organisations, the citizen's panel, service users and other members of the public between April and July 2018. We received 175 responses. • Discussion groups and interviews with children, young people and adults with learning disabilities, parents/carers and parents with learning disabilities. This element was led by the North Wales Citizen's Panel. • Consultation events for service providers and local authority and health |

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| | <p>staff. We had around 60 providers and over 100 staff attend the events. A full consultation report is available.</p> |
| 3.02 | <p>The strategy has been written based on the findings of the consultation and the draft strategy is now being shared widely for further comments. This includes:</p> <ul style="list-style-type: none"> • A joint meeting of members of the North Wales Learning Disability Partnership, Managers of Services for Disabled Children Group, representatives from BCUHB from children’s and adults services and representatives from Additional Learning Needs Education services. • Consultation with representatives from Public Health Wales, North Wales Regional Equality Network, Supporting People, Violence Against Women, Domestic Abuse and Sexual Violence, Welsh Government’s Improving Lives Programme and a lead for primary care services in BCUHB. • Around 280 people on the mailing list for the project including service providers, staff and members of the public. |
| 3.03 | <p>The draft strategy has also been or will be going to the following regional groups before approval by the six local authorities and the health board:</p> <ul style="list-style-type: none"> • BCUHB Strategy, Partnerships & Population Health Committee • BCUHB Stakeholder Reference Group • North Wales Adult Services Heads (NWASH) • North Wales Heads of Children’s Services (NWHoCS) • North Wales Leadership Group • Regional Partnership Board <p>The final draft of the strategy is due to go to the Regional Partnership Board for approval in November 2018 after which it will go through the approval processes of the six local authorities and the health board.</p> |

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| 4.00 | RISK MANAGEMENT |
| 4.01 | <p>The risk that the level of integration will not meet Welsh Government requirements under the Social Services and Well-being (Wales) Act 2014. To mitigate we will take a partnership approach to the project.</p> |
| 4.02 | <p>The risk that the process won’t involve service users, parents and carers in a meaningful and co-productive way. To mitigate we will embed participation in the process and consider commissioning a specialist organisation to support. Documents will be produced in easy-read format where possible.</p> |
| 4.03 | <p>A well-being impact assessment has been written for the strategy which includes anti-poverty, environment and equalities issues.</p> |

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| 5.01 | Appendix 1 - Draft North Wales Learning Disability Strategy |
| 5.02 | Appendix 2 - Draft North Wales Learning Disability Strategy Consultation Report |

| | |
|-------------|---|
| 6.00 | LIST OF ACCESSIBLE BACKGROUND DOCUMENTS |
| 6.01 | <p>North Wales Population Assessment North Wales Regional Plan</p> <p>Contact Officer: Neil Ayling Telephone: 01352 704511 E-mail: neil.j.ayling@flintshire.gov.uk</p> |

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| 7.00 | GLOSSARY OF TERMS |
| 7.01 | <p>(1) Active offer: providing a service in Welsh without someone having to ask for it.</p> <p>(2) Asset-based approach: bringing people and communities together to achieve positive change using their own knowledge, skills and lived experience around the issues they encounter in their own lives. It is about recognising the strengths in individuals and a community and using those to solve problems instead of focussing on the deficits or problems in a community.</p> <p>(3) Co-production: An asset-based approach that enables people providing and people receiving services to share power and responsibility, and work together in equal, reciprocal and caring relationships.</p> <p>(4) Integrated services: for example, social services and health services working more closely together so that people receive a 'seamless service', where they don't experience delays or fall through the gaps between services because of the way the services are set up.</p> <p>(5) Learning Disability: The term is used to describe an individual who has a significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence); and / or a reduced ability to cope independently (impaired adaptive functioning); which started before adulthood and has a lasting effect on development.</p> <p>(6) Regional Partnership Board: Regional Partnership Boards were set up in each region by the Social Services and Well-being (Wales) Act 2014 to drive the strategic regional delivery of social services in close collaboration with health. In North Wales the board currently meets monthly and membership includes the local authorities, the health board, third sector representatives, service user and carer representative as well as co-opted members from the North Wales Police, Welsh Ambulance Services Trust, and North Wales Fire Service. More information is available at:</p> |

<https://www.northwalescollaborative.wales/regional-partnership-board/>

(7) **Statutory duty:** this is something the council must do by law.

(8) **Work package:** this is a list of tasks that need to be carried out as part of a larger project. The work package includes details of what needs to be done, who will do it and by when.



CYDWEITHREDFA GWELLA GWASANAETHAU
GOFAL A LLESIANT **GOGLEDD CYMRU**

NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Learning Disability Strategy

Work in progress

2018 to 2023



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Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
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Version control

Please note: This draft document is a work in progress. Please send any comments to sarah.bartlett@denbighshire.gov.uk by **26 September 2018**.

| Version | Date | Changes | Author |
|---------|----------|--|--------|
| 0.10 | 05/09/18 | Added findings from the consultation and restructured. Shared for further feedback. | SB |

An Easy-Read version of the draft strategy is available.

Draft

Contact us

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People with learning disabilities will have a better quality of life; living locally where they feel 'safe and well', where they are valued and included in their communities and have access to effective personal support that promotes independence, choice and control.

(Mobius UK, 2008)

Our vision for North Wales

The strategy promotes the principles of the Social Services and Well-being (Wales) Act 2014.

- **Voice and control:** putting the individual and their needs at the centre of their care and giving them a voice in and control over reaching the outcomes that help them achieve well-being.
- **Prevention and early intervention:** increasing preventative services within the community to minimise the escalation of critical need.
- **Well-being:** supporting people to achieve their own well-being and measuring the success of care and support.
- **Co-production:** encouraging individuals to become more involved in the design and delivery of services.

In the strategy we focus on how health and social care services can work better together and look at the areas people have told us matters to them:

- having a good place to live
- having something meaningful to do
- friends, family and relationships
- being safe
- being healthy
- having the right support

Within each of these areas we include:

- the needs of people with profound and multiple learning disabilities; and,
- support through changes in life from early years to ageing well, including the needs of older carers and the transition from children's to adult's services.

We are committed to strengthening Welsh language services and providing an active offer through the Mwy na geiriau/More than just words framework.

As a long term aim to provide the best quality services to everyone in North Wales we aim to integrate services across the region over the next 10 years.

Draft

Introduction

Support for people with learning disabilities is a priority in the [North Wales Regional Plan \(Area Plan\)](#) based on what people told us was important to them as part of the [population assessment](#) produced by the [Regional Partnership Board](#).

The Social Services and Well-being (Wales) Act 2014 includes a legal duty for Regional Partnership Boards to prioritise the integration of services in relation to people with learning disabilities (Welsh Government, 2015).

This strategy sets out how we will work towards integrated learning disability services in North Wales. It has been developed jointly by the six North Wales councils and Betsi Cadwaladr University Health Board (BCUHB) supported by Public Health Wales.

About the strategy

The strategy focusses on the needs of children, young people and adults with learning disabilities in North Wales. It also includes the needs of autistic people who also have a learning disability. The strategy sits alongside other North Wales strategies and programmes including:

- The [North Wales Together for Mental Health Strategy](#)
- The [North Wales Integrated Autism Service](#)
- The North Wales Carers Strategy [\[add link\]](#)
- The work of the Children's Transformation Group as part of the Regional Partnership Board's children and young people's work-stream. This includes a priority for children and young people with complex needs.
- Additional Learning Needs strategies and plans
- Local Housing Strategies

What do we mean by the term *learning disability*?

- a) The term *learning disability* is used to describe an individual who has:
 - a significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence); and / or
 - a reduced ability to cope independently (impaired adaptive functioning); which started before adult-hood and has a lasting effect on development (Department of Health, 2001).
- b) The term *learning difficulty* is used in education as a broader term which includes people with specific learning difficulties such as dyslexia (Emerson and Heslop, 2010).

What do we mean by the term *profound and multiple learning disabilities* (PMLD)?

The term *profound and multiple learning disabilities* (PMLD) is used to describe a people with more than one impairment including a profound intellectual impairment (Doukas et al., 2017). It is a description rather than a clinical diagnosis of individuals who have great difficulty communicating and who often need those who know them well to interpret their responses and intent. The term refers to a diverse group of people who often have other conditions including physical and sensory impairments or complex health needs.

What do we mean by the term *autism*?

The term *autism* is used to describe a lifelong developmental condition that affects how a person communicates with, and relates to, other people. Autism also affects how a person makes sense of the world around them. It is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. About 50% of autistic people also have a learning disability.

What do we mean by the terms *parents and carers*?

We use the term *parents* to mean those who bring up children including mothers and fathers, foster carers and adoptive parents, step-parents and grandparents.

We use the term *carers* to mean unpaid carers of all ages who look after family members, friends, neighbours or others because of a learning disability.

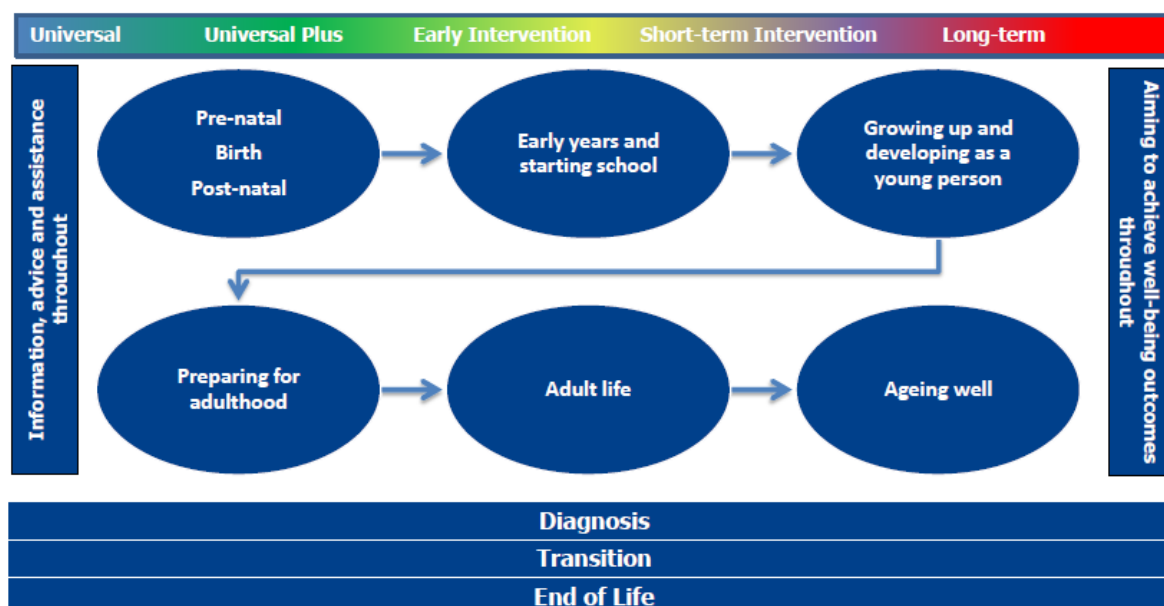
A *parent carer* is a parent or guardian who has additional duties and responsibilities towards their child because their child has an illness or disability. Parent carers will often see themselves as parents rather than carers, but they may need additional services to meet the needs of their child.

The social model of disability

The strategy is based on the social model of disability, which recognises that disabled people are people with impairments who are disabled by their environment. We use the term *learning disability* in this strategy as it was the preferred term of the people with learning disabilities that we spoke to and it is widely recognised and used. We acknowledge that this language may not reflect fully the principles of the social model and that people have different opinions about the language they prefer to describe themselves that can change over time. The debate will be welcome and hopefully helps us towards a common understanding about the use of language.

Whole system, lifespan pathway for producing good lives

The strategy takes a life span approach to Learning Disability Services based on the model below (National Commissioning Board, 2017). The model highlights the importance of pathways that move people from universal services to interventions and back again as well as the need to achieve well-being outcomes and provide information, advice and assistance throughout the pathway. Issues around diagnosis, transition and end of life care can occur at any point in the pathway.



How we wrote the strategy

The strategy is based on the findings of the population assessment and regional plan produced by the Regional Partnership Board which both involved consultation with a wide range of people. The [Learning Disability Partnership](#) used this information to develop a set of themes for the strategy which we agreed with the [Learning Disability Regional Participation Group](#) before going out to a wider consultation about the themes, what works well at the moment and what needs to be improved. The consultation involved children, young people and adults with learning disabilities and their parents/carers, local council and health staff in children's and adults' services, third and independent sector providers, members of the North Wales Citizen's Panel and others.

Alongside the consultation we collated baseline data and research to inform the strategy and worked with a wide range of services to make sure the main messages in the strategy reflect the needs of the region and complement related strategies and plans. Throughout the process we worked closely with the [Learning Disability Regional Participation Group](#).

The consultation generated a lot of useful information which has been included in the strategy. All the reports produced have been made publically available so that they can be used to inform other work. The main consultation report brings together information about the consultation process, methods, promotion, response and findings. The reports are available here:

- North Wales Learning Disability Strategy Consultation Report [\[Add link\]](#)
- [North Wales Strategy: Local authority and health staff event 18 July 2018](#)
- [North Wales Provider Forum Event 9 April 2018](#)

The strategy is based on the principle of co-production, which is:

“An asset-based approach that enables people providing and people receiving services to **share power and responsibility**, and work together in equal, reciprocal and caring relationships” (Co-production Network for Wales).

We want to see co-production embedded at all stages of this strategy from the planning and commissioning to design, delivery and evaluation. While co-production is the aim that we are working towards it is likely to be an ongoing process of learning and experimentation. For example, while we involved a wide range people in writing this strategy, the size and scale of the project meant we used more traditional methods of consultation such as questionnaires and workshops. There are likely to be better opportunities to truly co-produce service design, delivery and evaluation as we put the strategy into action at a local level. This will mean focussing on co-production where it will make the greatest difference to people’s lives.

Background

There is a long history of successful and innovative partnership working between learning disability services in North Wales arising from the All Wales Learning Disability Strategy in the 1980s. This provided dedicated funding for community care as the staged process of closing hospitals began. It was based on the rights of people with a learning disability to an ordinary pattern of life within the community; be treated as an individual; and, have additional help and support in developing their maximum potential.

In 2008 Mobius UK were commissioned by the North Wales Social Care and Well-being Services Improvement Collaborative to suggest how services should develop so that people with learning disabilities can enjoy life as citizens in their community rather than as less than fully engaged recipients of services (Mobius UK, 2008). This work developed a [vision for learning disability services](#) in North Wales with service users and carers and made recommendations under two strands. The first was about making the most of opportunities in council strategies for communities and citizens to ensure inclusion of people with learning disabilities. The second strand relates to the joint development of services between the six local authorities and health

in ways which support greater independence and choice, including joint commissioning. It included a review of good practice in the six local authorities.

One of the outcomes of the Mobius report was the creation of the North Wales Commissioning Hub in 2012 as a partnership between the six local authorities and BCUHB. The hub built on the work of a Regional Learning Disability Manager, a jointly funded post which resulted in improved procurement and service delivery for North Wales Adult Services. The original scope for the hub was to commission care home placements (including with nursing) and residential school services for all children, young people and adults with complex needs. Regional commissioning arrangements were reviewed in 2015 and it was agreed to transfer some commissioning activities back to local authorities and focus the regional commissioning function on strategic commissioning activities.

Currently, the North Wales Commissioning Board oversee the regional commissioning work supported by a Regional Business Manager and a Commissioning/Procurement Officer based within the North Wales Social Care and Well-being Improvement Collaborative.

North Wales Learning Disability Partnership

The North Wales Learning Disability Partnership was set up to drive forward improved services based on mutual understanding across the six councils and health.

The group includes representation from:

- North Wales Head of Adult Services
- Head of Strategy Learning Disability & Mental Health Division (BCUHB)
- Six Local Authority Service Managers
- Senior Learning Disability Community Nurse (BCUHB)
- Senior Learning Disability In Patient Services Nurse (BCUHB)
- Regional Project Manager
- Psychology Clinical Lead (BCUHB)
- Psychiatry Clinical Lead (BCUHB)
- Therapy services (SALT, OT and/or Physio BCUHB)

Participation

The Learning Disability Partnership recognise the vital contribution that the learning disability community across the region can make to shape and influence the services that they receive. This means working together; informing, listening, feeding back, acting, reviewing, and making ourselves accountable to the people we are working for and with.

The Regional Participation Strategy sets out a framework for ensuring that the work of the partnership is effective and citizen-focussed and that it meets the needs of the people with learning disabilities and their families (North Wales Learning Disability Partnership, 2015b). The strategy sets out a framework for how people with learning disabilities are involved in the work of the partnership.

Learning disability participation is coordinated across the six councils and each county has its own local participation network/forum supported by advocacy. The Learning Disability Regional Participation Group (LDRPG) was been supported by a Regional Participation Officer for two years, jointly funded by the six local authorities and health. The LDRPG reviewed the model of support during 2017 and agreed to employ a person with learning disabilities with support to co-ordinate the group. The co-ordinator will be based in a third/voluntary sector organisation.

Legislation, policy and guidance

Social Services and Well-being (Wales) Act 2014

The act aims to improve the well-being of people who need care and support, and carers who need support. The act changed the way people's needs are assessed and the way services are delivered - people will have more of a say in the care and support they receive. The law also promotes a range of help available within the community to reduce the need for formal, planned support.

This strategy is based on the principles of the act and it forms part of the Regional Partnership Boards approach to meeting its legal duty to prioritise the integration of services in relation to people with learning disabilities

A Healthier Wales: our Plan for Health and Social Care

Welsh Government (2018a) have produce A Healthier Wales in response to the Parliamentary Review report (Welsh Government, 2018d). The plan set out a long term vision of a 'whole system approach to health and social care', which is focussed on health and well-being. It is based around a Quadruple aim:

- Improved population health and well-being
- Better quality and more accessible health and social care services
- Higher value health and social care
- A motivated and sustainable health and social care workforce.

There are ten national design principles to drive this change and transformation which are: prevention and early intervention, safety, independence, voice, personalised, seamless, higher value, evidence driven, scalable and transformative services.

The quadruple aim and design principles have informed the development of this strategy and the action plans.

Learning Disability Improving Lives Programme

The Welsh Government programme has developed recommendations in the areas of early years, housing, social care, health and well-being and education, employment and skills for people with learning disabilities. The review took a lifespan approach from pregnancy to end of life. The three key priorities are:

1. To reduce health inequalities – through reasonable adjustments to mainstream services and access to specialist services when needed.
2. To improve community integration, including increasing housing options closer to home; integrated social care, health and education; and, increased employment and skills opportunities.
3. To enable improved strategic and operational planning and access to services through streamlined funding, better data collection, partnership working and more training and awareness.

The programme reflects the priority areas in Prosperity for All (Welsh Government, 2017b). The Improving Lives priorities have been incorporated into this strategy.

Additional Learning Needs and Education Tribunal (Wales) Act 2018

The act will introduce the following changes.

- Introduce the term Additional Learning Needs (ALN) to replace the terms ‘special educational needs’ (SEN) and ‘learning difficulties and/or disabilities’ (LDD).
- Legislation that covers the age range 0 to 25. This will replace the two separate SEN systems covering children and young people of compulsory school age and young people in post-16 education.
- A single individual development plan (IDP) to replace the existing variety of plans for learners in schools and further education.
- Increased participation of children and young people in the planning process, so planning is something done with them rather than to them.
- High aspirations and improved outcomes. This will be the focus of the IDPs.
- A simpler and less adversarial system. The process of producing and revising an IDP should be much simpler than is currently the case with statements of SEN and should avoid the adversarial nature of the existing approach.
- Increased collaboration and information sharing between agencies. New roles are created to support this – Additional Learning Needs Coordinators in education settings; Designated Educational Clinical Lead Officers in health boards; and Early Years ALN Lead officers in local authorities.
- Avoiding disagreements and earlier disagreement resolution about the IDP or the provision it contains.

- Clear and consistent rights of appeal including a right of appeal to a tribunal where disagreements about the contents of an IDP cannot be resolved at the local level.
- A statutory ALN code to set out the duties of local authorities and other organisations responsible for the delivery of services to children and young people with ALN.
- A bilingual system where services must consider whether provision is needed in Welsh and take all reasonable steps to secure it.

Well-being of Future Generations (Wales) Act 2015

The Well-being of Future Generations (Wales) Act 2015 requires us to think about the long-term impact of our decisions, work better with people, communities and each other and to prevent persistent problems such as poverty, health inequalities and climate change.

There are four Public Services Boards (PSBs) in North Wales established by the Well-being of Future Generations (Wales) Act 2015. The purpose of the PSBs is to improve the economic, social, environmental and cultural well-being in their area by strengthening joint working across all public services in North Wales. Each PSB has a well-being assessment and a well-being plan which set out how the needs of the area and how they plan to work together to address them.

We have produced a Well-being Impact Assessment to help us consider the long-term impact of the strategy on the social, economic, environment and cultural well-being of the region, Wales and the world.

Equality and human rights

The Equality Act 2010 introduced a public sector equality duty which requires all public bodies including the council to tackle discrimination, advance equality of opportunity and promote good relations. An Equality Impact Assessment has been undertaken to identify any potential inequalities arising from the development and delivery of this strategy.

A key part of the Equality Impact Assessment is consulting with people who may be affected by the strategy and in particular people with protected characteristics. The protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race

- Religion and belief
- Sex
- Sexual orientation
- Welsh language

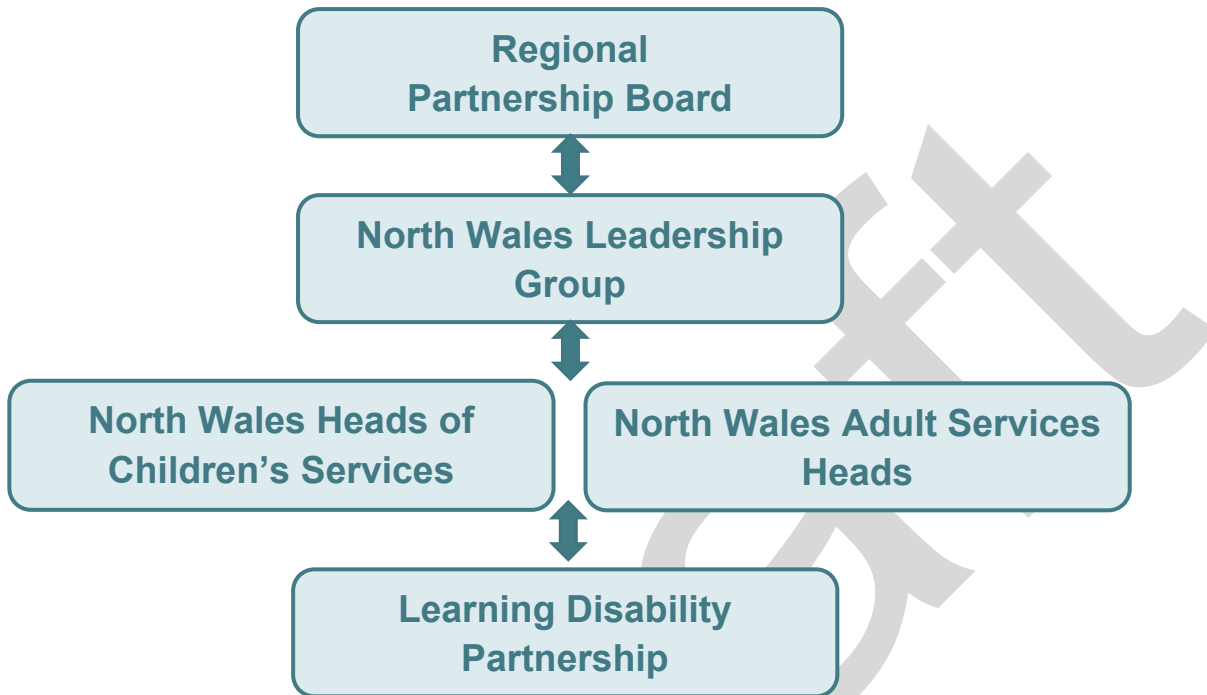
More information about the consultation and engagement that took place to develop the strategy is available in the consultation report [\[add link\]](#).

The strategy aims to tackle discrimination, advance equality of opportunity and promote good relations for people with learning disabilities. People with learning disabilities may have other protected characteristics and experience additional disadvantage because of these which we need to take account of. For example, older people with learning disabilities and people with profound and multiple disabilities and the use of the Welsh language.

The Human Rights Act 1998 sets out the basic rights we all have because we are human. They help protect people by giving public services, including health and social care services, a legal duty to treat people with fairness, equality, dignity, respect and autonomy. Services developed in response to this strategy also need to be based on the UN Convention on the Rights of the Child (UNCRC), the UN Principles for Older Persons (UNPOP) and the UN Convention on the Rights of Persons with Disabilities (CRPD).

Governance

The [North Wales Learning Disability Partnership](#) will put the strategy into action in partnership with people with learning disabilities, parents, carers and organisations who provide care and support. Governance will be provided through the groups below.



Regional Partnership Board

The Regional Partnership Board was established to meet Part 9 of the Social Services and Well-being (Wales) Act 2014. Membership includes:

- Lead members for Social Services from the six local authorities
- Directors of Social Services from the six local authorities
- Third sector representatives
- A service user and carers representative
- Health board representative
- Co-opted members from North Wales Police, North Wales Fire and Rescue Services, North Wales Ambulance Service, Local Authority Chief Finance Officer (section 151), and the Executive Director of Public Health (BCUHB)
- Head of Regional Collaboration – Business Management Support

More information about the board including a full membership list is available online here: www.northwalescollaborative.wales/regional-partnership-board

North Wales Leadership Group

The North Wales Leadership Group meets during Partnership Friday, a series of regional meetings that take place once a month. Membership includes the six Directors of Social Services and the three Area Directors from BCUHB.

North Wales Adult Services Heads (NWASH)

NWASH also meet during Partnership Friday. Membership includes the heads of Adult Services from each of the six local authorities in North Wales.

North Wales Heads of Children's Services (NWHoCS)

NWHoCs also meet during Partnership Friday. Membership includes the heads of Children's Services from each of the six local authorities in North Wales.

Draft

What we know about the population

Population assessment: what we found out

- There are around 810 children with a severe or profound learning difficulty and 2,900 adults with learning disabilities receiving services in North Wales. The actual number of people with learning disabilities may be higher.
- The number of people with learning disabilities needing support is increasing and people with learning disabilities are living longer. These trends are likely to continue. There are also an increasing number of older carers (including parents and family) providing care and support for people with learning disabilities.
- People with learning disabilities tend to experience worse health, have greater need of health care and are more at risk of dying early compared to the general population.
- There are likely to be more young people with complex needs needing support.

The full population assessment including an easy-read and audio-visual version is available online at: www.northwalescollaborative.wales/north-wales-population-assessment. The figures have been updated for this strategy and updated charts and tables are available on request.

Children and young people

There are around 102,000 pupils in North Wales, the total school-age population but there is a lack of reliable data available about the number of children and young people who have a learning disability ([see appendix 1](#)). Estimates suggest there are around 5,000 children in North Wales with a moderate learning difficulty, 650 with a severe learning difficulty and 160 with a profound learning difficulty. Council's in North Wales currently support around 700 disabled children and young people assessed as in need of care and support. Around 5,200 children aged under 16 are in receipt of Disability Living Allowance in North Wales.

Projections based on trends in the overall population show that the number of children with learning disabilities is likely to increase slightly over the next 5 to 10 years and then decrease slightly by 2035 ([see appendix 1](#)) as the overall number of children and young people decreases.

The improved survival rates of pre-term babies and increased life expectancy for children with complex disabilities are likely to lead to an increase in the number of children in need of care and support and in the number of adults with more complex needs (Doukas et al., 2017)

Adults

Table 1 below shows the number of adults with learning disabilities living in each local authority by age group in North Wales. These figures are based on the learning disability registers maintained by local councils, which only include those known to services and who wish to be registered. The actual number of people with a learning disability may be higher.

Table 1: Number of adults with learning disabilities by age, 2016-17

| | Age 16-65 | Age 65+ | Total |
|--------------|-----------|---------|-------|
| Anglesey | 270 | 40 | 310 |
| Gwynedd | 530 | 65 | 590 |
| Conwy | 440 | 55 | 500 |
| Denbighshire | 420 | 55 | 470 |
| Flintshire | 480 | 40 | 530 |
| Wrexham | 420 | 50 | 470 |
| North Wales | 2,600 | 300 | 2,900 |

Source: StatsWales, Disability Registers

Note: Data has been rounded and may not sum. The Disability Register also includes data for children under 16 but this hasn't been included here due to problems with data collection.

Since 2012-13 the number of adults aged 16 to 65 with learning disabilities has remained similar each year. The number of adults aged over 65 with learning disabilities has risen over the last five years by 23% across North Wales from around 230 in 2011-12 to 300 in 2016-17.

Projections suggest that the number of adults 18 and over with moderate learning disability is likely to increase in North Wales by around 6% by 2035 and the number of people with a moderate or severe learning disability is expected to increase by around 3% by 2035 (see [appendix 1](#)). The number of adults aged 18 to 64 is expected to decline slightly so this increase is due to an increase the number of people aged 65 and over. Due to increased life expectancy it is predicted that the number of people with learning disabilities aged 65 and over will increase by between 20% and 30% by 2035 (see [appendix 1](#)).

Parents with a learning disability

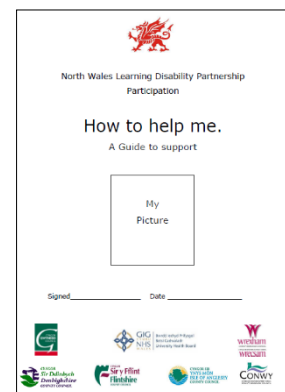
There is no data currently available on how many parents have a learning disability although this is something Welsh Government are planning to research further (Welsh Government, 2018b). A survey in England found that 7% of people with learning disabilities interviewed had children (Emerson et al., 2005). Using this figure estimates there could be around 200 parents with learning disabilities in North Wales. Just over half the parents in the survey looked after their children and other estimates suggest that between 40 and 60% of parents with a learning disability have their children taken into care (Stewart and McIntyre, 2017).

There are around 1,100 children looked after and the number is increasing year on year with a 13% increase in North Wales over the last five years compared with a 3% increase across Wales as a whole. [Improving support for parents with learning disabilities](#) may help to reduce the numbers becoming looked after.

What people have told us

Learning disability participation is coordinated across the six councils and each county has its own local participation network/forum supported by advocacy. The regional participation group have been working on the topics below (North Wales Learning Disability Partnership, 2015a).

- 1. Leisure.** People with learning disabilities said they can struggle to attend social events in the evening or have to leave early because of staff handovers or transport issues. Staff attending from the region are working on ideas to enable people to 'stay up late'. This may include local councils re-writing contracts with providers. The participation group chose to promote a 'Friendship group' currently being run in Conwy by a person with learning disabilities to be replicated across the counties
- 2. Places people live.** On the whole, people with learning disabilities in North Wales are happy with where they live. The problems they experience tend to be with the way support is provided, particularly when it is inflexible. For example one person said they had to give 24 hours' notice to access money which meant they missed out on buying the dress they wanted at the market. To help with this the group have written a book called 'How to help me' which people with learning disabilities can keep with them, to have their say and to help support staff understand how they would prefer to be supported.
- 3. Health.** There are a number of initiatives in North Wales to help improve the health of people with learning disabilities. The group have been working on how well people are aware of these and how the take-up can be improved. These include:
 - Annual health checks.
 - Learning disability nurse based in hospitals who can help people with learning disabilities communication and to complete a traffic light assessment.
 - Public health leaflets about health checks designed to be easier to read
 - Opportunities for physical exercise and healthy eating.



The group are also looking at the quality of mental health services for people with learning disabilities.

Other issues identified by the group include employment and pay for employment; keeping safe when out and about and when using the internet; and hate crime. A group aiming to reduce stigma have produced a poster and video encouraging people to report incidents of disability hate crime (Conwy Connect, 2014).

In March 2017 the group held a regional event on the theme of relationships. The purpose of the event was for people with learning disabilities to have their say about matters that are important to them. The group chose subjects that they would like to lead on which included: Lesbian, Gay, Bisexual and Transgender (LGBT); marriage; living with your partner; communication; confidence and relationships in a self-advocacy group; and, a speed dating event. The group also invited people to talk about keeping safe in general and keeping safe online. The event highlighted that attendees wanted help to meet new people, including making friends and dating, and to know more about relationships including sex, sexual health and keeping safe.

Discussion groups held to inform the population assessment highlighted the need for paid work to give people a feeling of self-worth and acknowledge their worthwhile contribution to society. People with learning disabilities also said they would like more opportunities to join in socially with groups from all areas of society, not just those arranged for those with disabilities only. Another theme was the need for good transport to access services (a particular problem in rural areas) and a number of people expressed the desire to learn to drive.

A review of person centred plans found people with learning disabilities said that the things that work well are their homes (the people they live with and the things they do at home) and leisure (getting out and about and being a part of their community). New things mentioned that work well are having access to technology, such as Wi-Fi and a laptop, and well managed medication. Whereas the things that were not working well were mobility and health (particularly aging, getting around or the increasing effects or chronic health problems) and coping with anxieties and managing behaviours. New things mentioned include problems with the housing environment (often these were little things but they were having a big impact), friendships, relationships and loneliness - people said they wanted more friendships (Denbighshire County Council, 2016).

Feedback from parents of disabled children

Feedback from engagement sessions with parents for the population assessment highlighted the following common themes:

- The time taken for assessments to take place and delays in accessing support was considered to be too lengthy. Need to “be quicker when a cry for help is given”. Support while waiting for assessments or confirmation of diagnosis was also cited as important.

- Concern about the lack of available help to care for their children, particularly for those who are full time carers and single parents, if they are ill and in the school holidays.
- Felt they needed more support to maintain their own emotional wellbeing – including extra help, respite/short-breaks, learning more coping strategies, baby sitters and support for emotional wellbeing. This was a concern when juggling work and caring for a disabled child and professionals who listen was suggested as being important. The physical and emotional impact of managing behaviour problems on parents was also significant. Including; temper, difficulties communicating and safety concerns.
- The impact of social isolation and support to get out of the home for both children and parents. Including direct payments for family outings, suitable afterschool clubs or day care was needed.
- Parents reported that it would help them to cope if there was better understanding from the wider community regarding disabilities and more acceptance of disabilities that you can't see.
- Better facilities for families of disabled children.
- More support from voluntary and charity sector.
- Issues managing their children's anxiety when in public or not in their care.

In depth interviews carried out with parents of disabled children in North Wales identified the importance of good support and information during the process of diagnosis, including the need for emotional support (Conwy County Borough Council, 2013). The study also highlighted the need for consistent, accessible support and efficient systems, for example to provide specialist equipment. Most of the families mentioned the need for carer breaks including frustrations with getting the kind of flexible breaks they need and the benefits to the whole family when it works well. Families mentioned the impact of caring on their finances and employment opportunities and the impact on siblings. They also spoke about their fears and anxieties including fears for their children's future, supporting them to be independent and what would happen when they were no longer there to care for them. Many of the families also spoke about the stigma associated with disability including their own reactions and reluctance to ask for help as well as the need to improve awareness and support from the wider society.

Feedback from disabled children

- The children talked about the difficulties that they have meeting with friends outside school time. When you are younger there are special needs play scheme, they are not suitable if you are older. The children said they would like a club where they can meet their friends.

- Some children said they found noisy environments difficult such as going into large shops, swimming pools or sports centres.
- Some children would like to go out alone but parents are worried about other children bullying or taking advantage of them.
- The children said how difficult it was for them to make decisions.
- One child said because their mobility was not good they had difficulty getting around especially going downhill. This inhibits his social and leisure activities.
- The children said that they rely on their parents to help them with the things that they find difficult and one child had a social worker who took him out.
- The children would like a greater range of activities to do outside school such as art workshops, outdoor activities, trips to activity parks and somewhere to have fun, meet friends, to do cycling music and dance.
- The teachers said that they would like more information about what is available for children now that some of the play schemes have closed down.

Feedback from staff and partner organisations

Feedback from staff highlighted the complexity and interdependency of issues facing disabled children and young people and their families, including difficulties around transition from children's services to adult's services. They also highlighted an increase in the number of disabled children with very complex needs.

A questionnaire circulated for the population assessment highlighted that people want to be treated as equal to the rest of the population, they needed help to feel part of the community and to express themselves (Isle of Anglesey County Council et al., 2016). In particular, organisations feel that there is not enough support or opportunities for people with learning difficulties to work and not enough support or opportunities for them to develop new relationships.

They also identified a lack of long term low level support for people who have learning difficulties but do not reach the threshold for a learning disability diagnosis and who are unlikely to be ever fully able to maintain a housing tenancy independently.

National consultation (CSSIW, 2016)

When asked about their needs most people spoke about their relationship with their care manager and other staff. Concerns were largely about reliability (turning up on time); dependability (doing what is promised); and availability (having a care manager in the first place).

The findings about providing effective care and support were:

- We need to improve the quality of information about the help that might be available. Concerns about the format of information – for example, too many words, small size of fonts and not enough pictures.
- Concerns about feelings of vulnerability and risk in the community.

They also identified 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.

Learning Disability Strategy Consultation

In January 2017 a meeting ‘Going Forward Together’ was held with staff and partners, facilitated by BCUHB, to inform the development of this strategy. The discussions looked at current strengths and challenges and what needed to change. The guiding principles discussed were:

- Shared responsibility to implement the legislation.
- Person first, learning disability second.
- Right support at the right time to the right people in the right place.
- No-one to experience delays in support due to disagreements between services. Shared responsibility to ‘fix it’.

In addition to the consultation findings above we asked a wide range of people for their views about what needed to be included in the strategy. Many of the findings have been incorporated within the strategy and a full report is available [\[add link\]](#).

Some of the main messages from the consultation were as follows.

- Need for real choice and control with a focus on rights and equality for people with learning disabilities. The importance of taking a person-centred approach.
- More inclusion and integration of people with learning disabilities into the wider community. Including the need for staff training about specific learning difficulties and an awareness that not all disabilities are visible. There was a lot of support for the idea that we should ‘help each other’ but there were also some concerns about the pressures this could put on people.
- The support people receive from family and providers often works well and there was praise for dedicated and committed staff. Specific services were mentioned as

working well including carer breaks, social services, health services, charities, third sector and independent organisations including advocacy services.

- Joint working between social care and health was highlighted as something that works well in some areas and something that needs to be improved in others including better information sharing systems and issues around funding.
- There were also mixed views about how well direct payments and support budgets worked for people. Some said they worked well for them and other commented that they need much more support to use them and shared difficulties of finding a direct payment worker.

The consultation also highlighted issues that can prevent people from experiencing good outcomes including:

- **Support for carers:** Carer breaks was mentioned by many people in the consultation. Some of the specific issues include a lack of short breaks for families, provision for people with more complex needs such as challenging behaviour and autism and regular and predictable provision that is open all year round. People mentioned the importance of considering the impact on families, including the needs of siblings of children with learning disabilities. Also the importance of listening to parents and supporting parents/carers to building resilience and develop coping mechanisms. People also mentioned the needs of older carers and planning for the future when they may be no longer able to provide care.
- **Funding:** There was concern about having enough funding available for services. A few people mentioned the need to work together and consider merging budgets to try and address these issues and the need to make better use of technology.
- **Transport:** People mentioned how important transport was to them for inclusion in activities including having someone who can drive them, bus passes and subsidised transport. People also mentioned the orange wallet system that helps people with using public transport.
- **Access to information:** A few people mentioned the need for more information about the services that are available, details of who is able to access support from them and availability of services in Welsh. The staff consultation highlighted the importance of promoting and developing [Dewis Cymru](#) as a source of information about the services and support available in local communities.
- **Workforce development:** People talked about the importance of training and support for staff, particularly support workers. Also the importance of training the wider workforce, such as training for GPs about the needs of people with learning disabilities and how to access community teams.

What we know about current services and what needs to change

People with learning disabilities often need support with many aspects of their lives. This support can come from their friends and families or their local community as well as from local councils, health services and/or the third sector and can include help with:

- having a good place to live
- having something meaningful to do
- friends, family and relationships
- being safe
- being healthy
- having the right support

Within each of these areas we include:

- the needs of people with profound and multiple learning disabilities; and,
- support through changes in life from early years to ageing well, including the needs of older carers and the transition from children's to adult's services.

The current spend by social services and health directly on learning disability services in North Wales is over £130 million. This does not include additional services which provide support such as housing, leisure, third and voluntary sector support and so on.

Table 2: Revenue expenditure, adults aged under 65 with learning disabilities

| | £ thousands | £ thousands |
|---|-------------|-------------|
| <i>Social services expenditure (2016-17)</i> | | |
| Supported living / community living | 36,000 | |
| Residential care placements | 20,000 | |
| Day care | 13,000 | |
| Direct payments | 8,200 | |
| Home care | 6,400 | |
| Assessment and care management | 5,800 | |
| Other services to adults aged under 65 with learning disabilities | 5,200 | |
| Nursing placements | 1,000 | |
| Total social services | | 96,000 |
| <i>BCUHB expenditure (2015-16)</i> | | |
| Mental health and learning disabilities division (including continuing health care) | 37,000 | |
| Primary care and other contracts | 590 | |
| Total BCUHB | | 38,000 |
| Total spend learning disability services | | 130,000 |

Please note this information is taken from Welsh Government returns and does not include spending on children and older people with learning disabilities because of the way the data is collected.

Local authorities also spend around £220 million of capital each year in North Wales for personal social services. This includes spending on buildings and housing related to all kinds of personal social services, not just for people with learning disabilities.

Early years

Support for parents with a learning disability is included in [the right support section](#).

We want every child with a learning disability to have the best start in life.

Diagnosis and assessments

In the consultation parents mentioned challenges around waiting for assessments, the time taken and issues around needing to wait for a certain age for an assessment. Parents also said they needed better support and understanding from professionals while waiting for an assessment. Support is also needed following a diagnosis, which may include counselling for parents.

Support for parents

Support should begin before birth with good information and support available from midwives and health visitors.

It's important that parents have access to parenting courses that are specifically geared towards parents of young children with learning disabilities. Courses need to be sensitive to the needs of parents awaiting diagnosis as a parent in the consultation said that being sent on parenting courses felt like being blamed for their child's additional needs.

Parents told us there was a need for good information and advice. This information should be joined-up so health, social care and education staff are giving the same messages. It should also be available to people early on. At one of the strategy workshops the following guide was recommended: '[A Parent's Guide: Improving the well-being of young children with learning disabilities](#)' produced in collaboration between the University of Warwick, Cerebra, Mencap, the Challenging Behaviour Foundation and parents of children with learning disabilities. There is also information available and through Family Information Services and on [Dewis Cymru](#).

Childcare and short breaks

Each local council in North Wales produced a Childcare Sufficiency Assessment in 2017, which includes an assessment of the provision for disabled children. These

highlight that in all areas there is a need for childcare for children with additional needs and the action plans set out how this will be addressed. Initiatives to support childcare for disabled children include pre-school referral or pre-school support schemes to support children with additional needs in pre-school settings; a Childcare Brokerage officer post which supports parents / carers of children with a disability to access suitable childcare and play provision; using the Welsh Government Out of School Childcare Grant to fund assisted places or 'helping hands' scheme; and, providing training for childcare staff.

Short breaks are activities for children and young people, usually occurring away from the home, that allow them to have a good time with others – peers and adults, while also giving a break to parents/carers from their caring role.

The short breaks can range from an hour or more planned activity to overnight stays with alternative carers. Some short breaks can involve the whole family having quality time together, by having assistance for trips out or leisure activities.

A report by the Children's Commissioner for Wales (2014) highlighted the importance of appropriate, accessible and good quality short breaks. The report found that the provision of short breaks is a complex matter due to different eligibility criteria and range of provision in each council and because each family has a different set of circumstances and needs. Some of the issues identified include issues around transition and support for children and young people aged 18-25 such as young people wanting to continue using the residential facility they were used to after they turn 18 and suggest continuing until they finish education. Other barriers included the accessibility of universal services, transport and awareness of the support available. The report also highlights the importance of the language used around short breaks, the perception and understanding of it among children and young people and the importance of independent advocacy. They found that some children and young people believe the main purpose of a short break is for parents/carers to have a break from them, whereas it should be for mutual benefit.

Childcare and short breaks also a priority in the Welsh Government (2018c) Improving Lives Programme:

'To ensure there is adequate childcare and short break solutions for children with a learning disability to enable families to live an ordinary life including going to work where possible.'

Early intervention

Family-focussed support is available in some areas from Flying Start and across North Wales from Families First and Team Around the Family (TAF), known as Together Achieving Change (TAC) in Wrexham.

Early intervention is also a priority in the Welsh Government (2018c) Improving Lives Programme:

- To improve life chances by building on the team around the family approach to reduce the number and impact of Adverse Childhood Experiences (ACEs) experienced by children with a learning disability.
- To reduce inappropriate use of medication and restraint through increasing the use of a range of evidence based interventions for example Positive Behavioural Support and active support to ensure early intervention of challenging behaviour and prevention where possible

Speech, language and communication needs

Speech, language and communication needs (SLCN) are common in children and young people who have other diagnoses such as an autism spectrum disorder and learning difficulties (The Communication Trust, 2010). It is estimated that around 3% of children have SLCN as part of another condition such as autism, hearing impairment, general learning difficulties; and, 1% of children have the most severe and complex SLCN which prevents them from expressing their basic needs.

A study to map the current provision of speech, language and communication support in Wales (Holtom and Bowen, 2016) looked at the continuum model for meeting SLCN below which where needs are met through actions around prevention, identification, assessment, intervention and review.

| Level | Examples |
|----------------------------|---|
| Universal (Tier 1) | Education settings and health visitors |
| Targeted (Tier 2) | Targeted intervention within education settings |
| Specialist (Tiers 3 and 4) | Speech and language therapists (SLTs), specialist advisory teachers working directly with children and supporting universal and targeted services (for example, training) |

The review identified that for this model to be effective the services needed:

- Capacity and consistency at each level including skills and knowledge; a sufficient workforce (size and funding); and clear roles and responsibilities.
- Those involved need to use the right tools such as which are effective, accessible, appropriate and implemented well.
- Those involved need to work together as no single service or person can meet a child's SLCN.

Children with complex needs

Children with complex needs are a priority for the Children's Transformation Group as part of the Regional Partnership Board's children and young people's work-stream so we have not duplicated this work in this strategy.

Early years: the change we want to see

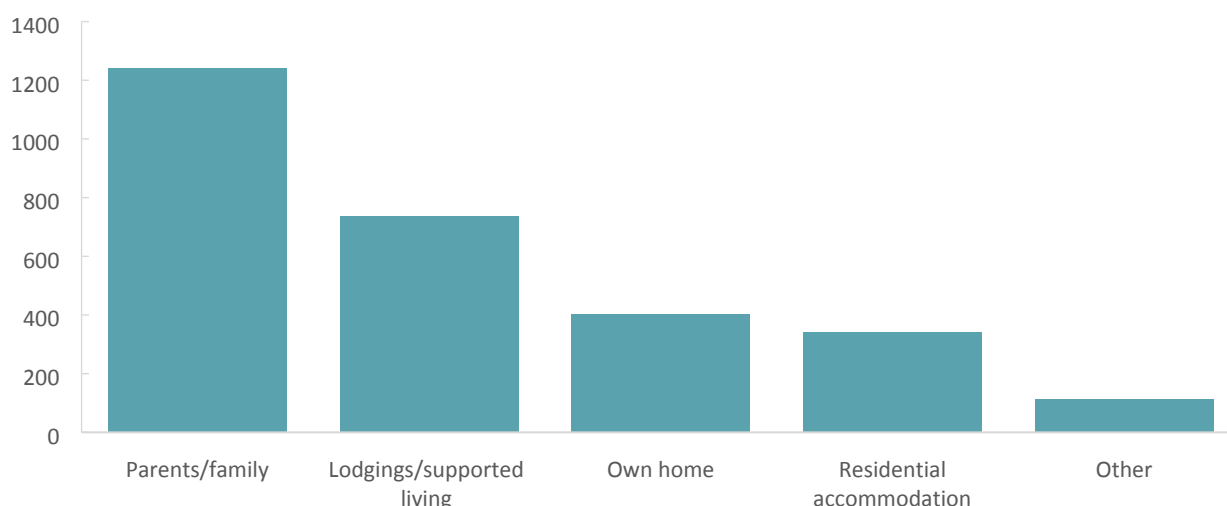
- Fewer people will fall between the gaps in services.
- Carers will have access to a range of flexible carer breaks.
- People with learning disabilities and their parents/carers will have access to good consistent information and advice.

Having a good place to live

Most children and young people with learning disabilities live with their parents/family. There is no data available showing how many children with learning disabilities live in foster placements but in total there are around 120 disabled children looked after in North Wales ([see appendix 1](#)).

Figure 1 shows that the most frequent living arrangement for adults with learning disabilities is in community placements with their parents/family.

Figure 1: Community, residential and other accommodation placements, 2016



Source: Adults receiving services at the 31st March 2016 and range of services during the year, Welsh Government

(a) The 'Other' category includes health placements and foster placements

Welsh Government is currently developing guidance in the commissioning of supported living services and regional procurement exercise is taking place for supported living providers in North Wales.

Housing for people with profound and multiple learning disabilities (PMLD)

The Raising our Sights guide to housing (Mencap and PMLD Network, 2013) says that people with PMLD have very complex housing needs including:

- **The physical environment** including adaptations, equipment and the space needed to meet the person's needs
- **The location** of the housing to allow people to remain close to family, friends and their communities
- Wherever they are living, the person will need **individualised and skilled support** for their health, social and well-being needs from appropriately trained staff.

There should be a range of options and a person-centred approach to planning to find the model of housing and care that is right for the individual. This may include supported housing, extra care housing, shared lives, residential care, home ownership and different types of tenancies.

Community based, residential services and nursing care

In North Wales there are around 1,900 adults with learning disabilities who receive community-based services, around 280 who receive residential services and around 26 who receive nursing care within a care home ([see appendix 1](#)).

The North Wales Adult Services Heads (NASH) have agreed to explore the use of the national Integrated Health and Social Care Collaborative Commissioning Programme framework agreement for younger adults (18-64 years) with mental health and learning disabilities in residential and nursing care homes.

Deprivation of Liberty Safeguards

Under the Human Rights Act everyone has a right to liberty unless a legal process has been followed. The aim of the Deprivation of Liberty Safeguards (DoLS) is to provide legal protection for vulnerable people who are deprived of their liberty, to prevent arbitrary decisions and to give rights to appeal. The safeguards apply to people who lack capacity to consent to care or treatment and are living in residential or nursing homes or hospital in-patients. There were 160 DoLS referrals made by each local authority for people with learning disabilities during 2016-17 ([see appendix 1](#)).

Out of area placements

[The numbers will need updating once the final returns are received]

Data collected for the strategy found that there were around 15 children and young people aged under 18 who were placed out of county or region. Less than five of these were placed out of county by choice, for example, because they are closer to family or because have been placed with family (Connected Person) out of county for

safeguarding reasons. Ten of the children had a severe learning disability. The most common need was around challenging behaviour followed by autism, physical disability and hearing impairment. Most of the out of county placements were in foster placements or specialist residential schools. The most common placement length was for between 2 to 4 years with less than 5 placements for over 10 years.

For adults there were around 130 people placed out of county or region, with 10 of these placed out of county by choice, for example to be closer to family. The numbers are split fairly equally between people with a severe, moderate or mild learning disability. Around half of the people placed out of county had needs around challenging behaviour. The next most common need was autism followed by mental health (dual diagnosis), forensic and physical disability. Less than 5 people were placed out of county with needs relating to visual and hearing impairments and dementia in each category. The majority of placements were residential and around a quarter of the placements were in hospital. Around 10 of the placements were tenancy based with less than 5 placements in each of shared lives and specialist residential school. There were a range of placement lengths with no real differences in placement lengths between people in placements by choice and others. There were around 20 people who had been in a placement out of county for 10 years or more.

Supporting People

The Supporting People programme is a Welsh Government programme providing housing-related support to help vulnerable people to live as independently as possible. The total budget for Supporting People in North Wales for 2018-19 is around £30 million of which £8.2 million has been allocated to supporting people with learning disabilities.

There is a North Wales Regional Collaborative Committee (RCC) to drive forward effective and efficient delivery of the programme at a regional and local level and is linked to the Regional Partnership Board. Learning disabilities is a priority area for the RCC in the 2017-20 strategic plan.

Planning for future accommodation needs

The Wales Audit Office (2018) estimate that local councils in Wales will need to 'increase investment by £365 million in accommodation in the next twenty years to address both a growth in the number of people with learning disabilities who will need housing, and the increase in the number with moderate or severe needs'. This figure includes increases in costs due to inflation.

For North Wales, this will mean we need to plan for between 80 and 190 additional placements by 2035. The increase is estimated to be greatest in Wrexham followed by Gwynedd and then Denbighshire. Anglesey are estimated to see a decline in the

number of placements needed. Conwy and Flintshire are estimated to either have a small increase or small decrease.

The cost of these additional placements at current prices is estimated to be between £2.4 million and £7.3 million by 2035 and would be around 10 times as much if estimated inflation is included.

Having a good place to live: the change we want to see

- There will be fewer out of area placements.
- More people with learning disabilities will have choice and control over where they live and how they are supported.

Having something meaningful to do

This section is about having something to do that's meaningful and is chosen by the individual. It includes play, leisure and sport; education and training; day opportunities, work opportunities and paid employment.

Play

Play is a fundamental part of a healthy childhood and it is every child's right to be able to play. Play is defined in the Welsh Government Play Policy as freely chosen and personally directed. The right to play is enshrined within article 31 of the United Nations Convention on the Rights of the Child (UNCRC) and further defined within General Comment 17. The comment on article 23 about the rights of disabled children states:

“Play has been recognised as the best source of learning various skills, including social skills. The attainment of full inclusion of children with disabilities in the society is realised when children are given the opportunity, places and time to play with each other (children with disabilities and no disabilities)”

Children with learning disabilities can face additional barriers to accessing play opportunities, the Bevan Foundation found:

“Disabled children and young people face barriers from lack of provision, lack of support, poor access to buildings and negative attitudes which, notwithstanding legislation and policies, prevent them from participating like non-disabled children and young people”

Each local council in North Wales has produced a play sufficiency assessment as part of their play sufficiency duty. A survey undertaken for one of the assessments found that 46% of disabled children said that they were satisfied with their play opportunities compared to 70% overall. Another found that parents of children with complex needs

were particularly concerned about the attitude and actions of others and people's understanding of 'hidden' impairments like autism and ADHD.

The assessments show that a lot of work has taken place to understand and provide for the needs of disabled children and to make sure play projects and providers have access to a range of resources to support inclusion. For example, delivering inclusive play training to providers, activity programmes for disabled children, providing one to one support workers in mainstream provision, providing small grants for equipment training or resources and buddy schemes.

The play sufficiency assessments also set out the actions which each area is planning to improve play opportunities for disabled children including better partnership working, providing disability inclusion training, sharing resources and mentoring mainstream clubs who want to become more inclusive. Challenges to providing inclusive play opportunities include lack of accessible transport, particularly in rural areas and funding for services.

A list of resources available to support inclusive play is available from [Play Wales](#).

Sport and leisure

People with learning disabilities often face barriers to accessing socialising or leisure opportunities, for example they may not drive or may need support to use public transport. If local councils did not provide this support then some people would not be able to have a social life.

In the consultation people told us that they were involved in many different kinds of sport and leisure activities including:

“volunteering, snooker, tennis, wheelchair basketball, ten pin bowling, playing pool, Men's Sheds, magazines, star wars figures, art and art classes, cinema, shopping, watching TV and films, swimming, colouring, computer games, newspapers, ironing, watching and playing football, music, theatre, dancing, going out every night, sports clubs, buzz club, curry night, going out for meals, walking and holidays.”

People said that there needs to be more leisure activities and opportunities for people with learning disabilities, more integrated community-based activities and mixed groups.

Many of the solutions are low-cost and each county has a different way of funding these services. Some are funded as part of other provision, for example, a provider running disco nights. Others use small grants (either from the council or other funders) or informal arrangements. The provision varies depending on demand and geography. There are opportunities to make sure these services are more user led. For example,

the 'Friendship group' currently being run in Conwy by a person with learning disabilities.

[Disability Sport Wales](#) provides an online database of disability-specific or disability-inclusive sport opportunities.

Education and training

There are 9 special schools in North Wales with a total of 1,300 pupils, including Ysgol Plas Brondyffryn, the North Wales regional centre of excellence for teaching children on the autistic spectrum. Many children and young people with learning disabilities attend mainstream schools ([appendix 1](#)).

For more information about support for pupils with Additional Learning Needs in North Wales please see each council's strategies and plans.

Day opportunities and work opportunities

By *day opportunities* we mean formal support for people during the working week which is provided away from their home – this includes work opportunities which tend to have a vocational focus or are based in a business setting. Each county has a mix of direct payments, in-house, independent sector and social enterprises, with a range of services and work based activities in each local council.

A *social enterprise* is a business with profits re-invested back into its services or the community. A *cooperative* is a group acting together voluntarily to meet economic and social need. Local councils have a new duty to promote social enterprises and co-operatives which involve people who needs care and support. Day opportunities are an area we would like to encourage social enterprises and co-operatives to provide.

Paid employment

We would like to see more people with learning disabilities in paid jobs. We don't know how many people with learning disabilities in North Wales currently have paid jobs but estimates suggest they are far less likely to have a job than the general population. Estimates from England suggest around 6% of adults with learning disabilities known to their local authority have a paid job. In the consultation many of the people who had paid jobs said that they were important to them although some people said they were concerned that they would struggle to find work. There is some support available at the moment, for example from:

- Disability Advisers in the Jobcentre
- Careers Wales
- [Supported employment agencies](#)

Active support for people with profound and multiple learning disabilities

Active support is an approach for people with very profound needs who are not able to do typical activities independently and has three components:

1. Interacting to Promote Participation. People who support the individual learn how to give him or her the right level of assistance so that he or she can do all the typical daily activities that arise in life.
2. Activity Support Plans. These provide a way to organise household tasks, personal self-care, hobbies, social arrangements and other activities which individuals need or want to do each day, and to work out the availability of support so that activities can be accomplished successfully.
3. Keeping Track. A way of simply recording the opportunities people have each day that enables the quality of what is being arranged to be monitored and improvements to be made on the basis of evidence.

Each component has a system for keeping track of progress, which gives feedback to the staff team and informs regular reviews (Jones et al., 2014).

Having something meaningful to do: the change we want to see

- More people with learning disabilities will be involved in their local community.
- More people with learning disabilities will have paid jobs.
- Increased take-up of support budgets / direct payments.

Friends, family and relationships

The [what people have told us](#) section highlights the need for more opportunities for people to develop friendships and relationships. This includes opportunities to join in socially with groups from all parts of the community, not just events arranged for people with learning disabilities.

Friends, family and relationships: the change we want to see

- More people with learning disabilities will be involved in their local community.

Being safe

Children and young people

Often as a result of their disability, disabled children are more vulnerable to abuse and neglect in ways that other children and the early indicators of abuse or neglect can be more complicated than with non-disabled children (HM Government, 2006).

Young people with learning disabilities may be more vulnerable to county lines drug gangs and child sexual exploitation.

County lines drug gangs are those where an urban criminal gang travels to smaller locations to sell heroin/crack cocaine. The gangs tend to use a local property, generally belonging to a vulnerable person, as a base for their activities. This is often taken over by force or coercion (cuckooing). They pose a significant threat to vulnerable adults and children who they use to conduct and/or facilitate this criminality.

The Sexual Exploitation Risk Assessment Framework (SERAF) tool includes learning disability as a vulnerability factor for child sexual exploitation.

Adults

Each year there are on average around 210 safeguarding concerns raised in North Wales concerning adults with learning disabilities ([appendix 1](#)). In the last five years there have been around 50 crimes in North Wales where the victim had a learning disability, including people with Down's syndrome, ADHD and Autism ([appendix 1](#)).

Children and adults with learning disabilities may be at risk of financial abuse. This is any theft or misuse of a person's money, property or resources by a person in a position of, or expectation of, trust to a vulnerable person. Common forms of financial abuse are misuse by other of a vulnerable adult's state benefits or undue pressure to change wills.

Forced marriage statistics show that there was a year on year rise in the number of people with learning disabilities being reported who may be at risk or subject to a forced marriage from 2010-16 (North Wales Safeguarding Board, 2017). Forced marriage is where one or both people do not consent or lack the capacity to consent to the marriage and pressure or abuse is used.

North Wales Safeguarding Boards

The [North Wales Children's and Adults' Safeguarding Boards](#) are in place to make sure the citizens of North Wales are adequately prevented and protected from experiencing abuse, neglect and other kinds of harm. They have produced 7 minute briefings for professionals about the issues described above including warning signs and advice about what to do in response.

Positive risk taking

Safeguarding children, young people and adults from the risks described above also needs to be balanced against the risk of overprotecting people which can affect their well-being (Community Care, 2015).

The importance of positive risk taking was highlighted in the consultation. People spoke about how other elements of this strategy can support safeguarding in a way that promotes independence. Such as the importance of people with learning disabilities being involved in their community so that there are people around who know them and can look out for them and the potential uses of technology.

The [Safe Places scheme](#) is now running in some parts of North Wales. A safe place helps vulnerable if they feel scared or at risk while they are out and about in the community and need support right away.

Criminal justice system

An estimated 20-30% of offenders have learning disabilities or difficulties that interfere with their ability to cope within the criminal justice system (Talbot, 2008). This group is at increased risk of reoffending where support services and programmes don't meet their needs and can be targeted by other prisoners when in custody (Talbot, 2008).

A multi-agency task and finish group in Wales have developed a guidebook called 'Access to Justice' (2013) to support the 'responsive and appropriate management of adults with a learning disability in the criminal justice system in Wales. This work aims to take forward the recommendations of the Prison Reform Trust No One Knows programme.

The North Wales Police and Crime Commissioner (2017) is working with the health board to improve the response to vulnerable people that present to criminal justice agencies and target services and support to help people in crisis.

Being safe summary: the change we want to see

- More people with learning disabilities will be involved in their local community.
- More people with learning disabilities will use technology safely to help them be more independent.

Being healthy

Mental health

Children with learning disabilities are more likely to have mental health needs than the general population and these can start early in life (Toms et al., 2015). An estimated 30% to 50% of children who have a learning disability will also have mental health needs (National Institute for Health and Care Excellence, 2016). Research suggests that there's a high level of unmet need for mental health services for children with learning disabilities (Toms et al., 2015). This was highlighted in the consultation where people commented that access to mental health needed to be quicker for children with learning disabilities and also more support for their parents.

Research suggests that the prevalence of mental health needs in adults with learning disabilities was 41% or 28% when behaviours that challenge were excluded (Cooper et al., 2007). There is a risk that mental health needs in people with learning disabilities may not be identified due to assumptions that behaviour and symptoms are because of their learning disability (National Institute for Health and Care Excellence, 2016).

The Children's Commissioner for Wales (2018) identified a persistent and serious gap in mental health provision for young people with a learning disabilities. They found that continuity of care issues are often address by child services continuing to work with young adults, although this creates issues around suitability of services and costs. They also found that joint clinics between children's and adult health care providers were perceived as positive by young people and their families.

The Together for Mental Health in North Wales strategy sets out how we plan to improve mental health services in North Wales (Betsi Cadwaladr University Health Board, 2017).

Screening programmes

The uptake of screening programmes in North Wales for everyone eligible was as follows.

- Cervical screening: 70% of women eligible (25 to 64 year olds) were tested within 3.5 years and 77% were tested within 5 years at 1 April 2017. This is similar to the all Wales take up (Public Health Wales, 2017c).
- Breast screening: 71% of women eligible (50 to 70 year olds) took up the invitation in 2015-16. The all Wales take up was 74% and the minimum standard for update is 70% (Public Health Wales, 2017b).
- Bowel screening: 51% of men and women eligible (60 to 74 year olds) were screened within 2.5 years at 1 October 2016. The all Wales take up was 52% (Public Health Wales, 2017a).

The uptake of screening tests for people with learning disabilities who are known to the Health Liaison Team was as follows.

- Cervical screening: 6% of women eligible were tested during the year (17 out of 305)
- Breast screening: 10% of women eligible were tested during the year (10 out of 102). This figure may be slightly undercounted as it is not always filled in on the annual health check.
- Bowel screening: 9% of men and women eligible were tested during the year (6 out of 65).

Although some of the differences in the level of uptake may be due to undercounting there is still a large difference between the take up of screening by people in the whole population and people with learning disabilities.

Healthy lifestyles

There is a record of Body Mass Index (BMI) for 454 adults with learning disabilities in North Wales (excluding Conwy) and 178 of those had a BMI in the obese range (30 or higher). No adults had a BMI in the underweight range. The data was not available from Conwy GPs.

These figures suggest around 39% of the population of people with learning disabilities in North Wales have a BMI in the obese range. In the population as a whole, around 20% of people in North Wales have a BMI in the obese range (Welsh Health Survey, 2015).

This suggests that we need to do more to make sure that people with learning disabilities have opportunities for physical exercise and healthy eating.

Chronic conditions

Adults with learning disabilities may also have a chronic condition such as coronary heart disease; diabetes; asthma; dysphagia (swallowing problems) or epilepsy. The data we have about the number of people who have a chronic condition and a learning disability in North Wales is incomplete. A study of GP records of adults with learning disability in England found that people with learning disabilities had higher prevalence of epilepsy, severe mental illness and dementia as well as moderately increased rates of underactive thyroid and heart failure (Carey et al., 2016). They found that the prevalence of chronic heart disease and cancer were approximately 30% lower than in the population as a whole. This is surprising as people with learning disabilities have a higher prevalence of risk factors for chronic heart disease, so researchers think it may be that these conditions aren't being identified as well. They also suggest that lower rates of smoking and alcohol use among people with learning disabilities may contribute although there isn't any evidence to confirm this at the moment.

Dementia

People with learning disabilities are more at risk of developing dementia as they get older (Ward, 2012). The prevalence of dementia among people with a learning disability is estimated at 13% of people over 50 years old and 22% of those over 65 compared with 6% in the general older adult population (Kerr, 2007). The Learning Disability Health Liaison Service in North Wales report that people with learning disabilities are four times more likely to have early onset dementia. People with Down's Syndrome are particularly at risk and can develop dementia 30-40 years earlier than the general population with rates of 40% at around age 50 (Holland and others, 1998).

Mortality

People with a learning disability are living longer. This is something to celebrate as a success of improvements in health and social care. For example, there has been a dramatic change in life expectancy for people with Down's Syndrome since the 1930s rising from age 10 to around age 50 over the course of 70 years (Holland, 2000).

However, people with learning disabilities are still at more risk of dying early compared to the general population and are more likely to die from causes that could have been prevented (Mencap, 2012, Hosking et al., 2016).

Annual health check

In North Wales 2,900 people with learning disabilities aged 18 and over are eligible for an annual health check and around 1,700 people (57%) had the health check in the last year.

There are 116 GP practices in North Wales, of which 71 are signed up to delivering the learning disability annual health check.

In-patient units at Bryn y Neuadd

The inpatient learning disabilities services within Mental Health and Learning Disabilities Division provides highly specialised person centred care for people with learning disabilities within a safe environment. They provide a range of specialist services, inclusive of assessment and treatment; rehabilitation; assessment and treatment for people with profound and multiple needs and therapeutic support services in a specialist learning disability hospital setting. There are currently three wards within the Learning Disability Inpatient Service at Bryn y Neuadd hospital. During 2016-17 there were around 50 admissions to these units due to mental health needs, challenging behaviour and/or physical health needs.

Continuing health care

There are 280 people with learning disabilities in receipt of continuing health care funding in North Wales. Of these, 224 are jointly funded between health and social services and 56 are fully funded by health.

Admissions to an Acute Hospital

There is a North Wales shared care agreement for carers supporting patients with a learning disability in hospital for use when the ward has identified that there is a need for additional support. Some people with learning disabilities will benefit from having their own familiar support while in hospital which can reduce anxiety, prevent diagnostic overshadowing and help support the hospital to make reasonable adjustments.

Communication standards

The Royal College of Speech and Language Therapists (2013) have produced five good communication standards, which are reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. The document includes links to useful resources. The standards are:

- **Standard 1:** There is a detailed description of how best to communicate with individuals.
- **Standard 2:** Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.
- **Standard 3:** Staff value and use competently the best approaches to communication with each individual they support.
- **Standard 4:** Services create opportunities, relationships and environments that make individuals want to communicate.
- **Standard 5:** Individuals are supported to understand and express their needs in relation to their health and well-being.

Being healthy: the change we want to see

- More people with learning disabilities will take up cancer screening opportunities when offered.
- Reduced demand on specialist learning disability services.
- Fewer people will fall between the gaps in services.

Having the right support

We want to provide the right support at the right time to the right people in the right place. To provide support that helps people to do what they want, gives them choice and control over their own lives and promotes positive risk taking.

Having the right support with changes and transitions

The services people need will change throughout their lives. These changes, or times of transition, can include:

- moving from school to college;
- moving from school or college into work; or,
- moving from living with parents into their own place;

The services available to support people may also change at specific times, for example, moving from children's services to adult services at age 18. Some services in

North Wales co-produce transition plans to support young people age 14 to 17 with this change and others have a lifetime disability service so they don't use formal transition plans. In this case the outcomes (what matters to people) in relation to the transition are recorded in the statutory care and support plans.

The Children's Commissioner for Wales (2018) has spoken to young people, parents and carers and professionals throughout Wales about their experiences and views about transitions to adulthood for young people with learning disabilities. The key messages from young people and their families were:

- Young people's participation in planning and decision-making appears to be very low – this means that their different priorities and specific interests can get missed.
- Parents play a crucial role and are relied upon to do so, but often feel overwhelmed and anxious about the future – they need support and recognition.
- Some young people face a considerable change in how much support they receive after the age of 18 due to different thresholds rather than a sudden change in need – contrary to the Social Services and Well-being (Wales) Act 2014.
- Every service has different ways of transferring to over-18s services. Having a key worker or transition service is very valuable.
- Social isolation is a problem for many – even though friendships are rated as young people's top priority.
- There are very limited opportunities for work and apprenticeships, with no supported employment opportunities – despite evidence suggesting this is particularly effective.
- Young people, parents and professionals all agree that young people with learning disabilities are still expected to slot into services that already exist, with limited options if that doesn't fit their needs.
- Where young people and their families reported good experiences, they had been involved, they were clear about the process, they felt well supported by a keyworker, lead professional or dedicated transitions service and they often had access to a youth-centred provision that helped young people prepare for adulthood and expand their social and community networks.

Support for people with profound and multiple learning disabilities (PMLD)

People with profound and multiple learning disabilities (PMLD) need a high level of support to lead good lives as described in this strategy. A group of family members, education, health and social care professionals have developed a set of Service Standards to be used by commissioners and providers of services for people with PMLD (Doukas et al., 2017). The standards have been developed to be used as an internal auditing tool and they recommend that they are used as part of an annual

self-assessment process with action plans developed to address areas that need improving. They include standards for organisations around leadership, quality, staff development (skills and confidence), physical environment, communication, health and well-being, social, community and family life.

Additional resources on how to improve services for adults with PMLD are available in the Raising Our Sights guides available from www.bit.ly/raising-our-sights-guides.

End of life care

The [lifespan pathway](#) included at the start of the report highlights how end of life care may be needed at any point in the pathway.

A report by the Care Quality Commission (2016) identified inequalities in end of life care for people with learning disabilities. This included a lack of understanding of people's individual needs; not identifying people who are approaching the end of life at an early enough stage because of poor access to physical healthcare; poor communication, for example, health and social care staff making assumptions about people's ability to 'cope' with discussions about end of life. The Welsh Government (2017a) has published their Palliative and End of Life Care Delivery Plan which sets out how they plan to improve the delivery of all aspects of palliative and end of life care including support for people of all ages and the needs of those experiencing bereavement.

The service standard for people with PMLD is that 'The organisation ensures each person has an End of Life Plan in place, in consultation with the person, their family and other appropriate members of the circle of support' (Doukas et al., 2017).

Carer breaks

Each county has respite services which give families a break. The arrangements vary from county to county but include respite 'beds' in Care Homes, Adult Placements for respite, short breaks and use of Direct Payments.

There is a North Wales Carers' Strategy [\[add link\]](#) and carers journey mapping carried out to inform the strategy highlighted how important it was to have the right support in place for the person cared for in order to support the carers. We have reviewed the provision of respite/short-term break resources for individuals with a learning disability or complex needs and their carers in North Wales (Hay, 2017) and developed a set of recommendations which we will implement as part of the strategy.

Carer breaks have traditionally been referred to as 'respite' although the term has also been associated with respite from something that is a burden so we are starting to use the term 'carer breaks' in preference.

See the [early years section](#) for more information about short breaks for children with learning disabilities.

Advocacy

The Welsh Government describes advocacy as having two main themes:

“speaking up for and with individuals who are not being heard, helping them to express their views and make their own informed decisions and contributions, and, safeguarding individuals who are at risk”.

There are different forms of advocacy which include:

- **Self-advocacy** when individuals represent and speak up for themselves.
- **Informal advocacy** when family, friends or neighbours support an individual to have their wishes and feelings heard, which may include speaking on their behalf.
- **Independent volunteer advocacy** involves an independent and unpaid advocate who works on a short term, or issue led basis, with one or more individuals.
- **Formal advocacy**, which can refer to the advocacy role of staff in health, social care and other settings where professionals as part of their role consider the wishes and feelings of an individual and help make sure they are addressed properly.
- **Independent professional advocacy** involves an independent professional advocate who is trained and paid to undertake the role. They must make sure individuals' views are accurately conveyed irrespective of the view of the advocate or others as to what is in the best interests of the individuals.

There are self-advocacy groups for people with learning disabilities in each county in North Wales.

It is important to involve and ‘listen to’ people with profound and multiple learning disabilities (PMLD). Advocacy for people with PMLD may involve ‘representational advocacy’ where an independent advocate speaks on their behalf and families are also important advocates for people with PMLD. When commissioning advocacy services for people with PMLD we need to take into account the observational and listening skills of the advocate and ability to communicate in a variety of ways with the individual and family members, a good understanding of human rights as well as giving the right amount of time (Mencap and PMLD Network, 2013).

Support for parents with a learning disability

The research suggests that best practice for supporting parents with a learning disability should include the following (Stewart and McIntyre, 2017).

- Early identification of parents with learning disabilities so that appropriate support can be put in place. This will need to address concerns parents may have about discrimination and assumptions about their ability to parent.
- Good partnership working to make sure parents with learning disabilities don't fall between services. For example, a person may not have been eligible for learning disability services before having parental responsibility. Also need to make sure staff are aware of the needs of people with learning disabilities, how to support them and make reasonable adjustments. This includes GPs, midwives and health visitors, social workers working in child protection and family support services and advocates and others working in family courts.
- Early assessment of parenting skills that identifies strengths as well as support needs and gives people time to develop their skills. For example, by using the Parents Assessment Manual (PAMS). Multi-disciplinary support should be available to help people address any issues identified.
- Make sure information is accessible including information about pregnancy and childcare and especially any information about child protection proceedings.
- Support should be family focussed, adapted to the family's needs and take a strengths-based approach. Some families will need on-going or long-term support.
- Promote the use of independent advocacy and self-advocacy. In child protection proceedings generic advocacy may not be sufficient as advocates will need knowledge of child protection law and the needs of people with learning disabilities. In our consultation parents with a learning disability said it was important that they get to have their say too.

One of the childcare sufficiency assessments mentioned the importance of access to childcare for parents with learning difficulties.

As part of the Improving Outcomes for Children Ministerial Advisory Group phase 2 work programme (Welsh Government, 2018b), *Workstream 2: Assessment of Risk and Edge of Care Services* includes actions to:

- Undertake research to identify the number of children who have parents with a learning disability who no longer live at home and the reasons behind their change of status.
- Develop guidance for reducing the number of looked after children taken from parents with a learning disability.

Looked after children are also a priority in the Welsh Government (2018c) Improving Lives Programme which aims to 'improve the outcomes of parents with a learning disability and their children to ensure a good quality of life'.

There is a network for parents with a learning disability in North Wales supported by [Learning Disability Wales](#). It is open to parents whether their child lives with them or not and provides an opportunity to share experiences and stories with each other with each other and also with social services and Welsh Government.

The right support: the change we want to see

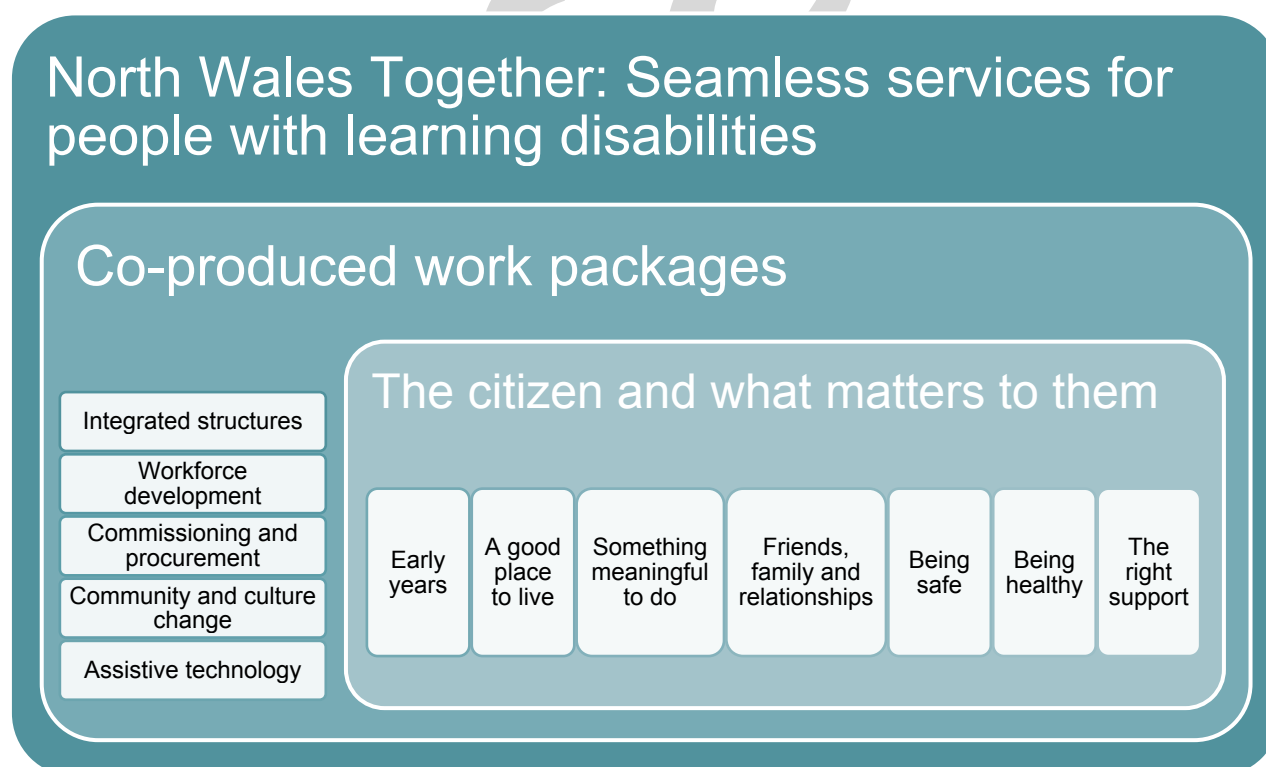
- Fewer people will fall between the gaps in services.
- No-one will experience delays in support due to disagreements between services.
- Increased take-up of support budgets / direct payments.
- People with learning disabilities and their parents/carers will have access to good consistent information and advice.

Draft

Putting the strategy into action

To achieve our vision and provide services based on what matters to people (a good place to live, something meaningful to do and so on) we have planned five work packages that will set out *how* we will change things in order to achieve good lives for people with learning disabilities. The work packages will include actions to improve support throughout people’s lives and meet the needs of people with profound and multiple learning disabilities. They will take an asset-based approach to build on the skills, networks and community resources that people with learning disabilities already have. The diagram below shows how the different parts of the project will fit together.

Putting the strategy into action will include not just people who provide specific learning disability services. To achieve our vision we need to co-produce services with people with learning disabilities and their parents/carers and share power and responsibility for making these changes. We also need to work closely with staff in the six local authorities and the health board outside of specific learning disability services such as GPs to improve communication and understanding of the reasonable adjustments that people with learning disabilities may need to access health care and other public services. The key to achieving our vision will be to work with local communities to make sure people with learning disabilities are truly valued and included in their communities.



Integrated structures

Making sure health and social services work together better to support people with learning disabilities.

We want an integrated service where no citizens fall between the gaps in services with seamless transitions through changes in life. We will build on current good practice across North Wales with integrated health and social care teams and lifespan approaches to disability services to develop models and structures that provide seamless care to the individual.

Actions

- Review current models of integration and share best practice across the region.
- Reduce any duplication of record systems so people only have to 'say it once'.
- Make sure there is sufficient support for the health issues of older people with learning disabilities, including people with dementia.

How we will know if we've made a difference

- New integrated structures will be in place.
- Fewer people will fall between the gaps in services (identified through consultation and engagement, feedback and complaints).
- No-one will experience delays in support due to disagreements between services.

Workforce development

Making sure staff know how to communicate well with people with learning disabilities in Welsh or English and can make changes to support them well. This will help people get the health care they need.

We want to see more awareness of disability issues among the wider public sector workforce including the reasonable adjustments that can be made to provide people with learning disabilities fair and equitable access to services and other community resources.

Actions

- Bring different parts of the workforce together to share best practice.
- Develop a consistent value-based skill set for staff across the region.
- Provide support for the wider workforce, including GPs and healthcare assistants about reasonable adjustments and preventative measures.
- Work with Public Health Wales to improve the take-up of cancer screening by people with learning disabilities.

How will we know if we've made a difference

- More people with learning disabilities will take up cancer screening opportunities when offered.
- Reduced demand on specialist learning disability services.
- People with learning disabilities and their parents/carers will have access to good consistent information and advice.

Commissioning and procurement

Work with other organisations to make sure we have the types of housing and support people need.

We want to move towards person-centred, outcome models of commissioning where the process is led by the person to deliver services that develop self-reliance, improve quality of care, reduce demand and re-invest in new forms of care.

Actions

- Explore and pilot pooled budgets between health and social care in a locality.
- Provide sustainable models of support jointly by health and social care to meet the needs of individuals with complex needs. This should include addressing the unmet need for high end jointly funded nursing placements for adults with severe learning disabilities who have health related needs.
- Increase recruitment to the shared lives / adult placements scheme.
- Continue to explore and develop housing options to meet the needs of people with learning disabilities in partnership with other organisations.
- Improve the use of and support available for support budgets / direct payments.
- Support older carers and make sure they have the support and carer break (respite) services they need. This should include 'planning ahead' services for families which includes work to identify hidden carers and assess their needs for support.
- Implement the recommendations of the *Development of Respite/ Short-term Break Resources across North Wales for Individuals with a Learning Disability or Complex Needs and their Carers* report (Hay, 2017)

How will we know if we've made a difference

- There will be fewer out of area placements.
- More people with learning disabilities will have choice and control over where they live and how they are supported.
- Increased take-up of support budgets / direct payments.
- Carers will have access to a range of flexible carer breaks.

Community and culture change

Work with the local community to make sure people with learning disabilities can access lots of different activities and meet new people if they want to. Help more people with learning disabilities to get paid jobs.

We want to raising awareness and build friendships and relationships within an inclusive community to make the most of the assets, resources and skills available.

Actions

- Work with local employers to develop employment opportunities for people with learning disabilities as well as other day opportunities.
- Build on the work of community navigators, local area coordinators and social prescribing models to develop a co-productive, scalable structure for community inclusion.

How will we know if we've made a difference

- More people with learning disabilities will be involved in their local community.
- More people with learning disabilities will have paid jobs.

Assistive technology

Find ways to use technology like alarms and mobile phones to help people be more independent.

Actions

- Developing skills, knowledge and training about the potential of existing technologies (such as mobile phones and voice controlled personal assistants like Alexa) to support people with learning disabilities.
- Develop the provision of assistive technology for people with learning disabilities.
- Provide more support for people with staying safe when using the internet.

How will we know if we've made a difference

- More people with learning disabilities will use technology safely to help them be more independent.

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Appendix 1: Baseline data

This appendix includes the baseline data gathered to inform the strategy.

Children and young people

There are reliability issues with much of the data collected about children with learning disabilities due to differences in the definitions used and the way data is collected.

There are around 102,000 pupils in North Wales, the total school-age population. Table 2 below shows the number of pupils who have a learning difficulty. The way education services define learning difficulties as moderate, severe or profound is different to the way social services assess whether someone needs support from learning disability services. These figures can't therefore be used to tell how many young people are likely to need support from learning disability services as adults.

Table 1: Number of pupils with a learning difficulty, 2016-17

| | Moderate | Severe | Profound | ASD |
|--------------|----------|--------|----------|-------|
| Anglesey | 335 | 135 | 20 | 125 |
| Gwynedd | 820 | 130 | 50 | 115 |
| Conwy | 360 | 45 | 30 | 325 |
| Denbighshire | 250 | 85 | 30 | 375 |
| Flintshire | 885 | 95 | 40 | 245 |
| Wrexham | 695 | 115 | 30 | 295 |
| North Wales | 3,345 | 605 | 200 | 1,480 |

Source: PLASC, Welsh Government, [Stats Wales](#)

Numbers have been rounded to the nearest 5.

Table 2: Estimated number of children aged 0-17 with a learning difficulty

| | Moderate | Severe | Profound |
|--------------|----------|--------|----------|
| Anglesey | 777 | 100 | 25 |
| Gwynedd | 700 | 91 | 22 |
| Conwy | 1143 | 148 | 36 |
| Denbighshire | 818 | 106 | 26 |
| Flintshire | 494 | 64 | 16 |
| Wrexham | 1,095 | 142 | 35 |
| North Wales | 5,027 | 651 | 160 |

Source: Daffodil, estimates based on prevalence in the population

Table 3 shows the number of children receiving care and support who have a disability or Statement of Special Educational needs.

Table 3: Number of children receiving care and support with a disability or Statement of Special Educational Needs (SEN) (2017)

| | Children with a disability | Children with a Statement of SEN |
|--------------|----------------------------|----------------------------------|
| Anglesey | 75 | 65 |
| Gwynedd | 245 | 175 |
| Conwy | 155 | 120 |
| Denbighshire | 90 | 35 |
| Flintshire | 65 | 40 |
| Wrexham | 65 | 75 |
| North Wales | 695 | 505 |

Source: Children Receiving Care and Support Census, Welsh Government, StatsWales

Numbers have been rounded to the nearest 5.

Table 4: Number of children aged 0-17 with a moderate learning difficulty, 2017 to 2035

| | 2017 | 2020 | 2025 | 2030 | 2035 | Predicted change between 2017 and 2035 |
|--------------|-------|-------|-------|-------|-------|--|
| Anglesey | 490 | 505 | 505 | 480 | 450 | -46 |
| Gwynedd | 820 | 820 | 830 | 840 | 860 | 38 |
| Conwy | 780 | 790 | 780 | 750 | 700 | -76 |
| Denbighshire | 700 | 720 | 730 | 710 | 690 | -15 |
| Flintshire | 1,140 | 1,150 | 1,140 | 1,080 | 1,030 | -120 |
| Wrexham | 1,100 | 1,130 | 1,150 | 1,130 | 1,120 | 29 |
| North Wales | 5,030 | 5,100 | 5,130 | 4,980 | 4,840 | -190 |

Source: Daffodil, estimates based on prevalence in the population

Numbers have been rounded so may not sum.

Table 5: Number of children under 16 in receipt of Disability Living Allowance (DLA) February 2018

| | Age under 5 | Aged 5 to under 11 | Aged 11 to under 16 | Total |
|--------------|-------------|--------------------|---------------------|-------|
| Anglesey | 50 | 190 | 180 | 420 |
| Gwynedd | 70 | 300 | 290 | 660 |
| Conwy | 80 | 410 | 410 | 900 |
| Denbighshire | 100 | 380 | 480 | 960 |
| Flintshire | 120 | 490 | 490 | 1,100 |
| Wrexham | 100 | 510 | 620 | 1,230 |
| North Wales | 510 | 2,270 | 2,460 | 5,240 |

Source: ONS (from Nomis)

Numbers have been rounded so may not sum.

Adults**Table 6: Number of adults aged 18 and over predicted to have a learning disability, 2017 to 2035**

| | 2017 | 2020 | 2025 | 2030 | 2035 | Predicted change between 2017 and 2035 |
|--------------|--------|--------|--------|--------|--------|--|
| Anglesey | 1,300 | 1,300 | 1,300 | 1,300 | 1,300 | -20 |
| Gwynedd | 2,400 | 2,400 | 2,400 | 2,500 | 2,500 | 170 |
| Conwy | 2,200 | 2,200 | 2,200 | 2,200 | 2,200 | 20 |
| Denbighshire | 1,800 | 1,800 | 1,800 | 1,900 | 1,900 | 120 |
| Flintshire | 2,900 | 2,900 | 2,900 | 2,900 | 2,900 | 60 |
| Wrexham | 2,600 | 2,700 | 2,800 | 3,000 | 3,100 | 440 |
| North Wales | 13,100 | 13,300 | 13,400 | 13,700 | 13,900 | 780 |

Source: Daffodil

Table 7: Number of adults aged 18 and over predicted to have a moderate or severe learning disability, 2017 to 2035

| | 2017 | 2020 | 2025 | 2030 | 2035 | Predicted change between 2017 and 2035 |
|--------------|-------|-------|-------|-------|-------|--|
| Anglesey | 260 | 260 | 250 | 250 | 250 | -20 |
| Gwynedd | 480 | 490 | 490 | 500 | 510 | 30 |
| Conwy | 430 | 430 | 420 | 420 | 420 | -10 |
| Denbighshire | 360 | 360 | 360 | 370 | 370 | 10 |
| Flintshire | 590 | 590 | 580 | 580 | 580 | -10 |
| Wrexham | 550 | 560 | 580 | 610 | 630 | 80 |
| North Wales | 2,680 | 2,680 | 2,690 | 2,730 | 2,750 | 80 |

Source: Daffodil, estimates based on prevalence in the population

Note: The number of adults aged 18-64 is predicted to decline by around 25 people, which is why the increase in the total adults aged 18 and over is lower than the increase in the total adults aged 65 and over.

Table 8: Number of adults aged 65 and over predicted to have a learning disability, 2017 to 2035

| | 2017 | 2020 | 2025 | 2030 | 2035 | Predicted change between 2017 and 2035 |
|--------------|-------|-------|-------|-------|-------|--|
| Anglesey | 370 | 390 | 420 | 440 | 460 | 90 |
| Gwynedd | 580 | 590 | 620 | 660 | 690 | 120 |
| Conwy | 660 | 680 | 730 | 790 | 840 | 190 |
| Denbighshire | 480 | 500 | 540 | 590 | 630 | 150 |
| Flintshire | 680 | 720 | 770 | 850 | 920 | 240 |
| Wrexham | 570 | 600 | 660 | 730 | 800 | 230 |
| North Wales | 3,330 | 3,490 | 3,730 | 4,060 | 4,350 | 1,010 |

Source: Daffodil, estimates based on prevalence in the population

Table 9: Number of adults aged 65 and over predicted to have a moderate or severe learning disability, 2017 to 2035

| | 2017 | 2020 | 2025 | 2030 | 2035 | Predicted change between 2017 and 2035 |
|--------------|------|------|------|------|------|--|
| Anglesey | 50 | 50 | 50 | 60 | 60 | 10 |
| Gwynedd | 80 | 80 | 80 | 90 | 90 | 10 |
| Conwy | 90 | 90 | 90 | 100 | 110 | 20 |
| Denbighshire | 60 | 70 | 70 | 80 | 80 | 20 |
| Flintshire | 90 | 100 | 100 | 110 | 120 | 30 |
| Wrexham | 80 | 80 | 90 | 90 | 100 | 30 |
| North Wales | 450 | 470 | 490 | 520 | 550 | 110 |

Source: Daffodil, estimates based on prevalence in the population

Expenditure on services

Local authorities had spent around £85 million a year in North Wales on services for people with learning disabilities as shown in table 4 and 5 below. This increased to £96 million in 2016-17 due to transfers to meet the cost of providing support to former Independent Living Fund (ILF) recipients.

Table 10: Social services revenue expenditure, adults aged under 65 with learning disabilities

| | 2011-12 | 2012-13 | 2013-14 | 2014-15 | 2015-16 | 2016-17 |
|--------------|-------------|---------|---------|---------|---------|---------|
| | £ thousands | | | | | |
| Anglesey | 8,134 | 6,936 | 6,812 | 7,180 | 7,763 | 8,373 |
| Gwynedd | 12,733 | 12,223 | 13,105 | 13,386 | 14,931 | 15,911 |
| Conwy | 16,791 | 16,095 | 16,401 | 16,362 | 16,729 | 18,676 |
| Denbighshire | 11,685 | 12,001 | 12,045 | 12,781 | 9,993 | 14,230 |
| Flintshire | 18,676 | 17,650 | 17,697 | 17,959 | 20,194 | 21,814 |
| Wrexham | 16,368 | 16,096 | 15,811 | 15,163 | 14,440 | 17,122 |
| North Wales | 84,387 | 81,001 | 81,871 | 82,831 | 84,050 | 96,126 |

Source: Revenue outturn data collection, Welsh Government, StatsWales

Table 11: Social services capital expenditure on personal social services

| | 2011-12 | 2012-13 | 2013-14 | 2014-15 | 2015-16 | 2016-17 |
|--------------|-------------|---------|---------|---------|---------|---------|
| | £ thousands | | | | | |
| Anglesey | 21,619 | 25,428 | 24,105 | 21,288 | 43,976 | 36,640 |
| Gwynedd | 35,752 | 42,470 | 41,461 | 32,417 | 35,534 | 29,309 |
| Conwy | 28,009 | 28,704 | 38,630 | 27,966 | 19,426 | 30,478 |
| Denbighshire | 39,733 | 38,345 | 42,003 | 35,662 | 88,562 | 42,964 |
| Flintshire | 43,026 | 39,821 | 38,058 | 40,401 | 140,301 | 63,493 |
| Wrexham | 56,042 | 42,250 | 45,144 | 54,847 | 219,453 | 84,208 |
| North Wales | 224,182 | 217,018 | 229,401 | 212,581 | 547,252 | 287,092 |

Source: Capital outturn (COR) data collection, Welsh Government, StatsWales

Compliments and complaints

Overall during 2016-17 local council and health services received around 40 formal complaints about learning disability services. Most complaints are resolved informally. The numbers are too few to identify any trends or issues developing across North Wales.

The number of formal complaints received by local authority learning disability services is listed in the table below. The numbers can't be compared against each other or year to year as they are counted differently. For example, some services include children and adults while others include adults only and some figures are for a whole disability service rather than the learning disability service. The data shows how the number of complaints increases when services change or are reduced.

Table 12: Number of formal complaints received, Learning Disability, 2016-17

| | 2014-15 | 2015-16 | 2016-17 |
|--------------|---------|---------|---------|
| Anglesey | <5 | <5 | <5 |
| Gwynedd | 10 | <5 | <5 |
| Conwy | 5 | 5 | 10 |
| Denbighshire | 5 | 5 | 5 |
| Flintshire | 20 | 60 | 10 |
| Wrexham | 30 | 10 | 10 |
| BCUHB | <5 | 10 | <5 |
| North Wales | 80 | 90 | 40 |

Source: Local authority data collection

Numbers have been rounded to the nearest 5.

Local authorities and health services also receive compliments about the work they are doing well.

Children in need of care and support

There is no consistent data available about the number of children with a learning disability in foster placements. The number of children in North Wales on the learning disability register in foster placements is 23 in 2016-17 which seems like an undercount. The table below shows the total number of looked after disabled children.

Table 13: Number of disabled children looked after at 31 March 2017

| 2014-15 | |
|--------------|-----|
| Anglesey | 15 |
| Gwynedd | 25 |
| Conwy | 15 |
| Denbighshire | 30 |
| Flintshire | 30 |
| Wrexham | <5 |
| North Wales | 120 |

Source: Children receiving care and support census, StatsWales.

Numbers have been rounded to the nearest 5

Community based, residential services and nursing care

Please note, the data is not available for 2015-16 due to reduced data collection.

Table 14: Number of adults (over 18) with a learning disability who receive community-based services

| | 2010-11 | 2011-12 | 2012-13 | 2013-14 | 2014-15 |
|--------------|---------|---------|---------|---------|---------|
| Anglesey | 170 | 126 | 154 | 172 | 174 |
| Gwynedd | 246 | 255 | 275 | 203 | 332 |
| Conwy | 324 | 358 | 393 | 398 | 381 |
| Denbighshire | 222 | 256 | 277 | 288 | 295 |
| Flintshire | 422 | 368 | 398 | 418 | 424 |
| Wrexham | 281 | 271 | 268 | 285 | 276 |
| North Wales | 1,665 | 1,634 | 1,765 | 1,764 | 1,882 |

Source: StatsWales

Table 15: Number of adults (over 18) with a learning disability who receive residential services

| | 2010-11 | 2011-12 | 2012-13 | 2013-14 | 2014-15 |
|--------------|---------|---------|---------|---------|---------|
| Anglesey | 37 | 37 | 29 | 34 | 28 |
| Gwynedd | 15 | 23 | 34 | 41 | 49 |
| Conwy | 73 | 83 | 74 | 75 | 69 |
| Denbighshire | 55 | 50 | 49 | 49 | 52 |
| Flintshire | 44 | 42 | 46 | 42 | 52 |
| Wrexham | 43 | 39 | 40 | 36 | 34 |
| North Wales | 267 | 274 | 272 | 277 | 284 |

Source: StatsWales

Table 16: Number of adults (over 18) receiving nursing care (Independent sector care homes)

| | 2010-11 | 2011-12 | 2012-13 | 2013-14 | 2014-15 |
|--------------|---------|---------|---------|---------|---------|
| Anglesey | 2 | 2 | 3 | 4 | 3 |
| Gwynedd | 0 | 0 | 0 | 2 | 2 |
| Conwy | 10 | 15 | 16 | 17 | 15 |
| Denbighshire | 0 | 0 | 0 | 0 | 1 |
| Flintshire | 1 | 3 | 4 | 7 | 4 |
| Wrexham | 16 | 4 | 2 | 1 | 1 |
| North Wales | 29 | 24 | 25 | 31 | 26 |

Source: Stats Wales

In-patient units at Bryn y Neuadd

- Mesan Fach Assessment and Treatment Unit
- Tan y Coed rehabilitation provision
- Foelas assessment and treatment unit for people with PMLD.

The number of admissions of people with learning disabilities who were admitted to in-patient units in Bryn y Neuadd in 2016-17 were as follows.

- 16 admissions to Mesen Fach due to challenging behaviour.
- 22 admissions to Mesen Fach due to mental health needs.
- Less than 5 admissions to Mesen Fach with additional physical health needs and 5 admissions to Foelas with physical health needs.
- 5 people were admitted once or more to both in-patient and mental health and learning disability care for management of challenging behaviour during the year.

Deprivation of Liberty Safeguards

The table below shows the number of DoLS referrals made by each local authority for people with learning disabilities during 2016-17.

Table 17: Number of Deprivation of Liberty Safeguards (DoLS) referrals, 2016-17

| | 2016-17 |
|--------------|---------|
| Anglesey | 14 |
| Gwynedd | 25 |
| Conwy | 65 |
| Denbighshire | 27 |
| Flintshire | 21 |
| Wrexham | 8 |
| North Wales | 160 |

Source: Local authority data collection

Schools

Table 18: Number of special schools and pupils in North Wales, 2017-18

| | Number of schools | Number of pupils |
|--------------|-------------------|------------------|
| Anglesey | 1 | 92 |
| Gwynedd | 2 | 215 |
| Conwy | 1 | 221 |
| Denbighshire | 2 | 277 |
| Flintshire | 2 | 209 |
| Wrexham | 1 | 295 |
| North Wales | 9 | 1,309 |

Source: Pupil Level Annual School Census (PLASC), Welsh Government, Stats Wales

Safeguarding

The table below shows the numbers of crimes in each county although the numbers are not large enough to show any trend over time or significant differences between counties.

Table 19: Number of crimes linked to victims with learning disabilities

| | 2012-2016 | |
|--------------|-----------|-------------|
| | | North Wales |
| Anglesey | 5 | 2012 5 |
| Gwynedd | 5 | 2013 10 |
| Conwy | 10 | 2014 15 |
| Denbighshire | 10 | 2015 5 |
| Flintshire | 10 | 2016 20 |
| Wrexham | 10 | |
| North Wales | 50 | Total 50 |

Source: North Wales Police

Numbers have been rounded so may not sum.

The table below shows the number of safeguarding concerns in each county in North Wales.

Table 20: Number of adult safeguarding concerns concerning adults with learning disabilities

| | 2012-13 | 2013-14 | 2014-15 | 2015-16 |
|--------------|---------|---------|---------|---------|
| Anglesey | 20 | 30 | 20 | 25 |
| Gwynedd | 20 | 35 | 15 | 30 |
| Conwy | 55 | 60 | 60 | 50 |
| Denbighshire | 20 | 30 | 15 | 40 |
| Flintshire | 30 | 55 | 50 | 35 |
| Wrexham | 30 | 30 | 30 | 50 |
| North Wales | 180 | 240 | 190 | 230 |

Source: StatsWales

Numbers have been rounded so may not sum.



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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Learning Disability Strategy Consultation report August 2018

Draft



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board



Iechyd Cyhoeddus
Cymru
Public Health
Wales



Draft

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Introduction

An Equality Impact Assessment was undertaken to identify potential inequalities arising from the development and delivery of the North Wales Learning Disability Strategy. The information gained through this process has been used to develop the North Wales Learning Disability Strategy.

This report provides details of the consultation undertaken as part of the Equality Impact Assessment and provides evidence of how we are meeting the requirements of the public sector equality duty.

Background

Support for people with learning disabilities is a priority in the [North Wales Regional Plan \(Area Plan\)](#) based on what people told us was important to them as part of the [population assessment](#) produced by the [Regional Partnership Board](#).

The Social Services and Well-being (Wales) Act 2014 includes a statutory duty for Regional Partnership Boards to prioritise the integration of services in relation to people with learning disabilities (Welsh Government, 2015).

The Learning Disability Strategy sets out how we will work towards integrated learning disability services in North Wales. It has been developed jointly by the six North Wales councils and Betsi Cadwaladr University Health Board (BCUHB) supported by Public Health Wales.

Actions and plans developed to implement the strategy will need an Equality Impact Assessment to assess their potential impact.

Public sector equality duty

The Equality Act 2010 introduced a new public sector duty which requires all public bodies to tackle discrimination, advance equality of opportunity and promote good relations. The table below outlines the duties of public bodies.

| Public bodies must have due regard to the need to: | Having due regard for advancing equality means: |
|---|--|
| Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited under the Act. | Removing or minimising discrimination, harassment or victimisation suffered by people due to their protected characteristic. |
| Advance equality of opportunity between people who share a protected characteristic and those who do not. | Taking steps to meet the needs of people from protected groups where these are different from the needs of other people. |

Foster good relations between people who share a protected characteristic and those who do not.

Taking steps to build communities where people feel confident that they belong and are comfortable mixing and interacting with others.

Councils in Wales also have specific legal duties set out in the Equality Act 2010 (Wales) regulations 2011 including assessing the impact of relevant policies and plans – the Equality Impact Assessment.

In order to establish a sound basis for the Learning Disability Strategy we have:

- reviewed the performance measurement and population indicator data recommended in the data catalogue provided by Welsh Government, along with other relevant local, regional and national data
- consulted as widely as possible across the North Wales region including with the general public, colleagues and people with protected characteristics;
- reviewed relevant research and consultation literature including legislation, strategies, commissioning plans, needs assessments and consultation reports.

Details of the local, regional and national data, the literature review and a summary of the consultation findings is provided in the [population assessment report](#) and the [regional plan consultation report](#).

This report sets out the additional consultation carried out for the Learning Disability Strategy:

- who we have consulted with;
- how we have consulted; and
- the consultation feedback.

Consultation principles

A key part of the Equality Impact Assessment is consulting with people who may be affected by the Learning Disability Strategy and in particular people with protected characteristics. The protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion and belief
- Sex
- Sexual orientation
- Welsh language

Case law has provided a set of consultation principles which describe the legal expectation on public bodies in the development of strategies, plans and services. These are known as the Gunning Principles:

1. Consultation must take place when the proposal is still at a formative stage.
2. Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response.
3. Adequate time must be given for consideration and response.
4. The product of the consultation must be conscientiously taken into account.

Local councils in North Wales have a regional citizen engagement policy (Isle of Anglesey County Council et al., 2016) This is based on the national principles for public engagement in Wales and principles of co-production which informed our consultation plan.

Consultation and engagement

A significant amount of consultation and engagement had taken place with children, young people and adults with learning disabilities and their parents/carers for the population assessment and regional plan. This included work undertaken by the North Wales Learning Disability Participation Group which includes representatives from self-advocacy groups across North Wales. This work has been used to inform the development of the strategy alongside the additional consultation and engagement work that took place specifically to inform the strategy.

Consultation process

We developed a draft set of themes for the strategy based on the engagement findings so far which we consulted on with the North Wales Learning Disability Participation Group and the regional provider network. These were then shared widely as part of the consultation along with a vision for learning disability services in North Wales (developed as part of regional work by Mobius in 2008). We asked people the following questions.

Consultation questions

1. Do you think these are the right areas to look at?
2. What do you think works well at the moment?
3. What do you think needs to be improved? Please include your ideas for improving services and ways to make the most of the resources already in our communities, including people with learning disabilities, friends and family, community groups, voluntary organisations and professionals.

We also produced an easy read version of the questionnaire in consultation with the Learning Disability Participation Group.

The timetable for the development of the Learning Disability Strategy was as follows.

| Month | Actions |
|----------------------------|--|
| January 2017 | Initial visioning event (Going Forward Together). |
| September 2017 | Scoping of capacity to develop the strategy. |
| October 2017 to March 2018 | Project plan agreed. Baseline data collected to inform the strategy. |
| April to July 2018 | Engagement and co-production with people who use services, carers, providers, front-line staff and other stakeholders. |
| August to September 2018 | Revise the strategy, agree priorities and draft action plans. |
| October to December 2018 | Consult on revised strategy and produce the final draft. |
| January 2019 | Final draft strategy to appropriate boards and committees for approval |

Consultation methods

The consultation methods we used were:

- Online questionnaire and easy read questionnaire circulated widely to staff, partner organisations, the citizen's panel, service users and other members of the public.
- Discussion groups and interviews with children, young people and adults with learning disabilities, parents/carers and parents with learning disabilities. This element was led by the North Wales Citizen's Panel.
- Consultation events for service providers and local authority and health staff.

Promotion plan

Details of the consultation including an online questionnaire and easy read version of the questionnaire were made available on our website

www.northwalescollaborative.wales/. We promoted the link through the Learning Disability Partnership members (representing the six local authorities and health) and to people on the learning disability strategy mailing list which included members of the regional provider forum. Initial emails were sent out on 23 April 2018 with a reminder on 11 June 2018. A press release was sent out through each of the six local authorities and health board.

North Wales Citizens Panel Citizen Panel shared the survey through Facebook, the website (www.laisygogledd.wales/), letters and phone calls and face to face meetings. The majority of responses came from fact to face meetings.

In addition the link to the online survey was sent to the county voluntary councils below, asking them to circulate it to their networks:

- Mantell Gwynedd (Gwynedd)
- Medrwn Mon (Anglesey)
- CVSC (Conwy)
- DVSC (Denbighshire)
- FLVC (Flintshire)
- AVOW (Wrexham)

To help reach people with protected characteristics the link was circulated by the North Wales Regional Equality Network to their members with a request to circulate widely.

Information was sent to members of the:

- Regional Partnership Board
- North Wales Leadership Group,
- North Wales Adult Social Services Heads (NWASH),
- North Wales Heads of Children's Services (NWHoCS)
- North Wales Citizen's Panel

Presentations on the strategy were given at the following meetings:

- North Wales Learning Disability Partnership
- North Wales Managers of Services for Disabled Children
- North Wales Regional Event for Self-Advocacy Groups
- BCUHB Strategy, Partnerships & Population Health Committee
- BCUHB Stakeholder Reference Group
- Conwy COG4 Partnership Group
- North Wales Adult Services Heads (NWASH)
- North Wales Heads of Children's Services (NWHoCS)
- North Wales Leadership Group
- Regional Partnership Board

We also attended a meeting of a regional network for parents with learning disabilities.

Social Care Wales circulated to the third sector representatives on the regional population assessment leads network and Learning Disability Wales have shared details on their Facebook pages.

Consultation and engagement review

There were 175 responses in total to the consultation and around 200 views of the regional plan page on the website.

Table 1 below shows the breakdown by members of the public and representatives of the organisations and table 2 shows the number of people with different protected characteristics who took part in the survey.

Table 1 and table 2 show that the majority of responses were from people with a learning disability including parents with a learning difficulty. We reached people in all age groups, people who have a disability or long standing illness/health condition and carers, Welsh and English speakers. We had responses from women and men although there were not as many responses from men. We also had a small number of responses from people with different marital statuses, ethnic identity, sexuality and gender identity. We did not get many responses from people with protected characteristics of national identity (other than from the UK and Ireland) or religion. We did make sure the survey and reminders were sent to groups and networks of people with these protected characteristics. We will also make the people responsible for implementing the strategy aware of these gaps in the consultation so they can take any additional action needed to eliminate potential discrimination.

Please note, the tables below only reflect the answers given to the equality questionnaire. For a full picture of the engagement with people with protected characteristics these figures should be considered alongside the list of organisations who responded to the consultation as well as [organisations](#) who responded to the regional plan consultation and the [organisations and service user groups](#) who responded to the more in-depth engagement carried out for the population assessment that informed the regional plan.

We used this data to monitor the responses while the consultation was open and encouraged groups representing under-represented groups to share the survey and take part.

Table 1: Number of responses by members of the public and organisations

| Type of response | Number | % of responses |
|--|--------|----------------|
| Person with a learning disability | 70 | |
| Representative of an organisation | 65 | |
| Parent or carer of a person with a learning disability | 30 | |
| North Wales Citizen Panel Member | 60 | |
| Parent with learning difficulties | <5 | |
| Total | 175 | |

Some people may have ticked more than one box. Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not sum.

Table 2.1: Age

| Age | Number |
|--------------------------|---------------|
| 0-24 | <5 |
| 25-34 | 5 |
| 35-44 | 20 |
| 45-54 | 40 |
| 55-64 | 20 |
| 65 and over | 5 |
| Prefer not to say | 15 |
| No information available | 75 |
| Total | 175 |

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not sum.

Table 2.2: Sex

| Sex | Number |
|--------------------------|---------------|
| Female | 70 |
| Male | 30 |
| Prefer not to say | <5 |
| No information available | 75 |
| Total | 175 |

Table 2.3: Ethnic identity

| Ethnic identity | Number |
|--------------------------|---------------|
| White | 100 |
| Black or mixed heritage | <5 |
| Prefer not to say | <5 |
| No information available | 75 |
| Total | 175 |

Table 2.4: Preferred language

| Preferred language | Number |
|--------------------------|------------|
| Spoken English | 80 |
| Spoken Welsh | 10 |
| Spoken English and Welsh | 15 |
| No information available | 75 |
| Total | 175 |
| Written English | 90 |
| Written Welsh | 5 |
| Spoken English and Welsh | 10 |
| No information available | 75 |
| Total | 175 |

Table 2.5: Disability

| Disability | Number |
|--|-----------|
| Learning disability / difficulty | 70 |
| Long standing illness/health condition | 15 |
| Physical impairment | <5 |
| Mental health condition | <5 |
| Sensory impairment | <5 |
| Total number of people | 75 |

The total above does not sum as some people had more than one disability.

Table 2.6: Religion

| Religion | Number |
|--------------------------|------------|
| Christian | 45 |
| None | 30 |
| Other | <5 |
| Prefer not to say | 25 |
| No information available | 75 |
| Total | 175 |

Table 2.7: Sexuality

| Sexuality | Number |
|--------------------------|---------------|
| Heterosexual / straight | 85 |
| Lesbian, Gay, Bisexual | <5 |
| Prefer not to say | 15 |
| No information available | 75 |
| Total | 175 |

Table 2.8: Carers

| Carer | Number |
|--------------------------|---------------|
| Yes | 35 |
| 1-19 hours | 15 |
| 20-49 hours | 10 |
| 50 hours or more | 10 |
| No | 60 |
| Prefer not to say | 10 |
| No information available | 75 |
| Total | 135 |

Table 2.9: Marital status

| Marital status | Number |
|--|---------------|
| Married or in a same sex civil partnership | 60 |
| Single | 10 |
| Divorced or legally separated | 5 |
| Widowed | <5 |
| Prefer not to say | 20 |
| No information available | 75 |
| Total | 175 |

Organisations represented in the online survey

Below is a list of organisations whose staff took part in the online consultation. We also held engagement events for providers and local authority and health staff so more individuals and organisations took part in the consultation than are listed here. In addition the draft strategy was shared widely to provide a further opportunity for individuals and partner organisations to influence and shape the strategy.

Local authorities and health

- Betsi Cadwaladr University Health Board
- Isle of Anglesey County Council
- Gwynedd Council
- Conwy County Borough Council
- Denbighshire County Council
- Flintshire County Council
- Wrexham County Borough Council

Responses from health staff included the Community Learning Disability Team, Learning Disability Nurses, Occupational Therapy, children's learning disability services, in-patient services for people with learning disabilities.

Responses from local authority staff were mainly from within social services departments, from both children's and adults' services.

Service user groups and organisations

- AVOW (County Voluntary Council)
- Cartrefi Cymru Coop (Not for profit domiciliary care agency)
- Centre of Sign-Sight-Sound (Supporting people with a sensory loss)
- Clwyd Alyn Housing Association (Housing provider)
- Community Transport Association (Supporting inclusive and accessible community transport across Wales)
- Conwy Connect (An independent voluntary organisation working on Conwy county promoting the rights of adults with a learning disability to have equal choices and opportunities)
- Grange Residential Care Ltd (Residential care home for adults with learning disability and/or Autism Spectrum Disorder (ASD) in St Asaph.
- Flintshire Learning Disability Planning Partnership (a group including service user representatives, advocacy, service user providers and parents)
- Home Instead Senior Care (Health care provider)
- Job Centre Plus (Delivering a service with the aim of supporting people into work or coaching them to understand the services that are available for people who have disabilities and health conditions).

- Lifeways (Supported Living Provider for adults with learning disability/mental health).
- Mencap (Support individuals with a learning disability).
- MHC (Social Care) UK Limited (Provide residential services for people with learning disabilities, autism, and co morbid diagnosis and people with functional mental health)
- NWAAA Self Advocacy Groups
- Potens (Private limited company providing support to younger adults in Wales, England and Northern Ireland. We support adults with learning disabilities and mental health issues.
- PSS (Shared Lives Adult Placement)
- Stand North Wales CIC (Parents support)
- Voyage Care (Provide support to individuals)

Draft

Consultation findings

Consultation survey

Research methods

The survey was carried out between 23 April 2018 and 20 July 2018, see above for details of how it was promoted and who took part. The answers to the open ended questions were coded using the Catma software. In the analysis we have tried to give a sense of how often themes were mentioned by saying whether comments were by one person, a few people or by many people. This is not to say that just because one person raised an issue that it's not important and it may also reflect the views of many other people, which we can check and investigate further.

Potentially identifying information such as names of people and organisations has been removed from the quotes used.

Findings

Overall 93% of respondents agreed with the themes for the strategy. Comments in support of the themes include:

“The areas are perfect, they cover many aspects of daily living and are concise”

“They are all important to make me happy”

Suggestions for additional themes or expanding the themes included:

- The need for real voice, choice and control with a focus on rights and equality. One person said we need to go beyond questionnaires or consultation towards a truly co-produced strategy and co-produced services.
- More inclusion and integration of people with learning disabilities into the wider community. Including the need for staff training about specific learning difficulties and an awareness that not all disabilities are visible.
- Advocacy support for individuals.
- Support for people with profound and multiple learning disabilities, complex health needs and/or challenging behaviour.
- Support for people who also have other needs such mental health needs, who have autism or involvement in the criminal justice system and forensic needs.
- Carer breaks (respite) – including for people with profound and multiple learning disabilities; jointly commissioning breaks for people with challenging behaviours and additional health needs; and, access for people with learning disabilities to

holidays without their parents. Need to consider the impact on carers of providing care and support.

- Having enough money to live on.
- Early intervention, for example “listen when a family is crying out for help before it reaches crisis point’.
- Early years and having the right start in life.
- The importance of transport.
- The needs of older people with learning disabilities and older carers.

There were 7 people with learning disabilities (4%) who commented that they were not sure that some of the things were important to them including being healthy, being safe, a good place to live and the right support. Other things that were important to people were the way they were treated, for example support workers that understood that they ‘like a clean house’.

Services that work well

- The support people receive from family and providers was the most often listed as something that works well, for example, “being supported by people who know me, my routines and my behaviours” and “I get good help from my advocate and the support workers that come and see me”.
- In addition to good support workers other staff were mentioned for example “I have a good social worker” and “some places work well where you have good staff teams”.
- Some people mentioned joint working between local authority colleagues, co-located teams and multi-agency teams, social services working well with third sector organisations.
- People’s work was also mentioned as working well for example “I am supported in my work at [name of workplace]. I really like it there” “I work in [name of workplace] 2 days a week. This is very good for me as I am learning basic living skills”.
- Carer breaks (respite) for example “Respite has also been an important factor for us as a family and [name of provider] have been a major part in this and have provided us with support we could only dream of”.
- A few people mentioned support budgets, direct payment and person centred approaches as working well.
- Good education was mentioned by a couple of people, including a residential college.
- Charities that provide activities such as swimming.

- The acute liaison service with additional comments that it needs to be used and improved.

A couple of people also said that nothing works well at the moment.

What needs to be improved

The feedback on what needs to be improved is broken down by theme below. In addition to this there were issues that can prevent people from experiencing good outcomes under all of the themes, which are:

- **Support for carers:** Carer breaks (respite) was mentioned by many people in the consultation. Some of the specific issues include a lack of short breaks for families, respite provision for people with more complex needs such as challenging behaviour and autism and regular and predictable respite that is open all year round. Someone also mentioned the need for safe places and activities in the community where support workers can take young people with complex needs to give families a break. For example “There is a lack of short breaks for families and without this we have seen many families going into crisis resulting in out of county placements that are far away” and “without regular breaks families cannot survive”. People mentioned the importance of considering the impact on families, including the needs of siblings of children with learning disabilities. Also the importance of listening to parents and supporting parents/carers to building resilience and develop coping mechanisms. People also mentioned the needs of older carers, for example:

“Something needs to be done about the huge number of elderly carers to: a. Ensure that they are physically fit enough to continue caring b. To gradually introduce their adult sons/daughters to services so that it won't be such a shock for them when their parents are no longer able to care. To estimate the likely cost of providing services to this group of clients in the future.”

- **Funding:** having enough funding available for services, for example “Budget cuts are hitting statutory services and this will impact on individuals, groups and families” and “The government needs to fund services for vulnerable people!”. A few people mentioned the need to work together and consider merging budgets to try and address these issues and one person mentioned the issue that providers and direct payment recipients may have to pay back pay for sleep-ins. Another person mentioned that we need to make better use of technology.
- **Transport:** people mentioned how important transport was to them for inclusion in activities including having someone who can drive them, bus passes and subsidised transport. People also mentioned the orange wallet system that helps people with using public transport. One person said: “I miss out on evening activities as none of my family drive so I rely on taxis which are expensive”.

- **Access to information:** A few people mentioned the need for more information about the services that are available, details of who is able to access support from them and availability of services in Welsh. One person suggested sharing information about offers available at local facilities such as the leisure centre or theatre.
- **Workforce development:** Some people talked about the importance of training and support for staff, particularly support workers. Also the importance of training the wider workforce, such as training for GPs about the needs of people with learning disabilities and how to access community teams. Some of the feedback and suggestions included:

“Often support workers are low paid and are not given training and support”

“Thorough inspections and better recruitment for services who provide care for people with complex needs, people need to be free from abuse, services must act on staff poor practices.”

“Most [staff] have no understanding of impact on people’s lives, assuming because they can do something everyone can.”

“Ask individuals and their families to input into training for professionals - especially for decision-makers.”

“Adequate training for support staff: up to date information about the needs and rights of people who have a learning disability; respect for people with learning disabilities; mental capacity act and making choices/decisions; communication/ learning/wishes and feelings of people - identifying the needs of each individual and adapting approach; losing labels and 'seeing' the person; enabling as opposed to doing for; people with learning disabilities trained to deliver training; limiting the use of support staff mobile phones while they are working; encouraging support staff to join in with activities rather than just taking a person to a venue and sitting on the side-lines, observing.”

“Good supportive management style for the service provider is important as is regular audit/ supervision interviews”

Many people mentioned the importance of **joint working between health and social care** and other partners to provide good services and to address funding issues. A few also suggested better information sharing systems between health and social care. Comments included:

“Maybe it would help if health and social care budgets were merged for some services to stop health and social care fighting over who pays for what.”

“I find that a lot of the work the community nurses are doing now is focused around assessment for funding and funding applications, this takes time away from nursing interventions and a lot of the hands on work that used to be done by community nurses. It would be good to have a specific role or link nurse for

completing health funding applications, and this to be separate from the community nursing role to free up the role for doing specific health interventions.”

“There needs to be more understanding of what other areas can provide and look at replicating that in the local area.”

“working across teams and organisations e.g. CAMHS and disability services, child and adult disability.”

“I think all local authorities should all be working in the same way so... you know you are giving information that is up to date and consistent.”

“Managerially, Betsi Cadwaladr University Health Board and Social Services need to work better together, shared targets etc”

We also asked people for **ideas to improve services that would make the most of resources already in our communities**, including people with learning disabilities, friends and family, community groups, voluntary organisations and professionals. There was a lot of support for the idea that we should ‘help each other’ as well as for the improving inclusion within the wider community, for example,

“We need to access all services from all sectors, community groups and voluntary organisations”

“Clearly there is a need to reduce the number of organizational services and to get more community-based activities that people with learning disabilities attend / contribute”

“It should be remembered that the biggest steps need to be taken by society, not by the individual. A simple example of this is as follows - a person sits at the doorstep of a building, sitting in a wheelchair. The 'problem' is not the person. The problem is the lack of a ramp.”

“I believe that the contribution of individuals to communities is important as well as taking action, whether they are small or large towards greater independence.”

But there were also some concerns about the pressures this could put on people. For example,

“What things could people do to help each other? People could share experiences of Direct Payments, form co-operatives, pool Direct Payments etc. However, at [over 60] years of age I have had enough and am very disillusioned. I just want to retire and be my son’s mum – not his care manager! The SS&WB Act talks a lot about co-production and using “natural

supports". Whilst I am not against these things you can't rely on the good will of volunteers. Families like ours have spent years fighting for services for our sons/daughters. We can't be expected to have the time and energy to form co-operatives or social enterprises or charities to set up alternative services for our sons/daughters. Generally speaking I think that Adult Social Care is an inefficient bureaucratic organisation which is not really focussed on the best interests of people with learning disabilities (although there are individuals working within Adult Social Care who are really dedicated and doing their best for people.) I think we need an alternative model of support."

"Voluntary groups are always trying to find money to support their work and this can often fall on a small group of volunteers ~ could some work together and share the load?"

A good place to live

A few people mentioned where they live as one of the things that is working well. For example,

"I have a good life with my adult placement, I have my own room and a dog and a proper family"

"I live in a supported living house we have a support worker with us at all times so we know that we are safe, we enjoy living together in a girls house and going out together."

Another person said advocacy was important in helping them find a place that suited them. For example,

"I got a lot of help from advocacy to move house because I wasn't happy and I didn't feel safe in my old house so I moved to a better flat, I got to choose my flat and I decorated it and put what furniture I wanted in it."

People wanted to have more choice about who they live with. Some people said that having pets was important to them.

One person suggested that,

"Local Authority and Health need to be looking at purchasing pre-built houses to accommodate individuals with a learning disability that is in their county whilst staying away from the typical 'learning disability community'"

A few people said that their needs to be more investment in accommodation and accommodation-related support particularly for young people.

Out of county

A few people mentioned issues with out of county placements. One person said there were problems with timely decision making and that some of their cases had been to panel 4 or 5 times. Another that,

“We hit a lot of housing issues due to certain counties refusing to place people form out of county. If a person wants to live in a particular place they should be able to.”

Something to do

A few people mentioned the importance of having something meaningful to do, not just something to do. Making a difference was really important to a number of the people we spoke to. For example:

“I like to go to meetings to tell people what is important to other people in other counties.

“I like to help people in the shop, I think people need more jobs.”

“I like making a difference to people and talking to people.”

Many people mentioned their jobs as something that works well. Work was often mentioned by people as important because it's a chance to spend time with friends and people they get on well with.

There were a lot of different leisure activities that people mentioned as important to them including: volunteering, snooker, tennis, wheelchair basketball, ten pin bowling, playing pool, Men's Sheds, magazines, star wars figures, art and art classes, cinema, shopping, watching TV and films, swimming, colouring, computer games, newspapers, ironing, watching and playing football, music, theatre, dancing, going out every night, sports clubs, buzz club, curry night, going out for meals, walking and holidays. A few people mentioned that there need to be more leisure activities and opportunities for people with learning disabilities, more integrated community-based activities and mixed groups.

There were some concerns about day services and suggestions that we should move to a more inclusive and integrated model, for example:

“I do not believe that the "day service" model is sustainable, it is institutionalised and focuses on containment rather than community integration. We should be focusing on liaising with private sector companies as employers for individuals - giving individuals purpose and reducing social stigma.”

“Why do we still have day centres where people sit around drawing and painting when they could be integrated into society as a positive member of the community?”

“More access to supported employment and movement from that to paid employment.”

There were other concerns about a lack of jobs and suitable activities, for example:

“I think I’m going to struggle to find work when [work placement] closes.”

Some suggestions included:

“Leading by example, coming from both Health and Social Services by employing people with learning disabilities”.

“More collaboration with Disability Advisers in Jobcentre as we have access to the benefits of the people who access all our services and as a requirement to receive benefits we have an obligation to meet the carers and the people with health conditions and disabilities (where possible of course) to ensure they are informed of their rights and provision available to them.”

Children, young people and families

People spoke about the importance of disabled children attending sessions with their friends and including children in existing local groups in the community such as leisure centres or theatres. Need to encourage local groups to support children with learning disabilities and understand that not every disabled child will need one to one support. Need a wider range of activities and also to better share information about the activities available.

Education

A couple of people mentioned issues with the process of statementing, requesting a statement and delays. One person said we needed to review residential schools to see if we are “getting value for money, appropriate support and quality support”. Another said that educational settings need to provide ‘consistency, routine and structure’. And another that,

“I think everyone with a need should have access to laptops in school as a given extended time automatically for exams and if a one to one support is recommended by professionals then it should be implanted without question by the place of learning.”

Friends, family and relationships

Many people said that friends, family and relationships were important to them. People also talked about good relationships with staff and work colleagues. A few people also mentioned that having pets was important to them. For example,

“I think family is important, I live with an adult placement with other people and she is lovely and helps me a lot.”

“My boyfriend is important to me”

When asked what needs to happen a few people mentioned being involved in the community and more support to access community activities as well as meeting friends and partners. For example,

“I would like a relationship, to get married and live with my husband”

“People need to be supported to maintain and develop relationships with friends and partners in a way that puts their own interests first and not the needs of their parents/carers and support workers first.”

“We live in an area where more can be done to access the outdoors we need more accessibility to outside organisations and with this I believe people with learning disabilities will gain trust friendships”

“More support for friendships and relationships - why can't someone pop in to a friend's shared house for a coffee? Why do they always have to do things with the people they live with?”

“Individuals should be encouraged to work based on their ability. They need to be empowered by friends and family to become citizens within their own community.”

Being safe

People commented on the importance of safeguarding vulnerable people so that they can feel safe when accessing their communities. This includes treating people with respect so they don't feel looked down on. One suggestion was having more police on the beat so that they can get to know their community and community members can get to know them. Another person said that more help is needed for people when they get teased for having a disability, they said “me and my girlfriend used to get teased a lot but now we just ignore them”.

Being healthy

People highlighted the need to look at the mental health needs as well as the physical health needs of people with learning disabilities and the need to reduce stigma around mental health. A few people commented that people may not think about mental health when they think of 'being healthy'.

Some people mentioned the need for improving support for people with learning disabilities in hospitals. For example,

“Improvement is needed in hospital settings when people with a learning disability are admitted onto general wards.”

“Learning disability acute liaison nurses need to be available in hospitals at all times to support people. Not just Monday to Friday between the hours of 9am and 5pm. An effective system to flag people with learning disabilities who may need extra support/reasonable adjustments when they arrive at hospital needs to be introduced.”

“Responsibility and awareness needs to be shifted into the community - in an ideal world, we wouldn't need learning disability nurses.”

“Sometimes in our experience health professionals are excellent and are willing to work collaboratively with providers (who after all know the individuals we support best). I would single out GP practices, District Nurses and Ambulance staff here. However, hospital staff often seem too busy or just unwilling to take the time to listen and develop an understanding of how people communicate, what their general needs are, and how our staff can assist them in providing the best possible service.”

One person highlighted the need to improve acute health services and highlighted the need to use the resources developed by the Paul Ridd foundation to improve care in hospitals.

One person mentioned the need for better communication between medical professionals, health visitors, midwife and patient and their family. Another mentioned the need for more consistency when young people move to adult services and gave the example of different CHC funding guidance. A few people mentioned difficulties accessing services and getting doctor's appointments, for example:

“I would like for hospital letters to be easier to read as they are complicated”

“Access to GP appointments – I have to ring at 8 o'clock in the morning for an appointment”

One person mentioned the need to improve services between acute services and community services, including the need for additional Occupational Therapists,

“The link between inpatient and community needs to be bridged better with more services in the community to aid in managing and support people to reduce placement break downs and to better care for people in placement and in their own homes.”

Another person mentioned the need to be aware of sensory loss,

“Many, many people with a Learning Disability also have a sensory loss which is often overlooked, whether that be because of the tests that are performed or because their carer simply misses the loss and puts issues with communication down to the Learning Disability. We need to ensure that more people are able to access the tests, making sure the tests are explained fully, and that carers are made aware of the signs of a sensory loss, and the prevalence within the Learning Disability Community.”

Children, young people and families

People commented that access to mental health needed to be quicker for children with learning disabilities and also more support for their parents.

The right support

People highlighted the importance of having the right support with changes in life and transition but also said that this theme needs to cover more than that. This includes supporting people to be independent, to have choices, good communication and being treated well by support workers. One person reiterated a point from the ‘Going Forward Together’ Event that a key principle is ‘delivering the right care at the right time by the right people’.

Good support was often mentioned as something that works well for people. A few people mentioned how important it was to be independent, have choices about the support they receive and have the right amount of support.

“If I could choose my hours to have support so I can have a social life”

“Would be better if we had more support workers so we could do more and gain more independence.”

“[it’s important to me] to make my own decisions, to be treated as an individual, to live independently as long as possible”

People talked about the importance of people being nice to each other, being treated with respect and also being supported by people that they know and work well with. Example of where this isn’t working well include:

“[Support worker] is a nice man but doesn't work well for me.”

“I'm not happy with my support workers I don't like them being rude.”

Good communication and team work and helping each other were also very important to people. For example,

“listen, teamwork, explain things clearer”

“We also need to ensure that the communication needs of people are met at all times, and that parents and/or carers are not the sole people able to assist with communication.”

One person mentioned the importance of helping people to understand what the right support is, for example:

“Do people have choices in their support in order to differentiate between good and less good?”

There were ideas about how to improve the support available, including:

“We need to look at how resources can be better utilised, for example, transportation to events and staffing ratios.”

“Providers need to liaise with each other, get together, re-unite individuals.”

“Thinking outside the box and even working with staff from another shared house to enable people to do something they would otherwise not be able to do.”

“We need more services for these high-end individuals to prevent them from having to go out of county/ a long way from home for support, as often the families want to support them within their homes and in the community but feel unable to due to without increased support and without feeling more able to integrate in the community”.

“We also inform groups of holiday dates and he is always offered a service within the time frame that it can't be utilised, and are never offered a last minute cancellation, when we have asked. Kids don't show up and there is no consequence for those parents. Aware can be for health reasons, but if the LA is paying for a service for 10 kids and only 5 show, call parents and see if they are local. Even an hour can save a parent's sanity.”

“A "state of the art safe house" facility, NOT a hospital, in times of crisis or emergency for people on the spectrum. A place where they feel supported and understood, NOT a place where they feel they are being punished for some unknown crime.”

“Good support that is known and trusted by the individual that can help them to grow by teaching some basic skills towards greater independence. This involves the service member being there from the interview stage and selecting the appropriate candidate. It also means consistency whereby the support is not chopped and changed to suit the providing agency. By consistency it allows the individuals chance to build a trusting relationship which is important for the well-being of the individual.”

There were also concerns about people who may not be eligible for services or who fall between services eligibility criteria, for example, between learning disability services and mental health.

“Some individuals do not meet the 'formal' threshold for services and can potentially miss out on receiving assessment and services if their IQ is deemed not to identify them as having a learning disability.”

Children, young people and families

Parents mentioned challenges around waiting for assessments, the time taken and needing to wait for a certain age for an assessment. Parents also said they needed better support and understanding from professionals while waiting for an assessment. For example “not try to blame the parents about their child’s behaviour while waiting for an assessment... they sent me on parenting courses and making me believe it was all my fault”.

For parents with a learning disability, one person said that it’s important that they get to have their say too.

Suggestions for improving services included:

“We need more services that are going to support children and their families with complex needs and there needs to be more understanding of what other areas can provide and look at replicating that in the local area”

Support budgets, direct payments and person-centred support

These were mentioned as working well by a few people who took part in the survey, for example,

“Direct payments present an opportunity for people on the margins of society to take back control of the support they need and exercise genuine choice over the life decisions that the majority of us take for granted. Some people are benefitting from these opportunities and in turn, are shaping the types of support that they need.”

There were also some concerns about Direct Payments including comments that people need much more support to use them and difficulties finding a direct payment worker. One person gave an example of the difficulties they had had with direct payments:

“Son currently gets Direct Payments and we employ his PSAs ourselves. We have been doing this for 3 years. We had no support from Social Services apart from the DP Support provided by [name of provider]. This support was inadequate. Running and managing a service for my son is akin to running a

small care company. There was too much work and too many responsibilities. So we decided to give up last July and asked for extra funding to buy in a service from a Provider. Social Services agreed to this but more or less left it up to us to find the Provider and arrange a TUPE transfer. In the end there was only one Provider who could offer a service and we are still struggling with the TUPE transfer. So we have been struggling for 10 months with not enough staff because a part-time member of staff left and we were unable to replace her and the situation still is not resolved... People with severe learning disabilities and their families need a lot more support to use Direct Payments. The DP set-up also needs to be sustainable as parents will not be able to do all the management of staff themselves for ever. Maybe having an organisation (e.g. a co-operative) to be the employer would be better”

Support with changes in life and transition

A few people mentioned the importance of good transition from children’s to adults’ services. Comments included:

“More consistency across health services when young people move to adult services e.g. CHC funding guidance is different”

“Looking at the needs as a whole of the children growing up within mainstream and special schools before they enter adult services should be a priority to assist with the needs and services for the future, adult services can then develop their services according to the needs locally.”

A few people mentioned the needs of older carers and supporting people to be ready for changes, for example,

“Important to discuss realistic future care plans with carers for their loved ones sooner rather than later.”

“Earlier planning and interventions required, but also creativity around service provision in order for people to continue to live in what are often loving environments - shared care, downsizing accommodation, extra care where the parent and person can continue to live together with their differing and changing needs and outcomes being well accounted for.”

Conclusion

Overall the vast majority of people consulted were supportive of the themes. Based on the feedback received we have amended them to clarify what we mean by ‘right support’, add ‘family’ to the ‘friends and relationships’ theme, change ‘something to do’ to ‘something meaningful to do’, include a separate ‘early years’ theme and make sure that a lifespan approach and the needs of people with profound and multiple learning disabilities are included throughout the strategy. The other findings and

ideas for improving support will be incorporated into the strategy and action plans. This report will also be made publically available so that the details can be used to inform other work.

‘Going Forward Together’ Event

The event was an initial staff/partner engagement session on ‘Developing our Learning Disability Strategy’ that took place on 17 January 2017 involving 28 staff from across BCUHB and the six local authorities. The event was facilitated by BCUHB to inform the development of this strategy. The discussions looked at current strengths and challenges and what needed to change.

The event identified the following key themes for the development of a strategy:

- Joint working through a shared vision/shared values
- Service user and co-production
- Leadership, governance and accountability
- Commissioning
- Staffing (including links to North Wales Workforce Development Strategy)
- Staff involvement in the development of the strategy

The guiding principles discussed were:

- Shared responsibility to implement the legislation.
- Person first, learning disability second.
- Right support at the right time to the right people in the right place.
- No-one to experience delays in support due to disagreements between services. Shared responsibility to ‘fix it’.

The key observations and actions were:

- The staff that attended understood the need to work together to build a robust strategy for learning disabilities – they all contributed to the whole event with very few delegates having to leave early.
- The overall consensus was that a shared vision and values would need to be developed to underpin the strategy. This work commenced during the session but would be further enhanced
- The core capabilities of the Learning Disabilities service was not as easy to describe by the delegates and therefore some further analysis/discussion would lead to a better understanding of the current state.
- It was acknowledged that this was a starting point and further continuous engagement would be required in order to develop the Learning Disability Strategy for North Wales.
- Involving people with lived experience was agreed as a critical next step.

- Programme of work to be developed following the lessons learnt from the Mental Health strategy development.
- Agreement that the LD Partnership Group was key but work was required on Terms of reference and membership.

Provider forum

The first North Wales provider forum was held on 9 April 2018 and around 60 people attended from across the region. The full report is available at <https://www.northwalescollaborative.wales/learning-disability-provider-forum-9-april-2018-event-feedback/>.

Based on the feedback from the day the themes for the strategy were updated before they went out to wider consultation. Other findings included more detailed definitions of the themes, principles and values (including Welsh language and culture, advocacy and self-advocacy) and the barriers faced (including transport issues). There was discussion about the wide range of people who needed to be involved in the development of the strategy which informed the project's communication and consultation promotion plans.

Staff engagement event

The local authority and health staff event was held on 18 July 2018 and over 100 people attended from across the region. The full report is available at: <https://www.northwalescollaborative.wales/learning-disability-strategy-local-authority-and-health-staff-event/>

Event findings

The event provided more information about what needed to be included under each of the strategy themes as well as ideas for actions under each theme. Overall findings were:

- Make sure we include people with profound and multiple learning disabilities in the strategy – consider a 'sub-strategy' focussing on this group. Also include people currently living in a 'hospital environment' and people who need support due to pre-offending behaviour or offending behaviour.
- Continue to promote and develop [Dewis Cymru](#) as a source of information about the services and support available in local communities.

The event highlighted importance of:

- Working together, joint commissioning and planning, pooling resources and sharing skills and good practice across North Wales. Shared responsibility and addressing of shortfalls when things change.

- Culture change - raising awareness and building friendships and relationships within an inclusive community to make the most of the assets, resources and skills available.
- Taking a person-centred approach.
- Workforce development. Suggestions included a clear pen portrait / skills for staff providing support and training for the wider workforce, including GPs and healthcare assistants, about reasonable adjustments and preventative measures.
- Making links between the different themes, for example, having the right support is key to good outcomes in all of the themes and all the themes contribute to good health.

Draft

References

Isle of Anglesey County Council, Gwynedd Council, Conwy County Borough Council, Denbighshire County Council, Flintshire County Council and Wrexham Council 2016. North Wales Regional Citizen Engagement Policy. NWASH.
Welsh Government 2015. Social Services and Well-being (Wales) Act 2014: Part 9 Code of Practice (Partnership Arrangements).

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Eitem ar gyfer y Rhaglen 6



SOCIAL & HEALTH CARE OVERVIEW SCRUTINY COMMITTEE

| | |
|------------------------|------------------------------------|
| Date of Meeting | Thursday 4 October 2018 |
| Report Subject | Progress for Providers |
| Cabinet Member | Cabinet Member for Social Services |
| Report Author | Chief Officer for Social Services |
| Type of Report | Strategic |

EXECUTIVE SUMMARY

This report provides the Health and Social Care Overview Scrutiny Committee with an update on 'Progress for Providers – Creating a Place Called Home ... Delivering What Matters' including recent success at the Social Care Wales Accolades 2018.

The report also provides an opportunity to raise awareness of the project and its outcomes.

RECOMMENDATIONS

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| 1 | Members to recognise the impact of 'Progress for Providers – Creating a Place Called Home Delivering What Matters' |
| 2 | Members consider actions and initiatives underway to further develop the programme. |

REPORT DETAILS

| 1.00 | EXPLAINING PROGRESS FOR PROVIDERS |
|------|---|
| 1.01 | In Flintshire we have 26 Nursing and Residential Care Homes which support over 800 older people to live well. The majority of these homes are owned and managed by local business men and women who face significant challenges to ensure their businesses and the care sector are successful |
| 1.02 | One of the recent key changes in the care sector has been the introduction of the Social Services and Well-being (Wales) Act 2014 which required the sector to move away from commissioning task based services and instead move towards ensuring providers support people to achieve their own personal outcomes and to promote well-being. |
| 1.03 | Flintshire County Council appreciated that we had important assets to draw on when facing these challenges. We are proud of the positive relationship we have with our providers and their willingness to engage in creating and developing new approaches and solutions to address these new ways of working. |
| 1.04 | The importance of resident's lived experience has also been apparent for some time and Flintshire recognised the importance of enabling people to make choices about the things that matter most to them giving them more control over the services that support them to live their lives. |
| 1.05 | This ethos was also reflected in the Older People's Commissioner for Wales Report of 2014 'A Place to Call Home? – A Review into the Quality of Life and Care of Older People Living in Care Homes in Wales' (Appendix 1). |
| 1.06 | To take the concept forward Flintshire engaged with Helen Sanderson Associates and a leadership steering group was formed. An open invitation was extended to all residential care homes in Flintshire and 16 of the 26 committed to be part of the programme. |
| 1.07 | These homes have embraced on a journey alongside the Council's own in-house provider services, social work teams, OTs, management teams and many more to implement person centred practice including 'One Page Profile', 'Good Days and Bad Days', 'Working/not working' and more. |
| 1.08 | In order to recognised the milestones the care homes were making in achieving on their journey of implementing person centred care practices, Flintshire developed its own 'Progress for Providers' a self-assessment toolkit. The toolkit clearly sets out Flintshire's expectation around the delivery of individualised care and it supports Responsible Individuals and Managers and leaders within homes by providing a range of person centred tools which help staff teams change the way they support people and how they engage with family and friends. The 'Progress for Providers' toolkit also helps providers promote greater choice and control for those who receive care which allows providers to really focus on what matters most to each person. |
| 1.09 | To show the progression, Flintshire introduced 3 levels of accreditation which are validated by the Flintshire Contract and Commissioning Team in |

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| | partnership with the Care Home Managers. The Bronze, Silver and Gold accreditation help manager check their own progress of time and demonstrate publicly that they are making continued progress along the road to truly person centred care. |
| 1.10 | In September 2018 the project was publicly recognised, winning the Social Care Wales Accolades Awards for 'Excellent outcomes for people of all ages by investing in the learning and development of staff'. The project was also a finalist in the Association for Public Service Excellence (APSE) Awards - 'Celebrating outstanding achievement and innovation within UK local government service delivery', also held in September 2018. |
| 1.11 | Demonstrating the true partnership approach to this programme, the Social Care Wales Accolades Award was collected by Sue Hale, Care Inspectorate Wales; Sandra Stacey, Manager Llys Gwenffrwd Residential Care Home; Ceri Cartwright, Contract Monitoring Officer FCC; Tracey McLintock, Contract Monitoring Officer FCC; Craig MacLeod, Senior Manager Children and Workforce FCC, Cllr Christine Jones, Cabinet Member for Social Services and Emma Hill, Manager Phoenix House Residential Home (Appendix 1 - pictured left to right). |
| 1.11 | Progress to Date |
| 1.12 | Currently 14 Residential Care Homes in Flintshire have achieved Bronze accreditation. Flintshire's Contract Monitoring Officers will soon be carrying out a short review of these homes that have achieved the Bronze standard to ensure that person centred practice is sustained and embedded, and homes will then be invited to work towards Silver accreditation. |
| 1.13 | Work is underway developing guidance and paperwork for Silver and the Contract and Commissioning Team are also developing Progress for Providers for Domiciliary Care by creating a secondment opportunity for an individual with a domiciliary care background to come and work with the team to develop and pilot the programme in this sector. |
| 1.14 | Work is also underway to adapt the programme for Nursing Care providers initially working with those who have dual service delivery (Residential and Nursing Care). This work commenced recently and several Flintshire Nursing Homes have already been using some of the person centred tools with their residents. |

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| 2.00 | RESOURCE IMPLICATIONS |
| 2.01 | Continued development through the Commissioning and Contract Monitoring team with one individual to be seconded to the team on a short term basis to adapt the programme for Domiciliary Care. |

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|-------------|--|
| 3.00 | CONSULTATIONS REQUIRED / CARRIED OUT |
| 3.01 | During the initial design and implementation phase, consultation events and activities were held with all stakeholders. |
| 3.02 | With the development of the programme into Domiciliary Care and Nursing Care further consultation and collaboration work is being undertaken with representatives from both sectors to ensure the tools and guidance is fit for purpose. |

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| 4.00 | RISK MANAGEMENT |
| 4.01 | None |

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| 5.00 | APPENDICES |
| 5.01 | Appendix 1 – Award photograph |
| 5.02 | Appendix 2 – Older People’s Commissioner for Wales Report ‘A Place to Call Homes? - A Review into the Quality of Life and Care of Older People Living in Care Homes in Wales’ |

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| 6.00 | LIST OF ACCESSIBLE BACKGROUND DOCUMENTS |
| 6.01 | None. Contact Officer: Jane Davies, Senior Manager Safeguarding and Commissioning Telephone: 01352 702503 E-mail: jane.m.davies@flintshire.gov.uk |

| | |
|-------------|---|
| 7.00 | GLOSSARY OF TERMS |
| 7.01 | (1) Social Care Wales - A Welsh Government created national body created to leave and support service improvement in Wales by building a confident workforce in social care. |
| 7.02 | (2) Social Care Wales Accolades - The Accolades are the biennial awards that recognise, celebrate and share excellent practice by organisations, groups or teams in social work, social care across Wales. |
| 7.03 | (3) Older People’s Commissioner for Wales - The Older People’s Commissioner for Wales is an independent voice and champion for older people across Wales, standing up and speaking out on their behalf. The current Commissioner is Heléna Herklots CBE. |



Mae'r dudalen hon yn wag yn bwrpasol



Older People's Commissioner for Wales
Comisiynydd Pobl Hŷn Cymru

A Place to Call Home?

A Review into the Quality of Life and Care
of Older People living in Care Homes
in Wales

An independent voice and
champion for older people

Ydalen 159



The Older People's Commissioner for Wales

The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales. The Commissioner and her team work to ensure that older people have a voice that is heard, that they have choice and control, that they don't feel isolated or discriminated against and that they receive the support and services that they need.

The Commissioner and her team work to ensure that Wales is a good place to grow older, not just for some but for everyone.

How to contact the Commissioner:

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Twitter: [@talkolderpeople](https://twitter.com/talkolderpeople)

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Published November 2014

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Foreword

When older people move into a care home, all they are doing in effect is moving from one home to another. The word 'home' should mean something special, a place that we hope will be filled with friendship, love and laughter.

Regardless of where we live when we are older, or how frail we are, we will all want to feel respected and valued and be able to do the things that matter to us. We all want, regardless of our age or frailty, or where we call home, to have the very best quality of life. This is why I chose to focus my Review on the quality of life and care of older people in the place they should be able to call home.



At our best, and I have personally seen much of our best, we are ambitious, bold, challenging of ourselves, creative and innovative. At our best, our care homes in Wales, our care staff and our services, give people the best quality of life they could have. However, many of the older people and families that I have supported and those who have contacted me as part of my Review have shared with me examples of care that not only fall below the standard of care that people have a right to expect, but are also unacceptable.

My Review has been the biggest inquiry ever undertaken in Wales into the quality of life and care of older people in care homes and the lives they live. Led by me, with the support of an advisory board of experts in the field of residential and nursing care, as well as older people and carers, it combined a national questionnaire, to which over 2,000 people responded, and extensive written and oral evidence from 93 organisations. I also met and heard directly from care home owners and managers. At its heart, however, were visits to 100 care homes across Wales to meet with residents, their families and staff to ensure I was able to deliver what I promised my Review would do: give a voice back to older people, their families and those who care for and care about them.

The findings of my Review make for hard reading, but in failing to acknowledge the changes required we undermine the good care there is and prevent ourselves from achieving what we are capable of in Wales. My Review makes very clear the impact of failing to get it right upon the people living in care homes and the price that is paid when failures occur, which, for too many, is simply too high.

A simple concept needs to be reclaimed across residential care: that it is not just about being safe or having basic physical needs met, essential as these are, it is also about having the best quality of life, in whatever way that is defined by an individual older person. Within the current social care system, there is no formal way to recognise or reinforce crucial values such as compassion, friendship and kindness, self-determination, choice and control. Yet these values are key to quality of life and

must now be placed at the heart of the residential and nursing care sector.

I recognise that there are many changes to our health and social care services underway, both at a strategic and local level in Wales, through legislation, modernisation programmes and collaborative approaches. Whilst I strongly welcome this progress, a key question I have asked throughout my Review is a simple one: are the changes underway sufficient to deliver the change that older people want and have a right to see? In determining the areas where further action is required, I have been conscious of current constraints without losing the ambition that we should have in Wales. I have linked my action back to the current and developing policy agenda in Wales, in particular to the Social Services National Outcomes Framework.

My Review is about people and the lives they lead, the value we place on those lives and the value we place, as a nation, on older people. We should be ambitious as a nation on behalf of older people, not just because we are in public service, or because the people I am representing through this Review are some of the most vulnerable people in our society, but because of who older people are. They are not a group apart, they are our family and friends, the people who raised us and taught us, the people we care about and who care about us. They still have much to contribute and should be seen as important members of our communities.

My Review follows shortly after the adoption and launch, by the Welsh Government, of the Declaration of the Rights of Older People in Wales, which reminds us all of our duties towards older people. Through my Review I want to set a new benchmark in respect of the duty of care owed to older people. In doing this, a strong and clear signal is sent: that older people living in care homes in Wales are valued.

I would like to thank all of the older people who have responded to my calls for evidence and helped to shape the outcome of this Review. I would also like to thank my amazing team of Social Care Rapporteurs. Together they have helped me to keep my promise to give a voice back to older people living in care homes in Wales.

All of us who work within public service in Wales have both a responsibility and a real opportunity, through our collective effort, to make good practice standard practice. Based on the good practice that I have seen through my Review, the passion and dedication of so many public service staff and care home providers and the opportunities afforded to us by new legislation, I have no doubt that this is achievable.



Sarah Rochira
Older People's Commissioner for Wales

Key Findings

This section presents the key findings of my Review in respect of four key areas related to the quality of life of older people living in care homes in Wales.

- Day-to-Day Life
- Health and Wellbeing
- People and Leadership
- Commissioning, Regulation and Inspection

These key findings draw together the evidence from my questionnaire, Social Care Rapporteurs' visits to 100 care homes and written and oral evidence submitted to me through the Review.

Day-to-Day Life

Social Participation

- There is a lack of social stimulation within care homes that can lead to older people withdrawing, both physically and emotionally, which has a significant impact on their health, wellbeing and quality of life.
- Residents often do not have choice and control over the activities that they are able to participate in and are not supported to do the things that they want to do when they want to do them.
- There is a lack of awareness amongst care staff about the specific communication needs of people living with dementia and/or sensory loss, as well as the needs of Welsh language speakers, which can significantly reduce opportunities for social participation.

Meaningful Occupation

- Only a small number of care homes enable residents to participate in meaningful occupation, activities that are essential to reinforce an individual's identity, such as making tea, baking, gardening, setting the table, keeping pets, taking part in religious services and helping others.
- In many cases, risk-aversion and a misunderstanding of health and safety regulations act as barriers and prevent opportunities for meaningful occupation.

Personal Hygiene, Cleanliness and Comfort

- While residents' basic hygiene needs are generally being met, the approach to personal care is often task-based and not delivered in a person-centred way that enables an individual to have choice and control.

- The personal hygiene needs of residents with high acuity needs, such as those living with dementia or a physical disability, are sometimes not met, with care staff reporting that they found it difficult or lacked the training to provide personal care in these circumstances.
- There are significant variations in the ways in which residents are assisted in using the toilet. Some care homes take a tasked-based approach, which can have a detrimental impact both on an individual's independence and their dignity, while others respond to residents' needs in a respectful and dignified way, assisting them to use the toilet as and when they require.
- Incontinence pads are often used inappropriately, with residents being told to use them, despite the fact they are continent and able to use the toilet. Pads are also not changed regularly. This causes significant discomfort and has a disabling impact on mobility and independence, stripping people of their dignity entirely in some cases.

Personal Appearance

- Residents are generally supported to choose which clothes and accessories they wear in order to maintain their personal appearance. This is essential to reinforce an individual's identity and ensure that they feel comfortable, relaxed and at home.

The Dining Experience

- Mealtimes are often a 'clinical operation', seen only as a feeding activity, a task to be completed, which means there is very limited positive interaction between staff and residents and a lack of a positive dining experience.
- Residents often have little choice about what to eat, and when and where to eat, which can lead to residents having no control over a fundamental aspect of their daily lives.
- There is a lack of positive communication and interaction between residents and care staff, which is essential to ensure that residents' choices and preferences are taken on board and they are encouraged to eat.
- In many cases the dining experience does not reflect the needs of the individual or enhance quality of life, instead it is structured to be functional and convenient for the care home.

Care Home Environment

- Many care homes have a functional, institutional and clinical feel, with a design and layout that is often unsuitable, rather than being homely, comfortable and welcoming.

- Care homes are often not dementia friendly, lacking in helpful features such as pictorial signage or destination points, which can result in increased confusion, anxiety and agitation among residents living with dementia.
- There is a lack of consideration of the needs of residents with sensory loss, with a lack of assistive equipment, such as visual alarms, hearing loops, stairwell lighting, handrails and clearly marked ramps, essential to allow residents to move around the care home as safely and as independently as possible.

Factors Influencing Day-to-Day Life

- Care homes are often characterised by institutional regimes, where a task-based approach to delivering care concentrates on schedules, processes and checklists, rather than the needs of an individual.
- There are clear variations in the quality of care provided, even within individual care homes, which means that older people are often not receiving the level of care they have a right to expect.
- Older people and their families can have low expectations about quality of life in a care home.
- Older people did not expect anything more than an adequate quality of life in a care home.
- The role of independent advocacy and its importance is neither fully understood nor recognised and there are significant variations in the availability of and access to advocacy services. There is little evidence that independent advocacy services are being actively promoted within care homes.
- The ability of third sector organisations to deliver independent advocacy services is often affected by unstable and unreliable funding.

Health and Wellbeing

Prevention and Reablement

- Inadequate staff resources and training can lead to risk averse cultures developing that can result in inactivity and immobility amongst residents. Similarly, restrictive applications of health and safety regulations can prevent an individual moving freely around the care home. Immobility can actually contribute to a fall, which is inevitably more damaging to an older person's physical and emotional wellbeing.
- Access to preventative healthcare and reablement services, such as Physiotherapy, Occupational Therapy, Speech and Language Therapy and Podiatry, is severely limited within care homes. Where such services are

available, often people are waiting too long to access them, a delay that means it is often not possible to reverse the physical damage or decline that has already occurred.

- The culture of care homes is often built upon a dependency model, where it is assumed that people need to be ‘looked after’. This approach often fails to prevent physical decline and does not allow people to sustain or regain their independence.

GPs

- There are significant variations in how older people living in care homes are able to access GP services, with particular issues around appointment processes and out of hours services.
- There is often a reliance on telephone diagnoses from GPs, which can lead to medications being prescribed incorrectly and potentially dangerous polypharmacy.
- There are often delays in the transfer of medical records, which impact upon the ability of GPs to assess an older person’s health needs when they move into a care home. This is a particular issue when an older person is discharged from a hospital in one Health Board area to a care home in another.

Sensory Loss

- Older people are not routinely assessed for sensory loss upon entry into a care home and there is also a lack of on-going assessment for sensory loss for older people living in care homes. This can result in many older people living with an undiagnosed sensory loss, leading to difficulties in communication that can often be misinterpreted as dementia and lead to a failure to meet an individual’s care needs.
- There is limited awareness in care homes about sensory loss and its impact, which means that a large number of older people could be missing out on essential assistance and support.
- There are issues around the basic maintenance of sensory aids and care staff are often unaware of how to support individuals to use them. This can mean long delays and avoidable visits to hospital to carry out basic maintenance.

Diet

- There are significant variations in the quality of food provided to residents in care homes, from meals that included fresh produce and lots of fruit and vegetables to meals with a ‘ready meal’ appearance.

- There is a limited understanding within care homes about the dietary needs of older people, in particular the importance of meeting an individual's specific dietary needs, and a 'one size fits all' approach to residents' diets is often adopted.
- There is a lack of support to assist and encourage older people to eat, something particularly important for people living with dementia and/or sensory loss. This is often due to care staff being unaware that an individual requires assistance and can result in older people struggling to feed themselves, which has a detrimental impact on their health and wellbeing and can lead to malnutrition in some cases.

Oral Hygiene

- Many care home residents rarely or never have access to a dentist, which results in a significant deterioration of people's oral health.
- Care staff rarely receive training on oral hygiene and are therefore unable to maintain the oral health needs of older people effectively or are unaware of how to identify a problem that needs to be referred to a dentist.

People and Leadership

Care Staff

- Working with emotionally vulnerable, cognitively impaired and frail older people is emotionally, mentally and physically challenging and demanding. Many care staff are generally kind and committed and are trying their best to deliver high standards of care in a pressured environment with limited resources and support.
- Care work currently has a particularly low social status, reflected by low pay, long working hours, poor working conditions and a lack of opportunities for professional development and career progression.
- Registration and regulation of care staff would be an effective way of driving up the status, identity and value placed on delivering residential and nursing care for older people.
- Many care homes are understaffed, sometimes chronically, which can significantly increase the pressure placed on care staff and can result in them having less time to interact with residents as they become more task-orientated to ensure that their essential core duties are undertaken.
- The recruitment and retention of high quality care staff is vital to older people's quality of life. Many of the best care homes are those with high morale among care staff and low staff turnover.

- Current basic mandatory training for care staff, which consists only of manual handling, fire safety and health and safety training, does not sufficiently prepare individuals to understand the needs of older people and provide the appropriate support. Furthermore, a significant number of care staff (estimated to be 40% of the workforce) are delivering care without even this most basic of training.
- Values based training, which includes themes such as dignity and respect, attitudes and empathy and equality and human rights, is essential to ensure that care staff not only fully understand the needs of older people living in residential care, but can also understand what it feels like to be an older person receiving such care. This is essential to be able to provide truly person-centred care and not simply follow a task-based approach.

Nursing Staff

- There is often disparity between the standards of nursing in the NHS and the standards found in nursing care homes. This can be due to a number of factors, including limited clinical supervision, a lack of peer support in nursing homes and a lack of opportunities for professional development.
- It is more difficult to recruit nurses to work in nursing care homes due to a lower standard of pay and conditions, more isolated working environments and a general negative perception of nursing care homes.
- There can be confusion about roles and responsibilities for clinical treatment and care between the NHS and nursing care homes due to assumptions that nurses working in nursing care homes can ‘do everything’. This means that the NHS often does not provide support in a proactive way.

Care Home Managers

- Effective leadership is a common factor amongst good care homes and strengthening management and leadership skills delivers better outcomes. A Care Home Manager plays a key role in modelling person centred care on a daily basis and is essential to improve the quality of interactions between residents and care staff to ensure that a task-based approach is not used in the delivery of care.
- The breadth of a Care Home Manager’s role, as well as competing priorities and demanding workloads, can result in a lack of time to drive the cultural change often required within care homes.
- There is a clear need for effective and on-going support for Care Home Managers, both in the form of additional training and specialist and peer support, due to the increasing demands and expectations that are now placed on this role.

- The role of a Care Home Manager can be too much for one individual to balance and a more equitable balance between the Care Home Manager and the responsible individual (e.g. care home owner) can deliver better outcomes for older people.

Workforce Planning

- Workforce planning is challenging due to a lack of demographic projections about future demand for, and acuity levels within, care homes. It is therefore not possible to quantify the 'right' number of care staff needed in the future.
- The unregulated nature of the care home workforce in Wales, which means that data is not held on the number of care home staff in Wales, can also lead to difficulties around effective workforce planning.
- In relation to nursing staff, workforce planning is not effective as it is based only on the needs of Health Boards and does not consider the needs of residential care. This can cause particular issues around the recruitment of qualified and competent nurses to work in EMI (Elderly Mentally Infirm) settings.
- There are issues around the recruitment of qualified and competent Care Home Managers and there is a lack of effective planning for current and future needs.

Commissioning, Inspection and Regulation

Commissioning

- The statutory focus of commissioning processes has been on contractual frameworks and service specifications rather than the quality of life of older people living in care homes.
- There is a lack of shared intelligence and joint working in contract monitoring to ensure that older people are safe, well cared for and enjoy a good quality of life.
- Commissioners are often experts in procurement but are often not experts in social care and do not fully understand the increasingly complex needs of older people.

National Minimum Standards

- The National Minimum Standards¹ (The Standards) are reinforcing a culture of tick box compliance, rather than creating an enabling culture where older people are supported to have the best quality of life.
- The Standards are insufficient to meet the needs of the emotionally vulnerable and frail older people now living in care homes.

- The Standards do not explicitly outline how to provide enabling care and support to older people with sensory loss and/or cognitive impairment and dementia.

Availability of Care Homes

- The residential and nursing care market in Wales is volatile and fragile. There are a number of barriers that can discourage providers from entering the market in Wales.
- A lack of registered Care Home Managers and a shortage of appropriately skilled nursing staff are risk factors to both the quality of care being provided and the ability for a provider to continue provision.
- The choices available to older people are often restricted by a lack of capacity in some areas, which can result in older people having to move away from their family and communities or live in a care setting that is not entirely appropriate for their needs or life.
- There is no overview at a strategic level to ensure sufficient and appropriate care home places for older people in Wales, both now and in the future.

Self-funders

- The current lack of knowledge about the number of self-funders in Wales living in care homes has an impact on the quality of life of older people as it is not clear what support and advice individuals are receiving and the extent to which or how the quality of care that self-funders receive is monitored.
- Residents who are self-funders and their families are fearful about raising concerns and complaints with a provider because of the perceived risk that they may be asked to leave the residential home and would not know how to manage such a situation without support.
- The health and care needs of self-funders are not sufficiently monitored and are therefore often not recognised and acted upon by visiting Local Authority and Health Board staff because they only monitor the individuals who are funded by their bodies.
- Local Authorities and Health Boards are unable to fully plan for the future needs of the older population and required provision of residential and nursing care if they are unaware of the total number of self-funders living in care homes, or how many self-funders are likely to live in care homes in the future.

Regulation and Inspection

- Quality of life is not formally recognised by the system in the way that it implements regulation and inspection at present and there is too great a reliance simply on formal inspection.
- The current inspection approach adopted in respect of nursing homes means that there is currently not a system-wide approach to ensuring effective scrutiny of the delivery of healthcare within residential and nursing care settings.
- The potential for the regulation and inspection system to be strengthened through the use of Community Health Councils and Lay Assessors to monitor healthcare and wider quality of life within care homes has not yet been fully explored.

Key Conclusions and Required Change

My key conclusions, which are drawn from the key findings of my Review, as well as my own casework and on-going engagement with national and local government across Wales, provide a high level assessment of those areas where change is required. This change is underpinned by clear outcomes to ensure that Wales, in taking forward the action contained within this report, stays focused on the overall aim of my Review: that quality of life sits at the heart of residential and nursing care in Wales.

The overall conclusion of my Review is clear: Too many older people living in care homes have an unacceptable quality of life and the view of what constitutes 'acceptable' needs to shift significantly.

Our best care homes are empowering, enabling, flexible, welcoming and friendly, communities in their own right but also still part of the wider communities in which they are located. The older people who live in these homes have the very best quality of life that they could. In our best care homes, older people are safe, can regain their independence, have a sense of identity and belonging, and are supported to live better lives. This care is a tribute to the many dedicated care home staff across Wales, as well as others who work within our social care system.

However, this is not the case for all care homes. Too many simply focus on the functional aspects of care, with a reliance on a task-based approach, rather than delivering care that is person-centred. Too many care homes are focused on an unchallenged dependency model that prevents older people from maintaining their health, wellbeing and independence for as long as possible. For too many older people their lives in care homes can be without love or friendship and people can be lonely and sad.

Too often, there is an acceptance by organisations and the 'system' of an overall level of care that is simply not good enough. Much of what is now considered to be acceptable should be considered unacceptable in 21st century Wales and falls below the standard that older people have a right to expect. Care delivered without abuse or neglect is not the same as good care.

Through undertaking my Review I have drawn the seven conclusions below. Underneath each conclusion I make clear the change that needs to take place and the outcomes that must be delivered. The actions required, including lead responsibilities and time scales, are contained in the Requirements for Action section on page 98.

1. Too many older people living in care homes quickly become institutionalised. Their personal identity and individuality rapidly diminishes and they have a lack of choice and control over their lives.

When older people move into a care home, too often they quickly lose access to the things that matter to them that give their lives value and meaning and are an integral part of their identity and wellbeing, such as people, places and everyday activities. Older people are often not supported to do the things that matter to them but instead have to fit into the institutional regime often found in care homes, losing choice and control over their lives.

This is due, in part, to a risk-averse culture, but is also indicative of a system in which the dignity and respect of older people is not sufficiently protected and older people are not seen as individuals with rights. This is exacerbated by de-humanising language too frequently used, such as ‘toileting’, ‘feeding’, ‘bed number’ or ‘unit’ that further strips older people of their individuality, their dignity and the concept of the care home as their home. For too many, a daily culture of inactivity and a task-based approach to delivering care, centred around the functional aspects of day-to-day life such as getting up, eating, formalised activity hours and going to bed, leads to institutionalisation and a loss of value, meaning and purpose to life.

The change I expect to see:

Older people are supported to make the transition into their new home, are seen and treated as individuals, have choice and control over their lives, enabling them to do the things that matter to them, and are treated at all times with dignity and respect.

Evidence of this will include:

Older people receive information, advice and practical and emotional support in order for them to settle into their new home, beginning as soon as a decision to move into a care home is made (Action 1.1 & 1.2).

Older people’s physical, emotional and communication needs are fully understood, as are the issues that matter most to them, and these are reflected in the services, support and care that they receive (Action 1.1).

Older people have real control over and choice in their day-to-day lives and are able to do the things that matter to them, including staying in touch with friends and family and their local community (Action 1.1).

Older people are aware of their rights and entitlements and what to expect from the home (Action 1.2).

Older people are clear about how they can raise concerns and receive support to do so (Action 1.2).

Older people are supported to maintain their continence and independent use of the toilet and have their privacy, dignity and respect accorded to them at all times (Action 1.1, 1.3, 1.5).

Mealtimes are a social and dignified experience with older people offered real choice and variety, both in respect of what they eat and when they eat (Action 1.1, 1.4).

Older people are treated with dignity and respect and language that dehumanises them is not used and is recognised as a form of abuse (Action 1.1, 1.3, 1.4, 1.5, 4.6).

Older people living in care homes that are closing, as well as older people that are at risk of or are experiencing physical, emotional, sexual or financial abuse, have access to independent or non-instructed advocacy (Action 1.6).

2. Too often, care homes are seen as places of irreversible decline and too many older people are unable to access specialist services and support that would help them to have the best quality of life.

Older people want to maintain their physical and mental health for as long as possible. However, formal health promotion is absent from many care homes. Too many older people are not being offered preventative screening or interventions, such as falls prevention, mental health support, speech and language therapy, occupational therapy, physiotherapy and wider re-ablement, which would enable them to sustain or regain their independence, mobility and overall quality of life. This is a particular issue when older people move into care homes after periods of ill health or following hospital admissions.

The lack of this specialist support, which would be more readily available if they were still living in their own home, can hasten frailty and decline, both physical and mental.

The change I expect to see:

Older people living in care homes, through access to health promotion, preventative care and reablement services, are supported to sustain their health, mobility and independence for as long as possible.

Evidence of this will include:

Older people benefit from a national and systematic approach to health promotion that enables them to sustain and improve their physical health and mental wellbeing (Action 2.1).

Older people receive full support, following a period of significant ill health, for example, following a fall, or stroke, to enable them to maximise their independence and quality of life (Action 2.2).

Older people's risk of falling is minimised, without their rights to choice and control over their own lives and their ability to do the things that matter to them being undermined (Action 2.3).

The environment of all care homes, internally and externally, is accessible and dementia and sensory loss supportive (Action 2.4).

3. The emotional frailty and emotional needs of older people living in care homes are not fully understood or recognised by the system and emotional neglect is not recognised as a form of abuse.

Older people living in care homes need to feel safe, reassured and that they are cared for and cared about. The current focus on task-based care, together with the absence of a values-based approach, can lead to care and compassion, simple kindness and friendship, too often being missing from older people's lives in care homes. Their emotional and communication needs are often misunderstood and neglected, with the needs of older people with dementia frequently poorly understood. As a consequence, they are too frequently labelled as 'challenging' or 'difficult', which places them at risk of unacceptable treatment and the inappropriate use of antipsychotics. The absence of emotional care is not recognised as emotional neglect, which, in turn, is not recognised as a form of abuse.

The change I expect to see:

Older people in care homes receive the care and support they need to sustain their emotional and mental wellbeing and anti-psychotic drugs are not inappropriately used. Residents feel safe, valued, respected, cared for and cared about, and care is compassionate and kind, responding to the whole person.

Evidence of this will include:

All staff working in care homes understand the physical and emotional needs of older people living with dementia and assumptions about capacity are no longer made (Actions 3.1 & 3.2).

Older people are supported to retain their existing friendships and have meaningful social contact, both within and outside the care home. Care homes are more open to interactions with the wider community (Action 3.3).

Older people are able to continue to practice their faith and maintain important cultural links and practices (Action 3.3).

The mental health and wellbeing needs of older people are understood, identified and reflected in the care provided within care homes. Older people benefit from specialist support that enables them to maximise their quality of life (Action 3.4, 3.5).

Older people are not prescribed antipsychotic drugs inappropriately or as an alternative to non-pharmaceutical methods of support and NICE best practice

guidance is complied with (Actions 3.4 & 3.5).

Emotional neglect of older people is recognised as a form of abuse and appropriate action is taken to address this should it occur (Action 3.6).

4. Some of the most basic health care needs of older people living in care homes are not properly recognised or responded to.

Too many older people living in care homes do not have access to the basic functional screening and primary healthcare that would have been available to them while living in their own home, such as regular access to GP services, eye health, sight and hearing tests, podiatry services, oral health advice, medication reviews and specialist nursing care.

Older people are unable to access services to which they are entitled, undermining their health and wellbeing. As a result of this, their ability to do the things that matter to them and communicate effectively can be significantly compromised.

The change I expect to see:

Older people living in care homes clearly understand their entitlements to primary and specialist healthcare and their healthcare needs are fully met.

Evidence of this will include:

There is a consistent approach across Wales to the provision of accessible primary and specialist health care services for older people living in care homes and older people's healthcare needs are met (Actions 4.1, 4.2 & 4.5).

Older people in nursing care homes have access to specialist nursing services, such as diabetic care, tissue viability, pain management and palliative care (Action 4.1, 4.2).

Older people are supported to maintain their sight and hearing, through regular eye health, sight and hearing checks (Actions 4.1, 4.2 & 4.3).

Older people are able to, or supported to, maintain their oral health and retain their teeth (Actions 4.1, 4.2 & 4.3).

Older people have full access to dietetic support to prevent or eliminate malnourishment and to support the management of health conditions (Actions 4.1, 4.2 & 4.3).

Care staff understand the health needs of older people and when and how to access primary care and specialist services (Action 4.3, 5.4).

Older people receive appropriate medication and the risks associated with polypharmacy are understood and managed (Action 4.4).

Older people are able to challenge, or have challenged on their behalf, failures in meeting their entitlements (Action 4.5).

5. The vital importance of the role and contribution of the care home workforce is not sufficiently recognised. There is insufficient investment in the sector and a lack of support for the care home workforce.

Care staff and Care Home Managers play a fundamental role in ensuring that older people living in care homes have the best quality of life and should be seen as a national asset to be invested in.

However, despite working in highly challenging and difficult circumstances, they currently receive low pay, often have poor terms and conditions, work long hours, lack training and work in a sector that is rarely seen as having a valuable status.

There is insufficient support available to care staff to ensure that they have the skills, knowledge and competencies required to deliver both basic and high quality care and there are limited opportunities for continued professional development and career progression.

Despite the high acuity levels of many older people living in care homes, there is no standard approach to staffing levels and required competencies and, for many care home providers, support is only available to them once the quality of their services has declined to an unacceptable level.

The change I expect to see:

There are sufficient numbers of care staff with the right skills and competencies to meet the physical and emotional needs of older people living in care homes.

Evidence of this will include:

Care homes have permanent managers who are able to create an enabling and respectful care culture and support care staff to enable older people to experience the best possible quality of life (Action 5.1).

Older people are cared for by care staff and managers who are trained to understand and meet their physical and emotional needs, including the needs of people with dementia and sensory loss, and who have the competencies needed to provide dignified and compassionate care (Action 5.2).

Older people receive compassionate and dignified care that responds to them as an individual (Action 5.3, 5.4, 5.5).

Care homes that want and need to improve the quality of life and care of older people have access to specialist advice, resources and support that leads to improved care and reduced risk (Action 5.6).

Older people are safeguarded from those who should not work within the sector (Action 5.7).

The true value of delivering care is recognised and understood (Action 5.8).

6. Commissioning, inspection and regulation systems are inconsistent, lack integration, openness and transparency, and do not formally recognise the importance of quality of life.

At present, there is an inconsistent and geographically variable focus on quality of life within commissioning, which is too often seen as a functional task-based process. Although there is action being taken at a local level in Wales to better recognise quality of life and the Welsh Government has published a new Social Services National Outcomes Framework, this has yet to translate into a consistent and systematic approach to the commissioning, regulation and inspection of care that has quality of life at its heart and is reflected in the way that commissioning, regulation and inspection are implemented.

There are competing and inconsistent demands upon providers, both in relation to standards and reporting, as well as an inconsistent approach to joined-up working, information sharing and the use of information to better evaluate quality of life and care.

Within nursing care homes there is also a lack of independent inspection from a healthcare perspective and there is currently not sufficient scrutiny of access to healthcare within residential care settings.

There is a lack of information that can be meaningfully used by older people, their families and those who care for and support them, to judge the quality of life, care and safety in individual care homes. There is also a lack of information in the public domain from commissioners and providers about the quality of care they provide or are accountable for.

Too many older people struggle to raise concerns and feel that their concerns are acted upon in an unsatisfactory way. There is also, too often, a lack of any evaluation of the quality of care outside of formal inspections.

The change I expect to see:

Quality of life sits in a consistent way at the heart of regulation, provision and commissioning, inspection and reporting. Providers, commissioners and the inspectorate have a thorough and accurate understanding of the day-to-day lives of older people living in care homes and this information is shared effectively to promote on-going improvements and reduce the risk of poor care. There is greater public reporting on the quality of care homes within Wales and older people have access to meaningful information in respect of the quality of care provided within individual care homes. There are effective ways in which the views of residents and

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their families are sought and used to support continuous improvement.

Evidence of this change:

Quality of life sits consistently at the heart of the delivery, regulation, commissioning and inspection of residential and nursing care homes (Action 6.1).

Commissioners, providers and inspectors have a thorough understanding of the day-to-day quality of life of older people living in care homes (Action 6.2, 6.3).

Older people's views about their care and quality of life are captured and shared on a regular basis and used to drive continuous improvement (Action 6.2, 6.3).

The quality of life and healthcare of older people living in nursing homes is assessed in an effective way with clear and joined up annual reporting (Action 6.4, 6.5, 6.6).

Older people have access to relevant and meaningful information about the quality of life and care provided by or within individual care homes and there is greater openness and transparency in respect of the quality of care homes across Wales and the care they provide (Action 6.7, 6.8, 6.9, 6.10).

Older people are placed in care homes that can meet their needs by commissioners who understand the complexities of delivering care and are able to challenge providers about unacceptable care of older people (Action 6.11).

7. A current lack of forward planning means that the needs of older people in care homes will not be met in the future.

There is not a clear national understanding of what the future need for residential and nursing care will be, nor an understanding of how acuity levels within care homes are likely to further change as a result of wider changes in the model of health and social care within Wales and the potential for further development of other models that combine housing and care, such as extra care, has not been fully explored.

This means that there is a lack of effective forward planning for, and action to ensure, the future supply of appropriate, high quality care home places in Wales with the appropriate numbers of specialist staff required, in particular in respect of nursing care.

There are already parts of Wales that are unable to meet current demand, in particular in respect of care of older people with high levels of dementia and nursing care needs.

The change I expect to see:

There are sufficient numbers of care homes in Wales, or alternatives to traditional care homes, in the places that older people need them to be, that are able to provide high quality care that meets the needs of older people.

Evidence of this change:

Forward planning ensures there is a sufficient number of care homes, of the right type and in the right places, for older people (Action 7.1).

Forward planning and incentivised recruitment and career support ensures that there are a sufficient number of specialist nurses, including mental health nurses, to deliver high quality nursing care and quality of life outcomes for older people in nursing homes across Wales (Action 7.2, 7.3).

Impact of not delivering the change required

If we fail to deliver the change I have outlined in my report, we fail older people. We fail those who need us, expect us and require us, through our collective leadership, to act on their behalf. If we fail, the price will not be paid by those of us in public service, it will be paid by some of the most vulnerable people in society and the price that they will pay will be too high.

Within my Requirements for Action (Page 98) I make clear what the impact of this failure will be upon older people. This should drive all of us in public service to do everything that needs to be done to support, protect and stand up for those who are most vulnerable and ensure that older people living in care homes in Wales have the very best possible quality of life.

Why I Carried out my Review

In 2013, I published my priorities as Commissioner, based on extensive engagement with older people across Wales, in effect their priorities. In my Framework for Action, I clearly signalled that I expected to see significant improvements in the quality of, availability of and access to, health and social care. Specifically, that quality of life sits at the heart of residential and nursing care, that people with dementia and other groups of older people needing specific support have their needs met and that older people have voice, choice and control over how they receive services, care and support.

Whilst residential care is not an option for everyone, and increasingly need not be as a result of significant work within Wales to support people in their own homes, for many older people it continues to be a key way in which they receive the care and support they need and, in years to come, will be particularly important for our frailest and most vulnerable older people.

The majority of older people living in a care home will have moved there as a result of complex health conditions, disability or frailty, which meant that they could no longer live safely in their own homes. Many of these people, just a few years ago, would have been cared for in community hospitals or long-term care of the elderly wards.

This means that the 23,000 care home residents in Wales² are amongst the most vulnerable people in society, often as a result of significant levels of cognitive impairment, sensory loss and emotional frailty, as well as physical ill-health, which, too often, can leave them without an effective voice and powerless.

For example, 80% of older people living in residential care will have a form of dementia³ or cognitive impairment. Similarly, it is estimated that 70% of people aged over 70 have some form of sensory loss, a figure that rises significantly among people aged 80 and over^{4,5}.

Older people in care homes, however, must not be categorised by their health conditions or be seen as a homogenous group. Older people living in care homes are diverse, with individual needs and wishes. The diversity of older people, which covers the breadth of race, gender, language, disability, sexual orientation, trans status and religion or belief, must be recognised and the care they receive must be sensitive to their individual needs.

I travel the length and breadth of Wales meeting with many older people living in care homes, as well as care staff, and I have seen for myself the impact that high quality care, which meets people's individual needs, can have on their lives. I have spoken frequently about the many excellent examples of health and social care in Wales and the many dedicated staff in both the public and private sector.

However, I have also received an increasing amount of correspondence about the quality of life and care of older people in care homes across Wales and I have had to provide individual support to older people and their families who have found themselves in the most distressing and unacceptable of circumstances to ensure that they are safe and well cared for.

As a result, I have spoken publicly many times about what I consider to be unacceptable variations in the quality of life and care of older people in care homes. I have been clear that we fail to keep too many older people safe and free from harm, that too many older people are not treated in a compassionate and dignified way and that, for some, their quality of life is unacceptable.

I recognise that much work has been undertaken and is taking place within Wales to address specific aspects of social care. The National Assembly for Wales' Health and Social Care Committee's Residential Care Inquiry, for example, examined how effective the residential care sector was at meeting older people's needs, with a focus on the process by which older people enter residential care. Similarly, the Social Services and Wellbeing (Wales) Act 2014 aims to transform the way that social services are delivered in Wales. Furthermore, forthcoming legislation in the form of the Regulation and Inspection Bill offers a real opportunity for quality of life to become a key part of regulation and inspection processes. There is also work underway across Wales, in some places significant, at a local level, both within Local Authorities and Health Boards and by care home providers, to address a wide range of aspects of residential and nursing care.

However, despite this work, I wanted, and required, a higher level of assurance that the action being taken would ultimately translate to safer, high quality care for older people living in care homes and that having the best quality of life would become the outcome that sits at the heart of residential and nursing care across Wales.

It is for the reasons outlined above that I took the decision to undertake a Review into the quality of life and care of older people living in care homes in Wales, using my powers under Section 3 of the Commissioner for Older People (Wales) Act 2006.

Focusing on and Defining Quality of Life

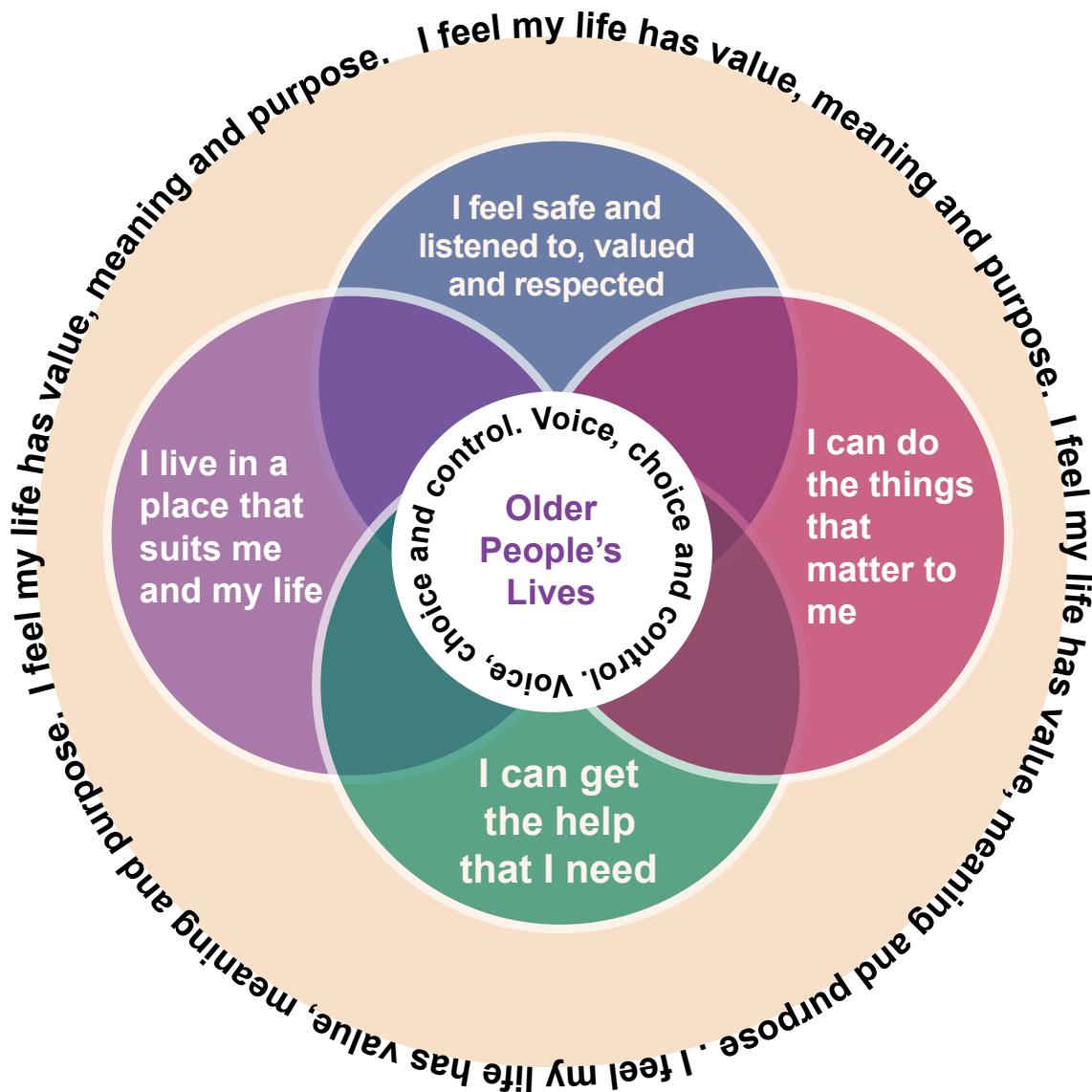
My extensive engagement with older people and care staff in care homes has made it clear to me that life is precious and life is for living, regardless of your age or how frail you may be. It is not sufficient for older people to be just safe and physically well cared for in care homes, essential as these are. Despite the importance of quality of life, through my engagement with older people, it became clear to me that this was systematically missing from our residential and nursing care sector.

Our quality of life as we grow older is hugely important to all of us and should be formally recognised and sit at the heart of the residential and nursing care sector in Wales to ensure that older people living in care homes have lives that have value, meaning and purpose. It is for this reason that my Review focuses on quality of life.

Older people have told me that their lives have value, meaning and purpose when they:

- Feel safe and are listened to, valued and respected
- Are able to do the things that matter to them
- Are able to get the help they need, when they need it, in the way they want it
- Live in a place which suits them and their lives

Figure 1. Quality of Life Model



Older people are very clear that they want to have a strong voice and meaningful control over their lives, both in their day-to-day life and how they are supported and cared for. The extent to which they do will have a direct impact on their quality of life and, in many cases, increase the positive impact of services.

How I Carried out my Review

In order for my Review to achieve its aims, I drew together a number of different approaches, including an extensive literature review, a questionnaire for older people, their families and carers, focus groups, written and oral evidence and visits to care homes to observe and understand the day-to-day lives of older people. To support me in these visits, I recruited a team of 43 Social Care Rapporteurs from a wide range of backgrounds and selected an observation tool that considers a range of quality of life factors such as control over daily life, personal safety and social participation and aligns with my own quality of life model.

Commencing in October 2013, the process for my Review comprised five phases:

Phase 1: (October 2013 – January 2014)

- Review team undertakes comprehensive review of research literature about residential and nursing care.
- Adoption of ASCOT, the Adult Social Care Outcomes Toolkit (Appendix 6), as the framework against which to consider quality of life factors for older people living in care homes.
- Development of a detailed questionnaire for older people, their families and the general public to share their experiences of residential and nursing care. The questionnaire considered factors such as physical and psychological health, social relationships, and the care home environment.
- Formal launch of the Review process, with extensive media coverage across Wales.
- Wide distribution of the questionnaire to every care home in Wales, third sector organisations, older people's groups, 50+ forums and Assembly Members to reach as many older people and their families as possible across Wales. Alongside this, the Review team undertook work with the media, particularly local newspapers, to promote the Review and call for evidence.
- Review team receives over 2,000 questionnaire responses.
- Review team gathers written evidence from the bodies subject to the Review (Appendix 3), with a particular focus on current systems in place and action underway to promote the quality of life of older people living in care homes.
- Review team also gathers extensive written evidence from a wide range of organisations that represent and work on behalf of older people, including professional bodies, third sector organisations and recognised experts in the delivery of residential and nursing care.

- Review team receives a total of 53 written submissions (Appendix 4).
- Review team recruits and trains 43 Social Care Rapporteurs (Appendix 2) to prepare them for visits to care homes during Phase 2.

Phase 2: (January 2014 – May 2014)

- Review team selects 100 care homes at random for visits by Rapporteurs. The selection process ensures that the care homes represent the diverse cultural and demographic context of Wales.
- Rapporteurs make unannounced visits to 100 care homes across Wales, seven days a week, to observe older people and to hear directly from them about their experiences and expectations.
- Review team undertakes a series of engagement events and focus groups across Wales to capture the views and experiences of the families of older people living in residential and nursing care, those providing independent advocacy and representatives of groups whose voices are seldom heard.
- Review team gathers oral evidence at roundtable discussion sessions with organisations that represent and work on behalf of older people, including professional bodies, third sector organisations and recognised experts in the delivery of residential and nursing care.
- Review team undertakes an analysis of the extensive evidence received.

Phase 3: (May 2014 – September 2014)

- Review team undertakes evidence and scrutiny sessions with bodies subject to the Review to discuss and consider the written evidence provided in greater detail and to obtain further information about their understanding of the day-to-day realities of living in residential and nursing care, the change required to improve quality of life and whether current action (planned or underway) is sufficient to deliver this change.
- Review team undertakes a second round of evidence and scrutiny sessions with bodies subject to the Review in order to cross-reference against evidence gathered from the Review questionnaires and care home visits.
- Review team analyses oral evidence from a total of 82 bodies gathered during roundtable discussion sessions and formal evidence / scrutiny sessions (Appendix 5).
- Writing of Review report and development of Requirements for Action.

Phase 4: (November 2014)

- Review report published.
- Requirements for Action issued to public bodies subject to the Review that state what must be improved, changed or implemented to ensure that quality of life sits at the heart of residential and nursing care across Wales.

Phase 5: (February 2015)

- Deadline for responses to Requirements for Action. The public bodies to whom Requirements for Action are directed must demonstrate what action they will take to comply with them.
- Publication of a register detailing Requirements for Action and what action will be taken by public bodies.
- Agreed action is implemented and mechanisms agreed and adopted to provide assurance that this action has delivered the intended outcomes.

Day-to-Day Life

Literature Review

It is clear that the choice and control that an individual has over their daily life is fundamental to a good quality of life.

This is reflected in the volume of literature that explores aspects of day-to-day life in care homes. The National Development Team for Inclusion (NDTi) and the Centre for Policy on Ageing has identified 7 key domains⁶ over which older people value having choice and control, one of which is the need for a meaningful daily life.

“Older people need to have their views and experiences taken into account on an on-going basis to have real choice and control in decisions that affect them.”⁷

Tom Owen, collaborating with the Joseph Rowntree Foundation, Age UK, City University and Dementia UK, conducted research for the My Home Life (MHL) study, ‘Promoting Quality of Life in Care Homes’. The study identified that the principles of voice, choice and control correspond with the three MHL ‘personalisation themes’, designed to promote a more relationship-centred approach within care homes:

- Maintaining identity: ‘See who I am!’
- Sharing decision-making: ‘Involve me!’
- Creating community: ‘Connect with me!’⁸

Owen’s findings go on to report that care home residents need to be “seen as individuals and given a ‘voice’ to express who they are and what they want (maintaining identity)”. In addition, there needs to be “more than one way of doing things (choice), especially in situations of collective living”, and older people need “to have ‘control’ over what is the right option for them (sharing decision-making)”⁹.

Relationship-centred care is central to Nolan et al’s work on the Senses Framework. The conceptual phase, together with practical work from a related project ‘Dignity on the Ward’¹⁰, identified the Senses Framework as a potential framework for practice. These studies suggest that in the best care environments all participants experience a sense of:

- Security – to feel safe
- Belonging – to feel part of things
- Continuity – to experience links and connection
- Purpose – to have a goal(s) to aspire to
- Achievement – to make progress towards these goals
- Significance – to feel that you matter as a person¹¹

“Where there is a community that supports older people, relatives and staff, a greater connection is developed through which choice and control can be realised. This finding is not new; it reflects a strong body of knowledge surrounding relationship-centred care.”¹²

The Commissioner’s own research has found that access to advocacy is key to older people exercising voice, choice and control at all stages of decision-making, from deciding to enter, whilst living in residential care, or when moving from it, and is particularly important as a safeguard for those in a position of vulnerability¹³. However, research has found that there is a lack of access to and awareness of advocacy and information for residents and their families^{14,15}, especially during the process of choosing and entering residential care¹⁶, and without this support it may not be possible for older people to have real voice and choice over their day-to-day lives.

Voice and choice is not only fundamental to promoting the bigger, overarching themes above, it also plays a crucial role in almost every day-to-day decision. For example, a large number of studies indicate that social participation and daily activity are key: “meaningful activity, recreational opportunities, expressive arts or one-to-one activities can make a significant contribution to the overall living environment in care homes”¹⁷. The urge to engage in purposeful and meaningful activity is a basic human drive and this in-built motivation does not diminish or disappear as people age¹⁸.

However, social participation and meaningful occupation are often seen as one and the same. Whilst both can mean some form of general activity, the real difference is in the outcome as experienced by the resident. Social participation is about enabling someone to feel part of the community and engaging with fellow residents. It is vital in encouraging residents to become a part of community life and “turning boredom, lethargy, sleeping and staring into space into positive social interactions”¹⁹. The result of this approach can mean that a resident is more closely connected to and involved in the community life of their home.

However, meaningful occupation focuses more on the concept of wellbeing through specific purpose, which is often aligned to what an individual did previously, such as a former carpenter having opportunities to undertake woodwork.

Research suggests that meaningful occupation engenders a sense of purpose, as well as self-worth, and can help to develop and maintain independence by promoting choice and control in the daily life of residents.

The College of Occupational Therapists has taken a very practical approach to person-centred care to ensure that people are able to continue to live active lives, which enables them to maintain their independence and do the things that matter to them²⁰.

“The traditional service-led approach has often meant that people have not received the right help at the right time ... However, occupational therapists have always

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taken a client-centred approach, which is consistent with the principles and practice of personalisation.”²¹

Choice is vital to improving and maintaining quality of life. The NICE Quality Standard, Mental Wellbeing of Older People in Care Homes, states that [older people] “should be encouraged to take an active role in choosing and defining [daily] activities that are meaningful to them”²². It is therefore crucial that older people in care homes have the opportunity and are encouraged to take part in activity in all its forms, “including activities of daily living, that helps to maintain or improve their health and mental wellbeing”²³.

Choice around personal cleanliness is fundamental to maintaining a good day-to-day quality of life. Having the option to determine the timing and frequency of baths and showers, for example, is crucial. However, the physical act of washing is only one aspect of personal cleanliness; the psychological impact on daily life also needs to be considered. Research has shown that “having a clean and respectable appearance and pleasant environment is key to maintaining the self-esteem of older people”²⁴. In addition, “hygiene and cleanliness is seen as a key indicator of standards within a [care] home”²⁵.

Improving the mealtime experience of adults living in residential care can also be a major factor and a facilitator in improving the care, general health and wellbeing, as well as the quality of life, of older people²⁶.

The physical layout and design of a care home impacts on the daily life of residents. In general, care homes and hospitals are designed to “fulfil an institutional purpose, a purpose which does not enrich life for persons with physical disabilities, memory, perceptual or behavioural challenges”²⁷. However, a care home can be so much more.

A wide range of research draws attention to the importance of building design that encourages and promotes a welcoming and homely space “which allows for privacy when necessary, as well as their [a resident’s] overall desire to have a home that supports relaxed behaviour, common in a domestic setting”²⁸.

It is vital that a positive culture of care underpins an individual’s day-to-day life. A recent Joseph Rowntree Foundation report, ‘Learning for care homes from alternative residential care settings’, highlights the importance of developing a positive culture for caring. The report argues that “a positive organisational culture has the potential to impact on the lives of residents, families and staff”²⁹.

Key areas identified in the report stress the importance of person-centred and relationship-based care. Fundamental to these approaches is the placement of the individual and their families at the centre of care planning. This approach focuses on individuals’ strengths and interests rather than on assessing what they can’t do³⁰.

However, there are other factors to consider. “Studies that have examined the impact of residential services emphasised that features of a positive culture are

complex and depend on...organisational structures, management arrangements, the physical environment, skilled staff and teamwork, and positive staff and resident relationships”³¹.

A key element in improving cultures of care is the need to eliminate a process and/or task-driven approach in which residents have things done to or for them rather than with them. “The prevalent model in care emphasises the debilitating effects of old age where staff take on the role of custodians who ‘do things to’ residents. This devalues staff as much as residents. A more positive model is one which emphasises personal growth for residents and staff with a shared commitment to ideas, values, goals and management practices by residents, staff and relatives”³².

A positive culture also means that all residents, their families and staff members are provided the opportunity to be involved in decision-making processes that affect them. A culture of open communication and information sharing needs to be encouraged enabling all stakeholders to be involved in decision-making processes. Quality improvement is more likely to be successful in homes with a culture that promotes innovation and staff empowerment³³.

Although the literature identifies the importance of person-centred and relationship-centred care as fundamental to improving cultures of care, it is also important to note the emphasis on knowing the resident and understanding his or her needs and preferences. Studies stress the importance of an individual’s right to privacy and guidelines published over the past 20 years have emphasised the importance of valuing privacy, dignity, choice, rights, independence and fulfilment.

Residents should be able to maintain their privacy at all times, and staff should respect this. This includes privacy of their personal care, confidentiality of any information owned by or kept about the resident and privacy of their personal space³⁴.

Treating residents with dignity and respect is a vital part of residential care and must be ensured in order to maintain a positive culture within a care home and enhance good quality of life. It is also worth emphasising that staff need to be treated with dignity and respect if they are to deliver dignified care to residents^{35,36}.

Review Findings

Social Participation

The majority of Rapporteurs reported that many residents spent their time sat in chairs placed around the edge of the lounge, an arrangement that is not conducive to conversation and interaction. In many cases, the TV was left on with no subtitles and no-one watching, its volume making conversation difficult, if not impossible. A number of Rapporteurs also reported that residents were sat in poorly lit surroundings for a significant amount of time until care staff noticed and turned lights on.

For residents who were bed-bound, many were 'left alone' for long periods of time, with interactions limited to task-based care, such as the administering of medicines, and no opportunities for social participation.

The lack of social stimulation within care homes has a significant impact on the wellbeing and quality of life of older people. This can often lead to older people withdrawing, both physically and emotionally, which further restricts potential opportunities for social participation.

Rapporteurs described residents as being withdrawn, seeming 'bored' and 'listless'. Many residents spent much of their time dozing or sleeping, with some choosing to remain in their rooms.

“People were left all day every day without any form of social stimulation, nothing to do whatsoever, day after day...” Family Member (Questionnaire Response)

“A really good home is where residents are motivated to do things and not just sit in a chair in front of the telly all day.” Chartered Society of Physiotherapists (Oral Evidence)

Many Rapporteurs also commented on the lack of interaction between staff and residents, with little conversation about anything other than the care task in hand or asking a resident quickly if they were 'OK'.

In only a small number of the care homes visited, Rapporteurs reported that where care staff interacted with residents in a more meaningful way, such as by reminiscing with them and talking about their lives, older people knew that they mattered and felt valued and part of a community within a homely environment.

Staff told Rapporteurs that they did want to engage more with residents but felt that they did not have the time or simply lacked ideas on how to do so and therefore continued to focus on checklists rather than residents' quality of life.

Good Practice: Dementia Care Matters – Being a Star Programme³⁷

This eight day training programme aims to improve self-awareness among care staff, giving them the practical skills to deliver truly person-centred care for people living with dementia.

The programme allows staff to develop emotional intelligence and develop specialist skills to enhance the quality of life of residents.

The course concentrates on the following key messages and objectives:

- We don't do person-centred care, we need to be person-centred.
- Experiencing the person's journey through dementia. (Cont...)

- Interpreting feelings behind words.
- Noticing controlling care. Feel it, see it, hear it.
- Growing in confidence and changing the moment. Skills in ‘The Butterfly Approach’.
- Mealtimes with meaning. Well-being is the key to life.
- Appreciating what is behind behaviours.
- Relationships matter and closeness is what counts in ‘later stage’ dementia care.

The evaluation of the programme found that the workshops appear to have had a positive impact on practice, with an increase in positive social interactions observed and an appropriate decline in neutral and restrictive care. This approach appears to offer significantly more potential to change practice and cultures than traditional approaches to training.

The importance of meaningful interaction between care staff and residents is often not recognised due to a clinical approach to care delivery that does not recognise the need of the whole person. This can lead to an ‘us and them’ culture that can result in care staff perceiving residents only as a series of care needs and tasks, rather than individuals who they can enable to lead a life that is as active as possible.

In many instances, Rapporteurs reported that residents simply sat doing nothing. Many residents, particularly those with high acuity needs, sensory loss or those with dementia, were entirely reliant on care staff to engage, interact and participate.

“Frank lives in a care home in North Wales and communicates in British Sign Language but his paid carers are unable to communicate with him. This means that the only time he is able to communicate with others is when his family travels from Birmingham to visit him.” **Action on Hearing Loss (Written Evidence)**

Evidence from the Commissioner’s roundtable discussion with organisations working with people living with sensory loss clearly showed a lack of awareness amongst care staff about the specific communication needs of people living with sensory loss and the impact this can have on social participation.

“[A resident said] I don’t know what is going on, I can’t hear anyone very well and I need guidance with the craft as my sight is very poor.” **Deafblind Cymru (Oral Evidence)**

Rapporteurs also reported that many residents whose first language was Welsh were unable to communicate in their language of choice due to the lack of Welsh-speaking care staff. This is particularly important for residents with dementia, who are often no longer able to communicate in English as their dementia progresses. Residents reported that it was important for them to be able to communicate in Welsh and that they were frustrated that they were unable to do so. Evidence from Gwynedd Council, which has a proportionally high number of Welsh speakers, supported this, stating that the language in which people converse has a direct impact on their quality of life and care.

The lack of awareness about the specific communication needs of individuals can lead to frustration, confusion and distress for residents; being unable to communicate with care staff and fellow residents can lead to a decline in an individual's physical and emotional wellbeing.

Rapporteurs found that many care homes employed a dedicated activities coordinator, who was responsible for ensuring that activities were available for residents.

Rapporteurs identified a small number of exemplary care homes where the activities coordinator played a vital role in ensuring that all residents were engaged with other residents and care home staff and that opportunities for residents to participate and enjoy doing the things that matter to them were readily available.

“The home has a wonderful activities coordinator who does lots of activities with the residents. My father is a quiet sort of man who doesn't always want to join in, but she is always cheerful and encouraging.” Family Member (Questionnaire Response)

“One activities coordinator literally took the activities to people's rooms to ensure that those who were bed-bound could participate socially in some way.” Social Care Rapporteur

Good Practice: Care Home, Caerphilly

At a Caerphilly care home, the activities coordinator works to deliver both spontaneous and programmed activities with a range of people with dementia in a group and on a 1:1 basis. Her interventions have encouraged previously non-verbal residents to talk, reduced agitation and welcomed families back into the heart of the care home with regular tea parties, film afternoons and fundraising activities.

In many care homes, the introduction of activities coordinators has had a positive impact on the quality of life of residents, although there is great variation in implementation and outcomes of this role. With the right skills and resources, the

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activities coordinators are an invaluable resource to challenge accepted practices and embed new and innovative ways of thinking around engaging and stimulating older people, regardless of their physical and cognitive abilities.

Rapporteurs observed that where the role works most effectively, it is because the coordinator has been supported by the Care Home Manager to ensure that all care staff engage both in planned and spontaneous activities in order that all residents are enabled to live an active life in the place they call home.

However, in the majority of the homes visited, opportunities to take part in meaningful activities were severely limited. In many cases there was a lack of flexibility that meant that residents could only participate in the planned and structured programme of activities and were not supported to do the things that they wanted to do when they wanted to do them.

Furthermore, even when books, newspapers, magazines, games and IT were present, a lack of staff time and encouragement to enable residents to use them meant that resources often went unused.

In the exemplar care homes visited, the care homes in which residents seemed to have the best quality of life, it was clear that the Dementia Care Matters model of care, which is people-centred rather than systems-based, was used to ensure that staff were engaging and participating meaningfully with residents. Staff were able to encourage conversation by knowing about a person and their life before moving into a care home and by referring to the things they enjoy, as well as their likes and dislikes. Furthermore, relationships between staff and residents were based on genuine friendship, empathy and understanding.

A significant number of Rapporteurs reported that residents would like more outings and activities outside of the home. While some of the homes visited organised regular trips and outings, such as trips to the beach, shopping trips and trips to the theatre, these opportunities were often limited due to a lack of staff availability, access to transport or cost implications.

Many residents also told Rapporteurs that it was the care home's decision as to whether they were allowed or not allowed to leave the home, meaning that some did not have a choice to participate in activities outside of the care home environment.

Rapporteurs reported that some care homes engaged with the wider community, as well as groups and organisations, on a regular basis to enable residents to enjoy activities and experiences that would not usually be available within the home. Examples included local schools visiting to perform for and interact with residents, animal charities visiting with dogs and cats, and faith leaders holding religious services.

However, these kinds of opportunities were significantly lacking in the majority of care homes visited, where the care home was not open to interactions with the wider community.

Care homes that enable residents to interact with the wider community are able to enhance the lives of residents through initiating and maintaining links with individuals, groups and organisations. Without this, residents do not feel connected to their communities and are unable to develop relationships with individuals beyond family members and care staff.

Meaningful Occupation

The role of meaningful occupation in reinforcing an individual's self-esteem and identity, and the positive impact this can have on their quality of life is frequently underestimated. Being enabled to make a contribution through meaningful occupation allows individuals to feel valued, have a sense of continuity, be reassured by a familiar role or task and know that they continue to matter.

Only a small number of care homes visited enabled residents to participate in meaningful occupation, activities that are essential to maintain an individual's identity, such as making tea, baking, gardening, setting the table, keeping pets, taking part in religious services and helping others.

“Allowing my sister to access the kitchen so that she could clean up, wash dishes and make scones made all the difference.” Family Member (Questionnaire Response)

“Attending a church service in the home meant that my Mam could actually experience rare moments of peace and calm.” Family Member (Questionnaire Response)

One Rapporteur gave an example of a home in the Vale of Glamorgan where residents were supported to use their skills to maintain the care home's garden. They were involved in the garden's design and were able to choose the plants and flowers that they wanted. Residents also grew vegetables that were used as part of the care home's menu. Residents also looked after chickens, selling eggs to care staff to raise money for their activities.

Another positive example identified by a Rapporteur during a visit to a home in Rhondda Cynon Taf was the use of volunteer befrienders, recruited from the community, to visit and share skills with residents and support them to do the things they like and enjoy, such as arts and crafts, woodwork and baking.

Providing residents with a choice to do the things that they want to do can help them to build relationships and give them a sense of achievement, as well as supporting them to be more active and engaged. Specifically for residents living with dementia, meaningful occupation is vital as it provides an important link to the past and enables them to contribute and feel valued within the care home, reducing levels of confusion, anxiety and agitation.

In the care homes visited where meaningful occupation was enabled, Rapporteurs reported that residents were often more physically active, more engaged and less likely to report boredom and loneliness.

“My Mum has been given small jobs in the kitchen, preparing vegetables on the odd occasion. It’s wonderful to see the enjoyment and feeling of self-worth Mum has gained from this small act of kindness by the staff.” Family Member (Questionnaire Response)

However, the majority of care homes visited did not provide opportunities for meaningful occupation to residents. In many cases, barriers, that could often be easily overcome, were put in place that prevented access to areas of the home where meaningful occupation would take place, such as the kitchen, laundry room and the garden. For example, residents were often prevented from undertaking simple tasks for themselves or others, such as making a cup of tea, which ultimately impacts upon an individual’s independence. This was often informed by an attitude of risk-aversion and a misunderstanding of health and safety regulations.

Enabling care homes will actively look for ways to overcome perceived risks and health and safety barriers to support residents to do the things that matter to them, an essential element in an individual’s quality of life.

“Undertaking a simple risk assessment has allowed one care home in Cardiff to take residents ice-skating each year as this is what they said they want to do.” Age Cymru (Oral Evidence)

Good Practice: My Home Life Cymru

Gwynfor was able to talk with the independent advocate and said that he had been forgotten about and that no-one cared about his wishes. It transpired that Gwynfor was a keen gardener but had no access to the garden outside. The advocate advised the care home manager on how she could conduct a risk assessment to ensure Gwynfor’s safety and allow him to begin to go outside. This resulted in a change in Gwynfor’s behaviour as over time he became less agitated and was able to enjoy spending time outside. Gwynfor told the advocate that it was the first time that anyone had really listened to him in many years.

Personal Hygiene, Cleanliness and Comfort

Personal care is an integral part of an individual’s day-to-day life and the ways in which this is delivered has a direct impact on their dignity and wellbeing.

The majority of Rapporteurs found that the residents they observed were clean and that help and support was provided by care staff to residents who were unable to maintain their own personal hygiene. Residents reported that care staff were sensitive to their needs and they greatly valued the support they received.

Rapporteurs did comment, however, that it was often not possible for residents to have a bath or shower when they wanted to due to rota systems being in place as a result of a lack of facilities and/or staffing levels.

“Perhaps baths are not offered often enough, but this is I think through shortness of staff.” Family member (Questionnaire Response)

“I’ve never had a shower in my life, but I can’t have a bath as there’s not one here. So my carer uses a flannel to wash me.” Resident (Care Home Visit)

While basic hygiene needs are generally being met in a sensitive way, the approach to personal care is often task-based and not delivered in a person-centred way that enables an individual to have choice and control, an essential part of their quality of life.

In addition, a number of Rapporteurs commented that personal hygiene needs were sometimes not met for some residents with high needs, such as those living with dementia or a physical disability, with care staff reporting that they found it difficult to provide personal care in these circumstances.

Without the necessary training for care staff, older people will be unable to receive the personal care that they require in a sensitive and supportive way that meets their needs.

There were variations in the ways in which residents in the homes visited were assisted in using the toilet. Some homes saw using the toilet as a structured task that took place at specific times during the day, which resulted in residents being lined up and told when to use the toilet. This tasked-based approach to continence management can have a detrimental impact both on an individual’s independence and their dignity.

Other homes, however, responded to residents’ needs in a respectful and dignified way, assisting them to use the toilet as and when they required.

Rapporteurs found that incontinence pads were widely used in the homes visited and that some residents were told to use these despite the fact that they were continent and able to use the toilet, albeit with assistance.

“Carers told my husband to go in his pad (in front of me). This is something that he would never have wanted. I used to take him [to the toilet] all the time while looking after him at home.” Family Member (Questionnaire Response)

Evidence from the Commissioner's questionnaire also showed that incontinence pads were not changed regularly, with residents often left in discomfort for hours.

“Visiting in the afternoons I often had to ask staff to change my mother's pad as she was ‘leaking’. The difficulty getting her from her room to downstairs meant that she did not get her pad changed before lunch nor even immediately after. The result was always embarrassing, distressing and humiliating to her.”

Family Member (Questionnaire Response)

The inappropriate use of incontinence pads can cause severe discomfort and have a disabling impact on people's health, particularly around mobility and independence, stripping them of their dignity entirely in some cases.

Personal Appearance

Rapporteurs found that the majority of residents were supported to maintain their personal appearance and this aspect of their identity. Clothes were generally clean, pressed and in a state of good repair. However, issues around residents' clothing were identified during visits, such as clothes going missing while in the laundry.

“A frequent complaint is that clothes go missing after having been sent to the wash and no explanation is given. I appreciate that it is difficult to wash everyone's clothes separately, but my relative takes pride in having nice underwear etc. and I do not feel it is right for her to suffer the indignity of wearing other people's clothes.” Family Member (Questionnaire Response)

Some homes visited have systems in place, through personalised laundry baskets, for example, to ensure that clothing is not misplaced or mixed up and that residents are always able to wear their own clothes and have a choice about what to wear.

Some homes visited also supported residents to dress in clothes associated with their earlier lives, something particularly important for people living with dementia who often find comfort in particular, familiar clothing. An example of this was at a home in north Wales, where a resident with dementia was supported to wear clothing that reflected his time in the Navy.

Other good practice observed by Rapporteurs included hairdressers and beauticians regularly visiting homes and female residents being supported to use their handbags, wear their favourite jewellery items and choose their favourite perfume.

An individual being able to express themselves through their appearance, such as choice over the clothes and accessories they wear, enables them to feel comfortable, relaxed and at home. Furthermore, it reinforces their personal identity and has a positive impact on their quality of life, providing a connection to their past, particularly important for residents living with dementia.

The Dining Experience

Mealtimes are a key part of an individual's day and their experience during these times has an impact on their health and their quality of life. Mealtimes should therefore be more than a task-based feeding activity. They should be social occasions where residents are fully engaged and are able to enjoy the dining experience.

Rapporteurs described that this was rarely the case and that meal times were often a 'clinical operation', with staff wearing plastic aprons and gloves. While hygiene was understood as a factor, this functional appearance reinforced the notion of meal times as a task-based feeding activity and did not provide a dining experience, which is an important aspect of maintaining quality of life.

When mealtimes are seen as 'feeding', merely as a task to be completed, there is a lack of positive interaction between care staff and residents. This can lead to an 'us and them' culture developing, which can lead to an institutional feel within many care homes.

Rapporteurs observed that communication between staff and residents, as well as communication between residents themselves, was either non-existent or solely based on the task in hand. A number of Rapporteurs reported that residents sat in silence at the table, with the only staff interaction being the placing of food on the table or occasionally offering a drink.

Rapporteurs also observed that many older people sat alone at lunch for over 30 minutes, with no social interaction before uneaten meals were cleared away.

Good communication between staff and residents during mealtimes is essential. Without this, the needs of residents will not be met, their choices and preferences will not be taken on board and they will not be encouraged to eat. Furthermore, without support and encouragement from care staff during mealtimes, residents are at risk of losing their physical ability to feed themselves, essential to allow them to exercise choice about how they eat their food and vital to support their independence.

The majority of Rapporteurs observed that there was some choice in the meals available and that residents were involved in meal planning in some of the homes visited, something confirmed by a number of questionnaire responses from family members.

“Residents have a good choice of food.” Family Member (Questionnaire Response)

“They are also willing to provide a favourite meal if anyone asks.” Family Member (Questionnaire Response)

However, this choice was often limited to only two options and daily menus were often not visible or accessible by residents. There was also little evidence that best practice was being used around providing pictorial representations of the meals on the menu or that sample meals were plated up and shown to residents for them to understand what was available. While kitchen staff worked with residents to plan menus in a small number of the homes visited, this was not the case for the vast majority.

“Residents are often given a plate of something, without being asked what they would like. I have seen hot plastic cups of tea being thrust into residents’ hands when they have limited dexterity. No choice is offered, even though there may be a choice on the board (two choices) of a mix and match available from one meal option. Tea time meal mainly consists of a sandwich.” Family Member (Questionnaire Response)

Outside of formal dining times, Rapporteurs reported that there were significant variations in the availability of food and drink throughout the day and that interactions between care staff and residents were often limited, with a lack of meaningful engagement, physical support and encouragement.

“The residents were not even offered a choice of biscuit. Likewise they weren’t able to add their own sugar or milk to their tea and coffee. This may be for very good reasons, but very disempowering.” Social Care Rapporteur

“The trolley is rolled up and if no one asks for a drink, they don’t get it. These are people with dementia that need to be encouraged to eat and drink.” Family Member (Questionnaire Response)

A lack of choice about what to eat, and when and where to eat, can lead to residents having no control over a fundamental aspect of their daily lives. This results in a dining experience that does not reflect the needs of an individual but rather the needs of the system.

Good Practice: My Home Life Cymru

When a resident who has dementia arrived in the dining room for lunch a care worker asked, “Elsie have you come to join us for a meal, where would you like to sit?” The resident sat in her usual chair and was introduced to the other diners by the staff member, even though she knew them all and sat with them every day. The chef came out and presented all the diners with plated meals of what was available; all condiments were on the table including gravy. The care worker asked each resident, “where would you like your gravy?” None of the residents wore an apron or protective clothing, and after the meal no one’s clothing was stained.

Good Practice: Care Home, Cardiff

There is a great emphasis on treating people with dignity and respect. Menus were chosen through a “Come Dine With Me” experience, where residents and family members sampled a range of foods on offer and chose their favourites for the menu. The kitchen staff will always make alternatives if someone does not want what they have chosen and the chef always checks people are happy with their food. When soft foods are served, moulds, piping and other innovative techniques are used to ensure that the food is beautifully presented and offers a range of textures, so it looks and tastes as close to non-pureed food as possible.

Care Home Environment

Many Rapporteurs commented that the homes they visited often had a functional, institutional and clinical feel, rather than being homely, comfortable and welcoming, which can have a detrimental impact upon residents’ quality of life.

Rapporteurs also reported that the majority of the homes visited were old buildings that had been adapted for use as a care home. Whilst Rapporteurs reported that many homes were well decorated and that many residents’ rooms were personalised, the design and layout was often unsuitable, particularly for people with sensory loss and/or dementia. In some cases, residents who were neither related or in an intimate relationship were found to be sharing rooms, something which is no longer acceptable in other parts of the UK.

Evidence from the College of Occupational Therapists stated that the physical structure of buildings and use of some older properties as care homes can act to reduce mobility:

“For example, in one situation where nursing residents were moved from the ground floor to the 1st floor in order to open up more nursing home beds. This move left residents with no access to a communal living room or suitable bathing facilities on the 1st floor. The lift in this section of the home was too small for use with any nursing residents with specialist seating.”

Evidence from Action on Hearing Loss Cymru also stated that a lack of assistive equipment such as visual alarms, hearing loops and other adaptations, is affecting people’s independence, privacy and dignity. For example, bedroom doors may be kept open as a result of a lack of flashing doorbells in care homes, which can lead to older people with hearing loss losing their right to privacy.

In a number of cases Rapporteurs observed that the homes they visited were poorly lit, with no consideration of the importance of lighting, particularly for residents with deteriorating eyesight and sight loss, had a lack of hand rails and clearly marked

ramps, which impeded residents' ability to easily and safely move around the home environment without support.

A number of Rapporteurs reported that the care home environment was not designed to meet the needs of older people. Notice boards, for example, which provide essential information for residents, such as information about activities, advocacy services and other local information, were often hard to reach or difficult to see.

A number of questionnaire responses from family members also highlighted a lack of private space available in the care home, such as seating areas separate to lounge areas, that could be used instead of a resident's room to allow them to spend time with their loved ones.

Many of the homes visited were not dementia friendly, with a lack of pictorial signage, destination points and sensory areas, such as memory walls or rummage boxes.

“Memory walls or areas are becoming more common and one home had memory boxes where people could handle items like coins or look at pictures. But they often seem to be an afterthought, hidden away rather than an integral part of the design of a building.” Social Care Rapporteur

Dementia friendly care home environments, where features such as pictorial signage or destination points are used, are lacking, even in EMI and nursing care environments. This can result in increased confusion, anxiety and agitation among residents living with dementia.

Good Practice: RNIB Cymru

RNIB Cymru has produced a new guide called 'Homes for people with sight loss and dementia: A guide to designing and providing safe and accessible environments'³⁸.

The guide offers clear and simple guidance on how to design, refurbish and maintain accommodation in a way that will best support people with sight loss and dementia.

The guide was developed in conjunction with housing associations, care providers, academic experts, access consultants, people with dementia and organisations that support people with dementia.

The effective use of design can reduce the impact of sight loss and dementia, maximise independence and safety and reduce falls and other safety risks.

The impact that specific aspects of the built environment can have on older people has also been identified by some care homes.

“My residential manager came to me and said our bathrooms are boring. I’ve got residential dementia clients that I need to encourage to take a bath and I want to make them interested to reduce the challenge... So she got little shelving, matching towels, little LED candles and fairies, all where they would be looking up at the wall when they were in the bath and just made it so pretty - a different place. But she didn’t stop there she spread it through the whole home and you walk into any bathroom now and it’s alive.” Care Home Manager (Oral Evidence)

A well designed care home environment can be enabling and therapeutic, supporting residents in their daily lives. Conversely, a poorly designed care home that lacks the necessary adaptations can have a significant impact on residents, particularly those with sensory loss and dementia, disabling their ability to live as independently as possible and increasing the risk of falls and accidents.

Factors Influencing Day-to-Day Life

In gathering evidence about the day-to-day life of older people living in care homes, a number of broad themes were identified that impact upon an individual’s quality of life.

Institutional Regime

The majority of Rapporteurs reported that the care homes visited were characterised as institutional regimes, a cross between a hospital and a hotel. It often seemed that systems in place within the care home took priority over the needs of residents.

Rapporteurs observed that there was a task-based approach to delivering care that concentrated on schedules, processes and checklists, rather than the needs of an individual, particularly around personal care and eating.

Written and oral evidence from Age Cymru, Alzheimer’s Society, British Geriatric Society, British Association of Social Workers, the Royal College of Nursing and the Neath Port Talbot Social Care Academy supported this view, stating that an institutional culture of task-based care had a detrimental impact on their quality of life.

“Well my priority is safeguarding people from cultures of care, that is my main priority... many staff don’t understand how a poor attitude, an institutional culture can really affect the person who they’re caring for.” Neath Port Talbot Social Care Academy (Oral Evidence)

In care homes where an institutional regime exists, the focus is on ‘the system’ and not on meeting the needs of an individual or creating a homely environment. This leads to a culture of task-based care where positive relationships between residents and care staff are less likely to develop. This can result in older people having a lack

of choice and control over their lives and losing their sense of identity, which has a detrimental impact on their quality of life.

Variations in care

Evidence from the Commissioner's questionnaire and Rapporteurs identified significant variations in the quality of care provided, even within individual care homes.

A small number of family members and Rapporteurs identified exemplary care being provided to residents, which was delivered in a sensitive and compassionate way. One Rapporteur, for example, observed care staff using a hoist to move a resident from her chair to her wheelchair. They explained each step of the process clearly and in detail and also provided reassurance both verbally and by holding her hand throughout.

“Mum can't wait to come back after we've taken her out after lunch. That shows how much she loves living here.” Family Member (Questionnaire Response)

“The staff are all very attentive and caring towards my mother. They make everyone feel like they belong there and are their own little community.” Family Member (Questionnaire Response)

The majority of Rapporteurs, however, observed care that was 'neutral', where there was little meaningful interaction between staff and residents. This type of care was characterised by a lack of good communication or physical contact and a task-based approach.

“Staff are doing their jobs and ticking the boxes, but little imagination or personalisation is going on.” Social Care Rapporteur

Evidence from family members identified some concerns over the quality of care provided, while a small number of Rapporteurs also witnessed inappropriate and controlling care, where residents were patronised, ignored, spoken over or called derogatory names. When this type of care was delivered it was with a poor attitude and no awareness or sensitivity to the individual they were assisting. This was particularly evident in the case of residents with high needs and those living with dementia and/or sensory loss. Rapporteurs observed carers continually using their mobile phones, only interacting with other carers and displaying little interest in the residents.

“I feel like my grandfather is talked down to. I very much think he is 'still in there' despite not being able to talk. He is a bright man and I wish he was treated like it.” Family Member (Questionnaire Response)

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“Most staff are pretty good, but one or two can be pretty patronising – some care staff seem to think that they should treat older people as if they were children.” Family Member (Questionnaire Response)

Everyone has the right to be safe, well cared for and have the best quality of life, regardless of their needs or where they are receiving care. Unacceptable variations in care and disparity between care homes, mean that older people are often not receiving the level of care they have a right to expect, care that should be truly person-centred and delivers the best quality of life.

Low expectations

Evidence from professional bodies and the third sector highlighted that older people and their families can have low expectations about quality of life in care homes. This can be driven by a range of factors such as the fact that moving into a care home is often not seen as a positive choice, but rather as a last resort, and a media portrayal of care homes that concentrates on failures and poor care.

“There is a big difference between being safe and having a good quality of life.” Age Cymru (Written Evidence)

It was also suggested that low expectations can result from a culture of learned helplessness in which older people are the passive recipients of task-based care that does not acknowledge nor value them.

“People’s expectations become reduced because ‘how can we keep fighting it?’.” College of Occupational Therapy (Oral Evidence)

This was supported by evidence from the Commissioner’s questionnaire, which highlighted that residents and their families can have low expectations about quality of life in a care home.

“For me she is safe, but life for her is sad. At least she is not abused.” Family Member (Questionnaire Response)

“I’ve only been here for three months. There’s not much to do, but you get used to it.” Resident (Questionnaire Response)

“There’s nothing to do, but I’m happy.” Resident (Questionnaire Response)

Many responses showed that people did not expect anything more than an adequate quality of life in a care home, something that was reflected in observations made by many Rapporteurs during their visits. They identified a culture of acceptance in which older people simply ‘made do’.

Advocacy

“Lots of people here can’t talk for themselves. They don’t have a good quality of life, but aren’t in a position to do anything about it.” Social Care Rapporteur

“You are powerless.” Resident (Questionnaire Response)

Rapporteurs found little evidence of independent advocacy services being actively promoted within the care homes they visited. It was clear that the role of advocacy and its benefits were not widely understood and that there were significant variations in the availability of and access to advocacy services.

Evidence from Age Cymru stated that the availability of independent advocacy may be limited as some care staff may feel undermined by the presence of independent advocates and do not understand their distinct role.

“Many staff in care homes consider that they advocate for residents on a day-to-day basis and do not recognise the value of independent advocacy.” Age Cymru (Oral Evidence)

Where advocacy services were available, it was clear that they were having a positive impact on the lives of older people.

“I find independent advocates have helped us a lot. We had, actually, a person coming and going of their own time, talking to the families and residents. And the feedback to us and the support, I think, improved the quality of the staff and the culture as well. I think they are very, very important people to be available in any care home... And they’re supporting us, they’re not against us. Anything, any problem we have, we are very open with them but I think that is very important. I think their presence is very, very important in any care home...” Care Home Manager (Oral Evidence)

Evidence taken during the roundtable discussion on advocacy highlighted that independent advocacy is critical in improving the quality of life and care of older people by ensuring that their voices are heard and that their rights are upheld. However, the evidence demonstrated that the value of independent advocacy was not sufficiently understood or even recognised by many care homes, Local Authorities and Health Boards.

Written evidence from Local Authorities and Health Boards also indicated that there are often limited opportunities for older people’s voices to be heard outside of formal complaints procedures, reinforcing the need for independent advocacy services.

During the roundtable discussion, many examples of excellent independent advocacy services across Wales were highlighted. Despite this, however, the ability of third sector organisations to deliver services is hampered by unstable

and unreliable funding sources and a lack of understanding of the value that their presence can bring.

The roundtable discussion on advocacy raised concerns that, as a result of funding from the Big Lottery's AdvantAGE programme coming to an end, the future availability of independent advocacy is at significant risk.

“Our funding finishes at the end of October, but really we have got to stop taking referrals in July or August because we can't leave people high and dry.”
Age Connects Wales (Oral Evidence)

Evidence from the British Association of Social Workers indicated that independent advocates have an essential role as they can focus entirely on the needs of an older person, unlike those who may have traditionally provided advocacy.

“Whilst social workers should be expected to advocate on behalf of their clients, this can often be extremely difficult in practice due to the potential conflict with their employers... Families and friends often have their own views and perspectives on a situation, so it is dangerous to assume that these are the same as the older people.” **British Association of Social Workers (Oral Evidence)**

Care homes are older people's homes, places where they should be able to have a strong voice and choice and control about the life they want to live. Older people should therefore be fully involved in any decisions that will affect their lives and it is clear that in these situations an independent advocate is often best placed to provide support and speak out on a person's behalf.

Health and Wellbeing

Literature Review

Many older people who live in care homes have high levels of healthcare needs³⁹. Reports have suggested that around three-quarters of care home residents have a disability and that 57% of women and 48% of men needed help with one or more 'self-care' tasks⁴⁰.

A recent cohort study of the health status of residents in UK care homes observed that the average number of diagnoses per participant (6.2) and the prevalence of stroke, dementia, Parkinson's disease and osteoporosis were higher than those previously reported for similarly aged UK residents who did not live in care homes. The findings confirm the hypothesis that "multi-morbidity is a defining feature of the care home population, and implies a requirement for expertise in geriatric medicine that may be beyond that of some GPs"⁴¹.

Furthermore, this study found that while there might be an increased need to access services due to "cognitive impairment, behaviour disturbance or malnourishment, residents had contact with the NHS on average once per month"⁴².

Physical health is fundamental to quality of life and as research suggests, older people have substantial and complex healthcare needs requiring a full range of healthcare services. However, a great deal of evidence suggests that care home residents are not always receiving the healthcare services they should. In some instances, residents are paying for services that should be provided under the NHS⁴³.

Dementia is perhaps the most prolific health issue to affect older people in residential care with an estimated 80% of care home residents living with dementia in the UK⁴⁴. One in 14 people over 65 years of age and one in six people over 80 years of age has a form of dementia. It is estimated that by 2021 there will be over 1million people with dementia in the UK⁴⁵. Diagnosis rates in Wales are just 38.8 per cent, which means there are still around 28,000 people in Wales who are living with dementia and have not been diagnosed⁴⁶.

Dementia can mask a range of other health issues. According to recent research, physical comorbidity is very common in people with dementia and leads to "excess disability and reduced quality of life"⁴⁷. Epilepsy, delirium, falls, oral disease, malnutrition, frailty, incontinence, sleep disorders and visual dysfunction are found to occur more frequently in people living with dementia⁴⁸. However, physical comorbidity is often treatable.

Older people living in care homes are three times more likely to fall than if they lived in their own homes but, in many cases, taking the right action can help to prevent people from falling. Whilst preventing falls should be a priority, services need to achieve this while allowing residents to be as independent as possible⁴⁹. NICE

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recommends initiatives such as strength and balance training for older people, as well as regular exercise, to enable them to avoid falling as much as possible⁵⁰.

The Social Care Institute for Excellence (SCIE) recognises that reablement leads to improved health and wellbeing of older people living in care homes and also reduces the expenditure required for on-going support⁵¹. By enabling older people to do things for themselves in care homes, as opposed to doing things for them, their independence is not only increased but their individual outcomes also improve. SCIE has stated that people that have accessed reablement services welcome the emphasis on helping them to gain independence and better functioning⁵².

Sensory loss is particularly prevalent among older people: estimates suggest that 1 in 9 people over the age of 60 and 1 in 3 people over the age of 85 are living with sight loss⁵³. According to research by the Welsh Local Government Association (WLGA), there will be an 11.25% increase in the prevalence of sight loss in the next 10 years, correlating to an ageing population and a growing incidence in key underlying causes of sight loss such as obesity and diabetes⁵⁴.

1 in 6 people are estimated to be affected by hearing loss in Wales. The majority of those with hearing loss are older people and the prevalence increases with age: 71.1% of those over the age of 70 are living with hearing loss⁵⁵. According to the Medical Research Council (MRC) there will be a 14% increase in prevalence every 10 years⁵⁶, again correlating to an ageing population. The World Health Organisation estimates that by 2030 adult onset hearing loss will be in the top 10 disease burdens in the UK, above diabetes⁵⁷.

It is estimated that 18,850 people in Wales are currently affected by both visual and hearing impairments. 62% of the deafblind population is aged over 70⁵⁸.

The links between dementia and sensory loss are well evidenced. According to RNIB, at least 2.5% of people will have both dementia and sight loss by the age of 75⁵⁹. As the population ages, the number of people with both dementia and sight loss will increase⁶⁰.

In care homes, studies indicate a higher proportion of residents may have both conditions. People with mild hearing loss have nearly twice the chance of developing dementia compared to people with normal hearing. The risk increases threefold for those with moderate and fivefold for severe hearing loss. People with advanced dementia will often have sensory loss as a result of age related eye conditions and / or damage to the brain due to the disease⁶¹.

The literature highlights that food and diet is a contributing factor that impacts upon residents' quality of life⁶², health and well-being, with malnutrition or 'under-nutrition' acknowledged as a particular problem in long term care institutions^{63, 64, 65}.

One in three older people are affected by malnutrition upon entry into residential care homes⁶⁶ and if their diets are not properly managed, the clinical consequences can include: impaired immune response, reduced muscle strength, impaired wound

healing, impaired psycho-social functioning and impaired recovery from illness and surgery⁶⁷.

NICE has stated that the healthcare cost of managing malnourished individuals is twice that of non-malnourished individuals due to a higher use of healthcare resources. It has placed effective intervention on malnutrition as the third highest in top clinical guidelines to produce savings. Malnourished residents will have greater healthcare needs in the care home, have a higher admission rate to hospital and, during those admissions, will spend longer in hospital⁶⁸.

The British Dental Association has highlighted that there are high levels of unmet dental need in care home residents, with many only receiving dental care when they develop a problem. Residents of care homes are more likely than older people living in their own home to suffer from mobility as well as cognitive impairments which both tend to have negative impacts on oral health. Poor oral health in older people has wide ranging health implications, from the more obvious impacts of pain and discomfort in and around the mouth and jaw, to the follow-on effects that difficulties in chewing can have on nutrition and general health⁶⁹.

Policy is very clear that NHS services should be provided on the basis of need. In spite of this, there is evidence of variations in the provision and funding of key elements of NHS services for care home residents. These variations can result in unfair access and even discrimination⁷⁰.

The availability of and access to high quality healthcare is a basic human right⁷¹ and research suggests that localities should therefore focus attention on re-establishing multidisciplinary and multi-agency healthcare support for older people in long-term care⁷².

The National Assembly for Wales' 'Inquiry into Residential Care for Older People'⁷³ recognises this and highlights the need to improve the safeguarding and protection of older people in residential care through improvements to ensure access to good healthcare. Access is also a priority in the work of My Home Life Cymru, which states that primary care organisations should review their provision to ensure that residents have access under the NHS to all services⁷⁴.

The literature highlights the importance of partnership working to develop new initiatives that give residents, their families and carers greater voice and control with regard to accessing healthcare⁷⁵. Healthcare services for older people living in care homes should ideally incorporate multidisciplinary, multi-agency specialist teams.

Teamwork is also an important element in the availability and provision of healthcare and is a consideration picked up by the Promoting Excellence in All Care Homes study (PEACH). This research indicates the importance and clear health benefits of effective leadership and supervision within the care home in fostering good teamwork⁷⁶.

There are, of course, many examples of good practice in care homes that show that care and support can be delivered effectively to improve quality of life for residents⁷⁷. However, all too often, these practices are fragmented and patchy.

Despite being a basic entitlement, many older people are routinely denied the benefits of primary, secondary and community health services.

Review Findings

Prevention

Care homes need not be seen as places of immediate decline, where preventative and reabling interventions are assumed to have little value. Whilst the prevention and reablement agendas have been identified as essential to reduce pressure on primary health care services, it seems their importance is not yet recognised in care homes.

“To maintain health and wellbeing, residents require physical, mental and social stimulation. Yet some care homes are very task orientated. Basic care needs such as washing and dressing, feeding and toileting, can take a considerable time for residents with complex care needs, leaving little time for other activities.” **College of Occupational Therapists (Oral Evidence)**

Evidence from the Chartered Society of Physiotherapists stated that if people are more physically active, an essential element of the prevention agenda, then they will be at less risk of falling and money could potentially be saved from the use of wheelchairs and emergency admissions to hospital.

“A problem reported to us by community physiotherapists is that they perceive clients to be too inactive throughout the day. Furthermore, many of the activities offered are seated and do not present a challenge to posture and balance.” **Chartered Society of Physiotherapists (Oral Evidence)**

Their evidence also highlighted the dangers of immobility for the whole body system, stating that being seated all day means that individuals can lose capacity in all body systems. These secondary complications can often lead to an increased use of medication and preventable hospital admissions.

This was reflected in evidence from the College of Occupational Therapists that stated that activity is not an added bonus of care but an essential requirement to enable residents to actively participate in daily life. They also stated that when a person is left for long periods without movement or stimulation, a number of detrimental physical and psychological changes occur. Physically, muscles waste, the heart atrophies, blood pressure rises and the risk of pressure sores increases. Psychologically, listlessness and boredom, depression and lethargy, and confusion and disorientation can occur, alongside a loss of confidence and skills. This can create a life and environment that is full of negative impact.

Good Practice: North Wales Care Home Falls Multi Factorial Risk Assessment and Care Plan

Public Health Wales' North Wales Falls Prevention Project has developed a care tool for care homes to use to implement NICE guidance on Falls (2013)⁷⁸. This is a collaborative project, consisting of key stakeholders including Care Forum Wales, CSSIW and District Nurses.

The Care Tool is a package of support that includes:

- Guidance for completion
- Multifactorial Risk assessment
- Summary Care Plan
- Record of referrals and follow up
- Record of unmet needs
- Review recording
- Support documents - footwear suitability / nutrition prompt / culprit medication

This has been further supported by on-going partnership work, training and support to care homes to enable them to implement falls prevention within current processes, for example pre-arrival assessment, care planning, and falls review to assess the culprit.

Good Practice: College of Occupational Therapists – Living Well through Activity in Care Homes Toolkit 2013⁷⁹

This resource has been designed for care home staff to enable residents to live a more active life.

The toolkit provides a range of suggestions for changing traditional approaches to task based care through outlining approaches that care staff could implement from a 5 minute chat with a resident, to assistance in the kitchen and gentle exercise.

The benefits of residents living more active lives in care homes are also outlined in terms of an improved sense of physical and emotional wellbeing, a sense of belonging, as well as increased talking, smiling and laughter.

Evidence from the College of Occupational Therapists stated that equipment and furniture in use at a care home can make a huge difference to an individual's health and mobility. Access to profiling beds, correct seating and appropriate cushions can all enable older people to have reduced pain and greater mobility. A person's individual requirements must be considered as a 'one size fits all' model is not effective.

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“...Limited or no access to appropriate and safe seating within nursing homes can result in residents being restricted to bed for months (sometimes years). This is not necessarily because they can’t sit out of bed, but because their needs have not been assessed and appropriate seating has therefore not been provided.” College of Occupational Therapists (Written Evidence)

Rapporteurs regularly reported that residents were often sat in identical chairs that ‘looked uncomfortable’ and were propped up by cushions. This can cause hips to become misaligned, which can lead to muscle wastage, immobility and pain. Rapporteurs also reported that care staff seemed unaware of bad posture or poor seating and the impact that this can have in reducing a resident’s mobility and causing pain.

Evidence from the Chartered Society of Physiotherapists stated that a lack of staff resources can lead to risk-averse cultures developing within care homes, which can result in inactivity and immobility amongst residents.

“A lack of resources leads to risk aversion. Care staff use wheelchairs and hoists rather than give people time to walk to dinner, walk to the garden, etc.” Chartered Society of Physiotherapists (Oral Evidence)

Rapporteurs often observed a restrictive application of health and safety that overruled an individual’s right to move freely around the care home. Rather than keeping an individual safe, the resulting immobility can actually contribute to a fall, which is inevitably more damaging to an older person’s physical and emotional wellbeing. It is essential that any risk assessment conducted in a care home balances an individual’s right to autonomy against the potential risk to themselves and others if this right is upheld.

Reablement

Evidence from the Chartered Society of Physiotherapists stated that reablement services within care homes are lacking. They stated that often people are waiting too long for vital reablement services and that this delay means that it is often not possible to reverse physical damage or decline that has occurred. Providing reablement services as soon as they are required provides the best possible opportunities for regaining independence and delivers better health and wellbeing outcomes for older people living in care homes.

Evidence from a senior manager at HC-One also highlighted that reablement services for older people in care homes are less accessible than similar services for other vulnerable groups.

“I saw a resident was having problems with food and swallowing and I said ‘right, let’s get Speech and Language Therapy (SALT) in to sort this out’. The Tudalen 215

managers looked at me and said ‘they don’t tend to come into our settings’. And I said ‘why not?’. I was used to somebody within a week to look at something, give a review, help and support. Everyone I spoke to was saying ‘No, older residents don’t tend to get that support’. I don’t know if that’s across the board, but it did worry me that we can’t get the support that they were entitled to as quickly as younger adults can. It wasn’t just SALT, I’m using that as an example, it just hit me in the face because the lady who was choking was obviously going to lose weight and be malnourished and we could have done something very quickly.” **HC-One (Oral Evidence)**

Evidence from the British Geriatric Society also highlighted the difficulties in accessing specific therapies such as physiotherapy and speech and language therapy. They suggested that this is the result of reablement services not being seen as important within care home settings.

This was reflected in questionnaire responses from residents and their families, who highlighted that access to specialist healthcare and other therapies is often limited.

“Basics are covered but the home needs to be more open and proactive contacting professionals for support.” Family Member (Questionnaire Response)

“I have had to ask over 4 weeks for a chiropodist to attend to the long nails on mum’s feet. In the end, I sought out the chiropodist and asked that she cut mum’s nails, which she did very shortly afterwards.” Family Member (Questionnaire Response)

In the questionnaire responses from residents, all residents stated that they never have access to a physiotherapist. The majority also stated that they never have access to a speech and language therapist and that they never or rarely have access to a podiatrist. This means that the majority of older people in care homes are unable to access specialist healthcare that could have a positive impact on their health, wellbeing and quality of life.

Evidence from Age Alliance Wales highlighted particular issues around access to reablement services for stroke survivors.

“It is well known that Wales has a chronic shortage of therapy services available to stroke survivors. This includes Physiotherapy, Occupational Therapy, Speech and Language Therapy, psychological, cognitive and emotional therapy, dietary and nutritional therapy. Access to these specialist therapies can become more restricted for stroke survivors living in care homes. As a consequence, continuing rehabilitation can be compromised. Best practice from other parts of the UK demonstrates that outcomes are significantly improved for stroke survivors in residential care when care staff

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work closely with multi-disciplinary stroke teams. Stroke survivors living in residential care are not systematically offered the best chances of recovery.”
Age Alliance Wales (Written Evidence)

Occupational Therapy, Physiotherapy and seating equipment all play a vital role in maintaining the mobility of older people living in care homes, but the evidence clearly shows that this support is often not easily accessible and older people’s independence is not being maintained. The culture of care homes is often built upon a dependency model, where it is assumed that people need to be ‘looked after’, which often fails to prevent physical decline or allow people to regain their independence.

GPs

Evidence from care home managers showed that where good relationships are developed with GPs, this has a positive impact and delivers better outcomes for residents as there will be regular visits that allow a GP to review their patients’ overall health, undertake medication reviews and review care plans.

“I’ve got a really good GP. We sit down and discuss [residents’] weight, diet, mental health, psychological state and that’s great.” **Care Home Manager (Oral Evidence)**

However, the fact that in some care homes one practice will deliver care for all residents, whereas in other care homes residents will receive care from multiple practices means that there can be issues around developing and maintaining positive relationships between GPs and care homes.

Written and oral evidence from bodies representing health professionals, as well as evidence from care home managers, also stated that there are significant variations in how older people living in care homes are able to access GP services, particularly around appointment processes.

Evidence from care home managers stated that it was often difficult to get an appointment with a GP, due to the inflexibility of the GP’s appointment booking system.

“‘Why didn’t you ring before ten?’ We get that all the time, ‘why don’t you ring before ten?’. Because they were perfectly alright before ten. All people don’t get ill before ten o’clock only.” **Care Home Manager (Oral Evidence)**

This inflexibility can lead to delays in obtaining a proper diagnosis and support, which is essential as, without timely access to basic and easily administered health care, a simple condition could quickly escalate.

Similar issues were identified in evidence from the British Medical Association, the Royal College of GPs and Shropdoc in terms of out-of-hours GP services. They highlighted how these services have been under-resourced for a number of years and are spread too thinly, something that has a significant impact on older people living in care homes who are more reliant on this provision. They stated that care home staff may phone the 'out of hours' service for advice at night, but without a link to their daytime practice, care plans may be overlooked, which can lead to unnecessary hospital admissions. This is particularly an issue with agency staff working in care homes.

Care Home Managers also stated that difficulties in obtaining a proper diagnosis can often lead to medication being prescribed over the phone, which could put residents at risk.

“We are not a nursing home, I do not have nurses on the premises. On the phone, I mean, we could only say what the symptoms we see are and we might be wrong, he might give the wrong diagnosis.” Care Home Manager (Oral Evidence)

Evidence from the Royal College of Physicians, Royal College of GPs, the Royal Pharmaceutical Society and the British Geriatrics Society stated that older people are at risk of potentially dangerous interactions between multiple medications due to medication error. This clearly demonstrates the importance of medications being properly prescribed and the need for regular medication reviews.

Evidence from 1000 Lives Plus stated that being improperly prescribed medication is a particular issue for people living with dementia who experience behavioural and psychological symptoms of dementia (BPSD). They stated that antipsychotics are overprescribed for the treatment of BPSD and that they are often used ahead of non-drug therapies, contrary to NICE/SCIE guidance, often leading to severe side effects. They also highlighted that antipsychotics can be discontinued in 70% of people with BPSD without worsening symptoms.

“The reduced use of antipsychotic medications in care homes needs to be a top priority for Health Boards, particularly given the evidence from local pilot testing and audits of the effective implementation of the 1000 Lives Dementia Care Improvement Target 3, but there is a problem at the moment in the spread of this good practice, it is not spreading wide enough or fast enough, particularly in terms of the continued use of inappropriate anti-psychotic medications for older people, who have entered a care home following a stay in hospital.” 1000 Lives Improvement Service (Written Evidence)

Evidence from Aneurin Bevan University Health Board stated that mental health in-reach services in Torfaen provide advice and guidance to residential and nursing care home staff to improve the quality of care being provided for those living with

dementia and prevent the use of anti-psychotic medication wherever possible. They stated that potential savings may be made with mental health in-reach services:

“There has been a definite reduction in admissions to our Mental Health Assessment Unit from care homes. The consequence of this would have a probable effect on patients receiving continuing healthcare as they are treated early and there is a reduction of transfer to a higher dependency/category of care. There is also a resulting possibility of reducing an increase in morbidity and mortality by keeping the person in a familiar environment.” Aneurin Bevan University Health Board (Written Evidence)

Good Practice: Abertawe Bro Morgannwg University Health Board – Mental Health in-reach service

Abertawe Bro Morgannwg University Health Board is delivering a residential care mental health in-reach service in Bridgend.

A multi-disciplinary team works with older people in care homes to support care staff and ensure on-going mental health assessments and the appropriate use of medication. The service also provides training to care staff and managers on dementia care.

The team uses a monitoring system and referral co-ordinator to allocate the frequency of visits and to ensure a crisis point is not reached before mental health specialists are sought.

Access to specialist mental health care has improved as a result of this proactive and preventative approach. Mental health admissions have fallen by 50% since 2009 and its Continuing Health Care budget has been contained, with a simultaneous decrease in the use of long stay beds⁸⁰.

The Royal College of General Practitioners also stated that there are difficulties around the transfer of medical records. This impacts upon the ability of GPs to deliver the enhanced service contract for care homes, which includes the need to assess an older person within a fortnight so that their health needs are understood by their GP and action can be taken if required. This delay can be up to six weeks if someone is discharged from a hospital in one Health Board area to a care home in another.

“Information exchange between existing and new GPs (residents frequently change their doctor when they move into a care home) must take place on the day that the person moves into the care home – this is frequently not the case and can lead to medical mismanagement.” Royal College of Physicians (Written Evidence)

Whilst demographics have shifted and models of care have changed over the years, with older people now receiving care in care homes rather than long-term care of the elderly hospital wards, it is clear that the role of the GP must adapt to ensure that older people are able to access the services they need.

Evidence from the British Geriatrics Society also stated that as care systems change, GPs would benefit from additional support, which could be delivered through community geriatricians, to ensure that the increasingly complex needs of older people living in care homes are met.

Sensory Loss

One in five people in Wales have a form of sensory loss, a figure that increases dramatically with age – 70% of 70 year olds have a form of sensory loss, for example, rising to 80% for 80 year olds and 90% for 90 year olds⁸¹.

Sensory loss can have a significant impact on older people's quality of life, particularly within care homes, and can lead to loneliness, isolation and depression.

Evidence from Action on Hearing Loss, Deafblind Cymru and RNIB Cymru, taken at the Sensory Loss roundtable, identified that older people are not routinely screened for sensory loss upon entry into care homes. Their evidence also showed that there is a lack of regular/ongoing screening for sensory loss for older people living in care homes.

This lack of testing/screening can result in many older people living with an undiagnosed sensory loss, which can often be misinterpreted as dementia and lead to a failure to meet an individual's care and communication needs.

Action on Hearing Loss gave an example of a care home in which 13 out of 25 residents were already diagnosed with hearing loss. However, after screening all residents, a further 11 were identified as having hearing loss.

“It is without dispute that there are thousands of people living in residential care in Wales who are unable to hear but have not been diagnosed with hearing loss. This means that they are missing out on the support that is available for them to hear better.” Action on Hearing Loss Cymru (Written Evidence)

Evidence provided by RNIB Cymru and Optometry Wales highlighted that where sight tests were undertaken in care homes, they were often carried out by large optometric companies that do not tailor these tests to meet the needs of older people. They are therefore not testing for conditions that can cause sight loss, such as glaucoma or Age-related Macular Degeneration, and also often fail to identify pre-existing conditions.

It is essential that sight tests are regularly undertaken and that sight loss is properly diagnosed and managed as evidence from RNIB Cymru identified that sight loss can have a direct impact on an individual's mobility and safety. They stated that sight loss can restrict an individual's ability to move around the home freely, which can not only result in a decline of an individual's overall physical health, but also increase the risk of falls or other injuries.

The roundtable discussion highlighted that there is a general lack of awareness in care homes about sensory loss and its impact. This was confirmed by Rapporteurs who reported that many care home managers stated that sensory loss did not affect any of their residents. Given the prevalence of sensory loss amongst older people, this is almost certainly not the case and means that a large number of older people could be missing out on essential assistance and support.

Good Practice: Action on Hearing Loss / Age Cymru

In 2013, a bilingual booklet, 'Quality of life for residents with hearing loss', was distributed to all care homes in Wales. The booklet discusses the issues faced within care homes around hearing loss, how these can have an impact on quality of life and how members of staff can better support residents to enjoy a good quality of life. It contains information about how to identify hearing loss, how to support residents with hearing loss and how to support people living with hearing aids.

Evidence gathered from family members and through the sensory loss roundtable discussion highlighted issues around basic maintenance of glasses and hearing aids as well as a lack of awareness from care staff on how to support individuals to use them.

“There was no consideration of my father's poor sight, and his profound deafness. His hearing aids were often off or batteries were flat.” **Family Member (Questionnaire Response)**

“Residential Care providers tell us that they struggle to train their staff to maintain hearing aids due to high staff turnover. This means that residents are usually poorly supported if their hearing aids need cleaning or a change of batteries. This can mean long delays until a long and often unnecessary trip to the hospital audiology department for what is a simple maintenance task.” **Action on Hearing Loss Cymru (Written Evidence)**

Good Practice: Action on Hearing Loss

During 2013/14, Action on Hearing Loss worked with eight residential care homes across Swansea, Bridgend, and Neath Port Talbot. Their aim was to improve dignity in care for older people through delivering training and information to front-line care staff and managers to increase their awareness of hearing loss.

158 care home staff were trained in total covering the following areas:

- How to identify hearing loss, the impact of hearing loss, and what interventions or actions to take to address this.
- How to support people with hearing aids, cleaning and maintenance. Tips and advice on how to communicate effectively with people with hearing loss.
- Adjustments and assistive products that are available.
- Local services, groups and organisations.

The training resulted in a greater awareness and understanding of the equipment available to help with hearing loss and tinnitus and how this equipment can help with effective communication on a daily basis.

Care staff were also trained on how to use specialised assistive equipment, such as the Sonido, which is a personal listening device that can significantly improve communication between staff and residents and can help individuals with the isolation that so many of them feel when they are unable to communicate.

Danny, a blind gentleman and very hard of hearing, experienced the difference that the Sonido can make. Using the device he could instantly hear the trainer and his carer and could have a conversation in Welsh, something that he hadn't done for years.

Diet

In the majority of survey responses, residents disagreed or strongly disagreed with the statement 'the food and drink available is of a good quality'.

“After the cook leaves at 1.30, the only thing available is sandwiches and biscuits, not a lot of choice for tea and supper. No fruit, no salad. Food is very repetitive. Sandwiches are often freezing cold.” Resident (Questionnaire Response)

Rapporteurs generally reported that the food they observed being eaten during mealtimes was 'acceptable', but significant variations were observed in the quality of the food provided in the care homes visited. While a number of Rapporteurs

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described fresh produce and lots of fruit and vegetables being provided as part of meals, others described a 'ready meal' appearance to the food provided. On occasion, serious concerns were raised about the unacceptable quality of the food available and the fact that it would not meet older people's dietary needs.

Oral evidence was taken from the Unified Menu Planning Project, a project designed to improve the nutritional standard of meals provided in care homes and to educate care home managers, care staff and cooks/chefs about how to reduce malnutrition. Members of the project's steering group, from Public Health Wales, Torfaen County Borough Council and Aneurin Bevan University Health Board, stated that there is a lack of understanding within care homes about the dietary needs of older people, particularly the importance of meeting an individual's specific dietary needs.

“My friend has a problem with swallowing some foods and it has taken some time for the home to adapt to the food that she can eat. This is improving but slowly. She tends to get a lot of mashed potato.” Friend (Questionnaire Response)

They highlighted that a resident who is overweight and has diabetes would need a healthy eating approach, with a controlled intake of sugars, whereas a resident who is at risk of malnutrition would need a fortified diet. However, they stated that this individualised approach was not common and that care homes often adopted a 'one size fits all' approach. An example given was of a care home that was told to increase the fats and sugars in one resident's diet but decided to do this for all residents. Another example given was of a care home where all residents were found to be on a 'soft' diet, where foods are mashed, pureed or simmered in liquid, which would not have met the individual needs of all residents.

The roundtable discussion also highlighted the myth that because a person is in a care home they lose their appetite and require smaller portions of food. Portion sizes should be based on an individual's choice and need, not based on a 'one size fits all' approach.

During the roundtable session a lack of support to assist older people to eat was identified, something often due to care staff being unaware that an individual would require assistance.

“Food is poor at times, dry which is hard for him to eat. There is limited help and I go in and feed him and others.” Family Member (Questionnaire Response)

“Mealtimes can be a trying time when sitting too far away from the tray on an easy chair and trying to balance the chair and being left to fend for oneself. Due to her disabilities my mam is unable to gain access to food and water unless they are within her reach and I have found sandwiches left on the windowsill.” Family Member (Questionnaire Response)

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This was also observed by Rapporteurs, who saw residents playing with their food and plates being taken away without food having been eaten. Rapporteurs also commented on the fact that some bed-bound residents were given trays that were placed too high for them to eat from comfortably resulting in them struggling to feed themselves.

Dementia Care Matters also identified that it is vitally important to assist older people living with dementia to eat, but more than that to also encourage them to eat, both directly through care staff and indirectly by providing readily available snacks and food that is easy to eat.

Alzheimer's Society state that finger foods are a good solution for people with dementia who may have difficulties with co-ordination or struggle to use cutlery as they are prepared in a way that makes them easy to pick up and eat with the hands.

Evidence from RNIB Cymru and Action on Hearing Loss identified that eating can also be difficult for people with sensory loss, particularly those with dual sensory loss. If a person's hearing and sight loss is severe, it is essential that they know that the food is there and are supported to eat it.

Evidence from the nutrition roundtable stated that food supplements are often thought of as a 'safety blanket' in care homes, which can contribute to a culture where the importance of diet and encouraging and assisting people to eat is not recognised.

Evidence from Prescribing Support Dieticians also stated that in some cases food supplements are being wrongly used instead of meals, as a more convenient and cheaper option for care homes.

It is estimated that 16-29% of older people living in care homes in Wales are malnourished⁸², something that has a significant impact on their health and wellbeing.

Whilst a number of existing health issues can cause malnutrition amongst older people, in many cases it could be easily prevented by ensuring that older people are supported and encouraged to eat a diet that they enjoy.

Action to ensure that the dietary needs of individuals are met and that malnutrition is prevented wherever possible is essential to maintain the health, wellbeing and quality of life of older people living in care homes. Effective intervention on malnutrition is identified by NICE⁸³ as essential to reduce preventable healthcare costs and the number one clinical intervention to prevent admissions to hospitals.

Whilst there is some good practice underway in Wales around food, nutrition and malnutrition, this is often limited and demand for support often outstrips supply.

Good Practice: Aneurin Bevan University Health Board

Aneurin Bevan University Health Board has a dedicated Community Nutrition Support Team that works with local care homes to educate and advise care staff on food and nutrition.

Using the 'food first advice', they have provided useful and practical information about fortifying foods, having nourishing drinks and snacks between meals, increasing calorie and protein intake, preventing weight loss and promoting weight gain, and how to eat well with a small appetite.

The Community Nutrition Support Team noted that in the care homes where this training had been delivered and staff were trained about nutrition, the fortifying of food was fully understood, food record charts were more widely used, and there were a greater number of activities to encourage residents to eat.

Oral Hygiene

Oral evidence from the Welsh Government's Senior Dental Officer stated that there is often a perception that the vast majority of older people will have dentures, something that was true for 90% of the population in 1987. However, advances in dental services, improved oral health products and public health promotion have resulted in this figure dropping significantly to an estimated 50%.

The Senior Dental Officer stated that as original or restored teeth may require a more complex level of care compared to dentures, many older people are dependent on others for their oral hygiene as their ability to use a toothbrush has diminished.

Good Practice

Hywel Dda Community Dental Service offers a certified oral health training package to all nursing and care homes within the health board area. The programme, 'Reason to Smile', offers practical advice and support on good oral hygiene, such as what toothbrushes and toothpaste to use, how to use them and how to identify specific issues such as mouth ulcers. A telephone advice line is also available to help care staff to access additional support.

Evidence from Cardiff University's Nursing and Residential Care Home Oral Health and Access to Dental Care Survey (2008)⁸⁴ confirmed this, stating that oral hygiene within a care home is often dependent on the ability of care staff to administer oral care. They highlighted that care staff in one in three care homes are assisting residents with oral hygiene, despite having received no training for this. Furthermore, the follow up Wales Care Home Dental Survey (2010 -11)⁸⁵ stated that "care home residents are more in need of regular dental checks to assist in supervision of any

disease in their mouths. Given lower reported levels of regular dental checks, this presents a challenge to both care homes and dental services”.

Evidence from residents and family members also identified concerns about oral hygiene, with the majority of survey responses stating that residents rarely or never have access to a dentist.

“There is absolutely no regular check service from dentists.” Resident (Questionnaire Response)

“There is a problem with providing regular and good dental cover.” Resident (Questionnaire Response)

A number of responses also highlighted that a lack of access to dentistry services had resulted in oral health deteriorating significantly.

“My mother’s teeth were left to rot in her mouth.” Family Member (Questionnaire Response)

“Since I’ve been here, all my teeth have fallen out. I am so ashamed to speak or smile.” Resident (Questionnaire Response)

In addition to issues identified around oral hygiene, evidence also showed that access to dentistry services is also an area of concern.

To address this concern, the Welsh Government’s National Oral Health Plan 2013-18⁸⁶, part of its Together for Health programme, gives a commitment to equitable access to dentistry for all, particularly ensuring services for the most vulnerable.

Despite this commitment, the plan acknowledges that access to NHS dental care is limited in some parts of Wales and that some care homes have reported difficulties in obtaining routine and emergency dental care.

Written evidence provided by the British Dental Association stated that the Community Dental Service would be well-placed to deliver dentistry services within care homes, but is under extreme pressure as high street dentists are no longer able to provide a domiciliary service.

However, the Senior Dental Officer stated that the Welsh Government plans to develop a strategic programme for delivering effective mouthcare for residents in care homes across Wales to address the concerns raised by family members and residents about the lack of access to dental care and support for daily oral health care, which will help to ensure more consistent and effective mouthcare for older people in care homes across Wales.

People and Leadership

Literature Review

Whilst social care staff face a range of pressures in carrying out their day-to-day roles, they are largely doing the best they can under extreme pressure[s]. As Kitwood has asserted, “poor care is not deliberate”. However, it is noted that a greater culture of support is needed to improve matters. This is explicitly acknowledged in a recent PANICOA report⁸⁷, which suggests that although staff are “typically hardworking and committed to delivering respectful care” that promotes independence, this was often undermined by workload pressure.

The report also states that stress and burnout were “not uncommon”, driven by recruitment and retention problems, and that staff managed these pressures by focusing on “meeting urgent physical needs at the cost of providing more relationship-centred care”, and providing “reactive care,” undertaken as a series of unrelated tasks.

The report concludes that the “good treatment of staff will be likely to result in the good treatment of those for whom they care”, particularly fair reward systems, a culture of trust and openness and management of workload pressures⁸⁸.

To further improve matters, the PANICOA report calls on UK governments to ensure regulators set and monitor standards for minimum staffing levels that care homes would be required to meet. It also said councils must work with providers to agree practicable staff to resident ratios “sufficient to ensure the safe and respectful care of older people at all times”, and to use this as the basis for a “fair and accurate fee structure”⁸⁹.

Minimum standards in Wales require that staffing numbers and the skill mix of qualified/unqualified staff are appropriate to the assessed needs of the service users, as well as the size, layout and purpose of the home, at all times⁹⁰ and with reference to qualifications, Minimum Standards call for at least 50% of care staff to hold NVQ level 2 in care or a similar qualification recognised by the Care Council for Wales, or a higher level qualification in care⁹¹.

For some specific job roles and settings, workers are required by the Welsh Government to register with the Care Council for Wales. The current mandatory qualification for Care Home Managers in adult care homes is a Level 5 Diploma in Leadership for Health and Social Care Services (Adults’ Residential Management) Wales and Northern Ireland⁹².

Whilst Minimum Standards and mandatory qualifications are necessary, Dementia Care Matters (DCM), which works to change care home cultures and environments, asserts that “competencies and qualifications are no match for emotional intelligence”⁹³. DCM also recognises the value of leadership, emphasising that

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“emotional support for staff trying their very best has to be at the core of services aiming to be person centred”⁹⁴.

Staff support may also address the problem of staff turnover and retention. There is a continuing concern over an on-going shortfall of social care staff “of about 8%, with a turnover of about 30% in the first 2 years of employment”⁹⁵. This shortfall suggests an “unmet delivery of care to meet peoples’ needs and the high turnover suggests that recruitment practices are not finding and keeping staff with the right values to sustain them in their jobs. Both of these factors have an influence on quality. Staff turnover also costs money in recruitment and agency staff costs to fill the gaps”⁹⁶.

In 2012, the Royal College of Nursing conducted a poll of 600 nurses working in care homes in which more than a third (38%) of respondents said they thought the homes were understaffed, with a lack of full-time registered nurses. Almost half (48%) of respondents said that care homes were accepting residents to fill empty beds, despite fears about levels of care⁹⁷.

The combination of low levels of morale and extreme pressure at work has a detrimental impact on the workforce. This is critical, because morale is directly linked to the quality of the output that a workforce delivers⁹⁸. If the challenges that care homes face remain overlooked year on year, it is likely that the morale of its workforce will continue to deteriorate. This has worrying implications for the quality of care staff can deliver and could result in a further reduction of the workforce as more staff leave, further compounding existing problems⁹⁹ and, in turn, having a detrimental impact on the quality of life and care of residents whose life can be marked by constant change and disruption.

Review Findings

Care Staff

“A care home is as good as its staff.” Resident (Questionnaire Response)

Care staff play an essential role in whether or not residents have a good quality of life. The pressures faced by care staff in fulfilling this role, however, should not be underestimated as working with emotionally vulnerable, cognitively impaired and frail older people, often for very low pay, is emotionally, mentally and physically challenging and demanding.

Comments from the questionnaire clearly showed that relatives and residents understood that care staff were working in a pressured environment and that, in many cases, they were doing ‘their best’ with limited resources.

Rapporteurs also reported that care staff were generally kind and committed, trying their best to deliver high standards of care, often in difficult circumstances. It was clear that the best care homes were those where care staff felt valued and supported.

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To ensure that care homes are the best that they can be, the residential care workforce must be seen as a professional national asset and must be valued and supported so they have resources available to deliver truly person-centred care.

It is clear, however, that this is not the case: care work currently has a particularly low social status, reflected by low pay, long working hours, poor working conditions and a lack of opportunities for professional development and career progression. Similarly, a care home can be an isolating environment and a place with limited access to peer support.

This can lead to care staff having low morale and becoming demotivated, which can lead to poor staff retention and a culture of ‘neutral care’ delivered in a task-based way with a lack of compassion and focus on an individual’s needs.

Evidence from the Care Council for Wales (CCW) stated that registration and regulation of care staff would be an effective way of driving up the status, identity and value placed on delivering residential care for older people. They clearly stated that “it is not a matter of whether regulation should be introduced, but how” and are currently undertaking work to determine how this system might work.

Staff Capacity

“Staffing is an issue. We are already stretched. If one or two people go off sick, it’s very difficult to cope.” Care Home Manager (Oral Evidence)

“When I visited, the staff were doing their best, but they were in short supply.” Family Member (Questionnaire Response)

Rapporteurs reported that Care Home Managers and care staff regularly stated that they were understaffed, sometimes ‘chronically’. This was particularly evident at weekends: it was rare to find a senior manager on the premises and staffing levels were reported to be below normal service levels.

When the Commissioner’s team contacted the care homes on the morning of a visit, a number of homes requested that the Rapporteurs visit at another time because their staffing levels were low or the manager was unavailable.

“We could do with an extra pair of hands.” Care Home Manager (Care Home Visit)

“I’d love to see people get out more, but we just don’t have the staff.” Care Home Manager (Care Home Visit)

Understaffing in care homes can significantly increase the pressure placed on care staff, which can result in them having less time to interact with residents as they become more task-orientated to ensure that their essential core duties are undertaken. This lack of person-centred care can have a significant impact on an

older person's quality of life as care is often delivered with limited time and with a lack of compassion.

Written and oral evidence from care home providers, Care and Social Services Inspectorate Wales (CSSIW), Local Authority Commissioners and the Royal College of Nursing (RCN) identified that low staffing levels are often the result of difficulties in the recruitment and retention of care staff. A number of reasons were stated for this, including poor levels of pay, low morale, long working hours that can include 12 hour shifts as part of a 60-70 hour week and the role of a care worker not being seen as a desirable and viable professional career option. This is a particular issue in rural areas and areas where the need for Welsh language speakers is high, as the number of potential care workers with the right skills can be especially limited.

The recruitment and retention of high quality care staff can play a vital role in older people's quality of life; Rapporteurs observed that the best care homes were those with high morale among care staff and low staff turnover, where many of the staff had worked for decades.

**“If you haven't got a happy and good staff team, then you haven't got a home.”
Care Home Manager (Oral Evidence)**

Care home providers also identified the importance of career progression to attract people to the care sector, particularly for younger people at the start of their careers:

“We are, in lots of ways, at a loss in not being able to recruit carers at sixteen. In England you can do that, in Wales they have to be eighteen. If you can bring them on an apprenticeship scheme and train them from the start, chances are they will stay. But also you're developing the workforce of the future. Within that they have to have some sort of development.” Barchester Healthcare (Oral Evidence)

Evidence from CCW stated that due to a shortage of staff, many care staff are employed without a reference in place. This means that the National Minimum Standard 22 (Recruitment Outcome), which states that 'service users are supported and protected by the home's recruitment policy and practices', is not being met in many cases.

Similarly, in order to meet legal requirements around staffing numbers, many care homes regularly use agency staff to provide the support required. Agency staff may find it more difficult to build relationships with residents due to their irregular and inconsistent working patterns.

“In order to get the right levels of staffing, we tend to end up with agency staff and it's a huge impact, people who don't know the home, they don't know the residents... Their systems are different. So you have residents who

see different faces constantly, if you are using agency every day they don't have relationship building, people don't understand their needs. But for safety's sake we have to do it, we have to have nurses on duty." **HC-One (Oral Evidence)**

The impact that staffing issues can have on older people's quality of life was clearly outlined in evidence from the RCN, which stated that:

"Poor staffing leads to poor care. Overwork and chronic understaffing are key contributing factors to the development of a culture of learned helplessness. So, when things go wrong in patient care, failings have become the norm, so they [staff] are far less-likely to recognise when a problem with care occurs." **Royal College of Nursing (Oral Evidence)**

Training

During their oral evidence session, CCW outlined the mandatory training that individuals must undertake before they can deliver care in a care home setting. This basic training consists only of manual handling, fire safety and health and safety training and does not sufficiently prepare individuals to understand the needs of older people and provide the appropriate support.

It is also particularly concerning that, according to evidence from CCW, only an estimated 60% of care staff have completed this mandatory training, which means that a significant number of care staff across Wales are delivering care without even the most basic of training. This also means that the National Minimum Standard 21 (Staff Qualifications Outcome), which states that 'service users are in safe hands at all times' is currently not being met in a significant number of cases, potentially putting older people at increased risk of injury or harm.

"They had no training. I asked and the only training they had received was health and safety, and manual handling, they had no idea of how to meet a resident's needs, particularly people with dementia." **Family Member (Questionnaire Response)**

"There are a lot of good carers but they lack better training." **Family Member (Questionnaire Response)**

Evidence from Age Cymru stated that the basic training currently provided is not sufficient and that 'mandatory dementia awareness, equality and human rights and basic values training should be provided to all residential care staff. This should include dignity and respect principles, attitudes and values, empathy, equality and human rights awareness and challenging negative stereotypes'.

Evidence from Alzheimer's Society reflected this, stating that staff need knowledge, both about the impact of dementia on the resident and also around practical components of care, to deliver high quality care to residents living with dementia. They stated that dementia training should be holistic and cover a range of aspects of care provision in both practical and personalised areas, such as providing care that promotes dignity and respect and communicating effectively with a person with dementia, essential to be able to understand their wishes and needs.

This values-based training would ensure that care staff not only fully understand the needs of older people living in residential care, but can also understand what it feels like to be an older person receiving such care. This empathy is essential to be able to provide person centred care and not simply follow a task-based approach.

Good Practice: Neath Port Talbot Social Care Academy – Care For Your Future

Neath Port Talbot Social Care Academy has been developed to support the sector in the recruitment of quality social care staff.

The Care for Your Future course sits within the 'Social Care Academy' and its programme starts with 'Delivering Dignity' which focuses on the question 'how can we be sure that every person is supported through an ethos of dignity and respect each and every day of their lives?'

The Academy is open to people who are able to attend a six month programme of workshops on a two weekly basis and equally attend as a volunteer for four hours per week in a care setting, where they will be guided by a mentor who has previously completed this training and has a full understanding of delivering compassionate care.

One carer who had completed the training stated:

"Today I've realised that for the last twelve years I've just provided what you call token care. I've given people good food and I've put them to bed in a clean bed, but not with compassion and not ever realising how do they feel at this moment."

Good Practice: Care Forum Wales – Driving Dignity in Wales Toolkit

This toolkit has been developed with the help of Practitioners and Managers working in social care in Wales. It contains a selection of material they believe may be useful when carrying out induction, running refresher CPD seminars or just in general staff training.

The toolkit is built around four principles that should underpin service delivery:

Principle 1: Promote autonomy, personal identity and empowerment

Principle 2: Engender respect

(Cont...)

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Principle 3: Communicate effectively

Principle 4: Ensure privacy

The toolkit has eighteen parts and includes a wide range of information for care staff about what dignity means to older people, meeting people's personal preferences, the principles of person centred care and the impact of language.

The toolkit brings together best practice from across Wales to ensure that dignity in care is promoted.

In addition to values based training and up-skilling, further practical training for care staff can also deliver better outcomes for older people.

Evidence from Shropdoc, for example, stated that training staff to undertake simple health assessments, such as temperature, pulse, blood pressure and glucose levels, would enable more detailed health information to be provided during initial contact with GPs, resulting in more accurate diagnoses.

However, evidence from Care Home Managers and independent providers stated that limited staff time and workforce pressures often restricted access to training opportunities for care staff. Furthermore, wider support to access training opportunities is limited. This means that staff are often not able to learn and develop new skills that could enhance the quality of life of older people living in residential care.

Nursing Staff

Oral evidence from the RCN stated that there was disparity between the standards of nursing in the NHS and the standards found in nursing homes. They identified a number of reasons for this, including limited clinical supervision, a lack of peer support in nursing homes and a lack of opportunities for professional development, as well as nurses often having to make decisions on their own as they have no one to discuss issues with. These factors can be a particular issue in smaller nursing homes.

The RCN also stated that it is more difficult to recruit nurses to work in nursing homes due to a lower standard of pay and conditions, more isolated working environments and a general negative perception of nursing homes.

This can often result in newly qualified nurses being recruited to nursing homes who may have limited experience in working with older people and may require additional support and training. Retaining these nurses can also be difficult as many will move to a nursing role within the NHS.

Their evidence stated that Health Boards do not have a primary care strategy for nurses working in the residential care sector, which means that workforce planning

for Wales is based on the needs of the NHS and has failed to consider the needs of Welsh citizens living in residential care.

Whilst nurses working in nursing homes have a wide range of care skills, there will always be instances when older people will need timely access to specialist healthcare. The Commissioner received evidence from the RCN, Care Home Managers and independent providers that demonstrated there can be confusion about roles and responsibilities for medical treatment and care between the NHS and nursing care homes.

Evidence received from Care Home Managers stated that there are assumptions that nurses working in nursing homes can 'do everything', which means that the NHS often does not provide support in a proactive way.

“She [NHS professional] said ‘what sort of nursing home are you that you can’t do a male catheterisation?’. But with an EMI psychiatric nursing home you don’t very often find a gentleman with advanced dementia with a catheter. The nurse felt ‘that big’.” Care Home Manager (Oral Evidence)

Evidence taken during the roundtable discussion on health also highlighted the historical attitude towards nurses working in care homes:

“When I joined the Health Board in 2008 or 2009, there was an appalling attitude to nursing homes. It was very negative, they were somehow below us and I was quite shocked at that because I’m from primary care, I’m a General Practitioner... I think we’ve come on leaps and bounds, I think there’s an awful lot of respect for our colleagues in the independent sector. They’re not NHS nurses but they’re still nurses... I think there is a long way to go yet, I still think that our opinions of care homes lacks a lot so I think there is still some work to do.” Abertawe Bro Morgannwg University Health Board (Oral Evidence)

It is clear that on-going support to nurses working in care homes, whether from their peers or from the wider health system, is vital, not only to ensure that they have the skills and experience necessary to carry out their role effectively, but also to ensure that older people are receiving the care they need.

This is something that was acknowledged by Health Boards across Wales during the roundtable discussion on health:

“There are some great examples of secondary care being provided in nursing homes that prevents people from coming into secondary care type services. We’ve got a range of those, so a question of Health Boards is, given that this is happening and it’s producing great results, why aren’t you doing that everywhere? (Cont...)

...So the reflection of our board is that there's great practice in parts of our board, but why aren't they consistently and reliably doing this everywhere because it saves us money, it saves us time?" **Abertawe Bro Morgannwg University Health Board (Oral Evidence)**

Good practice: Betsi Cadwaladr University Health Board - Residential Care Liaison Nurse Project

The aim of this project is to take a proactive approach to maintaining the health of residents living in a residential care home, thus enabling them to stay in their home environment, preventing hospital admissions and being transferred to a nursing care home.

A trained nurse with the District Nursing team will coordinate and support the 29 registered residential care homes within the Health Board area. Initially a 12 month pilot project is planned where the liaison nurse will develop the role within one home over a four to six month period with a view of extending it to three homes within the year.

The team's initiative will be to support the care homes by assisting them in identifying training and development needs and assisting them in enhancing their practise.

Care Home Managers

"A manager who is caring and has a friendly manner with staff and relatives can make all the difference in a care home..." **Alzheimer's Society (Oral Evidence)**

"Some of the best care homes I saw had an ethos that came straight from the manager. An ethos that is shared with the staff and means that the focus was delivering care in people's own home and this should be done respectfully and unobtrusively wherever possible." **Social Care Rapporteur**

Written evidence from Age Cymru stated that effective leadership is a common factor amongst good care homes and that strengthening management and leadership skills in care homes delivers better outcomes.

This was supported by evidence from Dementia Care Matters who stated that the manager plays a key role in modelling person-centred care on a daily basis, essential to improve the quality of interactions between residents and care staff, and ensure that a task-based approach is not used in the delivery of care.

"In all dementia care homes that really provide a new culture in dementia care, this rests with a manager who knows how to lead, rather than just manage. Improving a dementia care home requires a significant amount of drive and

commitment to enable culture change. Maintaining the momentum of culture change can be particularly challenging. Task orientation is deeply ingrained. Achieving real outcomes for older people means that care homes need inspiring leaders.” **Dementia Care Matters (Written Evidence)**

It is clear that Care Home Managers who strive to deliver the best quality of life for residents have recognised the limits of a task-based approach to care delivery. For example, during their roundtable discussion, Care Home Managers spoke about cultivating a family spirit in their homes, as well as the need for emotional energy and passion ‘in bucket-loads’ to maintain a positive care environment and drive cultural change.

“I’ve invested a massive amount of emotion in my home and that’s what rubs off, if you’ve got that depth of feeling about the people you’re looking after and loving, then the staff to take that on board, it cements huge relationships between the people you’re looking after. And the people I’m looking after are all of the people in my building, there’s 51 residents, there’s 53 care assistants and I guarantee one thing if they [care staff] don’t like it, they won’t stay.” **Care Home Manager (Oral Evidence)**

Whilst the Care Home Managers who gave evidence were committed to delivering the best care and quality of life for older people, they were clear that the breadth of their role, competing priorities and demanding workloads resulted in a lack of time to drive the cultural change required within their care homes.

This was reflected in evidence from Age Cymru who stated that it is the manager who will demand high standards and drive a positive culture in a care home. However, the complexity of a manager’s role, which often combines the role of lead clinician, operations manager, finance manager and marketing director, can affect their ability to do this.

“A manager should lead by example and free up time, away from their own tasks, to spend quality time with the staff and people who are at the care home...show everyone that they matter.” **Rhondda Cynon Taf County Borough Council (Written Evidence)**

Support for Care Home Managers

“Many [Care Home Managers] are isolated – they don’t have opportunities to discuss issues with people in similar roles. Access to learning is limited.” **Care Council for Wales (Oral Evidence)**

Care Home Managers must hold certain qualifications in order to register with the Care Council for Wales, which ensures that they are professionally qualified to

undertake their role. However, Care Home Managers clearly identified the need for and value of effective and on-going support, both in the form of additional training and specialist support.

“I think there’s a paucity of higher level support, certainly of education. You’re a manager or you’re a nurse, that’s it, you don’t need any further [training]... Well you do, you need loads. Well I personally do.” Care Home Manager (Oral Evidence)

“I think that we’re very stand-alone aren’t we and kind of forgotten maybe because not a lot of people know what to do to make a good home.” Care Home Manager (Oral Evidence)

In their evidence, CCW highlighted a number of reasons why care home managers may feel that they need additional support.

The main reason they stated was that the role of a Care Home Manager has significantly changed over recent years as the needs of older people living in residential care have become more complex. The definition and status of a Care Home Manager has not kept up with the increasing demands and expectations that are now placed on this role. CCW recognise that this ‘lag’ needs to be addressed and initiatives are being explored that will ensure that Care Home Managers are equipped to become ‘leaders of practice’, such as continuing personal development delivered through post-qualification training. CCW stated that the development of a career pathway and Continuing Professional Education and Learning (CPEL) Framework¹⁰⁰ will provide an opportunity to contribute to the professionalisation of the care home workforce, drive up standards of care and provide care home managers with the knowledge and skills that they need.

Furthermore, CCW stated that the component parts of the Care Home Manager role are “too much for one individual to balance”. There needs to be a more equitable balance between the care home manager, who should be a leader of practice and responsible for the delivery of high quality care, and the responsible individual (e.g. care home owner) who should carry corporate responsibility for the way the home is run.

Evidence from Embrace Group, an independent provider, described more successful care homes as those that delegated responsibility across staff with different skill sets. In these homes the manager will work closely with a deputy to continuously deliver high quality care and culture even in their absence.

In their evidence, CCW highlighted that training opportunities for Care Home Managers are limited, outlining a number of reasons why this is currently the case. They stated that financial and time pressures have resulted in difficulties around releasing and funding care managers to receive training. They also stated that there is a lack of parity in the investment into health care and social care, with between

£70k and £100k of public funding used to train a nurse and only £5k used to train a social care manager. Furthermore, they highlighted that the proposed changes to funding arrangements in Wales are likely to reduce access to funding for training opportunities for people aged 24 and over, which could have a negative impact upon the professional development of care home managers.

It is essential that learning provision is made available that is of high quality, regulated, flexible, sustainable and cost-effective in order to deliver the Social Services and Wellbeing Outcomes Framework in care homes.

Good Practice: Aneurin Bevan University Health Board (ABUHB) - Clinical Lead Forum

ABUHB has developed a clinical lead forum to bring together Care Home Managers with other key organisations, such as CSSIW and Care Forum Wales, on a regular basis.

The forum provides an opportunity to consider and discuss various topics including contract compliance and monitoring, Deprivation of Liberty Safeguards, Protection of Vulnerable Adults and the development and sharing of good practice.

These forums are greatly appreciated by both the Care Home Managers and ABUHB as they enable reliable on-going communications.

Workforce Planning

Evidence from CSSIW stated that workforce planning is challenging due to a lack of demographic projections about future need therefore it is not possible to quantify the 'right' number of care staff as this will vary depending on the support needs of individuals living in residential or nursing care homes.

“One of the things we battle with as an inspectorate is staffing sufficiency. There are no set number ratios and that is both a good thing and a bad thing. The bad thing is it is very hard for us to hold people to account for the number of staff that they’ve got on duty. On the other hand, you need to be flexible in terms of people’s increased dependency.” CSSIW (Oral Evidence)

Evidence from the Care Council for Wales stated that the unregulated nature of the care home workforce in Wales, which means that data is not held on the number of care home staff in Wales, can also lead to difficulties around effective workforce planning.

Evidence from the RCN identified that, in relation to nursing staff in particular, there is a lack of effective workforce planning. They stated that this planning is based on the needs of Health Boards and the hospitals they run and does not consider the needs of residential care.

Evidence from Carmarthenshire County Council and Rhondda Cynon Taf County Borough Council also stated that they have significant issues around the recruitment of nurses, particularly in recruiting Registered Mental Health Nurses and nurses to work in EMI care homes.

Issues around recruiting EMI nurses were also highlighted in evidence from Caerphilly County Borough Council.

“The EMI capacity, particularly in nursing capacity, is a real problem for us. Not so much on a residential EMI capacity, we’re doing okay on that. But it’s proving very difficult to persuade providers to go and provide those EMI nursing facilities. It is not an attractive market for them to move into. So those capacity issues, I can only see continuing, to be honest.” **Caerphilly County Borough Council (Oral Evidence)**

Local Authorities have also stated that the recruitment and retention of Registered Mental Health Nurses, alongside the higher cost of specialist nursing care in EMI settings, is a significant barrier to providers entering and sustaining this type of provision, especially in rural areas.

The Care Council for Wales also identified that a number of Care Home Managers are not registered and, although succession planning has improved, there are still gaps in the number of registered managers that are needed for the future.

“Whereas there is some evidence of succession planning in that there were more services with more than one person qualified and registered as a manager than in 2012, there still needs to be careful succession planning for the service.” **Care Council for Wales (Written Evidence)**

Without the correct workforce – the right number of staff, with the right skills, in the right places – residential care provision will be unstable and unable to meet the needs of older people living in residential care both now and in the future.

Commissioning, Regulation and Inspection

Literature Review

Local Authorities in Wales currently face the twofold obstacle of rapidly rising costs in adult social care and significant budgetary constraints. Alongside this, the increased demand due to demographic changes, and the increasing complexity of needs and acuity levels of older people means that the task of providing care has become more intensive and complex.

Whilst current policy strongly promotes services that enable older people to remain in their own homes for longer, the importance of high-quality residential and nursing care cannot be underestimated, given the known increase of older people in Wales over the next decade, particularly those over the age of 80 and levels of disability, chronic ill-health and corresponding frailty.

It is clear that as the number of older people continues to grow in Wales there will be a corresponding increase in the demand for care to be delivered in a residential or nursing setting.

Guidance from both the Welsh Government¹⁰¹ and the Institute of Public Care¹⁰² have advised that in order to ensure there is sufficient, appropriate provision for current and future needs, commissioners must have a good understanding of the existing market upon which to conduct an analysis and then make a judgement.

However, CSSIW's National Review of Commissioning for Social Services in Wales 2014¹⁰³ found that 'services are not sustainable in the traditional commissioning model'. Although the Review found that Local Authorities recognised this, they did not find evidence of an in depth analysis of the needs and resources of communities, and the sustainability of future services.

Furthermore, research by LE Wales (Future of Paying for Social Care in Wales, First Report to the Welsh Government, April 2014) found that accurate information about people who funded their own residential care was not available, "There may well be a significant number of these self-funders that are not captured here. For example, it has been estimated that in England, 43% of individuals staying in care homes were fully self-funded in 2013"¹⁰⁴.

Without knowledge of the numbers of those older people who will require residential or nursing care, it is not possible for commissioning and future planning to be sustainable, and fully meet the future needs of older people in Wales.

Around 90% of care home provision for older people is supplied by the independent sector, i.e. voluntary and for-profit organisations¹⁰⁵. According to recent market analysis, the last five years has seen a significant increase in demand for residential and nursing care in line with an ageing population. However, industry revenue has

not grown substantially and is only expected to increase at a compound annual rate of 0.2% in the five years between 2013 and 2018¹⁰⁶.

Market analyses have also highlighted the following factors that have the potential to adversely impact commissioning costs and the sufficiency of the care home market:

- Staffing and pay levels
- Running costs
- Care home fees¹⁰⁷

These factors are particularly significant in Wales where “profit as a percentage of income most clearly lags behind the UK average”. This is in part as a result of high staff costs relative to fee income¹⁰⁸.

Pay levels in the sector will continue to be an issue, with operators perhaps seeking to limit pay increases in line with the national minimum wage. This, according to Colliers International Research, would be a false economy as staff, especially senior staff, have to be incentivised and rewarded for maintaining high care and amenity standards and effectively marketing the homes’ services. If a business in the healthcare sector loses its senior motivated staff, it will typically result in deteriorating standards and profit¹⁰⁹.

However, research indicates that despite these challenges “expenditure could be reduced through more effective and collaborative commissioning, including procurement of services”¹¹⁰.

In their review of Commissioning in Adult Social Care, the Care and Social Services Inspectorate for Wales (CSSIW) identified that “current commissioning arrangements for dementia services will not deliver sustainable services for adults who need care and support in Wales”¹¹². The report goes on to highlight that the “current and projected service demands for adult social care services and the resulting financial pressures present a significant challenge to Local Authorities and Health Boards if they are to meet the current and future needs of vulnerable citizens”¹¹³.

The field work for the CSSIW Review was specific to five regions and was conducted in Blaenau Gwent, Vale of Glamorgan, Swansea, Merthyr Tydfil and Flintshire. However, findings reflect the broader landscape across Wales and illustrate the current situation faced by all of Wales’ 22 Local Authorities and 7 Health Boards. The Commissioner recognises the importance of this review and welcomes its recommendations, with particular emphasis on those that called for Local Authorities and Health Boards:

- to integrate health and social care provision, and develop joint plans for the commissioning of services;
- to develop outcomes based commissioning strategies, with contract monitoring and review;

- to ensure that joint commissioning plans have appropriate governance arrangements¹¹⁴.

Research by the Joseph Rowntree Foundation shone a light on Essex County Council's approach to commissioning social care. It shows that the Council has shifted its commissioning approach from "top-down monitoring, inspection and regulation to one that builds relationships, invests in the development of care home staff, and instils a shared vision for care and support for older people"¹¹⁵.

The 'Essex approach' builds upon the work of My Home Life, which aims to improve quality of life in care homes through a relationship-centred approach that focuses on building positive relationships and connections between and among older residents, care home staff and managers, and with commissioners¹¹⁶.

A core feature of the Essex approach is "the simultaneous focus on commissioning and provision; the council did not just expect care homes to change and improve, but required sustainable, systemic improvements across the health and social care community. Putting this approach into practice, Essex replaced the previous Quality Monitoring team in the council with a small Quality Improvement (QI) team, changing its relationship from a 'hands-off', punitive approach to monitoring, to working alongside care homes to achieve better outcomes for older residents. The My Home Life themes have become part of the council's contracting and procurement processes, meaning that funding and contractual decisions are based on quality outcomes, rather than traditional measures such as numbers of people or beds"¹¹⁷.

In short, good commissioning should involve identifying the needs to be met and the desired outcomes, planning how best to meet those needs, procuring high quality and cost effective services and monitoring service delivery to ensure outcomes are being achieved¹¹⁸.

Through improved commissioning, adult social care can achieve better outcomes for service users, carers and families; make sure services are designed to meet the needs of service users; make the best use of resources; and keep an on-going check on the quality and impact of services.

Commissioning is not simply a process of analysis, procurement and review. "Values and principles shape who gets what, how, when and where"¹¹⁹. It is these values and principles that will determine the quality of life that older people in Wales will be enabled to achieve through residential care.

In addition to quality monitoring activities that commissioners will undertake, the Care and Social Services Inspectorate for Wales is the body responsible for inspecting social care and social services to make sure that they are safe for the people who use them¹²⁰, and it regulates and inspects residential and nursing care homes based on compliance with the National Minimum Standards, and inspection tools that it has developed.

The Welsh Government White Paper, 'The Future of Regulation and Inspection of Care and Support'¹²¹, has proposed to change the regulation and inspection of care and support. A forthcoming 'Regulation and Inspection Bill' will introduce an outcomes based inspection regime, the involvement of citizens in inspection, require providers to produce an annual report on their services and widen the workforce role of the Care Council for Wales into service improvement, and rename it the National Institute of Care and Support. The proposals to develop an outcomes based inspection regime could see a move away from compliance with National Minimum Standards, and support the changes that have been identified in research needed within commissioning.

Review Findings

Commissioning

Evidence from Health Boards and Local Authorities highlighted that Local Authorities are generally the lead partners in commissioning.

Local Authorities base their commissioning practices on 'Fulfilled Lives, Supportive Communities', the Welsh Government's 2010 commissioning framework, guidance and good practice¹²². This established a set of 13 commissioning standards, along with guidance on nine key commissioning challenges at a strategic level.

To fully understand the different approaches to commissioning in Wales, the Commissioner required information from Local Authorities and Health Boards that confirmed:

- What they are commissioning
- Whether they are commissioning for quality of life
- How they monitor and seek assurance that the quality of life and care will safeguard and promote the wellbeing of older people

The majority of responses from Local Authorities and Health Boards clearly highlighted that the statutory focus has been on contractual frameworks and service specifications rather than seeking assurances about the quality of life of older people living in care homes. This was confirmed by CSSIW's National Review of Commissioning for Social Services in Wales 2014¹²³, which found that there was an inadequate focus on the quality of care provided and people's quality of life.

Residential and nursing care homes form part of the whole health and social care 'system', and should be treated as such in an inclusive and consistent manner. Therefore, when a Local Authority or Health Board commissions a place for an individual within a residential or nursing care home, their responsibility should be to not only lay out service specifications and to ensure that the care package can be delivered within their fee structure, but to also actively seek on-going assurances that an older person is safe, well cared for and has a good quality of life.

The evidence from Health Boards showed that this has often not been the case and that commissioning and monitoring in the past has focused solely on the clinical, nursing element of a placement and not even on wider primary healthcare needs let alone the full quality of life of an individual. However, as Hywel Dda University Health Board demonstrated in their oral evidence, they are now beginning to take steps to widen the scope of their review visits.

“The review officers that go in were previously concentrating on the reviews around the health care, for the nursing care etc. However we’ve enhanced that now so they’re looking at the environment and considering other aspects of the home and what’s being delivered, how that’s being managed.” Hywel Dda University Health Board (Oral Evidence)

According to the Welsh Government’s NHS Wales Planning Framework¹²⁴, Health Boards have a responsibility to plan ‘for the health of the entire population (not just planning for the services they provide)’. They therefore have a responsibility to ensure quality of life for all older people living in care homes, not just the individuals for whom they commission care home places.

Both Betsi Cadwaladr University Health Board and Hywel Dda University Health Board have taken action to ensure that the health of all older people in care homes is considered by introducing ‘residential liaison nurses’ whose role is to up-skill care staff in basic, but essential, healthcare issues such as continence care and to access and deploy specialist nursing support where necessary from the local primary care teams.

Evidence from Health Boards demonstrated a commitment to a change of focus during commissioning and monitoring, moving away from a clinical focus towards a more holistic approach for the benefit of an individual.

“There’s a great deal of work that needs to go on in terms of how we commission the care from the residential homes and the nursing homes. So we are very clear from the outset what their [an individual’s] expectations are. Like a contract of care really and what they’re expecting to deliver and work with us in partnership.” Betsi Cadwaladr University Health Board (Oral Evidence)

However, it is clear that these changes are at an early stage of moving towards a clearer, more ‘person focused’ approach to commissioning that can operate alongside a Health Board’s wider healthcare obligations to their whole population.

Responses from Local Authorities showed that while some have used service specifications to ensure that older people are supported to enjoy their basic human rights, there is an overall lack of quality assurance that is centred around quality of life, in current commissioning practice.

However, the majority of Local Authorities did state their intention to implement some form of quality monitoring tool in the near future, or that their current processes were under review.

Some Local Authorities are taking innovative approaches to their commissioning and fee structures in order to drive up quality. Bridgend County Borough Council, for example, has set up a 'quality fee standards system' that bases the fees paid to providers on the achievement of care standards that are higher than the current National Minimum Standards.

“[The ‘quality fee standards system’] Sets out principles and outcomes we want within care homes locally. They act as a positive vehicle for us to set out our high expectations around self-determination, lifestyle choice and preferences...” **Bridgend County Borough Council (Oral Evidence)**

While this could be used as a tool to drive up the quality of care that is provided in care homes within an area, there is the risk that, when under financial pressures, providers could become reliant on a higher 'quality fee' for the delivery of lower care standards and struggle to remain sustainable if the 'quality fee' is consequently removed.

Newport City Council described the joint work they are undertaking with Torfaen County Borough Council and local providers, to develop a fee methodology. Their fee modelling group is also considering how quality monitoring tools, that include a greater focus on quality of life, can be introduced.

“Torfaen and Newport at the moment have got a working group... to develop a fee methodology across both patches of Gwent. As part of that fee modelling group we've also got a quality group that's made up of some representatives from providers, and we're hoping to develop a common quality framework that providers can use that will help us and aid us with contract compliance, but will focus more on the quality of life and the experience of the older person within residential care.” **Newport City Council (Oral Evidence)**

Evidence from independent providers highlighted the difficulties in operating across different parts of Wales because there can be significant differences between the process of service specification and the practice of contract monitoring in different areas. This was also supported by evidence from Local Authorities and Health Boards and has been recognised by the Welsh Government, which stated, in Sustainable Social Services for Wales: A Framework for Action (2013)¹²⁵, that '... doing everything 22 times is not an option... The way in which commissioning, procurement and service delivery are organised must also change'.

Good Practice: Flintshire County Council

To ensure that quality of life is a core element of the commissioning process, Flintshire County Council has introduced an outcomes based quality monitoring process, which is based on consultations with older people and families about their expectations of residential care. The framework looks at 9 specific outcomes that care homes are required to deliver for older people:

1. Independence
2. Control over daily life
3. Rights, relationships and positive interactions
4. Ambitions (to fulfil, maintain, learn and improve skills)
5. Health (to maintain and improve)
6. Safety and security (freedom from discrimination and harassment)
7. Dignity and respect
8. Protection from financial abuse
9. Receipt of high quality services

This approach has now been agreed as the basis for the North Wales Quality Monitoring Framework for Care Home Placements.

A common framework across North Wales is a positive step to reducing the burden on providers, improving clarity regarding what care homes must deliver for older people, and ensuring that out of county placements can be delivered to consistent standards.

One of the defining elements of the framework in Flintshire is that it is carried out through an on-going quality monitoring approach that facilitates feedback from all residential care professionals. This process, described as a “quality circle”, enables information to be shared effectively, an essential part of any monitoring process.

“It’s about people sharing intelligence, and some of that’s about hard evidence that they’ve gathered during their professional visits or people bringing feedback that they’ve had because they’ve had contact with families or whatever. Also, hearing about changes that have happened in homes in staffing, [etc] and then we look at themes.” Flintshire County Council (Oral Evidence)

The quality circle is open to all professionals, such as social workers, district nurses and inspectors, as well as those providing day-to-day services within residential care, such as hairdressers and chiropodists. Residents groups and family members are also able to participate and provide any relevant information, which is essential

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as, according to Margaret Flynn, who is leading the independent review into alleged abuse of older people in care homes in the south Wales valleys, they “notice the daily inattentions that pave the way for more serious transgressions and on-going cumulative neglect”.

A proactive approach to assurance that ensures intelligence is gathered at an early stage to identify issues before they become ‘full blown problems’ and also triangulates evidence from a wide range of professional sources, older people, families and care staff is essential for commissioners to evaluate the quality of life provided by care homes. This approach will enable the identification of factors that have been highlighted as ‘risks’ by the Welsh Government, CSSIW, Care Council for Wales, Local Authorities and Health Boards, such as the departure of a Care Home Manager, high turnover of staff, withdrawal of placements by other Local Authorities, or financial instability.

“It’s really trying to get in and work with the provider and trying to understand what problems that provider may be having so they don’t cause a problem further down the line. Staffing issues are an obvious candidate...if this needs more forceful action on our part as commissioner then we use our provider performance process.” **Caerphilly County Borough Council (Oral Evidence)**

The majority of written and oral responses from Local Authorities and Health Boards did not illustrate the ways in which shared intelligence and joint working were used in contract monitoring to ensure that older people were safe, well cared for and enjoyed a good quality of life. Instead their responses focused on the process, or strategy, of a formal annual review and complaints procedure and appeared to forget the individual, and their voice, which should sit at the heart of the quality process.

In some cases, the only information used regarding the quality of care appears to be from CSSIW inspection reports, with increased scrutiny being a reactive approach to issues raised by CSSIW, POVA (Protection of Vulnerable Adults), or through the Escalating Concerns process.

A report from the inspectorate alone cannot provide the depth of information needed to assure those commissioning services that older people are safe, well cared for and have a good quality of life.

Another issue identified in evidence from Local Authorities was that, those commissioning a wide range of services on behalf of older people are not experts in social care and do not fully understand the increasingly complex needs of older people, for example the increasing prevalence of older people living with dementia. It is therefore clear that there is an urgent need to up-skill those commissioning services in order to drive cultural change through outcomes based commissioning that has a clear vision of what good looks like.

The CSSIW National Review of Commissioning for Social Services in Wales 2014¹²⁶ identified that ‘current commissioning arrangements for dementia services will not deliver sustainable services for adults who need care and support in Wales’. Some Local Authorities provided evidence that demonstrated that they have recognised the urgency of this issue and have brought in expert advisers to assist.

Bridgend County Borough Council, for example, highlighted the work of their dementia liaison team, provided by the Alzheimer’s Society, and how important the third sector is in providing knowledge and external support to commissioners.

Similarly, Caerphilly County Borough Council is working with Dementia Care Matters, a consultancy that works to transform the culture of care in care homes for people living with dementia, to work with their commissioning team to improve the judgements they make about quality of life and care outcomes for older people. This has resulted in further training for a number of officers so that they can use this knowledge to raise the standards of residential care that they commission for older people.

Other evidence identified different approaches that aim to establish what good looks like from the perspective of an older person.

Monmouthshire County Council, for example, have taken steps to address the previous lack of individual voices within their contract monitoring procedures through initiating a ‘what matters conversation’. This helps social workers to find out what matters to older people before they enter care homes to inform the contract monitoring process.

A similar approach has been adopted by Aneurin Bevan University Health Board, who have developed ‘Care Home Ask and Talk’ (CHaAT) to capture the views of residents in care homes. This will be further enhanced by the Big Lottery funded Community Voice programme to develop an engagement project in care homes across Newport, Monmouthshire, Caerphilly and Blaenau Gwent.

The pilot phase of the project will place volunteers in four care homes so that they can identify ways in which services could be more tailored to take into account the views and concerns of older people.

These kinds of approaches are essential to ensure that commissioners are able to determine whether the care they are commissioning will deliver the best quality of life for an older person.

National Minimum Standards

In addition to the requirements set out in the Care Homes (Wales) Regulations 2002, the National Minimum Standards are used to determine whether care homes are providing adequate care and are meeting the basic needs of the people who live there.

Evidence from a range of organisations, including CSSIW, HC One, Bupacare, Western Bay collaborative, Caerphilly County Borough Council, Association of Directors of Social Services (ADSS) and the Welsh Local Government Association (WLGA) stated that the standards are reinforcing a culture of compliance to the bare minimum, rather than creating a culture where older people are supported to have the best quality of life.

The quality of life of older people needs to be articulated much more clearly within the standards and not seen as separate to personal care and clinical treatment. This separation has contributed to the current culture of task-based care where the recording of bowel movements, whilst important, is prioritised against the wider issue of an individual's quality of life. Quality of life should be the umbrella under which all other standards sit.

Evidence was also received that the National Minimum Standards are insufficient to meet the needs of the emotionally vulnerable and frail older people now living in care homes. Alzheimer's Society, RNIB Cymru, Action on Hearing Loss and DeafBlind Cymru criticised the standards for being unable to promote and uphold the rights of some of the most vulnerable older people. The standards do not clearly outline how to provide enabling care and support to older people with sensory loss and /or cognitive impairment and dementia.

Evidence from CSSIW also highlighted the limitations of the National Minimum Standards and their impact on older people.

“People expect us to police the basic standards, that’s all they want a regulator to do. Our view is that this isn’t good enough and actually the basic standards don’t promote equality.” CSSIW (Oral Evidence)

They stated that to address these limitations, they have undertaken a ‘modernisation programme’ that uses new inspection tools and represents a fundamental change to CSSIW’s approach to regulation and inspection.

Since 2012, they have used the Short Observational Framework for Inspection (SOFI)¹²⁷ to assess the quality of care in residential care where traditional interviews and conversations are difficult. This approach allows inspectors to evaluate the quality of interactions within care homes, interactions that fundamentally shape an individual’s quality of life, and has been welcomed by a number of care home managers who gave evidence to the Review.

“I found the way they’re inspecting, using the SOFI observation, has really helped in how we’ve perhaps not noticed how people interact with each other. When they’re doing maybe washing, or helping them with their hair, or bringing them a cup of tea. I think it really highlighted to me that that was an area that needed improving.” Care Home Manager (Oral Evidence)

However, Care Home Managers have reported a variance in individual inspectors' ability to utilise the new tool effectively and, as at any time of transition, there have been inevitable misunderstandings about CSSIW's changing approach.

Availability of Care Homes

Standard 10 of the Welsh Government's 'Commissioning Framework and Good Practice Guidance'¹²⁸ focuses on the need to promote service sustainability. Commissioning therefore has a central role to play in both the quality of life of an older person, as well as the wider current and future sufficiency and sustainability of residential and nursing care.

As part of the Welsh Government's prevention and integration agenda, an increasing number of older people are being supported to remain living in their own homes for as long as possible. This is to be welcomed when it is what the individual wants in order to maintain their independence and to deliver the best individual outcomes and quality of life.

The number of emotionally vulnerable, cognitively impaired and frail older people is likely to rise, meaning that the needs of those older people will be more complex and at a higher acuity than previously. The numbers of older people who may need the support provided in care homes must therefore be fully understood in order for providers and commissioners to plan effectively for the future.

However, CSSIW highlighted issues around insufficient planning, a lack of demographic assessment and projection into the future needs of older people living in care homes at both a national and Local Authority level.

“Demographic needs 2014 - Where is it? Where is the strategic plan that would then look at the cost as well as the provision? Within that provision, how much is required to be within sheltered housing accommodation, on then to residential care and nursing care homes. Where is that data? It's got to focus on people's needs and it's got to help to develop a market that will meet those needs.” CSSIW (Oral Evidence)

CSSIW also stated that without this planning there is “an immediate pressure which creates behaviours that are very much about day-by-day solutions rather than actually identifying what percentage of that population are going to be most vulnerable and what you therefore can do both within the community setting to prevent... [and ensure] meaningful residential as well as early intervention... Then you're working out how much residential care are you ever going to need and have you go it?”

Despite progress by Local Authorities on market position statements, there is no overview at a strategic level to ensure sufficient and appropriate care home places for older people in Wales, both now and in the future. Furthermore, there is also

a lack of data about the current and future needs of the 'oldest old' in terms of health, disability, incidence of cognitive impairments, sexuality, belief, and ethnicity. A finding reflected in the Joseph Rowntree Foundation's Better Life Programme, which recommends continued investment in data sources to further understanding of health, disability, economic and social well-being in old people. The planning of residential and nursing care homes for older people requires accurate projections of the future numbers and needs of older people to ensure that residents can live in a care home appropriate for them and have the best quality of life.

Despite the on-going and changing need for residential and nursing care across Wales, and recent efforts to support managing supply, evidence received demonstrated the volatile and fragile nature of the market sufficiency of residential and nursing care in Wales.

Evidence from CSSIW also demonstrated that although it is difficult to clearly identify a particular barrier to achieving market stability and sufficiency, the result is that Wales is not an attractive place for providers to enter.

“Wales is not actually a sharp place to come in to as a provider. There are loads of barriers ... The biggest issue for Wales is the fact that there are 22 different Local Authorities commissioning.” CSSIW (Oral Evidence)

The Care Council for Wales and independent provider HC-One highlighted that the lack of registered care home managers in Wales is both a risk factor to the quality of care being provided and the ability for a provider to continue provision.

A shortage of appropriately skilled nursing staff was identified by the Royal College of Nursing in their evidence as a barrier to market sufficiency. They stated that workforce planning is premised on the needs of the NHS Health Boards and the hospitals that they run, as opposed to the needs of the whole population. This shortage in nursing staff has a particularly detrimental impact on older people living with dementia who may need access to specialist mental health nursing care.

Evidence from Local Authorities also highlighted that, as well as difficulties in accessing or recruiting specialist nursing staff, the higher cost of providing this specialist mental health nursing care was a significant barrier to providers entering and sustaining provision, especially in rural areas.

This market volatility can have a significant impact on the lives of older people. The collapse of the Southern Cross Healthcare Group in 2011, for example, which ran over 750 care homes with 31,000 residents across the UK, resulted in a great deal of uncertainty and upheaval for many vulnerable older people and their families.

Evidence from many Local Authorities stated that they have begun, on a local or regional basis, through their commissioning processes and the development of market position statements, to discuss whether current provision matches the needs of the older population in their area. Tudalen 251

Evidence from Carmarthenshire County Council demonstrated that they took action in the form of a 'payment premium' to encourage the provision of specialist care for people living with dementia after their own market analysis showed a shortage in this area.

“We put a dementia premium on, to try and diversify providers, because we recognised that there was an increased need for dementia care ...we added a dementia premium and we felt that would encourage some of the residential care providers to diversify into dementia care, and that did work. I think it was partly linked to their own market analysis because they saw that was the way the trend was going in terms of people coming in. So you can influence and shape in terms of ... obviously that was linked to a financial incentive, really, but I think that has worked in our county.” Carmarthenshire County Council (Oral Evidence)

However, the majority of Local Authorities recognised that the choices available to older people are often restricted by a lack of capacity in some areas, despite their best efforts to support choice. This can result in older people having to move away from their family and communities or live in a care setting that is not entirely appropriate for their needs.

“We’ve always strived to ensure that people have their choice of home and in the past when it hasn’t been available then they may have stayed in hospital. That presents its own problems. Over the years the choice of homes has reduced as the supply has dwindled although more is coming on now. It does present a problem - clearly people want the home nearest to them, but that can still entail a significant degree of travelling and we try and fit in with the wishes of the older person and their carers.... it’s not always possible, particularly with the pressure on beds in hospitals.” Powys County Council (Oral Evidence)

“It is a very fragile situation because if we take certain decisions we could destabilise the market completely. An example of that would be that we would be very strong on wanting to get rid of shared rooms. It is a disgrace that we are still doing it in Wales. They knocked this out in England five/ten years ago yet we’re still doing it in Wales. As soon as we moved on that we would have loads of beds that would go out of the market. It’s because they haven’t got the capacity.” CSSIW (Oral Evidence)

Evidence from Care Forum Wales identified that current fee structures are acting as a barrier to entry and that providers feel under pressure from Local Authorities to deliver increasingly complex care at lower costs during times of budgetary pressures.

Local Authorities also stated that there are real issues in terms of the stability of the market at the moment and that smaller locally owned homes are particularly vulnerable as they do not have the capacity to overcome the barriers outlined above.

“Potentially we could lose the small ones, the smaller, locally owned homes are the ones that are potentially vulnerable under that. Because they don’t have the capacity to deal with those issues..... So there are real issues in terms of the stability of the market at the moment.” **Caerphilly County Borough Council (Oral Evidence)**

The closure of smaller homes, particularly those in rural areas, is a particular concern as larger providers are less likely to be attracted to these areas due to the sparse population and lower workforce availability, leaving significant gaps in market sufficiency in an area for future years.

In order for older people in Wales to access high quality residential and nursing care that meets their needs, there must be a sufficient number of appropriate care settings, of the type that older people want, in the places that they need them. The evidence has shown that this is not the case and that there are a number of barriers working together to prevent older people being able to choose where they want to live and what type of care services they receive.

Self-funders

It is not known exactly how many older people arrange and pay for their care independently of a Local Authority, or Health Board in Wales, although many of the respondents to the Commissioner’s questionnaire were self-funders, or rely on their families to support ‘top-up’ payments so they can remain in their care home.

Evidence from the Association of Directors of Social Services (ADSS) stated that self-funders are not empowered individuals. Often they may be completely unknown to social services and, as a result, do not have the awareness of, or access to, support that all individuals may need while living in a care home.

This current lack of knowledge about the number of self-funders in Wales who are living in care homes has an impact on the quality of life of older people because it is not clear what support and advice individuals are receiving and the extent to which the quality of care that self-funders receive is monitored. This also means that Local Authorities and Health Boards have difficulties in planning for future need and provision.

Support Available for Self-Funders

Evidence from the ADSS highlighted that self-funders must be thought of from the outset, including whether they have access to support, information and advocacy, for the commissioning process to be considered consistent and competent.

Evidence from the British Association of Social Workers stated that self-funders will often receive less support from a social worker during the decision making process to move into a care home and while they live there. They stated this is often due to a lack of time, pressure on social worker case loads and the greater responsibility that social workers have towards those individuals whose care is funded through a Local Authority.

Many questionnaire responses from residents who are self-funders and their families stated that they are fearful about raising concerns and complaints with a provider because of the perceived risk that they may be asked to leave the care home and would not know how to manage such a situation without support. A lack of support means that older people who pay for their own care may be less well placed to raise concerns about the quality of their care and, as a consequence, may experience unacceptable quality of care.

Quality of Care Delivered to Self Funders

When Local Authorities and Health Boards are monitoring the quality of care that is provided in care homes to older people, this is against the National Minimum Standards and additional standards that they may have set when they commissioned a package of care for an individual. Any quality monitoring therefore only applies to those individuals whose care is commissioned by the Local Authority or Health Board and not to individuals who have arranged and paid for their care independently.

Evidence from Health Boards demonstrated that professionals that monitor the quality of care, such as Nurse Assessors, may not be aware of the circumstances and healthcare needs of individuals who pay for their own care, because their focus is on monitoring quality for funded residents.

“When our Nurse Assessors go in, [they are] going in to review the placement. They are reviewing not just the standard of nursing care but that person in that environment and the holistic care that that person is given...And it’s about, I suppose, do our mechanisms take account of everything. I think if you were going back a few years it probably didn’t but I think we’re definitely seeing a shift now.” **Hywel Dda University Health Board (Oral Evidence)**

Local Authorities also gave evidence that stated that they did not have any access or rights to look into the quality of care or experiences of self-funders.

“We get basic data. We ask the providers to tell us, but that’s as far as it goes, as far as Carmarthenshire’s concerned. We don’t have any access or rights to visit or ask self-funders about their experience.” **Carmarthenshire County Council (Oral Evidence)**

Questionnaire responses from the families and friends of self-funders stated that the health of their relatives had deteriorated quickly and was not recognised and acted upon by any visiting Local Authority and Health Board staff because they only monitored the individuals who were funded by their bodies.

It is perhaps reasonable to assume that when a commissioning body enters a residence, they will take appropriate action if they become aware of unacceptable care that is being provided to an individual, regardless of their funding. However, as self-funders are not included in regular quality monitoring, an issue must be serious enough to come to the attention of the commissioning body before any action can be taken.

Future Planning

Local Authorities and Health Boards are unable to fully plan for the future needs of the older population and required provision of residential and nursing care if they are unaware of the total number of self-funders living in care homes, or how many self-funders are likely to live in care homes in the future.

If a Local Authority conducts a market position statement to identify current and future needs, but it is not aware of the number of self-funders, its predicted needs and planning could be inadequate to support the provision of care that is the right type, quality and price.

Evidence from Local Authorities during the commissioning roundtable discussion stated that self-funders often paid more for their care compared to those whose places are funded by a Local Authority.

“What I don’t find fair is providers who can provide a service for somebody on the Local Authority rate if they’re a service user of a Local Authority, but then charge a couple of hundred pounds more if somebody’s self-funding, and I think that’s really appalling.” Local Authority Commissioner (Oral Evidence)

Regulation and Inspection

The Care and Social Services Inspectorate for Wales (CSSIW) is the body responsible for the regulation and inspection of care homes across Wales. They inspect against the Care Homes (Wales) Regulations 2002 and the National Minimum Standards, which, as highlighted above, do not give sufficient focus to quality of life.

This has been recognised by CSSIW who stated in their evidence that the National Minimum Standards are no longer sufficient to deliver and monitor quality of life. They stated that their desire to move away from the ‘tick box’ approach to inspection has contributed to their modernisation programme, which includes the development of the SOFI tool described above and the proposed development of a Quality Judgement Framework, which will have a much greater focus on quality of life.

This modernisation programme is an important step forward to ensure that the quality of life of older people in care homes becomes a key element of the regulation and inspection system. However, CSSIW do not have responsibility for inspecting healthcare delivery in care homes, which is a key part of an individual's quality of life.

While Healthcare Inspectorate Wales is the body responsible for inspecting healthcare in Wales, they stated in their evidence that they do not inspect the standard of health care delivery within care homes as this falls outside of their remit.

“We don’t do work in the homes ourselves. We don’t have an on-going day to day responsibility in the inspection of how that’s done within homes, or the way in which LHBs commission.” Healthcare Inspectorate Wales (Oral Evidence)

This means that there is currently not appropriate or effective scrutiny of the delivery of healthcare in nursing care homes.

Evidence from the Board of Community Health Councils in Wales (CHCs), who have the power to monitor the delivery of NHS funded care and identify areas in which improvements must be made, stated that they could potentially address this gap as they have access to 400 community volunteers with a knowledge of the health service and a willingness to enter residential settings and monitor the delivery of healthcare. However, they have received conflicting legal advice from the Welsh Government and independent lawyers about the extent to which the powers under their legislation allow them to enter care homes to monitor the delivery of healthcare. This means that the potential for CHCs to monitor healthcare within care homes has not yet been explored.

“We’ve already got training packages in place and it’s just that there’s no point in delivering it unless we can get in there and do it, but we’re ready to go. We’ve been ready to go for eight years now and it’s been eight years - I have been pushing this issue.” Board of Community Health Councils in Wales (Oral Evidence)

Utilising CHC members to undertake monitoring work in care homes would also introduce a broader lay-perspective into the inspection system, something that has been successful in other parts of the UK and would support the Welsh Government's aim to 'actively engage citizens within our regulation and inspection regime', something that is currently being explored as part of work around the forthcoming Regulation and Inspection Bill.

Evidence from providers, Local Authorities, Health Boards and the inspectorate has demonstrated that a range of different commissioning, monitoring and inspection methods are used to quality assure care.

As commissioners, Local Authorities and Health Boards demonstrated that while they will commission and quality assure against the National Minimum Standards, they may also set other higher standards for providers to reach that as a result will vary across Wales. In addition to the future development of new inspection frameworks by CSSIW, there is significant variation in the understanding of 'quality of life' and how this is monitored.

When this is combined with the evidence that suggests the provision of healthcare in residential settings is not currently being sufficiently regulated and inspected, the current commissioning, regulation and inspection system is not working in an integrated and consistent way to ensure older people can achieve the best quality of life regardless of the particular care home or area in which they live.

The Regulation and Inspection Bill provides an opportunity to set out a single outcomes framework for quality of life and care of older people in care homes rather than the current system of National Minimum Standards. The framework would ensure alignment between all of the agencies involved in the planning and delivery of care, from providers to commissioners to inspectors, essential to ensure that quality of life truly sits at the heart of residential and nursing care.

An enabling and integrated approach to regulation and inspection is essential to drive improvements and support the delivery of care that has quality of life at its heart. Whilst a range of work has begun to move towards this approach, the regulation and inspection system still currently has an insufficient focus on quality of life.

Requirements for Action

My required actions range from system changes to changes around very specific aspects of care. In formulating these actions, I have sought advice from a wide range of experts and I have focussed on action that will have the most impact, clearly linking my actions to intended outcomes. I have linked my required actions back to the current and developing policy agenda in Wales, in particular to the National Outcomes Framework, as well as the opportunities afforded to us by forthcoming legislation and the good practice that already exists in Wales.

Any change, particularly systemic change that reboots the system and redefines an approach to care, needs strong leadership and drive to ensure that it delivers in a way that is meaningful to the older people that the change is intended to benefit. Without taking away from the leaders in their own fields that there are across Wales, there is a clear role for the Welsh Government to lead from the front, both in respect of expected change and providing support to our wider services and the organisations under my Review to ensure not just that the change outlined in my report is delivered, but that the intended outcomes are delivered as well.

Following formal agreement, in line with the requirements of the Commissioner for Older People (Wales) Act, of the action that will be taken by the bodies subject to my Review, I will also agree how compliance against these actions will be reported and how assurance will be provided that the intended outcomes have been delivered.

Whilst there will be some resource implications to implement the required actions, I have been conscious of constraints on public finances and realistic in laying out my expected outcomes and action.

If the change required that has been identified in my Review is not delivered, the price that is paid by older people will be too high. Increasingly, in the years to come, a failure to act will expose public bodies and independent providers to litigation, reputational damage, time spent undertaking remedial action or formal investigations into failures in care and will further increase pressures upon the NHS and social services.

Key Conclusion 1: Too many older people living in care homes quickly become institutionalised. Their personal identity and individuality rapidly diminishes and they have a lack of choice and control over their lives.

Link to Welsh Government policy and legislative areas: National Outcomes Framework for the Social Services and Wellbeing Act 2014, Declaration of the Rights of Older People in Wales, A Framework for Delivering Integrated Health and Social Care for Older People with Complex Needs, Integrated Assessment, Planning and Review Arrangements for Older People.

| Required Action | Outcome | Impact of not doing | By whom /By when |
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| <p>1.1 A national approach to care planning in care homes should be developed and implemented across Wales. This must support:</p> <ul style="list-style-type: none"> The full involvement of the older person to ensure they have an effective voice, including advocacy support where necessary. This may include independent advocacy or advocacy under the Mental Capacity Act. Ensuring the older person's personal history, social and cultural interests, occupation, achievements, likes, dislikes and aspirations are understood and reflected in their future life. This must include meeting the diverse needs of older people who are lesbian, gay, bisexual or trans, | <p>Older people receive information, advice and practical and emotional support in order for them to settle into their new home beginning as soon as a decision to move into a care home is made (Action 1.1, 1.2).</p> <p>Older people's physical, emotional and communication needs are fully understood, as are the issues that matter most to them, and these are reflected in the services, support and care that they receive.</p> <p>Older people have real control over and choice in their day-to-day lives and are able to do the things that</p> | <p>Older people are unable to settle into their new home, which has a detrimental impact upon their health and wellbeing.</p> <p>The individual needs, wishes and aspirations of older people are not recognised or understood and as a result their ability to do the things that matter to them is significantly undermined, as is their quality of life and mental wellbeing.</p> <p>Older people are unable to communicate effectively, which leads to an increased risk of isolation, withdrawal and emotional neglect.</p> <p>Older people are denied their rights to self-determination,</p> | <p>Welsh Government</p> <p>November 2015</p> |

those who are Black, Asian or minority ethnic and those with or without religion or belief.

- Transitional support once a decision has been made to move to a care home to ensure that the care planning process begins prior to moving into the care home.
- Meeting the emotional needs of older people to ensure they feel safe, valued, respected, cared for and cared about.
- Meeting the communication needs of people living with dementia and/or sensory loss.
- The needs of Welsh language speakers and those for whom English is not their first language.
- Entitlements to healthcare and assessment for and referral to healthcare services.
- Individual rights versus risk management.
- Multidisciplinary assessment (across Health Boards, Local Authorities and including specialist third sector

matter to them, including staying in touch with friends and family and their local community.

autonomy and control over their lives.

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| <p>organisations) and specialist clinical assessment.</p> <p>This guidance should clearly align to the new National Outcomes Framework, which underpins the Social Services and Wellbeing (Wales) Act 2014.</p> <p>National reporting of the quality of care plans and care planning against the national guidance and against the intended outcomes of the national Outcomes Framework should be undertaken annually (see action 6.10).</p> | | | |
| <p>1.2 All older people, or their advocates, receive a standard 'Welcome Pack' upon arrival in a care home that states how the care home manager and owner will ensure that their needs are met, their rights are upheld and they have the best possible quality of life. The Welcome Pack will make explicit reference to:</p> <ul style="list-style-type: none"> • How the care home manager will support the resident as they move into their new home. • Standard information about their human rights in line with the Welsh Declaration of the Rights of Older People.* | <p>Older people are aware of their rights and entitlements, and what to expect from the home.</p> <p>Older people are clear about how they can raise concerns and receive support to do so.</p> | <p>Older people are unaware of the support that should be available to them while making the transition into their new home, which can lead to low expectations and a lack of accountability for providers.</p> <p>Older people are at risk of neglect and abuse as they are unaware of who to speak to should they need help in making a complaint or need support to stand up for their rights.</p> <p>Older people are at risk of not receiving that to which they</p> | <p>Welsh Government & Care Home Providers</p> <p>March 2016</p> |

- A Statement of Entitlement to health care support.*
- Support to sustain and promote independence, continence, mobility and physical and emotional wellbeing.
- Ensuring their communication needs are met, including people with sensory loss.
- Maintaining friendship and social contact.
- Support to help them maintain their independence and to continue to be able to do the things that matter to them.
- The development and maintenance of their care and support plan and what will be included in it.*
- Ensuring a culture of dignity and respect and choice and control over day-to-day life.
- The skills and training of staff.
- Their right to independent advocacy and how to raise concerns. *

(The areas marked with * should be standard in format to ensure

are entitled to, leading to an undermining of their health, wellbeing and quality of life.

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| consistency across Wales) | | | |
| 1.3 Specialist care home continence support should be available to all care homes to support best practice in continence care, underpinned by clear national guidelines for the use of continence aids and dignity. | Older people are supported to maintain their continence and independent use of the toilet and have their privacy, dignity and respect accorded to them at all times (Action 1.1, 1.3, 1.5). | | Welsh Government Guidance April 2015 Health Boards Implementation December 2015 |
| 1.4 National good practice guidance should be developed and implemented in relation to mealtimes and the dining experience, including for those living with dementia. | Mealtimes are a social and dignified experience with older people offered real choice and variety, both in respect of what they eat and when they eat (Action 1.1, 1.4). | Older people do not enjoy mealtimes, are at increased risk of malnutrition and ill health through a lack of support at mealtimes and miss out on meaningful and important social interaction. The dignity of older people is significantly undermined. | Welsh Government April 2015 |
| 1.5 An explicit list of 'never events' should be developed and published that clearly outlines practice that must stop immediately. The list should include use of language, personal care and hygiene, and breaches of human rights. | Older people are treated with dignity and respect and language that dehumanises them is not used and is recognised as a form of abuse (Action 1.1, 1.3, 1.4, 1.5, 4.6). | Unacceptable practice continues and goes unchallenged. | CSSIW March 2015 |
| 1.6 Older people are offered independent advocacy in the following circumstances: | Older people living in care homes that are closing, as well as older people that are | Older people are unable to secure their rights or have their concerns addressed, which | Local Authorities & |

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| <ul style="list-style-type: none"> • when an older person is at risk of, or experiencing, physical, emotional, financial or sexual abuse. • when a care home is closing or an older person is moving because their care needs have changed. • when an older person needs support to help them leave hospital. <p>For those with fluctuating capacity or communication difficulties, this should be non-instructed advocacy.</p> <p>When a care home is in escalating concerns, residents must have access to non-instructed advocacy.</p> | <p>at risk of or are experiencing physical, emotional, sexual or financial abuse, have access to independent or non-instructed advocacy.</p> | <p>places them at increased risk of harm.</p> <p>An increased risk of adult practice reviews and civil litigation.</p> | <p>Care Home Providers & Health Boards</p> <p>April 2015</p> |
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Key Conclusion 2: Too often, care homes are seen as places of irreversible decline and too many older people are unable to access specialist services and support that would help them to have the best quality of life.

Link to Welsh Government policy and legislative areas: Social Services and Wellbeing (Wales) Act and National Outcomes Framework, Sustainable Social Services: A Framework for Action, Together for Health – Stroke Delivery Plan 2012-16

| Required Action | Outcome | Impact of not doing | By whom / By when |
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| <p>2.1 A National Plan for physical health and mental wellbeing promotion and improvement in care homes is developed and implemented. This draws together wider health promotion priorities, as well as particular risk factors linked to care homes, such as loneliness and isolation, falls, depression, a loss of physical dexterity and mobility.</p> | <p>Older people benefit from a national and systematic approach to health promotion that enables them to sustain and improve their physical health and mental wellbeing.</p> | <p>Older people are at increased risk of falls and ill health.</p> <p>Older people’s physical and mental health will decline more quickly than it needs to and they have an earlier need for more specialist care.</p> <p>An increase in workload and pressure for the care home workforce.</p> <p>An increase in referrals to NHS services, as well as earlier and longer hospital admissions for older people.</p> | <p>Lead Welsh Government</p> <p>March 2016</p> |
| <p>2.2 Older people in care homes have access to specialist services and, where appropriate, multidisciplinary care that is designed to support rehabilitation after a period of ill health.</p> | <p>Older people receive full support, following a period of significant ill health, for example following a fall, or stroke, to enable them to maximise their independence and quality of life.</p> | <p>Older people have reduced mobility, increased frailty and loss of independence, with an increased risk, due to immobility of significant health problems, such as pressure ulcers, pneumonia and deteriorating</p> | <p>Health Boards and Local Authorities in partnership</p> <p>July 2015</p> |

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| <p>2.3 A National Falls Prevention Programme for care homes is developed and implemented. This should include:</p> <ul style="list-style-type: none"> • Enabling people to stay active in a safe way • Up-skilling all care home staff in understanding and minimising the risk factors associated with falls • The balance of risk management against the concept of quality of life and the human rights of older people, to ensure that risk-averse action taken by care staff does not lead to restrictive care. <p>National reporting on falls in care homes is undertaken on an annual basis (see action 6.8).</p> | <p>Older people's risk of falling is minimised, without their rights to choice and control over their own lives and their ability to do the things that matter to them being undermined.</p> | <p>mental health.</p> <p>Older people are at an increased risk of falls leading to reduced mobility, increased frailty and loss of independence, with an increased risk, due to immobility of significant health problems, such as pressure ulcers, pneumonia and deteriorating mental health.</p> <p>Significant financial impact on the NHS due to increased admissions.</p> | <p>Welsh Government</p> <p>November 2015</p> |
| <p>2.4 The development and publication of national best practice guidance about the care home environment and aids to daily living, such as hearing loops and noise management, with which all new homes and refurbishments should comply. This guidance should also include mandatory small changes that can be made to care homes and</p> | <p>The environment of all care homes, internally and externally, is accessible and dementia and sensory loss supportive.</p> | <p>Older people are unable to move around the care home safely and independently or do the things that they enjoy.</p> <p>Older people struggle to communicate with each other and staff, leading to isolation and withdrawal.</p> | <p>Welsh Government</p> <p>July 2015</p> |

outdoor spaces to enable older people with sensory loss and/or dementia to maximise their independence and quality of life.

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Key Conclusion 3: The emotional frailty and emotional needs of older people living in care homes are not fully understood or recognised by the system and emotional neglect is not recognised as a form of abuse.

Link to Welsh Government policy and legislative areas: Together for Mental Health - A Strategy for Mental Health and Wellbeing in Wales, National Outcomes Framework 2014, Mental Health (Wales) Measure 2010, National Dementia Vision for Wales 2011 and the Intelligent Targets for Dementia. NICE Dementia Quality Standard 2010. NICE Dementia Quality Standard (2010) and NICE Clinical Guideline 42. November 2006 (amended March 2011)

| Required Action | Outcome | Impact of not doing | By whom / By when |
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| <p>3.1. A national, standardised values and evidence based dementia training programme is developed that covers basic, intermediate and advanced levels of training, which draws on the physical and emotional realities of people living with dementia to enable care staff to better understand the needs of people with dementia.</p> | <p>All staff working in care homes understand the physical and emotional needs of older people living with dementia and assumptions about capacity are no longer made (Action 3.1, 3.2).</p> | <p>Older people are at risk of emotional neglect, as well as continuing to be misunderstood and labelled as 'challenging' or 'difficult', because the care home workforce is unaware of how to communicate and respond to their needs.</p> | <p>Welsh Government November 2015</p> |
| <p>3.2 All care home employees undertake basic dementia training as part of their induction and all care staff and Care Home Managers undertake further dementia training on an on-going basis as part of their skills and competency development, with this a specific element of supervision and performance assessment.</p> | | <p>Older people feel anxious and fearful, confused and disorientated and their ability to have control over their lives is undermined.</p> <p>An increase in hospital admissions and a greater need for health care as a result of older people's needs not being understood or met. A greater risk of incidences of unacceptable care. A significant increase in the</p> | <p>Local Authorities & Care Home Providers Begin January 2016</p> |

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| | | <p>pressures faced by the care home workforce.</p> <p>A wider perception across society that residential and nursing care lacks compassion.</p> | |
| <p>3.3 Active steps should be taken to encourage the use of befriending schemes within care homes, including intergenerational projects, and support residents to retain existing friendships. This must include ensuring continued access to faith based support and to specific cultural communities.</p> | <p>Older people are supported to retain their existing friendships and have meaningful social contact, both within and outside the care home. Care homes are more open to interactions with the wider community.</p> <p>Older people are able to continue to practice their faith and maintain important cultural links and practices.</p> | <p>Older people living in care homes are lonely and socially isolated, lack opportunities for meaningful social contact and their ability to practice their faith and important cultural practices is lost. Care homes are isolated within and from their communities, undermining the care and wellbeing of older people and access to wider community resources and support.</p> | <p>Care Home Providers & Local Authorities</p> <p>November 2015</p> |
| <p>3.4 In-reach, multidisciplinary specialist mental health and wellbeing support for older people in care homes is developed and made available, including:</p> <ul style="list-style-type: none"> • An assessment of the mental health and wellbeing of older people as part of their initial care and support plan development and their on-going care planning. • Advice and support to care staff | <p>The mental health and wellbeing needs of older people are understood, identified and reflected in the care provided within care homes. Older people benefit from specialist support that enables them to maximise their quality of life.</p> <p>Older people are not prescribed antipsychotic drugs inappropriately or</p> | <p>Older people living with dementia are at risk of accelerated cognitive decline and the inappropriate use of antipsychotic drugs. On-going mental health issues significantly undermine their quality of life.</p> <p>An increase in workload and pressure upon care staff.</p> <p>An earlier need for specialist residential care and an increase in Continuing Healthcare Costs.</p> | <p>Health Boards</p> <p>November 2015</p> |

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| <p>about how to care effectively for older people with mental wellbeing and mental health needs, including dementia, and when to make referrals.</p> <ul style="list-style-type: none"> • Explicit referral pathways and criteria for referral. • All residents on anti-psychotics are monitored and assessed for potential withdrawal and reviews are conducted in line with NICE guidelines. | <p>as an alternative to non-pharmaceutical methods of support and NICE best practice guidance is complied with (Action 3.4, 3.5).</p> | | |
| <p>3.5 Information is published annually about the use of anti-psychotics in care homes, benchmarked against NICE guidelines and Welsh Government Intelligent Targets For Dementia.</p> | | | <p>Health Boards September 2015</p> |
| <p>3.6 The development of new safeguarding arrangements for older people in need of care and support in Wales should explicitly recognise emotional neglect as a form of abuse, with this reflected in guidance, practice and reporting under the new statutory arrangements.</p> | <p>Emotional neglect of older people is recognised as a form of abuse and appropriate action is taken to address this should it occur.</p> | | <p>Welsh Government November 2015</p> |

Key Conclusion 4: Some of the most basic health care needs of older people living in care homes are not properly recognised or responded to.

Link to Welsh Government policy and legislative areas: Fundamentals of care, National Service Framework for Older People, Together for Health: a Five Year Vision for NHS Wales, Setting The Direction, Together for Health: Eye Health Care Delivery Plan for Wales 2013-2018, NHS Wales Delivery Framework 2013-14 and Future Plans, Rural Health Plan – Improving Integrated Service Delivery across Wales, Together for Health: A National Oral Health Plan for Wales 2013-18, National Outcomes Framework for the Social Services and Wellbeing (Wales) Act 2014.

| Required Action | Outcome | Impact of not doing | By whom / By when |
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| <p>4.1 A clear National Statement of Entitlement to primary and specialist healthcare for older people in care homes is developed and made available to older people, including:</p> <ul style="list-style-type: none"> • Access to regular eye health, sight and hearing checks • Dietetic advice and support • Access to podiatry and dentistry services • Access to specialist nursing services • GP access and medicines support • Specialist mental health support • Health promotion and reablement support <p>This must cover both residential and</p> | <p>There is a consistent approach across Wales to the provision of accessible primary and specialist health care services to older people living in care homes and older people’s healthcare needs are met (Action 4.1, 4.2, 4.5).</p> <p>Older people in nursing care homes have access to specialist nursing services, such as diabetic care, tissue viability, pain management and palliative care (Action 4.1, 4.2).</p> <p>Older people are supported to maintain their sight and hearing, through regular eye health, sight and hearing</p> | <p>Older people are unable to see or hear properly, undermining their ability to communicate and their independence, placing them at greater risk of isolation and falls, emotional withdrawal and poor mental health (Action 4.1, 4.2, 4.3).</p> <p>Older people in nursing homes have preventable physical health conditions, unnecessary pain and their overall wellbeing is undermined through on-going poor management of chronic health conditions.</p> <p>Older people lose their teeth unnecessarily and are unable</p> | <p>Lead Welsh Government</p> <p>March 2015</p> |

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| <p>nursing care.</p> <p>Care home providers ensure older people receive information about their healthcare entitlements as part of their 'Welcome Pack' (see action 1.2).</p> | <p>checks (Action 4.1, 4.2, 4.3).</p> <p>Older people are able to, or supported to, maintain their oral health and retain their teeth (Action 4.1, 4.2, 4.3).</p> <p>Older people have full access to dietetic support to prevent or eliminate malnourishment and to support the management of health conditions (Action 4.1, 4.2, 4.3).</p> | <p>to eat the foods they prefer; individuals' specific dietary needs are not met, which can lead to malnutrition and undermines their overall health.</p> <p>An increase in workload and pressure for the care home workforce.</p> <p>An increase in hospital admissions due to falls and a lack of primary care support to maintain independence.</p> <p>A failure to deliver on the Social Services National Outcomes Framework and the Fundamentals of Care for older people in residential and nursing care homes.</p> | |
| <p>4.2 A formal agreement is developed and implemented between the care home and local primary care and specialist services based on the Statement of Entitlement. This should include:</p> <ul style="list-style-type: none"> • Referral pathways, including open access • Waiting times • Referral and discharge | | | <p>Health Boards & Care Home Providers</p> <p>April 2015</p> |

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| <p>information</p> <ul style="list-style-type: none"> • Advice and information to support the on-going care of the older person in the home • Access to specialist services for older people in nursing homes, in line with the Fundamentals of Care Guidance. | | | |
| <p>4.3 Care staff are provided with information, advice and, where appropriate, training to ensure they understand and identify the health needs of older people as well as when and how to make a referral.</p> | <p>Care staff understand the health needs of older people, and when and how to access primary care and specialist services (Action 4.3, 5.4).</p> | | <p>Health Boards November 2015</p> |
| <p>4.4 Upon arrival at a care home, older people receive medication reviews by a clinically qualified professional, with regular medicine reviews undertaken in line with published best practice.</p> | <p>Older people receive appropriate medication and the risks associated with polypharmacy are understood and managed.</p> | <p>Older people are at risk of potentially dangerous interactions between multiple medications.</p> | <p>Health Boards Begin April 2015</p> |
| <p>4.5 Community Health Councils implement a rolling programme of spot checks in residential and nursing care homes to report on compliance with the National Statement of Entitlement and Fundamentals of Care.</p> | <p>Older people are able to challenge, or have challenged on their behalf, failures in meeting their entitlements.</p> | <p>Older people living in care homes are denied access to an independent health watchdog and there is no independent challenge to failures to meet healthcare entitlements.</p> | <p>Welsh Government November 2015</p> |

Key Conclusion 5: The vital importance of the role and contribution of the care home workforce is not sufficiently recognised. There is insufficient investment in the sector and a lack of support for the care home workforce.

Link to Welsh Government policy and legislative areas: Social Care Workforce Development Programme, Sustainable Social Services for Wales: A Framework for Action, Social Services and Wellbeing Act, National Outcomes Framework, Integrated Assessment, Planning and Review Arrangements for Older People

| Required Action | Outcome | Impact of not doing | By whom / By when |
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| <p>5.1. A national recruitment and leadership programme is developed and implemented to recruit and train future Care Home Managers with the right skills and competencies. The programme should include accredited continuous professional development for current and future care home managers and should support them to be leaders of practice and champions of a positive care home culture.</p> <p>Annual national reporting on the availability of skilled and competent Care Home Managers in care homes across Wales, including the impact of vacancy levels upon older people's quality of life and care.</p> | <p>Care homes have permanent managers who are able to create an enabling and respectful care culture and support paid carers to enable older people to experience the best possible quality of life.</p> | <p>Care homes are without or share managers and care homes are without leadership or overview.</p> <p>Managers do not have the skills, competencies or support required to ensure the delivery of safe and high quality care.</p> <p>An increased risk of unacceptable quality of life and care for older people.</p> <p>There is a lack of information available to support workforce planning.</p> <p>There is a lack of opportunity for the professional development of Care Home Managers.</p> | <p>Care Council for Wales</p> <p>April 2016</p> |
| <p>5.2 The development and implementation of a national standard acuity tool to include guidelines on staffing levels and skills required to</p> | <p>Older people are cared for by care staff and managers who are trained to understand and meet their physical and</p> | <p>A lack of time and skills places pressure on care staff that impacts upon the quality of life of older people and leads to a</p> | <p>Welsh Government & Care Home</p> |

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| <p>meet both the physical and emotional needs of older people.</p> | <p>emotional needs, including the needs of people with dementia and sensory loss, and who have the competencies needed to provide dignified and compassionate care.</p> | <p>focus on task-based care, which increases the risk of potential emotional neglect.</p> | <p>Providers April 2016</p> |
| <p>5.3 A standard set of mandatory skills and value based competencies are developed and implemented, on a national basis, for the recruitment of care staff in care homes.</p> | <p>Older people receive compassionate and dignified care that responds to them as an individual (Action 5.3, 5.4, 5.5).</p> | <p>Older people are cared for by people who do not understand and are not able to meet their needs (Action 5.3, 5.4, 5.5).</p> | <p>Care Council for Wales & Care Home Providers From September 2015</p> |
| <p>5.4 A national mandatory induction and on-going training programme for care staff is developed and implemented. This should be developed within a values framework and should include:</p> <ul style="list-style-type: none"> • The physical and emotional needs of older people, including older people living with dementia. • Adult safeguarding, emotional neglect and ‘never events’. • How to raise concerns. • Good communication and alternative methods of communication for those living | | <p>Older people receive care and support from care staff who do not have the skills, values or competencies to work in care homes, which can place older people at risk of harm and/or emotional neglect.</p> <p>Poor practice goes unchallenged due to a lack of appropriate training and a lack of support for those who want to raise concerns.</p> <p>An increase in workload and pressure on care staff.</p> | <p>Care Council for Wales December 2015</p> |

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| <p>with dementia and/or sensory loss.</p> <ul style="list-style-type: none"> • Supporting without disabling. • The rights and entitlements of older people. • Care, compassion, kindness, dignity and respect. | | | |
| <p>5.5 All care homes must have at least one member of staff who is a dementia champion.</p> | | | <p>Care Home Providers September 2015</p> |
| <p>5.6 A National Improvement Service is established to improve care homes where Local Authorities, Health Boards and CSSIW have identified significant and/or on-going risk factors concerning the quality of life or care provided to residents and/or potential breaches of their human rights.</p> <p>The national improvement team should utilise the skills of experienced Care Home Managers, as well as other practitioners, to provide intensive and transformational support to drive up the standards of quality of life and care for residents as well as to prevent and mitigate future safeguarding risks.</p> <p>This service should also develop a</p> | <p>Care homes that want and need to improve the quality of life and care of older people have access to specialist advice, resources and support that leads to improved care and reduced risk.</p> | <p>Older people live in care homes where poor practice continues, their quality of life is poor and they are at risk of emotional abuse and neglect.</p> <p>The resources of commissioning teams are diverted to supporting failing care homes.</p> <p>An increase in workload and pressure for care staff.</p> | <p>Welsh Government Lead in partnership with Local Authorities, Health Boards, Care Home Providers September 2016</p> |

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| <p>range of resources and training materials to assist care homes that wish to improve in self-development and on-going improvement.</p> | | | |
| <p>5.7 The Regulation and Inspection Bill should strengthen the regulatory framework for care staff to ensure that a robust regulation of the care home workforce is implemented for the protection of older people.</p> | <p>Older people are safeguarded from those who should not work within the sector.</p> | <p>Older people receive care and support from care staff who do not have the skills, values or competencies to work in care homes, placing older people at risk of harm and emotional neglect.</p> <p>Vetting and barring procedures to prevent employment of unsuitable staff provide only partial protection for older people living in care homes.</p> | <p>Welsh Government April 2018</p> |
| <p>5.8 A cost-benefit analysis is undertaken into the terms and conditions of care staff. This analysis should include the impact of the introduction of a living wage and/or standard employment benefits, such as holiday pay, contracted hours and enhancements.</p> | <p>The true value of delivering care is recognised and understood.</p> | <p>There is a restricted recruitment pool due to continued difficulties in recruiting people with the right skills, values and competencies.</p> | <p>Welsh Government January 2016</p> |

Key Conclusion 6: Commissioning, inspection and regulation systems are inconsistent, lack integration, openness and transparency, and do not formally recognise the importance of quality of life

Link to Welsh Government policy and legislative areas: Sustainable Social Services for Wales: A Framework for Action, Social Services and Wellbeing Act, National Outcomes Framework

| Required Action | Outcome | Impact of not doing | By whom / By when |
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| <p>6.1 A single outcomes framework of quality of life and care, and standard specification, is developed for use by all bodies involved in the regulation, provision and commissioning, and inspection of care homes and should flow through to become a defining standard within the future Regulation and Inspection Act. It must include references to the following*:</p> <ol style="list-style-type: none"> 1. Independence and autonomy 2. Control over daily life 3. Rights, relationships and positive interactions 4. Ambitions (to fulfil, maintain, learn and improve skills) 5. Physical health and emotional wellbeing (to maintain and improve) 6. Safety and security (freedom from discrimination and harassment) | <p>Quality of life sits consistently at the heart of the delivery, regulation, commissioning and inspection of residential and nursing care homes.</p> | <p>There are unacceptable variations in the standards set for the care of older people, an inconsistent focus on quality of life and inconsistent and conflicting requirements upon providers.</p> | <p>Welsh Government April 2015</p> |

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| <p>7. Dignity and respect 8. Protection from financial abuse 9. Receipt of high quality services</p> <p>*Source: Flintshire Outcomes Framework</p> | | | |
| <p>6.2 Care home providers, commissioners and CSSIW should develop informal and systematic ways in which to ensure they better understand the quality of life of older people, through listening to them directly (outside of formal complaints) and ensuring issues they raise are acted upon.</p> <p>Annual reporting should be undertaken of how on-going feedback from older people has been used to drive continuous improvement (see action 6.10).</p> | <p>Commissioners, providers and inspectors have a thorough understanding of the day-to-day quality of life of older people living in care homes (Action 6.2, 6.3).</p> <p>Older people's views about their care and quality of life are captured and shared on a regular basis and used to drive continuous improvement (Action 6.2, 6.3).</p> | <p>Issues are not addressed before they become significant, impactful and costly to remedy (Action 6.2, 6.3).</p> <p>Opportunities to make small changes that can make a significant difference to quality of life and care are missed.</p> <p>Safeguarding issues are not identified at an early stage.</p> <p>Older people feel ignored, powerless and unable to influence issues that affect their lives.</p> | <p>Care Home Providers & Local Authorities & Health Boards & CSSIW</p> <p>April 2015</p> |
| <p>6.3 Lay assessors are used, on an on-going basis, as a formal and significant part of the inspection process.</p> | | | <p>CSSIW</p> <p>April 2015</p> |
| <p>6.4 An integrated system of health and social care inspection must be developed and implemented to provide effective scrutiny in respect of the quality of life and healthcare of older people in nursing homes.</p> | <p>The quality of life and healthcare of older people living in nursing homes is assessed in an effective way with clear and joined up annual reporting (Action 6.4, 6.5, 6.6).</p> | <p>Poor practice is not identified and older people are placed at increased risk of harm or do not receive that to which they are entitled (Action 6.4, 6.5, 6.6).</p> | <p>Welsh Government lead (Action 6.4, 6.5, 6.6)</p> <p>December 2015</p> |

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| <p>6.5 Annual integrated reports should be published between inspectorates that provide an assessment of quality of life and care of older people in individual nursing homes.</p> | | | |
| <p>6.6 An annual report on the quality of clinical care of older people in nursing homes in Wales should be published, in line with Fundamentals of Care.</p> | | | |
| <p>6.7 Annual Quality Statements are published by the Director of Social Services in respect of the quality of life and care of older people living in commissioned and Local Authority run care homes. This should include:</p> <ul style="list-style-type: none"> • the availability of independent advocacy in care homes • quality of life and care of older people, including specific reference to older people living with dementia and/or sensory loss • how the human rights of older people are upheld in care homes across the Local Authority • the views of older people, advocates and lay assessors about the quality of life and care provided in care homes | <p>Older people have access to relevant and meaningful information about the quality of life and care provided by or within individual care homes and there is greater openness and transparency in respect of the quality of care homes across Wales and the care they provide (Action 6.7, 6.8, 6.9, 6.10).</p> | <p>A lack of transparency undermines older people's ability to make appropriate decisions, undermines wider public confidence and acts as a barrier to systemic change.</p> | <p>Local Authorities - Outline AQS September 2015</p> |

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| <ul style="list-style-type: none"> • geographic location of care homes <p>Further details of reporting requirements should be included as part of the Regulation and Inspection Bill.</p> | | | |
| <p>6.8 Health Boards include the following information relating to the quality of life and care of older people in residential and nursing care homes in their existing Annual Quality Statements:</p> <ul style="list-style-type: none"> • the inappropriate use of anti-psychotics • access to mental health and wellbeing support • number of falls • access to falls prevention • access to reablement services • support to maintain sight and hearing <p>Further areas for inclusion to be developed as part of the AQS guidance published annually.</p> | | | <p>Health Boards</p> <p>September 2015</p> |
| <p>6.9 The Chief Inspector of Social Services publishes, as part of her Annual Report, information about the</p> | | | <p>CSSIW Annual Report</p> |

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| <p>quality of life and care of older people in care homes, which includes the following:</p> <ul style="list-style-type: none"> • the quality of life of older people in care homes who are bed-bound • the quality of life of older people in care homes living with dementia • the quality of life of older people in care homes living with sensory loss • the implementation of care plans in older people's care homes • the accuracy of external statements from independent providers • how the human rights of older people are upheld in care homes across Wales | | | |
| <p>6.10 Care home providers report annually on the delivery of quality of life and care for older people. This will include:</p> <ul style="list-style-type: none"> • Quality of life of older people against the Standard Quality Framework and Supporting Specification. | | | <p>Care Home Providers December 2015</p> |

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| <ul style="list-style-type: none"> • Levels and skills of staff including staff turnover, use of agency staff and investment in training • Number of POVA referrals, complaints and improvement notices, including full details on improvement action when a home is in escalating concerns. | | | |
| <p>6.11 A national, competency based, training programme for commissioners is developed, to ensure that they understand and reflect in their commissioning the needs of older people living in care homes, including the needs of people living with dementia.</p> | <p>Older people are placed in care homes that can meet their needs by commissioners who understand the complexities of delivering care and are able to challenge providers about unacceptable care of older people.</p> | <p>Older people are placed in care homes that are unable to meet their needs.</p> <p>Commissioners are unable to challenge poor practice.</p> | <p>Care Council for Wales</p> <p>December 2015</p> |

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Key Conclusion 7: A current lack of forward planning means that the needs of older people in care homes will not be met in the future.

Link to Welsh Government Policy and legislative areas: Sustainable Social Services for Wales: A Framework for Action, Social Services and Wellbeing Act, National Outcomes Framework.

| Required Action | Outcome | Impact of not doing | By whom / By when |
|--|--|---|---|
| <p>7.1 A national plan to ensure the future supply of high quality care homes is developed, which includes:</p> <ul style="list-style-type: none"> • a national demographic projection of need, including anticipated trends in and changes to the type of provision required as a result of increasing acuity and dependency. • a clear statement on the preferred type of provider base/ market in Wales. • a national analysis of barriers to market entry. • a clear statement on investment to grow social enterprise and co-operative social care sectors, particularly in areas with a low provider base. • a clear action plan to deliver the preferred provider base/market. | <p>Forward planning ensures there is a sufficient number of care homes, of the right type and in the right places, for older people.</p> | <p>Older people are not cared for in their own communities or in a location of their choice and live in care homes that are unable to meet their acuity and dependency levels</p> | <p>Welsh Government January 2016</p> |

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|---|--|--|--|
| <p>7.2 NHS Workforce planning projections identify the current and future level of nursing required within the residential and nursing care sector; including care for older people living with mental health problems, cognitive decline and dementia.</p> | <p>Forward planning and incentivised recruitment and career support ensures that there are a sufficient number of specialist nurses, including mental health nurses, to deliver high quality nursing care and quality of life outcomes for older people in nursing homes across Wales (Action 7.2, 7.3).</p> | <p>Nursing care homes close due to difficulties in recruiting qualified and competent nurses or older people are placed in care homes that are unable to meet their needs (Action 7.2, 7.3).</p> | <p>Welsh Government March 2015</p> |
| <p>7.3 The NHS works with the care home sector to develop it as a key part of the nursing career pathway, including providing full peer and professional development support to nurses working in care homes.</p> | | | <p>Health Boards March 2016</p> |

Next Steps

Requirements for Action

The Commissioner's Requirements for Action clearly outline the change that is needed to drive up the quality of life and care of older people living in care homes across Wales.

The Commissioner expects, as do older people and the large number of individuals and organisations that responded to her Review, that the public bodies subject to her Review will take concerted action to deliver the change required and through this to embed quality of life at the heart of residential and nursing care within Wales and ensure that older people receive that to which they are entitled.

Implementation of the Commissioner's Requirements for Action

The Commissioner has requested, in line with the Commissioner for Older People (Wales) Act 2006, that the bodies subject to the Requirements for Action in this report provide, in writing, by 2 February 2015, an account of:

- How they have complied, or propose to comply with the Commissioner's Requirements for Action; or
- Why they have not complied with the Requirements for Action; or
- Why they do not intend to comply with the Requirements for Action.

Formal written notices will be issued to any bodies that fail to respond or provide inadequate information. If the response received is not deemed satisfactory after this process, the Commissioner reserves the right to draw it to the attention of the general public.

Requirements for Action / Recommendations Register

The Commissioner is obliged to keep a register of the recommendations made in the report and the actions taken in response. The register must be available for the general public to view. It will be published on the Commissioner's website and made available to individuals on request.

Thanks and Acknowledgments

As Commissioner, I would like to express my sincere thanks to all of those who have been involved and provided support throughout the Review process. I would particularly like to thank:

- The thousands of older people and their families who provided evidence to the Review through questionnaire responses and other correspondence.
- Care home residents across Wales for allowing my team of Rapporteurs to visit their homes, observe their lives and hear first-hand about their experiences.
- My team of social care rapporteurs, who gave their time and dedication so generously and without whom the visits to 100 care homes across Wales would not have been possible.
- My Expert Advisory board, my Equalities and Welsh Language Advisory Board and my Older People and Carers Advisory Board, who provided invaluable knowledge, expertise and support throughout the Review.
- Care Home Managers and care home staff across Wales who facilitated visits by Rapporteurs and provided essential information and evidence to the Review.
- All of the individuals, groups and organisations who supported my call for evidence and distributed Review information and questionnaires across Wales on my behalf.
- All of the individuals, groups and organisations that provided written and/or oral evidence to the Review.
- The bodies subject to the Review for supporting my call for evidence and providing extensive written and oral evidence.
- My team of dedicated staff, who all played an essential role throughout the Review process.

My Review would not have been possible without the collective dedication and support of everyone above. A big thank you to you all.

Appendix 1: Members of the Commissioner's Advisory Boards

Commissioner's Advisory Board

- Laraine Bruce MBE. Care Checker
- John Moore Programme Manager, My Home Life Cymru
- Prof. John Williams Head of Department of Law and Criminology, Aberystwyth University
- John Vincent Chair, Welsh Senate of Older People
- Sue Phelps Director, Alzheimer's Society Wales
- Steve Milsom Former Deputy Director of Social Services, Welsh Government
- Susan Kent MBE. SRN. RSCN. Former Vice Chair, Aneurin Bevan University Health Board
- Nick Andrews Research and Practice Development Officer, All Wales Social Care Research Collaboration Project
- Steven Williams Volunteer Director, Crossroads Care South East Wales

Welsh Language and Equalities, Independent Advisory Board

- Heledd Thomas Office of the Welsh Language Commissioner
- Aliya Mohammed Chief Executive Officer, Race Equality First
- Alicja Zalensinska Director, Tai Pawb
- Shameem Nawaz Community Development Officer, Marie Curie Hospice
- Prof. Robert Moore North Wales Race Equality Network
- Dr. Roiyah Saltus Principal Research Fellow, Faculty of Life Sciences and Education, University of South Wales
- Dr. Paul Willis Senior Lecturer Public Health and Policy Studies, Swansea University
- Paula Walters Director, NHS Centre for Equality and Human Rights
- Jim Stewart Interfaith Council for Wales
- Paul Warren Director of Policy and Planning, Diverse Cymru
- Rachel Lewis Age Cymru Diversity Networks
- Eileen Smith Liaison Officer, Cardiff Gypsy and Traveller Project

Older People and Carers, Independent Advisory Board

- John Vincent Welsh Senate of Older People
- Hannah Davies Dementia Champion
- Jill Thomas Carers Wales
- Ralph Stevens Chair, Caerphilly County Borough Council 50+ Forum
- Steven Williams Volunteer Director, Crossroads Care South East Wales
- Angela Roberts Former Director, Carers Trust

Appendix 2: Social Care Rapporteurs

The Commissioner recruited a team of 43 Social Care Rapporteurs to undertake visits to care homes across Wales as part of her Review. The Rapporteurs were experts by personal and professional experience in the fields of sensory loss, dementia care, caring, nursing and social work. Many of them came from leading organisations in the public and third sectors, such as Action on Hearing Loss Cymru, Age Cymru, Alzheimer's Society, Care and Repair Cymru, Cwm Taf University Health Board and RNIB Cymru.

To ensure that all Rapporteurs were able to carry out the tasks required to the highest standards, those who applied went through a rigorous recruitment process, which included a detailed competency based interview, references and an enhanced DBS check, to ensure that exemplar safeguarding protocols were followed.

All Rapporteurs received training in social research methods, based on the Adult Social Care Outcomes Toolkit (ASCOT), as well as learning about the realities of the care home environment and establishing a safe, respectful and non-impactful presence, to ensure that they were equipped to observe and report back on the quality of life of older people living in care homes across Wales.

Rapporteurs also received training on adult safeguarding and Protection of Vulnerable Adults (POVA), before signing a Code of Conduct and Adult Safeguarding Protocol.

The Code of Conduct described the standards of professional conduct and practice required of them as they carried out their duties under the delegated powers of the Commissioner for Older People (Wales) Act 2006.

Key Tasks

Social Care Rapporteurs were responsible for undertaking the following key tasks:

- Visiting care homes in pairs and using the ASCOT framework to undertake a period of observation and listen to the views of care home residents, family members, care home staff, including the Care Home Manager (if available), and independent advocates.
- Writing up and reporting on observations and interactions with older people and care home staff.
- Participating in a de-briefing session(s) to discuss observations and findings, and to ensure that research methods and reporting guidelines were consistently followed.

Visits to Care Homes

- A strategic sampling framework was developed by the Wales Institute of Health and Social Care to facilitate the random selection of care homes across Wales.
- Correspondence was sent to all care homes about the progress of the Commissioner's Review, providing a detailed summary about the role of the Commissioner's Rapporteurs and what to expect should they be selected for a random visit.
- All care homes selected received a phone call on the day of the visit, with Rapporteurs normally arriving within 1-2 hours of this phone call.
- On arrival at the care home, all Rapporteurs were required to introduce themselves to the Care Home Manager or the most senior member of staff on duty.
- Visits to care homes by Rapporteurs lasted an average of 3-4 hours. During this time, they undertook a tour of the care home environment, carried out detailed observations of care home residents and spoke with residents' family members and friends, as well as care home staff.

Appendix 3: Organisations Subject to the Review

Health Boards

- Aneurin Bevan University Health Board
- Abertawe Bro Morgannwg University Health Board
- Cardiff & Vale University Health Board
- Hywel Dda University Health Board
- Cwm Taf University Health Board
- Betsi Cadwaladr University Health Board
- Powys Teaching Health Board

Statutory Bodies

- Care and Social Services Inspectorate Wales (CSSIW)
- Care Council for Wales (CCW)
- Welsh Government

Local Authorities

- Blaenau Gwent County Borough Council
- Bridgend County Borough Council
- Caerphilly County Borough Council
- The City of Cardiff Council
- Carmarthenshire County Council
- Ceredigion County Council
- Conwy County Borough Council
- Denbighshire County Council
- Flintshire County Council
- Gwynedd Council
- Isle of Anglesey County Council
- Merthyr Tydfil County Borough Council
- Monmouthshire County Council
- Neath Port Talbot County Borough Council
- Newport City Council
- Pembrokeshire County Council

- Powys County Council
- Rhondda Cynon Taf County Borough Council
- City and County Council of Swansea
- Torfaen County Borough Council
- Vale of Glamorgan Council
- Wrexham County Borough Council

Appendix 4: Organisations that Submitted Written Evidence

Statutory Bodies

- Care and Social Services Inspectorate Wales (CSSIW)
- Care Council for Wales (CCW)
- Welsh Government

Local Authorities

- Blaenau Gwent County Borough Council
- Bridgend County Borough Council
- Caerphilly County Borough Council
- The City of Cardiff Council
- Carmarthenshire County Council
- Ceredigion County Council
- Conwy County Borough Council
- Denbighshire County Council
- Flintshire County Council
- Gwynedd Council
- Isle of Anglesey County Council
- Merthyr Tydfil County Borough Council
- Monmouthshire County Council
- Neath Port Talbot County Borough Council
- Newport City Council
- Pembrokeshire County Council
- Powys County Council
- Rhondda Cynon Taf County Borough Council
- City and County Council of Swansea
- Torfaen County Borough Council
- Vale of Glamorgan Council
- Wrexham County Borough Council

Organisations

- 1000 Lives Improvement Service
- Action on Hearing Loss Cymru
- Age Alliance Wales
- Age Cymru
- Alzheimer's Society
- Board of Community Health Councils
- British Association of Social Workers in Wales (BASW Cymru)
- British Dental Association
- British Geriatrics Society (BGS)
- British Medical Association Cymru (BMA)
- Care Forum Wales
- Chartered Society of Physiotherapy in Wales (CSP)
- College of Occupational Therapists (COT)
- Deafblind Cymru
- Dementia Care Matters
- Pennaf Housing
- Royal College of General Practitioners Wales
- Royal College of Physicians in Wales (RCP)
- Royal College of Nursing (RCN)
- RNIB Cymru
- Shropdoc Doctors Cooperative Ltd (Shropdoc)

Health Boards

- Abertawe Bro Morgannwg University Health Board
- Aneurin Bevan University Health Board
- Betsi Cadwaladr University Health Board
- Cardiff and Vale University Health Board
- Cwm Taf University Health Board
- Hywel Dda University Health Board
- Powys Teaching Health Board

Appendix 5: Organisations that Submitted Oral Evidence

Statutory Bodies

- Board of Community Health Councils
- Care and Social Services Inspectorate Wales (CSSIW)
- Care Council for Wales (CCW)
- Healthcare Inspectorate Wales (HIW)
- Welsh Government

Local Authorities

- Caerphilly County Borough Council
- Flintshire County Council
- Gwynedd Council
- Powys County Council
- Western Bay Collaboration (Bridgend, Neath Port Talbot and Swansea Councils)
- Welsh Local Government Association (WLGA)

Local Authority Head of Commissioning Roundtable:

- Blaenau Gwent County Borough Council
- Bridgend County Borough Council
- Caerphilly County Borough Council
- Carmarthenshire County Council
- Ceredigion County Council
- Denbighshire County Council
- Flintshire County Council
- Gwynedd Council
- Isle of Anglesey County Council
- Merthyr Tydfil County Borough Council
- Monmouthshire County Council
- Neath Port Talbot County Borough Council
- Newport City Council
- Pembrokeshire County Council

- Rhondda Cynon Taf County Borough Council
- City and County Council of Swansea
- Torfaen County Borough Council
- Vale of Glamorgan Council

Organisations

- Association of Directors of Social Services (ADSS)
- Age Cymru
- Alzheimer's Society
- British Association of Social Workers in Wales (BASW Cymru)
- British Dental Association
- Care Forum Wales
- Chartered Society of Physiotherapists (CSP)
- College of Occupational Therapists (COT)
- Dementia Care Matters
- Neath Port Talbot Social Care Academy
- Royal College of Physicians in Wales (RCP)
- Royal Pharmaceutical Society
- Royal College of General Practitioners
- Royal College of Nursing (RCN)

Thematic Roundtables:

Advocacy

- Age Cymru Swansea Bay
- Age Connects Cardiff and The Vale
- Age Concern North Wales Central
- Age Connects Wales
- Alzheimer's Society
- HERC Associates

Housing

- Community Housing Cymru
- Cymorth Cymru
- Gwalia
- Hafod Care

- Linc Care
- Pennaf Housing Group

Learning Disabilities

- All Wales Forum (Parents and Carers)
- Cartrefi Cymru
- Ceredigion Forum of Parents and Carers
- First Choice Housing Association
- Mirus

Nutrition

- Aneurin Bevan University Health Board
- Cardiff and Vale University Health Board
- Public Health Wales
- Unified Menu Planning Project (Aneurin Bevan University Health Board & Torfaen County Borough Council)

Sensory Loss

- Action on Hearing Loss Cymru
- Deafblind Cymru
- RNIB Cymru

Health Boards:

- Abertawe Bro Morgannwg University Health Board
- Care Home In Reach Team Bridgend (Abertawe Bro Morgannwg University Health Board)
- Powys Teaching Health Board

Health Board Roundtable:

- Aneurin Bevan University Health Board
- Betsi Cadwaladr University Health Board
- Cardiff and Vale University Health Board
- Hywel Dda University Health Board

Health Board Commissioning and Healthcare Roundtable:

- Abertawe Bro Morgannwg University Health Board
- Aneurin Bevan University Health Board

- Betsi Cadwaladr University Health Board
- Hywel Dda University Health Board
- Powys Teaching Health Board

Independent Providers:

- Barchester Healthcare
- Bupacare
- Embrace
- HC-One

Care Home Manager Roundtable:

- Atlantic View, Cardiff
- Hafan Croeso, Glanamman
- Hafan Dementia Care, Ammanford
- Pontcanna House, Cardiff
- Quarry Hall, Cardiff
- Summerhill Group, South East Wales
- Sŵn-y-Môr, Aberavon
- Three Cliffs Care Home, Penmaen
- Talbot Court Care Home, Port Talbot

Equality Focus Group Sessions:

- Action on Hearing Loss
- African Caribbean Elder Society
- Dyfed Diners
- Hindu Council of Wales
- Muslim Council of Wales
- RNIB Cymru
- Somali Integration Society
- Swan Gardens Chinese Sheltered Accommodation
- Unique Transgender Network

Appendix 6: Adult Social Care Outcomes Toolkit (ASCOT)

Following an extensive literature review, the Commissioner decided to use the Adult Social Care Outcomes Toolkit (ASCOT), developed by the Personal Social Services Research Unit at the University of Kent and the London School of Economics, as the observation framework for care home visits.

The Toolkit describes eight domains that shape an individual's experience of social care and impact upon quality of life. The toolkit closely reflects the Commissioner's own Quality of Life Model.

| ASCOT Domains | Commissioner's Quality of Life Model |
|---|---|
| Control over daily life | I have voice, choice and control |
| Personal hygiene, cleanliness and comfort | I can get the help that I need |
| Food and drink | I can get the help that I need |
| Personal safety | I feel safe and listened to, valued and respected |
| Social participation and involvement | I can do the things that matter to me |
| Occupation | I can do the things that matter to me |
| Accommodation, cleanliness and comfort | I live in a place that suits me and my life |
| Dignity | I feel safe and listened to, valued and respected |

ASCOT also provides a way of capturing the experiences of older people who may not be able to describe their experiences directly, essential for older people who may have lost their ability to communicate or find traditional survey techniques difficult to understand.

ASCOT uses a mixed method approach, combining observation, semi-structured and structured interviews, as well as questionnaires. Evidence is gathered from the resident, both by observation and interview if appropriate, forming the foundation from which analyses are made about an individual's social care related quality of life. Additional evidence may also be gathered from residents' family members and friends, as well as care home staff, before a qualitative thematic analysis is utilised to analyse all data received.

For further information about ASCOT visit the Personal Social Services Research Unit website at: <http://www.pssru.ac.uk/index-kent-lse.php>

Appendix 7: Terms of Reference

A Review into the quality of life and care of older people living in care homes in Wales.

Proceeding under section 3 of the Commissioner for Older People (Wales) Act 2006, the Commissioner will Review the extent to which Local Authorities, Health Boards, Care Home Providers, Care and Social Services Inspectorate Wales (CSSIW), Care Council for Wales and the Welsh Government safeguard and promote the interests of older people living in residential and nursing care settings in Wales.

Specifically, the Commissioner will:

1. Seek the views of older people, their relatives, carers and others to understand the experiences of older people living within care homes in Wales.
2. Identify what Local Authorities, Health Boards, Care Home Providers, Care Council for Wales, CSSIW and the Welsh Government understand about the quality of life and care experienced by older people living in care homes.
3. Gather evidence about the procedures and actions that Local Authorities, Health Boards, Care Home Providers, Care Council for Wales, CSSIW and the Welsh Government have implemented in the past three years and have planned to safeguard the quality of life and care of older people and the evidence of their impact.
4. Consider whether current and planned changes are sufficient to drive up the quality of care and whether they will ensure that the interests of older people are safeguarded and promoted in care homes.
5. Make practical recommendations to Local Authorities, Health Boards, Care Home Providers and CSSIW as to what must be improved, changed or put in place to promote and safeguard the quality of life and care of older people living in care homes across Wales.

The terms of this Review do not include palliative or end of life care arrangements, extra care homes, sheltered housing or patients in specialist hospital long stay facilities. However, the Commissioner will share information and findings that may arise in these areas within the life of the Review with relevant bodies.

Review findings and required action

The Commissioner will publish recommendations that the public bodies subject to her Review will be expected to comply with. These recommendations will be focused on the overall aim of the Commissioner's Review, which is to ensure that quality of life sits at the heart of the provision of residential and nursing care in Wales.

Powers of the Older People's Commissioner for Wales

The Commissioner has the power to review arrangements for safeguarding and promoting the interests of older people in Wales, or the failure to make arrangements or discharge functions, through powers derived from Section 3 of the Commissioner for Older People (Wales) Act 2006.

The Review must be to assess whether and to what extent the arrangements are effective in safeguarding and promoting the interests of older people.

In determining the interests of older people, the Commissioner will have due regard to the United Nations Principles for Older Persons and the Human Rights Act 1998.

Power of entry and interviewing

Under Section 13 of the Commissioner for Older People (Wales) Act 2006, the Commissioner, or a person authorised by her, may, for the purposes of a Review, enter any premises, other than a private dwelling, for the purpose of interviewing an older person accommodated or cared for there, and may interview the older person with their consent.

Appendix 8: Glossary of Terms

Advocacy: Advocacy supports and enables people who have difficulty representing their interests to express their views, explore and make informed choices and obtain the support they need to secure and uphold their rights. Advocacy is a fundamental element of equality, social justice and human rights.

Antipsychotic: Antipsychotics are a class of psychiatric medication that are used to manage psychosis, primarily in bipolar disorder and schizophrenia. They are also used to manage aggression or psychosis in people living with dementia, but this is combined with a significant increase in serious adverse events¹²⁹. NICE guidance therefore states that antipsychotics should not be a routine treatment for people with dementia¹³⁰.

Bed-bound: Someone who is confined to bed, unable to be assisted to get up and someone who will frequently need assistance to be repositioned to avoid pressure ulcers.

Care home: A home for people with additional care and support needs, often described as a 'residential' or 'nursing' care home to specify the level of care provided.

A residential care home will provide a room, shared living environment, meals and personal care and assistance (such as help with washing and eating).

A nursing care home will provide similar support but will also employ registered nurses who can provide nursing care for people with more complex health needs.

The term 'care home' is used throughout this report to refer to residential and nursing care homes across Wales.

Care staff: Social care workers that are employed to assist and enable older people living in care homes through the delivery of personal care and support in their daily lives.

Cognitive function: The mental action or abilities of thinking, understanding and remembering. Where cognitive function is impaired, people will often have difficulties with day-to-day memory, planning, language, attention and visuospatial skills (the ability to interpret objects and shapes)¹³¹.

Commissioning: The process of ensuring that care services are provided effectively and that they meet the needs of the population. Responsibilities range from assessing local population needs, prioritising outcomes, procuring products and services to achieve those outcomes and supporting service providers to enable them to deliver outcomes for individual service users¹³².

Continuing Healthcare: NHS Continuing Healthcare is a package of on-going healthcare arranged and funded solely by the NHS. It can be delivered in any setting and can include the full cost of a place in a nursing care home.

Controlling Care: A term developed by David Sheard, Director of Dementia Care Matters, controlling care is based on the belief that the Care Home Manager and care staff know what is best for their residents. It is defined by regulation, domination or command of another. Residents receiving controlling care have limited to no control and a lack of voice or choice over the care provided. It is care that actually stops, prevents, restricts and controls what people can or cannot do in their own living area, dining areas and places they spend time¹³³.

EMI (Elderly Mentally Infirm): EMI care homes are designed for older people who have mental health difficulties or a disease of the brain, such as dementia.

High Acuity Needs: Acuity can be defined as the measurement of the intensity of care and support required by a resident. An acuity-based staffing system regulates the number of care staff, nurses and managers on a shift according to residents' needs and is not based solely on numbers.

Market Position Statement: A practical document to enhance market functioning, which draws together current and future population analysis, commissioning strategies and market and customer surveys to lay out the changes necessary to meet the needs of the population and how the Local Authority will support and intervene to achieve this¹³⁴.

Market Sufficiency: Residential care provision for older people is dependent on the availability of high quality care and care home places. When both are present there is market sufficiency.

National Minimum Standards (Wales): In addition to the requirements set out in the Adult Placement Schemes (Wales) Regulations 2004, the National Minimum Standards are used to determine whether care homes are providing adequate care and are meeting the basic needs of the people who live there. These standards, monitored by the Care and Social Services Inspectorate Wales (CSSIW), cover all aspects of life in a care home, including moving in, caring for residents, safety and privacy and complaints about standards of care.

Neutral Care: A term developed by David Sheard, Director of Dementia Care Matters, which refers to care that is task-based and process-driven with little emotional input from care staff¹³⁵. Examples include silent personal care, inattention to lethargy, interactions between care staff and residents that lack empathy and little understanding about the resident's life history, which results in an inability to facilitate social interaction and enjoyment.

Person-centred Care: Holistic (whole) care that focuses on the individual as a person with a unique identity, needs and wishes to enable them to live a fulfilled life, reinforce their sense of identity and achieve a sense of wellbeing. This includes

consideration of social, physical, intellectual, cultural, emotional, health and care needs.

Polypharmacy: The use of multiple medications at the same time. It is most common in older people, with care home residents reportedly taking an average of 7.2 different medications on a daily basis¹³⁶, many of which may be excessive or unnecessary prescriptions¹³⁷. Concerns about polypharmacy include increased adverse drug reactions, drug-to-drug interactions, a decreased quality of life and decreased mobility and cognition.

Prevention: An inclusive term that describes preventative interventions that can sustain and maintain people's health, wellbeing and independence. It is defined by Age Alliance Wales¹³⁸ as:

1. Any interventions designed to reduce the risk of mental and physical deterioration, accident, disease or ill health and / or to promote long-term physical, social, emotional and psychological wellbeing.
2. Services that enable people to live independently or support people to live independently for longer.
3. Services that aim to promote quality of life, self-determination and community.

Profiling Bed: A bed (usually mechanical/electric) that is specifically designed to increase the comfort and wellbeing of users. Benefits include a significant reduction in the risk of pressure ulcers, assistance to fluid drainage and improved mobility. A profiling bed also prevents the risk of back injuries in nurses and care staff through enabling safer repositioning and turning of the user.

Reablement: Help or assistance to enable people to learn or re-learn the skills necessary for daily living, often delivered after a period of ill-health, such as a stroke. While a focus on regaining physical ability is central, addressing psychological support to build confidence as well as social needs and related activities is also vitally important and often neglected¹³⁹.

Restrictive Care: A term developed by David Sheard, Director of Dementia Care Matters, which refers to a culture of care that is controlling and restrictive. It is defined by a 'them and us' attitude with carers doing things 'to' rather than 'with' residents. This is contrary to the principles of 'being person-centred'¹⁴⁰ and respecting, supporting and understanding both the person's current experience and their experience prior to their arrival in the care home.

Social Care Rapporteur: An individual appointed by the Commissioner to observe and report back on the quality of life and care of older people living in care homes in Wales.

Soft foods: Foods that are easy to chew and swallow. These are useful for people who have trouble chewing food or have difficulty swallowing and may therefore be at risk of malnutrition. They are also helpful for people who are too weak to chew regular foods.

Task-based Care: A term used to describe care that is carried out in a mechanical and institutionalised way without any connection to the individual concerned or awareness of them as a person. Also known as token care, task-based care is devoid of kindness, compassion and understanding, and is defined by a culture in which residents have things done ‘to’ and ‘for’ them rather than ‘with’ them.

Values-based Training: Training based upon the values that shape, determine and provide the foundations of how care should be provided such as kindness, compassion and understanding, and human rights.

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Mae'r dudalen hon yn wag yn bwrpasol

Eitem ar gyfer y Rhaglen 8



SOCIAL & HEALTH CARE OVERVIEW & SCRUTINY COMMITTEE

| | |
|------------------------|--|
| Date of Meeting | Thursday, 4 th October 2018 |
| Report Subject | Forward Work Programme |
| Cabinet Member | Not applicable |
| Report Author | Social & Health Care Overview & Scrutiny Facilitator |
| Type of Report | Operational |

EXECUTIVE SUMMARY

Overview & Scrutiny presents a unique opportunity for Members to determine the Forward Work programme of the Committee of which they are Members. By reviewing and prioritising the Forward Work Programme Members are able to ensure it is Member-led and includes the right issues. A copy of the Forward Work Programme is attached at Appendix 1 for Members' consideration which has been updated following the last meeting.

The Committee is asked to consider, and amend where necessary, the Forward Work Programme for the Social & Health Care Overview & Scrutiny Committee.

RECOMMENDATION

| | |
|---|--|
| 1 | That the Committee considers the draft Forward Work Programme and approve/amend as necessary. |
| 2 | That the Facilitator, in consultation with the Chair of the Committee be authorised to vary the Forward Work Programme between meetings, as the need arises. |

REPORT DETAILS

| | |
|-------------|---|
| 1.00 | EXPLAINING THE FORWARD WORK PROGRAMME |
| 1.01 | Items feed into a Committee's Forward Work Programme from a number of sources. Members can suggest topics for review by Overview & Scrutiny Committees, members of the public can suggest topics, items can be referred by the Cabinet for consultation purposes, or by County Council or Chief Officers. Other possible items are identified from the Cabinet Work Programme and the Improvement Plan. |
| 1.02 | <p>In identifying topics for future consideration, it is useful for a 'test of significance' to be applied. This can be achieved by asking a range of questions as follows:</p> <ol style="list-style-type: none">1. Will the review contribute to the Council's priorities and/or objectives?2. Is it an area of major change or risk?3. Are there issues of concern in performance?4. Is there new Government guidance of legislation?5. Is it prompted by the work carried out by Regulators/Internal Audit? |
| 2.00 | RESOURCE IMPLICATIONS |
| 2.01 | None as a result of this report. |
| 3.00 | CONSULTATIONS REQUIRED / CARRIED OUT |
| 3.01 | Publication of this report constitutes consultation. |
| 4.00 | RISK MANAGEMENT |
| 4.01 | None as a result of this report. |
| 5.00 | APPENDICES |
| 5.01 | Appendix 1 – Draft Forward Work Programme |
| 6.00 | LIST OF ACCESSIBLE BACKGROUND DOCUMENTS |
| 6.01 | <p>None.</p> <p>Contact Officer: Margaret Parry-Jones Overview & Scrutiny Facilitator</p> <p>Telephone: 01352 702427</p> <p>E-mail: margaret.parry-jones@flintshire.gov.uk</p> |

| | |
|-------------|--|
| 7.00 | GLOSSARY OF TERMS |
| 7.01 | Improvement Plan: the document which sets out the annual priorities of the Council. It is a requirement of the Local Government (Wales) Measure 2009 to set Improvement Objectives and publish an Improvement Plan. |

Mae'r dudalen hon yn wag yn bwrpasol

CURRENT FWP

| Date of meeting | Subject | Purpose of Report | Scrutiny Focus | Responsible / Contact Officer | Submission Deadline |
|--|---|---|----------------------------------|-------------------------------|---------------------|
| Thursday 15 th November 2pm | Safeguarding – Adults & Children | To provide Members with statistical information in relation to Safeguarding - & Adults & Children | Assurance | Chief Officer Social Services | |
| | Progression Model – Learning Disabilities | To receive a report on the Learning Disabilities Progression model. | Assurance | Chief Officer Social Services | |
| 31 st January 10.00 am 2019 | Community Health Council (to be confirmed) | | | Facilitator | |
| 28 th March 2pm 2019 | Learning Disability Day Care and Work Opportunities Alternative Delivery Model | To receive a progress report on the first year of operation as an alternative delivery model. | Assurance | Chief Officer Social Services | |
| | Q3 Council Plan monitoring | To enable members to fulfil their scrutiny role in relation to performance monitoring | Performance monitoring/assurance | Facilitator | |
| 23 May 2019 10.00 am | Third Sector update | Annual review of the social care activities undertaken by the third sector in Flintshire | | Chief Officer Social Services | |
| | Annual Directors Report | To consider the draft report. | | Chief Officer Social Services | |

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| | | | | | |
|--------------|---|---|----------------------------------|-------------|--|
| 18 July 2019 | 2018/19 Year End Reporting Council Plan Monitoring | To enable members to fulfil their scrutiny role in relation to performance monitoring | Performance monitoring/assurance | Facilitator | |
| | BCUHB & Welsh Ambulance Services NHS (Trust to be confirmed) | To maintain regular meetings and promote partnership working. | Partnership working | Facilitator | |

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Regular Items

| Month | Item | Purpose of Report | Responsible/Contact Officer |
|--------------------|--|--|------------------------------------|
| Nov/Dec | Safeguarding | To provide Members with statistical information in relation to Safeguarding - & Adults & Children | Chief Officer (Social Services) |
| May | Educational Attainment of Looked After Children | Education officers offered to share the annual educational attainment report with goes to Education & Youth OSC with this Committee. | Chief Officer (Social Services) |
| May | Corporate Parenting | Report to Social & Health Care and Education & Youth Overview & Scrutiny. | Chief Officer (Social Services) |
| Half-yearly | Betsi Cadwaladr University Health Board Update | To maintain 6 monthly meetings – partnership working. | Facilitator |
| May | Comments, Compliments and Complaints | To consider the Annual Report. | Chief Officer (Social Services) |