Agenda Item: 4

Meeting of:	**Healthy Living and Social Care Scrutiny Committee**
Date of Meeting:	**Tuesday, 11 January 2022**
Relevant Scrutiny Committee:	Healthy Living and Social Care
Report Title:	Cardiff and the Vale of Glamorgan Population Needs Assessment 2022
Purpose of Report:	To share the draft Cardiff and the Vale of Glamorgan Population Needs Assessment 2022 report with Elected Members of the Scrutiny Committee, to enable their contribution to the final report
Report Owner:	Emily Clark, Speciality Registrar in Public Health, Cardiff and Vale Local Public Health Team Fiona Kinghorn, Executive Director of Public Health, Cardiff and Vale University Health Board
Responsible Officer:	Director of Social Services
Elected Member and Officer Consultation:	Gaynor Jones, Amanda Philips, Nicola Hale (as members of the Population Needs Assessment Steering Group). A professional survey enabled collation of views from members of staff in the Vale of Glamorgan Council, the results of which are presented in the relevant chapters of the Population Needs Assessment.
Policy Framework:	Development and publication of the Population Needs Assessment is a statutory duty under Part 2 of the Social Services and Well-being (Wales) Act 2014. The duty requires that Local Authorities and Local Health Board form a partnership in order to conduct the assessment. The final report must be formally approved by the Local Authorities and the Local Health Board, to ensure that the information contained in the report is considered at the most senior levels. Once approved, assessment reports must be published on the websites of all Local Authorities and Local Health Boards.

Executive Summary:

- This is the draft report for the second Population Needs Assessment (PNA) for Cardiff and the Vale of Glamorgan, following the first published in 2017. The PNA should be read alongside the complementary Well-being Assessments for Cardiff and the Vale of Glamorgan to gain a comprehensive understanding of the region.
- The PNA was undertaken between May 2021 and March 2022 and provides an update of the 2017 report. Existing data and reports were used to inform the assessment, alongside dedicated engagement work in the form of surveys (for the public, children and young people, people in HMP Cardiff, and professionals/providers) as well as focus groups.
- Improvements in care and support services have been made across all population groups since the 2017 Population Needs Assessment, despite the challenges of COVID-19. COVID-19 has had a number of impacts, including increasing demand for services, especially mental health, and changing models of delivery for many services.
- The closing dates for comments on this draft population needs assessment is the 14th January 2022. The PNA will be considered by Cabinet on the 28th February and Council on the 7th March.

Recommendation

1. That the Scrutiny Committee considers the contents of the draft Cardiff and the Vale of Glamorgan Population Needs Assessment 2022 report, and helps to inform the final assessment report

Reason for Recommendation

1. To provide Elected Members with an opportunity to contribute to the Population Needs Assessment.

1. Background

1.1 Part 2 of the Social Services and Well-being (Wales) Act 2014 requires Local Authorities, in partnership with Local Health Boards, to assess the care and support needs of the population, including carers who need support. An assessment of the range and level of services to meet the identified needs should then be conducted. The Act aims to focus on and promote well-being; to empower people in their relationship with social services; and support co-production of solutions in provision of care and support.

1.2 A formal partnership between the Local Authorities of Cardiff and the Vale of Glamorgan, and Cardiff and Vale University Health Board has previously been established: The Regional Partnership Board. The Population Needs Assessment has been developed by the Regional Partnership Board together with representatives from the third sector, and following engagement work with local residents, service users, carers, health and social care professionals, and independent providers.

1.3 The Population Needs Assessment (PNA) should be undertaken every local government electoral cycle and should look forward to encompass the time period until the next iteration. The inaugural PNA was published in 2017 and this iteration is due for publication on 1st April 2022.

1.4 The Act specifies themes which should be included within the assessment, and allows for regions to include additional themes as appropriate to the local population. Examples of themes include children and young people; sensory impairment; and secure estate. These are presented in the draft report as individual chapters. Chapters include details of progress made since the 2017 Cardiff and Vale Population Needs Assessment; the impact of COVID-19; care and support needs identified; and the range and level of services required including preventative services, and assets that support people's well-being. Additional chapters describing the background, methods used, and demography of Cardiff and the Vale of Glamorgan are also provided.

1.5 Supplementary guidance issued in March 2021 by Welsh Government requested consideration of the Socio-Economic Duty, as well as the impact of COVID-19. Increased emphasis on housing needs and Welsh language was recommended. This iteration of the assessment presents these components within each chapter.

1.6 Well-being Assessments were conducted in both Cardiff and the Vale of Glamorgan Local Authorities concurrent to the Population Needs Assessment. Regular meetings were held between lead authors to promote cohesion between the assessments. The final Population Needs Assessment report will contain links to the Well-being Assessments to provide the reader with a comprehensive place-based understanding.

1.7 The Population Needs Assessment will provide input to the Market Stability Report and Area Plans.

2. Key Issues for Consideration

2.1 The Population Needs Assessment (PNA) is a legal requirement under the Social Services and Wellbeing (Wales) Act. The legal publication date is 1 April 2022. This version of the PNA is in draft form to enable relevant feedback prior to full sign off and publication.

2.2 The PNA feeds into both the Market Stability Report and Area Plan; and therefore is a crucial document for future planning purposes.

2.3 The overarching findings can be found in the Executive Summary; however each individual population group has bespoke care and support needs, and more detail can be found in the relevant chapter(s).

2.4 Cross-cutting findings identified across many chapters are outlined below; detailed findings for each theme are reported in the relevant chapter in the draft report.

2.5 An accompanying Equality and Health Impact is available.

2.6 Care and Support needs

Individual

- People's independence must be maintained and facilitated within decisions for care and support, employment and accommodation. Any such decisions should be based on consultation and co-production with the person they affect.

Community

- Social isolation was identified in the 2017 PNA and has been exacerbated for many due to COVID-19, with far reaching consequences for physical and mental health and well-being.
- Holistic approach to physical and mental health, which includes improved access to services including reduction in waiting lists.
- Information provision: many people were unaware of support available to them and would benefit from increased signposting.

Wider determinants

- Employment (paid or voluntary) was desired by many – to improve personal finances, as well as to provide a sense of purpose, reduce isolation, and to help protect people's mental health and well-being.
- Housing and accommodation needs to be available, accessible, safe, and supportive of what matters most to the individual, for example, enabling employment. Prevention and early help for homeless people needs to be enhanced.
- Inequalities were discussed in all chapters, especially in terms of socio-economic deprivation, access to services, and health outcomes. COVID-19 has had a disproportionate impact across the population, in part due to pre-existing inequalities in the social determinants of health that have been exacerbated by COVID-19 and restrictions.

Range and level of services

Prevention

The following were identified as being able to prevent needs arising or escalating, and may facilitate improved outcomes for people:

- Healthy behaviours such as physical activity to improve mental well-being and prevent falls.
- Early identification, diagnosis and intervention to support people at the right time, and promote better outcomes.
- Social support, including maintenance of a social role, and digital inclusion.
- Advocacy to enable people to express their views and wishes.
- Care focussed on delivering services as close to people's homes as possible.

Assets to support well-being:

- Individual sources of support across all groups included friends, families, and hobbies.
- Local community support like community groups, neighbours, and community-based organisations including religious places of workshop, choirs, and places to exercise.
- Local authority, NHS, and third sector services (both on a national and local footprint) were praised throughout engagement work.
- People with lived experience providing peer support (face to face or online) or as service providers were identified as important assets; and supported the need for inclusive recruitment across all sectors.
- Service users, professional leads, and providers identified the need for sustainable funding of statutory and third sector organisations to maintain and develop their services.

Community Services

- A whole system approach to care and support provision should prioritise continuity of care (for example, in transition between services); and joined up services between public, private and third sector providers for a "seamless" experience for service users.
- Equitable, accessible, and inclusive services; where access is tailored to the individual.
- Timely access to high quality care and support services.
- Respite care provision which is flexible and accessible to those who need it.
- Increased awareness of services available and the scope of their practice amongst service providers so that they can signpost.
- The social model of disability should underpin services; and language used should be respectful.
- Co-production at the heart of decisions.

Partnership approach

- Many respondents to engagement work did not ask for traditional care and support services, but identified that their needs could be met through supportive employers and access to education, accommodation provision which gives individuals choice, including over location, and supports independence, and a welcoming community and an enabling wider environment.

3. How do proposals evidence the Five Ways of Working and contribute to our Well-being Objectives?

Five Ways of Working:

3.1 **Long term:** the Code of Practice states that each assessment report must look forward to the subsequent report; i.e. five years. Each chapter within this draft report contains a section which considers what changes may take place over the next five years, and projects beyond this time period where data is available.

3.2 **Integration:** the Population Needs Assessment for Cardiff and the Vale of Glamorgan was written at the same time as the development of the Local Authority Well-being Assessments. Lead authors from each of these assessments met regularly during the development of the assessments, to ensure a cohesive approach. The final Population Needs Assessment report will contain links to the Well-being Assessment where relevant. The Population Needs Assessment will inform the Market Stability Report and Area Plans.

3.3 **Involvement:** consultation is not formally required under the Social Services and Well-being (Wales) Act 2014, however, the Code of Practice stipulates the need

for citizen engagement, which was emphasised in the Supplementary Guidance issued in March 2021. This assessment took the following approach:

3.3.1 Surveys:

- Public survey (available online, hard copy, and Easy Read).
- Children and young people survey (available online, hard copy, and Easy Read).
- Survey for people in HMP Cardiff (available as hard copy).
- Professional and provider survey (available online or hard copy).

3.3.2 Focus group discussions: 23 focus groups were conducted, to obtain rich information for each theme. The focus groups were led by Cardiff Third Sector Council, with input from third sector organisations. Further details are available in the draft report.

3.3.3 Existing engagement: findings from prior engagement work were included where possible.

3.4 Collaboration: the assessment was conducted as a partnership between the Local Authorities of Cardiff and the Vale of Glamorgan, Cardiff and Vale University Health Board, the Integrated Health and Social Care partnership (Regional Partnership Board), a member of the Market Stability Report team, and third sector representatives.

3.5 Prevention: each chapter relating to a theme in the report contains a section on services required for prevention. This is linked with assets identified from engagement work and from relevant literature as being supportive to people's well-being, enabling people to stay well.

Well-being Objectives: The Population Needs Assessment has well-being at its core. Key well-being objectives included within the assessment include the following:

3.6 A healthier Wales: the assessment of care and support needs, and the range and level of services is conducted to enable partners and other organisations to develop and improve services to support and promote health and well-being.

3.7 A more equal Wales: the Supplementary Guidance issued by Welsh Government requests the consideration of the Socio-Economic Duty. This is presented within each chapter in the assessment report.

3.8 A Wales of vibrant culture and thriving Welsh language: Welsh language is considered within each chapter in the assessment report.

A Wales of cohesive communities: Assets to support well-being were considered at the individual, community, and population level, and are included within each chapter in the assessment report.

4. Resources and Legal Considerations

Financial

4.1 There are no financial resources required at this stage. The statutory requirement that Area Plans (which will be informed by the final Population Needs Assessment report) should be developed and implemented subsequently will have potential financial implications. These implications should be discussed as part of the Area Plans.

Employment

4.2 There are no employment implications at this stage. Emerging findings reported in the draft assessment report highlight the importance of education, employment and meaningful activities. This includes inclusive recruitment, in particular into public sector positions.

Legal (Including Equalities)

4.3 The publication of a Population Needs Assessment is a statutory requirement under the Social Services and Well-being (Wales) Act 2014. Part 2 of the Code of Practice (General Functions) provides more detailed guidance.

4.4 The final report must be formally approved by the Local Authorities and the Local Health Board, to ensure that the information contained in the report is considered at the most senior levels. Once approved, assessment reports must be published on the websites of all Local Authorities and Local Health Boards.

4.5 Upon completion, assessment reports must be published on the websites of all Local Authorities and Local Health Boards involved in their production. A copy of the population assessment report must also be sent to Welsh Ministers at the time of publication.

4.6 The population assessment report should be drafted using accessible language so that it can be considered by members of the public. It is important the assessment report explains clearly how the local authorities and the Local Health Board have arrived at their decision in relation to the needs identified and the level of services required to meet those needs.

4.7 Local authorities and Local Health Boards must produce one population assessment report per local government electoral cycle.

4.8 In producing a population assessment report Local Authorities and Local Health Boards must be forwarded looking and consider the needs for care and support and needs for carers for the whole period up until the next population assessment is due for publication. However, given that circumstances may change, the partnership arrangement established to carry out the population assessment must keep the population assessment under review. The population assessment report should be reviewed as required, but at least once mid-way through the population assessment period. If this review identifies a significant change in the needs for care and support or the needs of carers, an addendum should be produced and similarly be published and sent to the Welsh Ministers.

5. Background Papers

Social Services and Well-being (Wales) Act 2014 Code of Practice (Part 2 General Functions) (2015) [online]. Available from: https://gov.wales/sites/default/files/publications/2019-05/part-2-code-of-practice-general-functions.pdf

Population Needs Assessments: Supplementary Advice for Regional Partnership Boards (March 2021) [online]. Available from: https://gov.wales/sites/default/files/publications/2021-03/population-needs-assessments.pdfPNA

let's talk
amser siarad

CARDIFF AND THE VALE OF GLAMORGAN

POPULATION NEEDS ASSESSMENT

2022

Contents

1. Executive Summary

Background

This is the second Population Needs Assessment for Cardiff and the Vale of Glamorgan, following the first published in 2017. The Population Needs Assessments (PNA) are required under the Social Services and Well-being (Wales) Act 2014, and must contain an assessment of the needs for care and support amongst the residents of Cardiff and the Vale of Glamorgan, and the range and level of services required to meet that need. The Act specifically asks for an assessment of nine named themes within the population, and allows for consideration of other themes relevant to the local area. These are presented here as individual chapters.

The PNA should be read alongside the complementary Well-being Assessments for Cardiff and the Vale of Glamorgan to gain a comprehensive understanding of the region. The Well-being Assessments, required under the Well-being of Future Generations (Wales) Act 2015, investigate social, economic, environmental and cultural well-being of an area, which provides a detailed overview of the wider determinants of health.

Methods

The PNA was undertaken between May 2021 and March 2022, and provides an update of the 2017 report. A number of different approaches were taken to collect information to provide a holistic and comprehensive assessment. Firstly, existing data, reports, and research were identified from a range of sources, including data from health, local authorities and third sector organisations. Dedicated engagement was carried out, including surveys for the general adult population, children and young people, residents of HMP Cardiff, and for professionals and providers. Twenty-three focus groups were conducted, led and supported by local third sector organisations. The branding developed for the 2017 Population Needs Assessment "*amser siarad*" / "*let's talk*" was used for the citizen engagement.

Professional leads were identified from Cardiff and the Vale of Glamorgan local authorities, Cardiff and Vale University Health Board, and other organisations where appropriate, in order to understand the context of each theme, and help guide the data collection and interpretation.

The assessment was overseen by a dedicated Steering Group, with representatives from Cardiff and the Vale of Glamorgan local authorities, Cardiff and Vale University Health Board, the Cardiff and Vale Regional Partnership Board, and those working on the Market Stability Report. The group reported to the Regional Partnership Board.

Demography

The population of both Cardiff and the Vale of Glamorgan has continued to increase, driven mostly by the 16-64 year-old age group, who now make up 65% of the population. One in five (18%) are aged under 18 in both local authorities, but the Vale of Glamorgan has a

higher proportion aged 65+ (21% compared to 14% in Cardiff). The total population is expected to increase further over the next two decades, with an increasing proportion of those aged 65+. The Vale of Glamorgan is projected to have the second largest whole population growth by percentage of local authorities in Wales.

The Welsh Index of Multiple Deprivation (WIMD) 2019 suggests that there are areas of established inequalities across the Cardiff and Vale region; with areas in the "Southern Arc" in Cardiff and areas in the East of Barry ranked as more deprived against the WIMD.

Key findings

Relevant findings for each population group are presented in the relevant chapter. Cross-cutting findings, those identified across multiple population groups, are presented below. Chapters should be considered together, as people may feel part of more than one theme.

Improvements in care and support services have been made across all population groups since the 2017 Population Needs Assessment, despite the challenges of COVID-19. COVID-19 has had a number of impacts, including increasing demand for services, especially mental health, and changing models of delivery for many services.

Care and support needs

Individual

- People's independence must be maintained and facilitated within decisions for care and support, employment and accommodation. Any such decisions should be based on consultation and co-production with the person they affect

Community

- Social isolation was identified in the 2017 PNA and has been exacerbated for many due to COVID-19, with far-reaching consequences for physical and mental health and well-being
- Holistic approach to physical and mental health, which includes improved access to services including reduction in waiting lists
- Information provision; many people were unaware of support available to them and would benefit from increased signposting

Wider determinants

- Employment (paid or voluntary) was desired by many – to improve personal finances, as well as to provide a sense of purpose, reduce isolation, and to help protect people's mental health and well-being
- Housing and accommodation needs to be available, accessible, safe, and supportive of what matters most to the individual, for example, an enabling employment. Prevention and early help for homeless people needs to be enhanced
- Inequalities were discussed in all chapters, especially in terms of socio-economic deprivation, access to services, and health outcomes. COVID-19 has had a disproportionate impact across the population, in part due to pre-existing inequalities in the social determinants of health that have been exacerbated by COVID-19 and restrictions

Range and level of services

Prevention

The following were identified as being able to prevent needs arising or escalating, and may facilitate improved outcomes for people:

- Healthy behaviours such as physical activity to improve mental well-being and prevent falls
- Early identification, diagnosis, and intervention to support people at the right time, and promote better outcomes
- Social support, including maintenance of a social role, and digital inclusion
- Advocacy to enable people to express their views and wishes
- Care focussed on delivering services as close to people's homes as possible

Assets to support well-being

- Individual sources of support across all groups included friends, families, and hobbies
- Local community support like community groups, neighbours, and community-based organisations including religious places of worship, choirs, and places to exercise
- Local authority, NHS, and third sector services (both on a national and local footprint) were praised throughout engagement work
- People with lived experience providing peer support (face to face or online) or as service providers were identified as important assets; and supported the need for inclusive recruitment across all sectors
- Service users, professional leads, and providers identified the need for sustainable funding of statutory and third sector organisations to maintain and develop their services

Community services

A whole system approach to care and support provision should prioritise:

- Continuity of care: for example, in transition from children's to adult services; between NHS services; between prison services and health and local authority services following release; leaving military service; and joined up services between public, private and third sector providers for a "seamless" experience for service users
- Equitable, accessible, and inclusive services, where access is tailored to the individual. For example, through interpreter provision; letters provided in large print; offering choice of face to face, telephone, or online services; and culturally sensitive services
- Timely access to high quality care and support services
- Respite care provision which is flexible and accessible to those who need it
- Increased awareness of services available and the scope of their practice amongst service providers so that they can signpost
- The social model of disability should underpin services; and language used should be respectful
- Co-production at the heart of decisions

Partnership approach

Many respondents to engagement work did not ask for traditional care and support services, but identified that their needs could be met through:

- Supportive employers and access to education, through provision of reasonable adjustments and inclusive recruitment, for example
- Accommodation provision which gives individuals choice, including over location, and supports independence
- A welcoming community and an enabling wider environment. People considered their communities as assets, but improvements remain to be made to increase awareness of the needs of others. For example, considerate use of public spaces for disabled people; bystander awareness of violence against women and domestic abuse; and accessible transport options

What happens next

The findings of this 2022 Population Need Assessment will be used to plan future "*deep dive*" research, strategic commissioning plans, and inform both the Market Stability Report and the Area Plan. As the COVID-19 pandemic and restrictions continue, some of the needs identified may be exacerbated further, and disproportionately so, for some population groups. The findings presented should therefore be considered in the context of continuing change. What is evident, however, is the need for all stakeholders to work closely together, and consider the person at the heart of their work.

2. Background to the Population Needs Assessment

Legal Requirement

The Social Services and Well-being (Wales) Act 2014 placed a duty on local authorities and Local Health Boards to firstly undertake an assessment of the care and support needs of the population, including carers who need support. Secondly, an assessment of the range and level of services required to meet those needs is required. The Population Needs Assessment (PNA) should place well-being at its core, and align with the Well-being of Future Generations (Wales) Act 2015 (1).

The Population Needs Assessment should work towards the development of preventive, integrated, people-centred, health and care services (1). The assessment will underpin regional plans and priorities for care and support service provision, for example, the Market Stability Report and the regional Area Plan. The first Population Needs Assessment was published in April 2017, with the publication of an Area Plan in March 2018.

Cardiff and the Vale of Glamorgan

This Population Needs Assessment encompasses the Local Authorities of Cardiff and the Vale of Glamorgan. Cardiff and Vale Regional Partnership Board was established to support and develop partnership working. Membership includes the City of Cardiff Council, Vale of Glamorgan Council, Cardiff and Vale University Health Board, Cardiff Third Sector Council, and Glamorgan Voluntary Service (2).

Themes

The Social Services and Well-being (Wales) Act 2014 requires the Population Needs Assessment to consider certain "themes", with scope to include further themes as relevant to the local region. The following themes are a statutory requirement:

- Children and young people
- Health / physical disabilities
- Learning disability / autism
- Mental health
- Carers who need support
- Sensory impairment
- Violence against women, domestic abuse and sexual violence
- Secure estate
- Older people

The following themes have been additionally included as they are of local importance:

- Asylum seekers and refugees
- Substance misuse
- Armed Forces Service Leavers (Veterans)

Many people living in Cardiff and the Vale of Glamorgan may consider themselves to belong in more than one of the themes listed. This has been acknowledged within each of the chapters in this assessment. Each chapter in this report suggests further related chapters to provide the reader with a comprehensive overview of the topic area.

The legislation requires an assessment of housing and accommodation, and so these findings have been presented within each population group. The recent Supplementary Guidance (3) advises that the impact of COVID-19 and consideration of the new Socio-Economic Duty (which came into effect in March 2021) is included in the PNA. These findings have been incorporated into each chapter.

Welsh Language and Equality Profile

The Social Services and Well-being (Wales) Act 2014 requires the PNA to establish the Welsh language community profile, and that the linguistic profile of the communities is incorporated into service planning and delivery (1). This should include profiling of the need for care and support services to be provided in Welsh, including the range and level of services required and gaps in current provision. Other language and communication needs are included in these sections where relevant, to aid person-centred service planning.

The Act requires that an Equality Impact Assessment must be conducted during the PNA process, including assessment of the protected characteristics of: age, race, sex and sexual orientation, gender reassignment, pregnancy and maternity, religion and beliefs, marriage and civil partnership, disability (1).

Well-being of Future Generations (Wales) Act 2015

The Well-being of Future Generations (Wales) Act 2015 requires each Public Services Board (PSB) to produce a Well-being Assessment. There are two PSBs in the area covered by this PNA: Cardiff, and the Vale of Glamorgan. Well-being Assessments must investigate social, economic, environmental and cultural well-being of the area. Links are made throughout this report where further detail is provided by a Well-being Assessment. [Insert references when available]

Market Stability Report

The Market Stability Report is an assessment of the overall sufficiency of care and support, and of the stability of the market for regulated services. It includes care homes (adult and children), secure accommodation, fostering and adoption services, advocacy, and domiciliary support as well as some non-regulated care and support services (4). The Market Stability Report builds on intelligence gathered from the PNA. The first Market Stability Report is due for publication in summer 2022.

Starting Well, Living Well, Ageing Well

This report is set out in line with the three Regional Programme Board (RPB) programmes: Starting Well, Living Well, and Ageing Well.

The Regional Outcomes Framework for Cardiff and Vale sets out the values, strategic aims, and eight core outcomes for the Cardiff and Vale Regional Partnership Board (5). The PNA must be informed by the National Outcomes Framework (1), and so alignment between the National and Regional Outcome Frameworks was identified during the Population Needs Assessment (Appendix 1).

3. Methods

Timeframe

The assessment was undertaken during the period May 2021 to March 2022.

Methods used

Methods were based on the 2017 Population Needs Assessment and updated for this report. The COVID-19 pandemic has influenced how communications and engagement events can be run. Engagement conducted for the Population Needs Assessment needed to adhere with and anticipate future guidelines and legislation, as well as consider people's individual wishes. A number of different approaches were taken to obtain the information required including gathering existing data, assessments and reports, as well as conducting bespoke engagement work for this Population Needs Assessment.

Engagement work, to gather qualitative data, utilised the existing "*amser siarad*" / "*let's talk*" branding which was also used for the 2017 Population Needs Assessment. A list of supporting organisations can be found in Chapter 24 Acknowledgments.

Public surveys

Three public surveys were developed:

- Adults in the general public (available online, hard copy, and Easy Read)
- Children and young people (available online, hard copy, and Easy Read)
- Adults in Her Majesty's Prison (HMP) Cardiff (available online, and hard copy)

The surveys were based upon the 2017 survey, updated to reflect the additional requirements. All surveys in all formats were available in English and Welsh. The children and young people survey was piloted by members of Cardiff Youth Board, and updated in line with their feedback.

Surveys were live between 17 September 2021 and 17 October 2021. The link to the online surveys (and details of how to request hard copies) were disseminated through a variety of organisations, including Cardiff and Vale University Health Board, Cardiff Council, Vale of Glamorgan Council, Glamorgan Voluntary Services, Cardiff Third Sector Council, as well as through organisations working in health and social care services, education, and youth services. The survey was advertised through social media, and was seen by 68,000 people on Facebook resulting in 241 people clicking on the link; and by 9,126 people on Twitter, with 66 people clicking the link. Several third sector organisations kindly helped people with completion, for example, through provision of digital access and translation into other languages.

A total of 661 general adult surveys were returned. Based on postcode, 402 were from Cardiff and 105 from the Vale of Glamorgan. A total of 191 adult respondents of the public survey would like to be involved in future engagement work.

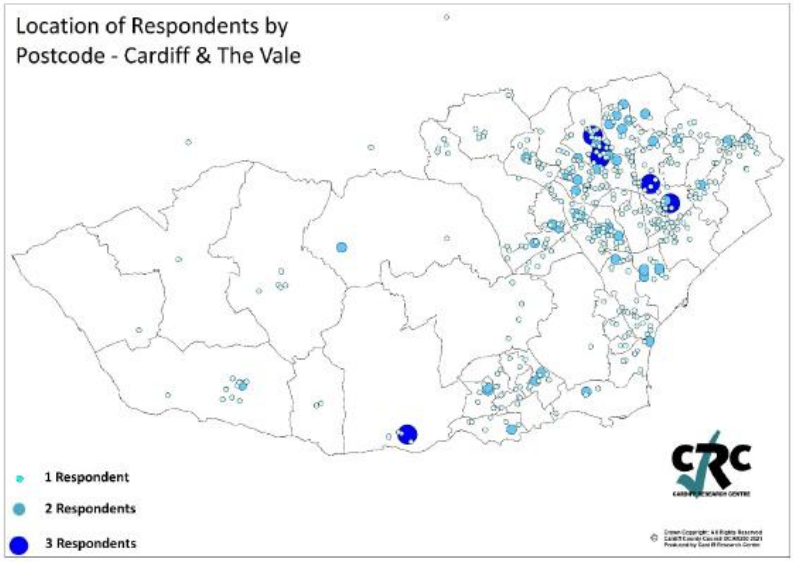


Figure 3.1. A map of location of survey respondents.

For the children and young people survey, 35 were returned. Cardiff Research Centre conducted the analysis of results for these surveys. Three adult and no children and young people Easy Read surveys were returned.

In HMP Cardiff, an online survey and 400 paper copies were distributed between 28 September 2021 and 8 October 2021; with 96 completed returns.

Focus group discussions

A focus group topic guide was developed from the requirements of the Population Needs Assessment (1) (3), and used the National Outcome Framework well-being outcome statements as an anchor from which to initiate discussion (6). Topic areas were discussed with focus groups as relevant to the population (for example, a focus on communication in the sensory loss groups). A list of the focus groups, including numbers of attendees, is given in the Appendix, and organisations supporting the establishment and running of focus groups are presented in the Acknowledgements.

A total of 23 focus groups were held. These were conducted by Cardiff Third Sector Council with support from Glamorgan Voluntary Services and third sector organisations. Three planned groups did not take place as either no participants could be identified, or the provider withdrew. A total of 132 people attended the focus groups (range 1-12, average 6 attendees). Although groups were small and cannot be representative of the population group, they do provide depth of insight.

Professional and Provider Survey

A survey for professionals and providers of care and support in the region was developed, based on the survey used in the 2017 Population Needs Assessment. It was available online and as hard copy, in English and Welsh, from 17 September 2021 until 17 October 2021. Awareness of the survey was raised through the same mechanisms as the public surveys. Cardiff Research Centre analysed the results.

The survey received 118 responses. Two-thirds were from an individual health or social care professional, with one-quarter completed on behalf of a group or organisation. Twenty percent of responses were from a staff member at Cardiff Council, and 12% from Vale of Glamorgan Council. Twenty percent of responses were from the health service employees, 19% from staff working for an independent care provider, and 20% were employees at a charity or third sector organisation.

Population and Service data

Existing data were taken from a number of sources. To improve cohesion between the Well-being Assessments and the PNA, the same indicators were used where possible, for example, in the Demography chapter. Indicators reported in the 2017 Population Needs Assessment were included in this report where relevant and where up to date information was available. Additional indicators and data were identified through review of data catalogues produced by Social Care Wales, and the Well-being Assessments. Discussion with professional leads identified further sources of information for inclusion.

Existing reports and assessments

Where possible, existing reports and assessments were incorporated to develop a comprehensive assessment of the needs of the population. Background information such as policies, strategies, and research reports were collated to understand the contextual environment. These were identified by professional leads; through review of relevant organisational webpages (for example, Welsh Government or third sector organisations websites); and literature review. Effort has been made to identify data specific to Cardiff and the Vale of Glamorgan. However, a great deal of research is conducted at a Wales-wide or wider level, and so findings have been included in this regional assessment where it is felt that findings are applicable and relevant locally.

Professional leads

For each chapter in the PNA, professional leads were identified from Cardiff and the Vale of Glamorgan local authorities, Cardiff and Vale University Health Board, and other organisations where appropriate to provide expert insight into the topic area. Professional leads (who are referred to throughout this report as "*professional leads*") identified key changes since the 2017 Population Needs Assessment, and key areas for investigation for this iteration of the assessment. Findings were shared with professional leads in November 2021 for their comment and feedback. Emerging findings were discussed with leads of the Well-being Assessments for Cardiff and the Vale of Glamorgan.

Oversight of the Population Needs Assessment

A steering group was established for the Population Needs Assessment which met on a monthly basis. The group reported to the Strategic Leadership Group, which reports to the Regional Partnership Board. Membership included a strategic lead and a data lead from each Local Authority; representatives from Cardiff and Vale University Health Board, Cardiff and Vale Regional Partnership Board, Cardiff and Vale Local Public Health Team, Cardiff Third Sector Council, Glamorgan Voluntary Services, Communications and Engagement, and

the Market Stability Report. The group was chaired by the representatives from Cardiff and Vale Local Public Health Team.

Steering Group meetings informed the PNA development process, as well as alignment with the Market Stability Report, Well-being Assessments, and other assessments and plans. Regular meetings with representatives from the Well-being Assessments and Market Stability Reports were conducted in between Steering Group meetings to improve cohesion between assessments.

Limitations of the assessment

COVID-19 has had a tremendous impact on population needs, which this assessment will detail. Due to uncertainty of the future evolution of the COVID-19 pandemic in terms of restrictions and risks at each stage of the Population Needs Assessment, a cautious approach was taken. For example, engagement work was planned in an online format, with opportunities for face to face interactions in the focus group where legislation allowed, and where participants and hosting organisations felt comfortable. The tight timeline within which engagement work needed to be conducted reduced participation in both surveys and focus groups. The Regional Partnership Board is developing its Communications and Engagement strategy which will address these difficulties and gaps, and will incorporate lessons learned. For example, some residents may not have digital access and may not wish to engage in face-to-face engagement, and so their views will continue to be sought in future work.

Some planned focus groups could not be held as no participants could be identified in the available time. The focus group for autistic adults became an interview with one individual; the substance misuse focus group included only two participants. Future engagement work will consider how best to garner the views of these population groups, working with partnerships that lead service commissioning and delivery in such arenas.

Limitations on publicly available quantitative data were noted, with some indicators last updated before COVID-19. The 2021 Census data will be available in 2022, which will be incorporated into future updates of the Population Needs Assessment.

Equality and Health Impact Assessment

The Code of Practice requests that an Equality Impact Assessment is conducted as part of the Population Needs Assessment (1). No negative impacts from any of the protected or health characteristics were identified, but it was recognised that engagement work did not capture a representative sample of the population of Cardiff and the Vale of Glamorgan, with under-representation from people who are trans; women who are expecting a baby, on a break from work after having a baby, or breastfeeding; people who are from an ethnic minority background; people who consider themselves: Buddhist, Hindu, Jewish, Muslim, or Sikh; those whose disability meant they were physically unable to participate in engagement and did not have an individual who could speak for them; and Gypsies and travellers. In addition, there was under-representation from people who are digitally excluded. The Equality and Health Impact Assessment is available as a separate document (7).

Recommendations for the Population Needs Assessment in future

The PNA Steering Group decided to take a novel approach to future iterations of the Population Needs Assessment. The Population Needs Assessment should ideally contain up to date data, be of local use and value, and with the vision of becoming a "living resource". As a first step towards this, future Population Needs Assessments for Cardiff and the Vale of Glamorgan will further develop this assessment and take a hybrid approach: a rolling update of quantitative data, and an intermittent update of qualitative data through bespoke engagement work. This approach aims to balance the need for relevant and timely information, within the resource requirements.

Liaison with Cardiff and Vale University Health Board, Cardiff Council and the Vale of Glamorgan Council, and the Regional Outcomes Framework will take place in order to develop a robust and regular reporting mechanism for quantitative indicators.

The Cardiff and Vale Regional Partnership Board will continually engage with the population to make sure that people are involved with their decisions. This will ensure that all their work is based on the priorities and experiences of people who use services and community spaces, now and in the future. The three programme areas: Starting Well; Living Well and Ageing Well, will engage with children, young people and adults to ensure lived experiences shape services across the region. The programmes will ensure this includes the full range of voices from Cardiff and the Vale's diverse population to build in the wide range of experiences and needs people have when making any developments.

Next steps

Recommendations were developed based on the triangulation of data, and are by no means exhaustive. Data gaps exist for each population group and further insight development may be required as a first action. This will include discussions between the Regional Partnership Board, which oversee the Population Needs Assessment, the Public Services Boards (which oversee the Well-being Assessments), and other partners.

The Regional Partnership Boards will ensure that relevant organisations work together to respond to the assessment findings. Local authorities are required to use this assessment within their service provision (1).

The Market Stability Report will further develop the findings of the Population Needs Assessment to both undertake a Market Sufficiency Assessment and to understand the market stability. The Cardiff and Vale Area Plan will be developed based on the findings of this Population Needs Assessment, alongside other local plans.

4. Demography

Current population structure

In 2020, there were 369,202 people living in Cardiff, and 135,295 in the Vale of Glamorgan (8). This is an increase of 11,706 people in Cardiff and 7,315 in the Vale of Glamorgan following the 2017 PNA (8). This change has been driven by the 16-64 age group who now make up 65% of the population, with that proportion being slightly higher in Cardiff than the Vale of Glamorgan. In both local authority areas, 18% of the population are aged under 16, which is a 2.7% decrease from 1991. The Vale of Glamorgan has a higher proportion of those aged 65+ (21% compared to 14% in Cardiff). These changes are shown in Figures 4.1 and 4.2.

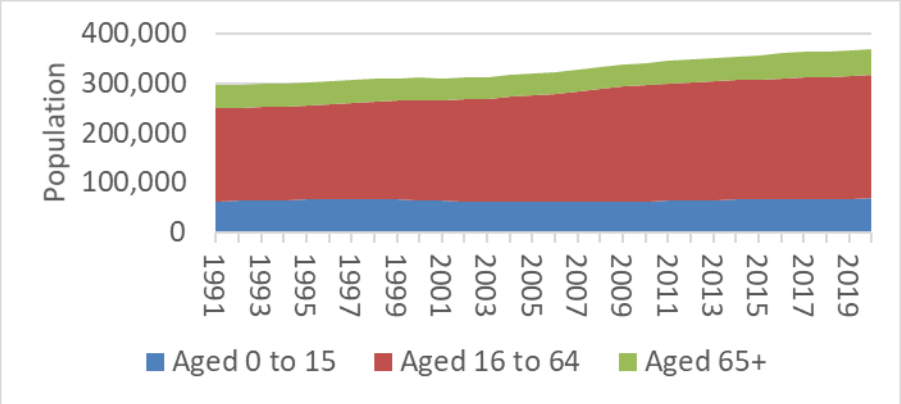


Figure 4.1. Population of Cardiff by age group, 1991-2020
Source: ONS (9)

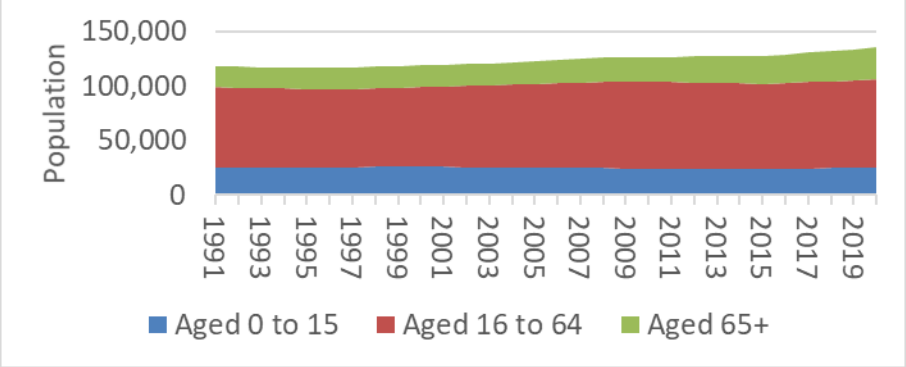


Figure 4.2. Population of the Vale of Glamorgan by age group, 1991-2020
Source: ONS (9)

Figures 4.3-4.4 demonstrate the age structure in Cardiff and the Vale of Glamorgan in 2018 and 2043. In 2018, there were a higher proportion of people aged 16-44 in Cardiff, and a higher proportion of people aged 45 and over in the Vale of Glamorgan. This reflects, in part, the number of students in Cardiff (10).

Anticipated population change

Based on the 2018 population projections, over the next decade the Vale of Glamorgan is anticipated to experience the second largest percentage population growth of any local authority area (after Newport) with a projected growth of 6%. By 2043, the population of Cardiff and the Vale of Glamorgan is projected to have a greater proportion of people aged

65+, who will make up 20% of the population (a 4% increase from 2018) (11) . Those aged 65 years and above made up 14% of the population in Cardiff in 2018, and 21% in the Vale of Glamorgan (21% for Wales). By 2043, this is expected to be 18%, 27%, and 26% respectively (11). Figures 4.3 and 4.4 compare the 2018 population age structure with the anticipated population in 2043, and demonstrate the increase in people aged over 65. It should be noted that population projections are developed based on assumptions on the determinants of population change (i.e., births, deaths, and migration), which are themselves based on historical trends, and do not allow for the impacts of future changes, for example, due to government policy. Migration projections are based on the previous 5 years and do not include short term migrants, i.e., those resident under 12 months. Projections become increasingly uncertain the further into the future they project (10). Therefore, projections should be interpreted with caution and reviewed periodically.

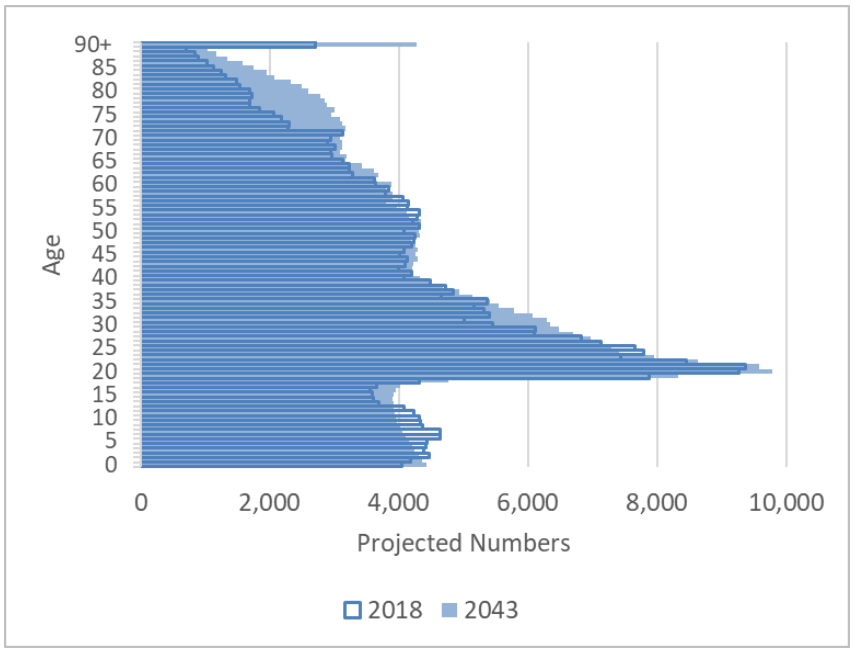


Figure 4.3. Comparison of population structure by age in Cardiff in 2018 with the expected population in 2043
Source: Stats Wales (10)

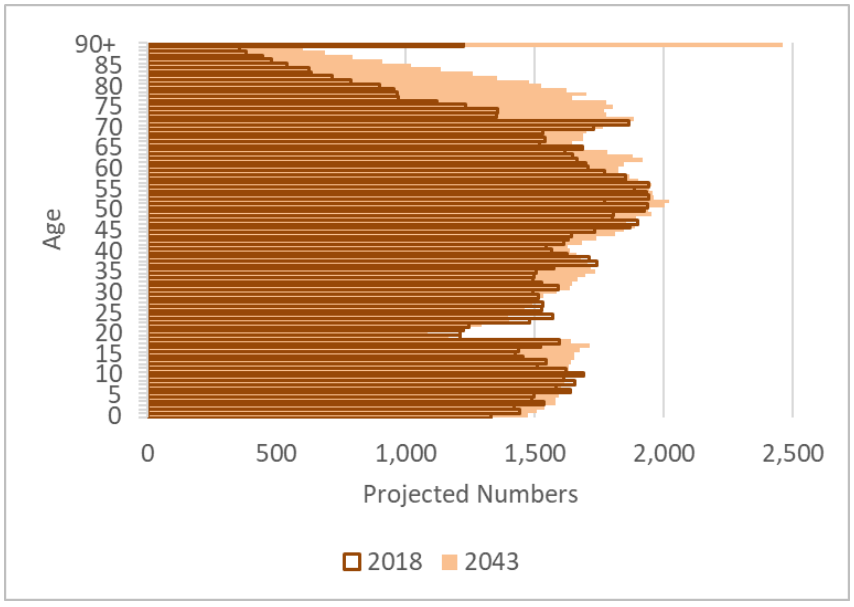


Figure 4.4. Comparison of population structure by age in the Vale of Glamorgan in 2018 with the expected population in 2043
Source: Stats Wales (10)

Drivers of population change

Births

Since 2013 the number of births per year has declined for Cardiff and the Vale of Glamorgan, in line with the picture across Wales (12). The General Fertility Rate has decreased from 2013-2019 from 56% to 44% in Cardiff, and from 61% to 53% (currently equal to the Welsh average) in the Vale of Glamorgan (11). Figures 4.5 and 4.6 show the age specific fertility rate over by age group, between 2013 and 2019. Of note, the age specific fertility rate has decreased over this period for all age groups under 34 years. Projections indicate that the recent downward trend in births (2010 – 2020) will remain relatively stable for approximately the next 10 years, and then follow a slight upward trend. It is projected that beyond 10 years, in Cardiff and the Vale of Glamorgan there will be an increase of approximately 10% in terms of the number of births in the area by 2043. This compares with a Wales-wide increase of approximately 5% across the same period. A number of factors influence fertility projections, such as fertility rates, age structure of the population, migration (migrants are concentrated at young adult ages), as well as other factors (13). Note that projections become less accurate the further into future they project, so these findings must be interpreted with caution.

Figure 4.5. A graph of age-specific fertility rate in Cardiff,
by age group, between 2013 - 2019
Source: ONS (12)

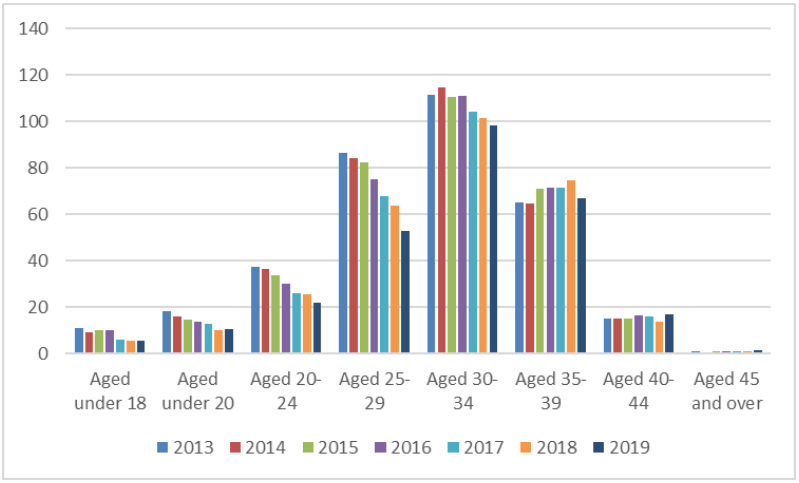
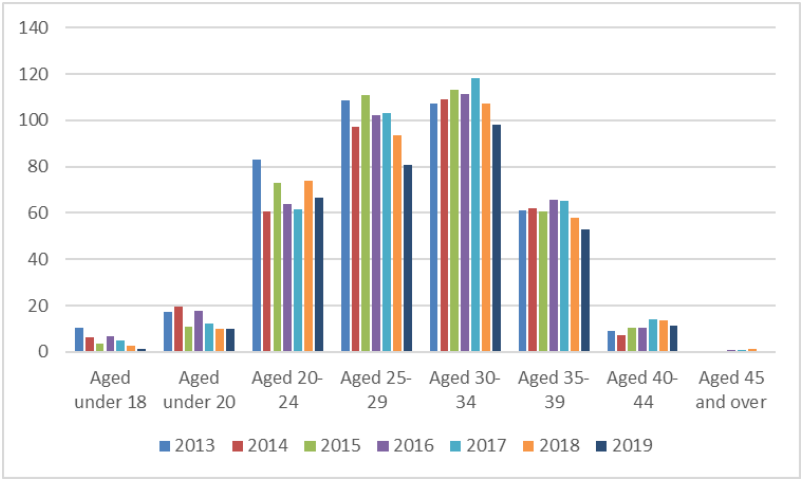


Figure 4.6. A graph of age-specific fertility rate in the Vale of Glamorgan,
by age group, between 2013 – 2019
Source: ONS (12)



Deaths

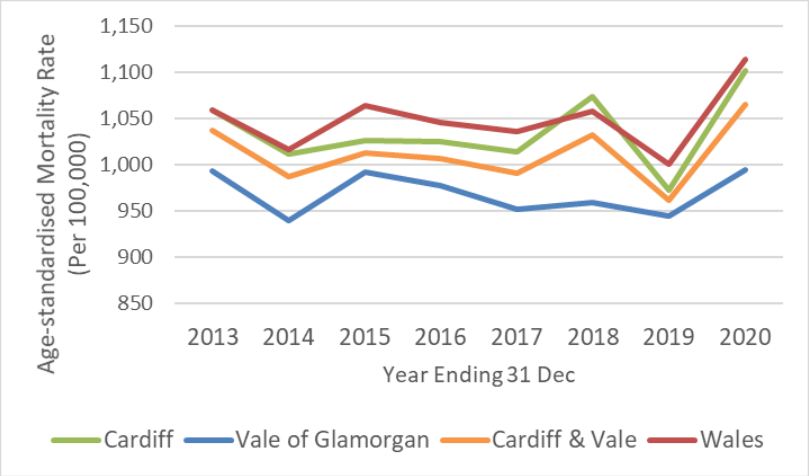
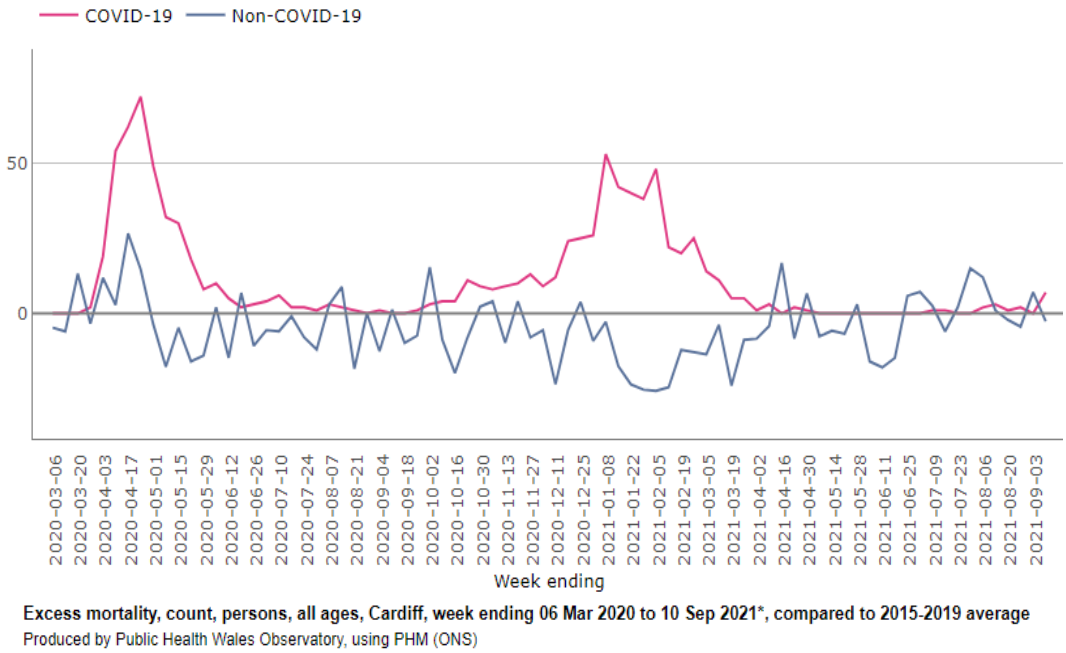


Figure 4.7. Age-standardised mortality rate between 2013 and 2020, for Cardiff, the Vale of Glamorgan, and Wales
Source: ONS (14)

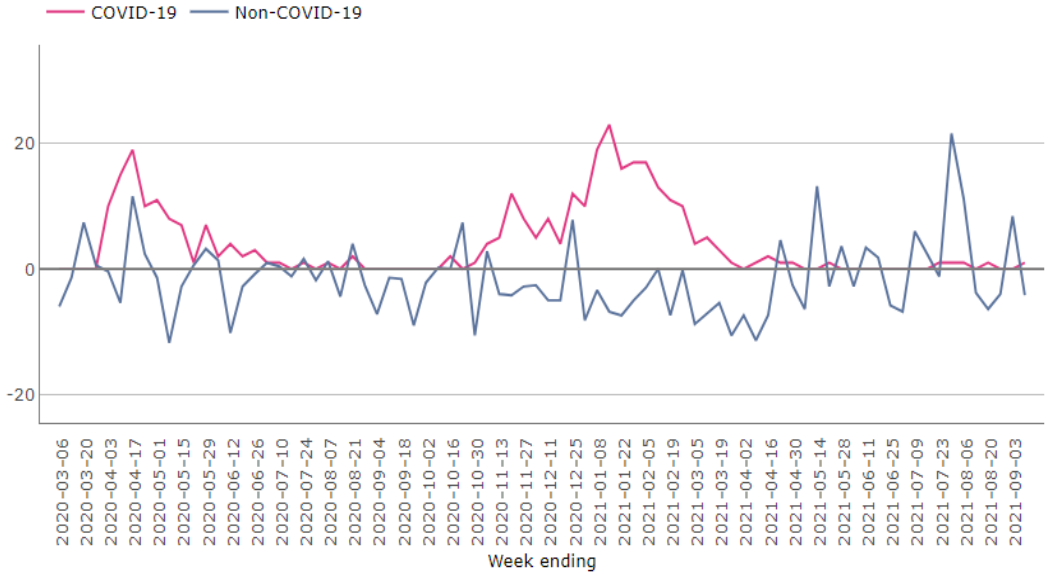
The age-standardised mortality rate for the Vale of Glamorgan is significantly below that of Cardiff (which is almost equal to the Wales-wide average). An increase in both the absolute number of deaths as well as the age-standardised mortality rate is observed for 2020, due to COVID-19. Figure 4.7 demonstrates an increase in age-standardised mortality rate in 2020, corresponding to the COVID-19 pandemic. Measures of excess deaths compare deaths in 2020, to the 2015-2019 average deaths for the same week. Excess deaths have been predominantly due to COVID-19. Across Wales, the first and second waves of COVID-19 are clear, with excess deaths of over 400 per week (where COVID-19 was mentioned on the death certificate). The lower numbers of COVID-19 deaths since July 2021 are thought to be in part due to high vaccination coverage. Non-COVID-19 deaths have been mostly below average between November 2020 and April 2021, and have been closer to average between April and September 2021 (15).

Figures 4.8 and 4.9 below demonstrate excess mortality for Cardiff and the Vale of Glamorgan, which follows a similar pattern as for all Wales for both COVID-19 and non-COVID-19 related deaths (16).



Excess mortality, count, persons, all ages, Cardiff, week ending 06 Mar 2020 to 10 Sep 2021*, compared to 2015-2019 average
Produced by Public Health Wales Observatory, using PHM (ONS)

Figure 4.8. Excess mortality in Cardiff for COVID-19 related deaths, and non-COVID-19 related deaths. Source: Public Health Wales Observatory (16)



Excess mortality, count, persons, all ages, Cardiff, week ending 06 Mar 2020 to 10 Sep 2021*, compared to 2015-2019 average
Produced by Public Health Wales Observatory, using PHM (ONS)

Figure 4.9. Excess mortality in the Vale of Glamorgan for COVID-19 related deaths, and non-COVID-19 related deaths. Source: Public Health Wales Observatory (16)

Migration

Between Wales and the rest of the UK, inward migration has generally exceeded outward migration since 2001 in the Vale of Glamorgan, whereas outward migration has been

marginally greater in Cardiff in most years since 2001 (17). Cardiff has seen total net in-migration for a number of years, which is driven by high levels of net international in-migration. The Vale of Glamorgan has also seen total net in-migration for a number of years, driven by migration within the UK. Over the next 15 years, net positive in-migration is anticipated (predominantly due to international migration) followed by 10 years of net out-migration (driven by movement within the UK). The Vale of Glamorgan is projected to have consistent levels of total net in-migration, driven by internal UK migration.

Healthy Life Expectancy

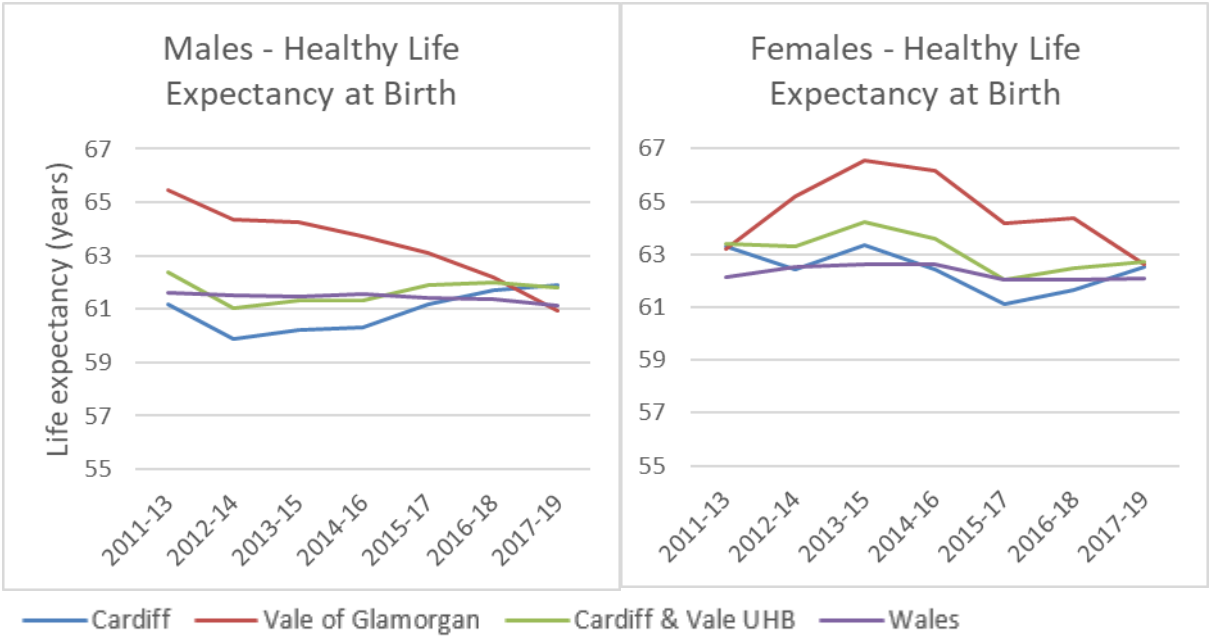


Figure 4.8-4.9. Healthy life expectancy at birth for males (Figure 4.8) and females (Figure 4.9), between 2011/13 and 2017/19. Source: ONS (18)

Healthy life expectancy at birth for males in Cardiff has increased over time and is currently above the Welsh average, whereas for females, healthy life expectancy at birth has fallen overall from the 2011-13 position, but has been rising steadily from following a low point in 2015-17 (18).

In the Vale of Glamorgan, healthy life expectancy at birth for males has fallen by almost 4.5 years between 2011 and 2019, and is currently slightly below the Wales average. For females, healthy life expectancy at birth has fallen by 4 years from a peak in 2013-15 (18).

Deprivation

The 2017 PNA identified the stark inequalities between areas within Cardiff and the Vale of Glamorgan, with no evidence that the gap between the most affluent and most deprived was reducing. The COVID-19 pandemic has shone a spotlight on inequalities as a root cause of the increased morbidity and mortality seen in some communities and the burden of restrictions falling on some people who are in the most vulnerable situations. This is explored in more detail in the Director of Public Health Annual Report, including differences in mortality, vaccination coverage, employment, and housing (19).

The Welsh Index of Multiple Deprivation (WIMD) 2019 suggests that there are areas of established inequalities across the Cardiff and Vale region; with areas in the 'Southern Arc' in Cardiff and areas in the East of Barry ranked as more deprived against WIMD. In Cardiff, 39 Lower Super Output Areas (LSOAs) are included in top 10% most deprived in Wales, while 3 LSOAs in the Vale of Glamorgan are ranked in the top 10% most deprived area in Wales (20). In Cardiff, around one-fifth of residents live in the most deprived 10% of lower super output areas (LSOAs) in Wales. Approximately 50% of Cardiff's population live in the 50% least deprived LSOAs (105 LSOAs), while for the Vale of Glamorgan, 65% live in the 50% least deprived areas (28 LSOAs) (21). Amongst children aged 0-4 years, Cardiff has both the most and least deprived middle super output areas in Wales, with income deprivation rates between 3% in Rhiwbina and Pantmawr, to 67% in Ely East (22).

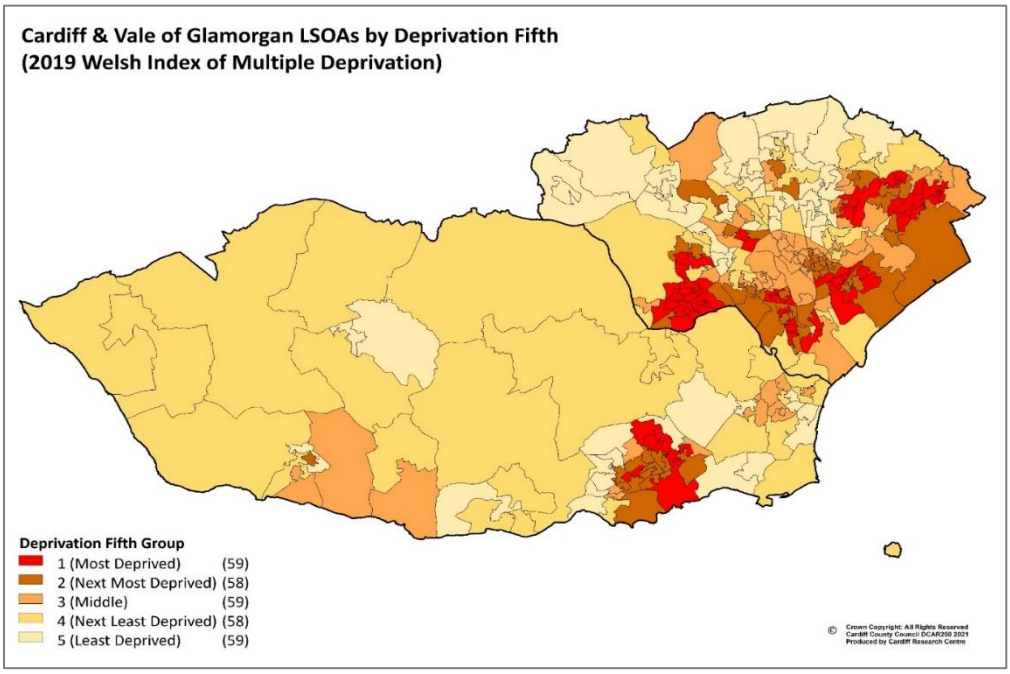


Figure 4.10. Cardiff and the Vale of Glamorgan LSOAs. Produced by Cardiff Council using 2019 Welsh Index of Multiple Deprivation Overall Ranks, Welsh Government (21)

Ethnicity

The Annual Population Survey identified an increase from 10.4% in 2004 to 20.1% in 2020 of people in Cardiff who are Black, Asian, or from a minority ethnic group. The Vale of Glamorgan has seen only a small increase in people who are Black, Asian, or from a minority ethnic group over the same time period (23).

Language

The 2011 Census identified that most (98.4%) of residents in the Vale of Glamorgan have English or Welsh as their main language. This is slightly higher than the Wales average (97.1%). Across Wales, Cardiff has the lowest proportion of people speaking English or Welsh as their first language at 91.7% (24) .

5. Children and Young People

This chapter should be read in conjunction with the following chapters: Children and Young People with Complex Needs; Children Looked After; Healthy Lifestyles and Long Term Conditions; Physical Disability; Learning Disability; Autism; Adult Unpaid Carers; Sensory Loss and Impairment; VAWDASV; Asylum Seekers and Refugees; Secure Estate

Recommendations

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Adopt the NEST Framework and No Wrong Door approach
- Strengthen actions to ensure information is accessible to children and young people; and they are invited to co-produce services so they are person-centred, and help children and young people feel valued
- Monitor emerging literature on long COVID in children and young people

Cardiff and Vale University Health Board to:

- Continue to promote preventative strategies including routine immunisations
- Continue to develop partnerships with Education services and embed the whole school approach to emotional health and wellbeing
- Increase funding available to mental health services for children and young people (25)
- Target waiting list times, especially for children and young people's mental health services
- Develop Integrated Model for Emotional Health and Well-being for Cardiff and Vale

5.1 Overview

Children and young people will be considered in this PNA as those aged up to 18 years of age, although age cut offs and ranges vary between services and policies. Children and young people may be included within many of the other population groups within this report. Children and young people with complex needs are discussed in chapter 6, and children looked after in chapter 7.

Table 5.1 demonstrates the number of children and young people in Cardiff and the Vale of Glamorgan, by age group, and as a percentage of the total population of the local authority. Cardiff has higher numbers of children and young people, but for those aged 0-4 and 5-15, the proportion of the population is similar. Cardiff has a higher proportion of young people aged 16-24 years (see also Chapter 4: Demography).

Table 5.1. The number (and percent of total population of local authority area) of children and young people in Cardiff and the Vale of Glamorgan, by age group, in 2020

	0-4 years	5-15 years	16-24 years
Cardiff	20,417 (6%)	47,578 (13%)	61,111 (17%)
Vale of Glamorgan	7,003 (5%)	17,914 (13%)	12,552 (9%)

Source: Stats Wales (8)

The Pupil Level Annual School Census (for children aged 5 – 15 years) from 2020/21 identifies 51% pupils as male, 49% female in both Cardiff and the Vale of Glamorgan, as per the Wales average (26). In Wales, 13% of children aged 5-15 years identify as from a Black, Asian, or minority ethnic group. This is 11% in Vale of Glamorgan; whereas Cardiff has a notably more diverse population with 36% from a Black, Asian, or minority ethnic group Cardiff (26) (note that the Annual Population Survey reports that 20% of the total population of Cardiff identify as from a Black, Asian, or minority ethnic group) (23).

Young carers

Young carers are children and young people under 18 years of age who provide care for someone else who has support needs, for example, due to a physical or mental health problem, a physical or learning disability, or substance misuse (27). Young adult carers are between the ages of 16 and 24. Their needs are considered in Chapter 15. The 2011 Census identified 1,579 young carers in Cardiff and the Vale of Glamorgan, but this is known to be an underestimation (28). The 2021 Census will provide updated figures when it is published in 2022. The YMCA Young Carers project supported 51 young carers in 2017/18, and 114 in 2020/21 in the Vale of Glamorgan (29). In Cardiff, the project supported 276 young carers in 2017/18, and 277 in 2020/21 (30). Of the 35 survey respondents, 11% (n=4) were young carers. Two reported caring for a sibling.

Across Wales, in 2018/19, 895 assessments of need for support for young carers were undertaken, of which 2 were in Cardiff, and 16 in the Vale of Glamorgan. This compares to 19 and 12 respectively in 2016/17 (31).

Engagement

Information for this chapter is taken from a range of reports and data sources. Thirty-five children and young people responded to the children and young people survey; and 30 respondents to the provider survey provided support for children and young people.

5.2 What has changed since 2017?

5.2.1 Pre-COVID-19

The following national initiatives have taken place since the 2017 PNA:

- The Children's Commissioner for Wales's report, No Wrong Door, in 2020 (32)
- The NEST Framework in 2021 (33) - more detail provided below
- The Additional Learning Needs and Educational Tribunal Act, which was launched in September 2021, and places the needs of children and young people at the centre of decisions for education through Individual Development Plans, and sets out the rights for appeal for decisions (34)

- The Integrated Care Fund (launched 2016/17) has changed remit over its course, enabling the funding of additional work streams (see details in relevant subthemes). The Transformation Fund (launched 2018) aimed to promote innovation; however, remaining funds have since been redirected to COVID-19 (32)

Regionally, the following have been implemented:

- Cardiff was the first city in Wales to develop the Child Friendly City Strategy in 2018. The UNICEF initiative includes the aims of empowering children and young people to understand their rights; and providing equality of opportunity and high-quality education (35). The Vale of Glamorgan Council supports the delivery of the Rights Ambassador programme which raises awareness of children's rights with children and young people across vale schools
- The Cardiff Children's Services Strategy (36) and the Vale of Glamorgan Children and Young People Services Service Plan (37)

5.2.1 COVID-19

The following themes were identified from the literature and engagement work as having been particularly impacted by COVID-19 or the restrictions, which were first introduced in March 2020.

Direct impacts of COVID-19

Between March 2020 to October 2021, 69 children and young people were admitted to hospital in Cardiff and Vale UHB with a primary diagnosis of COVID-19; of which 7 required high dependency or intensive care (38).

Long COVID describes the presence of symptoms four or more weeks after the original suspected COVID-19 infection, that were not explained by an alternative cause. Symptoms include weakness/tiredness, shortness of breath, and difficulty concentrating. The Office for National Statistics reports the numbers of people living in private households with self-reported long-COVID by age group, for the UK: 20,000 children aged 2-11 years are estimated to have long COVID, 49,000 children and young people aged 12-16 years, and 142,000 people aged 17-24 years (39). No data are available for long COVID at a local authority or health board level at this time.

Service changes due to COVID-19 and restrictions

The Paediatric Emergency Department saw a marked reduction in attendances (21,317 in 2020/21, compared to 34,900 in 2019/20). Reasons for attending the Emergency Department also changed with fewer accidents, but more thermal injuries/burns, likely reflective of spending more time in the home due to lockdown and restrictions (40).

Respondents to the provider survey articulated the increase in mental health needs, behaviours of concern, crisis presentations, and the need for respite. Providers reported changes in service provision, with closure of some services and switch to virtual provision where it was possible. Staff were concerned for future service provision, being unable to recover from backlog, increasing waiting lists, and funding difficulties.

Mental health impacts of COVID-19 restrictions

The pandemic response has had a significant negative impact on children and young people in Wales on mental health and well-being; with loneliness, isolation, and parental stress contributing (41). More Welsh children have been exposed to Violence Against Women, Domestic Abuse, and Sexual Violence (VAWDASV), reflected by increased calls to helplines (41). Welsh adolescents were found to be more vulnerable to the mental health impacts of pandemic restrictions than younger children or older adults; as were young people not in employment, education or training, and people from more deprived areas (41).

Regionally, there were increased attendances to the Paediatric Emergency Department for mental health disorders such as self-harm, suicidal ideation or attempt, eating disorders, and increased behaviours of concern which parents and carers could no longer manage at home (40). Increased attendances have put strain on specialist services such as CAMHS crisis teams (40). Figure 5.1 below shows the increase in admissions to hospital for an eating disorder amongst those aged 0-17 years (38). Note that these refer to admissions, not patients (there are 86 admissions in total between 2016/17 – 2020/21, corresponding to 51 patients).

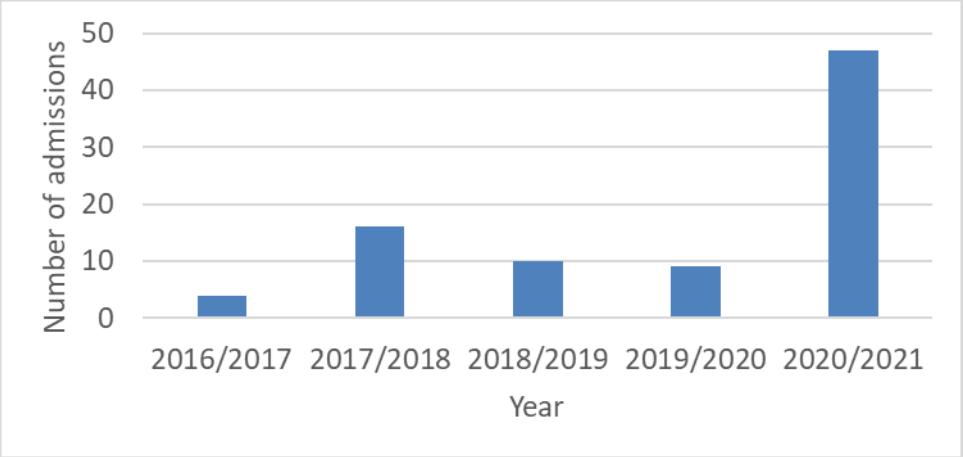


Figure 5.1. Number of inpatient admissions to Cardiff and Vale UHB with eating disorder, for people aged 0-17 years. Source: Cardiff and Vale UHB (38)

The Director of Public Health for Cardiff and the Vale UHB examines children and young people's mental health in detail in their 2021 annual report, with focus on the impact of COVID-19 (19). Supporting emotional well-being and mental health of children and young people is a key priority, with reference to the early years being a crucial period of development, and ACEs having a detrimental effect on adult mental health (19).

Overlapping and widening inequalities

The Health and Social Care in Wales update following COVID-19 identifies that often it is the same groups of children and young people who are negatively affected by policies implemented throughout the pandemic (25). Children who are most vulnerable include: children with additional learning needs; ethnic minority children; Welsh medium learners who do not speak Welsh at home; children who lack internet access; children with developmental delay; and children from deprived areas, especially those with no access to outdoor space (25).

The Children's Commissioner for Wales identified the impacts of lockdown and restrictions including: social impact of not seeing friends and family; interruption of education; increased exposure to violence at home (reflected by a 50% increase in calls to help lines) (42).

Exacerbation of educational needs

Interruption of schooling was identified in the Children's Commissioner for Wales' 'Coronavirus and Me' survey as a negative impact of COVID-19 restrictions. Negative consequences include the impact on learning and education on children and young people from more deprived areas, who already suffered worse educational outcomes. Lockdown and restrictions have widened these outcomes gaps. In this survey only 11% of 12-18 year-olds stated they were not worried about their education (42), with worries arising from the quality and unfamiliarity of the virtual learning environment and communication with teachers and schools (41). Challenges around home learning included digital access, the home environment, and additional learning needs (42). The importance of school for access to emotional health and well-being support was observed; alongside the role of schools in providing food and shelter, and promoting a sense of community and belonging (41). The financial impact on families of lockdown and restrictions has increased the number of children suffering food insecurity (43), at the same time as decreasing access to school meals. Survey respondents were also concerned about the impact on their education.

> ***"…isolating can mean missing out on important information in school which can reduce chances of getting a good grade" –*** young person, survey

Mitigating negative impacts and promoting positive impacts

In Wales, protective factors to mitigate the negative impacts of the coronavirus restrictions included routines, spending time outdoors, and understanding coronavirus and the mechanism of transmission (41). Some positive impacts of the COVID-19 pandemic were also identified including discovering and enjoying the outdoors; taking up new hobbies; spending more time with family; and reduction in pressure from social situations and bullying (41) (42).

5.3 What are the care and support needs?

The following areas were identified as care and support needs for children and young people, from literature and engagement work.

5.3.1 Individual

Young carers

The 2016 Cardiff and Vale of Glamorgan 'Young Carers Speak Out' report identified a lack of awareness of support available to young carers. Professional leads feel that this has now improved. A Young Carers Awareness Day was held in Cardiff and the Vale of Glamorgan in January 2020. The Young Carers in Schools Programme established a Peer Review Panel of

young carers across South East Wales, who review applications from schools applying for one of the three stages of the Young Carers in Schools Programme (28). Young carers have articulated needs with respect to mental health, wanting increased time for themselves to be a child or a young person, and support for their education.

Additional vulnerabilities

Unaccompanied asylum seeking children are considered in chapter 20. Some children may experience additional vulnerabilities if a parent or primary caregiver has experienced VAWDASV (see also chapter 17); is imprisoned (see also chapter 19); or has a substance misuse problem (see also chapter 18). These would all constitute an adverse childhood experience (ACE), which are associated with negative impacts across the life course (44).

Children and young people whose parent(s) are currently serving in the armed forces or have left military service (see also chapter 21) may experience both positive and negative impacts due to moving house, changing schools, making new friends and living abroad. However, negative impacts were identified around worry for their parent(s) whilst they were deployed, and missing their parent(s) (45).

Language and communication

English was an additional language in 17% of primary school pupils in Cardiff, 3% in the Vale of Glamorgan, and 6% across Wales in 2020/21 (26). In Cardiff, most (85%) of primary school pupils cannot speak Welsh, but 9% are fluent in Welsh. In the Vale of Glamorgan, 81% cannot speak Welsh, and 11% are fluent (46). The survey for this assessment asked what languages respondents spoke at home. Most spoke English (n=22, 85%); two spoke English using Augmentative and Alternative Communication (AAC) (8%); and one response was entered for each of Welsh, Gujarati, and Romanian.

In Wales, during COVID-19, most children in both Welsh and English-medium schools have been able to continue Welsh. In Welsh-medium schools, only 8% aged 7-11 and 15% aged 12-18 across Wales have not been continuing education in Welsh, and 31% of 7-11 year-olds and 26% of 12-18 year-olds in English-medium schools were not receiving opportunities to speak Welsh (42).

It is known that speech, language and communication difficulties in early childhood are associated with poor employment outcomes and poor mental health as adults, and are more common amongst young offenders, and those in areas of higher deprivation (47). Improving language development is one mechanism by which to reduce inequities, and break the intergenerational cycle of poor communication skills (48). The national prevalence of speech, language and communication difficulties is not known, however, the 2020 school census in Wales identified that 20% of children had special educational needs, of whom one third had speech, language, and communication difficulties (48). Welsh Government published 'Talk With Me: Speech, Language and Communication Delivery Plan' in 2020 (48). In Cardiff and the Vale, Speech and Language Therapists (SLTs) provide assessment, diagnosis and intervention to children and young people who have difficulties with speech, language, communication and swallowing difficulties. Services are provided in the family

home, nurseries and schools, and in healthcare settings. Support ranges from initiatives with Flying Start (a Welsh Government programme to improve outcomes amongst children under 4 years old living in disadvantaged areas in Wales (49)) which aims to prevent difficulties and to promote healthy eating habits, to multi-disciplinary specialist team support for families to manage the impact of complex and lifelong conditions such as deafness, learning disability and autism (38).

5.3.2 Community

There were 2,940 and 821 assessments of need for care and support undertaken in Cardiff and the Vale of Glamorgan respectively in 2018/19. This is an increase of 580 and 190, respectively, from 2016/17. Of these, in 2018/19, 352 assessments led to a care and support plan in Cardiff (data not available for the Vale of Glamorgan) (31).

Emotional health, mental health, and well-being

Primary Mental Health (PMH) service demand (for mild to moderate mental health concerns) has been found to be cyclical and tended to be associated with return to school after holiday periods. The Child and Adolescent Mental Health Service (CAMHS) attend to patients with more severe mental health concerns. Referrals follow a similar pattern to Primary Mental Health. The Crisis service sees patients presenting to the Emergency Department who require urgent care (38).

Figure 5.2 demonstrates the number of referrals to PMH, CAMHS, and Crisis since April 2019, and figure 5.3 shows the waiting list length.

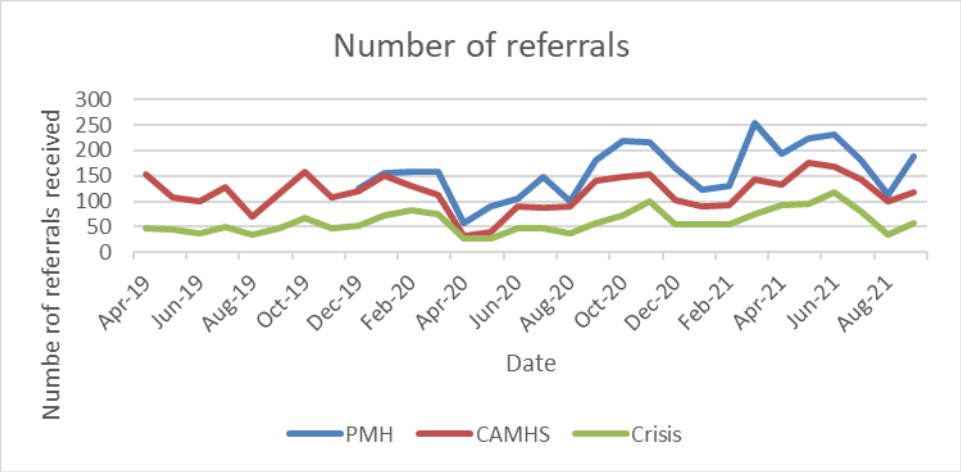


Figure 5.2. Number of referrals to Primary Mental Health, CAMHS, and Crisis Source: Cardiff and Vale UHB (38)

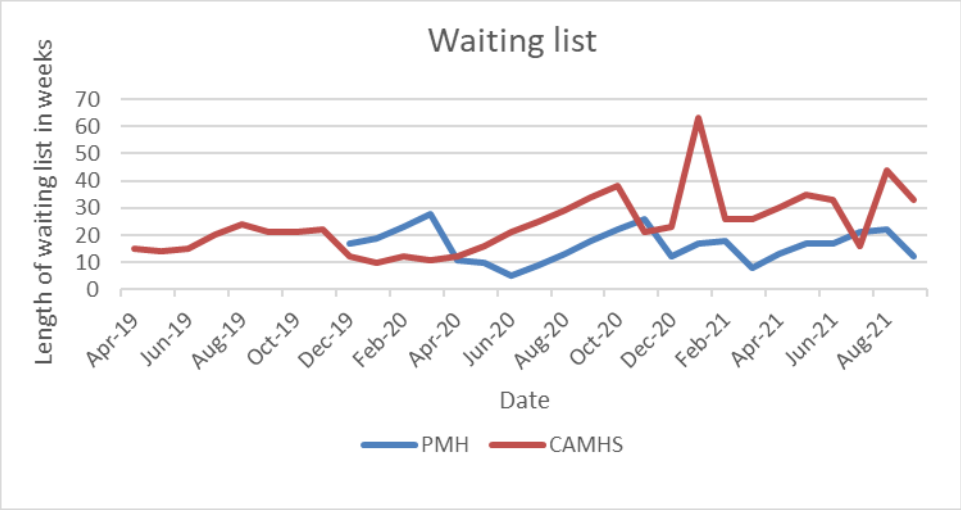


Figure 5.3. Waiting list length in weeks for PMH and CAMHS
Source: Cardiff and Vale UHB (38)

Amongst the 35 survey respondents, 12% rated their well-being as 3 or less out of 10, where 0 was the lowest and 10 the highest. Around half reported a score of 7+/10. The most commonly cited everyday problems experienced were emotional health (75% respondents); mental health (63% respondents); school (63%); and body image (45%). Two-thirds of survey respondents were worried for the future. Respondents were looking forward to taking part in sports/exercise; finishing college; gaining independence; getting a job and earning money; meeting new people and seeing new things; and "*being happy*". Six respondents wanted additional support to help them reach their goals, including help from family, and developing further skills from specialist teaching staff. Note that these survey results are not representative, but do support the importance of mental health and well-being.

County Lines

The Cardiff and Vale UHB Safeguarding Annual Report 2020/21 identifies County Lines as a national issue, particularly affecting the most vulnerable. Children and young people can be targeted and exploited through grooming and threats; intimidating young people into drug-related criminal activity, and associated violent behaviour such as knife crime. A multiagency approach including South Wales Police, Cardiff and Vale UHB, and education has been taken to provide training and raise awareness of when to suspect and how to manage this phenomenon (40). Chapter 19 has further information on youth justice.

5.3.3 Wider determinants of health

Deprivation

An evidence review of the human rights of children in Wales identified differential outcomes in health risk factors and outcomes, education, and wellbeing depending on socio-economic background (50). In terms of health, children aged 4-5 years in the most deprived decile were 76% more likely to be obese than those in the least deprived decile. Low birth weight and educational deprivation were also associated with income deprivation (51).

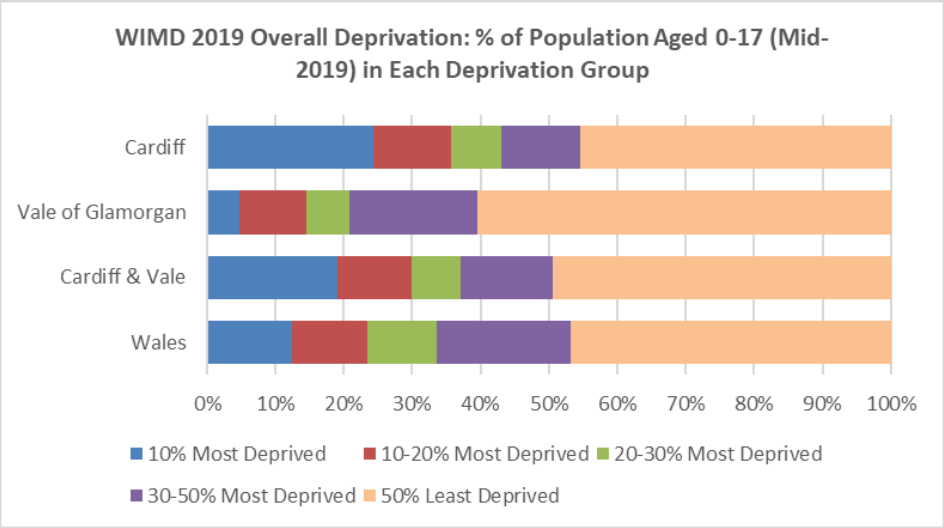


Figure 5.4. Proportion of the population AGED 0-17 within deprivation deciles, 2019

Source: Produced by Cardiff Council using Welsh Government data (22)

The most recent Welsh Index of Multiple Deprivation report uses 2016/17 data, and found that 28% of children in Wales aged 0-4 lived in income deprivation (range 17%-30%). This is the highest proportion by age group. Cardiff has the highest number of 0-4 year olds living in income deprivation (6,600 children) but sits just above the Welsh average at 29%; the Vale of Glamorgan has nearly 2,000 children in income deprivation (23%). Cardiff has both the most and least deprived middle super output areas in Wales, with income deprivation rates between 3% in Rhiwbina and Pantmawr, to 67% in Ely East amongst children aged 0-4 years. In both local authorities, this represents a decrease from 2012/13: where Cardiff had 33% and Vale of Glamorgan 27% of 0-4 year olds living in income deprivation (22).

Welsh Government published its review on socio-economic disadvantage and inequalities of outcome in November 2021, and identifies that the attainment gap is evident even in primary school. Disadvantaged children are less likely to complete qualifications, and have reduced education and financial outcomes compared to non-disadvantaged peers. This disadvantaged position is further exacerbated by housing inequalities, for example, through lack of suitable environment to complete homework. This is described as having a "cyclical" impact (52).

Twenty-six respondents of the survey answered questions relating to the Family Affluence Scale, also used by the School Health Research Network (53). Questions include whether the individual has their own bedroom; the number of computers/smart phones in the home; and the presence of a dishwasher. The Scale identified 7 of 26 respondents as low affluence, 14 as middle, and 5 as high affluence.

Free School Meals

One-fifth of school-age children in Wales in 2020 were eligible for free school meals, but amongst students with special educational needs, 45% were eligible (54). In the three years to 2021, 21% of primary school pupils in Wales were eligible for free school meals, with 15% in the Vale of Glamorgan and 25% in Cardiff (26). Three-quarters of those eligible, took up

free school meals. This is expected to increase with the end of the Government furlough scheme (54).

School exclusion rates are higher for those eligible for free school meals than those not eligible (50). Free school meals have been associated with improved nutrition, school attendance, and school achievements (43). The attainment gap in Cardiff between those eligible and not eligible for free school meals grows from 10% in Key Stage 2 to 31% in Key Stage 4 in 2018 (35). Across Wales in 2017/18, the percent of pupils achieving A*-C was consistently lower amongst those eligible for free school meals compared to those not eligible. For example, English 38% versus 70%; and 39% versus 71% in Maths (55).

Education and employment

Estimates from 2020 suggest between 9-11% of 16-18 year-olds across Wales are not in employment, education, or training (NEET) (56). Estimates for those aged 19-24 is 15%. This is the result of a gradual decrease in NEET for this age group following a peak of 23% in 2009-2012 due to the 2008 recession (56). Young people with disabilities, in particular those aged 19-24, are more likely to be NEET than those without disabilities. One fifth of disabled people are NEET at age 16-18; this is two-fifths at age 19-24 (56). No data at local authority level were available.

Of the 35 survey respondents, 66% were in school, 14% in college, 6% employed, 6% at university, and 3% were unemployed.

Housing

A notable proportion of the total number of households with dependent children accepted as eligible, unintentionally homeless and in priority need in Wales are in Cardiff: 420 of 864 households in 2016/17, and 363 of 1,005 households in 2018/19. The Vale of Glamorgan had 36 and 42 households respectively. No data were collected for 2019/20 due to COVID-19 (57).

There were similar trends in numbers of homeless households with dependent children in temporary accommodation: 354 in Cardiff (Wales total 780) in 2016/17, rising to 366 (Wales total 849) by 2019/20. In the Vale of Glamorgan, these values were 27 and 39 respectively (57).

Housing services in the Vale of Glamorgan have supported 198 young people (aged 16-24) who are homeless or at risk of homelessness in the preceding 12 months. Support includes managing a tenancy, budgeting skills, domestic skills, moving to more appropriate accommodation, reducing isolation, and signposting (58). In 2020/21, Cardiff Council's Young Person Gateway has provided accommodation and support for 162 young people. This includes accommodation within the Gateway alongside support in areas such as mental health, access to education, employment, and independent living skills. The tenancy training pathway has seen 70 young people positively move on into social housing with all continuing to maintain this accommodation. Llamau, in partnership with Cardiff Council, have worked with 76 young people to provide mediation in order to prevent homelessness

and allow young people, where safe and suitable to do so, to maintain their current accommodation (30).

5.3.4 Unmet needs

Survey respondents articulated concerns for the following, suggesting a need for further guidance and support. Note the small sample size of 35, which is not representative of the population of children and young people.

- Health worries: anxiety around a medical diagnosis, or recurrence of mental health problems
- Failure: not achieving exam success and the consequences; financial insecurity; "*not achieving my dreams*"
- The COVID-19 pandemic and the climate crisis

Gaps in knowledge and understanding stem from gaps in locally-available data as well as evolving and emerging events on a local and wider scale. These include:

- The number and characterisation of young carers – results from the 2021 Census are awaited
- Associations of socio-economic status and care needs
- Bullying in schools, and associated characteristics, such as protected characteristics
- Accompanied and unaccompanied asylum seeking and refugee children, and associated outcomes in terms of health and education/employment
- Emerging impacts of COVID-19, lockdown and restrictions including long COVID

5. 4 What are the range and level of services needed?

5.4.1 Prevention and assets

Healthy behaviours

The School Health Research Network survey reports the following amongst secondary school pupils in Cardiff and the Vale of Glamorgan:

- 2% of male and female respondents report smoking tobacco at least weekly
- 18% of males and 16% of females report ever trying e-cigarettes; with 2% using them at least weekly
- 7% of males and 5% of females have ever used cannabis
- 10% of males and 5% of females have spent their own money on gambling (53)

The National Child Measurement Programme data 2018/19 demonstrates that most children aged 4-5 are of a healthy weight (80% in the Vale of Glamorgan; 76% in Cardiff). In Cardiff, 13% are overweight, and 11% are obese. For the Vale of Glamorgan, the figures are 9% and 9% respectively. Compared to 2011/12, this represents a higher proportion of children being a healthy weight. At a national level, there is an increase in proportions of children being overweight and obese with increasing deprivation. The fifth of children who are least deprived have the highest proportion of children who are a healthy weight (59).

Reduction and mitigation of Adverse Childhood Experiences

ACEs comprise abuse, neglect, and household dysfunction (including parental substance misuse, violence, or separation), which have been associated with a variety of adverse

outcomes across the life course, such as poorer health and wellbeing, worse educational attainment, and increased risk of incarceration (44) (60). Half of adults in Wales have had at least one ACE. One quarter of 49-year old adults with four or more ACEs have at least one chronic disease, compared to 7% of those with no ACEs (44).

ACEs can be intergenerational. Protective factors have also been identified, which mitigate or attenuate the association with ACEs. This means that there is opportunity to intervene within an early intervention approach to support children and their parents, or through taking an ACE-informed approach. Pilot routine "ACE enquiry" in three areas in Wales found high levels of first disclosure of ACEs (over 40% of caregivers) (60). Welsh Government have prioritised ACEs in its programmes (44).

Vaccination

Public Health Wales data demonstrate that decreasing vaccine uptake of the 6 in 1 vaccine by 1 year of age in Cardiff, is currently below the 95% target. The Vale of Glamorgan is just above the target. Data on children receiving the first MMR dose by 2 years, two MMR doses by 5 years, and the pre-school booster by 5 years show that both Cardiff and the Vale of Glamorgan are below the set target for 2019/20 (61).

Analysis by Public Health Wales shows that socioeconomic inequalities are associated with smaller differences in uptake in younger children, with bigger uptake differences in teenagers in Wales (62).

Assets to support well-being

Amongst survey respondents, the most common source of support was a parent/guardian, with 83.3% of respondents having received help from them. More than half of those surveyed received support from friends (59%), school teachers (57%), or a GP (53%). Other sources of support included youth centre/youth workers, social worker, third sector, and online support, local clubs and groups, sports clubs, and social media.

Professional leads identified the Join the Dots service by Cardiff and Vale Action for Mental Health (CAVAMH) which supports children and young people to have an input into services.

Support available for young carers include the following:

- The Primary Mental Health team provides support for young carers and their families for anxiety, depression, stress, and relationship difficulties (27)
- Meic Cymru provides information, advice and advocacy (27)
- Action for Children work with young carers known to Children's Services; offer respite, and work to increase confidence and respond positively to challenges (27)
- Local authority support: in Cardiff, the Cardiff Family Gateway, and in the Vale of Glamorgan, Families First Advice Live provide information and signposting (27)
- The YMCA run Time 4 Me for young carers provides peer support (27)

5.4.2 Community services

Whole school emotional health

Advocated by the Together for Children and Young People 2 (T4CYP 2) programme, a whole school approach facilitates universal services and promotes joined up working (63). Welsh Government has published a framework on how to embed this approach to promote emotional and mental wellbeing (64). The 2021 annual report for the Director of Public Health in Cardiff and Vale UHB identifies that the education sector is well-placed for support provision, but recognises that local and national partners also have a key role, for example, through building resilience and positive behaviours (19).

Sustainable services

Professional leads identified that financial security for services is needed in order to maintain and build upon positive outcomes achieved so far.

5.4.3 Partnership approach

Person, not service, centred services

Professional stakeholders have articulated the need for services to join up, and provide holistic support that is seamless between services. Stakeholders for this report have identified that not all children and young people who have care and support needs will have a specified diagnosis. Services must be able to respond and support all children and young people based on their needs within universal services.

Figure 1 NEST diagram showing key areas, stakeholders and themes around early support and prevention.

The NEST (Nurturing, Empowering, Safe, Trusted) Framework promotes a person-centred, values-led, integrated whole system approach; supporting early help, the right help, and at the right time with the aim of improved mental health and emotional wellbeing (33). Collaboration across services including public and third sector will facilitate whole system approach and provide inclusive services for all those who may need them, rather than specialist interventions for specific groups. (3)

Figure 5.5. The NEST Framework (3)

In line with NEST, the No Wrong Door approach brings together services and asks services to wrap around children, young people, and their families, rather than asking those in need of care and support to understand a complex system (32).

A focus group respondent wanted a service priority to be: *"uncomplicating things*".

5.5 What is likely to happen in the future

The number of children aged 0-15 is projected to decrease in Cardiff by from 67,945 to 64,352 between 2020 and 2040, and increase slightly in the Vale of Glamorgan by from 25,000 to 25,207 between 2020 and 2040 (10). However, as a proportion, young people aged 15 and under were 18.5% of the population of Cardiff in 2020, and are estimated to make up 16.6% in 2040. For the Vale of Glamorgan, these values were 18.7% in 2020, and 17.2% in 2040. The absolute number of young people aged 0-15 in Wales will decrease in the same time period, as will the proportion of the total population – from 17.9% in 2020, to 15.9% in 2040 (10). Note that projections should be interpreted with caution as they are based on historical trends.

COVID-19 and the restrictions placed on children and young people will have direct and indirect impacts on children and young people's health for some time to come; this has been considered in the Welsh Government update on Health and Social Care (25). Public Health Wales is researching the impact of COVID-19 combined with Brexit and climate change, called the "triple challenge", which will have wide ranging, dynamic, and synergistic impacts across the wider determinants of health for children and young people (65).

5.6 Recommendations

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Adopt the NEST Framework and No Wrong Door approach
- Strengthen actions to ensure information is accessible to children and young people; and they are invited to co-produce services so they are person-centred, and help children and young people feel valued
- Monitor emerging literature on long COVID in children and young people

Cardiff and Vale University Health Board to:

- Continue to promote preventative strategies including routine immunisations
- Continue to develop partnerships with Education services and embed the whole school approach to emotional health and wellbeing
- Increase funding available to mental health services for children and young people (25)
- Target waiting list times, especially for children and young people's mental health services
- Develop Integrated Model for Emotional Health and Well-being for Cardiff and Vale

6. Children and Young People with Complex Needs

This chapter should be read in conjunction with the following chapters: Children and Young People; Children Looked After; Healthy Lifestyles and Long Term Conditions; Physical Disability; Learning Disability; Autism; Adult Unpaid Carers; Sensory Loss and Impairment; VAWDASV; Asylum Seekers and Refugees; Secure Estate

Recommendations

Cardiff and Vale University Health Board, Cardiff and the Vale of Glamorgan Local Authorities, education providers, and third sector to:

- Promote universal and targeted early intervention and preventative services including parental support
- Undertake training to increase awareness and promote services accessible and comfortable for children and young people with neurodevelopmental disorders
- Work to ensure the T4CYP 2 programme is fully embedded

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Share good practice and learning
- Address data gaps
- Address gaps in service provision
- Promote early help and preventative approaches in line with T4CYP 2
- Embed the NEST framework and No Wrong Door approach
- Address the increasing waiting list for assessment

Regional Partnership Board to:

- Lead on development and implementation of an integrated model for children and young people's emotional health and wellbeing

6.1 Overview

Children and young people with complex needs includes those with disabilities and/or illness; those who are care experienced; those in need of care and support; those at risk of being looked after; and those with emotional behavioural needs (3). It should be stressed that the term "*complex needs*" refers to the fact the *service provision required* is complex, and not the child or young person (32). This updated definition places additional focus on emotional health and well-being.

Children and young people with symptoms of autistic spectrum disorder, attention deficit and hyperactivity disorder (ADHD), or other conditions may be referred to neurodevelopmental assessment services for diagnosis. The neurodevelopment service in Cardiff and Vale University Health Board provides multidisciplinary assessment, intervention, information and support for patients and their families (66). For those who have received a diagnosis, post-diagnostic support may include multidisciplinary therapeutic interventions which best meet the child's needs (3). They provide support for the child or young person, as well as their families or carers. Inclusive support services are being developed so that children or young people who require support but do not have a diagnosis, and their families, are still able to receive the help they need.

The Cardiff Index, launched in 2016, has 784 children and young people registered, of which 5% are aged between 4-11 years; and 13.5% have social services involvement. Of those registered, the majority are registered for autism (n=250); developmental delay (n=136); and behaviour/emotional difficulties (n=118). These figures represent a large increase from 2017, when only 90 were registered (67). The Index in the Vale of Glamorgan has 823 children and young people registered; with 64 new registrations in the year 2020/21 and 27 children and young people deregistered for various reasons including becoming 18 (68). Over half (56%) live in Barry (45% in 2017). As per Cardiff, Autistic Spectrum Disorder is the primary reason for registration (36%); however, half of registrants have behavioural/emotional difficulties (69).

Engagement for this chapter comprises of eight parents of children living with cerebral palsy (aged 8-11 years) from a focus group discussion. Their views will not be representative of all children and young people, and their parents, guardians, or carers, but do provide lived experience which complements other data sources.

6. 2 What has changed since 2017?

6.2.1 Pre-COVID-19

The Integrated Care Fund, launched in 2014/15, released funds for children and adults with complex needs and children with learning disabilities in 2016/17, bringing the Integrated Autism Service within remit (32). The Integrated Autism Service was launched in 2017 and provides assessment and diagnosis for adults for learning disability and autism; and provides support to services users, their families and carers, and professionals (70).

Since the 2017 Population Needs Assessment, the Autistic Spectrum Disorder Updated Delivery Plan 2018-2021 has been published (71), as well as the Code of Practice on the Delivery of Autism Services 2021 (72). The Code sets out the range of support services for assessment, diagnosis, health and social care and broader work around training and awareness ranging.

The Together for Children and Young People (T4CYP) 2 Neurodevelopment Support agenda sets out a vision for services, implements pathways and standards, and works to improve outcomes and support for children and their families. It took over from the original T4CYP

programme which ran from 2015-2019 (63). The programme supports the Additional Learning Needs Act (34).

6.2.1 COVID-19

Welsh Government published it's report 'Locked Out: liberating disabled people's lives and rights in Wales beyond COVID-19' in 2021, which describes the impact of COVID-19 lockdown and restrictions on disabled people in Wales (73) (please see also Chapter 10). An intersectionality reference group, which included young people with disabilities in care, for the Locked Out report on people with disabilities and COVID-19 in Wales identified that young people were "*falling through the gaps*" in provision (73). This is echoed by the Care Quality Commission in England who document the impact of service disruption due to COVID-19 on children and young people, including the need to prevent gaps in care provision. Transition to adult services were identified as a priority area (74).

In addition, the Care Quality Commission described how the COVID-19 restrictions have placed strain on care and support providers, as well as children, young people and their families and carers as described throughout this report. Mitigating the negative impacts of service disruption (such as the pause in face to face services and the switch to virtual modalities) must be a priority. This should include care where it is needed to prevent placement breakdown (74).

6.3 What are the care and support needs?

6.3.1 Individual

Supporting independence

Welsh Government report that some disabled children and young people feel unable to use public transport on their own, instead relying on parents (75). Travel training for young disabled people may help increase independence (75).

Young people wish to have a voice in decision making locally as well as at a wider level. Vale Youth Speak Up enable young disabled people, aged 16-25, to participate in discussions and influence decisions, for example, around discrimination and bullying (75). The Children in Wales Getting More Involved in Social Care project enables disabled young people to provide training for peers and professionals, which increases knowledge of children's rights, and increases involvement in decisions (75).

A focus group with parents of children with cerebral palsy wanted their parent voice to be better heard, and to be more included within the decision making process.

Language and communication

The Vale of Glamorgan Index reports that 51% of registrants have communication and socialisation difficulties; and 39% have speech and language difficulties. In terms of methods of communication, 7% use Picture Exchange Communication Systems (PECS) and 3% use Makaton (68). The Cardiff Index reports that 5% of those registered have speech and language difficulties, and 4% communication and socialisation difficulties as their primary reason for registration (67). [Further data from Cardiff on communication needs pending]

Welsh Government has published a Welsh language impact assessment on the Code of Practice for the Delivery of Autism services (76).

6.3.2 Community

Access to assessment, care, and support

The Neurodevelopmental team conducts assessments for children and young people who require them (adults are assessed by the Integrated Autism Service). Figure 6.1 shows the number of referrals to the Cardiff and Vale Neurodevelopmental team since March 2020 (referrals prior to this date were in the range of 43 – 183 per month). Of note, is the increasing waiting list in terms of volume, but also the duration of waiting list from 58 weeks in March 2020, to 129 weeks in September 2021 (77).

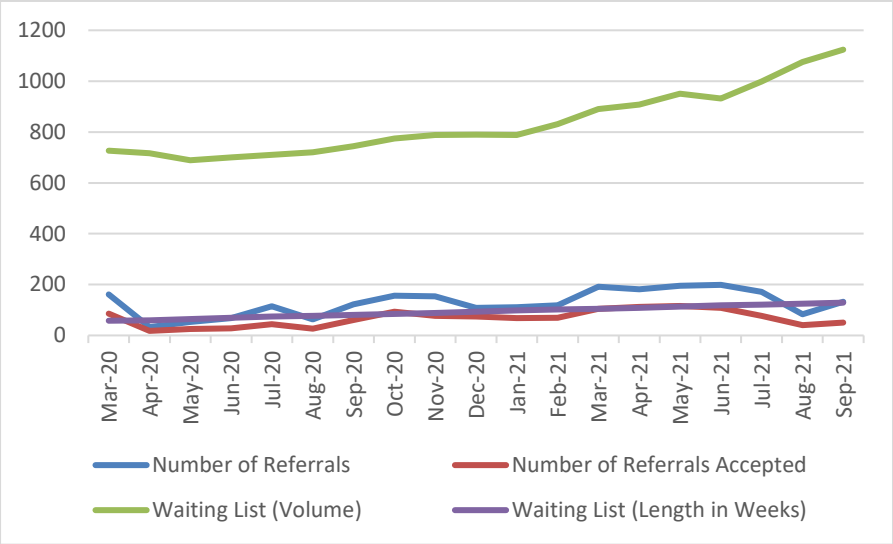


Figure 6.1. Referrals to the Neurodevelopmental Team, and waiting list measures (77)

People with learning difficulties across Wales have reported difficulties with the short health care appointment length, stating that they would like more time in order to understand the discussion (75).

Some specialist health services have been difficult to access by young disabled people, such as sexual health. In addition, Welsh Government report that despite being more likely to have additional healthcare needs such as poor mental health, they are unable to access services until the situation is more severe, such as at crisis point (75).

Post-diagnostic support

The Neurodevelopment team provide support through different mechanisms including referrals to Primary Mental Health; CAMHS; the Emotional Wellbeing Service; or to Families First and Cardiff Family Advice & Support. The Integrated Autism Service (IAS) does not work directly with children, instead working with their parents or carers to indirectly support the child. During 2020/21, 15 parents or carers were supported by IAS. Of the 585 new referrals received, 22 were from people aged 16-17, and 173 by those aged 18-25 (note that referrals are for a range of services and not just assessment) (77). Support provided by the IAS includes: advice on managing sleep difficulties; assessments and strategies to manage

triggers of behaviour that challenges; support transitions to adult services; training and support groups. In addition, services can be provided in conjunction with CAMHS or the learning disabilities team (77).

Transition of care from children's to adult services

The aim of transition is to promote independence in a safe and supported manner – for both the young person, and their parent or primary carer, who may struggle with the change in relationship, according to Welsh Government (75). A consultation in Cardiff and Vale for the regional joint commissioning strategy for adults with learning disabilities identified transition from child to adult services as a priority; and anticipated that between 2018/19 and 2020/21, approximately 19 people with learning disability would transition each year in Cardiff, and 9 in the Vale of Glamorgan (78). In the Vale of Glamorgan for the years 2016 and 2017 combined, 24 young people were assessed in the year they turned 18, of whom 22 had eligible care and support needs requiring input from the Adult Learning Disability Team. In 2020, 12 were assessed and 9 eligible for input from the Adult Learning Disability Team (29). In Cardiff, in 2020/21, of the 36 young people known to the Child Health and Disability Team, 33 transitioned to the Adult Learning Disability Team. In 2018/19, the figures were 25 and 20 respectively (30).

However, transition remains a challenge for many in Wales, citing lack of awareness of sources of support, inadequate signposting, and barriers to access. The role of parents as carers also changes as young people gain their independence, which can add stress to the relationship (75). Members of a professional workshop held in Cardiff and the Vale UHB stated families are often in limbo whilst they are transferring between services and transitioning to adult services (79).

The Multi Agency Transition Review Interface Group is a forum to discuss the needs, outcomes and resources required for young people in the 15-18 year old age group who have, or may have a need for care and support into adulthood. This forum runs in both Local Authorities and informs both individual and strategic planning (80).

Both Cardiff and the Vale have developed a support planning service, which comprises a person-centred assessment with people known to the teams to consider options for day opportunities. The specialist service focuses on opportunities to gain skills, enhance networks and inclusion within local communities. Both councils also have employment support for those who are interested in paid work. As with all service areas, this has been impacted by the COVID-19 pandemic but work is restarting to widen access to community options (29) (30).

6.3.3 Wider determinants of health

Deprivation

No local data are available relating to children and young people with complex needs. A reduction in Direct Payments has been experienced by recipients in Wales; therefore decreasing access to finance and increasing isolation with reduced well-being (75). In

contrast, Disabled Students' Allowance has improved equity of access to higher education (75).

Support provided by the IAS includes guidance on benefits and employment. The Code of Practice on the Delivery of Autism Services asks employers to promote inclusion of autistic people (76). Increasing awareness of inclusive recruitment will enable more autistic people to gain higher quality jobs.

Education and employment

Data from the Pupil Level Annual School Census demonstrate that the proportion of pupils aged 5-15 years with special educational needs is lower in the Vale of Glamorgan, and higher in Cardiff, than the Wales average. In Cardiff, 2.7% of pupils aged 5-15 years have a Statement of Special Educational Needs, compared to 0.6% in the Vale of Glamorgan, and 2% in Wales (26). In Cardiff, there were 9446 pupils with special educational needs in 2020/21, of whom 2,143 had a Statement (1639 in 2016/17). In the Vale of Glamorgan, there were 3,213 pupils with special educational needs, of which 439 pupils have a Statement of Special Educational Needs (378 in 2016/17) (81).

Welsh Government reports that many people still incorrectly assume that young disabled people are unable or unwilling to learn (75). This report calls for those in Education services to inspire young disabled people and aim for aspirational goals. They state that children with hearing or sight loss should be supported to feel confident traveling to and around school. Mainstreaming children with disabilities from an early age was proposed to increase acceptance, and could be supported by the establishment of inclusivity league tables (75). Welsh parents reported physical barriers affecting school experience (eg, steps in classroom), and were concerned regarding the transition from primary to secondary school.

Bullying is reported as a serious concern in both mainstream and additional learning needs schools, and further action is needed to address this in many schools in Wales (75). Three primary schools in Cardiff and the Vale of Glamorgan have undertaken Learning with Autism training between 2017 and 2018 (corresponding to 127 staff members), which helps staff adapt their communications and the learning environment to the needs of the child (82).

Supporting progression into employment or further education is beneficial for establishing and developing social relationships, supporting well-being (75). Welsh Government report that young disabled people want to access work, and should help co-produce pathways to employment. Those leaving education should therefore be signposted to specialist disability employment support (75).

Housing

The Cardiff Local Housing Strategy identified that demand outstripped availability for accessible homes of which many applicants had children with disabilities within the household (83). Children and young people with physical disabilities have experienced difficulties finding housing that meets their needs, and this is especially so in the private rented sector in Wales (75). Similarly, in the Vale, demand outstrips supply for accessible

homes. During the last two years the Vale's Council Housing New Build programme has increased the supply of purpose built adapted bungalows and flats. Within the Vale of Glamorgan Housing Strategy, there is a requirement for at least two adapted homes on new social housing grant funded developments. An Accessible Housing Panel was introduced in autumn 2020 in the Vale of Glamorgan, which considers each property on its suitability for the individual applicant, and conducts any necessary adaptations (29).

Some children require residential and specialist care, however, a priority should be prevention of the need for unnecessarily high levels of care, as such placements are more difficult to find, and are more likely out of area. Improving local health team resources to support positive behaviours and provide family-centred support would work towards this aim.

Social Care Wales report data on the number of placements and type for young people with learning disability. The total number of placements in Wales has decreased between 2015 and 2019 (2,842 to 2,342), but has increased in both the Vale of Glamorgan (68 to 108) and Cardiff (227 to 236). Most placements are in the community with their parents or family, with a minority placed in foster homes (6 in Vale of Glamorgan, 9 in Cardiff in 2019) (84).

In Cardiff and Vale of Glamorgan, some children and young people have experienced family placement breakdown due to needs arising from their neurodevelopmental disorder. This presents a challenge for local authorities who need to arrange placement at short notice, and may result in out of area placement. Early intervention can help reduce this risk (85).

6.3.4 Unmet needs

Engagement work identified the following as gaps in care and support:

- Children and young people without a diagnosis are missing out on care and support services
- Service provision: a lack of joined up care causes distress as children young people (and their parents or guardians) are moved between services; this is in part due to different IT systems and different uses of language between different services. In addition, difficulties were encountered with long durations until a diagnosis is reached; and a need for increased mental health support and opportunities for multidisciplinary appointments
- Support: a need for more peer support, and that this could be met by being mentored by another family to share lived experience. Support for the whole family was also identified
- More specialist sports opportunities and youth service provision

Gaps in our knowledge and understanding were identified as follows:

- The number and needs of children and young people who have care and support needs but do not fit an established pathway
- The number and needs of young people transitioning to adult services
- Socio-economic characteristics and Welsh language profile of children and young people undergoing neurodevelopmental assessment

6. 4 What are the range and level of services needed?

6.4.1 Prevention and assets

Early help

Early Help and Enhanced Support are a key pillar of the Together for Children and Young People 2 (T4CYP 2) programme (63). This stipulates a whole system approach. Early support for mental health concerns may help to avoid a crisis. Early Help services have recently experienced high levels of demand. Cardiff Family Gateway managed 12,359 calls and emails between November 2019 and November 2020; and supported 8,696 people. Cardiff Parenting received 686 referrals during the same time period, with 265 one-to-one psychology led parenting interventions (79). The Families First Advice Line in the Vale of Glamorgan provide Early Help, and received 1626 calls during the same time period (1013 were from professionals and 582 from parents or carers) (29). Of the total calls, the Families First Advice Line referred 340 to the Vale Parenting Service (29).

In Cardiff and Vale of Glamorgan, early identification and management of behaviours of concern could prevent ongoing difficulties into adulthood, which may reduce the risk of other complications such as contact with the criminal justice system, substance misuse, or mental health issues (86). Early intervention can additionally prevent placement breakdown, as well as being less costly. Regional mechanisms by which to provide this early intervention include development of life skills, parental support, and improving transitions of care (85).

Assets to support well-being

Professional workshops as part of the development of the integrated model for emotional health and wellbeing identified information provision for families, as well as services and programmes such as Flying Start, Family Gateway, Families First, Cardiff Parenting, Cardiff Family Advice & Support as supportive to the well-being of children, young people, and their families and carers.

Parents of children with cerebral palsy identified third sector organisations such as Cerebral Palsy Cymru and Shine Charity as assets, for their in-depth knowledge and advice. In addition, groups and coffee mornings with other parents of children with complex needs, to share lived experiences were helpful. Social services and social workers were also valued.

> ***"…one [social worker] in particular has been superb"*** – service user, focus group

> ***"…without [Cerebral Palsy Cymru] being there we would feel really lost" –*** service user, focus group

Other sources of support include Autism Wales, who provide resources for parents and carers, information on a wide range of topics including banks and dentists. Both Cardiff and the Vale of Glamorgan have outreach teams to support children in school. Both areas have a voluntary Index which offers support for children and young people and their families and carers.

6.4.2 Community services

Inclusive services considerate of the individual in their own context

Services need to be inclusive, accounting for the child or young person's communication needs (for example, use of Augmented and Alternative Communication (AAC) or language preferences), as well as access (79).

Services should include care and support tailored to the needs of children and young people as well as the family and carers, so that they can then care for the child or young person (79). Inclusivity of parents and carers should be a focus also, as men are underrepresented. This includes respite for families and carers, which is accessible and available in a timely manner, and provision of "wrap around" support in line with 'No Wrong Door' and NEST (79).

Care and support services must be timely, and considerate of the notion that some children and young people may need multiple sources of care and support, each with their own waiting list. Change in demand should be anticipated and services planned to meet this.

Services close to home, including accommodation

Services must be provided close to home. The Welsh Government White Paper 'Rebalancing Care and Support' notes that children are often placed far from home, which is more costly and increases strain and stress on families as well as children and young people (87). Sufficient accommodation should be available locally for children and young people; this should include a range of options to appropriately meet the needs of the individual.

6.4.3 Partnership approach

Integrated, whole system approach

Service providers (including third sector) should be aware of other services available and how to access them, in order to build resilience within the system, and improve signposting (79). This is championed by the No Wrong Door report (32) (87). This approach should streamline access and improve communication between providers, so information is not lost between services, and families do not need to repeat themselves. Variation in referral mechanisms and documentation used between services should additionally be streamlined with better collaborative working (79). The Complex Needs Service is trialling delivering a fully joined up health and social care service for children and young people with complex needs (85).

Engagement work identified that parents wanted a central point for information, for example, through a care coordinator: parents of children and young people with complex needs have experienced long waits for appointments, and a need to be proactive in order to arrange annual reviews. A "*road map*" of support available, and upcoming appointments may help with this.

Transition of care from children's to adult services

'No Wrong Door' reports that children and young people with learning disability experience a stressful period of transition to adult services (32). The T4CYP 2 programme includes

transitions as a core component within its Early Help and Enhanced Support work stream (63). Care and support provision should continue seamlessly through this period of transition, and focus on what matters to the individual. Cardiff and Vale RPB is developing a regional protocol for transition of young people with learning disabilities.

6.5 What is likely to happen in the future?

As the number of children and young people increases in Cardiff and the Vale, it is predicted that the number of children and young people with complex needs will change accordingly. Population projections suggest that the numbers of children with moderate, profound and multiple, or severe learning disabilities are likely to remain fairly similar over the next 20 years (88). In Cardiff, the number of children with learning disability is predicted to decrease from 3,027 in 2020 to 2,907 in 2040; in the Vale of Glamorgan a slight increase from 1,124 to 1,149 is predicted (88), likely reflective of the decrease in under 18 population predicted in Cardiff between 2018 and 2040 (89). Social Care Wales have predicted relatively stable numbers of children and young people with autism between 2020 and 2040 (1,370 to 1,316 in Cardiff; 509 to 520 in Vale of Glamorgan) (88). However, these figures are based on prevalence data. Neurodevelopmental services are currently recording increased referrals, waiting list times, and numbers of diagnoses of autism and anticipate this may lead to increased numbers of autistic children and young people in future (77).

In line with wider demographic changes, the population of people with learning disability is ageing. In addition, people with learning disability have increased likelihood of development of other comorbidities such as dementia (78) (90).

There is work ongoing for the development of an integrated Infant, Children & Young People's Emotional Wellbeing & Mental Health Needs model for the Cardiff & Vale Regional Partnership Board. The model aims to bring together examples of best practice and make use of local assets to provide universal, targeted and specialist services in an accessible and equitable way (79).

The Additional Learning Needs code will introduce some changes, for example, that some services may continue until age 25 (91).

6.6 Recommendations

Cardiff and Vale University Health Board, Cardiff and the Vale of Glamorgan Local Authorities, education providers, and third sector to:

- Promote universal and targeted early intervention and preventative services including parental support
- Undertake training to increase awareness and promote services accessible and comfortable for children and young people with neurodevelopmental disorders
- Work to ensure the T4CYP 2 programme is fully embedded

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Share good practice and learning

- Address data gaps
- Address gaps in service provision
- Promote early help and preventative approaches in line with T4CYP 2
- Embed the NEST framework and No Wrong Door approach
- Address the increasing waiting list for assessment

Regional Partnership Board to:

- Lead on development and implementation of an integrated model for children and young people's emotional health and wellbeing

7. Children Looked After

This chapter should be read in conjunction with the following chapters: Children and Young People; Children and Young People with Complex Needs; Healthy Lifestyles and Long Term Conditions; VAWDASV; Asylum Seekers and Refugees; Substance Misuse; Secure Estate

Recommendations

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to foster a culture whereby children looked after feel valued and listened to; are informed of choices available to them; and can influence decisions about their care
- Promote a preventative approach to prevent needs arising or escalating
- Ensure that children looked after have timely access to health and education services that they need, in order to meet statutory education requirements, close the inequalities gap, and promote their well-being (92)
- Develop of an integrated working model to promote seamless transition between services, including actions to be taken when children go missing from care, and interaction with the criminal justice system (92)

Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop additional placements close to home for children and young people
- Orientate services to be person-centred, building trust and rapport with children and young people, promoting a sense of value through co-production

7.1 Overview

Looked after children are children who are in the care of their local authority, or in receipt of accommodation from social services. They form part of the wider umbrella of children receiving care and support, which also includes child protection cases, and children or parents receiving support due to the child's illness or disability (93). Although looked after children (LAC) is the statutory term, the acronym in particular has been noted to invoke connotations of the child "*lacking*", therefore often the term "*children looked after*" (CLA) is used (93).

Data from 2018 identifies the following parental factors amongst CLA: mental ill-health (37%); substance misuse (36% of CLA); domestic abuse (29%); physical ill-health (12%) (94). See also chapter 18 (substance misuse). The Cardiff Youth Justice Health Needs Assessment

identifies that CLA are overrepresented in the youth justice system (95) (see also chapter 19: Secure Estate).

Information for this chapter is taken from various data sources, including a focus group with three children looked after. Twenty-three respondents to the provider survey worked with children looked after and 21 worked with care leavers aged under 24. These findings are not representative of all children looked after.

7. 2 What has changed since 2017?

7.2.1 Pre-COVID-19

The Integrated Care Fund made significant funding available for children at risk of being looked after, in care, or adopted in 2018/19 and 2019/20 (32). Cardiff published their Multi Agency Corporate Parenting Strategy 2021-2024 to describe how the council will fulfil their parenting responsibilities when the child or young person enters the local authority's care (96). The Vale of Glamorgan have published their corporate strategy for children who need care and support 2019-2023, which has early partnership working with families as a core component, to support families to stay together, amongst other objectives (97).

Both Cardiff and the Vale of Glamorgan have experienced large increases with 305 (+47%) and 75 (+41%) additional CLA respectively, compared to Wales with 1,560 additional CLA (+28%) between 2015 and 2020 (98). The number of children on the child protection register has decreased in the Vale of Glamorgan (95 in 2016/17; 65 in 2018/19) and decreased in Cardiff (190 and 185 respectively) (99). The majority of children in Cardiff in 2018/19 were on the child protection register for emotional abuse (46%), followed by neglect (30%), physical abuse (22%), and sexual abuse (3%). This follows the same pattern as the total for Wales. In the Vale of Glamorgan, the highest proportion of children were on the register for neglect (46%), followed by emotional abuse (38%) (99). Nationally, abuse and neglect cases have increased but this is thought to be due to better reporting (50).

7.2.1 COVID-19

Due to COVID-19 restrictions, young people in the focus group reported feeling isolated and needing to support each other. They were unable to see grandparents; contacts were cancelled; and one "*stayed in [their] room for the whole time*". One moved from the Vale of Glamorgan to Cardiff and didn't know anybody, which they felt impacted their confidence and mental health.

7.3 What are the care and support needs?

7.3.1 Individual

Autonomy and guidance

All focus group participants agreed with the National Outcomes Framework statement: "*I speak for myself and contribute to the decisions that affect my life, or have someone who can do it for me*". However, later, one participant stated they *"[don't] feel relevant – just another number in the system*". Young people want to feel valued and supported by

services, however, focus group discussions included "*no one cares"; "was told I would be helped and guided, not seen anyone since 19 and now 22*".

A review by the Wales Centre for Public Policy identified that better outcomes of CLA are linked to the focus on reunification of families; the involvement of children and families in care decisions; placements available; and how "*joined-up*" local services are (100).

"Future looks bleak. I'm stressed and worried. I don't know where to go for help and support. If you don't do it yourself you get nothing" – CLA, focus group

Language and communication

Data on Welsh or other language skills amongst children looked after is not routinely collected. Between 2014 and 2018, Care Inspectorate Wales report an increase in the number of residential child care managers and workers who speak some Welsh or are fluent (33% of managers and 38% of workers speak some Welsh or are fluent) (92).

Half of children in contact with the Cardiff youth justice service are known to children's services (96). Between 8-25% of children undergoing assessments through the Cardiff Youth Justice service have speech and language needs (95).

7.3.2 Community

Youth Justice

CLA are subject to disproportionate inequities, and are overrepresented within the youth justice system. The Cardiff youth justice health needs assessment recommends that providers of care and support for young people in youth justice systems, should additionally have links with services providing for CLA, as well as health and physical health professionals. The assessment notes that there is not yet a specific approach recommended as to the delivery of health services to this population group (95).

7.3.3 Wider determinants of health

Inequalities

Children in foster care in the focus group were aware of children's disadvantages and the wide inequalities between those in care and those not.

"Children in care should be able to and given the opportunity to do as well as those in families but they don't. There is a vast difference"" – CLA, focus group

Deprivation

Wales has a higher CLA rate per 10,000 children and young people than England; and the biggest difference in rates between most and least deprived communities in the UK (50). A 2017 study identified that a child in the most deprived decile in Wales was 12 times more likely to be a CLA than a child in the least deprived decile, throughout the study period 2008-2014 (101).

Education and employment

In Cardiff, 95% of CLA attend primary school (96). Nearly two-thirds (62%) of CLA at key stage 4 have special educational needs (96), and three-quarters of CLA in school have a Personal Education Plan (96). In 2018/19, 54% of care leavers were in education, employment, or training at 1 year in Cardiff (96).

In October 2021, all CLA aged 5 – 16 years in the Vale of Glamorgan had a Personal Education Plan in place. Most (89%) were in mainstream schools, and 40% had special educational needs. Most CLA in the Vale of Glamorgan after the age of 16 are in education, employment, or training: 95% of year 12; 92% for year 13, and 72% of year 14 aged young people. Since 2019, the Vale of Glamorgan has a designated member of the Vulnerable Groups Team who works in partnership with social workers from the 15+ Team, Careers Wales, carers and Post 16 education providers to ensure the school leavers access their post 16 destinations for education or training and support to ensure the young people looked after are on the right course. This has improved the numbers of looked after children accessing education employment or training post 16 (29).

Housing

Local Authorities have a responsibility to provide accommodation suitable for looked after children; and support families to stay together where possible with the aim of preventing the need for a child to be taken into care.

Increasing placements are required to meet the increasing numbers of children looked after. Notably in the Vale of Glamorgan, is the increase in those placed for adoption, residential settings, and placed with parents/person with parental responsibility. There is a similar position in Cardiff, with an additional increase in foster placements, and a reduction in those living independently (102). A 2020 review in Wales found an 84% increase in children and young people placed with new parents over the preceding 5 years (93). Although most (66%) of children are placed in their local authority, increasing numbers of children are being placed outside of Wales (255 in 2016, 365 in 2020), suggesting there may be difficulties finding suitable local placements (100). The average age in months of CLA being adopted is 35 in the Vale of Glamorgan; 42 in Cardiff, and 37 in Wales (103). This is corroborated by a 2019 Care Inspectorate Wales review, in particular as the needs of children are becoming more complex. Some children had experienced multiple placement breakdowns, negatively impacting their well-being and relationship forming (92).

Table 7.1. Numbers of children looked after by placement type and local authority

	Vale of Glamorgan			Cardiff			Wales		
	2012	2017	2020	2012	2017	2020	2012	2017	2020
Placed for adoption	*	5	15	15	25	40	255	245	245
Foster placements	165	165	165	425	490	595	4405	4425	4990
Placements in residential settings	10	10	20	30	55	90	225	355	535
Placed with own parents or other person with parental responsibility	25	40	60	35	95	180	550	725	1200
Living independently	*	*	*	35	60	40	105	130	130
Absent from placement or other	15	*	*	25	5	10	180	80	80

Source: Stats Wales (102)

Changes of placement can be disruptive to children's lives; in Cardiff in 2019/20, 8% of CLA had 3 or more changes of placement (96). In the Vale of Glamorgan, this figure was 12% (29). Supporting a child or young person when they leave care is a critical part of the process. Nationally, in 2018/19, 12% of 16-18 year olds leaving care experienced homelessness; compared to 21% in Cardiff in 2019/20 (96).

Despite these aims, young people in foster care in the focus group reported some negative experiences, feeling isolated as they are moved far from their families.

7.3.4 Unmet needs

All three focus group participants disagreed with the NOF statement "*I get the right care and support, as early as possible"*. Reasons for this include feeling as though services are not open, honest, or transparent; and feeling as though services "*do what they can to tick a box*" rather than address need and work together with families. Children want to be "*cared for and nurtured*", and "*knowing their roots is also important…shouldn't always have to be a fight for support and contact*". Young people felt as though they have *"little opportunity*". Young people wanted support officers to receive more training. They wanted foster parents to "*prove they are good parents"*.

Tension exists between the rights to a family life, and the duty to protect the child from harm, both of which are enshrined by the UN Convention on the Rights of the Child (104). One focus group participant reported that the family who loves and wants him were only allowed to contact him 12 times a year. Another stated he had "4 *foster families by 15…[my] grandparents wanted to foster [but this] wasn't allowed*".

Gaps in knowledge and understanding include the profile of Welsh and other languages amongst children looked after and children at the edge of care; and understanding of factors leading to placement breakdown, in order to better provide appropriate placements.

7. 4 What are the range and level of services needed?

7.4.1 Prevention and assets

The Integrated Family Support Team (IFST) is a partnership between the Vale of Glamorgan Council, Cardiff Council and Cardiff and Vale University Health Board. In conjunction with Flying Start and Families First, these programmes provide preventative and supportive approaches for families who need it. Successful working of these programmes acts to reduce harm to children and reduce escalation of care and support needs. The IFST intervenes where a child is described as being at "the edge of care", and is able to liaise with other local teams (such as the Early Intervention Team) to support children and their families through, for example, substance misuse intervention, or traumatic stress (105).

Half of children known to the Youth Justice Service in Cardiff receive input from Children's Services; and 15% are Children Looked After (96). [Data pending for the Vale of Glamorgan] Services should be aware of the association between ACEs and future interaction with the criminal justice system. Protective factors should be considered as a preventative mechanism.

Recommendations from the 2021 Cardiff Youth Justice health needs assessment are being progressed through partnerships including the Cardiff Youth Justice Service, the Cardiff Youth Justice Board, Children's Services, and South Wales Police (95). Recommendations include expanding the offer of well-being activities; increased involvement of families; and supporting crucial points of transition, for example, between secure estate and the community, and from children's into adult health, social care, and justice services (95).

Focus group participants stated neighbours and the local community were assets. Third sector organisations such as Grandparents Raising Grandchildren were named as supportive, including during periods of lockdown where mutual support was provided through telephone or online platforms.

Participants did describe negative experiences of being in foster care which directly undermine sources of support. They were unable to see their families, and said they had "n*o support or places to go"*.

7.4.2 Community services

Transparent services

Services provided must be transparent and accountable, as young people report broken promises: *"[I] was promised if I'm good can go home and visit family – never happened. It's not fair and services shouldn't be allowed to lie to children."* Young people perceive services to "*make it up as they go along*", for example, when judge's decisions do not match the evidence provided. Processes within the system need to be clear, so that young children can understand.

7.4.3 Partnership approach

Joined up services

The number of looked after children continues to increase year on year, despite policy supporting children to remain with their families and out of care, including prevention and early intervention schemes. Also too often children are placed far from home at great expense, removing them from their families and sourcing appropriate, regulated placements is often difficult. Alongside this the secure accommodation system often is unable to meet young people's needs and there continues to be a lack of investment in expanding residential care for looked after children with complex needs, to support them to remain close to home and transition to independent living. (87)

Co-production

Co-production is central to any service. Focus group participants were appreciative of the opportunity to be listened to. One suggestion to achieve this was through "*creating a befriending advocacy service – giving the child a voice, care about their welfare, and nurture them*".

"Thank you for helping and giving us a voice today" – CLA, focus group

7.5 What is likely to happen in the future?

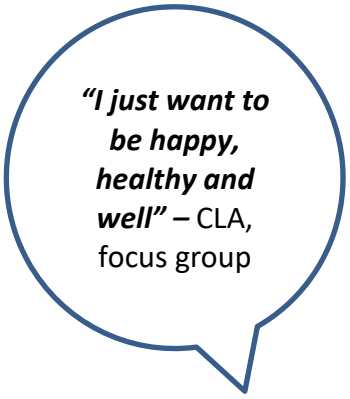
Welsh Government have prioritised reducing the number of children looked after by local authorities (25); and identify the importance of preventing the child from needing local authority care (87). However, numbers of children looked after have increased despite this, and the impact of COVID-19 and the challenges that children and young people in vulnerable situations faced during lockdown and restrictions is yet to be fully realised.

7.6 Recommendations

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to foster a culture whereby children looked after feel valued and listened to; are informed of choices available to them; and can influence decisions about their care
- Promote a preventative approach to prevent needs arising or escalating

- Ensure that children looked after have timely access to health and education services that they need, in order to meet statutory education requirements, close the inequalities gap, and promote their well-being (92)
- Develop of an integrated working model to promote seamless transition between services, including actions to be taken when children go missing from care, and interaction with the criminal justice system (92)



Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop additional placements close to home for children and young people
- Orientate services to be person-centred, building trust and rapport with children and young people, promoting a sense of value through co-production

8. Older People

This chapter should be read in conjunction with the following chapters: Healthy Lifestyles and Long Term Conditions; Physical Disabilities; Adult Mental Health; Cognitive Impairment including Dementia; Adult Unpaid Carers; Sensory Loss and Impairment; VAWDASV; Armed Forces Service Leavers (Veterans)

Recommendations

Cardiff and the Vale of Glamorgan Local Authorities, Cardiff and Vale University Health Board, and private providers to:

- Recognise the diversity of the "older people" group and provide services to meet the needs of such a diverse group, including transport options
- Continue to embed the Cardiff and Vale Rehabilitation Model
- Further develop existing collaborations to provide high quality end of life care
- Integrate care and support services to enable older people to live independently and well at home for as long as possible, for example, through the @home programme
- Promote the use of Dewis Cymru to increase awareness of available support services

Cardiff and the Vale of Glamorgan Local Authorities to:

- Support new building developments to meet the needs of an ageing population, and increase the provision of a variety of accommodation options to enable older people to make informed choices on where and how they live
- Implement the Housing Adaptations Strategic Framework; and ensure existing properties are appropriate, safe, and support older people's independence
- Apply urban design standards and accessibility criteria when redesigning existing infrastructure, for example, increasing the time for people to cross the road at a light-controlled pedestrian crossing (106)

Cardiff and Vale University Health Board and Primary Care to:

- Promote the Royal College of General Practitioners 'Tackling loneliness. A community action plan for Wales' amongst health care providers and partners to raise awareness of loneliness, and advise how lonely patients can be identified and supported (106)

8.1 Overview

In this Population Needs Assessment, older people are defined as people aged 65 and above (although it is accepted that in other contexts the age threshold may vary). For the purposes of this needs assessment, where possible we will also divide this population group into those aged 65-84, and those aged 85 plus. Older people are not a homogenous population

group, and will have different needs and wants. Age is a risk factor for many conditions such as dementia, cataracts and falls, which will influence individual people's care and support needs. The needs of people with dementia are discussed in chapter 14.

> ***"Older people are "us" and we need to respond with that in mind"*** – professional lead

Figure 8.1 and Table 8.1 show the wide variation in the numbers and percentages of people aged between 65 and 84 and aged 85 plus across primary care clusters in Cardiff and Vale. Western Vale has the highest percentage of people aged 65-84 (23%), however, Cardiff North has the highest number of those aged 65-84 (16,003). In contrast, Cardiff South East has the lowest percentage of people aged 65-84 plus (5.5%), but City and Cardiff South has the lowest numbers of 65-84 (2,475). Looking at the population aged 85 plus, Eastern Vale has the highest proportion of people aged 85 plus (3.4%), but Cardiff North has the highest population (2,859 people). Across Cardiff and Vale of Glamorgan there are an estimated 81,645 people aged 65 plus, as at mid-2020 (107).

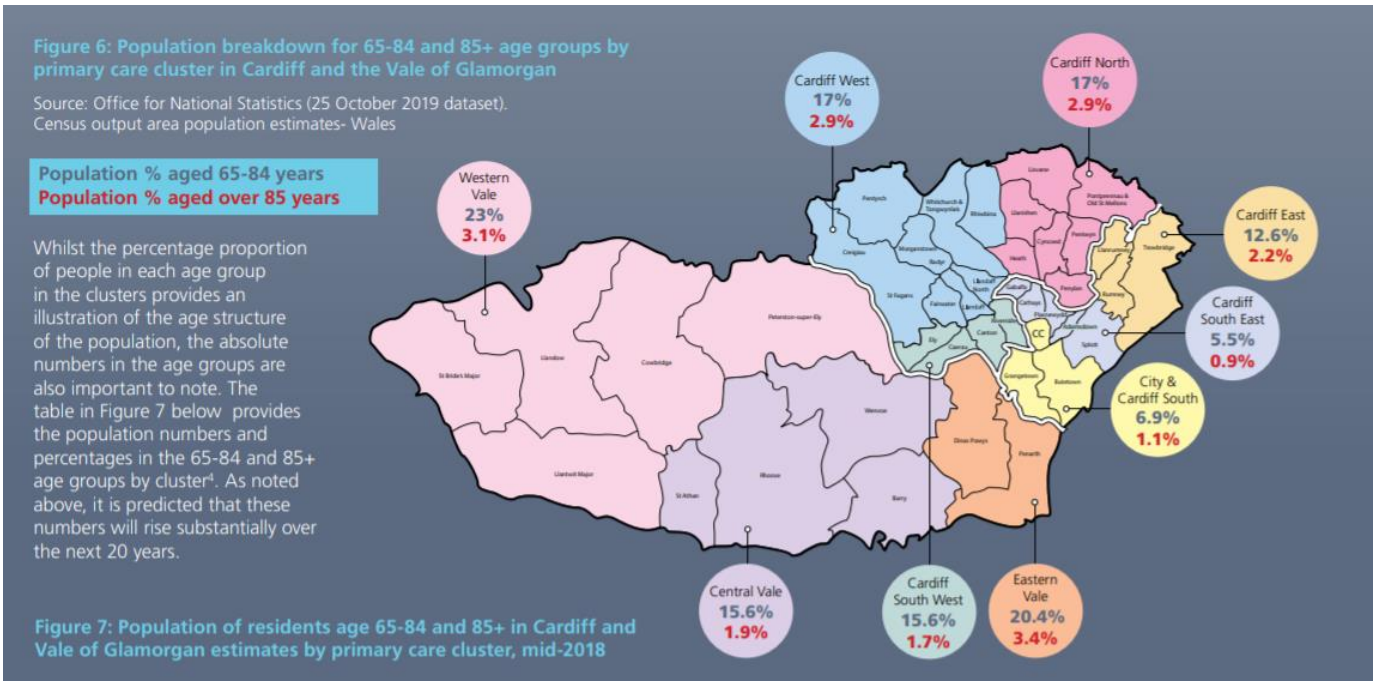


Figure 8.1. Demography of Primary Care Clusters in Cardiff and Vale of Glamorgan
Source: Office for National Statistics (107)

Table 8.1. Demography of Primary Care Clusters in Cardiff and Vale of Glamorgan

	Cardiff North	Cardiff West	Cardiff South West	City & Cardiff South	Cardiff East	Cardiff South East	Western Vale	Central Vale	Eastern Vale
Number of people aged 65-84	16,003	10,620	6,312	2,475	4,728	4,150	5,773	10,792	7,702
% of total population	17%	17%	15.6%	6.9%	12.6%	5.5%	23%	15.6%	20.4%
Number of people aged 85+	2,859	1,632	945	399	817	648	788	1,340	1,296
% of total population	2.9%	2.9%	1.7%	1.1%	2.2%	0.9%	3.1%	1.9%	3.4%
Total population (all ages)	96,923	62,850	56,016	35,639	37,352	75,468	25,293	69,025	37,847

Source: Office for National Statistics (107)

Across Wales, the number of people reporting 2 or more longstanding illnesses has remained at 21% in 2016/17 and 2019/20; similarly those reporting to be limited by the longstanding illness is similar at 33% in 2016/17 and 35% in 2019/20 (108) (see also chapter 9: Healthy Lifestyles and Long Term Conditions). As more people live to an older age, more people are likely to have two or more long term illnesses.

Engagement

Two focus groups were conducted: one for people aged 85-84 (4 participants) and one for people aged 85 and older (3 participants). Forty-five percent (n=293) of the 647 respondents of the public survey who provided their age were 65 or older: 172 were aged 65-74, 91 were 75-84, and 30 were 85 and older. Sixty-eight respondents of the provider's survey provided services for older people aged 65 and older. This is not representative of the population of Cardiff and the Vale of Glamorgan, but does provide additional depth of insight and lived experience.

8. 2 What has changed since 2017?

8.2.1 Pre-COVID-19

Nationally, the following has changed since the 2017 Population Needs Assessment:

- Welsh Government published 'Age Friendly Wales: Our Strategy for an Ageing Society' in October 2021, setting out the vision for Wales to be a place that supports people of all ages to live well and age well and where older people are celebrated (109).
- In 2020 Welsh Government published 'Connected Communities: a strategy for tackling loneliness and social isolation and building stronger social connections' (110). Whilst this issue does not solely impact older people, it is recognised that it

does impact their lives, and this strategy followed the 2017 inquiry by the National Assembly for Wales' Health and Social Care Committee into loneliness and social isolation which had a particular focus on older people (111).

- The rights of older people are enshrined in the Social Services and Well-being (Wales) Act 2014, which states that services should be prioritised in relation to older people with complex needs and long term conditions, including dementia (112). The Older People's Commissioner for Wales' strategy 2019-2022 (113) sets out their vision of celebrating an ageing society, supporting vulnerable older people and empowering people to understand their rights and access the support and services they need.

Regionally, the following changes have taken place:

- The impact of integrating health and social care services has been demonstrated through the Independent Living Service (ILS) provided by Cardiff Council and Wellbeing Service at Vale of Glamorgan Council Contact 1 Vale (C1V). This has focused on a prevention model since 2017. The aim of ILS is to reduce the need for social care, support people to stay living independently in their own homes and improve their well-being. The provision of a hospital based discharge support service has enabled collaborative working to help patients get home with the services they need in place, and improved partnership working with a range of sectors.
- ILS are a key partner in the South West Cardiff primary care cluster MDT (multi-disciplinary team) model, which began in 2019. GP practices in the cluster meet every other week to discuss individual patients' needs, many of these needs can be met outside of healthcare. Partners around the MDT table include ILS, and third sector service providers, who can support people with issues such as social isolation, adaptations needed in their home and financial support. The MDT partners can signpost them to services or activities which will meet their needs. Many older people have been supported through the MDT model, and it is planned to roll out this model in other clusters.
- The Well-being service in the Vale of Glamorgan offers a range of support to older people to meet their needs. Cardiff Well-being Support Service was set up in response to the pandemic and the needs around isolation, anxiety about going out and need for general support. Health and Well-being Mentors provide 1 to 1 support for a wide range of needs, and Community Inclusion Officers organise a range of community activities.
- Cardiff and Vale UHB, with Cardiff and Vale Local Authorities and other partners, have implemented the "@home" locality-based integrated care model within the Cardiff and Vale Regional Partnership Board, which aligns with the UHB long term strategy 'Shaping Our Future Wellbeing', which has a focus on community based care. This is a collaborative, person centred model, focused on prevention, early intervention and keeping people well.
- Both Cardiff and the Vale of Glamorgan local authorities are in the process of applying for Age Friendly status with the World Health Organisation, which is supported by both Public Service Boards.

- The 2019 Annual Director of Public Health for Cardiff and Vale report focussed on healthy ageing, and included three themes of: feeling a sense of meaning and purpose; having good social connections; and living in places that enable people to remain safe, active and independent (106).

8.2.1 COVID-19

Physical health and access to health care

COVID-19 has had a significant impact upon older people, including ill-health, mental and physical well-being, and mortality perspectives. The mobility and circulatory conditions of older people have deteriorated in lockdown and de-conditioning has occurred, potentially leading to increased risk of falls (114). Research has shown that age increases the risk of dying from COVID-19 due to deterioration of immune systems and being more likely to have long term conditions (115).

Focus groups with people aged 65+ and 85+ highlighted the following issues arising from COVID-19:

- Feeling that COVID has taken priority for healthcare services
- Difficulties accessing health services: *"Impossible to see any health service, doctors or dentist"*

> ***"…if you have anything that's not COVID it felt not important – just ignored and got worse but can't do anything about it"*** – older person, focus group

Mental health and well-being

There are increased risks of health anxiety, panic, and depression for older people, particularly those in institutions (116). COVID-19 has had adverse effects on the well-being of older people in care homes, for example, constraints on social contact due to suspension of indoor visiting (117). An Office for National Statistics survey across Britain during April-May 2020 found over 50% of the over 60s were worried about their well-being; of these 70% were worried about the future, 54.1% were stressed/anxious and 43.3% felt bored (118).

Loneliness and isolation have increased for many older people, and feelings of anxiety and fear have emerged due to the pandemic and lockdowns. People who were previously self-sufficient found themselves in need of support and their resilience and dealing with day to day issues decreased (119). Many older people have struggled with getting support when leaving hospital, sometimes leading to longer hospital stays.

Focus groups with people aged 65+ and 85+ highlighted feelings of helplessness*: "scared and lost many friends"* and loneliness due to isolation*: "not seeing family is the worst"; "afraid to go out"* due to COVID-19.

Professional leads corroborated these findings, identifying:

- Deterioration of mental and social well-being
- Increase in social isolation and loneliness

- Loss of confidence in going out and accessing activities and services
- Change of behaviour, staying in more, being less active
- The loss of social role, for example, through bereavement, retirement, or an inability to undertake a hobby or activity anymore had been identified as concern prior to COVID-19. With increased isolation due to pandemic restrictions, this is likely to be exacerbated
- Restrictions in accessing face to face services, for example toe nail cutting, exercise classes and social activities
- Financial insecurity

Digital exclusion

Although many more people aged over 55 have been able to get online, the digital divide has widened during the pandemic, with more services moving to online only (120). Digital exclusion has been an issue for many older people in accessing vital support services, not just because of a lack of equipment but a lack of confidence or a fear of using online services (119).

These findings were also identified by professional leads, leading to exclusion for those who cannot work in roles that require digital connections, social isolation, and problems accessing services which switched to being a virtual only service. However, there has been an increase in the number of older people who are using digital technology, particularly during the COVID-19 pandemic. Digital inclusion projects have supported people to get online and be taught how to use the technology to keep in contact with people, and access the internet. This can help address social isolation and loneliness.

Positive impacts of COVID-19

There have been some positive impacts observed due to the pandemic however. Services have had to adapt and in some cases this has resulted in more people being able to access them, and services have implemented flexible and agile ways of working. New connections have been made, and many people volunteered within their communities to support older people in particular with shopping, collecting prescriptions or befriending via telephone. Services integrated well and worked alongside each other, and new working patterns meant some flexibility for the workforce. COVID-19 has encouraged the development of digital solutions to link together. Health and social care staff have used technology to link people with their families, for example, tablets in care homes and hospital wards, so that families and loved ones can talk.

A report from the British Geriatrics Society (2020) highlights some innovations and collaborations to help protect and improve the care of older people during the pandemic (121), examples include:

- Anticipatory care intervention for those who are high risk
- Multidisciplinary team response to urgent care needs
- Hospital at home collaboration to keep people at home
- Multiagency approach for rapid guidance and support to care homes
- Advanced care planning to identify individual needs

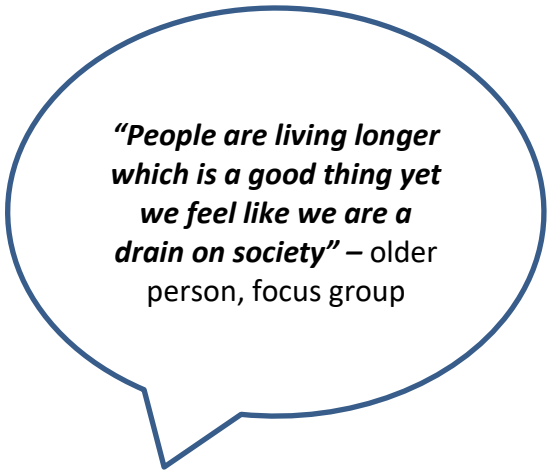
- Older people who were cared for on a children's ward experienced improved well-being due, in part, to the presence of children's nurses and play specialists and the creative, bright, and joyful ward design
- Integrated discharge planning
- Proactive rehabilitation with targeted physiotherapy prior to discharge
- Delivery of telephone and digital appointments

8.3 What are the care and support needs?

8.3.1 Individual

Resilience in older people

Third sector organisations articulated during the COVID-19 pandemic that there were increasingly divisive messages emerging from media which exacerbate intergenerational tensions, for example, talk of making sacrifices during the pandemic to "*protect*" older people. Third sector organisations identified the risk that older people, whose contribution to society is well documented, will increasingly be seen as a drain on resources and that their personal stories will be lost in the negative messages being disseminated. These negative attitudes and thinking can have an impact upon older peoples' mental health and well-being and should be tackled.



The importance of creating a society where people of all ages are equally valued is highlighted in the Royal Society for Public Health report, "That Age Old Question" (122). The report highlights that people with negative attitudes to ageing live on average 7.5 years less than those with more positive attitudes to ageing. Recent studies show they are also more likely to develop dementia. The Older People's Commissioner for Wales is leading the way in the UK through recognising this issue as detrimental to health and to society more widely, and her team has launched a campaign, "Taking Action Against Ageism" to encourage more people to recognise and challenge ageism. Age UK document the racism as well as ageism experienced by the Windrush generation, and others (123).

Diverse needs

Cardiff and Vale has a diverse population, with people from many different cultures and backgrounds, which is a great asset in our communities, but also means that needs can differ across the population. Services need to be able to adapt and respond to this diversity, as well as to the fact that the coming generations of older people will have different needs and offer different assets to the community, for example more will be familiar with digital technology as we move into the future.

It is expected that significantly more older people from minority ethnic backgrounds will need to access social care services in the future (117), due to families not being able to offer

the support they perhaps once did. Access to culturally sensitive and appropriate health and social care provision is a priority in the Race Equality Action Plan being developed by Welsh Government.

Long term health needs

Many older people live in good health, 56.7% of older people in Cardiff and the Vale were living in good health in 2017/18 – 2018/19 (56.1% in Cardiff, 58% in the Vale) (124). 71.6% of older people responding to the PNA survey rated their well-being as 'good' or 'very good' prior to the COVID-19 pandemic. This dropped to 52.8% in the last year due to the impact of COVID-19, but this was still the highest level amongst the groups surveyed.

Only 47.7% of older people in Cardiff and 50.2% in the Vale of Glamorgan live free from limiting long term illness (124).

Language and communication

There is no local data available on the Welsh language profile of older people living in Cardiff and Vale. The Strategy for an Ageing Society – Age Friendly Wales (109) specifies the importance of ensuring people can use Welsh language services in a way that suits them, and this is central to creating an age friendly Wales.

In Cardiff and Vale, Arabic, Polish, Bengali and Chinese are the four most common languages spoken after English and Welsh. Healthcare service providers have a responsibility to provide interpreters during consultations to ensure care provided is appropriate and culturally sensitive. Translation services are required for all interactions such as pharmacy and housing. Language was an issue raised by the focus groups participants, and in the survey around one in six (15.9%) older people felt the care and support received has not been in the language or communication format of their choice.

8.3.2 Community

Frailty and falls

The Healthy Ageing Programme in Wales (109) aims to increase activity among older people, reducing frailty and physical decline, and support people to live independently as they get older. Demand for services based on levels of frailty are predicted to increase due to the

increased numbers of older people in the future, and previous modelling predicted an increase in demand of up to 31% in Cardiff and the Vale between 2015 and 2025. Physical ability was by far the biggest issue preventing older people who responded to the PNA survey from being in control over their daily lives (62.9%).

Frailty can be a cause of falls, and falls are a key public health concern for older people. Telecare Cardiff undertook some analysis of clients who fell during 2020-21 and found that 84% of those who fell were repeat fallers, i.e. they had fallen more than once. Strength and balance loss was stated as the reason for most of these falls, followed by long term health conditions. Telecare are taking a proactive preventative approach to reducing falls among clients (125), and Cardiff and Vale UHB has developed a falls prevention service which launched in 2018 aimed at reducing people's risk of having a first fall.

Dementia rates are also predicted to rise which will impact upon service provision. For more information about the needs of people with dementia please see chapter 14, and for the needs of unpaid carers see chapter 15.

End of life care

High quality palliative care can improve the quality of life of a person with a life limiting illness, and support their loved ones. Welsh Government's 2017 Palliative and End of Life Care Delivery Plan has been extended until March 2022 (126). Palliative and End of life Care have been given new all Wales programme status and this work has commenced. The national framework for the delivery of bereavement care was published in October 2021, to support people in the period prior to, or following the death of a significant person in their lives (127).

Due to an aging population, an additional 135,000 annual deaths are projected by 2040 in England and Wales, compared to 2014. This is associated with a higher complexity of care with more than one serious illness contributing to their palliative care needs. Studies have estimated that approximately 75% of people who die would have benefitted from palliative care (128). Patterns of place of death have changed, with increasing proportion of deaths at home and in care homes, and a reduction in hospital deaths, between 2004-2014 in England and Wales (129). Marie Curie report that an increased number of deaths took place at home in 2020, compared to the 5 years prior, in part due to COVID-19 restrictions and changes in care and funding provision. Prior to the pandemic, although half of deaths took place in hospital, only 7% of people in the UK stated a preference to die in hospital (130). These changing patterns will impact the demand for, and expectations of, palliative and end of life care provision and delivery in all settings.

Advance Care Plans facilitate conversations between a person nearing the end of life, their family, and health and social care professionals, around the person's wishes and what matters to them, including care preferences, treatments, and their preferred place to die. Such discussions enable improved choice, control, and quality of end of life care for the person, and lessens the bereavement burden for their loved ones. Advance Care Plans are embedded into the Cardiff and Vale UHB 'Shaping Our Future Wellbeing Strategy 2015-2025' (131).

A review of Specialist Palliative Care Services in Wales published in 2021 identified that COVID-19 has brought end of life care into focus. Against a backdrop of the vision described by the Welsh Government long term plan "A Healthier Wales", which aims for services provided at, or close to, home in a seamless manner, the following priorities have been identified:

- Equitable provision of and equitable access to palliative and end of life care
- Build on the principles of value based health care, including patient reported outcome measures, and patient reported experience measures
- Learning from COVID-19, including co-production of care delivery; speed of clinical intervention, innovation, and policy; and placing palliative and end of life care centrally in future pandemic planning

Currently, Cardiff and the Vale UHB has a mixed provision of specialist provision between statutory and third sector services. They have a statutory inpatient specialist palliative care service with 24/7 consultant advice, and community nurse specialist support service to inpatient hospital sites at weekends during core hours. Most inpatient palliative care is provided in hospitals (132), although inpatient hospice care is provided by the Cardiff and Vale Marie Curie Hospice. Marie Curie in the Vale of Glamorgan, and City Hospice in Cardiff provide specialist palliative care input in the community including care homes. Marie Curie provides the Hospice at Home service across Cardiff and the Vale (133) works alongside district nurses, GPs and families/carers providing core end of life care in the community supporting people to remain at home where that is appropriate.

8.3.3 Wider determinants of health

Deprivation

Life expectancy is known to be associated with socio-economic status: in 2017, there was a life expectancy gap of 8.6 years for males and 6.6 years for females, between the most and least disadvantaged areas in Cardiff and the Vale of Glamorgan (106) (see also Chapter 4: demography). An analysis of life expectancy in Wales prior to COVID-19 found wide and increasing life expectancy gaps between the richest and poorest fifths in Wales. For females, respiratory disease, cancers and circulatory diseases were most influential, and for males, circulatory disease, cancers, and respiratory conditions contributed the most to the life expectancy gaps (134).

The Older People's Commissioner for Wales' report in 2019 identified that the healthy life expectancy gap was 18 years in Wales, between the most and least deprived areas (135). The report identifies that older people tend to have lower incomes than people aged under 60. Approximately one-third of people aged 60-74 in Wales receive an income of under £200 a week (£10,400 per year). Women are more likely to be poorer than men (135). Pensioners in the poorest fifth of the UK population are more likely to have one or no close friends, compared to pensioners in the richest fifth, in research conducted in 2014/15 and 2017/18 (136).

Financial barriers were prominent in focus group discussions, regarding access to care and support services, as well as leisure and community activities. Professionals supporting older people reported that cost of activities can be a barrier for older people. Financial barriers should be addressed when services are being provided.

Housing

Cardiff and Vale's ageing population has particular implications for the amount, type and location of accommodation which is specific to their needs. The majority of older people on the Housing Waiting List in both Cardiff and the Vale need one bedroom properties (29) (137). Poor or unsuitable housing can impact disproportionately on older peoples' physical and mental health, independence and well-being (137). An assessment of older person's housing accommodation undertaken for the Regional Partnership Board in 2018 (138) estimated a need for an additional 3,051 units of older persons' accommodation by 2035 in Cardiff, a mix of housing, housing with care and nursing care. In the Vale, the report forecast the need for an additional 1,297 units by 2035.

The Vale of Glamorgan Housing Strategy notes the anticipated demographic changes and increasing trends of the proportion of people with long term limiting illnesses. The need for housing to enable people to remain independent is emphasised, for example, through provision of high quality, affordable and suitable housing. Alongside this, enablement services, Telecare and Extra Care housing are considered (139). The Cardiff Housing Strategy, similarly, identifies mechanisms by which to promote people's independence, for example, through availability of specialist housing for older people (such as sheltered housing and extra care provision). For example, council sheltered housing schemes will include communal spaces, dementia-friendly features, offer charging and storage facilities for scooters, and be accessible and culturally inclusive. The Strategy highlights the Independent Living Services as a preventative support service to help maintain independence (140). A separate Older Person's Housing Strategy was published in Cardiff in 2019, which aims to improve existing houses, maintain independence, meet the needs of the most vulnerable, and tackle social isolation (137).

Older people responding to the PNA survey were more than twice as likely to report that their home was too big, compared to any of the other groups surveyed. Many older people require adaptations to their home to enable them to remain living independently (52% reported the need for adaptations in the PNA survey). The draft Housing Adaptations Strategic Framework developed by Welsh Government is aimed to provide stakeholders involved in the delivery of aids and adaptations, service users and other stakeholders with a framework which facilitates a more strategic and integrated approach to delivering adaptations services at a local level. The framework should become operational from April 2022. The framework includes the requirement to establish a common understanding of the population need and demand for adaptations and identify inequalities and links to RPBs and the population needs assessments (141).

Both Cardiff and the Vale of Glamorgan will be developing new residential units for older people in the coming years. In order for these to best benefit the health and well-being of the future residents, older people should be considered in the design of these

developments. For example, enabling people to travel by reliable and regular public transport, as well as walking or cycling is vital for older people to stay active and improve their health (142). Well maintained paths, adequate lighting, locating residential units close to existing services, and ensuring safe spaces for cycle storage all encourage walking and cycling. Charging points for electric mobility aids must be available and accessible at locations decided upon in tandem with those who use them.

8.3.4 Unmet needs

Professional leads identified the need to better understand what older people want from services, and giving greater consideration to how best to support people with cognitive impairment. Also a need to increase the support around addressing frailty. Focus group participants identified the following gaps:

- Better access to healthcare to meet needs: *"struggle to get an appointment, even in an emergency*"
- Better public transport systems
- Improved accommodation: "*Better sheltered housing"*
- Enhanced support: *"Better support for people to live independently"; "More support groups to meet with other people*"

Gaps in knowledge and understanding include:

- In depth knowledge and understanding of what older people want from services
- Consideration of how best to work with people with significant cognitive impairment
- A common understanding of the population need and demand for adaptations and identify inequalities within and between regions.
- A clear understanding of language needs for older people in Cardiff and Vale
- Benchmarking and the "social model of care"
- Where the gaps in service provision are
- Where to focus prevention work to have the biggest impact on reducing hospital admissions

8. 4 What are the range and level of services needed?

8.4.1 Prevention and assets

To address the issues facing people as they age, prevention is crucial as it can keep people healthier for longer, living independently, reduce the need for social care and demand for other services. These key elements around prevention have been identified by professionals and older people:

- Legal framework around mental capacity, Power of Attorney and Advanced Decision making
- Financial management and support
- Falls prevention services
- Mental health and resilience
- Digital inclusion
- Integrated health and social care services across sectors
- Addressing loneliness and social isolation

- Maintenance of social roles in families and communities, to give life a meaning

Assets to support well-being

Focus groups, discussions with professionals supporting older people and survey results highlighted sources of support and well-being for older people in Cardiff and the Vale.

> ***"I lead a rich and fulfilling life with lots of family and friends to support and spend time with"*** – older person, focus group

Family and friends were valued: "*I rely on family for many things*". Community-based settings as they support independence and well-being. 42.2% of survey respondents (older people) reported to attend a setting within their community. Examples of local assets include drop-in centres ("*support workers at drop-ins*"); over 60s clubs in community venues such as mosques, libraries/ hubs, clubs such as drama, books, cooking or gardening. Third sector organisations such as Age Connects, Age Cymru, Red Cross provided support, and the Alzheimer's society Dementia Friends programme was also helpful. Healthcare services were supportive and care home staff "*are superb, they take the time to care".* Extra care housing facilitate independence amongst people with care needs.

Dewis Cymru provides a list of local and national organisations that can provide help and support for residents across Wales, including Cardiff and the Vale, for a range of topics including well-being, safety, managing money, being at home, and looking after someone (143).

8.4.2 Community services

Rehabilitation and reablement

Rehabilitation describes the concept of providing personalised support to an individual to enable them to live as active and full a life as possible. This includes reablement, which describes the process of regaining skills and confidence. Rehabilitation can prevent a need arising or escalating, promote self-management, help recovery after an event such as a hospital admission, and span physical and mental health (144).

The five-tiered, evidence-based Cardiff and Vale Rehabilitation model, introduced in 2020, is shown in Figure 16.4. There are four "rehabilitation rules" that span all five tiers, indicated in blue double-headed arrows in the figure. The design principles (in red) are taken from the Cardiff and Vale UHB strategy 'Shaping our Future Wellbeing'. Rehabilitation aims to reduce health inequalities, promote independence, pre-empt and avoid crises, and enable people to enjoy a meaningful life at home where possible (144).

Figure 16.4. Cardiff and Vale Rehabilitation Model. Source: Cardiff and Vale UHB (144)

Transport

Transport was identified in the 2017 PNA as a way of improving people's independence and well-being (145). The Centre for Ageing Better published a report on barriers and enablers to active travel amongst people aged 50 to 70, with key themes around physical ability, confidence, proximity to amenities, maintained footpaths and cycle paths, social norms, and motivation (142). The Welsh Government Strategy for an Ageing Society incorporates public and community transport that is accessible to all older people, as a priority. Transport is viewed as critical to enable older people to realise their independence, participation, reduce isolation and loneliness, and access services. Barriers to access included poor co-ordination between transport systems, availability of public toilets, and seating. Free bus travel for those aged over 60 is continued in the new Wales transport strategy. Three key areas include development of demand responsive transport, improving bus services, and supporting people to plan their journeys door to door (109). Health services need to be accessible for older people, including by public transport. Age-friendly spaces are discussed in the 2019 Director of Public Health for Cardiff and Vale's annual report (106).

In Cardiff and the Vale, there are a number of third sector community transport providers, including Age Connects, Voluntary Emergency Service Transport, Hospital Transport Service, alongside others (146).

8.4.3 Partnership approach

Future thinking

The demographic shift will be a significant future challenge, and the demand for social care in particular is going to be rising. There are issues with recruitment in social care currently which need to be addressed, and there is a need to ensure services are sustainably funded. Societal changes such as employers enabling flexible retirement opportunities may impact the services demanded and utilised. Social care needs to be sustainably funded for the long term.

Person-centred services

Services need to be joined up. Prevention should be prioritised, in order to support older people to live and age well (109). Social prescribing (147) and provision of a wide range of support services can enable older people to have their needs met such as addressing isolation and potentially reduce their need for health and social care. The Royal College of General Practitioners has developed community action plans to tackle loneliness for each of the four UK nations. In Wales, the plan aligns with the Well-being for Future Generations Act, encourages partnership working between Primary Care and other services, and calls for everyone to take action to tackle loneliness (148)

Services need to be flexible enough to meet needs of the individual and their choices. There has been a positive shift towards supporting people to stay in their own homes, and to have rights to say what they want and need. More people are choosing not to live in residential care accommodation, but staying at home and receiving support there, which comes from a variety of sources including third sector. There is often still a need for nursing care at a point in people's lives however. A range of service providers needed to work jointly – health, local authority and third sector to provide the right care at the right time.

8.5 What is likely to happen in the future?

In Cardiff and the Vale of Glamorgan the number of people aged 65 to 84 years is expected to increase from around 70,000 people to around 93,000 people between 2019 and 2039. This will mean a rise from 14% of the total population in 2019 to 16.2% in 2039. Figure 8.2 illustrates the rate of growth expected in this age group between 2019 and 2039. It should be noted that predictions become less accurate the further forward into the future they project.

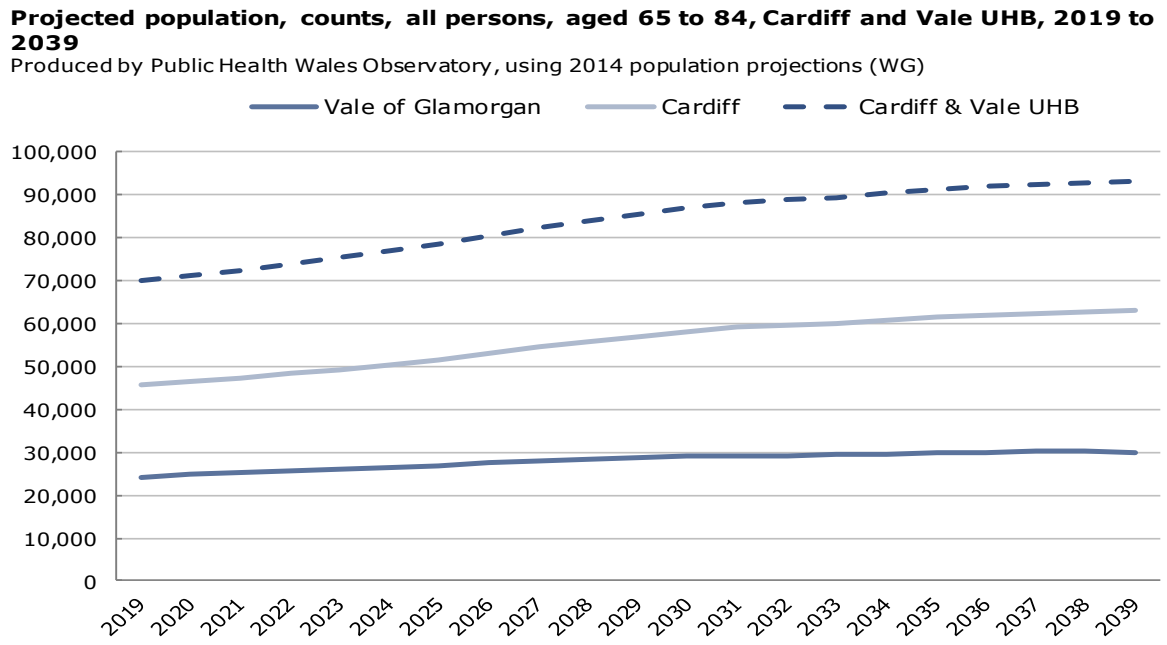


Figure 8.2. Projected population increase aged 65 to 84, 2019 to 2039
Source: Public Health Wales Observatory

The number of people who are aged 85 and over is expected to rise even more sharply, with numbers expected to double in the next 20 years. This will mean a rise from 2.4% of the total population in 2019 to 4.2% in 2039. Figure 8.3 illustrates this change.

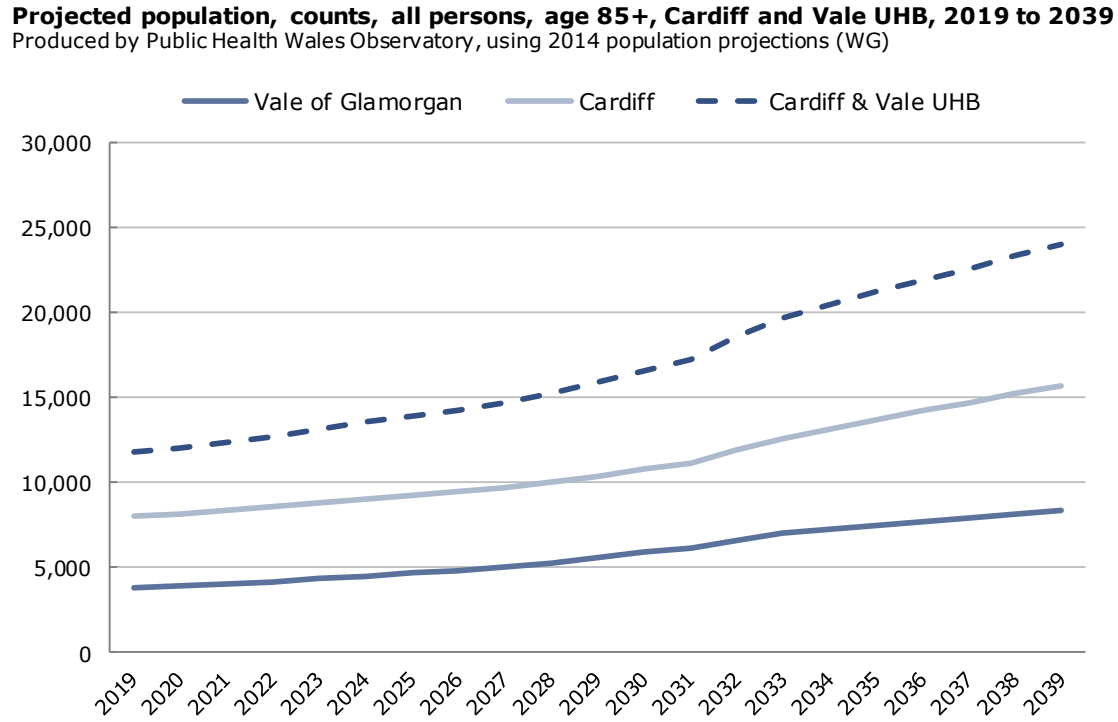


Figure 8.3. Projected population aged 85 and over, 2019 to 2039
Source: Public Health Wales Observatory

Health and social care will need to adapt and focus not only on the ongoing impact of the pandemic, but the need to continue to build an integrated system which delivers the best quality services for the population. Welsh Government will concentrate efforts on the "*whole system"* putting citizens at the centre and surrounding them with resilient local communities alongside primary and community care (25). Health services need to be agile and responsive and social care services caring, effective and linked seamlessly with local communities and health services, to provide support for those in their own homes.

Future demand for formal care for people is not simply linked to the fact that the population is ageing. However, the projected growth in the numbers of older people with complex care needs (including severe dementia) is highly likely to result in increased pressure on health and care services (149), for example, the number of older adults living with severe dementia is predicted to double by 2040 in Wales.

8.6 Recommendations

Cardiff and the Vale of Glamorgan Local Authorities, Cardiff and Vale University Health Board, and private providers to:

- Recognise the diversity of the "older people" group and provide services to meet the needs of such a diverse group, including transport options
- Continue to embed the Cardiff and Vale Rehabilitation Model
- Further develop existing collaborations to provide high quality end of life care
- Integrate care and support services to enable older people to live independently and well at home for as long as possible, for example, through the @home programme
- Promote the use of Dewis Cymru to increase awareness of available support services

Cardiff and the Vale of Glamorgan Local Authorities to:

- Support new building developments to meet the needs of an ageing population, and increase the provision of a variety of accommodation options to enable older people to make informed choices on where and how they live
- Implement the Housing Adaptations Strategic Framework; and ensure existing properties are appropriate, safe, and support older people's independence
- Apply urban design standards and accessibility criteria when redesigning existing infrastructure, for example, increasing the time for people to cross the road at a light-controlled pedestrian crossing (106)

Cardiff and Vale University Health Board and Primary Care to:

- Promote the Royal College of General Practitioners 'Tackling loneliness. A community action plan for Wales' amongst health care providers and partners to raise awareness of loneliness, and advise how lonely patients can be identified and supported (106)

9. Healthy Lifestyles and Long Term Conditions

This chapter should be read in conjunction with the following chapters: Children and Young People; Children and Young People with Complex Needs; Older People; Learning Disability; Autism; Adult Mental Health; Cognitive Impairment including Dementia; Adult Unpaid Carers; Sensory Loss and Impairment; VAWDASV; Asylum Seekers and Refugees; Substance Misuse; Secure Estate; Armed Forces Service Leavers (Veterans)

Recommendations

Cardiff and the Vale of Glamorgan Local Authorities, Cardiff and Vale University Health Board, and policy makers to:

- Anticipate the impact of demographic change on future service demands
- Consider the impact of socio-economic disadvantage on service users, and how services can be provided in a way to reduce inequities, in line with the Socio-Economic Duty

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Further progress accommodation solutions that meet the needs of the service users

Cardiff and Vale University Health Board to:

- Improve access to services, with a focus on mental health services
- Continue to develop and strengthen preventative health services

Policy makers to:

- Use the Triple Challenge lens to inform policies and strategies around issues impacted by Brexit, COVID-19 and climate change, such as food systems and diet (65)

9.1 Overview

This chapter considers lifestyle and health behaviours such as smoking, diet, physical activity, and prevention such as vaccination, as well as long term conditions.

Self-Assessed Health

The proportion of adults over 16 years in Cardiff and the Vale of Glamorgan stating their health is "good" or "very good" has remained fairly stable, with 75% in Cardiff, and 72% in the Vale of Glamorgan in 2018/20. Those reporting their health as "bad" or "very bad" has also remained stable: around 8% in Cardiff and 7% in the Vale of Glamorgan (150).

Across Wales, the number of people reporting 2 or more longstanding illnesses has remained at 21% in 2016/17 and 2019/20; similarly those reporting to be limited by the longstanding illness is similar at 33% in 2016/17 and 35% in 2019/20. Nineteen percent consider their activities to be limited a lot by illness (108).

Weight, physical activity, and diet

Two-fifths of adults in Cardiff and one-third in the Vale of Glamorgan are a healthy weight (BMI 18.5-25). Three-fifths in the Vale of Glamorgan, and 55% in Cardiff are overweight or obese (BMI over 25) (151). In both Cardiff and the Vale of Glamorgan, 29% of the population were active less than 30 minutes in the previous week (151). In Cardiff, 4% reported eating no fruit or vegetables the previous day (6% in 2016/18); for the Vale of Glamorgan, this was 7% in 2016/18 and 6% in 2018/20. One third (34%) of those in the Vale of Glamorgan and 26% in Cardiff reported eating 5 portions the previous day in 2018/20 (151).

The National Survey for Wales 2018/19 reports that 9% of respondents experienced a day in the last fortnight where they did not have a substantial meal due to a lack of money. This figure was 4% in 2017/18 (152). The Trussell Trust provides consistently increasing numbers of food parcels in Wales, although the figures for Cardiff and the Vale of Glamorgan between 2019/20 and 2020/21 do not show this pattern (Figure 6.1) (153). This may be due to measures taken by Welsh Government (such as holiday free school meals) or alternative provision at a local level (for example, Healthy Start Vouchers, or through Food Cardiff and Food Vale). People in the UK who are in poor health, have experienced eviction or divorce, and who lack access to support networks including friends and family, are more likely to need support from a food bank (154).

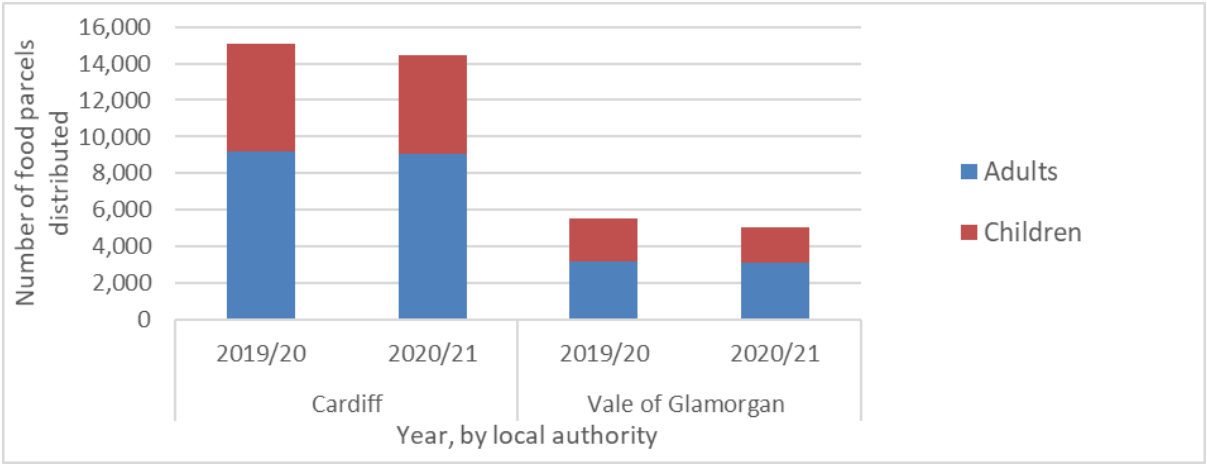


Figure 9.1. Number of food parcels distributed to children and adults by the Trussell Trust, by local authority.
Source: the Trussell Trust (153)

Healthy life expectancy

Healthy life expectancy provides an estimate of years spent in "good" or "very good" health, based on self-reported measures, and complements measures of life expectancy, which

estimates the average number of years an individual would live, were they to experience that area's current age-specific mortality rates for their whole life (155).

Life expectancy as well as healthy life expectancy is higher for females than males at national and local authority levels, for 2013/15 and 2016/18 (with the exception that healthy life expectancy in Cardiff is the same for males and females at 61.7 years) (156). Healthy life expectancy is above the Wales average for residents of the Vale of Glamorgan, and males in Cardiff. Of the data presented in Table 9.1 for 2016/18, the biggest difference between life expectancy and healthy life expectancy in 2016/18 was 21.2 years for females in Cardiff, which equates to 74% of life spent in good health. The smallest difference was seen for males in Cardiff (16.5 years) who have 79% of life in good health (156).

Prior to COVID-19, across the UK, healthy life expectancy for males was unchanged between 2014/16 and 2017/19; whereas a significant decrease was observed for females, from 63.7 to 63.3 years (157).

Table 9.1. Life expectancy and healthy life expectancy, by area, gender, and time.

	2013/15			2016/18		
	Life expectancy	Healthy life expectancy	% of life in good health	Life expectancy	Healthy life expectancy	% of life in good health
Cardiff						
Males	78.3	60.2	77%	78.2	61.7	79%
Females	82.6	63.5	77%	82.9	61.7	74%
Vale of Glamorgan						
Males	79.1	64.3	81%	79.3	62.2	78%
Females	83.2	66.5	80%	83.4	64.4	77%
Wales						
Males	78.4	61.5	78%	78.3	61.4	78%
Females	82.3	62.7	76%	82.3	62.0	75%
UK						
Males	79.2	63.1	80%	79.3	63.1	80%
Females	82.9	63.9	77%	82.9	63.6	77%

Source: ONS (156)

Information sources

The content of this chapter was developed using existing literature, strategies and reports and triangulating findings with professional leads and engagement work (297 survey respondents reported having a long term health condition or physical disability; 5 focus group participants with a long term health condition. Findings from a focus group with 10 homeless participants are also included). It should be noted that the views of those engaged are not representative of all people with long term health conditions in the population of Cardiff and the Vale of Glamorgan, but do provide rich information about their lived experiences.

9. 2 What has changed since 2017?

9.2.1 Pre-COVID-19

A "triple challenge" now faces health and social care services; this describes the combined impacts of Brexit, climate change, and COVID-19. These factors are dynamic and impacts are broad across the wider determinants of health. Public Health Wales calls the present time point a "*window of opportunity*" to implement policies to positively influence health, well-being, the economy, and the environment, in line with the ethos and aims of the Well-being of Future Generations (Wales) Act 2015 (65).

Nationally, the following key documents have been published:

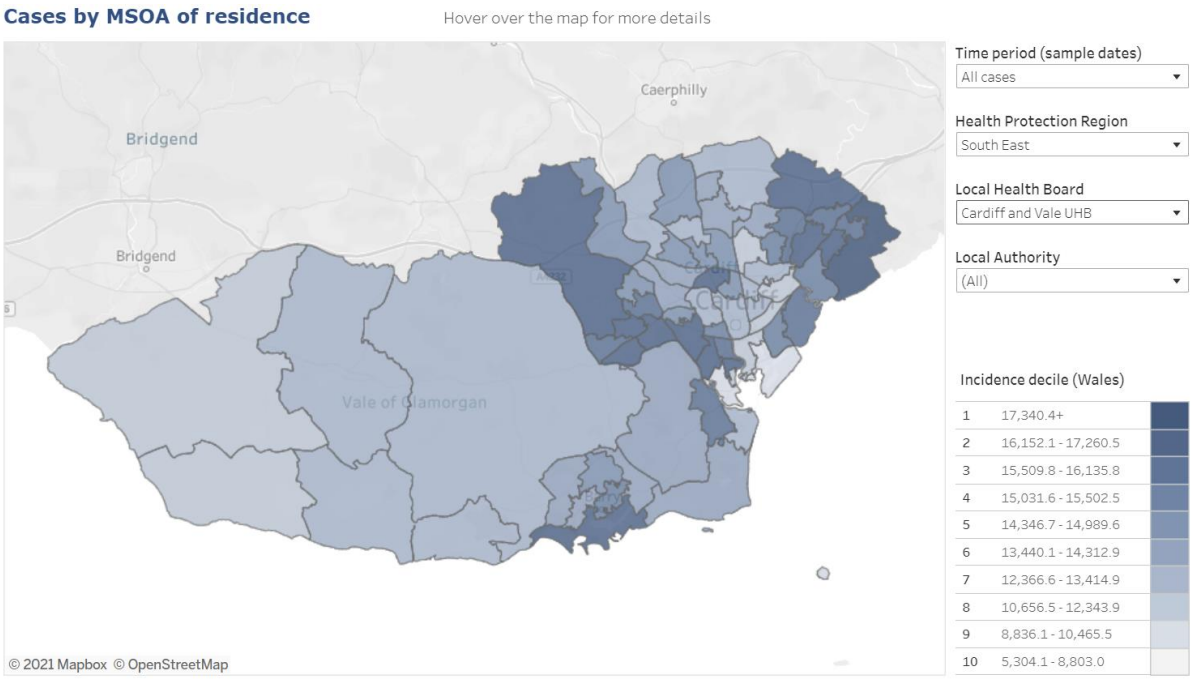
- A Healthier Wales: Welsh Government's plans for health and social care (158)
- Health and Social Care in Wales - sets out impact of COVID-19, key lessons learned, opportunities, challenges, risks, and priorities for the future (25)
- Healthy Weight; Healthy Wales: Welsh Government's long term strategy to prevent and reduce obesity in Wales (159)
- The draft Welsh Government tobacco control strategy for Wales and delivery plan is out for consultation between November 2021 and January 2022 (160)
- A health impact assessment of the "staying at home and social distancing policy" in Wales in response to the COVID-19 pandemic, published in June 2020, identified positive and negative impacts (161)

9.2.1 COVID-19

COVID-19 has had a disproportionate impact across Wales: those in more deprived communities with poorer living conditions, overcrowding, higher risk and lower paid jobs experienced worse outcomes from COVID-19 (25), and have demonstrated the overlapping and cumulative effect of the social determinants of health. Welsh Government identified four areas of COVID-19 related harm:

1. Direct harm from COVID-19
2. Harm from overwhelmed health and social care system
3. Hard from reduction in non-COVID-19 activity
4. Harm from wider societal actions and lockdown (25)

Figure 9.2 shows the number of COVID-19 cases in Cardiff and Vale University Health Board (162). The Cardiff and Vale Annual Director of Public Health 2020 report describes the impact of COVID-19 in more detail (19).



This map uses the Office for National Statistics' (ONS) middle layer super output areas (MSOAs) as defined by their 2011 boundaries. The case numbers are suppressed for any MSOA where there were fewer than three cases. The colours are defined by the decile an area falls under when ranked by their incidence per 100,000; with the highest 10% of MSOAs in Wales categorised as 1 and the lowest as 10.

Figure 9.2. A map of COVID-19 cases by Middle Super Output Area (MSOA), correct as at 04.11.2021.
Source: Public Health Wales Health Protection (162)

Direct harm from COVID-19

An estimated 42,000 people living in private households (1.4%) in Wales have self-reported long COVID of any duration (39). A social gradient is observed, with 2.1% of people in households in most deprived and 1.4% in least deprived areas experiencing long COVID for England and Wales (39). No data are currently available for Cardiff and Vale of Glamorgan on the prevalence of long COVID.

The COVID-19 age-standardised death rate per 100,000 for females in Wales was 138.1 between March 2020 and April 2021; with rates of 126.0 and 178.8 for females in the Vale of Glamorgan and Cardiff respectively. For males in Wales, the mortality rate was 220.0, with 222.5 in the Vale of Glamorgan and 325.2 in Cardiff (163).

Harm from overwhelmed health and social care system

The Audit Wales report "Taking care of the carers?" describes how the NHS has looked after its staff during the COVID-19 pandemic. Challenges in staff well-being prior to the pandemic were recognised, and so strong focus was placed on protecting staff from COVID-19 (for example, through infection prevention and control measures, and access to COVID-19 tests and vaccinations), as well as supporting mental health and psychological well-being. The report identifies the increased stress and exhaustion amongst staff, and highlights the need for continued support to prevent long term physical and mental health impacts. Investment into NHS staff to develop a motivated and healthy workforce was concluded to be essential

to the delivery of high quality health and care services that are safe, efficient and effective (164).

Welsh Government reports that health and social care services are concerned by staff fatigue, and consequent issues with recruitment and retention (25). One focus group participant expressed concern for staff providing services.

"It's how tired the NHS are: I regularly speak to my doctors and nurses and I see the strain" – service user, focus group

The homeless focus group experienced a negative impact on service provision, with delays in delivery. They recognised efforts to house homeless people during COVID-19, and the lack of evictions – but stressed that evictions were only one cause of homelessness; others included relationship failure, abuse, bereavement, and leaving prison.

Harm from reduction in non-COVID-19 activity

In the early stages of the COVID-19 pandemic, there was a reduction in GP attendances for possible cancer symptoms as well as a reduction in cancer screening, outpatient and accident and emergency attendances in Wales (25). Between March and November 2020, 3,500 fewer cancers were diagnosed compared to what might be expected for that period of time in Wales (25). Due to diversion of resources towards COVID-19, an increase in the number of patients waiting more than 36 weeks throughout the secondary care pathway was seen, alongside an increase in people waiting for diagnostic tests, and a reduction in elective procedures (25).

Harm from wider societal actions and lockdown

A total of 138,470 people were on the Shielding Patient List in Wales during the first lockdown which commenced in March 2020, with 6,000 in the Vale of Glamorgan, and 13,730 in Cardiff. In the Vale, 60 were less than 16 years, 3,395 were 16-69, and 2,545 were 70+; in Cardiff these figures were 250, 8,715, and 4,765 respectively (165). One focus group participant with a long term condition stated that COVID "*reduced your already limited areas of choice in your life*".

Around 16% of those employed in Wales worked in industries that closed at the start of the COVID-19 pandemic. Women, young people, disabled people, and those from an ethnic minority were more likely to work in those industries (166).

In the UK, COVID-19 has increased food insecurity, in particular amongst ethnic minority groups (167). Food insecurity and poverty increase the risk of hunger and obesity co-existing (167). Obesity has been associated with worse COVID-19 outcomes (25).

"The main barrier is the mental barrier that the pandemic has created in my mind" – person with a long term condition, focus group

Positive impacts

Some benefits have been observed, for example:

- Health and social care staff and patients/service users: embracing digital technological solutions including video consultation and remote working
- Community spirit: a desire to contribute, and the willingness of people to volunteer at local vaccination centres or food banks, or supporting more vulnerable members of the community, have demonstrated and developed community resilience
- Environmental: improvements in air quality through reduced traffic, as more people work from home
- Systems: successful elements of the pandemic response including demonstration of successful partnership working to create a whole system approach; and rapid implementation of diagnostic testing and digital systems (25)

9.3 What are the care and support needs?

9.3.1 Individual

Person-centred approach

The theme of wanting to be involved in decision making came from focus group participants of adults with a long term condition: *"You have to advocate for yourself otherwise you are not heard";* however, participants recognised the limits of their knowledge and wanted to be supported in such decisions.

> ***"Sometimes I am only confident to speak on things that I have knowledge of. I like people to speak for me but sometimes it's not then put as I would like it"*** – person with a long term health condition, focus group

Focus group participants mentioned issues which undermined their independence and well-being; getting support for the person they cared for was the biggest challenge they faced. Professional leads felt it was important to see the person, and not their diagnosis.

Language and communication

The National Survey for Wales reports that 11% of respondents in Cardiff and Vale were given the choice to receive treatment in Welsh or English (range 11-24% across Wales). Amongst Welsh speakers in Wales, 24% chose to receive treatment in Welsh (168). Social Care Wales report that only 2% of domiciliary care workers are fluent in Welsh and 15% have some Welsh in the Vale of Glamorgan. For Cardiff the figures are 3% and 27% (169).

9.3.2 Community

Access to health services

The 2020/21 National Survey for Wales identified that fewer respondents had seen a GP in the last 12 months compared to previously: in Cardiff and Vale, the figure was 67%, compared to 64% across Wales. The ease of booking a GP appointment in Wales was

improved in 2020/21 with 76% reporting ease (77% in Cardiff and Vale). In 2020/21, two-thirds of appointments were face to face, with 32% by telephone (152).

Most (84%) survey respondents across Wales stated they could get the right information to lead a healthy life; and 84% reported they could get the right information when unwell (152). There may be differences in access to services amongst different vulnerable groups, such as gypsy travellers, or sex workers, for example. Focus group participants who were homeless struggled to access certain services, particularly mental health services, and so were unable to make decisions about how best to deal with their complex needs. Homeless people have high prevalence of mental health disorders yet struggle to access mental health and other healthcare services. Homeless people are also more four times likely than the general population to attend the Emergency Department (170). Difficulties accessing services experienced by asylum seekers and refugees are described in chapter 20.

9.3.3 Wider determinants of health

Deprivation

A Welsh Government review of socio-economic disadvantage and inequalities of outcome published in November 2021 concludes that socio-economic disadvantage is associated with worse health outcomes, through complex mechanisms. Possible explanations include through worse access to opportunities for physical activities, poor dietary intake, and impacts on mental well-being (52).

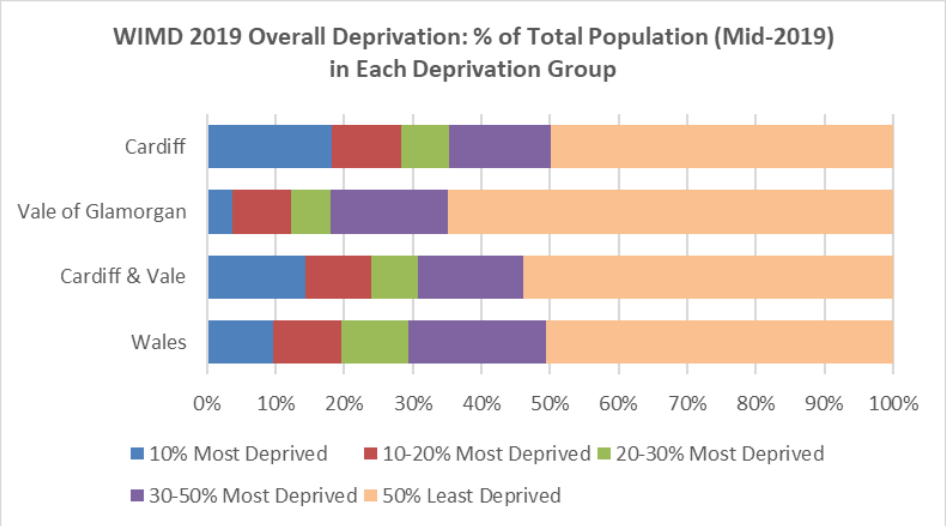


Figure 9.3. Proportion of the population in deprivation groups based on lower super output areas. Source: produced by Cardiff Council using Welsh Government data (20)

The National Survey for Wales 2019/20 identifies that 13% of adults in Cardiff and 8% in the Vale of Glamorgan live in material deprivation (a measure of poverty; the extent to which people can afford essential items such as heating and food), although this is not a significant difference (171). Figure 6.3 shows about half of the population of Cardiff live in the 50% least deprived Lower Super Output Areas, and one fifth in the 10% most deprived areas. More information can be found in Chapter 4 (Demography).

Across Wales, there is significant variation in levels of lifestyle behaviours according to deprivation:

- Smoking: 26% of those in the most deprived quintile, compared to 11% of those in the least deprived quintile
- No fruit/vegetables the day before: 12% in the most deprived compared to 6% in the least deprived quintile
- Less than 30 minutes' physical activity the week before: 41% in the most deprived compared to 26% in the least deprived quintile
- Drinking more than 14 units of alcohol/week: 13% in the most deprived quintile, compared to 21% in the least deprived quintile (note unhealthy alcohol intake is more prevalent in the least deprived group, in contrast to other risk factors) (151)

Housing

Welsh Government has recently published the draft Housing Adaptations Strategic Framework to aid the delivery of adaptations services at a local level, with an aim to operationalise this in April 2022. One of the key aims of the framework is to develop a common understanding of the demand and the need for adaptations. Adaptations can help maintain independence, reduce hospital admission and facilitate discharge, and delay or avoid residential care (141). In 2019/20, 34,341 adaptations were recorded in Wales: 55% delivered by Care & Repair, 37% by local authorities, and 8% by housing associations. Most (95%) cost £500 or less. The most common benefits for adaptations were falls prevention, followed by independent living (172).

Across Wales, 7% of adults have experienced homelessness. Those reporting 4+ adverse childhood experiences (ACEs) have were 16 times more likely to report homelessness than those without ACEs. Childhood Resilience Levels were found to protect against ACEs and were also associated with lower reporting of lived experience of homelessness. Examples of resilience assets include supportive teachers, a trusted relationship with a stable adult, and belonging to a community (170).

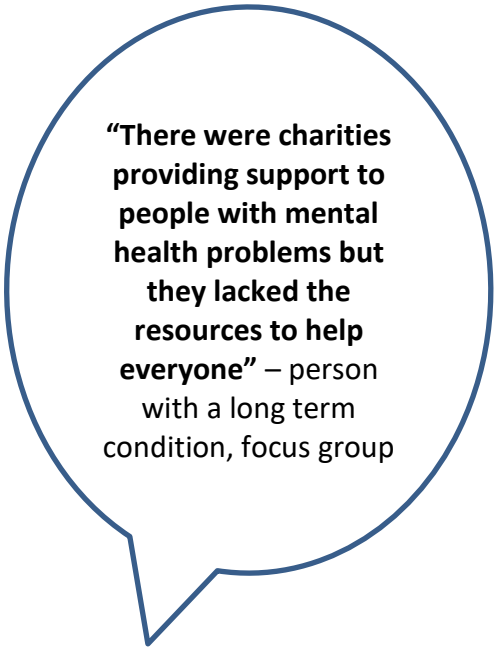
Focus group participants who were homeless felt that they had little control over what was happening to them and that they had been "*left*" homeless. The duration between referral from the Housing Options Centre to hostel accommodation was felt to take too long, which exacerbated chaotic situations. People tended to live in the immediate and did not plan for the future; delays in decisions were perceived as "*an eternity*". Participants found some rules troublesome: certain accommodation providers required people to leave by 9am, which prevented shift employment.

Housing was seen as the first key step in order to gain access to employment, healthcare, and other services, such as a key worker. Focus group participants felt that homeless people needed access to a key worker the most, but struggled to get this support. Homeless focus group participants named Huggard as critical for their independence, as without an address, they were unable to access other support. These findings were echoed in engagement conducted for the Secure Estate chapter (chapter 19).

9.3.4 Unmet needs

Focus groups have identified unmet needs:

- Mental health services linked to long term conditions: participants reported insufficient support for mental health issues associated with their situation. A number of comments were made in relation to the current support being offered via GPs with a theme coming through that people were much more likely to be directed towards medication rather than other sources of support (e.g. counselling, cognitive behavioural therapy). COVID was felt to have exacerbated the situation. Professional leads observed that early identification of mental health illness was needed, yet the culture around recognition of mental health needs often did not support this.
- Referral times: One participant stated that long referral times had effects on other aspects of life, for example, work.
- Awareness of available support: participants acknowledged that third sector organisations had variable levels of resources available; and that: "*support is there but you have to search it out*"



Gaps in knowledge included that the emerging science and research on COVID-19 and long COVID will continue to evolve. There is currently no local data on the prevalence or impact of long COVID and the potential for differential impact in different groups within the population.

9. 4 What are the range and level of services needed?

9.4.1 Prevention and assets

Prevention has a strong focus in the 'Health and Social Care in Wales – COVID-19 update', including promotion of the Healthy Weight; Healthy Wales strategy to tackle obesity and to prevent diabetes and musculo-skeletal problems. Wider determinants of health also have preventative effects, such as employment and financial resilience (25).

COVID-19 vaccination

Cardiff and Vale University Health Board have administered 383,386 first doses of the COVID-19 vaccine, 346,329 second doses, and 58,423 booster vaccines as at 31.10.2021 (173). Across the Health Board, there are inequities in vaccine coverage, for example, with lower coverage in Black, Asian, Mixed, and Other ethnic groups compared to White ethnic groups, across all age groups. Actions have been delivered to decrease the gap, with some success. Inequities are also observed across Wales between the most and least deprived areas (19).

Assets to support well-being

Assets to support people's well-being identified in the 2017 Population Needs Assessment (145) were thought to still be valid by professional leads. Engagement work identified that, at the individual level, friends, family, and peer support was helpful. Community-based assets included community projects, and third sector organisations (such as Huggard). However, it was identified that "*to benefit from their support you need to have time and resources of your own*". The Carers Gateway and Advocacy Gateway, as well as online help, were sources of support (a finding echoed in other chapters in the PNA). Statutory organisations, and Welsh Government initiatives such as Access to Work were helpful. This scheme provides funding for equipment for the workplace, travel costs; car adaptations; interpreters; and other forms of practical support (174).

"If I hadn't found the support groups online I don't think I would be here. It took me 16 years to get a diagnosis. There is no mental health support"– person with a long term condition, focus group

"I live in a very good place, I know there is support if I need it" – person with a long term condition, focus group

9.4.2 Community services

Access to services

Timely access to the services is critical, with mental health services most commonly discussed. Services should be provided in a location and format that is accessible to the user, and promotes health, well-being, and enables them to achieve what matters to them.

Long COVID rehabilitation service

Cardiff and Vale UHB have adapted the Cardiff and Vale UHB Model for Rehabilitation (further details in chapter 8) to develop the COVID-19 Rehabilitation Model. This model addresses the rehabilitation needs of those recovering from COVID, as well as those who have experienced paused planned care, those who have avoided healthcare services during periods of restrictions, and those who are socially isolated or in shielded groups. An accompanying website (www.keepingmewell.com) was launched to provide guidance (175).

9.4.3 Partnership approach

Connected services

Housing is a critical basis for employment and access to other services. Focus group participants felt *"trouble makers"* were turned away when they needed increased support for complex needs. Services should be connected so that individuals can be signposted to

more suitable sources of support. Awareness of support available should be high amongst staff working in public-facing services as well as amongst service users and bystanders.

9.5 What is likely to happen in the future?

The Welsh Government White Paper Rebalancing Care and Support remarks on the challenging climate due to: COVID-19, austerity, the complexity of the care and support landscape given the number of providers; and different commissioning bodies and funding mechanisms (87). Welsh Government aims to develop a national framework where services are designed based on quality, value, outcomes, simplicity, sustainability, partnerships, and co-production (87).

The report 'Health and Social Care in Wales – COVID-19: Looking Forward' from Welsh Government refreshes the health and social care action plan 'A Healthier Wales'. The core of the plan is a whole system approach, with people at its core, and seamless integration between health and social care services (25).

Demographic change is anticipated as outlined in chapter 4. This will impact on the anticipated prevalence of care and support needs. In terms of lifestyle behaviours, the Future Trends report predicts that smoking prevalence will decrease, whilst obesity and the proportion of people eating fewer than 5 fruit and vegetable portions a day will increase (176). The persistence of the life expectancy and healthy life expectancy gap between the least and most deprived is expected to continue in Wales (176).

Understanding the prevalence and impact of long COVID, and planning for COVID-19 recovery including building on positive impacts (such as digital progress and alternative forms of delivering care) whilst minimising harms will be a priority. A Public Health Wales report details the unequal implications of Brexit on poverty, health and well-being in Wales, in the context of the COVID-19 pandemic. For example, impacts on the labour market and consequent staff shortages in health and social care; and disproportionate impacts on the poorest and most vulnerable, for example, through increases in the price of food, or reduced funding for preventative public services (177).

9.6 Recommendations

Cardiff and the Vale of Glamorgan Local Authorities, Cardiff and Vale University Health Board, and policy makers to:

- Anticipate the impact of demographic change on future service demands
- Consider the impact of socio-economic disadvantage on service users, and how services can be provided in a way to reduce inequities, in line with the Socio-Economic Duty

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Further progress accommodation solutions that meet the needs of the service users

Cardiff and Vale University Health Board to:

- Improve access to services, with a focus on mental health services

- Continue to develop and strengthen preventative health services

Policy makers to:

- Use the Triple Challenge lens to inform policies and strategies around issues impacted by Brexit, COVID-19 and climate change, such as food systems and diet (65)

10. Physical Disability

This chapter should be read in conjunction with the following chapters: Children and Young People; Children and Young People with Complex Needs; Older People; Learning Disability; Autism; Adult Mental Health; Cognitive Impairment including Dementia; Adult Unpaid Carers; Sensory Loss and Impairment; Secure Estate; Armed Forces Service Leavers (Veterans)

Recommendations

All agencies to:

- Undertake training on disability equality
- Ensure services are accessible to disabled people; including accessible information
- Reaffirm social model of disability (73)
- Work towards a positive and inclusive culture for disabled people
- Increase awareness of job opportunities for disabled peoples, and how to apply for reasonable adjustments with improved links to Access to Work.
- Increase availability of training for disabled people to further their independence, such as travel training (112)

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Continue to promote independent living

Cardiff and Vale University Health Board to:

- Continue to consider mental health alongside physical health in service developments

10.1 Overview

This sub-theme is concerned with the care and support needs of people with disabilities, including physical disability. People with a learning disability are included in the chapters regarding Children and Young People, and Learning Disability and Autism. People with sensory loss or impairment are included in Chapter 16. The Equality Act 2010 defines disability as "*a physical or mental impairment [which has] a substantial, long-term adverse effect on a person's ability to carry out normal day-to-day activities*" (178). Of note, many reports and data sources include a range of disabilities (including physical disabilities) as per the Equality Act 2010 definition, and do not disaggregate by disability type. Where information relates to a physical disability in this chapter, this is specified.

Welsh Government use the terminology "disabled people" in their reports to refer to people with disabilities (73) (75). The most preferred term amongst focus group participants was "disabled people", so this has been used throughout this chapter. One person who

preferred to be described as a person with a disability said she did not wanted to be defined by her disability.

Data from the National Survey for Wales identified that 32% of adults aged 16 or older in Cardiff, 37% in the Vale of Glamorgan, and 34% across Wales are limited by longstanding illness. These proportions are approximately halved when asked if limited a lot by longstanding illness (16% in Cardiff, 19% in the Vale of Glamorgan, and 18% in Wales) (150).

Estimates from the Annual Population Survey show increasing numbers of adults in Wales aged 16-64 responding that they have a disability. For Wales, these figures are 267,600 in 2013/15 to 416,600 in 2017/19, which equates to 21.9% of the population (179). Figure 10.1 demonstrates the number of people aged 16-64 who reported that they have a disability according to the Equality Act 2010 definition in the Vale of Glamorgan and Cardiff, in 2018-2020. In both local authorities, 19% of the population were disabled. By age band, in both local authorities, 11% of 16-24 year olds were disabled. For people aged 24-44, 16% in the Vale of Glamorgan and 15% in Cardiff were disabled, and for those aged 45-64, the figures were 25% and 29% respectively. A higher proportion of females are disabled compared to males, in both local authorities, across all age groups, with the biggest differences in people aged 25-44 in the Vale of Glamorgan (11% males and 22% females disabled), and those aged 45-64 in Cardiff (24% males and 34% females disabled) (180).

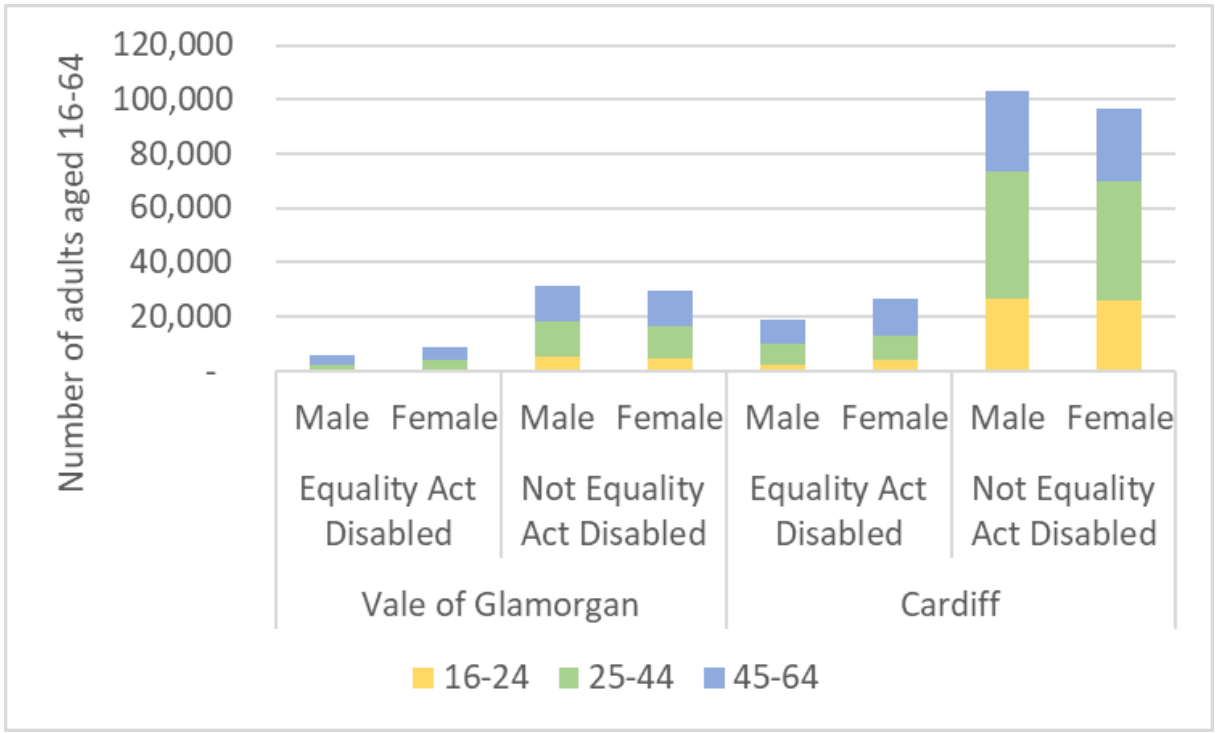


Figure 10.1. The number of people aged 16-64 who are disabled or not disabled based on the Equality Act 2010 definition by sex in the Vale of Glamorgan and Cardiff, for 2018-2020. Source: ONS (180)

Citizen voice was included from the public survey (292 respondents had a long term health condition or physical disability) and a focus group with 8 participants who had a neurological condition. Seventy-five respondents to the provider survey provided care and support services for people with a long term health condition or physical disability.

10. 2 What has changed since 2017?

10.2.1 Pre-COVID-19

Nationally, the following changes have taken place:

- Welsh Government published 'Action on Disability: The Right to Independent Living Framework and Action Plan' in 2019. The Framework defines independent living as: "*all disabled people having the same freedom, dignity, choice and control as other citizens at home, work, in education and in the community*" (75). The Framework is centred around the social model of disability, key legislation including the United Nations Convention on the Rights of Persons with Disabilities; and The Well-being of Future Generations (Wales) Act 2015 (75).
- The Disability Equality Forum published its report on the impact of COVID-19 on disabled people, entitled 'Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19'. This described the disproportionate impact that COVID-19 has had on disabled people, and identifies five overarching themes: the social versus medical model of disability; human rights; health and well-being; socio-economic disadvantages; and exclusion, accessibility, and citizenship (73).

Locally, service provision has changed as follows:

- The Cardiff and Vale Carer's Gateway was launched in 2020 in Cardiff and the Vale of Glamorgan. This provides information and support to unpaid carers in order to improve the quality of life for carers and the people they care for (181).
- The Cardiff and Vale Advocacy Gateway was developed in 2018, to provide access to advocacy for anybody who needs help to fully participate in their own care and support, including information and assistance with understanding the options available to them, and support to being heard and having control (182).

10.2.1 COVID-19

Focus group participants with a neurological condition stated that even prior to COVID-19, there were difficulties with accessing services. COVID-19 has exacerbated these difficulties, although participants felt that it was also being used "*as an excuse for poor services and inaccessible information*".

> **"*As we emerge from this pandemic, we must utilise every opportunity to improve services for everyone who needs them.*"** – person with long term neurological condition, focus group

Direct impacts of COVID-19

The 'Locked Out' report details the impact of COVID-19 on disabled people in Wales (73). Disabled people are disproportionately affected by COVID-19, with two-thirds of COVID-19 deaths in Wales being amongst disabled people. This was due to: discrimination, poverty, employment conditions, inadequate services, and inaccessible information (73). One-third of employed disabled people in Wales work in high-risk jobs (33.2%) which is higher than the general population (30.7%) (183).

In Wales, disabled people feel achievements made within the disability rights movement have been lost (73). For example, language used called disabled people *"vulnerable"* which undermined progress (73). Disabled people felt excluded physically and psychologically from public life, restricting their independence (73). Strategies did not consider individual circumstances, for example, people with visual impairment unable to socially distance or navigate restructured spaces; people with hearing impairment being unable to lip read due to masks; and increased street furniture adding difficulties for people with mobility impairments (73). However, one focus group participant identified the positive impacts of working from home to increase access to the workplace for disabled people.

Physical health

Access to medical care has been more difficult, with some conditions not being treated or treatment postponed, leading to deterioration in health for some disabled people (73), a sentiment echoed in focus groups. Focus group participants report that specialist neurological services staff were redeployed into the emergency response and this has impacted negatively on people living with neurological conditions. Virtual provision of services have been helpful. One participant, prior to COVID-19, took part in MS Society Cymru face to face active together circuit-style sessions.

> ***"… my strength grew and I was able to [take] my first steps using a walking frame. When the pandemic hit…I began to decline and was increasingly becoming unable to walk again. MS Cymru had moved exercise classes online which I joined and they helped me to begin walking once more"*** – person with a neurological condition, focus group

Mental health and well-being

In Wales, disabled people experienced a disproportionate negative impact on their mental health (73). Anxiety ratings have increased, are higher for disabled people (especially disabled women), and more disabled people worry about the impact COVID-19 has on their lives compared to non-disabled people (73).

Survey respondents with a long term condition or physical disability (n=277) mostly reported good or very good well-being before COVID-19 (60%), but this decreased over the last year (35%). Around half reported their health was around the same as before COVID-19, with a quarter reporting it had worsened a little. Focus group participants in peer support groups noted the increased need for mental health and well-being support.

Providers responding to the survey commented on changes in clients' needs: support for emotional, physical and mental well-being, financial hardship. Alternatives to face to face service provision has been challenging; and demand has increased.

> ***"I'm disabled, so can only work from home. Then suddenly everyone was working from home. Covid proved people can do their jobs from home, so more disabled people should be able to access working from home."*** – person with a neurological condition, focus group

Social care

Impacts on social care identified by focus group participants include the lack of carers available, which has had significant consequences for those reliant on help.

> ***"COVID has impacted on delivery of social care services ... I need to be put to bed at 8pm because of staffing shortages. On another day, 50 minutes after leaving me with breakfast, a different pair of carers turn up to give me lunch."*** – person with a neurological condition, focus group

10.3 What are the care and support needs?

10.3.1 Individual

Independence and advocacy

A focus group participant who used a wheelchair stated that their independence varied day by day according to whether car drivers had parked outside the house where they lived blocking their way out. Welsh Government recognises an enabling environment is needed to promote independence, considering access to wheelchair users, contrasts in rooms for people who are blind or partially sighted; and background noise levels (75). Three quarters (76%) of survey respondents with a long term health condition or physical disability felt they had full or adequate control over their life. Barriers to feeling in control included physical ability, lack of money, and emotional or mental health issues.

"The impact of COVID will go on for years and the needs of people living with neurological conditions will fall further down the priority list" – person with a neurological condition, focus group

Language and communication

The Welsh language strategic framework 'More than just words' emphasises that provision of Welsh language services is fundamental for some groups, including stroke services, and speech and language therapy services (184). One focus group participant explained the importance of care provision in Welsh.

"My first language is Welsh, I think in Welsh, I speak Welsh mainly. I struggle with English and when health and care professionals talk to me in English, I can't understand them properly. I have to take time to translate it to Welsh in my head first then think about what they've said then translate it back before I can answer. With cog fog this is so difficult and I know that I miss important things" – person with a neurological condition, focus group

Welsh Government in 'Action on Disability' makes clear that supporting the person's communication is paramount, and that individuals should not be expected to rely on others to arrange an appointment or in the consultation (75). Barriers identified during engagement for this Framework included inaccessible language and signs being too high for wheelchair users; and the subsequent impact that such barriers had on an individual's ability to travel independently (75).

Focus group participants with a visual impairment felt as though they had to constantly inform care providers of their need for accessible formats of information, and felt this had been worsened with COVID-19.

10.3.2 Community

Medical care

Provision of sufficient medical services to manage health conditions is needed. People in Wales with disabilities are more likely to experience mental health concerns (75). Focus group participants sought to emphasise the importance of helping people with their mental health problems at the same time as providing support to them for their long term physical health conditions.

> ***"Physical and mental health are like hand and glove"*** – person with a long term condition, focus group

Transport

Access to transport was identified as a need in the focus group as well as through other engagement work. Transport is a prerequisite for education, employment, exercise, appointments, and socialisation; a lack of transportation contributes to loneliness and lack of independence (75). Access to public transport includes needing physical space for wheelchair(s); the option to not book in advance; supportive staff members; and having bystander awareness and support (75). Barriers include poor pavement conditions and obstructive parking outside. Public sector buildings such as hospitals and leisure centres can be challenging due to a lack of lifts and toilet/changing facilities in Wales (75).

10.3.3 Wider determinants of health

Deprivation

Disabled people are more likely to live in deprived areas. In Wales, 8.1% of non-disabled people aged 16-64 live in the most deprived 10% of small areas in Wales, compared to 13.8% of disabled people of the same age who live in these areas (73). One-third of children living in a household with a disabled person were living in relative income poverty, compared to one-quarter of children in a household without a disabled person (73). COVID-19 has exacerbated pre-existing financial inequalities in Wales, with more disabled people reporting falling behind on bills (16% compared to 7% of non-disabled people) (73).

Welsh Government report that 14.5% of people in employment in Wales are disabled. The employment rate amongst disabled adults is 48.5%, and 80.6% amongst non-disabled adults (73). In the Vale of Glamorgan, the percentage of disabled people in employment has increased from 42% in 2014, to 59% in 2020. For Cardiff, the figures are 47% and 56% respectively. The gap between those in employment with and without disabilities has narrowed in the same period, from 36% in the Vale in 2014, to 20% in 2020; and from 25% to 22% in Cardiff. In the Vale, a higher proportion of females with disabilities were employed compared to males between 2014 and 2020. In Cardiff, since 2018, a higher proportion of males with disabilities have been employed than females (185). In Wales, disabled people are more likely to have lower paid, insecure jobs, and often choose freelance work in order to accommodate their needs (73). A higher proportion of employed

disabled people working in high risk occupations (with high potential exposure to COVID-19) compared to non-disabled people (73).

Welsh Government comments on the "*unacceptable*" nature of sustained disadvantage through these wider determinants of health (75). Across the UK, people with disabilities have experienced more food insecurity: people who have severe disabilities are five times more likely to be food insecure (167).

Survey respondents with a long term condition or physical disability were mostly able to keep up with bills (83%); had a small amount of money to spend on themselves (79%); and were able to keep their home warm in winter (74%). Therefore, a significant minority are really struggling to meet their financial needs.

Education and employment

The disability employment gap has increased in Wales, with disabled people being half as likely to be employed as people without disabilities (186). People with disabilities experience barriers to education and employment, which can be overcome through reasonable adjustment policies in Wales (75). Some disabled people may need assistance with finding a job; physical barriers such as transport and building access may prove prohibitive. Welsh Government reports that young disabled people can co-produce innovative and low cost solutions to enable them to gain the employment they want (75). Improved signposting and awareness to supportive schemes (such as Access to Work) for both disabled people and prospective employers was identified as a need by Welsh residents (75).

Housing

Most disabled people in Wales live in rented homes rather than owning their homes, with 46% of disabled people and 28% of non-disabled people in rented homes (73). Barriers to obtaining a mortgage include how benefit payments are considered, and the types of employment disabled people are more likely to have (73). Finding private rented accommodation that meets accessibility requirements may be more expensive and isolating (75). There is a recognised shortage of suitable and accessible housing (73) as new builds do not take accessibility needs into account, despite an ageing population. Fears around COVID-19 transmission risks have led to a reduction in requests for adaptations to housing in Wales (73).

Disabled people in Wales are more likely to live in overcrowded conditions (183). In 2018/19, 11% of Section 75 assessments (households who are eligible, unintentionally homeless, in priority need, and owed housing under the Housing (Wales) Act 2014) were from households where a member was vulnerable due to a physical disability (183).

People with a disability are more likely to have experienced domestic abuse than non-disabled adults aged 16-74; with prevalence at 7.5% and 3.2% respectively for men, and 14.7% and 6.0% for women in England and Wales (183). Within focus groups conducted for this report, there were participants who had experienced VAWDASV and a disability,

demonstrating the need for cross-sectoral thinking to ensure that housing is both suitable and safe.

10.3.4 Unmet needs

A number of unmet needs were identified in reports and engagement work:

- Person-focused care: For example, some disabled young people were unable to access sexual health services due to their disability (75). Financial pressures have resulted in closure of some services and groups, which negatively impacts disabled people's social inclusion (75). Survey respondents identified barriers to accessing support services, including emotional and mental health, lack of confidence, and transport.
- Medical care: delays in new treatments becoming available; holistic post-diagnostic support; support in between appointments; medical care closer to home; specialist psychological support
- Rehabilitation: focus group participants wanted access to rehabilitation services longer than the 6 weeks offered
- Respite: Focus groups identified that respite care could be improved; this was also discussed in the engagement for 'Action on Disability' by Welsh Government (75)
- Lack of domiciliary carers: a perception that carers had left their jobs to work elsewhere
- Understanding of long-term conditions: the 'Locked Out' report identifies thoughtlessness as a key contributor to disabled people not feeling valued, and feeling excluded through lack of access to essential services (73). Focus group participants reported a lack of understanding of their conditions by medical staff

Gaps in knowledge and understanding were identified: a lack of data on access to healthcare services for disabled people (186), although we have clear information on access to primary care assessments for people with learning disabilities

10. 4 What are the range and level of services needed?

10.4.1 Prevention and assets

Advocacy is a key tool for prevention; assisting with signposting to the right support. Information on services must be up to date to facilitate the individual receiving the right help from the right service at the right time. Information must be accessible to service users, taking their communication needs into account according to Welsh Government (75). Additionally, the Action on Disability framework calls for early intervention from health or social care as appropriate, so that a crisis point is not reached (75).

Employment

Welsh Government cites Disability Champions and disability award schemes as a mechanism by which to increase work opportunities (73), or through inclusive recruitment and Disability Confident Schemes (187). Prominent advertising of how to arrange reasonable adjustments within job descriptions and applications, as well as in the workplace, should help recruitment and retention.

Assets to support well-being

Professional leads identified that assets in the 2017 Population Needs Assessment (145) are still valid. Subsequent reports and engagement work have identified the following as particularly relevant at a community level: the Carers Gateway and Advocacy Gateway (identified by professional leads), as well as day centres, where service users appreciate the familiarity of the environment. Third sector organisations such as MS Society Cymru and Dystonia Society Cardiff and Vale Facebook group; as well as third sector helplines, peer support groups, online forums, and a wide range of other resources were valued. Access to higher education was improved through Disabled Students Allowance (75). Employment was identified to support independence, promote confidence, and build social networks (75). Children in Wales Getting More Involved in Social Care project enables young disabled people to train peers and professionals on participation, and have developed an app on exercising their rights (75). The Education Programme for Patients Cymru who provide self-management courses for people with a long term condition was identified by professional leads as supportive.

"I've only been out of the house three times since March 2020. I've always been independent and giving the reigns to somebody else has been difficult. But I've had to get used to it. Through MS Cymru I'm now doing tai chi, physio, yoga, coffee mornings, bingo, quizzes, knitting and crafts, choir and Time to Chat online. I'm so busy now I wonder, what did I do with my time before? I'm meeting with people living with MS from around Wales and the rest of the UK who I wouldn't have met ordinarily. It's wonderful making new friends" – person with a neurological condition, focus group

10.4.2 Community services

Signposting between services

One focus group participant stated of support services: *"It's an art to find out what's available"*. Signposting between different organisations, including for housing and benefits advice, would improve service user awareness. Half of survey respondents found it difficult to find information and advice available to them; suggesting respondents were not adequately signposted to advocacy services to assist them in finding and understanding information.

10.4.3 Partnership approach

Sustainable services

Many disabled people cited concerns around funding cuts; increasing pressure on services to meet needs; and their own deteriorating health. One focus group participant stated: "*Social care is in crisis and the most vulnerable will be left to fend for ourselves*". Providers' concerns for the future included funding, demand-resource mismatch, and staff shortages.

Culture and Attitudes

Disabled people experience hate crime: South Wales Police recorded 181 incidences of hate crime due to disability in 2018/19 (Wales total 443); and 8,256 for England and Wales combined. Since 2011/12, there has been a year on year increase in the number of recorded hate crime due to disability in England and Wales, with a 49% increase in numbers between 2016/17 and 2018/19. However, hate crime incidents recorded by South Wales Police between 2014/15 and 2018/19 have fluctuated between 137 and 218 (188).

To combat this, a supportive and enabling culture is needed: including an environment that promotes people's independence, and the presence of role models and prominent figures. For example, work is ongoing to overcome barriers (such as negative attitudes, physical access, and lack of communication support) to people with disabilities gaining public leadership roles such as local councillors (75). Staff training, including inclusion and diversity, is already incorporated in many workplaces. Educational material needs to be co-produced by people with disabilities (73). Focus group participants asked for service user participation, underpinned by a co-production and participation strategy to be developed.

10.5 What is likely to happen in the future?

The predicted number of people aged 65+ who struggle with activities of daily living is anticipated to increase by 38% from 22,845 in 2020 to 31,424 by 2040 in Cardiff and the Vale of Glamorgan (189). Although there are more females than males who are predicted to have difficulties with essential tasks; males will have more of an increase (40% compared to 36%). The greatest number of people and the greatest increase will be seen in the 80+ age group (189). These figures should, however, be interpreted with caution as estimates become increasingly uncertain the further into the future they project.

The White Paper on Rebalancing Care and Support observes the increasing care and support interventions to meet the needs of people who are disabled, or have severe long term illnesses, and are living longer (87).

10.6 Recommendations

All agencies to:

- Undertake training on disability equality
- Ensure services are accessible to disabled people; including accessible information
- Reaffirm social model of disability (73)
- Work towards a positive and inclusive culture for disabled people
- Increase awareness of job opportunities for disabled peoples, and how to apply for reasonable adjustments with improved links to Access to Work.

- Increase availability of training for disabled people to further their independence, such as travel training (112)

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Continue to promote independent living

Cardiff and Vale University Health Board to:

- Continue to consider mental health alongside physical health in service developments

11. Learning Disability

This chapter should be read in conjunction with the following chapters: Children and Young People with Complex Needs; Physical Disability; Adult Unpaid Carers; Sensory Loss and Impairment

Recommendations

Third sector, Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to base services on co-production; individual care and support plans should also be co-produced
- Focus services towards what is important for the individual, such as encouraging an active independent lifestyle, and promotion of friendships
- Build on existing provision to provide opportunities for work and activities, as per the Cardiff and Vale of Glamorgan Joint Commissioning Strategy (78)
- Ensure information provided is accessible and jargon free to improve service access and maximise their impact
- Identify and mitigate against inequities amongst people with learning disability

Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to promote the "community first" approach when planning placements and accommodation

Cardiff and Vale University Health Board to:

- Continue to improve uptake of annual health checks and screening

11.1 Overview

A learning disability is identified when an individual has a significantly reduced ability to understand new or complex information, to learn new skills with difficulties coping independently, which started before adulthood (86). Welsh Government has adopted the social model of disability, and it should be noted that although the term "*people with learning disabilities*" does not align with this model, this is currently the preferred term amongst members of All Wales People First (73). This chapter focusses on adults; children with learning disability are discussed in chapter 6.

The Cardiff and Vale of Glamorgan Joint Commissioning Strategy for Adults with Learning Disability 2019-2024 states that, in 2017, there were 7,081 adults in Cardiff estimated to have a learning disability, of whom 1,175 received support from the Learning Disability Services (equal to 78% of people with a moderate or severe learning disability). For the Vale of Glamorgan, 2,400 adults were estimated to have a learning disability, of whom 448

received support from Learning Disability Services. This represents 90% of those with a moderate or severe learning disability (78).

There is a voluntary register held within each local authority which has more up to date data, but this underestimates the number of people with learning disability: in Cardiff, there were 1,389 people with learning disability on the register in 2018/19; in the Vale of Glamorgan there were 496 people with learning disability on the register during this time period (190).

Engagement was conducted with 20 participants who attended one of three focus groups. In addition, 27 respondents to the public survey stated they had a learning disability or autism; and 61 respondents to the provider survey provided services for people with learning disability or autism. Their views are not representative of the population of people with learning disability in Cardiff and the Vale of Glamorgan, but provide depth of insight to complement other data sources.

11.2 What has changed since 2017?

11.2.1 Prior to COVID-19

The following changes have taken place since the previous Population Needs Assessment.
Nationally:

- Learning Disability Improving Lives Programme (2018), which promotes community support to reduce admissions, and promote early discharge (191).
- Improving Care, Improving Lives report by the National Collaborative Commissioning Unit in 2020, which highlights the care received by inpatients in learning disability hospitals (90).
- Reducing Restrictive Practice Framework in 2021 which applies to health and social care, education, and childcare settings (192).

Regionally:

- Cardiff and Vale Learning Disability Needs Assessment was published in 2018 (86).
- Publication of the Cardiff and Vale Joint Commissioning Strategy for Adults with Learning Disability in 2019 (78).
- Cardiff and Vale UHB service improvements including implementation in 2018 of 120 Learning Disability Champions in the University Health Board; two new UHB Acute Liaison Nurses in 2020; a daily report notifying of all inpatients with a learning disability; Easy Read feedback questionnaires; and launch of the "1000 Lives" care bundle (40).
- In Cardiff, a transition day service was developed for young people with complex needs and a further education college course for young people with complex needs is being piloted; child to adult services transition were improved through social services systems and staffing; and a support planner service that through person centred planning, supported people to access a wide range of inclusive community opportunities prior to COVID-19. The Vale of Glamorgan has a complex needs day service and young people are accessing community opportunities and college courses at Cardiff and Vale Barry college site.

11.2.2 COVID-19

Health impacts of COVID-19 on people with learning disability

In Wales, COVID-19 has disproportionately affected people with learning disability, resulting in a higher mortality rate not due directly to the learning disability, but due to other factors (73). Analysis of mortality data from March to May 2020 demonstrated a higher rate in the people with a learning disability as compared to the general population (193). Further analysis of data is needed to identify the direct impacts of COVID-19 on mortality and morbidity at the health board level. Professional leads have identified that people, their families, and service providers have worked hard to support people to remain safe.

People with learning disability are in a priority group for COVID-19 vaccination. However, getting the vaccination for COVID-19 has been challenging for some as learning disability was not recorded in their primary care medical records in Wales. The immunisation experience was reported to be better in the presence of a family member or carer; a healthcare professional who took additional time to explain the process; and personalised approaches to the vaccination such as administration at home or in the car (194).

The three Easy Read survey respondents reported neutral or good well-being before COVID-19 and currently. They felt their health is the same or better now than before COVID-19. One focus group participant was concerned about their weight: "*put on too much weight lately"* and praised interactions with the dietitian.

Carers of people with learning disability in Wales report fatigue and stress (194). A minority of carers in a Learning Disability Wales report had received respite (194).

Impact of COVID-19 restrictions

Focus group participants (n=20) identified COVID-19 restrictions as a barrier to doing what matters to them through the closure of community organisations; and the impact of physical distancing, limiting social interactions. Learning Disability Wales report that some school students who were unable to understand the restrictions, blamed school staff for limitations on socialisation, which had a negative impact on relationships between staff and students (194).

Welsh Government reported that those shielding have experienced loneliness and depression (73). Restrictions have negatively impacted relationships and people's sense of independence (73). Differing restrictions at different periods of time in different areas have contributed to stress and anxiety – in particular for individuals living in shared households (73).

The lack of face to face services is challenging for many service users, professionals, and carers. However, some people with learning disability have seen the reduction in services or virtual services as beneficial; and have identified new ways of connecting with others using digital platforms (73). Professional leads reported that some individuals preferred virtual communications, and increased access to services especially for those in the Vale of

Glamorgan, where transport may be difficult. In planning COVID-19 recovery, individuals' communication preferences should be taken into account.

A Learning Disability Wales report has identified a positive impact of COVID-19; stating "*new opportunities to learn skills previously not available to [people with learning disabilities] have emerged, which it was previously wrongly assumed would be beyond their capabilities*" (73).

Impact of COVID-19 on service delivery

Providers of care and support for people with learning disability and autistic people responding to the PNA survey identified that service users were: increasingly reliant on family members; had difficulties with isolation, mental health, financial hardship, and increasing challenging behaviours; and a lack of respite for carers.

Professional leads reported that staffing of services was challenging, with difficulties in recruitment and retention including of agency staff. In Cardiff and the Vale of Glamorgan, staff teams have transitioned to working at home. Services have worked hard to support staff wellbeing and develop new ways of working to meet local needs and outcomes. Many mainstream and specialist day opportunities temporarily closed during the pandemic. The local authorities were able to maintain complex day services albeit at reduced capacity. Third sector and private providers worked hard to maintain contact with individuals known to them and services reopened when government guidance allowed and worked to increase capacity as it becomes safe. Respite services continued but at a much reduced capacity during this period.

11.3 What are the care and support needs?

Many of the needs identified in the 2017 Population Needs Assessment remain valid.

11.3.1 Individual

Health

People with learning disability are more likely to have or develop other comorbidities; and face additional barriers to investigation and diagnosis. For example, 40% will develop moderate/severe hearing loss but are less likely to receive a diagnosis than the general population; 25-40% will develop mental health problems but these may not be diagnosed as they may be attributed to the learning disability. Dementia, vision loss, epilepsy and other conditions are much higher in people with learning disability than the general population (78) (86) (90). Dementia often presents at a younger age in people with learning disability, and is more prevalent: 22% amongst people with learning disability, and 5% in the general population aged 65+ (86).

The Royal National Institute of Blind People (RNIB) estimate that 10% of people with learning disability are blind or partially sighted and those living on their own are less likely to have received a recent eye examination than those living with support staff (86) (195). In Cardiff and the Vale of Glamorgan, an estimated 3,792 adults have learning disability and moderate/severe hearing loss (86).

Behaviours of concern can be prevalent in children and often persist without intervention; this increases the risk of substance misuse, mental health issues, and interaction with the criminal justice system (86).

Language and communication

Data from 2017 identified only 13 adults with learning disabilities in Cardiff who were Welsh speakers. This is anticipated to increase as more children and young people receive Welsh medium education (78).

Survey respondents wanted better support and wider understanding of non-verbal communication, and increased access to Makaton. Easy Read survey respondents wanted people to speak calmly, plainly, and without jargon. The small number of respondents to both surveys is acknowledged, and is not representative of the wider population of people with learning disability.

Friendships and relationships

Friendships, family, and partners are important to people with learning disability: *"Going on holiday with my mum, going on holiday with our group"*. The Cardiff and Vale of Glamorgan Joint Commissioning Strategy consultation identified the need for an active, fun social life for adults with learning disability (78).

Prior to COVID-19, 13/24 survey respondents said they felt lonely some or all of the time, whereas now 18/24 feel lonely. Easy Read survey respondents stated they spend some or lots of time with other people; as they did before COVID-19. All three respondents received help from family, a friend or a neighbour.

11.3.2 Community

Supported Autonomy and Co-Production

Professional leads observed that routine involvement of people with learning disabilities in consultations had improved, however, true co-production should be the aim. The Cardiff and Vale of Glamorgan Joint Commissioning Strategy includes co-production, collaboration, choice and control through listening and jointly finding solutions (78).

> ***"I ask my family for advice, they say it's my decision in the end"*** **–** person with learning disability, focus group

Focus group participants had strong opinions about their rights to independence and decision making, and believed that they exercise those rights: "*I speak for myself and contribute to the decisions that affect my life, or have someone who can do it for me"; "Nobody tells me what to do".* Some did acknowledge that this was within a framework of boundaries set by others: "*It's right for other people to advise, if they think it's the wrong decision they have to step in*". However, one person demonstrated increased reliance: "*I rely on other people to steer me and tell me what to do"*. Future independence was linked to moving into their own place with friends or a partner, but participants were

aware that their learning disabilities may make this challenging: "*I have dyscalculia, how am I ever going to move out and pay my bills?*"

Survey respondents with learning disability or autism mostly reported having adequate or full control over their lives (16/24); whereas 7 stated they had no or low control. All three Easy Read survey respondents reported they feel they are treated with respect, and that their voice was heard in decisions regarding their care and support.

Health care

Difficulties accessing healthcare was commented on in the focus group.

> ***"Doctors are all automated, you can't get a service, I just want to phone someone and make an appointment I can't do it online"***
> – person with a learning disability, focus group

A Wales-wide report on health care for people with learning disabilities identified concerns that not all people with learning disability had an up to date care plan with input from the full multi-professional team, however, many were positive regarding their care (90). The review noted that a community-first approach to care should be taken to avoid inappropriate or lengthy hospital admissions, and transitions should be carefully planned with all agencies involved (90). Restrictive interventions should be kept as a last resort (90) and a holistic approach should be employed to managing or preventing such use. Previous engagement identified the need for accessible and understandable information provision, the right support at the right time (including early, crisis, respite, and specialist support), and smooth transitions between children's and adult services (78).

Professional leads identified the importance of providing reasonable adjustments to improve access to healthcare. The Cardiff and Vale of Glamorgan Joint Commissioning Strategy will work towards this through co-production with the Learning Disabilities Partnership Group; and recruiting a Learning Disability Liaison Nurse to work in Cardiff and Vale UHB (78).

Transport

Affordable, accessible transport and access to assets were identified in focus groups. Professional leads observed that this is especially important in the Vale of Glamorgan due to its rurality. Focus group participants wanted to feel safe in their local community, for example, when walking the dog.

11.3.3 Wider determinants of health

Deprivation

There are no local data available on deprivation and learning disability; however, it is recognised more widely that social determinants of health including material deprivation (a measure of poverty; the extent to which people can afford essential items such as heating

and food (171)), contribute to the inequalities in health experienced by people with learning disability (86).

Focus group participants discussed their desire for good, secure, paid work – and emphasised the importance of work for their mental health. Financial worries impact on other decisions: "*Worried about financial things if I move, where do you start with all the bills?"* In both Cardiff and the Vale of Glamorgan, a Support Planning Service helps people identify vocational and leisure activities, such as voluntary work and community groups (78).

Easy Read survey respondents reported that they had a small amount of money to spend on themselves each week, and that they were able to pay bills and debts on time.

Education and employment

Focus group participants expressed their desire for a job, and were positive about getting support at work to help them do what matters to them. Small numbers of people with learning disabilities are undertaking foundation apprenticeships or traineeships (40 in Cardiff; 15 in the Vale of Glamorgan) (196). Professional leads identified establishment of roles with local colleges (such as Cardiff and Vale College) so that those who are unable to undertake a full course can still gain experience and life skills. Curriculum pillars on the Personalised Learning Pathway at Cardiff and Vale College include health and well-being, employability, community, and independence (197).

Complex day opportunities have improved in both Cardiff and the Vale of Glamorgan. Professional leads identified that Cardiff is skilled in positive behavioural support whereas the Vale of Glamorgan is skilled in dealing with complex health needs. Further development aims to provide holistic services in both areas. A pilot has been undertaken in Cardiff and Vale to increase day opportunities for those transitioning from school, through the development of an adult plan to enable people to stay local and reduce the number of people moving out of area for residential college. This has been positively received by people with learning disabilities, their families, and school staff; enabling people to maintain friendships and support networks (78).

Survey respondents with learning disability or autism were mostly in work or education prior to COVID-19 (15/24), and currently 14/24 remain in work or education. Four did not work due to illness or disability; and three were caring for a family member. Note that these are small numbers that are not representative of the wider community of people with learning disabilities.

Housing

Community placements for people with learning disability are offered in the person's own home, with parents/family, in foster home, or in lodgings/supported living, and should be considered the default for most people. For people in crisis, specialised community care should be the first port of call, with inpatient care reserved for those who cannot be safely managed in the community (90). A 2018 needs assessment for Cardiff and the Vale UHB identified that approximately 50% of people with learning disability were living in their own homes (86).

Of the 390 people open to the Vale of Glamorgan learning disability team in 2021, 71 were in supported accommodation and 46 in residential placements (including residential homes for older people, residential college and in and out of county placements). In addition, there were 23 households supporting 32 individuals in long-term adult placement (29). Seventeen people are in residential placements funded by Cardiff and Vale UHB (198).

In 2021, in Cardiff, there were 310 people living in local supported living accommodation, 26 people in adult placement, 109 people live in residential provision funded or part funded by Cardiff Council, and 41 people live in residential care funded by Cardiff and Vale UHB (30).

The Closer to Home Project within the Cardiff Housing Strategy aims to avoid out of area placements (83). In the Vale of Glamorgan, the Supporting People Programme has prioritised the provision of additional adult placements for people with learning difficulties or mental health issues (199). The Cardiff and Vale of Glamorgan Joint Commissioning Strategy prioritises "*having my own home*"; which will support people's independence, for example, developing the Adult Placement Service to enable friends to live together, as well as reducing the number of people placed out of area (78). Both Cardiff and the Vale of Glamorgan provide support for independent living that enables people and their families to have confidence in paying bills and dealing with safety at home.

Needs identified by focus group participants included addressing the long waiting list to move house; living more independently for example with a partner or friends; and being provided with more details on the property before moving in. Participants understood "*home*" to be a way of living and the people you live with rather than the physical building, therefore no responses were given around housing conditions; although it was felt that mental health needs needed to be taken into account by housing support services. Participants who lived on their own linked it to their independence*: "I'm quite happy and carefree".* These responses are in line with other engagement work in Cardiff and Vale of Glamorgan (78).

"I really enjoy doing my own thing, I feel more confident and independent, now I catch the bus on my own so it makes me feel more independent" – person with learning disability who lives on their own, focus group

11.3.4 Unmet needs

Engagement work and professional leads have identified the following areas of unmet need:

- Independence: a need for support for independent living that enables people (and their families) to have confidence in activities such as paying bills and dealing with safety at home
- Healthcare services: difficulties making an appointment; a need for more specialised mental health services; lack of forensic services for people with learning disability
- Employment: a need for more good quality secure jobs with support

The following gaps in knowledge were identified:

- Estimated numbers of people with learning disability are known, but comprehensive confirmed figures are not available
- Deprivation levels in populations of people with learning disability
- Sexual health needs amongst people with learning disability

11. 4 What are the range and level of services needed?

11.4.1 Prevention and assets

Prevention of comorbidities is crucial; especially given the increased prevalence of additional medical diagnoses amongst people with learning disability. Based on a regional needs assessment, people with learning disability are more likely to be under- or over-weight (73); weight management is therefore important and dietitians were respected in focus group discussions. However, other lifestyle risk factors such as smoking and drinking are at a lower prevalence amongst people with learning disability (73), and so may not require focussed attention to the same extent. Wider social determinants of health including having supportive communities are also preventative and key to well-being.

In 2016/17, 45% of people who were on the learning disabilities register in Cardiff and Vale had a health check with their GP (78). In 2019/20, of the 2158 patients on the GP learning disability register, 854 (36%) received an annual health check (38).

Focus groups and survey respondents identified many assets as supportive to their well-being. At a personal level, family, friends, partners, and pets were supportive: "*Walking my dog, he makes me happy*". However, some people were anxious about encountering things they were scared of, such as fireworks, and people on bicycles. Family were seen to facilitate access to services. People within the local community made focus group participants feel welcome, for example "*they know who I am, when I moved here my mental health got better*"; "*out in the street I feel independent, people make me feel like I am treated OK and not judged*".

The following organisations working within the local community were identified:

- Third sector organisations such as Cardiff People First, Vale People First, and Newport People First were identified as supporting people to make their own choices: *"[it] makes me happy"*. Voluntary work within local charities was appreciated

- Groups that provided a sense of purpose and social interaction were especially valued. These included local community assets such as church, cafes, local shops, green places for walking, exercise classes, and adult education
- Local Authority services such as social workers, and NHS services, for example dietitians

"[named staff member] is a very good listener, I can call her any time" – person with learning disability, focus group

Professional leads identified Dewis Cymru as a helpful resource.

11.4.2 Community services

Healthcare services

Healthcare services need to be aware of the high prevalence of comorbidities in people with learning disability. The higher mortality experienced by people with learning disability needs to be addressed as a priority in planning future services. Services need to provide early intervention, specialist intervention, and adopt a community-first approach (86). People with learning disability wanted to access healthcare themselves, for example over the telephone rather than booking an appointment online; services should consider the preferred method of communication by service users.

Work, volunteering and day opportunities

The Cardiff and Vale of Glamorgan Joint Commissioning Strategy promotes work, volunteering and day opportunities; people remarked on the positive impact in terms of confidence and independence. Existing services include day services, support planners (who work with people to understand their wishes in the development of care packages), and links with a number of third sector organisations and community groups. Future plans include focusing on people transitioning from child to adult services and building further links to develop more opportunities (78). Professional leads state that Cardiff Council have the Into Work scheme, providing specialist employment support for people with learning disabilities. The Vale of Glamorgan Council has Vale Communities for Work, a free programme that, through specialist support, helps job seekers in the Vale to access employment and volunteering opportunities.

"After college, 'T' was very isolated at home with few friends. A support planner helped them identify what they wanted to do and learn. This included confidence with travelling, making friends, doing an IT course, learning a sport and working towards employment. They were supported to find a full week of opportunities including IT courses, interest based social clubs, tennis lessons, and a referral to 'into work' which will support training, confidence building, and seeking employment" – case study, role of the support planner (30)

11.4.3 Partnership approach

Co-production is a keystone in current service provision The Cardiff and Vale Joint Commissioning Strategy plans to expand on this, for example, through including service users in contract monitoring and review meetings (78). Focus groups organisers reported that participants "*were very pleased to do this focus group and would like to do more, it made them feel more independent and like their opinions matter*". Provider survey respondents recommend availability of clear information free of jargon, and provision of documents in Easy Read including clock times.

11.5 What is likely to happen in the future?

The Cardiff and Vale Joint Commissioning Strategy estimates that the number of adults with learning disabilities in Cardiff will increase by 125 between 2017 and 2025; and will stay stable in the Vale of Glamorgan (78). In line with wider demographic changes, the population of people with learning disability is aging. In addition, people with learning disability have increased likelihood of development of other comorbidities such as dementia (78) (90), which will increase demand for and change the nature of care and support needs (87).

The Liberty Protection Safeguards will apply from April 2022 onwards, and protect people aged 16 and above who need treatment through deprivation of liberty but are unable to consent (200).

11.6 Recommendations

Third sector, Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to base services on co-production; individual care and support plans should also be co-produced
- Focus services towards what is important for the individual, such as encouraging an active independent lifestyle, and promotion of friendships
- Build on existing provision to provide opportunities for work and activities, as per the Cardiff and Vale of Glamorgan Joint Commissioning Strategy (78)
- Ensure information provided is accessible and jargon free to improve service access and maximise their impact
- Identify and mitigate against inequities amongst people with learning disability

Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to promote the "community first" approach when planning placements and accommodation

Cardiff and Vale University Health Board to:

- Continue to improve uptake of annual health checks and screening

12. Autism

This chapter should be read in conjunction with the following chapters: Children and Young People with Complex Needs; Healthy Lifestyles and Long Term Conditions; Physical Disability; Adult Unpaid Carers; Sensory Loss and Impairment

Recommendations

Third sector, Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to develop opportunities for co-production, and the involvement of autistic people in decisions around their care and support plans
- Improve data collection to better understand the number of autistic people, and associations with socio-economic deprivation and language needs.
- Embed the Code of Practice in the delivery of Autism Services
- Develop inclusive recruitment, for example, through the Disability Confident Scheme (187) or Positive About Working with Autism Programme (71)
- Improve wider societal awareness of autism and develop a supportive culture

Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop accessible and flexible respite services

Cardiff and Vale University Health Board to:

- Reduce waiting list times for assessment by the Integrated Autism Service

12.1 Overview

Autism spectrum disorder describes "*the group of complex neurodevelopmental symptoms, of variable severity, that are characterised by challenges in social interaction and communication and by restricted or repetitive patterns of behaviour, thought and sensory feelings*". Language in this chapter will align with the Welsh Government's Code of Practice on the Delivery of Autism Services, where "*autistic people*" is used instead of "*people with autism*", as preferred by those who contributed to the document (72).

In Cardiff, there are 1,370 autistic children and young people aged 0-17, and 509 in the Vale of Glamorgan. For those aged 18+, there are 3,201 autistic people aged 18+ in Cardiff, and 1,165 in the Vale of Glamorgan (88). Note that not all autistic people will have been diagnosed. The needs of autistic children and young people are considered in chapter 6.

The content of this chapter was developed using existing literature, strategies and reports and triangulating findings with professional leads and engagement work (27 survey respondents who had learning disability or autism (note that not all respondents answered all questions); 1 autistic person in an interview; and 61 respondents of the provider survey

supported people with learning disability or autism). It should be noted that the views of those engaged are not representative of all autistic people in the population of Cardiff and the Vale of Glamorgan, but do provide rich information about their lived experiences.

12.2 What has changed since 2017?

12.2.1 Pre-COVID-19

Nationally, the following has been implemented since the 2017 Population Needs Assessment:

- The Autistic Spectrum Disorder Updated Delivery Plan 2018-2021 was published (71), as well as the Code of Practice on the Delivery of Autism Services 2021 (72). The Code sets out the range of support services for assessment, diagnosis, health and social care and broader work around training and awareness raising.

Within Cardiff and Vale University Health Board:

- The Integrated Autism Service (IAS) was formally launched in Cardiff and Vale in September 2017, although it has been operational since September 2016.

12.2.1 COVID-19

Mental health

Across Wales, negative mental health impacts were particularly significant for autistic people during the pandemic, specifically depression and anxiety. This may be linked to social isolation and the financial impacts of COVID-19 restrictions (73). Lack of access to self-help activities further compound isolation (73). The 'Locked Out' report intersectionality reference group reported that following cessation of support for young trans people, trans autistic people had particular difficulty (73). The report identified that ambiguity around regulations has been particularly stressful for autistic people, in part due to "*vigilantism"* by others (73).

An interview conducted for the Population Needs Assessment identified the following concerns: "*my office closed because of COVID, I'm worried I might have forgotten how to do some of the things in my job. I was worried about going on the bus or being in busy places"*. Prior to COVID-19, 13 of 24 survey respondents felt lonely some or all of the time, whereas by October 2021, 18 of 24 felt lonely.

Impact on care and support provision

Face to face services were paused in line with government restrictions. For some clients and staff, this was difficult due to a reduction in access to services, or a dislike of alternative provisions of care (for example, virtual appointments). For some carers, this exacerbated stress and fatigue. However, for some service users, the lack of face to face services was beneficial, as the demands offered were reduced. In addition, for those who lacked transport, virtual services are more accessible.

The IAS had increased waiting times for new appointments and as at August 2021 it was 18 months (201). The Delivery Plan recommends a 26 week waiting time target from referral to assessment (71). During the 4 months where face to face services were stopped, no new

diagnoses were made. However, support for autistic adults, carers, and professionals was provided through non-face to face mechanisms (70).

Providers of care and support for people with learning disability and autism responding to the survey identified that service users were increasingly reliant on family members; had difficulties with isolation, mental health, financial hardship, and increasing behaviours of concern. There was also a lack of respite for carers.

Impact on workforce

Difficulties staffing services was observed during the pandemic, due to staff illness or self-isolation, or due to staff leaving. Respondents of the provider survey had provided more online or telephone services; and some had had to reduce the services that they offered.

12.3 What are the care and support needs?

12.3.1 Individual

Independence and person-centred care

Professional leads identified the need to support individuals to develop skills to enable them to live as independently as possible. This was echoed in an interview conducted for this assessment: *"I want to be taught how to do things so I will be able to cope after mum and dad are dead, worried I might not be taught enough while they are still alive"*. This individual felt autonomous, stating: "*I tend to try hard to do things, and when I come to the conclusion that I can't do things by myself I tend to ask".* A case study from Cardiff and Vale IAS reported in the National Autism Team 2019/20 Supplementary Annual Report states that the case had previously found it difficult to work with mental health professionals as they did not understand the case; however, the case was able to develop good rapport with the IAS Assistant Psychologist, which helped subsequent therapeutic interventions (202).

Language and communication

Welsh Government has published a Welsh language impact assessment on the Code of Practice for the Delivery of Autism services (203). In addition to this need nationally, regionally survey respondents wanted better support and wider understanding of non-verbal communication, with increased access to Makaton.

12.3.2 Community

Integrated Autism Service

The IAS provides diagnostic assessment of autism for adults who do not have a learning disability or meet the criteria for secondary mental health services; and their families, carers and professionals. Data from the IAS from 2020/21 shows that 1,589 people sought support from the IAS, of which 1,186 were new referrals from a range of people: 585 for diagnostic assessment or support for autistic people; 504 from professionals requesting training, advice or consultation; and 97 were carers requesting support. Over the year, 88 diagnostic assessments were provided (mostly in the last quarter, due to COVID-19 restrictions). This figure prior to the pandemic and in the financial year 2021/20 is significantly greater (70).

Access to timely diagnostic assessment is important, as demonstrated by feedback to the IAS. The IAS contributed the development of the Autism Code of Practice due to be published in 2021 and are represented in the National Autism Advisory Group.

"My whole life suddenly made sense – why I see things differently to others, find social situations awkward, struggle with change and unpredictability and like everything ordered and structured. This diagnosis has given me a renewed identity and purpose" – autistic person, feedback to IAS (70)

Transport

Professional leads identified the need for accessible and affordable transport, especially in the Vale of Glamorgan, which is more rural than Cardiff. This was echoed by the interviewee: "*my bus pass is helpful. It means I can get to work".*

Respite

Professional leads identified that carers of autistic people needed respite that was accessible, and flexible.

12.3.3 Wider determinants of health

Culture

The social model of disability has been formally adopted by Welsh Government, which recognises that a person with an impairment can become disabled by societal barriers, such as attitudes, physical and organisational infrastructure. The social model of disability enables people to feel and be more included (72).

The interviewee stated that the most important point they wanted to convey was around a lack of understanding from people around them.

"…too much misunderstanding, people just assuming that if I don't do something quickly that I'm not going to do it at all without being told, they just jump in" – autistic person, interview

Professional leads felt that autistic people are increasingly included in terms of public sector consultations, but there is still improvement to be made in terms of working towards true co-production.

Deprivation

No local data are available on the socio-economic characteristics of autistic people. Support provided by the IAS includes guidance on benefits and employment. The Code of Practice asks organisations to promote inclusion of autistic people (72). Increasing awareness of inclusive recruitment will enable more autistic people to gain higher quality jobs in Wales (187).

Skills development

Professional leads are working to improve skills development for autistic people, through liaising with local colleges to provide voluntary work and non-accredited courses. This will enable people to gain experience of college life, and contribute to promoting independence.

> ***"Volunteering in the shop and Ysgol-y-Deri helps me get up. I liked being able to help people like me in Ysgol-y-Deri. I can't do everything but by doing things other people have less to do." –*** autistic person, interview

Work-based learning provision in Cardiff for autistic people included 10 apprenticeships and 15 traineeships; fewer than five people were in apprenticeships and traineeships in the Vale of Glamorgan in 2019/20 (204).

> ***"I feel I have become a totally different person, with the fantastic new working pattern which I was granted thanks to the IAS, my confidence has doubled & I feel my assertiveness/speaking out has really improved since I started work again" –*** autistic person, Cardiff and Vale IAS (379)

Survey respondents with learning disability or autism were mostly in work or education prior to COVID-19 (15/24). In October 2021, 14 remained in work or education. Four did not work due to illness or disability; and three were caring for a family member.

Housing

Professional leads identified the need for supported / sheltered accommodation for some autistic people; currently individuals may have mental health placements but they are not sufficiently tailored in terms of support. Adult placements have been a positive experience, especially where people have been placed in a family home. Stakeholders have identified the need for a specialist autism facility for people in crisis in Wales.

The interviewee raised concerns about maintaining independence at home in the future, suggesting the need for support in advance of possible life changes: *"I'm worried about coping in my property when Granny is gone (granny is 97). I've had some good starts when granny has gone out."*

12.3.4 Unmet needs

Survey respondents wanted more autism-specific support, and age-appropriate inexpensive social groups and activities locally. The interviewee added that social connections were important: "*having more opportunities to make friends and meet people my own age would be good."*

Gaps in knowledge and understanding included:

- Lack of data on the number of autistic people in our population (with or without learning disability)
- Lack of data on accommodation needs for autistic people
- Lack of data on the Welsh language profile and deprivation levels amongst autistic people

12. 4 What are the range and level of services needed?

12.4.1 Prevention and assets

Advocacy work supporting specific challenges faced by autistic people enables person-centred care provision, appropriate signposting to other services, and confidence building (70). Appropriate and early referral to the right sources of support helps prevent further needs arising or escalating.

Assets to support well-being

The interviewee identified a number of sources of support including their family, who also help with money and appointments. Within the community, they identified work (paid and voluntary) as a particularly important support. The programme Engage to Change was identified as supportive of employment. Church was also helpful: "*going to church helps me to understand other people*". Survey respondents stated support from other autistic people was supportive, as were opportunities to exercise.

The IAS is an asset, identified as such by feedback provided to the service (70), and by the interviewee. Other sources of support include Autism Wales, who provide support on a range of topics from financial management to dental care. Professional leads identified

> ***"The people there were nice, and they helped me when I was struggling, I always struggle to get started but when I know how to do it, I can do it" –*** autistic person, interview

Dewis Cymru as a helpful resource.

12.4.2 Community services

Pathway approach

The IAS employs a pathway approach, so that autistic people and their carers can receive support throughout their journey. This includes an Autism Post-diagnostic Support Group. (70).

12.4.3 Partnership approach

Multi-sectoral working

The IAS has partnered with a range of agencies including the Welsh Local Government Association, the National Autism Team, third sector, local authority, and mental health services, and is open to autistic over the age of 18. The IAS promotes autism advocates and develops support networks. The Spectrum Star (an outcome measure focussing on the service user) is used to structure support (70). According to Welsh Government, sectors outside of health and social care need to be involved in training and awareness raising to develop a supportive culture (71)

12.5 What is likely to happen in the future?

The number of people aged 18-64 with an autism spectrum disorder is expected to increase by about 13% (425 people) between 2017 and 2035, with one third of the increase in the 35-44 year old age group. The biggest increase by proportion is in those aged 75+, with an anticipated 75% increase (230 people) between 2017 and 2035 (86).

The Code of Practice for the Delivery of Autism Services plans for Autism to become its own chapter in future Population Needs Assessments (72)

12.6 Recommendations

Third sector, Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Continue to develop opportunities for co-production, and the involvement of autistic people in decisions around their care and support plans
- Improve data collection to better understand the number of autistic people, and associations with socio-economic deprivation and language needs.
- Embed the Code of Practice in the delivery of Autism Services
- Develop inclusive recruitment, for example, through the Disability Confident Scheme (187) or Positive About Working with Autism Programme (71)
- Improve wider societal awareness of autism and develop a supportive culture

Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop accessible and flexible respite services

Cardiff and Vale University Health Board to:

- Reduce waiting list times for assessment by the Integrated Autism Service

13. Adult Mental Health

This chapter should be read in conjunction with the following chapters: Older People; Healthy Lifestyles and Long Term Conditions; Physical Disabilities; Cognitive Impairment including Dementia; Adult Unpaid Carers; Asylum Seekers and Refugees; Substance Misuse; Secure Estate; Armed Forces Service Leavers (Veterans)

Recommendations

All agencies to:

- Develop data systems to address the gaps in our knowledge
- Monitor the evolving understanding of the impact of COVID-19 on mental health
- Support housing transition to avoid homelessness for mental health service users

Cardiff and Vale UHB and Cardiff and Vale of Glamorgan Local Authorities to:

- Commission enhanced peer support services to promote independence
- Redesign mental health services so that waiting times decrease and there is easy access to mental health services when in a crisis
- Co-produce meaningful outcome measures with mental health service users
- Assess the efficacy of novel interventions, for example in the Recovery College

Third sector to:

- Promote independence and advocacy for people with mental health conditions

13.1 Overview

The WHO definition of mental health is that: *"Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community."* (205). In this context, the term "adult" refers to those aged 18 and over.

Measuring mental health in the population is frequently reliant on surveys based on samples of the population. The Office for National Statistics conducts an annual survey of well-being, for measures such as life satisfaction, feeling worthwhile, anxiety levels and happiness. For example, life satisfaction (a score from 0 to 10, where 10 is the highest possible level of satisfaction) has increased in both Cardiff and the Vale of Glamorgan overall, but has been higher in the Vale over the last 5 years. For the impact of COVID-19 on mental health, see section later on in this chapter.

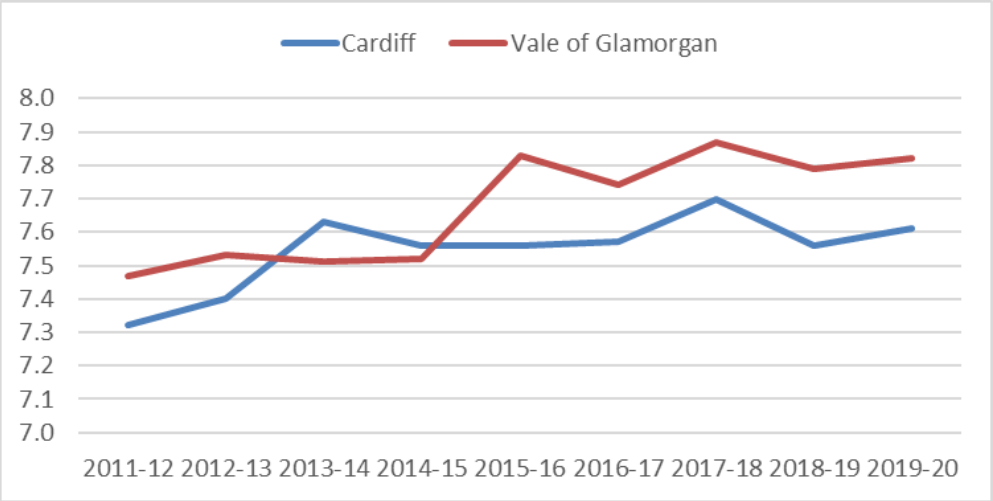


Figure 13.1. Average score of life satisfaction over time; Cardiff and Vale of Glamorgan, 2011-12 to 2019-20. Source: ONS (206)

According to findings from the National Survey for Wales, the percentage of people with a self-reported mental disorder has remained relatively stable over the last 3 years for Cardiff and the Vale of Glamorgan (see Table 13.1 below). This regional average masks a slight increase in the Vale of Glamorgan from 8% to 11% over the 3-year reporting period. This question was not asked in previous survey years and therefore there are no results prior to this reporting period.

Table 13.1: Age-standardised percentage of adults with a mental disorder, 2016-17 and 2017-18 to 2018-19 and 2019-20

Year	Cardiff	Vale of Glamorgan	Cardiff and Vale of Glamorgan	Wales
2016-17 and 2017-18	8%	8%	8%	9%
2017-18 and 2018-19	9%	9%	8%	9%
2018-19 and 2019-20	9%	11%	9%	10%

Source: Stats Wales (207)

Suicide is a response to a range of personal, community and societal factors (208). A small number of people will go on to die by suicide, which is tragic for all concerned. On review of Figure 13.2, suicide rates, whilst showing an undulating trend due to small numbers, have been below the Welsh average in recent years across Cardiff and the Vale of Glamorgan.

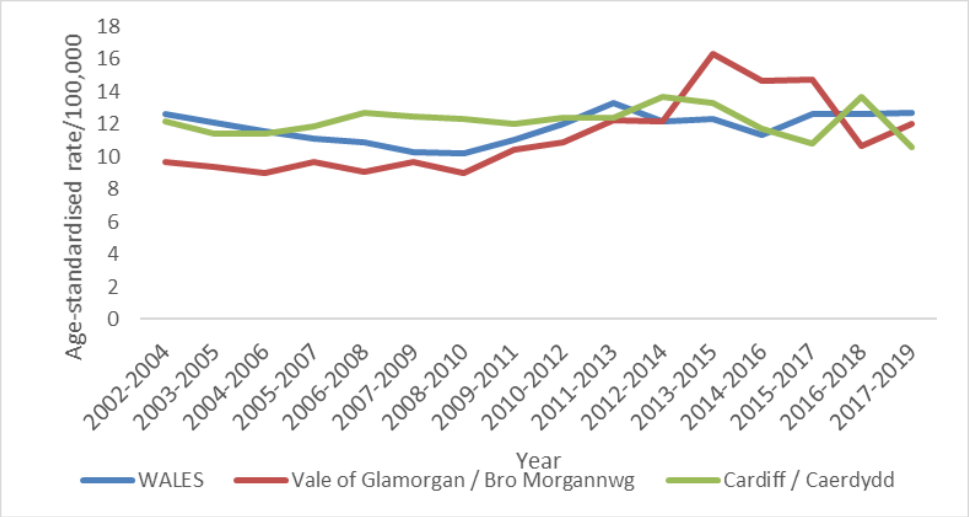


Figure 13.2. Age-standardised suicide rate per 100,000 population, 2002-04 to 2017-19. Source: ONS (209)

The content of this chapter was developed using existing literature, strategies and reports and triangulating findings with professional leads and engagement work (circa 100 PNA survey respondents; and four PNA focus group participants). It should be noted that the views of those engaged are not representative of all adults with mental health conditions in the population of Cardiff and the Vale of Glamorgan, but do provide rich information about their lived experiences.

13.2 What has changed since 2017?

13.2.1 Pre-COVID-19

The Welsh Government Strategy, Together for Mental Health (210), launched in 2012, has almost completed its 10-year term. The most recent Mental Health Delivery Plan will finish in 2022 (211). The key priorities include:

- Improving mental health and well-being and reducing inequalities
- Improving access to support for the emotional and mental well-being of children and young people
- Further improvements to crisis and out-of-hours provision for children, working age and older adults
- Improving the access, quality and range of psychological therapies for children, working age and older adults
- Improving access and quality of perinatal mental health services
- Improving quality and service transformation

Talk to Me 2 (208), the Welsh Government's strategy for suicide and self-harm prevention across Wales runs from 2015 to 2022. In South East Wales there has been a Regional Coordinator for Suicide and Self-harm prevention (covering Cardiff and Vale of Glamorgan; Gwent and Cwm Taf) in post since 2020. In Cardiff and Vale of Glamorgan our refreshed Suicide and Self-harm Prevention Strategy was launched in November 2021 (212). This multi-agency strategy and action plan, entitled: 'The right support, at the right time, in the

right way: working together to reduce suicide and self-harm', outlined the following overarching goals:

To reduce suicide and self-harm and their associated impacts in the population of Cardiff and the Vale of Glamorgan

- Reduce the number of people who take their own lives, or attempt to do so
- Reduce the number of people who self harm and the severity of injury in those who do
- Reduce the impact of suicide and self harm on those who care for individuals directly affected by these issues

Regionally, there have been several service developments over the last 5 years, in particular:

- A shift towards cluster and locality level working
- Cardiff and Vale Recovery College has been developed, running online courses for adults with mental health challenges, carers and for staff working in mental health
- St John's Ambulance is now commissioned to transfer service users in crisis to hospital, therefore decreasing the waiting time for this to happen
- Mental health services are moving towards trauma-informed care in the services that they provide and develop

13.2.1 COVID-19

Lockdown restrictions

During the early phase of COVID-19 restrictions (by May 2020), 43% of UK Psychiatrists were already seeing an increase in urgent and emergency mental health referrals and a 45% decrease in routine appointments (213). The Office for National Statistics (214) noted that there was a higher proportion of people in Great Britain reporting to be depressed during June 2020 (19.2%) as compared to between July 2019 and March 2020 (9.7%).

According to the Cardiff and Vale PNA focus group, some participants found the pandemic lockdown measures reassuring and they felt safer. However, some were anxious about the opening up of society and the increased risks of contracting the virus, leading to greater isolation.

As the pandemic progressed, by June 2021, the majority (59%) of people surveyed in Wales (circa 600 respondents) stated that their mental health had stayed the same, as compared to earlier on in 2020 (215). In contrast 33% stated that their mental health was "a bit worse" or "much worse" (215). More recently (since the beginning of May 2021), there has been a downward trend in those people surveyed who worried "a lot" about their own mental health and well-being with this sustained at 20% or lower since then, see Figure 13.3 below (216).

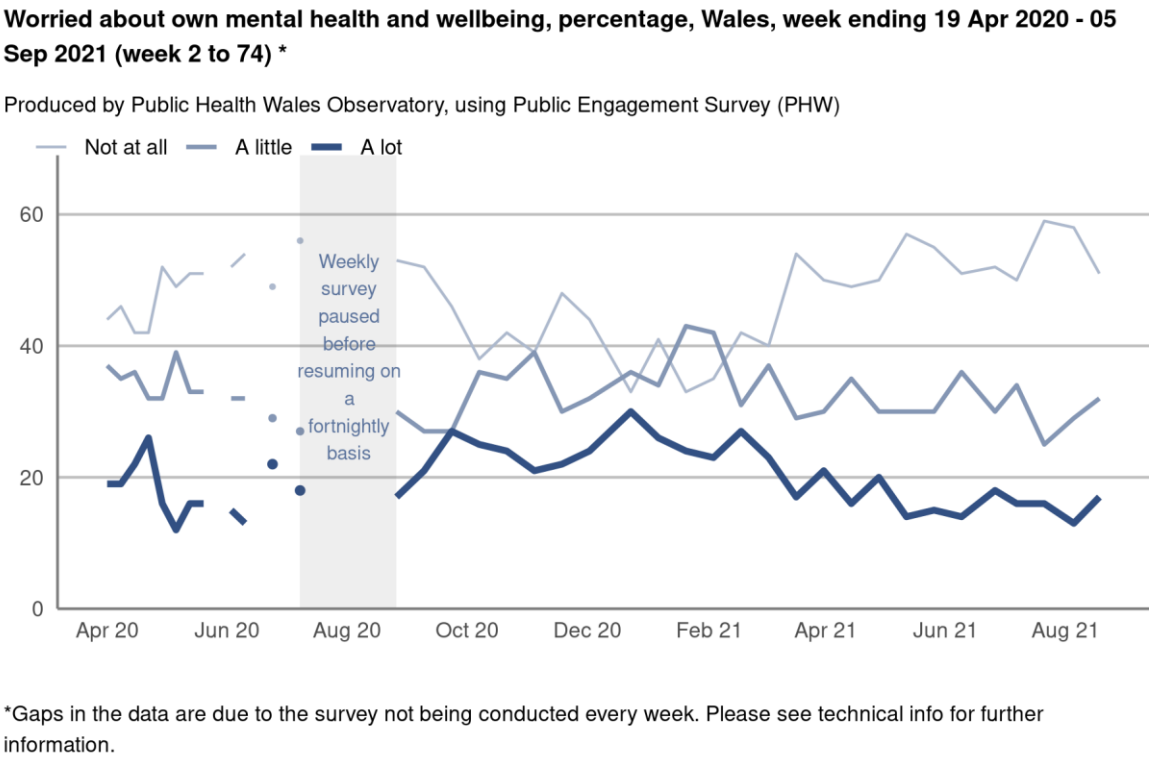


Figure 13.3. COVID-19 Recovery Profile – Mental Wellbeing, Wales
Source: Public Health Wales Observatory (216)

Care and support provision

The findings from the Cardiff and Vale PNA focus group were mixed in terms of care and support for mental health during the pandemic. Some participants welcomed the move to online services and meetings and hoped that this would continue post-pandemic with hybrid services / meetings. Third sector organisations were referenced as trying innovative ways of linking in, with Sefyll (CAVAMH), Ty Canna and Grassroots mentioned as positive examples. Some participants felt more able to reflect: *"Things slowed down and that was good, I had the time and space to work on myself".*

In contrast, others stated that services had become worse for them: *"My Primary Mental Health Service got a lot worse"* or *"CMHT [community mental health team] services that were vital fell apart, CPN [community psychiatric nurse] and Consultant left without being replaced, with awful consequences for mental health."*

13.3 What are the care and support needs?

13.3.1 Individual

Language and communication

According to 'More than just words' (217), mental health service users are a key group for services to be available in the Welsh language, and to receive the Welsh language offer. Unfortunately, there is little information on first language collected my mental health services. However, interpreters are provided on request when required.

13.3.2 Community

Timely access to services

An unpublished Mental Healthcare Needs Assessment, completed in August 2017 defined the care and support needs for working age adults in Cardiff and Vale of Glamorgan. A common theme was having timely access to support services, as there are frequently long waiting times for counselling and psychological therapy.

Treating physical and mental health conditions holistically

The unpublished Mental Healthcare Needs Assessment also references an English report that stated that 30% of the population have one or more long-term conditions; e.g. diabetes, arthritis, asthma, cardiovascular diseases, HIV/AIDs or certain cancers. It reported that at least 30% of all people with a long-term condition also have a mental health problem (218). This equates to around 9% of the adult population having both a long term physical health condition and a mental health condition, indicating a need to treat both holistically.

13.3.3 Wider determinants of health

Deprivation

Life satisfaction in Welsh adults varies between different communities. Based on Public Health Wales Observatory analysis, as at 2018 there was a 14% difference between the age-standardised percentage of the most and least deprived fifths' life satisfaction scores (219). Since 2013, there has been a consistent gap in life satisfaction between most and least deprived fifths communities in Wales, see Figure 13.4 (219).

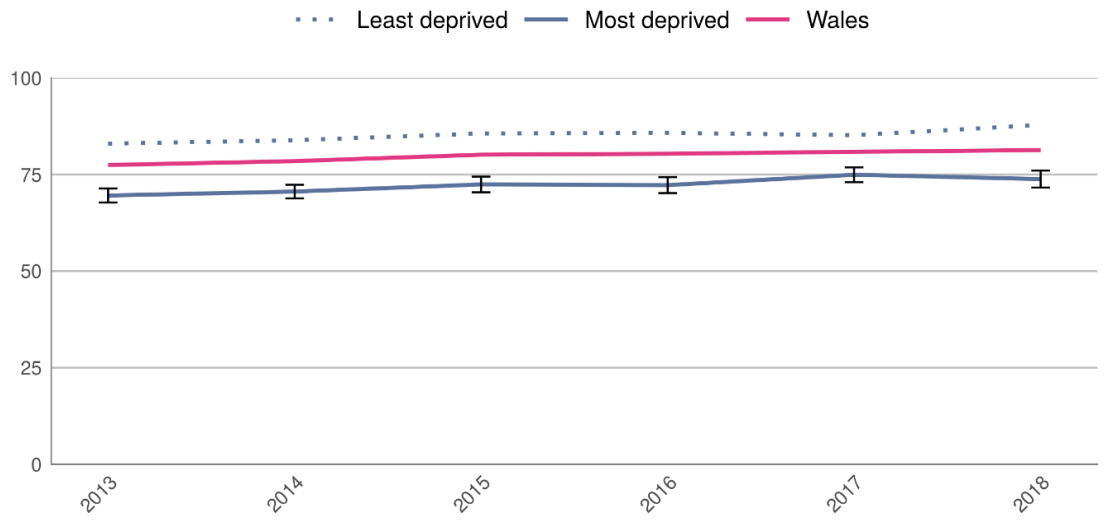


Figure 13.4. High sense of life satisfaction – age-standardised percentage, persons aged 16 plus, most and least deprived fifths in Wales, 2013-2018.
Source: Public Health Wales Observatory (219)

Socio-economic disadvantage also impacts upon suicide rates. Men who are from the most disadvantaged backgrounds have the highest rates of suicide in Wales, according to a Samaritans report (220). In order to counter this trend in Wales, the men who were generally socially disconnected and struggling with feelings of suicidality, told the Samaritans that the key elements of a successful service for them included: the ability for men to make a contribution; a feeling of being included; and the opportunity to work towards common goals (220).

Education and employment

In the UK, the estimated cost of mental health in the workplace was almost £35 billion in 2016/17, according to the Centre for Mental Health (221). This was due to: sickness absence; reduced productivity at work; and replacing those who leave due to their mental health (221). This demonstrates that employers need to cultivate a healthy working environment, promote well-being in the workplace, support those with mental health conditions and their return to the workplace (221).

The Health Foundation report that having good mental health is important for employment prospects and that unemployment creates stress and adverse health consequences; therefore the relationship between employment and mental health is bi-directional (222).

Across Cardiff and the Vale of Glamorgan the Out Of Work Peer Mentoring Programme is delivered by Platfform. They support people with a mental health or substance misuse problem to find their volunteering, training or employment opportunity goals, if they have been out of work for more than 12 months (aged over 25); or not in education, employment or training (aged 16-24).

Housing

Housing affordability and subsequent housing insecurity has a two-way relationship with mental health: prior mental health conditions have an impact on housing outcomes; and housing affordability (and therefore housing conditions) predict health outcomes, including mental health outcomes (223). Both Cardiff and the Vale of Glamorgan local authorities have Housing Strategies that support people with mental health conditions (83) (199).

> ***"I'm ok where I am currently but I will have to move out soon and I might become homeless and the uncertainty about the future is terrible"*** – Mental health service user, focus group

Local authorities in Wales have responsibility for assessing local needs regarding: housing-related support, strategic planning and commissioning housing-related services (224). Housing support can take many forms via the local authority or commissioned third sector provision. Settings of support can include: shared and self-contained specialist housing; or temporary housing solutions such as hostels, shared properties or self-contained housing

(199). Housing support was highly valued by PNA focus group participants: *"Moving out of a hostel to a flat has been challenging but overall positive with third sector services to support me."* Focus group participants felt that decent housing was *"central to well-being."* However, some people voiced that their housing situation was not meeting their mental health needs*: "My accommodation is a massive negative for my mental health and well-being, I have huge issues with my housing provider*." In some instances people's mental health was affecting their housing conditions: "*where I am now is better than previous places but because I'm unwell I'm not dealing with maintenance issues."*

Across Wales, the Housing (Wales) Act 2014 ensures that clients will be treated as in priority need should they find themselves homeless or threatened with homelessness. This legislation states that: *"a person who is vulnerable as a result of old age, mental illness or handicap or physical disability or other special reason, or with whom such a person resides or might reasonably be expected to reside"* can be considered in priority need for housing. In Cardiff, the pattern of homelessness is often associated with having multiple adverse childhood experiences, leading to mental health and substance misuse issues (225). The Cardiff Homelessness Strategy (225) states that Cardiff local authority aims to provide a person-centred, trauma-informed approach with multi-agency support to clients to prevent the "revolving door" of homelessness. The Vale of Glamorgan Homelessness Prevention Strategy has a focus on people receiving mental health services and includes the development of a robust hospital discharge process including from mental health wards (225) (226). Between April 2015 and March 2018, there was a 214% increase in those in priority need due to having a mental illness or learning disability in Cardiff (225). In November 2019 (over a 2 week period) there were an estimated 92 rough sleepers in Cardiff and 1 in the Vale of Glamorgan (227).

13.3.4 Unmet needs

Feedback from focus groups with mental health service users and carers, to Mental Health Clinical Board (Cardiff and Vale UHB) during 2018 and 2019, outlined the following areas for improvement:

- Involvement in service design
- Communication and information, for example: regarding decisions, discharge matters, and inter-agency communication
- Timely access to services
- Post diagnostic support
- Consistency of care
- An easy route through services
- Follow up on discharge from hospital
- Help with drug and/or alcohol problems

"It took 18 months to get psychological support following the referral" - Mental health service user, focus group

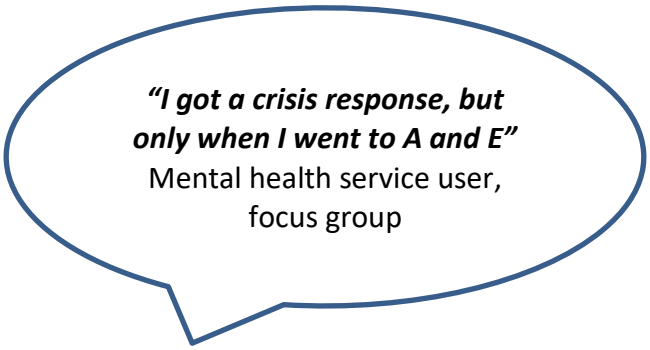
The PNA focus group undertaken had 4 participants, and therefore may not be generalisable. There were two key themes, which also resonated with the Mental Clinical Board's findings above:

Timely access to the right support at the right time

Based on the Cardiff and Vale PNA focus group's findings, some services were difficult to access due to lengthy waiting times. Examples given were: Advocacy Matters, Primary Mental Health Support Services and Psychological and Counselling services. Furthermore, Cognitive Behavioural Therapy, once provided by Cardiff Mind had ceased due to funding withdrawal. Experiences in getting the right support at the right time were largely unmet needs, based on the focus group findings. It was clearly stated that preventative or timely early intervention could prevent difficulties spiralling into a crisis situation.

A mental health crisis response service

The Cardiff and Vale PNA focus group participants thought that a mental health intervention when things are beginning to go wrong, or when people are in crisis would be important and may avoid attendance at the Emergency Department.



These unmet needs findings were corroborated by CAVAMH's report: 'My Say', which outlined that a significant proportion of people in Community Mental Health Teams (CMHTs) did not know who to contact in a crisis (228).

The key gaps in knowledge are:

- Knowing what the employment status and needs are for our population with mental health conditions
- Having meaningful outcome measures for our mental health service users
- The number of Welsh speakers known to services
- The effectiveness of specific interventions that have yet to be fully evaluated in Cardiff and the Vale of Glamorgan, for example, Recovery College
- The long term effect of COVID-19 on population mental health

13. 4 What are the range and level of services needed?

13.4.1 Prevention and assets

Prevention

The PNA focus group had 4 participants which is therefore not representative of all people with mental health conditions, but such settings do enable a depth of insight, albeit on a small scale. Focus group participants thought that a number of services had the potential to help with future well-being and work in a preventative manner. These included, on a personal level, social support and friends. One to one support, psychological support and Community Psychiatric Nurses were seen as helpful, as was mentoring and peer support.

Third sector organisations such as Advocacy Support Cymru, Bi-Polar UK, Speakeasy (legal advice and support), Sefyll (CAVAMH) were identified to offer preventative input. Day Support (such as that offered by Ty Canna and Mind in the Vale of Glamorgan) as well as Cardiff and Vale Recovery College were helpful.

Assets

The PNA focus group considered many of the same organsiations as assets to support their well-being, for example, one to one support, psychological support and Community Psychiatric Nurses were noted as helpful services for the individual. At a community level, friends and social networks, events (e.g. music, concerts), arts centres, cinema, eer support and clubs were considered supportive. Educational settings' mentoring and support systems were seen as invaluable, and voluntary work to help others, as well day centres, such as Ty Canna – "*offering "amazing" practical and social support*" were well regarded. Third sector organisations offering mental health support were seen as positive for example, Sefyll (part of CAVAMH), Bi-Polar UK and CCAWs (Community Care and Wellbeing Service).

Advocacy was a real source of support for many - Advocacy Support Cymru and Advocacy Matters were two organisations highlighted as being particularly helpful. Cardiff and Vale Recovery College was thought important for one's well-being and came highly recommended.

> ***"I would have lost my accommodation if it was not for my Advocate"*** - Mental health service user, focus group

In addition, professional leads identified that access to work initiatives provided support for people with mental health conditions. Other third sector assets include Mind in the Vale and Cardiff Mind. The need for sustainable funding of third sector organisations was identified.

13.4.2 Community

Maintaining independence

Maintaining a level of independence was a priority for PNA focus group participants: *"Volunteering opportunities and getting involved in activities."; "I need social support and I need social care support"; and "Befriending and peer support are vital."*

Timely access to services

Timely and consistent access to services was widely agreed as a priority for well-being in the future by focus group participants. Availability of psychological and counselling services was limited due to waiting times.

13.4.3 Partnership approach

Continuity of care

Continuity of care was deemed important by focus group participants. However, once in a service sometimes staff left or moved on, meaning that a consistent service was not always available.

13.5 What is likely to happen in the future?

National Survey for Wales' data shows that historically those being treated for a mental illness has increased from 9% in 2009 to 13% in 2015, based on the Future Trends Report (229). This may be because numbers with a mental illness have increased; or that there is increased awareness of mental illness, and therefore subsequent identification and treatment for this. In the future, projections show that there will be more people with a common mental disorder, as the population grows, see Table 13.1 below. This could lead to increased demand on services. It should be noted that these projections need to be treated with caution as many variables will affect an accurate future prediction.

Table 13.1. Cardiff and Vale of Glamorgan – Population projections for common mental illness

Year	2020	2025	2030	2035	2040
Female	43,552	44,210	45,323	45,855	45,754
Male	26,421	27,034	27,599	28,103	28,493

Source: Social Care Wales Population Projections Platform (88)

In the future, it is likely that, across Cardiff and Vale of Glamorgan, cluster level working will become the norm for mental health services. In addition, the development of 111 services for people in a mental health crisis is likely in the forthcoming year (2022).

13.6 Recommendations

All agencies to:

- Develop data systems to address the gaps in our knowledge
- Monitor the evolving understanding of the impact of COVID-19 on mental health
- Support housing transition to avoid homelessness for mental health service users

Cardiff and Vale UHB and Cardiff and Vale of Glamorgan Local Authorities to:

- Commission enhanced peer support services to promote independence
- Redesign mental health services so that waiting times decrease and there is easy access to mental health services when in a crisis
- Co-produce meaningful outcome measures with mental health service users
- Assess the effectiveness of novel interventions, for example in the Recovery College

Third sector

- Promote independence and advocacy for people with mental health conditions

14. Cognitive Impairment including Dementia

This chapter should be read in conjunction with the following chapters: Older People; Healthy Lifestyles and Long Term Conditions; Adult Unpaid Carers

Recommendations

All agencies to:

- Increase service user and carer input into service developments and their own person centred care plans
- Ensure that individual needs are person-centred
- Tailor the needs of unpaid carers of people living with dementia so that they have appropriate respite
- Have clear care, coordinated pathways for people with a progressive diagnosis so, individuals are not lost in the system

Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop the capacity of residential and nursing homes to accommodate the future needs of people living with dementia, both in terms of increased bed numbers and also dementia-friendly environments
- Support the needs of unpaid carers, who are often older people themselves, through the provision of information, advice and support
- In partnership with the third sector and Cardiff and Vale UHB, to further develop local communities to become dementia friendly

Cardiff and Vale University Health Board and Primary Care to:

- Support further developments in Primary Care through training and development to ensure that both physical and mental health needs are met for people living with dementia.
- Provide a personalised care pathway for a person living with dementia and their carer so that people can link in with support as needed

14.1 Overview

According to the Royal College of Psychiatry, dementia is: "*a group of conditions which affect memory*" (230). The problems are mainly due to memory loss and thought processing; they also get worse with time (are progressive) and are not due to normal ageing (230).

In contrast, mild cognitive impairment (MCI) is a less serious memory problem, and does not affect everyday life in such a major way as dementia (230).

The number of people on the general practice dementia register in Cardiff and Vale of Glamorgan was 3,370 as at 30 September 2020 (231), which equates to 0.7% population prevalence. However, the estimated number with dementia aged over 65 in 2020 was 5,773 (88), which means that over 42% of people with dementia are not on the general practice register as having a diagnosis. People with cognitive impairment are not recorded on a specific register within primary care. The needs of older people are discussed in chapter 8.

The content of this chapter was developed using existing literature, strategies and reports and triangulating findings with professional leads and engagement work (seven PNA focus group participants). It should be noted that the views of those engaged are not representative of all adults with cognitive impairment/dementia in the population of Cardiff and the Vale of Glamorgan, but can provide rich information about their lived experiences.

14.2 What has changed since 2017?

14.2.1 Pre-COVID-19

Since 2017, there have been many developments nationally and locally for people living with dementia and their unpaid carers. At a Wales level, the national Dementia Action Plan for Wales (232) was launched in 2018, with a commitment of £10 million a year in funding for various initiatives nationally and locally. In May 2018, the Cardiff and Vale of Glamorgan Dementia Strategy was launched during dementia action week; this was based upon a dementia needs assessment, completed in 2017 with multiple stakeholder engagement across the region. The vision for the Dementia Strategy 2018-2028 was that:

"*By 2028 the population of Cardiff and the Vale of Glamorgan will be dementia aware and will reduce their risk of dementia. People with dementia will have equitable and timely access to a diagnosis; they will have person-centred care delivered locally with kindness. Carers will feel supported and empowered*."

There were eight strategic objectives within the Cardiff and Vale of Glamorgan Dementia Strategy:

1. Dementia is everyone's business
2. The risk of dementia will be reduced and there will be a timely diagnosis
3. Access to services will be equitable
4. Services will be fully coordinated
5. Services will be delivered with kindness and compassion
6. Support will be centred on Primary Care
7. Carers will be for cared for
8. Crises will be avoided

In light of the national Dementia Action Plan for Wales and associated funding, regionally an audit took place regionally to identify key gaps against the national action plan, and new

initiatives were created from this analysis. The following services were funded through Dementia Integrated Care Funding from 2018 onwards:

1. GP diagnosis clinics based within primary care clusters.
2. A dementia "team around the individual", with memory link workers linked to primary care clusters and associated multi-professional team members.
3. A dementia training and development team aligned to the "Good Work" principles and to a dementia care mapping team.
4. Dementia Friendly Communities approach through the third sector (Marie Curie and Cardiff and Vale Action for Mental Health).

In 2021, the All Wales Dementia Care Pathway of Standards (233) were launched and Welsh Government also announced recurrent Memory Assessment Services funding for each Regional Partnership Board area. The aim of this was to increase dementia diagnosis rates across Wales. A variety of initiatives/pilots have been funded through this in order to meet this aim, and are currently being implemented with a view to full evaluation in 2022/23.

14.2.1 COVID-19

The COVID-19 pandemic has disproportionately impacted people living with dementia, and their unpaid carers, as outlined in this section.

Direct impacts

UK research suggests that delirium from COVID-19 can make it hard to identify COVID-19 in people living with dementia, which could impact their care (234). Internationally, people living with dementia frequently have other conditions, increasing the risk of complications from COVID-19 should they contract it (235). Further international research also found that people living with dementia had increased risk of infection; and should they contract COVID-19: worse outcomes, adverse impact on cognition and were harder to isolate (236).

In 2020, the most common pre-existing condition mentioned on death certificates amongst those dying of COVID-19 (in England and Wales), was dementia and Alzheimer's disease, at 18,420 deaths (237). This implies that people with dementia were disproportionately affected by the pandemic.

Lockdown restrictions

For people with young onset dementia, there was a mixed picture with some people reporting benefits, and some reporting disadvantages due to the COVID-19 restrictions, according to Young Dementia UK (238). They highlighted issues such as: lack of routine, feeling forgotten, loneliness, isolation, confusion, feeling vulnerable, losing skills, not being entitled to support, and loss of confidence (238). However, there were also many positive aspects to the pandemic, with some saying they had learnt new skills, found the virtual support beneficial, and some people felt less anxious as going out made them anxious previously (238).

Care and support provision

Mok et al (236) found that non-COVID related health care appointments were impacted, and that lack of social engagement and support may have resulted in a deterioration of the

condition, with isolation also affecting psychological well-being. This experience was also reiterated in recent (October 2021) focus group(s): ''*Services are greatly reduced or abandoned.*" Referrals into Memory Team also dramatically reduced during 2020/21 to 1,028; a decrease from an average of 1,533 over the four preceding years.

The Social Care Institute for Excellence (239) highlighted the key issues that people with dementia living in care homes might have, for example: not understanding the need for isolation, finding personal protective equipment frightening and struggling with communication. A further report: 'Safeguarding adults with dementia during the COVID-19 pandemic' (240) raised concerns that people living with dementia might be more vulnerable to abuse or neglect during the pandemic. This may be due to: social isolation, stress on carers, overstretched care staff, increased scams, increased domestic abuse, and new staff, volunteers, or support (240).

14.3 What are the care and support needs?

14.3.1 Individual

Language and communication

According to 'More than just words' (217), people living with dementia are a key group for services to be made available in the Welsh language. The reason being is that people living with dementia may revert back to their first language as the illness progresses. Data are not routinely available on first language for people in Memory Team or Mental Health services; however an interpreter can be provided on request. 'More than just words' emphasises the importance of the active offer in the Welsh language (217), this may be particularly important if people are unable to request services in the language of their choice.

14.3.2 Community

Based on a Cardiff and Vale of Glamorgan dementia health needs assessment (241), completed in 2017, people living with dementia have a wide range of care and support needs. Their needs include, but are not limited to, the following key issues:

1. Isolation and loneliness – with loneliness increasing cognitive decline
2. Being treated with kindness and compassion
3. Having services that are coordinated
4. Caring for unpaid carers – the wellbeing of carers has a direct impact on their relationship with the person living with dementia
5. Knowing what to do in a crisis – having the information available, and a timely service when in a crisis
6. Moving care and support to Primary Care – this would require training and support so that Primary Care staff feel supported
7. Inequality in access to services – a concern that without having relatives to advocate for the person living with dementia that their needs would not be met
8. Dementia being everyone's business – to include the development of dementia friendly communities and dementia friendly environments
9. Prevention/risk reduction of getting dementia – this includes cardiovascular risk reduction: a major cause of both Alzheimer's disease and vascular dementia.

14.3.3 Wider determinants of health

Deprivation

The association between deprivation and having dementia is complex. Based on the findings of a Race Equality Foundation report (242), it can be summarised that the prevalence of dementia is higher in more affluent areas, but that the incidence and risk of getting dementia in the first place is higher in more deprived areas. The reasons for this are that a higher life expectancy is associated with affluence and as age is the biggest risk factor for dementia, then the prevalence will be higher in the older, more affluent age groups. In contrast the risk factors for dementia, such as: high blood pressure in mid-life, cardiovascular disease and diabetes, are more common in people with lower socio-economic status, and therefore, new cases are more likely in more deprived areas and populations (242).

There is an additional risk that those from lower socio economic groups are more disadvantaged in being able to access services. Studies referenced in a UK report: 'Dementia, Equity and Rights' (242) identified that middle class populations were more successful at finding out about services, and that people with high education attainment were more likely to be referred to memory services. Home owners were four times more likely to be prescribed anti-dementia drugs than those in rental accommodation (242). The majority of carers are unpaid, and families who receive a diagnosis of a family member can experience financial hardship as a result of possible reduction of income and additional costs of care (242).

Employment

People who have young onset dementia, are aged under 65, and therefore may be in employment due to being of working age. Dementia UK report that employers need to be aware of the signs and symptoms of young onset dementia; and if a diagnosis is made to ensure that reasonable adjustments are in place to support people in the workplace (243).

Unpaid carers of people with young onset dementia also require flexible working arrangements to ensure that suitable support can be provided to the person with young onset dementia (243). Relatives who care for someone who has young onset dementia frequently have to leave their work, to support their loved one, creating further financial stress for the family (243).

Housing

The housing needs for people living with dementia range from being completely independent (at earlier stages), to having domiciliary care, to requiring a residential or nursing home placement for their own care and safety at the later stages of the dementia journey.

Cardiff Older Person's Housing Strategy 2019-2023 outlines the specific housing needs for people living with dementia (244). It outlines the importance of appropriate housing for promoting independence and decreasing the need for residential care; whilst also decreasing the pressure on health and social care services (244). As at 29 October 2021,

there were 489 residential home placements for Cardiff adults, of which 55 are with Mental Health Services for Older People (MHSOP) teams; there are a further 410 in nursing home placements, of which 77 are with MHSOP teams. MHSOP placements are highly likely to have dementia. These figures are for all adult service users and include all service users that Cardiff is paying for whether in or out of county. It is likely that the Dementia figures are higher than reported here.

Vale of Glamorgan's Housing Strategy outlines the anticipated increase in housing need for people living with dementia, due to the ageing population (139). It states that in recent years there has been a significant increase in older people's nursing home placements and elderly mentally infirm (EMI) placements (these are for people living with dementia). In the Vale of Glamorgan (as at 28 October 2021), there were 446 Nursing Home beds, and 286 Residential Home beds, of which 220 were for people with dementia. One care home had an additional 24 mental health beds.

''Home support is often dependent on an elderly spouse who is in need of care too'' – Unpaid carer of person living with dementia, focus group

Environmental adaptations to make the home "dementia-friendly" can help to support people living with dementia with orientation and to feel settled; therefore promoting independence. For example, having symbols on doors to help navigate individuals to food cupboards or the shower, or having assistive technology (245).

14.3.4 Unmet needs

Focus groups arranged over a range of dates and times with 7 participants, using a hybrid methodology (specifically for people with living with dementia), identified the following unmet needs (based on small numbers of participants, so only indicative):

- Memory Clinic to follow up people readily after their initial diagnosis, as this was not currently happening.
- Respite for unpaid carers. This was the single most sought after need.
- Being able to see a GP. They felt that Covid-19 restrictions had meant a reduction in support that was readily available previously; in some cases they felt that the hospital Emergency Department was the only answer.

From the perspective of professionals, the key gaps in our knowledge are having meaningful outcome measures for service users.

14.4 What are the range and level of services needed?

14.4.1 Prevention and assets

Prevention

Based on the focus group results and previous needs assessment work, the key preventative areas for people living with dementia include:

- Using service users and carers in service development, so that care is person-centred
- Ensuring that support is centred on Primary Care
- Ensuring that unpaid carers have sufficient respite care
- Ensure people living with cognitive impairment or dementia have access to advocacy where there is nobody else to represent them.

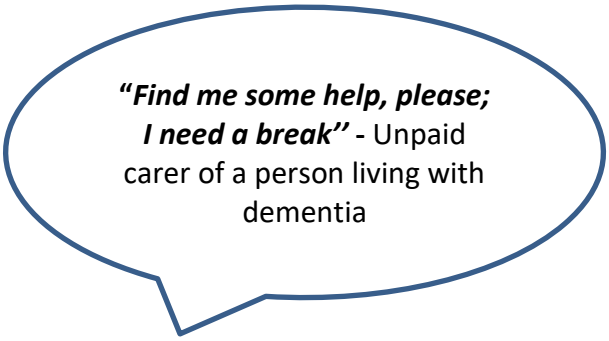
Assets

PNA focus groups (specifically for people with living with dementia) outlined the following assets as supportive to their well-being:

- At the individual level, in general, some people do get the support they need and others do not. It is highly dependent on having the ability to look for help or having someone who will look into support for you – this makes the provision inconsistent rather than tailored.
- Within the community, Forget Me Not Chorus was particularly mentioned as a source of support for people living with dementia. In particular face to face rehearsals were very much valued. The Dementia Café in Cathays Community Centre was also mentioned as a source of support during the COVID-19 pandemic.
- At a population level: some local authority services, Nexus (part of Cardiff and Vale Action for Mental Health (CAVAMH)) and Memory Clinic were most often mentioned as sources of support. In particular Nexus, for maintaining contact with as many older people as possible by telephone, email, online one to ones and meetings; and through CAVAMH, keeping Directions Handbook up to date and circulated.

14.4.2 Community services

Through the focus group(s) work, it was apparent that the following would be important to meet the unmet needs of people living with dementia:



- Involvement of service users and carers in decision making and planning of services across the board to make the provision useful at point of service. This should start with ensuring the person living with cognitive impairment or dementia is in control of their own care, either themselves or through an advocate
- GP services providing easily accessible, personal care in a timely fashion. Primary mental health care from GPs, and a willingness to identify physical ailments not connected to mental health but that may cause mental health difficulties if not addressed promptly
- The ambulance service being able to provide timely, accessible person-centred care.
- Respite care for unpaid carers
- Providing services in accessible formats. Dependency on technology has been exaggerated by COVID-19 and this is a major barrier for many older people. IT training was not the solution for them

Professional leads identified that third sector organisations (including Marie Curie and CAVAMH) across Cardiff and Vale of Glamorgan have developed dementia friendly communities at both strategic and grassroots levels to ensure that services and settings embrace the needs for people living with dementia and their unpaid carers. This can mean developing dementia friendly environments, and training staff to be knowledgeable and empathetic towards people living with dementia.

14.4.3 Partnership approach

Dementia Friendly Cardiff and Dementia Friendly Vale are the result of partnerships between Cardiff and Vale UHB, the respective Local Authority, Alzheimer's Society Cymru, and are supported by Marie Curie. Through the appointment of a Dementia Friendly Communities Coordinator for Cardiff and the Vale of Glamorgan, businesses and organisations are being supported to recognise the needs of people affected by dementia, and pledge their commitment to become more welcoming. With information and guidance from the Coordinator, simple and meaningful action is being taken to improve staff awareness, create more accessible physical environments, and increase the availability of information about dementia. This means that people affected by dementia can feel supported to continue to visit their local businesses and remain connected to their community for as long as possible (246).

14.5 What is likely to happen in the future?

Increasing age is the biggest risk factor for dementia, and therefore as our population ages and increases in number, the numbers of people living with dementia will increase over time. It is anticipated that numbers of people living with dementia will increase more steeply in the Cardiff area, as compared to Vale of Glamorgan (88). See Table 14.1 for further details.

Table 14.1. Cardiff and Vale of Glamorgan – Population projections for dementia

Year	2020	2025	2030	2035	2040
Vale of Glamorgan	2,041	2,386	2,758	3,152	3,493
Cardiff	3,732	4,271	4,894	5,562	6,103

Source: Social Care Wales Population Projections Platform (88)

14.6 Recommendations

All agencies to:

- Increase service user and carer input into service developments and their own person centred care plans
- Ensure that individual needs are person-centred
- Tailor the needs of unpaid carers of people living with dementia so that they have appropriate respite
- Have clear care, coordinated pathways for people with a progressive diagnosis so, individuals are not lost in the system

Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop the capacity of residential and nursing homes to accommodate the future needs of people living with dementia, both in terms of increased bed numbers and also dementia-friendly environments
- Support the needs of unpaid carers, who are often older people themselves, through the provision of information, advice and support
- In partnership with the third sector and Cardiff and Vale UHB, to further develop local communities to become dementia friendly

Cardiff and Vale University Health Board and Primary Care to:

- Support further developments in Primary Care through training and development to ensure that both physical and mental health needs are met for people living with dementia.
- Provide a personalised care pathway for a person living with dementia and their carer so that people can link in with support as needed

15. Adult Unpaid Carers

This chapter should be read in conjunction with the following chapters: Children and Young People; Older People; Healthy Lifestyles and Long Term Conditions; Physical Disability; Learning Disability; Autism; Adult Mental Health; Cognitive Impairment including Dementia

Recommendations

All agencies, in partnership to:

- Review the need for an updated carers directory, which is updated regularly and available digitally, and publicise widely

Provide respectful care that is culturally appropriate, with training where needed Cardiff and the Vale of Glamorgan Local Authorities to:

- Strengthen clear pathways for carers assessments within local authorities following a "what matters" conversation
- Capture first language needs in carers assessments
- Consider flexible respite needs for unpaid carers

Cardiff and Vale University Health Board to:

- Review the pathway for mental health support to unpaid carers, so that waiting time decreases

Employers to:

- Adopt reasonable adjustments for people with caring responsibilities so that worthwhile employment is maintained and finances for unpaid carers are optimised

15.1 Overview

The definition for unpaid carers is that: "*they provide support/care to an individual who has needs because of physical or mental health condition(s) or illness(es), or problems related to old age. Unpaid carers' status is self-reported*" (247).

In the context of this Population Needs Assessment, an adult unpaid carer is aged 18 or above; however this age cut off may vary by agency.

A Carers UK report acknowledged that the Welsh population had the highest proportion of people who were unpaid carers of the four UK nations at 70%, during the time period 1991 to 2018 (248). Notably, females (73%) were more likely to be carers than males (66%) in Wales, and the same gender bias was evident across the UK (248).

Cardiff and the Vale of Glamorgan has approximately 50,580 unpaid carers of all ages, based on the 2011 Census (249). The figures for unpaid carers (Table 15.1) are likely to be an underestimate of the true number, as data collection was over 10 years ago, and the overall population has grown in numbers since then. Additionally, Carers Wales have reported that in the first few weeks of the pandemic, in Wales alone, around 196,000 people became unpaid carers (250).

Table 15.1 below shows that the proportion of the population who are unpaid carers in the Vale of Glamorgan is the same as the national average (12%); however, in Cardiff it is less at 10%.

Table 15.1. Welsh residents by hours of unpaid care and local authority, 2011

Geographical area	All Usual Residents	Provides no unpaid care	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week	% non-carer	% unpaid carer
Wales	3,063,456	2,693,226	212,436	54,046	103,748	88%	12%
Vale of Glamorgan	126,336	110,761	9,939	2,050	3,586	88%	12%
Cardiff	346,090	311,085	21,671	4,729	8,605	90%	10%
Cardiff and Vale	472,426	421,846	31,610	6,779	12,191	89%	11%

Source: Stats Wales (249).

The content of this chapter was developed using existing literature, strategies and reports and triangulating findings with professional leads and engagement work (12 focus group participants; 111 respondents to the public survey; and 42 of 131 respondents to the provider's survey provided services for carers). It should be noted that the views of those engaged are not representative of all adult unpaid carers the population of Cardiff and the Vale of Glamorgan, but do provide rich information about their lived experiences.

15.2 What has changed since 2017?

15.2.1 Pre-COVID-19

Nationally, Welsh Government launched their strategy for unpaid carers in March 2021 (251). Within this 4 national priorities for unpaid carers were described (251):

1. Identifying and valuing unpaid carers
2. Providing information, advice and assistance
3. Supporting life alongside caring

4. Supporting unpaid carers in education and the workplace

Regionally, since 2017, the following changes were noted:

- Prior to the pandemic, 80% of GP surgeries in Cardiff and the Vale of Glamorgan were engaging with the Carers GP accreditation scheme
- To date 12 areas have achieved the Carer Friendly Accreditation across health and social care settings and 3 areas have achieved the Carer Friendly Advanced Accreditation. A further 5 are working towards their accreditation and 37 areas have expressed an interest in the Accreditation but, due to the pandemic, have yet to move forward with the portfolio
- Unpaid Carers awareness sessions have been held for some time for Cardiff and Vale UHB staff, however these ceased in 2021 due to the pandemic (Table 15.2) [Local authority and 3rd sector data pending]

Table 15.2. Cardiff and Vale UHB staff carers awareness sessions

Date	May 2016-April 2017	May 2017-April 2018	May 2018-April 2019	May 2019-April 2020	May 2020-April 2021
Training numbers	581	426	402	559	None due to Pandemic

Source: Cardiff and Vale UHB

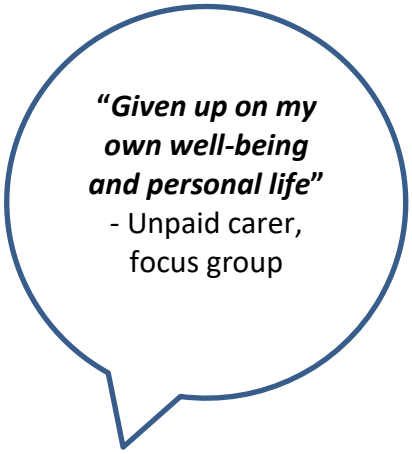
- Within Cardiff and Vale UHB, a Carers Lead was appointed in 2020, with the aim to aid a smooth transition for people on hospital discharge, back home with support to unpaid carers
- The Cardiff and Vale of Glamorgan Carers Gateway was launched in March 2020, with the key role of "*improving the quality of life for unpaid carers, and the cared for, in Cardiff and the Vale".* Carers Trust South East Wales, which runs the service, works with both unpaid carers and professionals to achieve this aim. During 2020/21 there were 526 referrals into the Carers Gateway service. The most common reason for referral was regarding parent and grandparent carer (21%), followed by physical disabilities (10%), chronic illness (9%), mental impairment (6%), and dementia (5%) (note that the reason was unknown in 33% of referrals).

15.2.1 COVID-19

Across Great Britain, during the COVID-19 pandemic more women (57%) than men (43%) were unpaid carers according to research by the Office for National Statistics (247). In addition, a much higher percentage of unpaid British carers self-reported that they had a disability (32%) as compared to the rest of the population (23%) (247). Sixty three percent of British unpaid carers were worried about the impact of the pandemic on their lives as opposed to 56% of non-carers (247).

Lockdown restrictions

The experiences of unpaid British carers during the pandemic were mixed, with some stating that it had allowed them to have more time, but with others stating that the loss of respite and external support has had a negative impact on their well-being (252). It was noted in a recent Cardiff and Vale PNA focus group that COVID-19 restrictions had demonstrated how good services were before they were "*taken away*". Many relationships between the person caring and the person cared-for had also deteriorated during the pandemic across Britain (252).



Due to the requirement to "*shield*" many British unpaid carers felt cut off from normal life/other family members (252). Stress, anxiety and depression and a feeling of isolation/loneliness increased for many British unpaid carers during the pandemic (252). This feeling was corroborated by the Cardiff and Vale PNA focus group participants. The participants also reported that their situation was not back to normal and that they were still hesitant to go out. Families often didn't want external agencies in their own home due to the risks of COVID-19, therefore they were struggling to cope with their situation, according to professionals. Working from home helped some British unpaid carers have more freedom to care, but had meant less of a break from the caring role (252).

Care and support provision

Time spent chasing services by unpaid Welsh carers increased during the pandemic, which increased their stress (252). A Cardiff and Vale PNA focus group also added that health appointments were often cancelled, and it was challenging to explain symptoms such as pain in a telephone appointment, especially when the carer considered their English to be not very good. British unpaid carers, deemed face to face sessions a better experience than video calls (252).

15.3 What are the care and support needs?

A Cardiff University report commissioned by Public Health Wales developed 4 key themes in their analysis of the main issues for unpaid carers in Wales prior to the pandemic: health and well-being, identities and relationships, services and systems, and education, employment and finances (252). These are described below.

15.3.1 Individual

Mental health and well-being

In Wales, unpaid carers experience stress, isolation and loneliness and poor mental health due to their caring responsibilities (252). Research in England between Sport England and Carers UK showed that unpaid carers had lower physical activity levels (46% inactive) as compared to the general population in England (33% inactive) (253). Three quarters (76%) of unpaid English carers aged 55 plus did not feel able to do as much physical exercise as they wanted to (253). Physical activity combats stress, anxiety and depression (253). The key barriers to taking part in physical activity included: not having the time to take part (88%);

not being motivated (71%); not being able to afford the costs (67%); and not having anyone to go and do physical activity with (59%) (253). In the Cardiff and Vale PNA survey, unpaid carers were the population group most likely to say that had no control over their lives (12.6%). In the same survey, 19.3% of survey respondents who were unpaid carers did not have time to address their own care needs; and 44% felt they were not sufficiently supported in their caring role.

Identities and relationships

Many unpaid Welsh carers did not recognise their status as an unpaid carer until they reached crisis point, and sought professional help (252). Many unpaid Welsh carers also stated that having a healthy relationship with the person cared-for would be critical for a successful future together (252).

Language and communication

There are no data on first language of unpaid carers in the region. A Cardiff and Vale PNA focus group participant's feedback was that language barriers were an issue for ethnic minority groups, trying to receive much needed support. Cultural needs were also identified as important, for example: the need for same-sex practitioners in some cultures.

15.3.2 Community

Services and systems

Professionals frequently do not ask about unpaid Welsh carers' needs or experiences (252). Carers Wales found that only 28% of carers in Wales reported that they had had a carers assessment (or a review of their assessment), in the last 12 months (254). Unpaid carers can also spend a lot of time chasing services to get support (252). Third sector support was highly valued by unpaid carers, especially peer support for younger adult carers (252). Flexible support was needed by Welsh unpaid carers (252). Of Welsh carers who had had an emergency admission for the person they care for, 30% felt that the admission could have been prevented if the person cared-for had had more care and support; 20% felt that more support for them as the unpaid carer (such as breaks from caring) would have prevented the admission (254). In the Cardiff and Vale PNA survey, unpaid carers were the population group most likely to find it fairly or very difficult to find information or advice about the services that are available at 50%.

15.3.3 Wider determinants of health

Deprivation

The Cardiff and Vale PNA focus group of unpaid carers stated that poverty led to digital exclusion as people needed either digital skills couldn't afford the technology. Professionals also mentioned that some unpaid carers would not have the means for a bus or taxi to take respite; this creates a 2-tier system for carers needing respite. Carers Wales' 'State of Caring Report 2019' (254) stated that 45% of Welsh unpaid carers say that they struggle to make ends meet and 68% report that they regularly use their own income or savings to support the person they care for. Twenty three percent of Welsh unpaid carers have been in debt as a result of caring; 8% cannot afford utility bills; and 4% cannot afford their rent/mortgage

payments (254). Almost three quarters (74%) of Welsh unpaid carers surveyed didn't receive any cash sum (direct payments or a personal budget) for themselves or for the person cared-for (254).

Education and employment

According to research by Cardiff University, many unpaid Welsh carers valued being in paid work, in addition to their caring role (252). Caring has a substantial impact on personal finances, particularly if one is a single carer in Wales (252). Many unpaid Welsh carers thought that the financial compensation through the carers allowance was insufficient (252).

> ***"The health of my mum deteriorated rapidly, I had to give up work, it's impossible to work and be a carer"*** - Unpaid carer, focus group

Housing

In the Cardiff and Vale PNA survey, 63% of unpaid carer respondents needed adaptations to their property, which was 17.8 % higher than the average of all respondents to that survey. This tallies with the Carers Wales perspective that home adaptations are vital in enabling people in need of care to remain in their own homes for longer (255). Where adaptations are not in place it creates a need for more formal support to manage the condition of the person cared-for within the home environment (255).

15.3.4 Unmet needs

The following care and support needs were identified as unmet by focus group participants:

> ***"Having to wait 6 months just for assessments – [feeling] unsupported as a carer and then a sense of guilt for these feelings"*** – Unpaid carer, focus group

- Supportive employment: employers were not supportive enough to meet unpaid carers' needs: *"[I] had to give up work… employer did not support flexible adjustments… used all leave for caring / hospital appointments… not had a holiday break in years"*
- Timely services: carers' assessments and counselling services waiting times are lengthy – *"waiting list is huge"*
- Resource waiting times are also lengthy: *"direct payments take a month to be approved on what's supposed to be a simple process"*
- Culturally appropriate services: services need to meet the needs of people from different cultural backgrounds

- Appropriate respite for unpaid carers: feedback from Carers Gateway participants during 2020/21 was that more respite services were needed for unpaid carers

Key gaps in knowledge identified included data on number of unpaid carers whose first language is not English.

15. 4 What are the range and level of services needed?

15.4.1 Prevention and assets

In order to prevent the needs of people cared-for from escalating, unpaid carers need more support, in terms of emotional, practical and financial resources to prevent a crisis situation.

Assets to support well-being

A virtual Cardiff and Vale PNA focus group was held on 27 October 2021, with 12 unpaid carers. Participants highlighted that in the Barry area there were less activities for unpaid carers than in Cardiff. Assets that were considered sources of support for carers' well-being included:

- Other parents who had children with care and support needs
- Community groups such as social groups, drama groups, as well as local cafes and places of worship. Specifically, church halls, Sunday circle, a mosque opening an over 60s club were identified
- Third sector organisations such as: Parents Federation was described as *"supportive";* Innovate Trust (providing support to disabled people) was "*amazing"* (in particular their respite service); and Women's Connect Zoom was cited as *"useful to socialise"* and to meet via WhatsApp and face to face. Voluntary organisations have been *"great*"
- Dewis directory of services: www.dewis.wales (256)
- Speech and language services were described as "*excellent"*
- Courses for carers at hospital were cited as *"excellent*" and carers found it helpful to meet others in similar situations

Professional leads identified the Cardiff and Vale Carer's Gateway as an important asset through provision of support and advice for unpaid carers, people who have care needs, and professionals.

15.4.2 Community services

Respect for the person cared-for

Services need to respect the needs of the person who needs care. Focus group participants highlighted the need for care service providers to undertake cultural training: ""*Lets age well" project with Women's Connect [First was] very helpful as it understands the needs of the culture".*

More support needed for unpaid carers

Unpaid carers need to be valued in their caring role. Support needs to be timely, for example, in terms of having a carer's assessment, as well as provide psychological and practical input.

15.4.3 Partnership approach

Unpaid carers need to know what services are available

Access to services needs to be made easier, by knowing what is available: *"if you don't know, it's not readily available for you to find out".* Focus group participants wanted a carers directory with full details of how and what to access was needed (despite one existing online, created in 2017).

15.5 What is likely to happen in the future?

As the population ages and increases in number, there are likely to be many more unpaid carers in our population, with a steady rise in both Cardiff and the Vale of Glamorgan (Table 15.3).

Table 15.3. Projected number of unpaid carers, Cardiff and Vale of Glamorgan, 2020-2040

Year	2020	2025	2030	2035	2040
Cardiff	40611	41401	42222	42828	43263
Vale of Glamorgan	16893	17472	17929	18302	18639
Cardiff and Vale total	57503	58874	60151	61130	61902

Source: Social Care Wales (88)

15.6 Recommendations

All agencies, in partnership to:

- Review the need for an updated carers directory, which is updated regularly and available digitally, and publicise widely

Provide respectful care that is culturally appropriate, with training where needed Cardiff and the Vale of Glamorgan Local Authorities to:

- Strengthen clear pathways for carers assessments within local authorities following a "what matters" conversation
- Capture first language needs in carers assessments
- Consider flexible respite needs for unpaid carers

Cardiff and Vale University Health Board to:

- Review the pathway for mental health support to unpaid carers, so that waiting time decreases

Employers to:

- Adopt reasonable adjustments for people with caring responsibilities so that worthwhile employment is maintained and finances for unpaid carers are optimised

16. Sensory Loss and Impairment

This chapter should be read in conjunction with the following chapters: Children and Young People with Complex Needs; Older People; Healthy Lifestyles and Long Term Conditions; Physical Disability

Recommendations

All agencies, in partnership, to:

- Increase awareness of specialist and support services to improve signposting (257); and improve joined working
- Promote awareness and normalisation of British Sign Language (BSL)
- Anticipate the increase in prevalence of hearing and sight loss in the future
- Increase opportunities for consultation and co-production
- Sign up to the Disability Confident Scheme (187) and develop inclusive recruitment. The D/deaf community (encompassing people who have profound hearing loss and use BSL (Deaf), as well as people who have hearing loss (deaf)) need more D/deaf and BSL users professionals embedded in services to ensure they are represented and that communication is not a barrier

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Undertake Deaf Awareness training for staff to improve the culture for service users, and co-workers who may have hearing loss
- Increase the number of Rehabilitation Officers for Visually Impaired people in line with recommendations (258)
- Design physical activity strategies and plans to increase D/deaf-friendly and D/deaf aware opportunities

Cardiff and Vale University Health Board and Primary Care to:

- Improve recording of Deaf people as Deaf in medical records so BSL interpreters can be appropriately booked (257), improving referrals, and experience of health care
- Take additional action to promote equity of access to healthcare services for D/deaf people compared to non-disabled people
- Support the newly established Inclusive Recruitment Team who ensure that they work to the Themes and Goals of the Disability Confident Scheme

16.1 Overview

The All Wales Standards uses the term "*people with sensory loss*" to describe:

- People who are Deaf, deafened, or hard of hearing
- People who are Blind or partially sighted
- People who are Deafblind (whose sight and hearing impairment cause difficulties with communication, access to information, and mobility (259)

Sight loss

There are an estimated 9,530 with sight loss in Cardiff, and 4,790 in the Vale of Glamorgan in 2021, giving a prevalence of 2.6% and 3.6% (prevalence in Wales: 3.5%). Of these, 1,240 and 640 people in Cardiff and the Vale of Glamorgan respectively have severe sight loss (blindness). In Cardiff, there are 40 children aged 0-16 who are blind, and 10 in the Vale of Glamorgan. Half of children who are blind or partially sighted have additional disabilities (260). People with learning disabilities are 10 times more likely to have sight loss than those without learning disabilities (260).

Hearing impairment

Documents use different terminology; this chapter aligns with that used by the All Wales Deaf Mental Health & Well-Being Group. Where specifically stated, people who identify as members of the Deaf community, who have profound hearing loss and use British Sign Language (BSL), are described as Deaf; whereas those with hearing loss or where it is not specified, the terminology "*deaf*" is used (257). Where both communities are described, "D/deaf" is used.

In Cardiff, 29,800 are estimated to have moderate/severe hearing loss; this figure is 15,500 for the Vale of Glamorgan. A further 660 people (Cardiff) and 340 (Vale of Glamorgan) have profound hearing loss, including 95 people of working age (20-64 years) (260).

Dual sensory impairment

The Royal National Institute of Blind people (RNIB) estimates that 21,300 people in Wales have any dual sensory impairment, of whom 1,860 live in Cardiff, and 910 in the Vale of Glamorgan (260).

This chapter was developed using existing literature, strategies and reports and triangulating findings with professional leads and engagement work: 38 survey respondents, 6 participants for the sight loss focus group, and 4 participants for the Deaf focus group, which was conducted in BSL. Forty-nine respondents of the provider's survey provided services for people with sensory loss or impairment. The views of those engaged are not representative of all people with sensory loss or impairment in the population of Cardiff and the Vale of Glamorgan.

16.2 What has changed since 2017?

16.2.1 Pre-COVID-19

Welsh Government published the Framework of Action for Wales 2017-2020 which details the integrated framework of care and support for people who are D/deaf or living with

hearing loss (261). The All Wales Deaf Mental Health & Well-being Group published their report on the hidden inequalities around mental and physical health amongst Deaf people in 2021 (257). Professional leads observed an increasing awareness of the existence and importance of intersectionality, which describes the "*complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, and classism) combine, overlap, or intersect especially in the experiences of marginalized individuals or groups"* (262).

Cardiff and Vale UHB is now the first Welsh Health Board to sign the British Deaf Association's British Sign Language Charter (263). The Health Board was highly commended by the Health Service Journal for transforming glaucoma eye care services in 2020/21 (264).

16.2.1 COVID-19

Independence and isolation

The Welsh Government published "Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19" in 2021. This report identifies difficulties disabled people have experienced during the COVID-19 pandemic, and states that people with visual loss have had their autonomy and mobility negatively impacted due to structural changes in the environment and learned routes. For example, new layouts in the town centre and changes to access to sighted guides (73).

The Royal National Institute for Deaf People (RNID) report that deaf people in the UK experienced increased isolation through reduced social interaction, masks, and social distancing; and that non-face to face options such as telephone contact weren't always suitable (265). Sight Cymru stopped in-person groups in 2020 but maintained contact through virtual meetings and phone calls.

The RNIB's research across the UK finds that people with sight loss considered technology a "*saviour*" (266); which was echoed in the PNA focus groups: "*I was stuck at home. Zoom has been very good. Without Zoom we'd all be lost*". However, people felt "*more disabled*" and as though their world has "*shrunk"* (266). Focus group participants discussed the difficulties of not being able to visit family members in hospital.

D/deaf focus group participants stated that as communication with D/deaf peers and friends is so important for well-being, the lockdowns restricted this and created a sense of isolation. This isolation impacted negatively on participants' mental health. The D/deaf community relied more on online resources despite it being difficult with BSL interpreters on online platforms.

> ***"Support groups are usually only in English. Some people have been prevented from attending as they are not able to speak English" –*** person with sight loss, focus group

Eight of 38 survey respondents with sensory loss reported that before COVID-19, they felt lonely some of the time, with 1 respondent feeling lonely all or most of the time. Over the last year, however, 18 feel lonely some or all of the time.

Access to public health information

Nationally, deficiencies in accessibility of public health information were observed, through lack of subtitles for audio content; lack of BSL versions of critical information; and a reliance on telephone hotlines (73) (265). The RNID polled its UK members regarding awareness of a video relay of Test and Trace, but 94% were not aware of this. Insufficient notice for key government announcements and a lack of BSL translation meant information was inaccessible to people with hearing loss. A new government role has been developed to lead on accessible communications from UK Government (265).

People with visual impairment may be unable to adhere to social distancing rules, and have subsequently experienced negative reactions from others; as well as being at increased risk of COVID-19 (266).

The focus group reported a lack of information on the pandemic and lockdown provided for the D/deaf community, so news often came from social media. Lots of D/deaf people struggle with written English and need BSL resources. The British D/deaf Association set up a daily BSL news summary specifically for the D/deaf community, which reduced isolation and panic: "*I would have been lost without them*".

Access to health and care services

In the UK, around half of people with hearing loss reported a negative impact of COVID-19 on access to care services, compared to one-sixth of people without an impairment (265). A survey amongst RNIB members puts this figure at 73%, with 4/10 concerned that their vision would worsen (73). Support provision and consultations provided over the phone or virtually provoked difficulties for people who are Deaf or hard of hearing, as they often use visual cues or lip reading. Masks also prohibit lip reading; therefore, face to face appointments were also difficult as people did not feel able to ask staff to remove their masks (265). Transparent masks have now been approved. Online technologies are not a direct replacement for face to face services, and many people who are deaf or visually impaired struggled to access virtual services (267); stating that 50% of communication is lost through a webcam (257). Cardiff and Vale UHB provided iPads to enable person-centred care, and to overcome the assumption that everyone has access to digital technology.

The RNID reports that deaf people who were shielding could only register for priority supermarket deliveries via telephone (265); similarly, people with visual loss experienced problems with accessing services in Wales (73). A higher proportion of disabled people experienced difficulties accessing essential products such as food and medication compared to non-disabled people (50% versus 17%) (265). One-fifth of respondents in RNIB research in the UK rationed food due to concerns regarding food deliveries (266). Those assisting deaf people were exempt from wearing a face mask, to aid communication, however as deafness

is a hidden impairment, many people were concerned for stigma and negative reactions by others (265).

Participants in the sight loss focus groups discussed that many services had stopped due to COVID-19 restrictions; but that online support such as through third sector organisations, groups, and clubs have been very helpful.

Cardiff and Vale UHB developed videos with subtitles, communication flash cards and provided accessible information regarding vaccinations (264).

Education and employment

COVID-related adjustments in the workplace may make it more difficult for D/deaf people to return to work, for example, through physical barriers between workspaces, face masks, and social distancing. For those working from home, the increased reliance on video and audio calls may present a barrier (265).

The National Deaf Children's Society report that children and their families are concerned regarding the lack of specialist support for their education, difficulties accessing online learning platforms, as well as difficulties communicating due to face masks in schools (268).

16.3 What are the care and support needs?

16.3.1 Individual

Independence and autonomy

Funds are now available in Wales for disabled people who would like to stand in local government elections, to cover costs such as travel and assistive technology (269). Increasing visibility of disabled people – including sensory loss – will help create an inclusive environment.

A focus group with D/deaf participants articulated that services are not always accessible to D/deaf users: many services (particularly medical) rely on the phone which is a barrier for the D/deaf community. D/deaf service users often have to rely on hearing family members to make phone calls and contact services on their behalf, affecting independence. They would like to see more D/deaf community groups and centres where the community can come together and gain support; and activities which are accessible.

Participants recalled there used to be specialist D/deaf social workers, but this service was replaced with general social workers who "*don't live a D/deaf life*", and *"provide help that they think you want rather than asking what help you really want".* This additionally emphasises the importance of person-centred services. Due to a lack of knowledge of the D/deaf community, there was poor signposting to services.

Physical and mental health

There is a synergy between sensory impairment and other medical conditions. For example, people living with dementia have increased prevalence of sight loss; dementia can make it more challenging to diagnose sight loss (260). Deaf people are more than twice as likely to

experience mental health disorders, such as anxiety and depression than hearing counterparts; this is in part due to their experiences of stress, discrimination, and isolation (257). COVID-19 has further exacerbated these inequalities (257). Deaf people report that they are not recorded as Deaf in their GP records, which has consequences for any subsequent referrals. Negative experiences lead to Deaf people disengaging from health care services (257).

Children and young people

In Wales, most (80%) school aged deaf children attend mainstream schools without specialist provision; with others attending mainstream schools with resource provision (9%), special schools not specifically for deaf children (10%), or undertaking home education (1%) (257). Nearly half of Teachers of the Deaf in Wales will likely retire in the coming 15 years (257).

Focus group participants stated that D/deaf children are not able to create a D/deaf identity, integrate into the D/deaf community, or form close connections with other D/deaf children/people without specialist D/deaf schools. Parents need to learn BSL, as do teachers and support staff – support staff are often not specialist or D/deaf themselves. There are a lack of D/deaf youth groups to bring D/deaf young people together to help create that identity. This lack of community for young D/deaf people makes it difficult for them to find out about services or access support, which leads to isolation and mental ill health.

Language and communication

Since 2004, BSL has been a recognised official language in Wales, with 4000 speakers in Wales (257). However, there are only 48 BSL/English interpreters with the relevant qualifications in Wales, below the target of 64 (257). Although interpreters can be booked for planned meetings, more spontaneous communication in healthcare settings (such as during an inpatient stay) is challenging (257).

There are no mental health practitioners in Wales with Welsh BSL, limiting culturally appropriate care for Deaf patients with mental health problems (257).

Access to information for Deaf people on how to book a BSL/English interpreter is also limited, often health care providers are not knowledgeable about the process, and confirmation that an interpreter will be present for an appointment is often lacking (257). Welsh language information is proactively offered, but people report needing to ask specifically for BSL (257).

Focus group participants with sight loss experienced similar barriers to access due to support provision available only in English.

> ***"Support groups are usually only in English. Some people have been prevented from attending as they are not able to speak English" –*** person with sight loss, focus group

Cardiff and Vale UHB has used funds from the Patient Experience Team to give staff the opportunity to learn BSL; some staff went to additional classes external to the Health Board. BSL information videos are now played on all hospital screens (264).

Focus group participants stated communication between D/deaf services providers and D/deaf service users is poor. There is a general lack of D/deaf awareness among the hearing community, and so organisations need more training and awareness. There needs to be easier ways to communicate with services, without relying on telephones, such as email or preferably a BSL speaker on video. Many native BSL users do not read or write in English. In many cases the D/deaf community just give up trying to access services. There is a need to employ more D/deaf people/native BSL users to embed the D/deaf community within service provision.

> ***"It is often difficult to communicate with professionals because they use a lot of technical language" –*** person with sight loss, focus group

16.3.2 Community

16.3.3 Wider determinants of health

Deprivation

The 'Locked Out' report includes people with sensory loss, and describes how disabled people are more likely to live in poverty and in more deprived areas than non-disabled people. This has been further exacerbated by the coronavirus pandemic (73).

The RNIB reports that only one in four blind and partially sighted people of working age are in employment. Local authority level data are not available. People who live in more deprived areas are at increased risk of sight loss (260); as are people on low incomes, with explanations including concerns regarding the cost of glasses or barriers to accessing optician or ophthalmic services resulting in people delaying appointments until they have symptoms (270).

Housing

Professional leads identified the need for statutory bodies, third sector organisations, and housing associations to collaborate better in order to build or adapt houses suitable for people with hearing or sight loss, for example, induction loops. This is equally the case in residential homes and the workplace. The planned new hospital in Cardiff will have induction loops built in, in order to normalise reasonable adjustments.

Concerns raised by focus group participants with sight loss included receiving sufficient care for them to stay in their own house in the future.

16.3.4 Unmet needs

Access to health services

A report investigating inequalities for Deaf people in Wales noted that there are no formal links between Deaf Child and Adolescent Mental Health Services (CAMHS) in Wales and the equivalent in the UK; whereas there are such arrangements between hearing services for CAMHS (257). There are ten National Deaf CAMHS centres in the UK, of which none are in Wales. The report identifies that 40% of Deaf people have mental health concerns, and estimates that around 1,000 of the 2,500 Deaf children and young people in Wales are at risk of mental health problems (257). Deaf CAMHS offer specialised services, including consultations in BSL. Often Deaf adult patients requiring inpatient admissions are transferred to England (257).

The sight loss focus group identified difficulties accessing health and social care services: "*it is very difficult to see a doctor physically…. I have to wait on the phone to get through for a very long time"; "GPs should know where to refer us for extra support. They don't know. Social Services should be there for help, support and advice."*

The D/deaf focus group articulated accessibility barriers to accessing support services, such as relying on phone calls to access services. Some GP services offer a signed video service, but not all. Most rely on a phone line to make appointments so D/deaf users have to go into the surgery to make an appointment or ask a hearing family member.

There is no specialist mental health provision for D/deaf people, making access to mental health services very difficult.

The participants would like to access fitness/health activities such as yoga or a gym, but these activities/organisations are not D/deaf friendly and very few staff/instructors are D/deaf aware. Public facing organisations and activities such as yoga/gyms need more D/deaf awareness to make access easier, such as through employing D/deaf people.

The focus group with D/deaf people articulated a real feeling that services had been cut, for example, funding for a D/deaf centre which has since been closed. The discussion included that comparatively small amounts of funding could be transformational, but are currently inaccessible.

Data gaps were identified around deprivation levels and sensory loss; and people with sight or hearing loss and other medical conditions.

16. 4 What are the range and level of services needed?

16.4.1 Prevention and assets

Newborn hearing screening

In Cardiff and Vale UHB, 99.9% of eligible and suitable babies are offered hearing screening, and 99.2% undergo newborn hearing screening (271). Of high risk babies referred, the average age of confirmation of hearing loss was 7.3 weeks (Wales average is 7.4 weeks) (271). Average age at hearing aid fitting was 13.7 weeks (Wales average 11.4 weeks) (271). Vision screening is assessed at multiple times during childhood (272).

Rehabilitation Officers for Visually Impaired people

The Wales Council of the Blind, in collaboration with other organisations, has reported that currently the number of Rehabilitation Officers for Visually Impaired people (ROVIs) is insufficient to meet need; and warn that this situation will escalate in coming years due to the anticipated increase in blind and partially sighted people (258). Furthermore, there are limited training places and existing ROVIs are due to retire, limiting capacity for future demand. ROVIs are considered essential under the Social Services and Well-being (Wales) Act 2014 for their role in prevention, and minimising the impact of impairment. People with a new diagnosis of sight loss receive help from ROVIs to conduct activities of daily living; and learn how to minimise risk of injury. Furthermore, ROVIs build confidence, promote independence, and provide practical and emotional support (258). In 2020, there was only 1 ROVI in Cardiff, and 1 in the Vale of Glamorgan, which is far below the minimum standard of 1:70,000 population (equating to 5.2 in Cardiff, and 1.9 in Vale of Glamorgan) (258). However, theme leads have identified that the ROVI waiting list in Cardiff and the Vale of Glamorgan is manageable, and Sight Cymru provide additional support which is beneficial for service users.

Falls prevention

Sight loss can lead to falls; the RNIB estimate that 540 falls in Cardiff and 290 in the Vale of Glamorgan amongst people aged 65 and over are directly attributable to sight loss (260). Prevention of sight loss, or appropriate management where possible, may help reduce the risk of falls. The National Institute of Health and Care Excellence (NICE) recommend that vision assessment and referral are carried out within a multifactorial intervention for people who are at risk of falls or who have fallen (273). This guidance has been incorporated into the Cardiff and Vale UHB Falls Framework (274).

Supportive environment and awareness

The Framework for Action calls for an environment that removes barriers and enables people to reach their full potential; and reduces inequalities (261). Co-production is one mechanism by which to enable people with sensory loss to collaborate with health and social care professionals, and the third sector (261).

One survey participant articulated the need for wider societal understanding of hidden disabilities as she was concerned regarding her mobility and potentially falling over; and demonstrates the impact of others' actions on their independence and confidence.

"I avoid busy walking times and routes with cyclists as very unsteady on feet and can't hear people. Too many incidents where cyclist got cross because I could not hear …. I am in favour of cycle paths that are segregated" – person with sensory loss, survey

The D/deaf community face inequalities from the wider community caused by physical barriers to communication rather than wider stigma or fear. Addressing these practical communication barriers is easier than changing mindsets. One participant worked within the hearing community and felt discriminated against, and so moved jobs to work with the D/deaf community where she feels more comfortable.

The D/deaf focus group highlighted a "*pushback*" after disclosing their D/deaf status. This was thought to be not due to stigma but a lack of awareness of D/deaf needs. This pushback discouraged the D/deaf community from seeking to access some non-essential services. Focus group participants felt D/deaf awareness is not sufficient among service providers and so services are generally inadequate for the D/deaf community. D/deaf people are not represented enough among decision makers and so policies are made by hearing people without understanding the needs and lived experience of the D/deaf community. Education to the wider population and service providers, and improving and increasing understanding would be the most important contributor to removal of barriers**.**

"A lack of awareness and understanding leads to break downs in communication" – Deaf person, focus group

Assets to support well-being

A number of assets that support people's well-being were identified. People with sight loss reported that despite lockdown restrictions, they were positive about support from the third sector: "*Age Alive and Sightlife meetings have been great [online]…[online] support groups run by the organisations have enabled us to socialise during lockdown*"; and *"Sight Cymru gave me so much support. Without them no-one would have told me anything".* One respondent wanted more support closer, as "*everything seems to be in the town centre".*

D/deaf focus group participants reported that D/deaf peers and friends are crucial to well-being and to support good mental health. Without regularly meeting with D/deaf friends one participant said that she would have become depressed and unwell. It is important to communicate with others who understand the D/deaf experience. With a lack of awareness among the hearing community, the D/deaf community is crucial to forming a D/deaf identity and to sharing information on services. One participant, previously a board member of a local D/deaf charity, has set up a D/deaf group of their own. The services that the group values were D/deaf originated – often in a response to what they felt were historic local authority cuts. These groups were seen as being a key part in meeting Future Generations obligations (especially around early intervention) and Local Authority Equality Requirements, but there were funding difficulties. The Royal Association for the D/deaf was also helpful.

> ***"Charities are helping us to socialise – good for our mental well-being"*** – person with sight loss, focus group

Survey respondents with sensory impairment report the church being a good source of support, alongside third sector and community groups (such as Friends of the Library; Gyspy Travellers Wales; Women Connect First; Sight Life Cymru; Women's Institute), and socialising over food and drink in cafes and restaurants or virtually. Barriers to accessing these assets included transport; and closure of groups and venues due to COVID-19 restrictions. Professional leads identified Deaf Hub Wales and the RNIB as useful assets locally.

16.4.2 Community Services

Health services

The Framework for Action states that people with sensory loss should be signposted in a timely manner to specialist services as appropriate, including speech and language therapists and counselling services (261). Young people in particular should have a seamless and timely transition to adult services (261).

Cardiff and Vale UHB has developed a phone first system to access Emergency Care. The service is also available via Textphone (for deaf or hard of hearing patients); or through Relay UK (for patients who are deaf, hard of hearing, or speech impaired) (264).

> ***"I would like free transport to hospital and to shopping centres, door to door"*** – person with sight loss, focus group

Focus group participants wanted to see their GP and other healthcare specialists face to face, and for the process to be easier and quicker. Care and support services should align with transport needs to ensure access for service users.

Social Care

Sight loss focus group participants wanted social workers or support workers to provide information and advice; help with forms; and emotional support. Specialist D/deaf social workers are also desirable, similar to previous provision, to help support D/deaf people by drawing on lived experience.

Education and employment

Support for people with hearing or sight loss to seek, gain, and thrive in employment has been discussed by professional leads. Fear of losing a job and stigma means people can be unwilling to declare their need for hearing aids. Employers can proactively inform prospective and current employees of support available for people with hearing or sight loss. Initiatives to achieve this include disability confident and inclusive recruitment, with added benefits of drawing from a wider pool of talent, and improving staff morale through evident support (187). Reasonable adjustments and adaptations, such as hearing loops, will help people with hearing impairment.

"Need to employ more native BSL users to embed the Deaf community within service providers" – Deaf person, focus group

16.4.3 Partnership approach

Person-centred services

Services need to be person-centred, so that the individual is able to do what matters to them. In line with this, independence should be promoted: *"One of my fears is how do we keep our independence? Plus who do we go to for help?"*

"I want to live a happy and healthy life. Old age demands quite a lot of physical health. I want to know the help is out there. I don't want to go out dancing, I just want to be able to go out for a walk" – person with sight loss, focus group

Some focus group participants commented that services were "*all or nothing*", for example regarding transport: "*I don't qualify, it's very black and white, there seems to be no in-between"* (sight loss focus group participant). Others commented that "*it is very difficult to get support from Social Services. It's all means tested. Support is rationed and it's very hard to qualify for support"* – focus group participant with sight loss. Professionals responding to

these findings state that Rehabilitation Officers for Visually Impaired people (ROVI) and Hearing Impairment Social Care Officer support is not means tested but it is based on assessment.

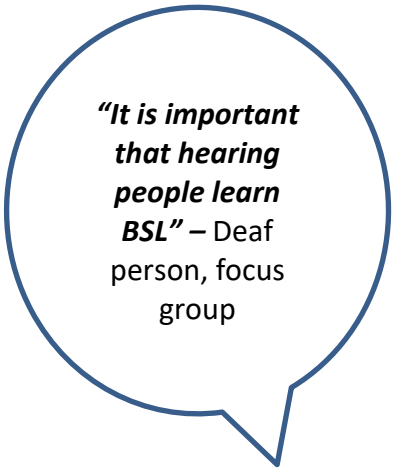
One survey participant demonstrated the potential for co-produced, person-centred, creative solutions: *"Would also be wonderful to have classes where elderly mix with children - this could be classes/events where can take grandchildren or ones where can interact with children e.g. in schools. Play games, read, crafts...children can be so uplifting for lonely older people. Needs to be accessible by bus and short walk or have adequate parking as a lot of us elderlies do not have a blue badge"*. Survey respondents articulated their desire to meet other people – in particular, people of a similar age, similar interests, or similar impairment.

Services should identify people's concerns for the future and seek to proactive support where possible. For example, one focus group participant was concerned that communication issues will negatively impact on decisions made about his health as he gets older; that hospitals and medical professionals will ask his family to make decisions for him, without consulting him, and that he will not be in control of his own care or make his own decisions. This is particularly worrying in relation to elder care. Given D/deaf people are born into hearing families there is a real fear of isolation in older years, exacerbated through cuts to D/deaf focused services.

Communication

All services need improvement to make accessibility easier and more D/deaf friendly. BSL users or D/deaf people need to be embedded within service providers and organisations (e.g., through employment) so that D/deaf people can communicate directly with someone who understands BSL and also the D/deaf experience.

Cardiff and Vale UHB has offered staff training in basic BSL and Deaf Awareness to enable staff to better meet patients' needs. In 2019/20, 200 staff had been trained (263). Members of the deaf communities have provided feedback to the health board that BSL is their first language; and to be aware of the use of jargon (263). Cardiff and Vale UHB is training staff in medical records to better identify people who may need BSL interpreters for appointments (263). Cardiff and Vale UHB is now the first Welsh Health Board to sign the British Deaf Association's British Sign Language Charter (263). Cardiff Local Authority staff have access to Deaf Awareness and BSL training (30). [Data pending from the Vale of Glamorgan]



16.5 What is likely to happen in the future?

The RNIB estimates an increased number of people will be living with sight loss over the next 10 years; from 9,530 to 12,700 in Cardiff (33% increase), and from 4,790 to 6,470 in the Vale of Glamorgan (35% increase) (260). Increases in diagnoses of common sight-

threatening conditions are all expected to increase; for example, cataract by 36% (Cardiff) and 38% (Vale of Glamorgan); and late stage age-related macular degeneration by 36% (Cardiff) and 41% (Vale of Glamorgan) (260).

The prevalence of diabetes is expected to increase by 22% in Cardiff (against a Welsh average increase of 9%, and 6% in the Vale of Glamorgan) between 2021 and 2030; which corresponds to a notable anticipated increase in sight loss due to diabetic retinopathy (17% increase; compared to 5% in Wales, and 1% in the Vale of Glamorgan) (260).

An increase in the number of people who have both deafness and sight loss is expected as older age is the leading cause; and the population of those aged 85+ will grow over the coming years (87). Strokes are a cause of sight loss; the risk of stroke also increases with age (260).

16.6 Recommendations

All agencies, in partnership, to:

- Increase awareness of specialist and support services to improve signposting (257); and improve joined working
- Promote awareness and normalisation of BSL
- Anticipate the increase in prevalence of hearing and sight loss in the future
- Increase opportunities for consultation and co-production
- Sign up to the Disability Confident Scheme (187) and develop inclusive recruitment. The D/deaf community need more D/deaf and BSL users professionals embedded in services to ensure they are represented and that communication is not a barrier

Cardiff and Vale University Health Board and Cardiff and the Vale of Glamorgan Local Authorities to:

- Undertake Deaf Awareness training for staff to improve the culture for service users, and co-workers who may have hearing loss
- Increase the number of Rehabilitation Officers for Visually Impaired people in line with recommendations (258)
- Design physical activity strategies and plans to increase D/deaf-friendly and D/deaf aware opportunities

Cardiff and Vale University Health Board and Primary Care to:

- Improve recording of Deaf people as Deaf in medical records so BSL interpreters can be appropriately booked (257), improving referrals, and experience of health care
- Take additional action to promote equity of access to healthcare services for D/deaf people compared to non-disabled people
- Support the newly established Inclusive Recruitment Team who ensure that they work to the Themes and Goals of the Disability Confident Scheme

17. Violence Against Women, Domestic Abuse, and Sexual Violence

This chapter should be read in conjunction with the following chapters: Children and Young People; Children Looked After; Older People; Healthy Lifestyles and Long Term Conditions; Physical Disability; Asylum Seekers and Refugees

Recommendations

All agencies to:

- Strengthen the availability of existing services to provide person-centred care with seamless and timely transition between agencies, for example, through supporting inter-agency communication
- Continue to improve awareness amongst victims, bystanders, and service providers on the recognition and management (including signposting) of VAWDASV
- Continue to deliver the required elements of the National Training Framework to all relevant staff and build on successes of Ask & Act and routine enquiry
- Improve the multi-agency response to identified risk factors, such as ACEs, through increasing understanding of factors that increase risk and an awareness of the lived experiences
- Continue to monitor evolving trends in forms of abuse and ensure services anticipate changes in demand
- Ensure continued investment in specialist support services and required delivery of high quality, needs-led, strengths-based and trauma-informed person-centred provision
- Increase practitioners' knowledge and understanding of perpetrator behaviour(s) to ensure that the accountability for the abusive behaviour remains with the perpetrator(s)

Cardiff and the Vale of Glamorgan Local Authorities to:

- Further develop target hardening and move on accommodation opportunities, so spaces are available in refuges for those who need it, and minimise disruption to victims who wish to stay at home
- Maintain, and where possible extend, a range of interventions to target known and potential perpetrators of abuse

17.1 Overview

Violence against women, domestic abuse, and sexual violence (VAWDASV) describes: "*Any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless of gender or sexuality. The abuse can be psychological; physical; sexual; financial; and emotional. The other components of VAWDASV are: rape and sexual violence; forced marriage; sexual harassment; female genital mutilation (FGM); so-called 'honour-based violence'; sexual exploitation through the sex industry/prostitution; stalking; and trafficking*" (275). Anyone can be subject to abuse, but women are more likely to be victims (276) (277). As per the Welsh Government strategy, this section encompasses all forms of gender based violence, domestic abuse, and sexual violence (277).

Data from South Wales Police recorded 14,092 offences in 2017, and 11,625 for 2021 that had taken place in the Cardiff and Vale area, for the following offence types: rape, stalking, harassment, sexual offences, violence with and without injury (278). Of these, 4,687 in 2017 and 3,795 in 2021 carried a domestic abuse flag (278).

Cardiff and Vale UHB data show a total of 267 adult safeguarding referrals were made in 2020/21 (40). A quarter of referrals were for physical abuse; 22% neglect; 14% sexual abuse; and 5% emotional abuse (40). Cardiff Local Authority data show 1,292 referrals were made of which 26% were due to domestic violence, 9% sexual violence, and 3% both domestic and sexual violence (30). The Vale of Glamorgan domestic abuse assessment referral co-ordinator has received 1,024 medium risk and 169 standard risk referrals in 2020/21. In addition, 446 high risk referrals were received by the Multi-Agency Risk Assessment Conference (279).

In 2019/20 the Recovery Information Safety Empowerment (Rise) Cardiff service received 6,263 referrals of which 1,158 were high risk. In 2020/21, an increase of 7% in referrals was observed, with 6,725 received, and more were high risk (1,475). Half of all referrals were police referrals and a third were directly from victims (30). [Data pending from the Vale of Glamorgan]

Male victims

Men can be victims of VAWDASV. Based on Public Protection Notice submissions in 2020/21 in Cardiff and the Vale of Glamorgan, approximately 20% of victims are male (2021 PPN submissions), and 80% female (8609 PPN submissions). Note that PPNs are submitted when there is concern, and may not constitute a crime. Additionally, these figures may contain repeat victims and so should be interpreted cautiously (279). In 2017, 4% of cases discussed at Cardiff's Multi-Agency Risk Assessment Conference (MARAC) were male victims. In the Vale of Glamorgan MARAC male victims accounted for 5% of cases discussed (276). The Health Independent Domestic Violence Adviser (IDVA) service at Cardiff and Vale UHB received 66 referrals for men alleging abuse in April 2020-March 2021 which equates to 13.2% of referrals received (198). Our regional strategy explicitly considers the needs of male victims.

Children and young people

In Cardiff and Vale of Glamorgan, during 2020/21, a total of 3,759 safeguarding referrals were made regarding children (3,380 were made in 2019/20). These were predominantly made by the Paediatric Emergency Department and community-based staff such as health visitors and school nurses (40). A reduction in referrals was observed from April to June 2020 due to reduced numbers of children being seen by healthcare professionals, due to COVID-19 restrictions (40). Most referrals (64%) were for child protection; and 3% for female genital mutilation (FGM) (40). Of the 293 child protection medicals undertaken in 2020/21, 194 were for physical assault; 21 due to neglect; and 35 for child sexual exploitation (40).

Cardiff Council has recorded that, as at the end of March 2020, 253 children were included on the Child Protection Register. Of these, 50% had experienced domestic abuse in the home, and 2% included sexual violence/abuse as a factor in the registration. For the end of March 2021, the total registrations had increased to 458, with 46% relating to domestic abuse and 3.5% to sexual violence/abuse (30). Equivalent data are not currently available for the Vale of Glamorgan.

Characteristics conferring increased risk

Some people with specific characteristics may be at disproportionately increased risk of abuse; and may additionally experience multiple overlapping barriers to seeking help and support (277). This includes minority ethnic women, Asylum seekers and refugees, disabled people, specific occupations such as the sex industry. (277). The Older Person's Commissioner for Wales has highlighted domestic abuse amongst older people, in particular where the individual has care and support needs, and noted that often the perpetrator may be in a position of trust, such as a family member (280). Older people may have additional vulnerabilities such as cognitive impairment; and may face barriers such as a perception that services are not for them; stigma; and fear of consequences (280). Estimates suggest approximately 15,000 people aged 60-74 in Wales have experienced domestic abuse (280). Around 13,000 incidents of abuse including neglect were reported in Wales in 2018/19 amongst people aged over 65, but this is considered an underestimate (280). The Health IDVA at Cardiff and Vale UHB has received increasing referrals from people aged 60+; from 13 in 2017, to 52 in January – October 2021 inclusive (198).

Information sources

Two focus groups (one virtual, one face to face) with a total of 9 participants were held, and 33 respondents to the survey had experienced domestic abuse or sexual violence. Thirty-five respondents of the provider's survey provided services for people experiencing VAWDASV. This is not a representative sample of the population of Cardiff and the Vale of Glamorgan, but does provide rich information to accompany other data sources used for this chapter.

17.2 What has changed since 2017?

17.2.1 Pre-COVID-19

Nationally, the following have changed since the 2017 PNA:

- Welsh Government has published the Wales Safeguarding procedures in 2019 (281), which were revised in 2021, as well as the National Action Plan Preventing and Responding to Child Sexual Abuse (282)
- In 2019, Welsh Government released the National Training Framework on VAWDASV guidance on statutory requirements for training across the public service and specialist third sector (283)
- The UK Government's Domestic Abuse Act 2021 has been published (284)
- Welsh Government is updating national VAWDASV strategy, which previously ran from 2016-2021 (277)

Regionally, the following documents have been published:

- Cardiff and Vale of Glamorgan Violence against Women, Domestic Abuse and Sexual Violence Strategy 2018 – 2023, from partners including NHS, police, and local authority (276). The strategy outlines the following priority areas: Prepare, Pursue, Prevent, Protect, and Support, and an annual report is published annually
- Tackling Violence Against Women and Girls: a Joint Strategy 2019-2024 from South Wales Police and Crime Commissioner (285)
- Cardiff & Vale Regional Safeguarding Boards published the Tackling Exploitation Strategy to protect children and adults at risk in 2020 (286)

The following services have expanded or have been commissioned regionally:

- The Women's Well-being Clinic, based in Cardiff Royal Infirmary, opened in May 2018. Most referrals are from Maternity at University Hospital of Wales but women can self-refer, for reasons including gynaecological, psychological, and FGM concerns (40)
- A pilot routine enquiry was introduced in the Emergency Department in the University Hospital of Wales at the same time as COVID-19 lockdown restrictions were introduced (March 2020). This led to an increase in referrals: during 2020/21, 8,668 "Ask and Act" referrals were made. COVID-19 restrictions meant patients attended alone, which likely facilitated the increase in positive disclosure. Routine enquiry is now standard practice (40). The implementation of routine enquiry in the Emergency Department is reflected in the increase number of referrals received by the Health Independent Domestic Violence Adviser (IDVA) at Cardiff and Vale UHB (198)
- RISE Cardiff is a new strategically designed and procured VAWDASV specialist service in Cardiff and is being delivered by a local consortium – the lead provider Cardiff Women's Aid has teamed up with third sector organisations Bawso and Llamau. The service, which commenced in April 2018, delivers an end to end pathway from advice and information, crisis interventions, emergency safety and protection, step down support, aftercare and recovery
- Atal y Fro were successful in being awarded the VAWDASV Service contract in the Vale of Glamorgan from July 2021
- Interactive support interventions for perpetrators of abuse, offering a range of provision from early intervention through to targeting those who pose high risk/high harm

17.2.1 COVID-19

Impact of COVID-19 on service demand

COVID-19 has increased the prevalence of risk factors of abuse – such as isolation, and reduced contact with support networks (280). The Women's Aid Federation of England identified that perpetrators had used government mandated restrictions as an additional way to coercively survivors, leading to more isolation and additional barriers to leaving (287). UK police identified a 9% increase in domestic abuse offences between April – June 2020 compared to the year before (280). Increased disclosure of domestic abuse has been, in part, attributed to people attending healthcare and other appointments alone (40). Decreased levels of emotional and mental health well-being, and unhealthy relationships were identified during COVID-19 (40).

An "Ask and Act" approach within healthcare settings resulted in a large increase in referrals (in May – July 2020, between 1,075 and 1,271 referrals/month were made, compared to 572 in April 2020), predominantly from the Emergency Department. However, the Cardiff and Vale Sexual Assault Referral Centre (SARC) saw a decrease in referrals between 2019/20 and 2020/21 (572 to 417 respectively) (40). A particular drop was noted in children and young people. The reasons for the decrease in referrals is unknown but professionals identified that it may have been influenced by COVID-19 and restrictions, causing changing patterns of behaviour such as a reduction in social contacts (impacting both contact with potential perpetrators, as well as contact enabling disclosure, such as a trusted adult in the case of children and young people). Many students usually resident in Cardiff were not present during the lockdown periods, which may also have had an impact (38). It is known that prevalence of sexual assault is higher than the referrals received by SARC (38).

A UK-wide report by the National Society for the Prevention of Cruelty to Children in 2020 identified that children and young people may be at risk of maltreatment during lockdown due to increased stressors in parents and caregivers (increasing the risk of child abuse); increased vulnerability of children and young people (for example, to online abuse); and a reduction in normal protective services (such as social connections) (288).

Impact of COVID-19 on service delivery

Over the past two years, Welsh Government has provided additional funding to local authorities to address the additional demands of the pandemic and the Ministry of Justice has also provided additional IDVA capacity.

Training, awareness raising, and campaigns have been postponed or adapted for online delivery due to COVID-19 restrictions. The mandatory Welsh Government National Training Framework roll-out has continued with Group 2 Ask and Act training delivered online since October 2020 to staff from Cardiff and Vale of Glamorgan Local Authorities, Cardiff and Vale University Health Board and Velindre NHS Trust. Focus group participants provided both positive and negative feedback: virtual consultation introduced access to support groups without having to leave home, however another stated: "*in a phone call, you can't see body language or non-verbal clues*".

Providers of services for people experiencing VAWDASV reported the following changes in the survey: fewer face to face assessments with more telephone consultations; an increased demand for mental health support (for staff as well as service users); lack of access to other community and third sector support services; reduced access to clinics and treatment; and the opening of new hostels.

17.3 What are the care and support needs?

17.3.1 Individual

Control and autonomy

Some focus group participants didn't feel listened to when they asked for help; or didn't feel as though they were taken seriously. Some stated they have no choice but to speak up for themselves as there was no one else to do this for them.

> ***"I have to speak up for myself, I don't have any other option" –*** VAWDASV service user, focus group

Language and communication

No definitive local data are available on the Welsh language preferences of VAWDASV victims. Focus group participants stated that for those who do not speak English or Welsh as a first language, information provision was inadequate. In addition, although interpreters may speak the same language, differences in dialect may result in the translation service offered being unsuitable. The terminology used was important.

> ***"If you asked a group of Somali women to come to a talk on domestic abuse, no-one would come because they don't identify with that term" –*** VAWDASV service user, focus group

Those accessing the RISE service in Cardiff whose first language is not English or Welsh account for 5% of all referrals. Language preferences may vary between different services within VAWDASV. The Women's well-being clinic receives referrals for gynaecological and psychological issues including pregnancy and FGM. The majority of women are from the Sudanese community (40).

17.3.2 Community

Awareness of VAWDASV

Increased awareness of VAWDASV amongst victims, people at risk, and bystanders through information provision, signposting, and support for actions including reporting to police is needed. This includes prominent information on the '*Live Fear Free*' helpline (an all-Wales

domestic abuse and sexual violence helpline) alongside local information campaigns organised by Local Authorities, Police and specialist VAWDASV services (275).

Awareness of available support

Public services should be aware of specialist and other services available, including schools, colleges and universities. A new initiative bringing together specialist providers, local authorities and higher and further education establishments ensures that information is shared and pathways to support and solutions to identified issues are jointly explored. The free VAWDASV awareness raising e-learning offered by Welsh Government has also been shared widely with third sector organisations, further and higher education establishments.

> ***"I've never heard of many of the services we've talked about today...Pull together a list of organisations and put it through people's doors."–*** VAWDASV service user, focus group

Staff training

All "*relevant authorities*" are required to train their staff in line with the National Training Framework. The region has strengthened the training consortium of Cardiff and Vale UHB, Velindre NHS Trust, the two local authorities and specialist providers, RISE and Atal y Fro, to roll-out delivery regionally and in a coordinated way.

Safeguarding adults and children training is required for all staff. Nearly three-quarters of health staff are level 1 trained (40). The Welsh Government National Training Framework is being implemented across UHB Clinical Boards, corresponding to 11,000 staff members (40). In addition, the Identification and Referral to Improve Safety (IRIS) programme provides training, support, and referral assistance to GP practices. Since its implementation, referrals have increased. IRIS is particularly effective at reaching older women; as it is underpinned by a longstanding relationship of trust with primary care (280). IRIS+ involves identifying and referring with perpetrators and children affected by abuse also (289)

Intersectionality

Increased understanding, support, and awareness of needs is needed, of people with specific characteristics, such as male victims, gypsy and traveller communities, and LGBTQ+ victims (289). Sex workers are less likely to report incidents to the police, and so specialist Sex Work Liaison Police Officers have been introduced in Cardiff and Swansea (276). Participants of a focus group for homeless people reported problems with domestic violence.

Perpetrator interventions

There is increasing evidence for the use of perpetrator focused interventions (275). The DRIVE programme for high risk/harm perpetrators was introduced in Cardiff in 2018, and

the Vale of Glamorgan in September 2020. The CLEAR programme targets men whose behaviour is unhealthy towards their partner, and continues in Cardiff within the "Change that Lasts" programme. A new accredited domestic abuse perpetrator programme "Driving Change" has also been implemented. Programmes ensure that relevant victims and children/young people are also supported by an IDVA (289).

17.3.3 Wider determinants of health

Deprivation

Financial abuse is a form of VAWDASV. There is no local data available regarding VAWDASV by deprivation. It is known that financial barriers prevent people from leaving their current accommodation, resulting in victims remaining in homes where they remain at risk of harm. Individuals without recourse to public funds (for example, asylum seekers) may be particularly vulnerable.

Addressing causes of financial barriers was important to focus group participants: *"I can't afford to live, because PIP [personal independence payment] has stopped. I need to work but don't feel ready. Cardiff Women's Aid has been a lifesaver in helping me".*

Housing

The Housing (Wales) Act 2014 requires consideration of whether someone is at risk of abuse in determining their ongoing residence in that accommodation (277). The Renting Homes (Wales) Act 2016 will support survivors of VAWDASV who have joint contracts with perpetrators, by enabling perpetrators to be evicted (277); this legislation is due to be implemented in 2022. Partners in Cardiff and Vale of Glamorgan are planning to assess the impact of the welfare reform changes and the Renting Homes Act on accommodation in 2023 (289). Local housing strategies have identified VAWDASV as a key cause of homelessness and vulnerable housing, and have proactively identified support mechanisms (199) (83).

Refuges are seen as critical for offering immediate, short term, protection by both survivors of abuse, and practitioners. A 2018 report stated 94% of women felt safer on exit from the refuge (275). However, refuges might not be suitable for all, and do place the onus on the victim to move and potentially also leave existing sources of support (275). Refuges may also offer additional support such as financial, health, immigration, legal, and employment services (275). Nationally, Welsh Women's Aid oversee the UK Routes to Support database (275). In Wales, in 2018/19, 2,156 women and 67 men were referred for refuge accommodation, of which 691 women and 35 men could not be accepted as either the refuge was full, or staff would have been unable to provide the specific support the individual required (275). Asylum seekers and others with no recourse to public funds may not be able to access refuges (275).

A delay in moving into a refuge can be detrimental: research by Women's Aid identified that whilst waiting for refuge accommodation, 49/166 experienced further abuse from the same perpetrator; 19 experienced abuse from additional perpetrator(s); 8 women slept rough; and 44 sofa surfed (287).

Refuge accommodation availability was increased during COVID-19. Cardiff's homelessness service worked with RISE Cardiff to improve housing support (289). Vale of Glamorgan Council worked with Atal Y Fro to increase refuge accommodation and support workers at the beginning of the pandemic due to the expected rise in demand. The contract was retendered in summer 2021, jointly with the Community Safety Team and the Police and Crime Commissioner, to align the services more closely and provide a more robust funding stream (29).

Suitable subsequent "move-on" accommodation options need to be available (275). A Wales-wide report identified a lack of move-on accommodation has meant that individuals stay longer than necessary in refuge accommodation, potentially impacting others who require refuge accommodation (275).

Where possible, victims should be supported to stay within their own homes (276). "Target hardening" describes the strengthening mechanisms available to facilitate victims staying in their own homes (275), for example, panic buttons, new locks, better lighting, CCTV (275); police support such as watch or drive by models (275). These help victims feel safe, and are best combined with local, specialist, community based support (275). However, additional support may be required for individuals in more complex circumstances, for example, private renters with rent arrears (275). Target hardening equipment is provided by registered social landlords and Cardiff and the Vale of Glamorgan local authorities (29) (30).

Offering choice to victims of VAWDASV regarding their housing and accommodation is key. Focus group participants had suffered a lack of autonomy from ex-partners and financial constraints. Participants wanted more support when they were homeless.

17.3.4 Unmet needs

Focus group participants identified difficulties accessing medical, mental, and dental health services, including specialist care such as tertiary medical services and physiotherapy. Participants had experienced delays in referral to mental health services due to lack of awareness of services, waiting list times, and a lack of signposting for other sources of help in interim. Some felt guilty for seeking help: *"I've been waiting for over a year for 1 to 1 counselling with the traumatic stress service".* It should be noted that the COVID-19 pandemic has affected access to healthcare generally.

> ***"I was assessed as suffering from PTSD and a priority for interventions but there's none available, I'm still waiting" –*** VAWDASV service user, focus group

Participants reported experiences of not feeling listened to within the healthcare, criminal justice system, or other support services: *"There's lots of things I would like to do but not*

able to. I feel I am ignored by agencies a lot of the time, so cannot do the things I want. I got no support when I needed it, agencies cannot meet the challenges I present with".

Gaps in knowledge include:

- Local understanding of prevalence and the nature and impact of:
  - Honour-based violence and stalking / harassment
  - Abuse of older people (280) and those who identify as LGBTQ+
- Impact of deprivation on VAWDASV
- The links between extremism and misogyny

17. 4 What are the range and level of services needed?

17.4.1 Prevention and assets

Prevention is a key component of both the national and regional strategies for VAWDASV (276) (277), through a collaborative approach (e.g., Public Service Board, Regional Partnership Board, and VAWDASV Executive, amongst others). The Violence Prevention Team is the first of its kind in the UK, and is embedded within the Emergency Department at University Hospital of Wales. It applies a public health approach to violence (40)

Primary prevention

- Schools-based intervention: such as those within current strategies through the Whole Education Approach, including Operation Encompass and compliance with the National Training Framework. Education was considered one of the most important points from the focus groups: "*Most important point from today is education, with educating children on relationships, right through to how we help people who have gone through trauma and family law."*
- The school-based Spectrum project raises awareness of VAWDASV; educates children around healthy relationships; and provides training for school staff (290).
- Whole School Approach: A pilot programme is ongoing in an area of Cardiff with minimal take-up of Spectrum and high cases of reported domestic abuse (289).
- A pilot programme employing a whole school approach is ongoing in Cardiff (289). Identification of Adverse Childhood Experiences (ACEs) and mitigation through promotion of protective factors – work is continued by South Wales Police and Crime Commissioner Violence Prevention Unit (289). *"I worry about my daughter going through what I've been through and the long term impact of domestic abuse on her."*

Secondary prevention

- Early Intervention: such as "Change that Lasts", a project funded by South Wales Police and Crime Commissioner and both local authorities through additional Welsh Government funding (289). Domestic homicide is often preceded by other forms of abuse, and victims may already have been known to services. It is therefore preventable in some cases with early intervention.
- Advocacy: the specialist providers in the region employ a number of IDVAs and Independent Sexual Violence Advisors (ISVA). The breadth of IDVA/ISVAs available has been increased through additional funding from the Ministry of Justice and Welsh Government. Since October 2016, Cardiff and Vale UHB employs the only

IDVA working within the NHS in Wales. The role encompasses provision of advocacy, support for victims of domestic violence (40). RISE has now re-appointed a male IDVA in October 2020 who provides support and acts as a positive male role model to people aged 11-25 years (289).

- Learning from Domestic Homicide Reviews will help to improve partner responses to victims (40), through delivering against the activities identified in the specific action plans.

Tertiary prevention

- Perpetrator provision: Includes very early intervention with those who recognise unhealthy behavioural traits, through to convicted perpetrators, and employ a strengths-based, future-focused approach. Programmes also consider any children the perpetrators may have (276).

Assets to support well-being

A number of assets to support well-being were identified by focus group participants. Interpersonal relationships with family ("*Spending time with my children is the most important thing for me"*) and sharing experiences with friends and colleagues were identified. Hobbies were important: "*I've invested in myself, listening to podcasts and doing meditation, which has changed my life".*

The value of community-based activities such as choirs and music groups, art exhibitions and craft clubs, religious settings, and sports clubs and gyms "*gym saves my sanity"* were acknowledged. In addition, third sector organisations such as Cardiff Women's Aid and Speakeasy Cymru (providing legal and financial advice) as well as volunteering opportunities and supportive work were identified. Local authority services such as education and support workers as well as NHS clinics such as SARC and mental health clinics were named as helpful. Participants also found online support groups and the Live Fear Free helpline supportive.

"The importance of talking about your experiences, whether that's with colleagues, friends, make friends, to raise awareness. People find their own way of healing, I write poems and place them all around Cardiff." –
VAWDASV service user, focus group

17.4.2 Community services

The Regional VAWDSAV Strategy, developed in 2018, mapped the services available in Cardiff and the Vale of Glamorgan.

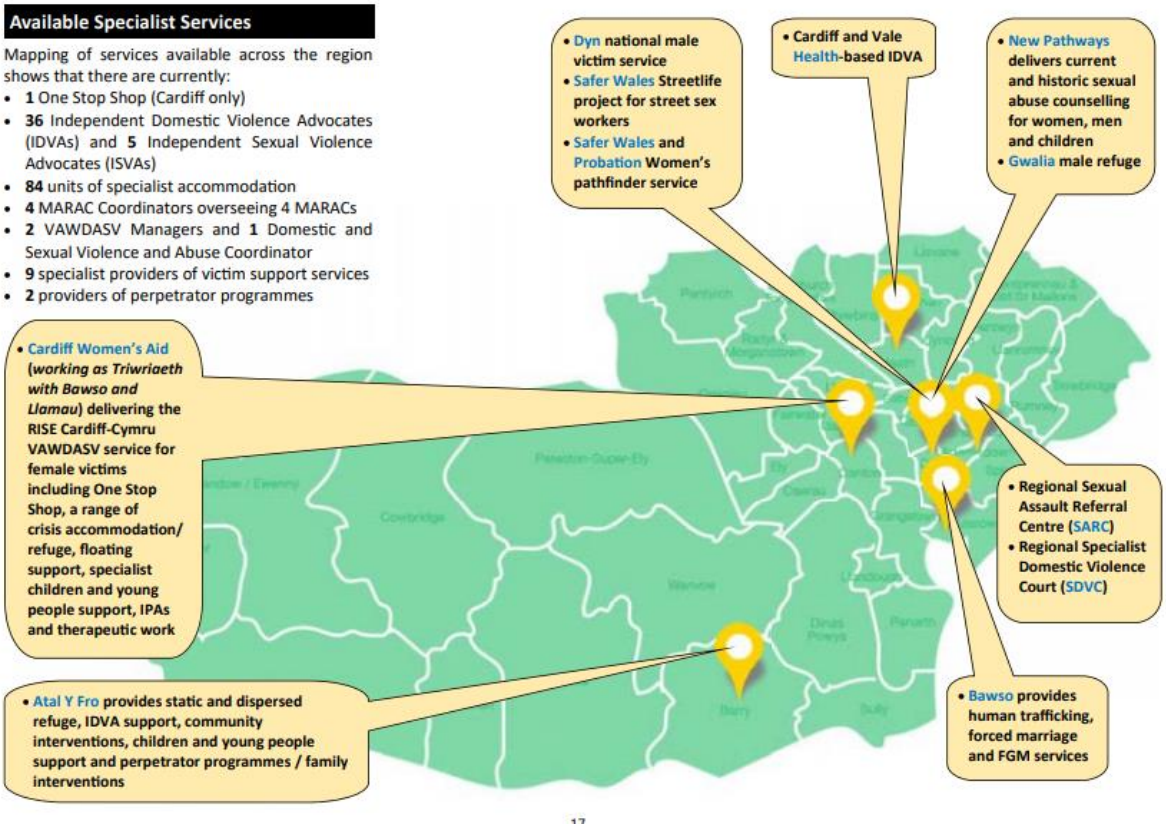


Figure 17.1. A map of specialist VAWDASV services. Source: Regional VAWDASV Strategy 2018-2023 (276)

17.4.3 Partnership approach

Integrated working

Since the development and implementation of the regional VAWDASV strategy in 2018, statutory and third sector services in the region have developed closer working relationships, policies and procedures to share and manage risk, try out new and innovative practices to intervene as early as possible and where not possible to deliver timely and often joint assessments and responses. It is acknowledged that VAWDASV also spans safeguarding, which is everyone's responsibility (40), and community safety. Therefore a whole system collaborative approach is essential.

However, liaison between services can still be improved so survivors are not required to repeat their story with each agency; and victims are more aware of opportunities for support. A focus is needed on timeliness of access to primary care, mental health services, and other specialist services.

Standardised pathway

The region uses a collaborative approach to delivery of staff training, with a new training plan to be developed as part of the revised regional VAWDASV strategy in 2022. The National Training Framework delivery has transferred online but has proved to be successful. Ask and Act training includes awareness of the local pathways into support and

the steps to take to raise safeguarding concerns for all staff that may come into contact with a victim or a perpetrator.

Standardised procedures are still needed across all health departments for identifying victims of abuse, and providing subsequent management (275). This includes routine enquiry which facilitates disclosure, following which actions to support and protect the victim can be made. In maternity, women are routinely asked by midwives and health visitors. In 2020/21, this led to 332 domestic abuse disclosures in Cardiff and the Vale of Glamorgan (40).

Person-centred services

Delivery of high quality, needs-led, strengths-based and trauma-informed provision by specialist third sector services is being promoted by Welsh Women's Aid and has already been implemented with specialist service providers across Cardiff.

Focus group participants felt that there was a need to maximise community-based assets and promote real connections between people. COVID-19 has shown that a blended approach to service delivery of face-to-face and via social media platforms is beneficial in offering more choice and access to a wider range of victims, especially for peer support and for recovery group work. Engagement has identified the importance of ensuring victims feel listened to and supported, in addition to providing the support: *"GP has been absolutely amazing and understood"*.

Participants were concerned regarding the sustainability of services due to funding pressures; and the mental health of staff providing care and support.

> ***"Important thing for me was that I've never spoken before about the things we've talked about today. To talk about what you've gone through and be so frank, I found it a bit strange. It would be great if there were opportunities for that to happen more" –*** VAWDASV service user, focus group

17.5 What is likely to happen in the future?

Nationally, Welsh Government is about to consult on the revised national VAWDASV strategy and is developing the 2022—2027 National Communication Framework to complement it (290). The new school curriculum has now been introduced (September 2021) and includes revised guidance on "Relationships and Sexuality Education", which may help prevent issues arising or escalating (290).

Regionally, a specialist service for male victims of domestic and sexual violence and abuse will be commissioned by the end of 2021. The SARC provision currently delivered by Cardiff

and Vale UHB will be recommissioned as part of a national review of SARC delivery. The regional VAWDASV strategy will be refreshed during 2022 in accordance with Welsh Government requirements.

As the population of Cardiff and the Vale increases, and as the age profile changes with a larger proportion of residents being in older age groups, increased demands on services are anticipated in line with the emerging concern of abuse of older people (40). Welsh Government are due to publish the Strategy for an Ageing Society which prioritises the ending of abuse of older people (280).

In response to wider media coverage of VAWDASV, stalking, spiking, murder, distrust of the police and increased displays of misogyny generally, it is likely that more victims will come forward and therefore demand for services will increase.

17.6 Recommendations

All agencies to:

- Strengthen the availability of existing services to provide person-centred care with seamless and timely transition between agencies, for example, through supporting inter-agency communication
- Continue to improve awareness amongst victims, bystanders, and service providers on the recognition and management (including signposting) of VAWDASV
- Continue to deliver the required elements of the National Training Framework to all relevant staff and build on successes of Ask & Act and routine enquiry
- Improve the multi-agency response to identified risk factors, such as ACEs, through increasing understanding of factors that increase risk and an awareness of the lived experiences
- Continue to monitor evolving trends in forms of abuse and ensure services anticipate changes in demand
- Ensure continued investment in specialist support services and required delivery of high quality, needs-led, strengths-based and trauma-informed person-centred provision
- Increase practitioners' knowledge and understanding of perpetrator behaviour(s) to ensure that the accountability for the abusive behaviour remains with the perpetrator(s)

Cardiff and the Vale of Glamorgan Local Authorities to:

- Further develop target hardening and move on accommodation opportunities, so spaces are available in refuges for those who need it, and minimise disruption to victims who wish to stay at home
- Maintain, and where possible extend, a range of interventions to target known and potential perpetrators of abuse

18. Substance Misuse

This chapter should be read in conjunction with the following chapters: Children and Young People; Children Looked After; Healthy Lifestyles and Long Term Conditions; Physical Disabilities; Adult Mental Health; Cognitive Impairment including Dementia; Secure Estate; Armed Forces Service Leavers (Veterans)

Recommendations

All agencies to:

- Take action to ensure services are accessible to the service user, with a focus on provision of face to face support and a reduction in the reliance on digital access for awareness of services, and service provision
- Monitor trends relating to alcohol and substance misuse in order to anticipate service needs, including misuse of over the counter drugs and the purchasing of on-line supplies of drugs
- Increase signposting of those in need, through awareness across the system of support provided by other services including public, private and third sector
- Increase awareness of Dewis Cymru, a website which enables individuals to find local and national organisations and services (256)
- Support the harm reduction agenda through
  - Increasing coverage of needle and syringe programmes (291)
  - Strengthen blood borne virus screening (291)
  - Continue to build partnership services to increase the provision of Take Home Naloxone (292)

Cardiff and the Vale of Glamorgan Local Authorities to:

- Work together with housing providers to identify those at risk of homelessness, and enable people to remain in accommodation (293)

Cardiff and Vale University Health Board and Primary Care to:

- Continue to develop mental health support provided alongside substance misuse support and treatment (293) to improve client outcomes
- Increase routine alcohol screening in Primary and Secondary Care to identify hazardous and harmful drinking behaviours

18.1 Overview

Substance misuse refers to the use of psychoactive substances in a way that is harmful or hazardous to health, including alcohol and illicit drugs. The use of such substances can lead to dependency with associated cognitive, behavioural and physiological problems. This

results in a strong desire to take the drug, difficulties in controlling use, persisting in its use despite harmful consequences, a higher priority given to drug use than to other activities and obligations, increased tolerance, and sometimes a physical withdrawal state (294).

The Vale of Glamorgan has the highest percent of residents in a local authority in Wales reporting average weekly alcohol consumption over 14 units (i.e., above guidelines) at 25% (151). The Welsh average is 19%, and 20% of Cardiff residents report exceeding guidelines in 2016/17 to 2019/20 (295). Amongst people reporting that they drink alcohol, residents of the Vale of Glamorgan report the highest average annual alcohol consumption at 660 units (compared to Cardiff at 523 units, and the all-Wales average at 531 units per year) in 2016/17 to 2019/20 (151). The Office for National Statistics report provisional data for England and Wales for the year 2020, which demonstrates the highest annual number of deaths from alcohol-specific causes since their time-series (started in 2001): 7,423 deaths (13.0 per 100,000 population). This reflects a 20% increase since 2019 (296). In Wales, three-year rolling average of deaths from alcohol-specific causes over the most recent six year reporting period shows that the European age standardised rate (EASR) of deaths per 100,000 population has increased since 2013-15, from 12.0 deaths to 12.7 deaths per 100,000 population in 2017-19. Cardiff and Vale UHB is slightly below the Wales average, at 11.9 (297).

The EASR for drug misuse deaths registered in 2019 in Wales was 5.6 deaths per 100,000 population compared with 7.2 deaths per 100,000 in 2018 (297). For Cardiff and the Vale, since 2015, rates have fluctuated between 3.9 (in 2017) and 7.0 in 2016 (297).

Cardiff and Vale Area Planning Board commissions a range of services to provide different levels and types of drug and alcohol treatment for children, young people, families, and adults. The drug and alcohol treatment system in Cardiff and the Vale is structured over four tiers, and ranges from basic harm minimisation and other advice; to inpatient detoxification, residential care and relapse prevention (298). Substance misuse services in Cardiff and Vale received 6,611 referrals, and treated 3,084 people during 2020-21. Alcohol was the most prevalent main problematic substance used by people over 18, followed by heroin, cannabis, and cocaine (298).

This chapter was developed by triangulating data from reports and other documents with information from professional leads and engagement work: 2 focus group participants; 19 survey respondents reported they have or had drug or alcohol addiction problems, although questions around alcohol consumption were answered by 508 participants from the PNA public engagement survey. Forty-seven respondents of the provider's survey provided services for people with substance misuse problems. Themes and quotes from engagement work conducted by Voices Action Change (a service user involvement project run by Cardiff and Vale Area Planning Board for people using substance misuse services and their families) between July and September 2021 was also included. During this period they engaged with 82 people through a range of mediums including during service provision, through social media, and at events (299). It should be noted that the views of those engaged are not representative of all people with substance misuse problems in Cardiff and the Vale of Glamorgan.

"[we want] to be respected in what we say and that our words matter" – substance misuse service user, Voices Action Change engagement (299)

18.2 What has changed since 2017?

18.2.1 Pre-COVID-19

Nationally, the following have been implemented since 2017:

- Welsh Government published 'The Substance Misuse Delivery Plan 2019-2022' (300) in October 2019. It sets out the key policy and operational priorities, informed by extensive consultation and engagement over a number of months during 2019. The onset of COVID-19 led to the Welsh Government reviewing the Plan to ensure that it reflected the work that has been, and will be, undertaken as a result of the pandemic (293)
- On 2nd March 2020, the Public Health (Minimum Price for Alcohol) (Wales) Act 2018 was implemented. Retailers selling or supplying alcohol must sell it at a minimum price of 50p per unit (301). The impact of the legislation on alcohol consumption and/or switching to other substances has not yet been evaluated

Across Cardiff and the Vale of Glamorgan, the following progress has been made:

- Cardiff and Vale Area Planning Board (APB) commissioned a substance misuse needs assessment in 2018 (292) to understand the need for services and inform future commissioning. It will result in the tender of a new Substance Misuse Alliance in 2022
- In 2020, a Health Needs Assessment of people who inject in public (302), and a full review of the Needle and Syringe Programme was undertaken in Cardiff and Vale. The recommendations from both of these will result in programmes of work during 2021/22, to ensure that people's needs are met
- In 2020/21 a review of Cardiff and Vale Needle and Syringe Programme was completed. The review recommendations have resulted in a programme of work across partner organisations which is currently being progressed
- There have been changes to treatment services in Cardiff and Vale since 2017, including the rapid upscaling in the prescribing of long acting buprenorphine injections (Buvidal) (298), as well as closer working between homelessness services and substance misuse services, which began before COVID, but was accelerated rapidly during the pandemic

18.2.1 COVID-19

Public Health England reported increased alcohol consumption during the pandemic, particularly amongst heavy drinkers, which is widening inequalities in health and driving an

unprecedented acceleration in alcoholic liver disease deaths (303). Despite pubs, clubs and restaurants closing for approximately 31 weeks during the national lockdowns, the total amount of alcohol released for sale during the pandemic was similar to the pre-pandemic years, suggesting people were drinking more at home (303).

The public engagement survey for this PNA found that since March 2020, almost one in four of 508 respondents feel their alcohol intake has increased, whilst one in six feel it has decreased (Figure 18.1).

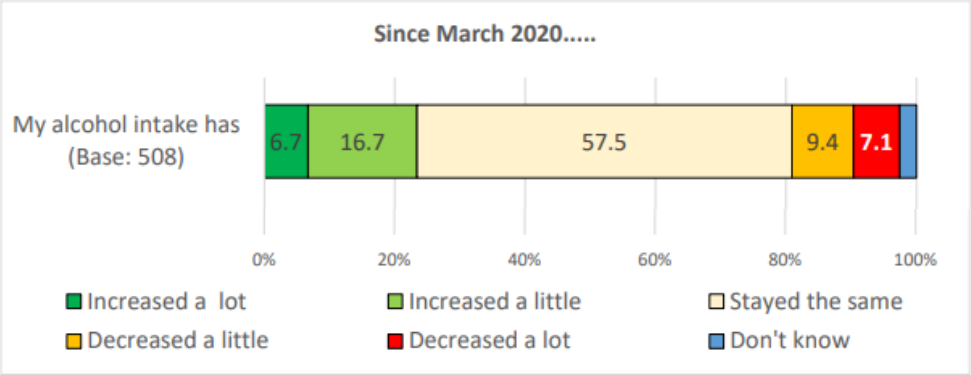


Figure 18.1. Results from the public survey regarding alcohol intake since March 2020

The focus group identified that isolation and the lack of face to face services caused increased alcohol intake and worsening addiction. Closure of services such as public libraries resulted in a lack of places to go and positive distractions. Other challenges identified by focus group participants included GP access. Welsh Government provided free food and accommodation during the pandemic, but this has now stopped. Theme leads clarified that Welsh Government offered funding for Local Authorities to coordinate and deliver accommodation during lockdown for homeless people and those who have no recourse to public funds.

A recent Cardiff and Vale of Glamorgan Regional Partnership Board Population Needs Assessment on the Impact of COVID-19 identified the following changes in need since 2017 in terms of changes in drug use: increase in complex patterns of poly drug use; increase in cocaine and stimulant use; increase in range of substance use; arrival of new drugs; misuse of prescribed medication, and a greater ease of purchasing (304).

Welsh Emerging Drugs & Identification of Novel Substances (WEDINOS) reported that despite COVID, there was not a substantial impact on drug markets or on types of samples submitted for analysis, with the exception of those received via night time economy settings. In the absence of samples from night club amnesty bins and other recreational use settings, we have seen a decline in ketamine, cocaine and other stimulants for profiling (305).

It is assumed that there will have been a reduction in detection of substance misuse in primary and secondary care, as healthcare services were disrupted.

18.3 What are the care and support needs?

18.3.1 Individual

Minimising risk of infectious diseases

Injecting drug use is a risk factor for blood borne viruses, and bacterial infections which can lead to amputation and, in some cases, can be fatal. Self reported use of higher risk injection sites such as the groin has been stable over the last 5 years at 20% in 2020/21 amongst people who inject opiods. Amongst those who inject stimulants, the percentage reporting using higher risk sites has increased from 17% in 2016/17 to 21% in 2020/21 (291).

Blood borne virus screening has been taken up by 7,405 people between the financial years of 2017 and 2021; although a 79% decrease on people being tested was observed in 2020/21. Fewer than 1% of individuals were positive for human immunodeficiency virus (HIV) or hepatitis B in 2020/21, however, hepatitis C antibodies were detected in 11% across Wales, and 15% in Cardiff and Vale of Glamorgan (291).

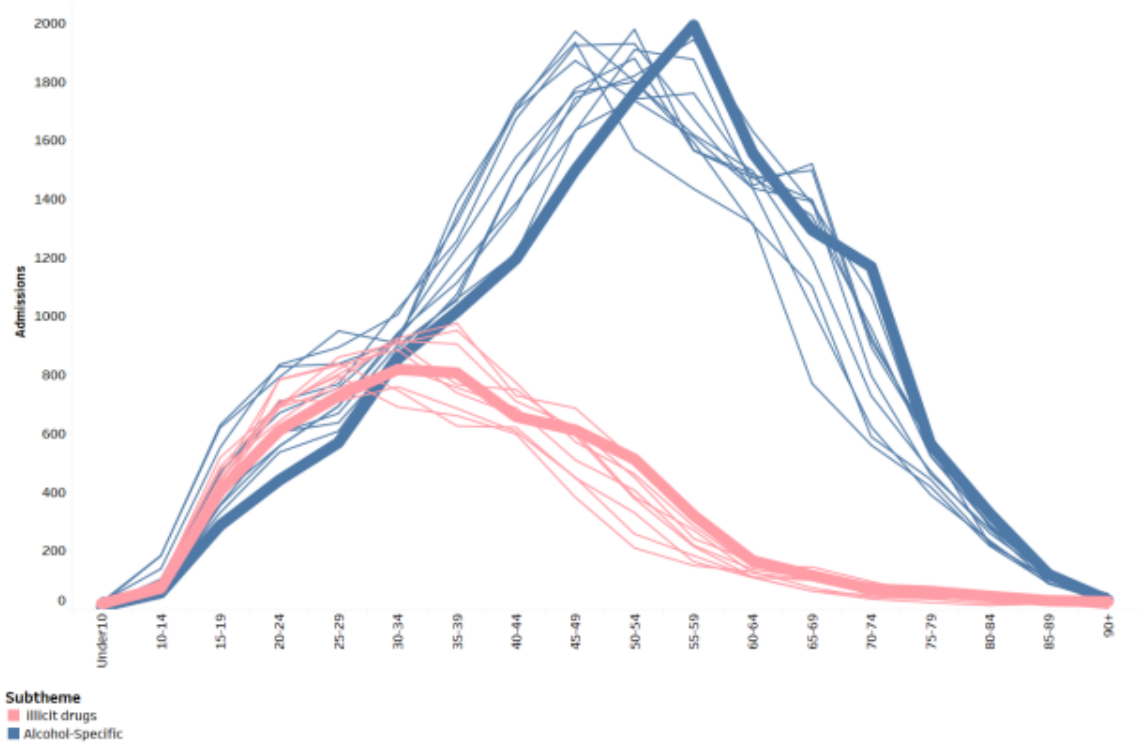
Language and communication

No data are available on the Welsh language profile of the population in Cardiff and the Vale who are affected by substance misuse. Healthcare and treatments service providers have a responsibility to provide information to service users bilingually, and to provide interpreters during consultations should they be required for a range of languages. Feedback to Voices Action Change identified that often jargon and acronyms are used in conversations as well as printed material, which service users struggle to understand and engage with (299).

18.3.2 Community

Medical care

Hospital admissions are a commonly used measure to assess the harms of alcohol and illicit drugs to individuals (297). Although hospital admissions are reflective of harms associated with use at the more problematic end of the alcohol and drug use spectrum, figures can provide a useful and consistent gauge of these harms over time. Broken down by age, comparable numbers of admissions for both illicit drugs and alcohol are observed from the 10-14 age groups up to the 35-39 age group, after which admission for illicit drugs fall steadily whilst those for alcohol related conditions continue to rise, peaking in the 55 - 59 age group (Figure 18.2). Twice as many individuals were admitted to hospital for alcohol-specific conditions than for illicit drug use in 2019-20 (297).



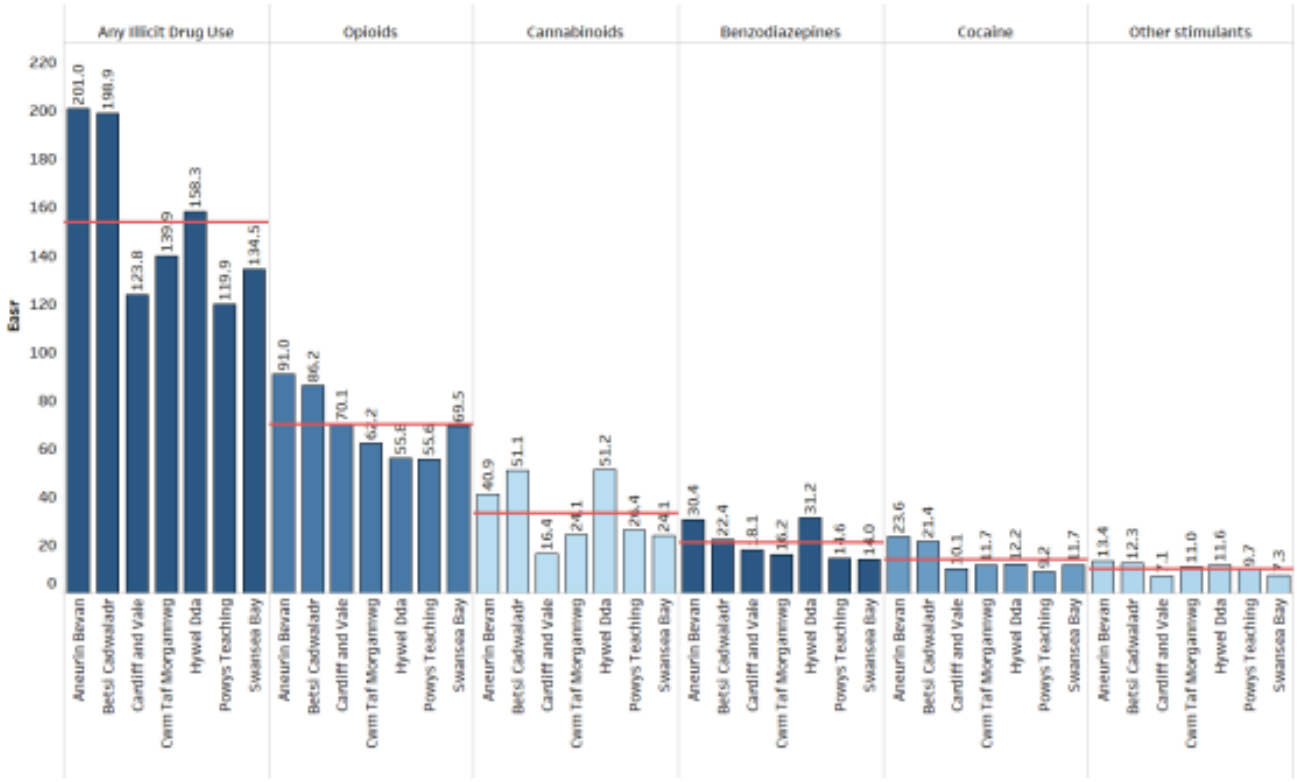
Source: Substance Misuse Programme / NHS Wales Informatics Service, 2020

Figure 18.2. Hospital admissions for alcohol-specific conditions and illicit drugs, 2010/11 to 2019/20. Data for 2019/20 is highlighted. Source: Public Health Wales (297)

Table 18.1 shows alcohol-related hospital admissions decreased in 2019-20 compared to 2018-19, but remain the same or elevated since 2015-16. Figure 18.3 shows illicit drug related hospital admissions by Health Board area of residence in Wales. Opioids had the highest rate (70.1), followed by benzodiazepines (18.1) in Cardiff and Vale (297).

Local Authority Area	EASR per 100,000 population 2019-20	Change since 2018-19	Change since 2015-16
Cardiff	291.7	-9%	0%
Vale of Glamorgan	300.2	-5%	10%
Wales	312.2	-8%	-6%

Table 18.1: European Age Standardised Rate per 100,000 population for individuals resident in Wales admitted to hospital for an alcohol-specific condition in any diagnostic position, 2019-20 (297).



Source: Substance Misuse Programme / NHS Wales Informatics Service, 2020

Figure 18.3. Illicit drug related hospital admissions by Health Board area of residence in Wales. Source: Public Health Wales (297)

Provision of mental health support alongside management of drug- or alcohol-related harm is key, due to the high prevelence of dual diagnosis of mental health concerns and substance misuse. An audit of referrals from the Emergency Unit at University Hospital Wales to the Liaison Psychiatry team found that 55% of referrals had substance misuse problems (292). The need for dual diagnosis support was echoed in engagement work conducted by Voices Action Change, as well as support and training for people in recovery around managing emotions (299).

18.3.3 Wider determinants of health

Counterfeit illicit drugs

WEDINOS reported that for the fourth consecutive year, the most commonly identified chemical group of psychoactive substances were benzodiazepines. The purchase of non-prescribed and non-controlled benzodiazepines, generally obtained through an online market, is a growing concern. Many benzodiazepine tablets available on illicit markets are counterfeit and may contain varying amounts of the active ingredients. As a consequence, the risk of adverse effects, development of dependency, hospitalisation or death are increased, particularly when alcohol and/or other drugs are taken alongside or within a short period (305).

Families, including children and young people

Parental substance misuse is an Adverse Childhood Experience (ACE), which are associated with negative impacts over the life course. The needs of children and young people whose parents use substances is often referred to as "*hidden harm*" and Cardiff and Vale UHB commissions a service for this (38). An "*ACE-lens*" has been applied to Welsh Government output relating to substance misuse (44). Research into the reasons for children being placed into care identifies the complex interplay of substance misuse, domestic abuse, and parental mental health problems. In March 2018, substance misuse was identified as a parental factor amongst 36% of Children Looked After in Wales (94). See also chapters 5-7 (Children and Young People).

> ***"You don't know you're losing everything until you look back"*** – substance misuse service user, focus group

Deprivation

There is considerable evidence of a linear relationship between substance misuse and deprivation (297). Figure 18.4 below illustrates that the proportion of all patients admitted for alcohol-specific conditions living in the most deprived areas was 2.7 times higher than those from the least deprived areas. In relation to illicit drug use, this figure rose to 5.2 times higher in Wales (297).

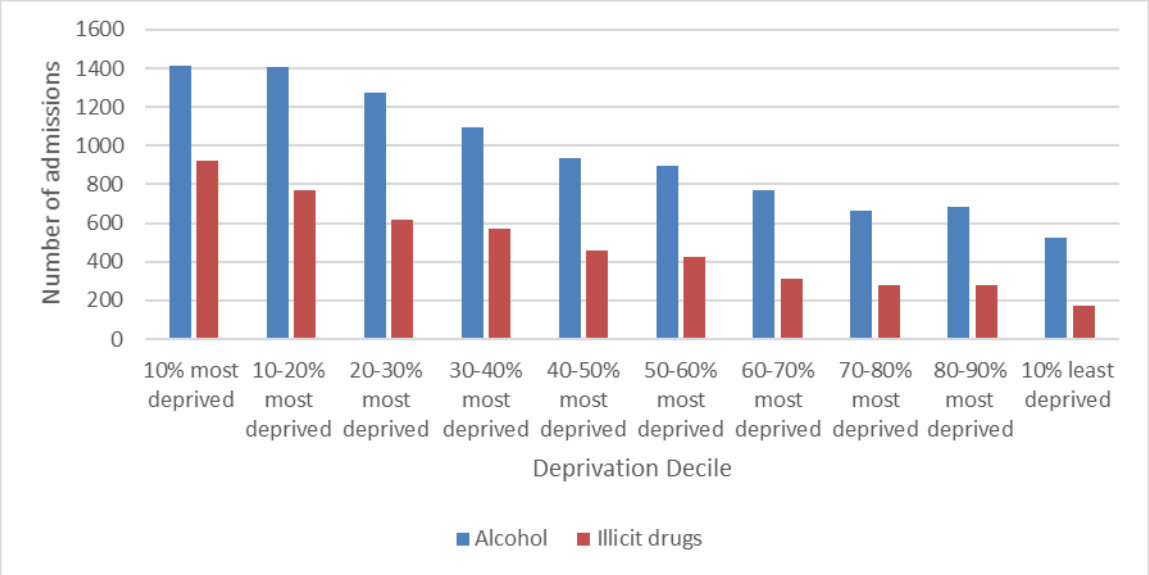


Figure 18.4. Unique individual admissions due to alcohol or illicit drugs in any diagnostic position, by deprivation decile, 2019-20. Data from Substance Misuse Programme / NHS Wales Informatics Service (297)

Amongst people who inject drugs reporting use of opioids or stimulants in Wales, three-quarters were unemployed. Of those injecting performance enhancing drugs, one third were unemployed (291).

Focus group participants were most worried about Universal Credit sanctions and poverty, and the possibility of not being able to afford the bills, food, or accommodation. Lack of access to the internet – which participants stated they couldn't afford – made it difficult to find a job.

Housing

Addiction to drugs and/or alcohol is both a cause and consequence of homelessness, and two thirds of homeless people cite drug or alcohol use as a reason for first becoming homeless (306). Improved closer working between homelessness services and substance misuse services was accelerated rapidly during COVID-19.

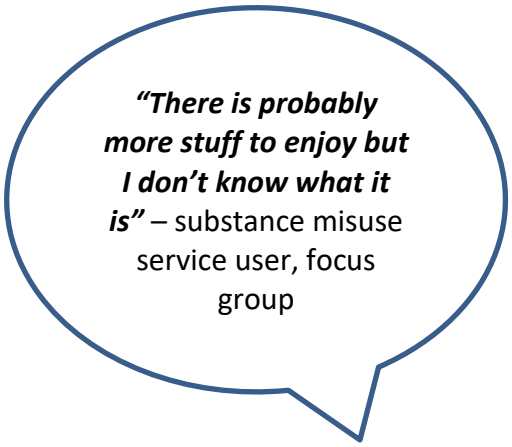
One focus group participant owned their own flat which offered security, although the participant did not have internet and struggled with bills such as for heating. Another participant lives in rented accommodation and relied on housing benefit, following a period of homelessness. The cost of housing and bills were seen as too high, and council accommodation was seen as insufficient for demand.

18.3.4 Unmet needs

Almost half of the 78 people who responded to the question in the public survey felt that advice on alcohol or drugs was currently available, but more is required.

The following unmet needs were identified by focus group participants, professional leads, and recent literature:

- Difficulties accessing online services. A recurrent theme throughout the focus group was of difficulties accessing online services – from healthcare; third sector services; to financial management (for example Universal Credit). Restrictions to digital communication devices can be common for those in recovery who are trying to distance themselves from previous contacts. Those who are older, have learning disability, or limited means were felt to be at increased risk of digital isolation and therefore service exclusion. Reliance on virtual services has been exacerbated by COVID-19. Services which can only be accessed by telephone requires both access to a (smart)phone and credit, which service users may be lacking. In addition to difficulties with digital isolation, loneliness and isolation were prominent factors in the participants' lives, and so they preferred and seek out face to face interactions with services. Voices Action Change engagement work has also identified that many service users do not have a phone and are unsure



how to use online platforms, which forms a barrier to accessing online support, in particular during COVID-19.
- Access to trauma therapy access is problematic, despite a trauma-informed workforce
- There is real concern about co-occurring mental health and substance misuse, and a perception that the mental health and substance misuse sectors do not work as well together as they should (292)
- Consideration of vulnerable groups within those experiencing substance misuse (for example, domestic violence, carers)
- Access to medical care, due to a lack of continuity of care, and long waiting lists for healthcare

The following areas were identified as gaps in data, with a need to understand:
- Why low numbers of children and young people are engaging with service provision
- Adults who are not accessing services
- The local impact of COVID-19 on substance misuse
- Evaluation of the impact of the introduction of the minimum unit price for alcohol
- The data gap of sexuality and substance misuse

18. 4 What are the range and level of services needed?

18.4.1 Prevention and assets

Early intervention of substance misuse

Earlier identification is required for alcohol screening and in primary and secondary care to identify harmful and hazardous drinking. Liaison with community-based groups who provide a broad range of early intervention and prevention services may help facilitate early referrals into alcohol or substance misuse services, and signpost to suitable sources of support. Engagement work by Voices Action Change identified that long waiting times for treatment was a barrier for them to get help, and many mentioned that their cases would sometimes get closed when they felt like they still needed help. Early intervention should include timely and ongoing treatment (299).

Surveillance of psychoactive substances

WEDINOS provides testing of unknown psychoactive substances in order to provide harm reduction advice, through the timely dissemination of information based on the identified chemical constituents (307). Ongoing monitoring of drug-related deaths with data to National Implementation Board for Drug Poisoning Prevention for their review (293).

Risk reduction for blood borne viruses and bacterial infections

Methods by which to reduce the risk of the development of serious infection as a consequence of high risk methods of drug taking include reduction of transmission, and early detection of infection.

Needle and syringe programmes provide sterile equipment within a harm reduction approach. The coverage (defined as clean injecting equipment for each injecting event) of these programmes is sub-optimal, with a Wales average of 22%. People accessing needle

and syringe programme via specialist providers were given approximately double the number of syringes over the course of a year compared to those attending a pharmacy. In Cardiff and the Vale, four-fifths of interactions occurred in specialist services (the Welsh average is one in three). COVID-19 has reduced use of the needle and syringe programme.

A key performance indicator for screening in substance misuse services is defined as "*all clients who are in contact with substance misuse services to be routinely tested on site…for blood borne virus infection (hepatitis B, hepatitis C and HIV) on at least an annual basis"* (291). This indicator aims to encourage increasing blood borne virus screening, and (where necessary) early treatment.

Assets to support well-being

In terms of assets that support people's well-being, focus group participants have limited support networks and personal relationships as a result of their addiction, and therefore relied on services and third sector organisations for interpersonal communication. Third sector organisations such as Adferiad and Huggard were named by focus group participants due to a non-judgemental approach, and targeted support. Community-based assets such as libraries and hubs provide somewhere warm to spend time (saving on home heating costs) and free access to computers for internet, learning, and reading. Computers were also used for online meetings with other support facilities, particularly during COVID-19 when face to face meetings were restricted. Other assets include the 12 steps programme, voluntary roles, for example with the Pantry, local groups such as football, English classes, and the Citizens Advice Bureau, although much of their provision is online which can be a barrier to those without computer/smart phone/internet access or skills.

> ***"Connection is the opposite of addiction"*** – substance misuse service user, focus group

NHS services such as primary care were helpful, although phone services were said to be not suitable for the digitally disenfranchised, with additional cost of phone calls on personal mobile phones. In addition, treatment services provide support to get and remain sober: *"while there, it is possible to forget about addiction for a while".*

Professional leads identified additional sources of support, including Dewis Cymru, and harm reduction models provided by social services, NHS services, and community hubs. A comprehensive assessment of services available is included in the 2018 Substance Misuse Needs Assessment (292).

18.4.2 Community services

Buvidal

Buvidal (an opioid substitute treatment) has been rolled out across the health board area during the COVID-19 pandemic, having been licensed by NICE in 2019. The toxicity and overdose risks are significantly reduced compared to methadone and heroin, and quality of life measures are significantly improved. In 2020/21, 288 people commenced Buvidal in

Cardiff and Vale, of which 175 came through the criminal justice system. Evaluation findings are due in Spring 2022 (298).

Overdose management

Take Home Naloxone with training on identification and management of an opioid overdose is a cost-effective mechanism to prevent fatal opioid poisoning. Currently, a range of services are providing Take Home Naloxone and associated training, including substance misuse services, HMP Cardiff, homelessness and hostel services, night time economy and hospitality, and the family and friends of people at risk (298) (308). Cardiff and Vale Area Planning Board successfully gained additional funding for Take Home Naloxone, with the aim of increasing availability of these kits amongst the housing and homeless sector, and the night time economy (298). Novel approaches to training on use of Take Home Naloxone have been employed with young people providing peer training, which has been well received by young people, and enables attitudes and stigma to be challenged.

18.4.3 Partnership approach

Person-centred services

Engagement work conducted for the Cardiff and Vale Area Planning Board identified that service users wanted to feel listened to, and be asked for their views. As part of engagement work, people wanted to receive feedback on how their comments had been used, and how their experiences had effected change. Suggestions around service user involvement and co-production were well received: "*it's easy for the hierarchy to become unintentionally distanced from service users".* Service users were very positive about people with lived experiences talking to them, as they felt that they had a better understanding of what they might have been going through (299).

> ***"Everyone's a human being, we all love, we all cry. I wish people like us, who use services, were less judged"*** – substance misuse service user, Voices Action Change engagement (299)

Connected services

The rapid upscaling in the prescribing of long acting buprenorphine injections (Buvidal) was pivotal in the response to COVID-19 which resulted in benefits for the individuals receiving the treatment, and also reduced the number of people having to attend clinical spaces and pharmacies on a daily basis (298).

The homeless population were housed by the two local authorities in hostels and hotels during the pandemic. Working closely with Cardiff and the Vale of Glamorgan Councils' homelessness services, vital support was offered to some of the most disadvantaged communities (298). Treatment services flexed and adapted service provision, developing

innovative ways of delivering interventions and support, including online and telephone support and in-reach to those housed in hotels and hostels. Knowledge and signposting to other wider activities and services may help to reduce isolation, and provide needed support. Continued close liaison between services must continue during COVID-19 recovery.

Cardiff and Vale Area Planning Board monitor the number of people disengaging from services within their key performance indicators. In 2020/21, 9.6% of service users disengaged between assessment and treatment, which was a 2% increase from the year prior (Welsh Government expect less than 20%) (298).

Addressing vulnerability

The specific needs of some especially vulnerable groups need to be considered more fully in forward planning of services – notably in terms of access and greater flexibility. Significant groups include:

- Armed forces service leavers (veterans)
- Carers - there is need for improved understanding of caring for someone, or experiencing their own issues with substance misuse (292) (304)
- Perpetrators and victims of domestic abuse (292) (304) - a need for improved access to treatment and shared awareness of underlying issues
- Those with formally diagnosed and likely Alcohol Related Brain Damage (ARBD)
- Sex workers - there is limited access to agencies and awareness of how best to support
- Those with addiction to prescribed medication (292)
- People with complex needs – there is a requirement for better alignment of services
- Ethnic minority communities – there is reasonable representation of ethnic minority groups within service provision in Cardiff and Vale, but further work needs to be done in assessing the more 'hidden' populations in those communities, where shame about alcohol use and criminal activity inhibit individuals, especially women, and their families from seeking help (292) (304)

Services must be accessible to these groups, and be mindful of their specific circumstances and needs.

18.5 What is likely to happen in the future?

In 2018, a WHO Global Status Report on Alcohol and Health projected an increase in alcohol consumption in the near future in the UK (309). Alcohol consumption is anticipated to have increased during COVID-19, particularly amongst heavy drinkers (303). England have experienced a 20% increase in total alcohol specific deaths compared to 2019. It is anticipated that Wales may experience a similar pattern.

There is considerable evidence of high levels of alcohol use among older people across the UK (292). Cardiff and the Vale both face significant increases in numbers of older people, many of who may require access to services late in life with little prior experience of accessing services.

18.6 Recommendations

All agencies to:

- Take action to ensure services are accessible to the service user, with a focus on provision of face to face support and a reduction in the reliance on digital access for awareness of services, and service provision
- Monitor trends relating to alcohol and substance misuse in order to anticipate service needs, including misuse of over the counter drugs and the purchasing of on-line supplies of drugs
- Increase signposting of those in need, through awareness across the system of support provided by other services including public, private and third sector
- Increase awareness of Dewis Cymru, a website which enables individuals to find local and national organisations and services (256)
- Support the harm reduction agenda through
    - Increasing coverage of needle and syringe programmes (291)
    - Strengthen blood borne virus screening (291)
    - Continue to build partnership services to increase the provision of Take Home Naloxone (292)

Cardiff and the Vale of Glamorgan Local Authorities to:

- Work together with housing providers to identify those at risk of homelessness, and enable people to remain in accommodation (293)

Cardiff and Vale University Health Board and Primary Care to:

- Continue to develop mental health support provided alongside substance misuse support and treatment (293) to improve client outcomes
- Increase routine alcohol screening in Primary and Secondary Care to identify hazardous and harmful drinking behaviours

19. Secure Estate

This chapter should be read in conjunction with the following chapters: Children and Young People; Healthy Lifestyles and Long Term Conditions; Physical Disabilities; Adult Mental Health; Cognitive Impairment including Dementia; Armed Forces Service Leavers (Veterans); Substance Misuse

Recommendations

All agencies to:

- Develop a culture of person-centred services, with increased voice for the person in prison
- Adopt an ACE- or trauma-informed approach to support those with ACEs, and reduce the risk of children with ACEs becoming offenders
- Consider the recommendations of the Cardiff Youth Justice Health Needs Assessment (95)

Prison health services to:

- Develop healthcare registers of long term conditions, which will enable appropriate reviews and referrals in line with national best practice
- Primary mental health services to continue to build and develop existing services to manage the increased demand

Cardiff and Vale University Health Board to:

- Develop systems which facilitate the sharing of health information from prison health services to primary and secondary health care providers

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Strengthen Local Authority housing pathways to plan release from prison and facilitate transition from HMP Cardiff (and other establishments) to community settings
- Provide more suitable housing options which increase the chance of successful reintegration into the community and employment, and reduce the risk of re-offending

19.1 Overview

This chapter focusses on the needs of people held within the secure estate, who will be referred to as people in prison (PIP). In Cardiff and Vale, secure estate comprises of Her Majesty's Prison (HMP) Cardiff, a public local remand Category B prison for males. There is no secure estate provision for young people, and women in Cardiff and the Vale of

Glamorgan, and so the care and support needs are discussed, with more of a focus on prevention and resettlement.

HMP Cardiff accepts those aged 18 years and above, who are remanded into custody in South East Wales. There are around 70-100 new receptions each week. The operational capacity is 779 (310). During the most recent inspection in 2021, 70% of men had been in HMP Cardiff less than three months (310). Between 0-3% are aged under 20; less than 5% of prisoners are aged over 60 (311). Health care is provided by Cardiff and Vale University Health Board (310). The prison links with probation services to provide continuity of care upon release.

Many men held at HMP Cardiff have characteristics or medical concerns which are discussed in other sections within this Population Needs Assessment. A survey conducted in HMP Cardiff for the PNA identified that 47% of the 96 respondents have a substance misuse problem (chapter 18); 47% have mental health condition(s) (chapter 13); and 25% have a long term health condition (chapter 9). The Prison Reform Trust states between 5-10% of adult prisoners in the UK has a learning disability; and 75% have mental health problems as well as substance misuse (312).

In general, people from minority ethnic communities are over-represented within prison populations in England and Wales (313). In November 2021, 14% of the population in HMP Cardiff are from a minority ethnic group (311).

Female prisoners

There is no provision for female prisoners in Wales. Women from Cardiff and the Vale of Glamorgan are usually transferred to HMP Eastwood Park, in South Gloucestershire in England. Between July and November 2021, 55 women have been released from HMP Eastwood Park to Cardiff and the Vale of Glamorgan, with an additional 9 women released directly from court following a period of remand at HMP Eastwood Park.

Children, young people, and youth justice

This chapter will not explicitly consider the needs of children and young people in the secure estate as these settings are not in Cardiff or the Vale of Glamorgan, however, key needs of children and young people around prevention and transition back into their local area are identified.

Small numbers of children and young people enter the Criminal Justice System in Cardiff and Vale. In the Vale of Glamorgan, up to 6 young people aged between 14 and 18 were in custody annually between 2016 and 2020. In 2020/21, no young people received a custodial sentence. In Cardiff, between 10 and 21 children were in custody in the period 2016-2020, and fewer than five in 2020/21 (314).

In line with the national picture, a reduction in custodial sentences was observed prior to COVID-19 restrictions, but this has reduced further since March 2020.

Young offenders from Cardiff and the Vale of Glamorgan are held in HMP Parc Young Offenders Institute (in Bridgend, Mid Glamorgan) which has capacity for 64 males aged 15-17 (315). Children and young people (male or female) aged 12-17 may also be held in Hillside Secure Children's Home in Neath for welfare purposes (316).

Half of young people in contact with Cardiff Youth Justice Service are known to Children's services; and one-sixth are children looked after (96). A health needs assessment of children in contact with Cardiff Youth Justice Service was conducted in 2021 (95). [Data from the Vale of Glamorgan pending]

Information sources

Input from professional leads (including representatives from local authority, NHS, and HMP Cardiff) complemented engagement work with people in prison (focus group with 8 participants, as well as a survey conducted in HMP Cardiff which received 96 responses). Nine respondents (of the 445 people who answered the question to the public survey) reported contact with the criminal justice system or time spent in prison, and less than three had had contact with the youth offending service. Thirty respondents to the provider's survey provided services for people who have spent time in prison, or been involved with the youth offending service.

19.2 What has changed since 2017?

19.2.1 Pre-COVID-19

The overarching landscape has changed from the 2017 PNA.

- The Health and Care Select Committee conducted an Inquiry into English prisons in 2018 (317), which the UK Government responded to (318). Her Majesty's Prison and Probation Service (HMPPS) is responsible for operations and management of prisons in both England and Wales, and hence this inquiry will have implications locally
- A national inquiry into offender health in Wales in 2019 made 25 recommendations, which were accepted by Welsh Government (319)
- The Female Offender Strategy (2018) and a Female Offending Blueprint for Wales (2019) support an early intervention and prevention agenda through a whole system approach. Both build on existing work around ACEs; and will strengthen a Welsh evidence base. There is focus on resettlement, reintegration, alternatives to custody, and supporting offenders, families and women at risk (320) (321)
- A Youth Justice Blueprint for Wales has also been developed in 2019. This emphasises the importance of aligning preventative approaches (such as Adverse Childhood Experiences (ACEs), school exclusion, homelessness), pre-court diversion, trauma-informed services, placement of children closer to home and improved resettlement arrangements (322). Welsh Government has additionally published standards for children in the youth justice system, which includes a standard on resettlement and transition (323)
- Probation services took over the role previously occupied by Community Rehabilitation Companies in 2021 (324)
- The Justice Committee have recently launched a mental health in prison inquiry (325)

Regionally, the following has changed:

- A Health and Wellbeing Needs Assessment of the needs of children in contact with the Cardiff Youth Justice Service, and their families, was published in June 2021. Its findings will form part of a wider Strategic Needs Assessment, as outlined in the Cardiff YJB Development Strategy 2020-2022 (95)
- In the Vale of Glamorgan, the Youth Justice Plan 2021-2023 was published (326)

At HMP Cardiff, a number of notable service improvements have taken place (327):

- Introduction of a brain injury worker in 2017
- A successful bid for funding from Welsh Government Prison Health Fund in May 2019 enabled the recruitment of a service development manager, four full-time qualified primary mental health practitioners and 1 primary mental health assistant practitioner. Funding was also received for the substance misuse work stream, to include 2 substance misuse nurses, additional pharmacy support, and an additional salaried GP
- Introduction of Buvidal for the treatment of opioid dependence in 2020

HMP Cardiff was inspected in 2019 and real progress from the 2016 inspection was observed, in particular in the domains of safety, respect, and purposeful activity which was felt to be a significant achievement given the concurrent challenging context. The inspector observed excellent relationships between staff and prisoners with positive effects on levels of violence, drug prevalence, and overall living conditions. (310)

19.2.1 COVID-19

Direct impacts of COVID-19

Public Health England's 'COVID-19 prison and other prescribed places of detention' guidance and HMPPS guidance is being followed in HMP Cardiff. Between March 2020 and February 2021, 277 cases were detected in HMP Cardiff; with 92 detected between March and November 2021. The vast majority of cases were community infections, detected through a programme of testing all new receptions (311). New receptions are tested on days 1 and 5, before being moved into the main population in line with national guidance. Men are offered COVID vaccines (including boosters) within 2 weeks if not up to date at a weekly vaccination clinic. In November 2021, 69% of men had had their first vaccine, and 52% their second. Professional leads have stated that HMP Cardiff is considered exemplar in terms of COVID-19 vaccination. Records are updated using the national Welsh Immunisation System so that information following release or transfer is accurate.

Lockdown restrictions

Changes in lockdown restrictions were variably received by focus group participants, but negative impacts on mental health were observed. Self-harm incidents have reduced during the pandemic. Professional leads report that men felt safer when unlocked in small groups, which translated into less violence and self-harm. Recent self-harm figures are currently below that of 2019 (328). In July 2021, there were 68 deliberate acts of self-harm by 29 men; in August there were 38 incidents by 23 men, and in September there were 24 self-

harm incidents by 21 men. The figures for September represent the lowest number of deliberate self-harm incidents recorded in a month during the previous 2 years (311).

Survey findings from men in HMP Cardiff show most (78%) respondents reported mostly or very good well-being prior to COVID-19; with 7 (8%) reporting mostly or very bad well-being. Only 42% responded that their well-being had been very or mostly good over the last year, with 19% reporting mostly or very bad well-being. The majority (91%) responded being able to stay in touch with family and friends whilst in HMP Cardiff; 87% reported being able to stay in touch during the COVID-19 lockdowns.

Care and support service provision

Focus group participants identified that many services were suspended during the COVID outbreak within HMP (emergency medical care continued). Access to care and support services has now resumed as normal (327). Professional leads identified that some services, such as dental, sexual health, and optometry, were paused to reduce the number of external healthcare professionals entering the prison site.

A rapid needs assessment in October 2020 in Cardiff and the Vale of Glamorgan identified the following positive and negative impacts of COVID-19 on secure estate:

- Service changes: new isolation procedures; change in staffing levels; pausing of visits; reduced movement of PIP
- Physical and mental health: reduction in self-harm; reduction in physical activity (250)

Youth Justice

It is apparent across Cardiff and the Vale of Glamorgan Youth Offending Teams that COVID-19 has created barriers for children to access support, for example, through reluctance to use virtual platforms, or technological problems. Professionals felt less able to engage directly with children (such as going for a coffee, or sports clubs) in the context of restrictions and identified difficulties accessing basic services such as the GP, dentist, and optician. However, virtual service delivery worked well for some children, for example, those intimidated by face to face meetings (95). In both Local Authorities, the majority of services were delivered remotely in light of restrictions, with face to face assessments or interventions provided where necessary (326).

19.3 What are the care and support needs?

19.3.1 Individual

Mental Health

Mental health disorders are known to be prevalent amongst people in prison – during a 2019 inspection of HMP Cardiff, 65% of PIP had a mental health problem (310). Mental health services have improved due to Welsh Government funding: in June 2021, 70% of standards for prison mental health services were met, compared to 51% in January 2020 (327). Data from September 2021 showed 21 people were on an assessment waiting list and 52 on the review list for primary care mental health. Of the 25 assessments conducted in September 2021, all were carried out within 28 days. The Assessment Care and Community

Team conducted 46 reviews for those who have or stated intent to self-harm or end their life (329). All men received into prison in September 2021 were screened for mental health concerns, and 56 referrals were made (329).

The Quality Network for Prison Mental Health Services report from 2021 is very positive. Care providers have a "*strong sense of direction*" whose work ethic goes "*above and beyond*". The funding was seen as critical to build the multidisciplinary team, strengthen relationships with other providers in the prison, develop referral pathways, and provide care that is patient-centred (327).

> ***"…impressive service development and improvement in the past year, despite the COVID-19 pandemic"*** - Quality Network for Prison Mental Health Services report

Long term conditions

Despite COVID, there has been successful recruitment of new GPs in HMP Cardiff, however, there remain ongoing difficulties with retention and recruitment (311). This impacts on the ability to provide more focus on areas such as long term condition management. Management of long term conditions in the secure estate should be consistent with the community (for example, annual asthma checks, referral to annual diabetic eye screening) in order to promote equity and reduce inequalities in health and healthcare access (330). Two-thirds of the 96 respondents to the survey administered in HMP Cardiff needed support for their health and well-being whilst in prison; 43% had a long term health condition.

Substance misuse

Drug and alcohol misuse is a known problem amongst those in the secure estate; including more risky behaviours such as injecting drugs (310). The secure estate provides an opportunity for substance misuse interventions (331). Amongst survey respondents in HMP Cardiff, 41% reported a drug problem and 28% an alcohol problem prior to entering prison.

The Dyfodol service meets every prisoner to discuss substance misuse and offers non-clinical psychosocial harm reduction advice and guidance, signposting and referrals as appropriate. Substance misusers for whom there is a link between misuse and offending, an assessment is provided, followed by collaborative progression planning, taking into account risks in terms of further offending and harm. Immediate needs will take priority, for example supporting prison clinicians in decisions about continuity of prescribing, or continuation of key time-limited work on reception and release. Long and short term goals are set and worked towards, all undertaken with acknowledgement of the prisoner's legal status and restrictions, current and future location (311).

Provision of Buvidal was commenced in HMP Cardiff in 2020. Where assessment judged that Buvidal could be beneficial for an individual, Buvidal was perceived to be a positive factor by enabling men to return to work, avoid areas associated with selling and using drugs, and reconnect with their families. These changes in lifestyle facilitated cessation of treatment at the end of the course. in November 2021, 22 men were using Buvidal, which is a reasonably stable figure, and is limited by funding available upon release when the individual returns to their local service (311).

After prison release, those who use drugs are at higher risk of drug poisoning (331). A review of Take Home Naloxone (a drug overdose management initiative implemented in Welsh prisons including HMP Cardiff, amongst other settings) demonstrated that 10% (n=41) of those who had used it had a recent release from prison (332).

Infectious diseases

Blood borne virus (BBV) screening is routine in HMP Cardiff. New diagnoses are referred to specialist healthcare services as appropriate. Vaccination is offered for hepatitis B to those eligible (311). There are plans to implement a High Intensity Test and Treat programme with funding available for a point of care testing machine (311).

The secure estate is known to be a tuberculosis (TB) risk factor: of the 97 TB cases in Wales in 2018, 10% were currently or had been in prison (333). HMP Cardiff supported a pilot programme of screening for latent TB in 2018. Approximately 600 men were screened, of which 7% were positive for latent TB; and one active TB case was identified. Only one-third completed treatment with barriers identified as transfers between settings; capacity of specialist healthcare professionals to attend the secure estate setting; and post-release follow up (331). Welsh Government funding is now available to HMP Cardiff to purchase onsite point of care testing equipment.

Sexual health

A review has identified that sexual health provisions across prisons in Wales compare poorly to community services (331). Access to sexual health services has reduced during COVID-19, but clinics have now restarted (October 2021) and most men can be seen within a fortnight (311).

Children, young people and youth justice

Children and young people may come into contact with the justice system in a number of ways. For example, they may have a family member in prison, or they may have committed an offence and come into contact with the youth justice system. They may also be supported to prevent their progression to offending.

Children who have a parent in prison are considered to have an adverse childhood experience (ACE). Support is required for the family to reduce the risk of intergenerational offending and transfer of ACEs from parent to child (334).

Children and young people are becoming increasingly involved in more violent activity and knife crime (such as through County Lines – see also chapter 5 on children and young people); sexual exploitation; and mental health disorders. A harmful sexual behaviour project has been launched locally in 2019 which educates young people on healthy relationships, the law, and consent (335).

The Cardiff Youth Justice needs assessment identified that many children in contact with the Youth Justice Service have complex health and well-being needs, with those who have experienced societal disadvantages or traumatic experiences more vulnerable (95). The needs assessment identified that 60% of those in contact with Cardiff Youth Justice Service were also in contact with Children's Services, approximately half were assessed as high or very high risk for safety and wellbeing, and there were concerns regarding the child's accommodation in one-third of children (95). The most important need identified was emotional well-being and mental health, with other needs including substance misuse support, speech and language provision, and health promotion (95). [Data from the Vale of Glamorgan pending]

The Cardiff Youth Justice needs assessment identifies transition points as a key need, both in terms of transitions between Children's and Adult Services, as well as in and out of the secure estate. This is echoed by the Vale of Glamorgan. Professionals contributing to the Youth Justice needs assessment felt continuity of service provision at these crucial time points could be improved (95).

Young people resident in Cardiff or the Vale of Glamorgan who are in the secure estate outside of their region may experience additional needs. National research on children and young people placed far from home shows that increasing distance between home and placement is associated with significantly fewer visits from professionals responsible for their care (336). Children far from home feel more lonely and isolated, and in particular, for Welsh children placed in England, they can experience bullying due to their distinct Welsh identity (336). Professional leads identified that family dynamics can be quite different when children and young people transition back home. Children and young people have specific resettlement needs, in terms of reintegration into education, training or employment; and suitable accommodation.

Women

In HMP Eastwood Park, pre-release teams identify accommodation and social inclusion needs, which Commissioned Rehabilitative Services are then able to support to facilitate successful transition from the secure estate to the community. Support is provided for accommodation, education, training, and employment, finance, benefits, and debt management (324). Specialist women's services are provided (324).

Language and communication

There is a lack of data on the number of Welsh-speaking prisoners and staff, nationally (336). The inspection of HMP Cardiff identified the presence of bilingual posters and signs, and some prisoners were learning Welsh, but prisoners were unaware that this may

translate into improved employment prospects. The library contained material on Welsh language and culture (310).

Half of survey respondents stated that the care and support received had been sensitive to the individual's culture, however, half disagreed. One respondent stated: "*I would like a gypsy meal at least once a month, you're allowed Ramadan so why not food from my culture.*"

19.3.2 Community

Safety

The 2019 prison inspection identified that HMP Cardiff had stable rates of violence (despite increasing rates of prison violence in other Welsh prisons) (310). Of note, 40% of PIP in HMP Cardiff were (potential) perpetrators of domestic violence (310).

Communication with community and other services

Cardiff and Vale UHB delivers healthcare services within HMP Cardiff; enabling continuity of care between prison and hospital services. However, not all of the information technology systems are linked. If PIP are transferred to other health board areas, they will be subject to local protocols which may introduce variability in management (331). COVID-19 vaccinations are recorded on the national Welsh Immunisation System so that accurate records can accompany the person following release or transfer.

19.3.3 Wider determinants of health

Deprivation

Home address data from HMP Cardiff records is not reliable due to high prevalence of homelessness or chaotic lifestyles; a person's address is taken from location of arrest.

Respondents of the survey completed in HMP Cardiff report 57% (n=53) had a job prior to prison; and 43% did not. Just under half of respondents (n=45; 48%) reported they had been able to build skills during their time in HMP Cardiff. Respondents wanted increased availability of courses to help them "*gain a trade*"; "*improve myself*"; find "*meaningful employment*"; and be "*useful in the real world*". Equipment such as laptops were identified as facilitators for doing courses.

> ***"[The] work ready course…really helped with rebuilding my life last time as I got a job through it"*** – PIP, focus group

Housing

A 2019 inspection of HMP Cardiff noted that living conditions in the prison had improved since the previous inspection (310). Whilst in prison, the distance from home impacts on visits from family and friends and may therefore have consequences for relationships (as well as risk of reoffending and substance misuse) upon release (336). This will be of particular concern to children and young people, and females, for whom there are no local

secure estate facilities. HMP Cardiff offers homework clubs for men which were paused during COVID-19 restrictions. These can be face to face, and virtual provision is possible for men whose family live too far away, or where COVID restrictions prohibit in-person visits.

On average, 200 PIP are released each month. A 2019 inspection of HMP Cardiff identified that 47% of PIP had been released without a home to go to, and there was inadequate follow up of individuals following release as to their accommodation (310). Homelessness is known to be linked to reoffending risk (310). The prison inspectorate has raised this concern with HMPPS and Welsh Government (310).

In the Vale of Glamorgan, Local Authority Housing staff are notified of prison release, and a resettlement offer is made. The pathway is supported by strong working relationships with Probation (29). [Information from Cardiff pending]

The survey conducted in HMP Cardiff identified that 45% of 96 respondents lived in private rented housing prior to prison; 27% in private (owned/mortgage) housing; and 13% were homeless. Three-quarters of respondents stated they did have a home to go to after prison. Just over half (54%) stated they did not know what support is available to help find housing upon release from prison. Free text responses highlighted concerns around housing being held for people after their release from prison; and imminent homelessness on release. People with no fixed abode were concerned they would end up back in prison, or in hostels with substance misuse problems. Respondents wanted more information and support finding suitable housing.

These findings were echoed in the focus group with HMP Cardiff residents, where people wanted housing and employment to be arranged well in advance of release to reduce anxiety. An address is vital for obtaining employment; a lack of housing means some people reoffend in order to access the security of a prison. A focus group including people who are homeless and had spent time in prison articulated that there was a lack of continuity between the probation service and housing services, leaving ex-offenders with too little support upon release and placing them at risk of homelessness and re-offending. Housing was seen as an essential first step.

Focus group participants stated housing and hostels are easier to access (at the time of the focus group, October 2021), but anticipate this will change with societal recovery from COVID-19. Hostels were felt to be of low quality and individuals may be housed with higher-risk offenders; therefore for some, prison cells are preferable. HMP Cardiff have commissioned a Task and Finish group to look at accommodation on release.

Participants explained that some housing requires a reliance on the benefits system such as job seeker's allowance. If housing is secured then working could jeopardise that, and losing

housing means homelessness and unemployment, and so ex-offenders often work "*off the books*".

19.3.4 Unmet needs

Engagement work identified that half of the 96 survey respondents in HMP Cardiff were satisfied with care and support services received. Unmet needs identified include:

- Access to healthcare: Focus group participants stated there was little continuity of care on entry to the prison (e.g., changes made to medications). They wanted increased access to mental health and dental appointments
- Healthy lifestyles: participants wanted more access to sports and exercise facilities, and a wider range of foods (more fresh fruit and vegetables)
- Being heard: only half of survey respondents felt sufficiently involved in decisions made about their care and support. Focus group participants stated they needed to make a fuss to be taken seriously, those who stay quiet do not get the help they need – there was a perception that prisoners need to learn to play the system.
- Facilities: HMP Cardiff should be for short term stays, and so is not designed to offer the wider range of activities and facilities that other prisons have. However, increased lengths of stay means prisoners felt they are missing out

Professional leads have identified the following:

- Access to Primary Care services is challenging at present
- Historical lack of use of "read codes" in prison health services. These underpin management of long term conditions and therefore impact negatively on:
    - provision of safe care in regard to clinical handover and continuity between healthcare practitioners within the prison
    - continuity and transfer of care to other prisons and the community
    - referral to appropriate screening services

  There needs to be a more consistent approach to the correct use of clinical coding
- Increasing demand for trauma-informed services including access to psychology and counselling services
- It is recognised that there is a need to develop nursing skills to better align with needs of PIP, and to consider the merits of further extended roles within HMP setting

Gaps in knowledge include:

- Data on ethnicity and sexual orientation are not currently routinely collected by HMP Cardiff health services
- Historical lack of recording of "read codes" used by primary care for long term disease management, therefore lack of understanding of burden of disease in HMP Cardiff

19. 4 What are the range and level of services needed?

19.4.1 Prevention and assets

Adverse Childhood Experiences / Trauma-informed approach

The 2018 Prisoner ACE survey was undertaken amongst adults (aged 16-69) in Welsh prisons. High levels of childhood ACEs were identified, with more than 8/10 experiencing 1 ACE, and 46% experiencing 4 or more. One-third had experienced a household member incarcerated. The proportion of people with 4+ ACEs increased with the number of times that individual had been in prison. Those with 4+ ACEs were 4 times more likely to have been in a Young Offender Institution. These findings support the potential for trauma-informed interventions to prevent those exposed to ACEs from offending (334).
Children of people in prison will be subject to an ACE; they will require proactive input for provision of protective factors and mitigation of other potential ACEs. Primary prevention of ACEs should take place alongside promotion of protective factors (such as a trusted adult relationship during childhood) (334).

Healthy behaviours

Exercise opportunities were identified as a source of support, in particular for mental health and well-being in the focus group and surveys. Seventy percent of survey respondents had been exercising during their time in HMP Cardiff, and access to physical activity was entered in several free text opportunities. Difficulties were experienced in accessing the gym during lockdown.

> ***"if it wasn't for training I would be in a bad frame of mind and my temper would be different, I did all of it myself"*** –
> PIP, focus group

Prevention of homelessness

As previously described, focus groups identified that avoidance of homelessness and preparation for life following release may help reduce the *"revolving door"* and risk of re-offending.

Youth Justice

The Cardiff Youth Justice needs assessment recommends a life-course approach is needed to prevent, identify and support these health and wellbeing needs, starting before birth and continuing through early years and schooling. Contact with the Youth Justice Service provides an opportunity to offer support (95).

The Vale of Glamorgan Youth Offending Service delivers early interventions alongside Media Academy Cardiff, Cardiff Youth Offending Service and South Wales Police to divert children and young people who have offended for the first time, from re-offending. This programme

is called Youth Restorative Disposals. In 2021, prevention and early intervention accounted for 50% of the Vale of Glamorgan Youth Offending Service caseload (326).

Assets to support well-being

Engagement with people in prison identified the following sources of support:

- **Healthcare**: named members of the healthcare team were positively regarded: *"[healthcare staff] goes above and beyond".* The Dyfodol and 12 steps programmes were helpful.
- **Library:** due to reopen soon for browsing. To retain access to books during COVID-19, prisoners indicated what genres they enjoy and books were selected and brought to them
- **Skills development:** education support and training courses were sources of support

> ***"[Healthcare staff] is a God send"*** – PIP, survey

Professional leads identified that HMP Cardiff offers education, training, and employment opportunities; a resettlement unit enables individuals to undertake work-based courses and offending behaviour programmes. In addition, the significant financial investment in mental health has enabled the formation of a primary mental health team in the prison which has had positive feedback.

19.4.2 Community services

High quality medical care

The principle of "*equivalence of care*" is key when considering healthcare in secure environments. This encompasses the idea that PIP are "*afforded provision of or access to appropriate services or treatment"* which are *"at least consistent in range and quality with that available to the wider community*" (337). The National Institute for Health and Care Excellence (NICE) has published guidance on the physical health of people in prison, encompassing health assessments on reception into prison, screening, general health advice, medicines, management of long term conditions, and continuity of healthcare. People should be offered equivalent health checks to those offered in the community, for example, learning disabilities' annual health check, and relevant routine NHS screening programmes (330).

Pharmacy provision

Pharmacy services provide vital functions beyond just medication provision, such as medicines reconciliation, reporting, prescribing and other tasks. The prison has recently had agreement to fund an additional whole time equivalent additional pharmacist, which will enable HMP Cardiff to take forward the recommendations from the Prisons' Inspector, such as pharmacy-led clinics, and medicine use reviews (310).

Operational management

Operational management and administration are the foundation of high quality services. A new operational manager is in place to support administration and operational functions within HMP Cardiff, and therefore support clinicians. They have helped to provide more

robust processes including use of capacity, booking procedures, information governance, and technical support for clinical staff. They have been critical in managing COVID response. Welsh Government have provided feedback to HMP Cardiff that the prison is "*exemplar*" (311). The administrative team take on the logistics such as booking hospital appointments and conveying medical instructions prior to the appointment (such as nil by mouth and special diets).

19.4.3 Partnership approach

Agency

Professional leads have identified the lack of agency people in prison experience, from choices around diet and exercise; controlling their environment; and attendance at healthcare appointments is reliant on security staff availability and may also be cancelled if a court appearance is scheduled for the same day. These factors may contribute to both physical and mental health.

For Youth Justice services, there is a focus on a co-created, collaborative, co-ordinated response from services (including Probation, Health, Substance Misuse) to support young people who are resettling from custody, or transitioning from children's to adult services (95) (326). Continuity of care as well as family involvement were identified as important (95).

Planning for release

The focus group discussed that careers and housing support could be accessed earlier in the sentence to prepare for release. Education and careers services could be integrated so that these could align with job opportunities at the end of the sentence, and prepare for life outside prison to reduce re-offending and the "*revolving door".* Work is planned to ensure men leave with all relevant health information (eg active referrals; future hospital appointments) once capacity allows.

19.5 What is likely to happen in the future?

The Ministry of Justice project an increase in number of prisoners aged over 60 in the coming years in England and Wales (331). No disaggregated data for Wales are available, however, between 2020 and 2026, the prison population in England and Wales is projected to increase by 19,465 (from 79,235 to 98,700). There is uncertainty around this projection due to the impact of the recruitment of additional police officers, how the courts will recover from COVID-19, and trends in risk factors for crime (338).

At HMP Cardiff, implementation the recommendations made by the Inquiry into provision of health and social care is a priority (339). Services are offered in line with the principle of equivalence: services cannot be the same in prison as in the community, and provision may exceed what is available in the community, in order to achieve equitable outcomes.

Youth offending services are moving towards trauma-informed service, in line with the Blueprint (322). There are ongoing discussions regarding the development of a secure establishment for women resident in Wales.

19.6 Recommendations

All agencies to:

- Develop a culture of person-centred services, with increased voice for the person in prison
- Adopt an ACE- or trauma-informed approach to support those with ACEs, and reduce the risk of children with ACEs becoming offenders
- Consider the recommendations of the Cardiff Youth Justice Health Needs Assessment (95)

Prison health services to:

- Develop healthcare registers of long term conditions, which will enable appropriate reviews and referrals in line with national best practice
- Primary mental health services to continue to build and develop existing services to manage the increased demand

Cardiff and Vale University Health Board to:

- Develop systems which facilitate the sharing of health information from prison health services to primary and secondary health care providers

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Strengthen Local Authority housing pathways to plan release from prison and facilitate transition from HMP Cardiff (and other establishments) to community settings
- Provide more suitable housing options which increase the chance of successful reintegration into the community and employment, and reduce the risk of re-offending

20. Asylum Seekers and Refugees

This chapter should be read in conjunction with the following chapters: Children Looked After; Healthy Lifestyles and Long Term Conditions; Physical Disabilities; Adult Mental Health; VAWDASV; Secure Estate

Recommendations

All agencies to:

- Provide training and ongoing support for all professionals working with asylum seekers, refugees, and undocumented migrants to improve quality of service provision within a trauma informed approach. To include rights, signposting, and access to care, support, and translation services
- Improve data collection; for example, better data coding
- Work towards co-location of health with other services such as mental health, benefits/ accommodation providers/third sector services for those who are most vulnerable, for example, destitute asylum seekers, undocumented migrants and those who moved in and out of the asylum system
- Multi-agency liaison; for example, dispersal linked to health and social services to improve continuity of care and support
- Facilitate integration and community cohesion (340)
    - Identify and build upon local community support for refugees and asylum seekers; which has been successful in other areas (340)
    - Increase awareness amongst asylum seekers and refugees, including children and young people, of the language, culture, and heritage in Wales (340)

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Encourage landlords to rent to refugees through formal support providers (341)

Cardiff and Vale University Health Board to:

- Consider different models of primary care to overcome known barriers to healthcare, for example, walk in clinics; opportunistic provision of care such as screening, vaccination and contraceptive services for those service users who are the most vulnerable and despite flexibility, would continue to struggle to fit in to the current model of care, for example destitute or failed asylum seekers, undocumented migrants and those who move in and out of the asylum system

20.1 Overview

The 1951 Geneva Convention defines asylum seekers as people who have left their country due to a *"well-founded fear of being persecuted*". Refugees are asylum seekers who have

had their application for asylum accepted by the host country (342). The 2017 PNA was written shortly after the largest displacement of people since the Second World War: globally, 1 in 113 people was an asylum seeker, refugee, or internally displaced in 2015 (340). Correspondingly, the numbers of people seeking asylum in the UK peaked at over 32,000 in 2015, and peaked again at nearly 36,000 in 2019 (343).

Policy on immigration and asylum is the responsibility of the UK Government (342). However, core determinants of health, such as health, education, and housing policies are devolved to the Welsh Government (340). Cardiff became a City of Sanctuary in 2014 (344) and Wales is aiming to be the world's first Nation of Sanctuary (345). There is one initial accommodation centre in Wales, in Cardiff, and four dispersal centres (Cardiff, Newport, Swansea, Wrexham) (342).

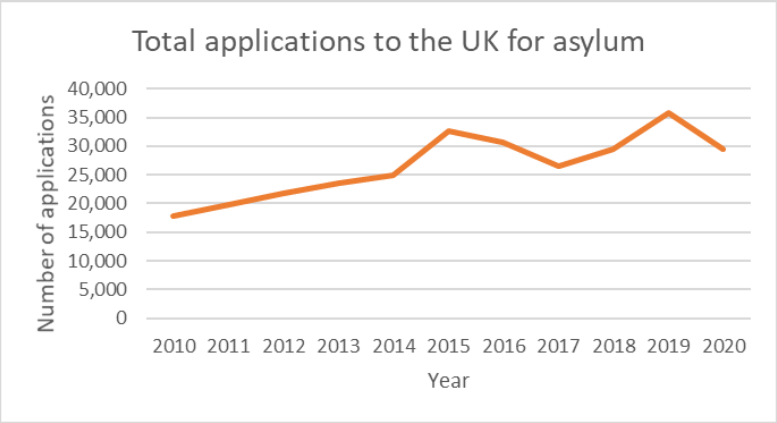


Figure 20.1. Total number of applications to the UK for asylum by year
Source: Home Office (343)

Figures for 2020 are likely to have been impacted by the COVID-19 pandemic, and mitigation measures such as lockdown (346). In 2018, Cardiff had 1,458 asylum seekers living in dispersed accommodation (compared to 957 in Swansea, 571 in Newport, and 162 in Wrexham) (342). The Syrian Vulnerable Persons Resettlement Scheme commenced in 2015 and has supported 854 refugees throughout all local authority areas in Wales (342). The Welsh Refugee Council supported 294 main applicants with status living in the Cardiff area (347). The Afghan Relocation and Assistance Policy supports individuals who have served British Armed Forces in Afghanistan. By September 2021, at least 230 Afghan individuals have been relocated to Wales (348).

The largest proportion of applications for asylum in Wales were from Iraq; followed by Iran, Albania, China, and Nigeria in 2020/21 (343). Eritrea, Iran, Pakistan, and Afghanistan have been in the top 10 countries of origin amongst asylum applications to the UK for the last 9 years (346). Just over half of asylum seekers in Wales are male, and most commonly aged 25-34 years (342).

Unaccompanied Asylum Seeking Children (UASC) are treated as Children Looked After, as per the Social Services and Well-being (Wales) Act 2014, and thus placed in foster families or supported living (342). The numbers of UASC have been increasing in Cardiff: from 5 in 2007, to 35 in 2020 (349). In 2018, there were a total (accompanied and unaccompanied) of 105 children seeking asylum in Wales (342).

Information sources

Two focus groups were held for this PNA: one virtual with 5 participants, and one face to face with 7 participants. None of the public survey respondents were an asylum seeker or refugee. Twenty nine of the 131 respondents of the provider's survey provided support to asylum seekers or refugees.

20.2 What has changed since 2017?

20.2.1 Pre-COVID-19

The National Assembly for Wales published an inquiry on refugees and asylum seekers in Wales in April 2017. Entitled "I used to be someone", the inquiry made 19 recommendations (340). These cover the strategic approach; improving community integration; improving the asylum process experience with a particular focus on housing, education, and employment; ensuring UASC needs are met; and making Wales a "Nation of Sanctuary" (340).

The 2019 Health Experiences of Asylum Seekers and Refugees in Wales (HEAR) study investigated adult asylum seekers and refugees' experiences of health and healthcare, including barriers and facilitators to care, through qualitative methods and a literature review (345).

The Afghan Citizens Resettlement Scheme was launched in 2021, which complemented the existing Afghan Relocation and Assistance Policy (348).

20.2.1 COVID-19

A study by Doctors of the World and the University of Birmingham in 2021 identified that refugees, asylum seekers, refused asylum seekers, and undocumented migrants experienced worse health, poor housing, and problems accessing healthcare. There was evidence that many of those with insecure immigration status are not registered with a GP, which subsequently reduces access to other NHS services, including COVID-19 vaccination (350). This was corroborated by professional stakeholders who stated that access to the COVID vaccine has been difficult. Vaccine hesitancy has been addressed by faith groups in local communities.

Professional stakeholders have observed a reduction in referrals to their services during COVID-19. This is thought to relate to a lack of people being moved through the system due to COVID-19 restrictions. Focus group participants commented on the reduction in services available with cancelled appointments, for example, in mental health support leading to worsening mental health. Participants did not like virtual appointments but stated it was better than nothing. Social isolation was a real concern, with participants stating "*community has closed down, after COVID*" although technology such as video calls were helpful. The closure of support services such as Oasis made it hard for asylum seekers to find activities to do, and reduced opportunities for peer support. The refugee community and their wider network translated and circulated government information on social media to ensure everyone was up to date – using tools such as WhatsApp.

> ***"it has affected my social life…I felt lonely, because I wasn't able to meet my family and friends" –*** asylum seeker/refugee, focus group

Respondents of the provider's survey identified increased mental health difficulties, social isolation, and challenges for people to access services. In terms of the impact of COVID-19 on their workforce, the following points were raised: stress and increased workloads, low morale, and isolation.

20.3 What are the care and support needs?

Asylum seekers, refugees, and undocumented migrants have quite varying needs depending on their current situation, and the path that they have taken prior. People arriving through resettlement schemes may have had access to medical care prior to travel; experience community support; and may have English language skills already. Those who have made their own way to Wales may have quite varied reasons for seeking asylum (such as war, sexuality, political beliefs) and journeys (such as human trafficking), and therefore varied care and support needs. Undocumented migrants may have additional needs to overcome fears of approaching formal services.

20.3.1 Individual

Autonomy and control

Asylum seekers, refugees, and undocumented migrants may be isolated as they are separated from support networks, friends and families (342). Focus group participants mostly felt in control of their situation; feeling as though they could put themselves first, and knowing where to go for help. They described uncertainty regarding the future, and a lack of confidence. Applications for asylum may take up to ten years which causes uncertainty and associated mental health concerns. Focus group participants who spoke English said that there were many English courses available to them and that English is easy to learn, making it easier for them to speak for themselves. Note that participant numbers were small and not representative of all asylum seekers and refugees in Cardiff and the Vale of Glamorgan.

Children and Young People

Children and young people seeking asylum may have additional needs. Children may have experienced the death of a parent(s); and may not have contact with any family (342). Those separated or unaccompanied are at increased risk of exploitation (340). Boys as well as girls are known to have experienced sexual assault (340).

Legal advice

Asylum seekers and refugees require access to high quality legal advice; as well as advice on education and employment rights. A pilot programme in England enables refugees, with leave to remain, access to Jobcentre Advisors to improve move on processes, and aims to reduce homelessness and destitution (340).

Language and communication

There are no local data available on the Welsh language profile of asylum seekers, refugees, and undocumented migrants, although based on data on country of origin, few asylum seekers, if any, are likely to have Welsh language skills. Free Welsh and English language classes for asylum seekers and refugees are provided by Welsh Refugee Council, amongst other organisations (351). Healthcare service providers have a responsibility to provide interpreters during consultations to ensure care provided is appropriate and culturally sensitive (342). Translation services are required for all interactions, such as with a pharmacy or housing providers. Focus groups identified that interpreters were provided at government offices and at the GP.

Asylum seekers identified a lack of English as a barrier to integration (340) (342) (345) (352). Provision of interpreters is available; however, care must be taken to consider specific characteristics, for example, gender, as the presence of a male interpreter may deter some women from discussing sensitive issues (342). Focus group participants stated there are lots of places to learn English and they found it easy to learn face to face in the college.

> ***"I'm trying to get involved with stuff with the Refugee Council as an interpreter, to help those who haven't had a chance to learn English yet"*** - Male Asylum Seeker, Ask Cardiff 2018 survey (352)

Language barriers have been identified in the focus group as detrimental to engaging with local peer support networks, whereby the predominant language within the group is neither English nor Welsh. Asylum seekers and refugees have also been inappropriately requested to act as interpreters for family members in hospital.

20.3.2 Community

Healthcare

Professional leads identified that individuals new to the UK may not understand the NHS healthcare system, including how to access the most appropriate service. Expectations of healthcare may vary due to different previous experience of health and illnesses; medical symptoms may be expressed in a manner reflective of culture (342).

People who have left countries with poor medical care and/or undertaken arduous journeys may have medical needs reflective of these (such as injuries; burns; infectious diseases; and

poor oral health). Females face additional concerns such as violence against women, domestic abuse, or sexual violence (VAWDASV); exacerbated by non-disclosure (not recognised as VAWDASV; and a lack of awareness of available help) and potentially a reliance to stay with the perpetrator (342). Women may also have obstetric or gynaecological needs related to sexual health and contraception, pregnancy, or female genital mutilation (342). A proportion of males have also experienced sexual violence, and disclosure can be particularly difficult due to cultural differences, perceptions and a deep sense of shame.

Mental health problems amongst asylum seekers and refugees in Wales are particularly prominent due to trauma experienced prior to or during travel (342). Lack of support structures may deepen these needs. The HEAR study identified that the stress of being an asylum seeker or refugee contributes to poor health (345). Individuals wanted help but did not want to be medicalised. Culturally-sensitive services are needed, with professionals aware of stressors specific to the population group (342) (340). Focus group participants identified uncertainty around the duration of the assessments for residency, and the outcome of the assessment, as a significant worry for the future.

Long term conditions such as hypertension and diabetes are common amongst asylum seekers and refugees in Wales. They often lack access to long term medical intervention (through poor health systems, displacement interrupting care) (342). Continuity of health care is challenging where short notice periods for relocation are given (345).

Professional stakeholders also identified that asylum seekers and refugees may have difficulties navigating access to health care, especially primary care, for example, due to telephone or online booking systems. Other additional needs include longer appointments, consideration of access such as transport – accommodation may not be provided close by healthcare services. Where language barriers exist, provision of translators is essential – individuals take friends and family members if no formal translation services are available (345) and this is both inappropriate and possibly incurs additional costs (e.g., transport). This co-location of services could be provided as a walk in "one stop shop" clinics for those who are most vulnerable.

Hate crime

Hate crimes are underreported. Incidence is in some cases linked to wider discourse such as concerns around immigration raised by voters during the European Union referendum, leading to community tensions (340). Asylum seekers and refugees may have negative prior experiences with police and other officials, and may therefore fear professionals in the UK (353). Hate crime can have a significant impact on mental health (353).

20.3.3 Wider determinants of health

Deprivation

The Socio-Economic Duty states there is "*no requirement for bodies to consider inequalities experienced by those persons subject to immigration control*" (354). However, asylum seekers and refugees are at high risk of becoming destitute (340). Asylum seekers receive

"Section 95 support" which is £36.95 a week, and are not allowed to work (340). As such, asylum seekers, refugees, and undocumented migrants are vulnerable to exploitation including for activities which put them at increased health risks (342). Some third sector organisations such as the Red Cross provide financial support for asylum seekers and refugees who are destitute or at risk (341).

Financial barriers were prominent in focus group discussions, regarding access to care and support services, as well as leisure and community activities. Participants in the focus groups described feeling a lack of confidence as a barrier to seeking employment; another participant's main worry was not being able to find a job to pay their bills. The HEAR study identified out of pocket expenses such as travel and childcare as a structural barrier to accessing services (345).

Education and employment

Asylum seeking children are enrolled into schools. Refugees wish to access education and employment – and such opportunities were discussed as assets. Asylum seekers are not permitted to work, yet expressed a desire for employment. Facilitators include language classes, accreditation of existing qualifications and job-specific support (such as that provided by Wales Asylum Seeking and Refugee Doctors Group) (340), and childcare.

Focus group participants explained a clear desire to integrate further into the community; and a feeling that they were being ignored in respect to present labour market shortages.

Housing

Accommodation is managed through UK government, however, housing standards are a devolved issue and can be enforced by local authorities (340). The Welsh Government inquiry identified that housing is not adequate for people's needs; and that this in part was due to a complex relationship between Welsh Government, the UK Home Office, and local authorities which all have differing responsibilities (340). Asylum seekers are reluctant to complain for fear of negative consequences on their application (340).

Professional stakeholders advised that not all asylum seekers and refugees will require housing support; however, those that do have variation in needs: UASC need foster placements, adults may be placed in Houses of Multiple Occupancy (HMOs), additional needs such as disabilities and suitable adaptations need to be taken into account. Single vulnerable refugee males are provided accommodation, but there is no equivalent for females. The YMCA has accommodation for single homeless people; this is followed up by a move-on scheme. Available accommodation appeared to be insufficient to meet demand when assessed in Wales in 2019 (341).

Poor finances and lack of employment are a barrier to housing. Many landlords in the private rented sector do not rent to refugees or those who are unemployed (341) (340); furthermore, the requirement for a deposit and rent in advance mean this is often not feasible (340). Asylum seekers have expressed a desire to work as well, but are not permitted to undertake paid employment. Note that across Europe, the right to work is variable with some countries permitting immediate right to work and others confer rights

after the passage of a set period of time if no decision has been made on the asylum application (355).

Asylum seekers granted refugee status are given a 28-day move-on period, which has been identified as challenging for people to obtain a National Insurance number, find employment or apply for benefits, and find housing (341) (340).

Asylum seekers and refugees who are victims of VAWDASV may be unable to leave their accommodation, if the perpetrator is the lead applicant on a claim. Although there are protocols in managing these situations, this still presents a challenge, and is reliant on disclosure by the victim, which in itself is subject to many barriers such as a lack of recognition, or fear of services (342).

Focus group participants identified overcrowding, a lack of adaptations for the individual's needs (such as for children, or disabilities), and a lack of consideration of the impact of health concerns of other HMO occupants on others. The state of housing was stated to be negatively affecting mental health. Another individual was concerned that they had not heard from the Home Office and that this would impact their progression in life. They were currently homeless, and needed a home to find a job and partner; but their lack of documents was a barrier to finding accommodation.

20.3.4 Unmet needs

Professional stakeholders identified gaps in healthcare services, and a lack of accessible primary care services for asylum seekers and refugees. Difficulty navigating the NHS was identified, with very little information and no organisation specifically to help asylum seekers/refugees to access healthcare. Often asylum seekers and refugees struggle to access primary care and are sent to the Emergency Department. Barriers to primary care include booking systems, lack of translation available at frontline reception, and IT poverty. The level of complexity with regards to physical and mental health along with socio-economic complexity makes the 10-20 minute appointment length inadequate. Dental care was hard to navigate and access. Access to appropriate mental health services was a particular concern given the trauma that many of these individuals have witnessed or experienced.

Professional leads identified that undocumented migrants may miss key healthcare support such as screening, as might asylum seekers or refugees who do not attend their CAVHIS screening appointment, are moved on, and then register with a GP practice. It is difficult to quantify how many people this may affect as this information is not collected. It should be noted that CAVHIS offers screening to all asylum seekers referred to them by the Home Office.

Focus group participants observed the following gaps in services:

- Lack of childcare which hinders ability to attend support groups
- Long waiting lists for services such as mental health support and housing repairs, and slow systems with unclear pathways

- Unable to access education or employment due to a lack of money and transport
- Language barriers: where peer support is provided in languages other than English and Welsh – for example, Arabic or Sudanese
- Lack of understanding of how to access and use NHS services

Data are lacking within a number of areas including a comprehensive understanding on the background and health needs for asylum seekers and refugees (342) (345); this also includes a lack of knowledge on vaccine uptake amongst asylum seekers and refugees. Initial steps to remedy this could include improved data coding. Little is known regarding undocumented migrants. Improved data is required around accommodation needs, for example, the numbers of people given leave to remain (341); and the number of people destitute or at risk of destitution (340).

20. 4 What are the range and level of services needed?

20.4.1 Prevention and assets

The 2017 PNA noted the need for training and awareness of asylum status and migration patterns for statutory and third sector partners (145). This is an ongoing need, especially as the context changes with additional resettlement schemes; changing services; and staff turnover.

Vaccination and long term condition management can prevent health conditions arising or worsening. Screening and management of diseases known to be prevalent in the country of origin or along an individual's journey will prevent both their worsening health as well as onward transmission to others.

Prevention of destitution is vital to prevent further mental and physical ill-health. This includes provision of advice regarding benefits, employment and housing (340). One of the focus group participants was recently released from prison and was unable to access support services or Immigration due to a lack of documents including ID. They are therefore homeless and sleeping rough and risks returning to drug dealing to secure an income.

Assets

> ***"There is lots of support here. The Welsh are very friendly – it is better than being in Manchester or Liverpool" –*** asylum seeker/refugee, focus group

Asylum seekers and refugees identified a number of assets that supported their well-being. Family, friends and neighbours were helpful: "*my neighbours used to leave food at the door for me during COVID and then call and ask if he needs anything else*". Third sector organisations such as Oasis, Community Care & Wellbeing Service (CCAWS), Sight Loss Cymru, and Red Cross were positively described: "*it is a good place to integrate with Welsh*

society"; *"Thank God [the befriender] is here for me and doesn't have an expiry date I'm blessed to have her"*. Local support groups such as the lesbian support group, well-being support groups, asylum seeker support groups (356), as well as churches and mosques: *"I go to the nearby mosque and it makes me feel good and happy"*, and leisure access such as the gym. Access to education (including English language classes) was identified by focus group participants, and professionals identified Cardiff and Vale College as an asset. Participants enjoyed their volunteering opportunities; professionals identified Into Work services as supportive (note that asylum seekers are not permitted to work).

Healthcare services including primary care and counselling were considered sources of support. CAVHIS has been identified by research in Wales as an asset, through provision of health screening, signposting, healthcare including maternity and child health (342) (345). Maternity services are particularly praised (342). Access to the NHS is important; while focus group participants feel it is often complex and slow, having access to a GP is unlike any other country. It is "*the best thing I have here*"

Professional leads recognised that not everything that matters to people is immediately available, and may not be until residency is secured.

20.4.2 Community services

Healthcare services

Healthcare systems must meet the medical needs of their patients, for example, providing blood-borne virus, tuberculosis, and parasite screening. Focus groups articulated the need for access to dentists. Appointments should be flexible to accommodate the needs of asylum seekers and refugees – allowing time for translation and to explore the complexity of health needs (342). Consultations should be culturally sensitive, for example, females may prefer a female GP to discuss sexual health (342). Drop-in services were mentioned by focus group participants as desirable. Focus groups discussed that healthcare felt as though it was offered at critical points, rather than as an intervention service.

Mental health problems – with origins prior to seeking asylum, during the process, or following arrival in the UK – is a prominent need with regards to the appropriate tier of provision. Many service users suffer with symptoms of traumatic stress as a normal reaction to experiencing or witnessing trauma. There is a need for a robust system which delivers psychoeducation and training or advice with regards to grounding and stabilisation techniques for the service user without medicalising a normal response to trauma. Focus group participants discussed the need for bereavement support groups, including for the loss of children. Respondents of the provider survey identified that education on use of the NHS would be helpful.

Support networks

Understanding the individual's social network (e.g., friends and family; local faith or sports groups; education or employment opportunities) enables support providers to promote physical and mental health (342). Consideration of the person in their wider context is crucial: for example, through provision of childcare, disability support groups. Financial and

transport barriers were mentioned throughout the focus group; these must be considered as determinants of access to services.

Services where people can build peer networks, be supported with the complexities of accessing services, and where activities can break isolation is critical. Asylum seekers wish for an organisation to link with the Home Office to support applications, and speed up the process.

20.4.3 Partnership approach

Cultural understanding

HEAR identify cultural understanding as critical (345). Focus group participants were fearful of data being shared with the Home Office. There was a resistance from participants to criticise, which is presumed to be in part given the fact that their residency and future is seen to be in remit of statutory decision makers. Equally when trying to make any comparison with past experiences within countries of origin, the group were reluctant to highlight that there was anything they missed. This would be linked to the psychological links to re-iterating the need for asylum linked to safety / well-being. Services provided should not only be mindful of this, but proactively address and overcome people's fears.

Systems working

Services must be joined up. Asylum seekers and refugees may feel disempowered; lack understanding of care and support services; suffer language, financial, and other barriers; be fearful of officials; and are therefore vulnerable within the community. Ensuring services are aligned; can proactively identify needs; and can signpost to other services is key. For example, building on the current requirement that housing providers should signpost individuals to CAVHIS for initial health screening (340). Signposting to voluntary or work opportunities should be included within this; professionals, focus group participants, and the literature all emphasise the importance of employment on physical, mental, and financial health (357).

The HEAR study identified that healthcare professionals needed improved knowledge to meet the needs of asylum seekers and refugees, encompassing medical care, but also legal and social considerations (345) (357). The development of "champions" to advocate for asylum seekers and refugees' needs and rights could be one way of achieving this, including help-seeking behaviours (345). All agencies providing services for asylum seekers and refugees must be able to combat misunderstandings, for example, preconceptions that photo identification is required to receive services. Professional stakeholders identified the need to provide an environment where stigma and fear can be overcome.

Services should provide information for asylum seekers and refugees on how to access healthcare (including out of hours and specialist services) and navigate services (357). Those refused refugee status are entitled to free healthcare, but may be reluctant to contact services (358) (357). HEAR reports that 94% of 201 asylum seekers and refugees were registered with a GP, but one in four did not know how to access emergency services via 999 (358).

> ***"People who are helping me currently help me holistically and are there for any questions I need to ask"*** – asylum seeker/refugee, focus group

Access to transport underpins access to all services and assets – currently this is compromised by lack of finances or lack of reliability (340).

Sustainability of services

Focus group participants were concerned regarding the sustainability of third sector organisations due to the reliance on voluntary funding. Ensuring needed and valued services can continue to operate, and communication of this will inspire confidence in service users, and reduce their anxiety that support structures might be taken away; "*the connection to the community will be broken".*

20.5 What is likely to happen in the future?

The UK Government have consulted on their New Plan for Immigration policy (359), which will likely impact on asylum seekers, refugees, and undocumented migrants in Cardiff and the Vale of Glamorgan.

20.6 Recommendations

All agencies to:

- Provide training and ongoing support for all professionals working with asylum seekers, refugees, and undocumented migrants to improve quality of service provision within a trauma informed approach. To include rights, signposting, and access to care, support, and translation services
- Improve data collection; for example, better data coding
- Work towards co-location of health with other services such as mental health, benefits/ accommodation providers/third sector services for those who are most vulnerable, for example, destitute asylum seekers, undocumented migrants and those who moved in and out of the asylum system
- Multi-agency liaison; for example, dispersal linked to health and social services to improve continuity of care and support
- Facilitate integration and community cohesion (340)
    - Identify and build upon local community support for refugees and asylum seekers; which has been successful in other areas (340)
    - Increase awareness amongst asylum seekers and refugees, including children and young people, of the language, culture, and heritage in Wales (340)

Cardiff and the Vale of Glamorgan Local Authorities and housing providers to:

- Encourage landlords to rent to refugees through formal support providers (341)

Cardiff and Vale University Health Board to:

- Consider different models of primary care to overcome known barriers to healthcare, for example, walk in clinics; opportunistic provision of care such as screening, vaccination and contraceptive services for those service users who are the most vulnerable and despite flexibility, would continue to struggle to fit in to the current model of care, for example destitute or failed asylum seekers, undocumented migrants and those who move in and out of the asylum system

21. Armed Forces Service Leavers (Veterans)

This chapter should be read in conjunction with the following chapters: Older People; Healthy Lifestyles and Long Term Conditions; Physical Disability; Adult Mental Health; Secure Estate; Substance Misuse

Recommendations

All agencies to:

- Consider the needs of veteran families, including children, of current and former armed forces service personnel

Ministry of Defence/ Armed Forces and Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop clearer pathways for veterans to support the transition into civilian life
- Consider development of a veterans ID card to give priority status to certain public services

Cardiff and Vale University Health Board to:

- Await the outcome of the all Wales review into the Royal College of GPs' Veterans Friendly Practice accreditation programme and consider the recommendations
- Increase healthcare professionals' understanding of veterans' needs and priority status through, for example, Welsh Government promotional material designed for Primary Care (360), and continuing to strengthen links between healthcare staff and the Armed Forces Champions

21.1 Overview

The Ministry of Defence (MoD) defines a veteran as "*anyone who has served for at least one day in Her Majesty's Armed Forces (Regular or Reserve) or Merchant Mariners who have seen duty on legally defined military operations*". A "*service leaver*" is someone who is in transition from or has ceased to be a member of HM Armed Forces (361). The term veteran is not necessarily something that all service leavers relate to for a number of reasons (length of their service, their age, or associating the term with involvement in World Wars), and therefore this could exclude them from accessing support and services that they are entitled to (362). For the purposes of this PNA, this chapter will refer to veterans.

There are currently no official figures available on the number of military veterans in the UK, but the latest estimation from the Ministry of Defence, using ONS data, is that there were 140,000 veterans in Wales in 2017 (5% of the total population) (363). Veterans are estimated to be predominantly white (99%), male (89%) and/or aged 65 and over (60%) (Figure 21.1).

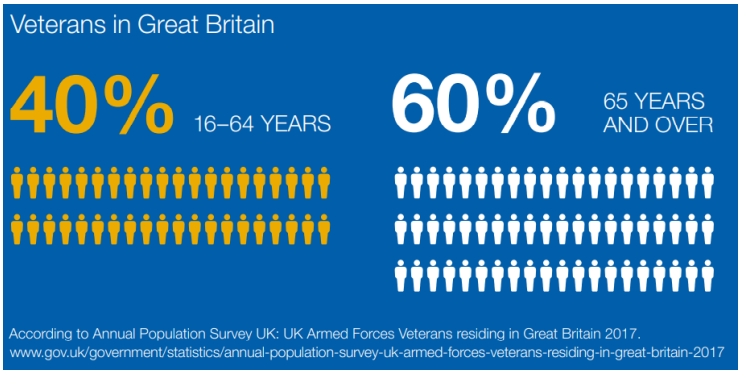


Figure 21.1 Age profile of veterans in Great Britain. Source: Annual Population Survey UK: UK armed forces Veterans residing in Great Britain 2017 (363).

As of March 2021, there were 2,689 veterans in Cardiff and Vale in receipt of a pension or compensation (364) under the Armed Forces Pension Scheme, War Pension Scheme or the Armed Forces Compensation Scheme (approximately 0.5% of the total population). 1,274 of these are in Cardiff, and 1,415 in the Vale of Glamorgan. However, there are many veterans who are not in receipt of a pension or compensation, so this figure is not a truly accurate representation of the number of veterans.

Cardiff and Vale University Health Board data recorded a total of 2,406 veterans registered with GP practices in 2021/22 (approximately 0.45% of the total GP registered population). This data is gathered using Audit Plus from "read codes" entered into the patients GP record. This information is shared on all Wales basis via the Primary Care Information Portal. This data is dependent upon a veteran providing their status when they register with a GP practice, so again will not be a true reflection of numbers as many veterans either have not declared their status when registering with a practice, or are not registered with a practice. Patients who have been registered with a practice for many years may also not be captured.

An estimation of veteran numbers by the Public Health Wales Observatory using ONS data and prevalence estimates from the Royal British Legion put the number for Cardiff and the Vale of Glamorgan area at around 20,330 veterans in 2020 (Figure 21.2).

Estimated veteran population*, all persons aged 16 and over, Cardiff and Vale UHB and local authorities, 2020

	Age group (Sum of the male and female tables)								Total
	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	16+
Vale of Glamorgan	90	200	430	870	980	1130	1470	1150	6330
Cardiff	410	810	1220	2050	2150	2020	2800	2540	14000
Cardiff and Vale UHB	510	1010	1650	2920	3130	3150	4270	3680	20330
Wales	**2630**	**5200**	**9980**	**20640**	**23210**	**27480**	**35980**	**28660**	**153790**

Produced by Public Health Wales Observatory, using MYE (ONS) and prevalence estimates from the Royal British Legion

*Estimated population rounded to the nearest 10

Figure 21.2 Estimated veteran population Cardiff and Vale UHB and local authorities, 2020. Source: Public Health Wales Observatory, using MYE (ONS) and prevalence estimates from the Royal British Legion

Engagement

A total of six veterans attended one of two focus groups, and amongst respondents of the public survey who answered the question, 6.3% stated they are a member or a veteran of the armed forces (28 respondents). This is not representative of the population of veterans of Cardiff and the Vale of Glamorgan. Twenty two of 131 respondents of the provider's survey provided support to veterans.

21.2 What has changed since 2017?

21.2.1 Pre-COVID-19

In 2018, the UK-wide Strategy for Veterans was published (365). In Wales, a Veterans' Scoping Exercise was undertaken to inform the strategy, which identified how services are being delivered, gaps in service provision and improvements that could be made. A delivery plan was developed highlighting key actions to address the gaps in service provision raised during the scoping exercise (366). Actions have included additional funding for Veterans NHS Wales to support mental health treatment, investment into health services, tackling loneliness and isolation, and to raise the profile of the needs of children of service personnel. The Supporting Service Children in Education Cymru, is a Welsh Local Government Association programme funded by Welsh Government since 2019. Veterans who have been in service within the last two years can access this programme to support their children.

Tros Gynnal Plant (TGP) Cymru, a third sector organisation based in Wales focusing on children, young people and families, collaborated with Veterans' NHS Wales on a three-year trial funded by Forces in Mind Trust. The trial provided community based mental health support service for ex-Service personnel and their families from Cardiff and the Vale of Glamorgan, who have a service-related mental health problem. Results are due (367). [Evaluation results requested from Forces in Mind Trust]

The Veterans' Trauma Network Wales (VTN Wales) was established in 2019 to provide a central service to support veterans with complex physical health needs, healthcare professionals and the third sector with advice on referral pathways, and can help with

accessing appropriate funding if necessary. VTN Wales was initially hosted by Cardiff and Vale UHB, and in January 2021 was transferred to the South Wales Trauma Network's Operational Delivery Network, hosted by Swansea Bay University Health Board.

The UK Government is introducing new legislation, as part of the Armed Forces Bill 2021, to further incorporate the Armed Forces Covenant into law, by bringing in a cross-UK duty to have due regard to the principles of the Covenant on public bodies in healthcare, housing and education. It is expected that the Bill will reach Royal Assent by late 2021, and enter into force in mid-2022.

The NHS has worked to raise awareness of veterans' needs with GPs and provided quicker access to the Veterans' NHS Wales service. Cardiff and Vale UHB remains strongly committed to deliver the Armed Forces Covenant and as a gold rated employer has sponsored an award at the 2019 and 2021 Wales' armed forces awards ceremony, to honour individuals who have strived to deliver care and support for veterans.

Veterans' NHS Wales has received 5,150 referrals since it launched in 2010 and has seen a year on year increase in referrals (368). The majority of veterans in 2019-20 presented with post-traumatic stress symptoms due to military trauma (72.7%), with depression and anxiety also common.

The Veterans' Advice Service is funded through the Armed Forces Covenant and provides support to veterans as a first point of contact for a wide range of concerns such as housing, finances and well-being. Veterans Advice Mentors are in post in both Cardiff and the Vale of Glamorgan, since 2017 and 2019 respectively. An Armed Forces Liaison Officer for Cardiff and the Vale is funded by Welsh Government and is responsible for raising awareness of issues affecting the Armed Forces community.

21.2.1 COVID-19

Around half (13) of the veterans responding to the PNA survey felt their health had worsened a little or a lot since March 2020. Referrals to Veterans' NHS Wales were lower than expected between October 2020 and March 2021 compared to the same period the previous year. During 2020, there was an increase in calls to the veterans' advice services in Cardiff and Vale due to impact of social isolation during lockdowns. This has continued into 2021. Social isolation continues to be a key issue for veterans. A participant in the focus group recognised that being in personal touch was extremely important to veterans during lockdowns:

> ***"Personal endeavour has made all the difference to some veterans – where key individuals in support services have made all efforts to stay in touch through phone calls, emails, visits and organising get-togethers whenever they have been possible – providing transport too"*** – veteran, focus group

21.3 What are the care and support needs?

21.3.1 Individual

Health needs

Mental health is a primary need for veterans. Together for Mental Health is the Welsh Government 10 year strategy to improve mental health and well-being (369). It includes plans to ensure mental health services for veterans are sustainable and able to meet needs in a timely manner and support for veterans is a priority. Veterans' physical health also interconnects with their mental and social well-being, such as the increased prevalence of mental health disorders in veterans with a physical impairment and the association of homelessness with physical disability and poor health status and substance use (370). Veterans have higher incidence of dual diagnosis of mental health and substance misuse disorders (371).

Families and children

Family members, including children, who are not serving personnel may have additional needs as a result of the impact of the lifestyle associated with the armed forces. Supporting Service Children in Education Wales (SSCE Cymru) conducted engagement work with children of service personnel, and identified positive and negative impacts around moving house; making new friends; changing schools; and living abroad. Parents being deployed was a source of negative emotions including worry that their parent(s) might be hurt, and missing their parent(s) (45). A Welsh Government consultation with veterans identified that a lack of support for families was a gap in services, in particular around families' access to healthcare (including mental health services), a lack of knowledge around the impact of service life on spouses, and accommodation and connection to the community (360).

Language and communication

No data are available on the Welsh language profile of the veteran population in Cardiff and the Vale. Veterans' NHS Wales ask all individuals at assessment would they like the interview in Welsh or English. No requests for Welsh interviews have been received in Cardiff and the Vale.

21.3.2 Community

Access to healthcare

The Welsh Government response to taking forward the strategy for veterans identified through consultation a number of key themes, and accessing healthcare featured strongly in the consultation feedback (366). The themes have also been reflected through focus groups and surveys with professionals working with veterans in Cardiff and Vale.

- Better information needed around veterans needs to help inform services
- A need for better understanding of priority treatment status by healthcare providers, including GPs
- A "flagging up" system of veteran status needed for healthcare services
- Veterans reported difficulty accessing mental health services in the NHS, though Veterans NHS Wales is perceived to be providing a good service
- Mental health support should include families

21.3.3 Wider determinants of health

Deprivation

Veterans with mental health difficulties were seen to be more likely to live in areas of the UK with higher deprivation levels, amongst those who sought support from Combat Stress in a 2017 study (372). Veterans living in areas of higher deprivation are more likely to be experiencing poor lifestyle behaviours such as excess alcohol consumption and smoking (it should be noted that, amongst the general population in Wales, increased deprivation is associated with increased smoking, but a higher proportion of people in the least deprived areas drink above Welsh Government guidelines compared to people in the most deprived areas (151) (see also chapter 9, Health and Long Term Conditions). A UK study of male veterans who had served in Iraq of Afghanistan reported significantly higher prevalence of alcohol misuse than non-veterans (373)).

Research with over 3,000 veterans in a longitudinal cohort study found that veteran hardship was mostly associated with factors linked to socio-economic status: age, education, and childhood adversity (374). Younger service leavers in particular were at higher risk of alcohol misuse and of unemployment and financial hardship.

Housing

Having access to suitable affordable accommodation when leaving the Armed Forces is crucial to enable personnel to transition successfully (375). Welsh Government is committed to ensuring that housing provision meets the needs of veterans, and veterans do have exemption from some of the qualification criteria for social housing such as having to have local connections. Housing was identified as the key need for veterans at the annual all-Wales Armed Forces conference in October 2021. Service providers identified that often veterans seeking accommodation are single and male, and it can be a challenge to find suitable accommodation immediately, meaning sometime temporary accommodation is the best option when first leaving the Armed Forces. Homelessness can be an issue for some veterans, who often seek support from the Veterans' Advice Service.

21.3.4 Unmet needs

The focus groups carried out with veterans identified the following gaps:

- Access to activities, social events and medical care have all been severely impacted by the pandemic
- Veterans' NHS Wales was recognised as providing an excellent service, but there can be long waiting times for treatment
- Respite is generally a big problem for carers which was exacerbated through the pandemic and continues to be a source of emotional and practical issues.
- Some veterans with dementia have failed to get the medical support needed – a particular problem being access to GPs with long telephone waits, lack of face to face consultations and home visits. They have also been adversely affected by the lack of social interaction and stimulation.

Gaps in knowledge and understanding were identified as follows:

- Further research needed into health needs for veterans in Cardiff and Vale, and particularly around mental health, alcohol and substance misuse
- Lack of data on the numbers of veterans
- Lack of information about the number of veterans currently registered with GP practices if they have not disclosed status

21. 4 What are the range and level of services needed?

21.4.1 Prevention and assets

The 2017 Population Needs Assessment identified the need to:

- Increase knowledge and resilience of families to support veterans and prevent family breakdown
- Increase awareness among mainstream services of veterans' needs

These are ongoing needs, and there is also a need to support veterans with health behaviours such as alcohol, substance misuse, and gambling. Enabling veterans to develop and maintain healthy behaviours such as physical activity once they leave the armed forces can require them needing to find new motivators other than needing to be fit for their job. Often the priority when leaving the forces is employment and housing, not physical health.

Assets to support well-being

Veterans identified a number of assets to support their well-being. These included family, friends, and neighbours: "*speak to friends on the phone, have my wife as a full-time carer*". Third sector organisations were seen as helpful: "*charities such as Woody's Lodge seem to be taking on the burden of assisting veterans and emergency service workers rather than other official bodies*". Cardiff and Vale Action for Mental Health (CAVAMH) was also supportive.

Organisations and clubs dedicated to veterans were named, including Veterans Advice Officers in local authorities, Veterans Mental Health Support Group (run by Nexus and Cardiff and Vale Action for Mental Health), NHS services such as Veterans' NHS Wales

("*provides an excellent service for veterans with Post Traumatic Stress Disorder although demand tends to challenge its resources*"), and the Armed Forces Forum. Third sector organisations providing specific support for veterans, such as Blind Veterans UK were helpful. Third sector organisations providing support for long term conditions such as the Forget Me Not Chorus were identified as helpful for veterans with dementia. Named members of the Council were identified as very supportive: *"[named individual] also provides an excellent service in support of veterans' welfare"*. Similarly, "*personal endeavour has made all the difference*" – key individuals in support services have made efforts to remain in contact with service users and overcome barriers to support provision (such as transport provision), which has been well received.

Professional leads have identified the Armed Forces Covenant as an asset. Each local authority in Wales has an Armed Forces Champion, who acts as a single point of contact and is able to advocate for those in the Armed Forces Community (376).

21.4.2 Community services

The focus group identified that veterans need their own support services to enable them to lead good lives – this is being currently provided very competently by the third sector. Services should provide easy to access medical care and Doctor's appointments.

21.4.3 Partnership approach

Transition support

When personnel leave the armed forces, whilst most make a successful transition, for other the transition into civilian life can be difficult (377). Preparation for leaving and having good support in place is key. Professionals working with veterans highlighted that some veterans do not know where to go to access services such as housing support, employment support, financial advice and gain access to NHS healthcare provision such as primary care.

21.5 What is likely to happen in the future?

In 2016 the veteran population in the UK was estimated to be around 5% of all household residents aged 16 and over, and this is projected to decrease year on year to 2-3% by 2028 (378). Public Health Wales Observatory estimates there will be around 12,500 veterans in Cardiff and Vale by 2030 (Figure 21.3).

Estimated veteran population*, all persons aged 16 and over, Cardiff and Vale UHB and local authorities, 2030

	Age group (Sum of the male and female tables)								Total
	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	16+
Vale of Glamorgan	90	200	210	500	770	920	620	510	3840
Cardiff	410	810	610	1180	1670	1670	1210	1140	8710
Cardiff and Vale UHB	510	1010	830	1680	2440	2610	1830	1650	12550
Wales	**2630**	**5200**	**4950**	**11850**	**18080**	**22812**	**15216**	**12850**	**93590**

Produced by Public Health Wales Observatory, using MYE (ONS) and prevalence estimates from the Royal British Legion

*Estimated population rounded to the nearest 10

Figure 21.3 Estimated veteran population Cardiff and Vale UHB and local authorities, 2030. Source: Public Health Wales Observatory, using Mid-Year Estimates (Office for National Statistics) and prevalence estimates from the Royal British Legion

Figure 21.4 illustrates the expected demographics of veterans in the UK in 2028. Just under half of all veterans will be of working age (aged 16-64), and every ten out of 80 veterans will be female.

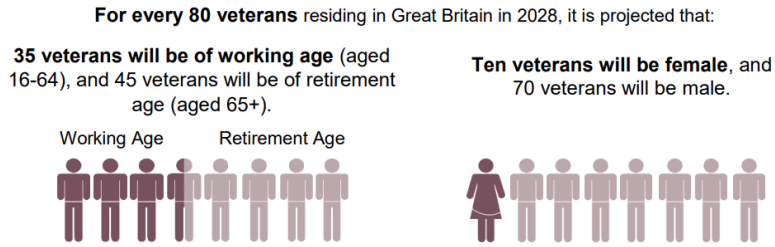


Figure 21.4. Population projections: UK Armed Forces Veterans residing in Great Britain, 2016 to 2028 (378)

21.6 Recommendations

All agencies to:

- Consider the needs of veteran families, including children, of current and former armed forces service personnel

Ministry of Defence/ Armed Forces and Cardiff and the Vale of Glamorgan Local Authorities to:

- Develop clearer pathways for veterans to support the transition into civilian life
- Consider development of a veterans ID card to give priority status to certain public services

Cardiff and Vale University Health Board to:

- Await the outcome of the all Wales review into the Royal College of GPs' Veterans Friendly Practice accreditation programme and consider the recommendations
- Increase healthcare professionals' understanding of veterans' needs and priority status through, for example, Welsh Government promotional material designed for Primary Care (360), and continuing to strengthen links between healthcare staff and the Armed Forces Champions

22. Appendix

Alignment of the National Outcomes Framework with the Regional Outcomes Framework

Regional Outcome Framework	National Outcomes Framework
Increasing time for people to live their lives	• Securing rights and entitlements and control over day to day life • Physical and mental health and emotional wellbeing
Increased living well in their own home and community	• Suitability of living accommodation • Physical and mental health and emotional wellbeing • Domestic, family and personal relationships • Social and economic wellbeing
Improved environment that enables people's choices	• Securing rights and entitlements and control over day to day life • Protection from abuse and neglect
More empowered workforce	• Securing rights and entitlements and control over day to day life
Better start for children and young people	• Physical and mental health and emotional wellbeing • Physical, intelligential, emotional, and social behavioural development • Protection from abuse and neglect • Education, training and recreation • Social and economic wellbeing • Suitability of living accommodation • Domestic, family and personal relationships • Contribution made to society • Securing rights and entitlements and control over day to day life
People get a safe response when in urgent need	• Securing rights and entitlements and control over day to day life • Protection from abuse and neglect
Decreased avoidable harm or mortality	• Securing rights and entitlements and control over day to day life • Physical and mental health and emotional wellbeing • Protection from abuse and neglect
Reduced wasted system resource	• Securing rights and entitlements and control over day to day life • Physical and mental health and emotional wellbeing • Protection from abuse and neglect

Sources: (5) (6)

Focus groups

The following focus groups were conducted for the Population Needs Assessment. The numbers of participants are shown in brackets.

- Infants, children and young people with disabilities, their parents or carers (n=8)
- Children looked after, adopted children, care experienced children, children on the edge of care (n=3)
- Older people (65-84 years) (n=4)
- Older people (85+ years) (n=3)
- Adults with a long term condition (n=5)
- Adults with a disability (n=8)
- Adults with learning disability x3 (n=7; n=5; n=8)
- Autistic adults (n=1; considered an interview rather than a focus group)
- Adults with a mental health illness (n=4)
- Adults with cognitive impairment/dementia (n=7)
- Adult unpaid carers of adults (n=12)
- Adults with sight loss (n=6)
- Adults from the D/deaf community (n=4)
- Women with experience of violence, domestic abuse, or sexual violence x2 (n=9 total)
- Asylum seekers and refugees x2 (n=9 total)
- Adults currently residing in HMP Cardiff (n=8)
- Armed forces service leavers (veterans) (n=6)
- Adults with substance misuse (n=2)
- Adults who are currently homeless / have experience of homelessness (n=10)

Unfortunately three planned focus groups did not take place as no participants could be identified in the timeframes available, or, the provider withdrew:

- Young people & young adults who require care and support due to, or experiencing transition to adult services
- Children and young people and families utilising neurodevelopmental assessment services/post-diagnostic support
- Gypsies and travellers

23. Glossary

AAC	Augmentative and Alternative Communication
ADHD	Attention Deficit and Hyperactivity Disorder
BBV	Blood Borne Virus
BSL	British Sign Language
C1V	Contact 1 Vale
C3SC	Cardiff Third Sector Council
CAMHS	Child and Adolescent Mental Health Services
CAVAMH	Cardiff and Vale Action for Mental Health
CAVHIS	Cardiff and Vale Health Inclusion Service
CLA	Children Looked After
CMHT	Community Mental Health Team
CPN	Community Psychiatric Nurse
EASR	European Age Standardised Rate
EMI	Elderly Mentally Infirm
FGM	Female Genital Mutilation
GP	General Practitioner
HEAR	Health Experiences of Asylum Seekers and Refugees
HIV	Human Immunodeficiency Virus
HMO	House of Multiple Occupancy
HMP	Her Majesty's Prison
HMPPS	Her Majesty's Prison and Probation Service
IAS	Integrated Autism Service
IDVA	Independent Domestic Violence Advisor
IFST	Integrated Family Support Team
ILS	Independent Living Service
IRIS	Identification and referral to Improve Safety
ISVA	Independent Sexual Violence Advisor
LGBTQ+	Lesbian, Gay, Bisexual, Transgender or Queer
LSOA	Lower Super Output Area
MARAC	Multi-Agency Risk Assessment Conference
MCI	Mild Cognitive Impairment
MDT	Multi-Disciplinary Team
MHSOP	Mental Health Services for Older People
MSOA	Middle Super Output Area
NICE	National Institute of Health and Care Excellence
NEET	Not in Education, Employment, or Training
PIP	Personal Independence Payment (except Chapter 19)
PIP	People In Prison (Chapter 19 only)
PNA	Population Needs Assessment
PSB	Public Service Board
PTSD	Post-Traumatic Stress Disorder
RISE	Recovery Information Safety Empowerment
RNIB	Royal National Institute of Blind People

RPB	Regional Partnership Board
SARC	Sexual Assault Referral Centre
SLT	Speech and Language Therapist
T4CYP	Together for Children and Young People
TGP	Tros Glynnal Plant Cymru
UASC	Unaccompanied Asylum Seeking Children
UHB	University Health Board
VAWDASV	Violence Against Women, Domestic Abuse, and Sexual Violence
VTN Wales	Veterans Trauma Network Wales
WEDINOS	Welsh Emerging Drugs & Identification of Novel Substances

24. Acknowledgements

We are extremely grateful to all residents of Cardiff and the Vale of Glamorgan who have contributed to this Population Needs Assessment, through completing the surveys, attending focus groups, and providing other input through other mechanisms. We would like to extend our thanks to the third sector and statutory organisations who have helped shape this report, through provision of information and insight, and with specific mention to the following organisations:

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- Age Cymru
- Cardiff and Vale Action for Mental Health (CAVAMH)
- Cardiff People First
- Cardiff Third Sector Council
- Cardiff Youth Board
- Cerebral Palsy Cymru
- Chinese in Wales Association
- Community Care & Wellbeing Service (CCAWS)
- Glamorgan Voluntary Services
- Grandparents Raising Grandchildren
- Huggard Centre
- HMP Cardiff
- Oasis Cardiff
- Richard Newton Consultants
- Sightlife – Sight Cymru
- South Wales Police
- Vale of Glamorgan Council - Autistic Spectrum Disorder Project
- Wales Neurological Alliance
- Women's Aid

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BWRDD PARTNERIAETH RHANBARTHOL
CAERDYDD A'R FRO

CARDIFF & VALE
REGIONAL PARTNERSHIP BOARD

For a hard copy of this report, or for further information,
please contact Hsc.Integration@wales.nhs.uk

Equality & Health Impact Assessment for

Cardiff and the Vale of Glamorgan Population Needs Assessment 2022

Please read the Guidance Notes in Appendix 1 prior to commencing this Assessment

Please note:

- The completed Equality & Health Impact Assessment (EHIA) must be
  - Included as an appendix with the cover report when the strategy, policy, plan, procedure and/or service change is submitted for approval
  - Published on the UHB intranet and internet pages as part of the consultation (if applicable) and once agreed.
- Formal consultation must be undertaken, as required[1]
- Appendices 1-3 must be deleted prior to submission for approval

Please answer all questions:-

1.	For service change, provide the title of the Project Outline Document or Business Case and Reference Number	Cardiff and the Vale of Glamorgan **Population Needs Assessment 2022** for the Social Services and Well-being (Wales) Act 2014
2.	Name of Clinical Board / Corporate Directorate and title of lead member of staff, including contact details	Cardiff and Vale Local Public Health Team Dr Emily Clark, Specialty Registrar in Public Health Hsc.Integration@wales.nhs.uk
3.	Objectives of strategy/ policy/ plan/ procedure/ service	The Social Services and Well-being (Wales) Act requires each region to produce a Population Needs Assessment (PNA) every electoral cycle. The PNA is due for publication by 1st April 2022, and will provide input to the Market Stability Report and Area Plans. The Regional Partnership Board (RPB) encompasses Cardiff and the Vale of Glamorgan Local Authority areas.

[1] http://nww.cardiffandvale.wales.nhs.uk/portal/page?_pageid=253,73860407,253_73860411&_dad=portal&_schema=PORTAL

		The PNA requires local authorities and Local Health Boards to form partnerships to assess: 1. The needs for care and support, and the support needs of carers in the local authority's area 2. The extent to which those needs are not being met 3. The range and level of services required to meet those needs 4. The range and level of services required to deliver the preventative services required in section 15 of the Act; and 5. How these services will be delivered through the medium of Welsh (1) The PNA must look forward until the next iteration in April 2027. The Code of Practice specifies that a broad range of individuals, groups, and organisations should provide input into the development of the Population Needs Assessment, and consider how to reach those seldom heard, for example, homeless people (1). Supplementary guidance issued in March 2021 states that careful consideration of communication needs should be given, for example, British Sign Language users (2). The Socio-Economic Duty was launched in March 2021 and is required to be included in the PNA. The following themes are required, by law, to be included: • Children and young people • Older people • Health / physical disabilities • Learning disability / autism • Mental health • Sensory impairment • Carers who need support; and • Violence against women, domestic abuse and sexual violence • Secure estate Three additional themes were chosen for inclusion as they are of particular relevance for the population of Cardiff and the Vale of Glamorgan • Asylum seekers and refugees

		• Substance misuse • Armed Forces Service Leavers (Veterans) The Code of Practice states the following regarding equality impact assessment and Welsh language: ***Equality Impact Assessments*** *93. As set out in chapter 1, local authorities must have due regard the United Nation Convention on the Rights of Persons with Disabilities, United Nation Convention on the Rights of the Child, and the United Nation Principles for Older Persons in relation to an individual person who needs care and support and carers who need support. In addition, the Public Sector Equality Duty contained in section 149 of the Equality Act 2010 requires all public authorities to have due regard to protected characteristics when exercising their functions.* *Local authorities and Local Health Boards must therefore undertake an Equality Impact Assessment as part of the process of undertaking a population assessment, which must include impact assessments on; Age, Disability, Gender Reassignment, Marriage and Civil Partnership, Pregnancy and Maternity, Race, Religion and Beliefs, Sex and Sexual Orientation.* (1) ***Welsh Language*** *121. When assessing the extent to which there are people who need care and support and carers who need support, local authorities and Local Health Boards should establish, and make clear in their population assessment report, the Welsh language community profile.* (1)
4.	Evidence and background information considered. For example • population data • staff and service users data, as applicable • needs assessment	Throughout the production of the Population Needs Assessment, consideration was given to inequalities and people with increased vulnerability. We were mindful of the “seldom heard voices” as this refers to under-represented people who may have care and support needs. Many factors can contribute to being seldom heard, of which some of these factors are themes

	• engagement and involvement findings • research • good practice guidelines • participant knowledge • list of stakeholders and how stakeholders have engaged in the development stages • comments from those involved in the designing and development stages Population pyramids are available from Public Health Wales Observatory[2] and the UHB's 'Shaping Our Future Wellbeing' Strategy provides an overview of health need[3].	within the Assessment, such as disabilities, age, communication impairments, and mental health problems. COVID-19 is known to have had a disproportionate impact on certain groups within the population. A meeting was held with the CAV UHB Equalities Manager, Specialist Health Promotion, and Welsh Language Officer early in the process (18.06.2021). The Steering Group included representatives from Cardiff Third Sector Council and Glamorgan Voluntary Services, as well as strategic and data leads from both local authorities, and representatives from CAV UHB and Public Health. For each population group, a meeting was held with professional leads from CAV UHB and each Local Authority, with additional attendees as relevant for the topic. The group discussed the key documents, policies, strategies, and developments since the 2017 PNA. Data sources for this iteration of the PNA was discussed. Engagement was based on the 2017 Population Needs Assessment and updated for this report. The coronavirus pandemic has influenced how communications and engagement events can be run. Engagement conducted for the Population Needs Assessment needed to adhere with and anticipate future guidelines and legislation, as well as consider people's individual wishes. Footfall in public spaces were less than prior to COVID-19. A number of different approaches were taken to obtain the information required to give a holistic overview of the care and support needs in Cardiff and the Vale of Glamorgan, and the range and level of services required to meet those needs. This included gathering existing data, assessments and reports; as well as conducting bespoke engagement work for this Population Needs Assessment. Three public surveys were developed:

[2] http://nww2.nphs.wales.nhs.uk:8080/PubHObservatoryProjDocs.nsf
[3] http://www.cardiffandvaleuhb.wales.nhs.uk/the-challenges-we-face

		• Adults in the general public (available online, hard copy, and Easy Read) • Children and young people (available online, hard copy, and Easy Read) • Adults in HMP Cardiff (available online, and hard copy) Cardiff Youth Board kindly piloted the children and young people's survey and provided feedback; which was incorporated into the final survey. A total of 661 general public surveys were returned; 35 surveys from children and young people; and 96 from HMP Cardiff. A professionals and provider survey was developed (available online and hard copy). A total of 118 responses were received. Surveys were disseminated through a variety of organisations, including Cardiff and Vale University Health Board, Cardiff Council, Vale of Glamorgan Council, Glamorgan Voluntary Services, Cardiff Third Sector Council, as well as through organisations working in health and social care services, education, and youth services. The surveys were also advertised through social media. Surveys are not representative of the population of Cardiff and the Vale of Glamorgan. A total of 23 focus groups were held across 18 (sub)themes. These were conducted by Cardiff Third Sector Council with support from Glamorgan Voluntary Services and third sector organisations. Focus groups were mostly virtual (12); with some hybrid (2); and 5 face to face. One population group ran two separate focus groups – one virtual and one face to face. A total of 132 participants (range 1-12) took part in the focus groups, which took place in October 2021.

		The following focus groups were held. Numbers of participants are given in brackets: • Infants, children and young people with disabilities, their parents or carers (n=8) • Children looked after, adopted children, care experienced children, children on the edge of care (n=3) • Older people (65-84 years) (n=4) • Older people (85+ years) (n=3) • Adults with a long term condition (n=5) • Adults with a disability (n=8) • Adults with learning disability x3 (n=7; n=5; n=8) • Autistic adults (n=1; considered an interview rather than a focus group) • Adults with a mental health illness (n=4) • Adults with cognitive impairment/dementia (n=7) • Adult unpaid carers of adults (n=12) • Adults with sight loss (n=6) • Adults from the D/deaf community (n=4) • Women with experience of violence, domestic abuse, or sexual violence x2 (n=9 total) • Asylum seekers and refugees x2 (n=9 total) • Adults currently residing in HMP Cardiff (n=8) • Armed forces service leavers (veterans) (n=6) • Adults with substance misuse (n=2) • Adults who are currently homeless / have experience of homelessness (n=10) Unfortunately three planned focus groups did not take place as no participants could be identified in the timeframes available, or, the provider withdrew: • Young people & young adults who require care and support due to, or experiencing transition to adult services • Children and young people and families using neurodevelopmental assessment services/post-diagnostic support • Gypsies and travelers

		The following organisations provided support with engagement work: • Adferiad Recovery • Age Cymru • Cardiff and Vale Action for Mental Health (CAVAMH) • Cardiff People First • Cardiff Third Sector Council • Cardiff Youth Board • Cerebral Palsy Cymru • Chinese in Wales Association • Community Care & Wellbeing Service (CCAWS) • Glamorgan Voluntary Services • Grandparents Raising Grandchildren • Huggard Centre • HMP Cardiff • Oasis Cardiff • Richard Newton Consultants • Sightlife – Sight Cymru • Vale of Glamorgan Council - Autistic Spectrum Disorder Project • Wales Neurological Alliance • Women's Aid Quantitative data were taken from open source, publically available, validated sources such as Stats Wales and Social Care Wales Daffodil Population Projection. Other indicators were obtained directly through personal communications with relevant organisations (for example, Welsh Refugee Council, Cardiff and Vale of Glamorgan Councils), or through a Freedom of Information request (for example, South Wales Police). Demography data were provided by Cardiff Council to ensure cohesion across the Well-being Assessment and Population Needs Assessment.

		Engagement frameworks were considered during the development of the engagement plan (e.g., Citizen's Engagement Framework; Children and Yong People National Participation Standards). **Limitations** COVID-19 has had a tremendous impact on the population, which the Population Needs Assessment will detail. It has also impacted on professionals working in operational and strategic roles which presented a challenge for the completion of this assessment. Additional challenges presented themselves in the form of the timeline with which the Population Needs Assessment was conducted; a novel approach to the Population Needs Assessment will be taken in future to mitigate this as detailed below. Due to uncertainty of the future evolution of the COVID-19 pandemic in terms of restrictions and risks at each stage of the Population Needs Assessment, a cautious approach was taken. For example, engagement work was planned for an online format, with opportunities for face to face interactions in the focus group where legislation allowed, and where participants and hosting organisations felt comfortable. The tight timeline within which engagement work needed to be conducted reduced participation in both surveys and focus groups. The Regional Partnership Board are developing their Communications and Engagement strategy which will address these difficulties and gaps, and will incorporate lessons learned. For example, some residents may not have digital access and may not wish to engage in in-person engagement, and so their views will be sought in future work as a priority. Only a minority of focus group participants (9/132) completed equalities monitoring forms, and therefore the results are not presented here. Feedback from focus group organisers has been shared with the Regional Partnership Board for consideration during planning of future engagement work. Feedback included: • The need for a longer lead in time to increase participation in focus groups

		• The Social Model of Disability, rather than the Medical Model of Disability, should be used • Improved access to the Easy Read survey • The length of the equalities monitoring form • The duration of the focus groups Future engagement will learn from these experiences and endeavor to address these concerns, through advanced planning, and bespoke consideration of each population group.
5.	Who will be affected by the strategy/ policy/ plan/ procedure/ service	The PNA will help shape the Area Plan and Market Stability Report. Although the assessment concentrates on the following population groups, many findings will be transferable to others not within the group. Some people will feel included in more than one of the themes. Themes included: Children and young people; Older people; Health and physical disabilities; Learning disability and autism; Adult mental health and cognitive impairment; unpaid Adult carers; Sensory loss and impairment; Violence against women, domestic abuse and sexual violence; Secure Estates; Asylum seekers and refugees; Veterans; Substance misuse. **As a needs assessment, the main impact of concern is that of under-representation of certain groups. This document will describe the characteristics of those who participated in engagement work. The findings of this assessment should therefore not be considered exhaustive.** **Those who are under-represented in engagement work include:** • Those who are digitally excluded • People who are trans • Women who are expecting a baby, who are on a break from work after having a baby, or who are breastfeeding • People who are from an ethnic minority background

		• People who consider themselves: Buddhist, Hindu, Jewish, Muslim, or Sikh • Those who were physically unable to participate in engagement and did not have an individual who could speak for them • Gypsies and travelers The Population Needs Assessment will take a hybrid approach in future iterations. This comprises a rolling update of quantitative data, and periodic refresh of qualitative data from engagement work. Therefore, this PNA report and Equality & Health Impact Assessment (EHIA) should be considered a first iteration; the beginning of an ongoing conversation between the Regional Partnership Board, and the residents of Cardiff and the Vale of Glamorgan. **We welcome comments and feedback on the PNA and the EHIA, as we seek to learn, improve, and develop. Please send these to Hsc.Integration@wales.nhs.uk**

6. EQIA / How will the strategy, policy, plan, procedure and/or service impact on people?

Questions in this section relate to the impact on people on the basis of their 'protected characteristics'. Specific alignment with the 7 goals of the Well-being of Future Generations (Wales) Act 2015 is included against the relevant sections.

How will the strategy, policy, plan, procedure and/or service impact on:-	**Potential positive and/or negative impacts**	**Recommendations for improvement/ mitigation**	**Action taken by Clinical Board / Corporate Directorate.**

			Make reference to where the mitigation is included in the document, as appropriate
6.1 Age For most purposes, the main categories are: • under 18; • between 18 and 65; and • over 65	No negative impacts of the PNA on age identified. However, children and young people were underrepresented in engagement work and so there may be additional views which were not captured by this assessment. The findings of the PNA should therefore not be considered exhaustive. Participants in the Children Looked After focus group were grateful for the opportunity to be listened to, suggesting that future engagement work with young people would be welcomed. Examples of key needs identified for children and young people include: • Emotional and mental health and well-being • Independence and having a voice • Role of education in learning and signposting, and it's interruption due to COVID-19 and restrictions Examples of key needs identified for older people (aged 65 or over) include: • Loneliness and isolation • Changes in behaviour due to COVID-19 and restrictions such as less activity, deconditioning • Financial insectary • Appropriate and accessible housing Age is explicitly considered in the following chapters:	RPB programmes are designed to support people at different stages of their life cycle: starting, living and ageing well. We want to deliver service that are tailored for people at different stages of life and our engagement will be designed to capture the experiences and opinions of people in each age category. Each chapter in the PNA has developed recommendations based on the key needs. Future plans	

- The chapter on **demography** (chapter 4) provides an overview of the current and projected age make up of Cardiff and the Vale of Glamorgan. Each chapter provides a summary of characteristics of the population in its introduction.
- **Children and young people** (those aged up to and including 17) are specifically considered in chapters 5, 6 and 7.
- **Older people** (those aged over 65) are discussed in chapter 8.

Some conditions increase in prevalence with age; for example, sight loss. RNIB provide data on the number of people with sight loss by age:

Estimated number of adults living with sight loss by age group (2021) Reference**:** (3)

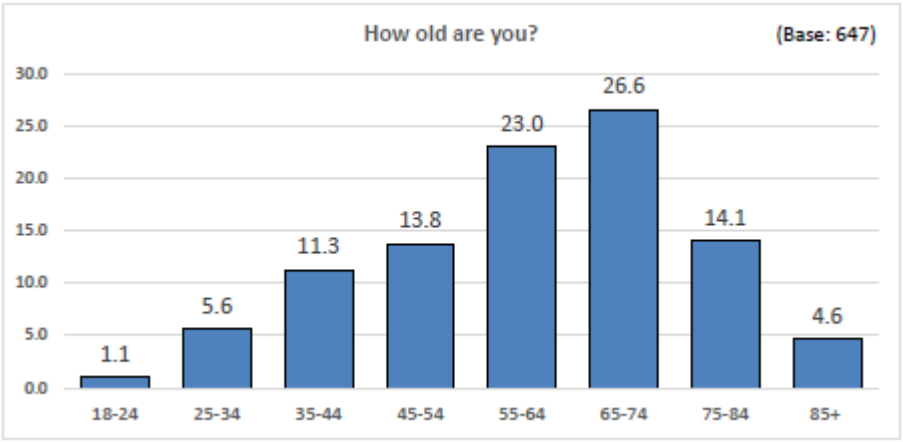
Area	Working age people aged 18-64	Older people aged 65-74	Older people aged 75-84
Wales	20,100	23,400	32,100
Cardiff	2,090	1,860	2,440
The Vale of Glamorgan	870	1,020	1,410

Through articulating the needs of specific age groups within the PNA, services can better meet them. This is a positive impact.

Engagement findings

Respondents of the general public survey had the following age profile:

and assessments should consider the findings of the PNA in their development.

	 Older people are more likely to be digitally excluded and therefore their full range of views may not have been captured by this survey. 26 of the 35 respondents of the children and young people survey provided their age; the breakdown is as follows: 42% were aged 12-15, 35% were aged 16-18, and 23% were aged 0-11. This is a small, self-selecting sample, and so their views cannot be extrapolated to the whole population of people aged under 18. Two focus groups which were planned did not take place, therefore the in-depth views of young people & young adults who require care and support due to, or experiencing transition to adult services, as well as children and young people and families utilising neurodevelopmental assessment services/post-diagnostic support were not captured by this PNA.		
6.2 Persons with a disability as defined in the Equality Act 2010	No negative impacts of the PNA on people with a disability were identified. However, feedback from engagement identified that the Social Model of Disability should have been used instead of the Medical Model of Disability when questions were framed and structured. This feedback will be considered during future citizen engagement.	The RPB has identified disability as a key focus in our phase 1 engagement as we recognise	

<table>
<tr>
<td>Those with physical impairments, learning disability, sensory loss or impairment, mental health conditions, long-term medical conditions such as diabetes</td>
<td>Disability is explicitly considered in the following chapters:

People with long term conditions are considered within the chapter “Healthy Lifestyles and Long Term Conditions” (chapter 9)
Disabled people are included within chapter 10, “Physical Disability”
People with a learning disability are considered in chapter 11; autistic people are included in chapter 12.
Adult mental health is discussed in chapter 13.
Cognitive impairment including dementia is discussed in chapter 14.
People with sensory loss and impairment are discussed in chapter 16.
People who have experienced substance misuse are discussed in chapter 18.
Many people in one chapter were also included in another; for example, people with learning disability are more likely to have or develop sight loss than the general population:

Learning disability and visual impairment in adults (2021)
Adults with learning disabilities are 10 times more likely to experience sight loss than the general population.
<table>
<tr><th>Area</th><th>Estimated number of adults with a learning disability and visual impairment (partial sight)</th><th>Estimated number of adults with a learning disability and blindness</th><th>Estimated number of adults with a learning disability and blindness or partial sight</th></tr>
<tr><td>Wales</td><td>3,970</td><td>1,120</td><td>5,090</td></tr>
<tr><td>Cardiff</td><td>420</td><td>120</td><td>540</td></tr>
<tr><td>The Vale of Glamorgan</td><td>170</td><td>45</td><td>215</td></tr>
</table>
Reference: (3)</td>
<td>people with disabilities will be particularly impacted if we redesign health and social care services. The RPB hopes that by bringing services closer to home and making them easier to navigate people with disabilities will find they have improved.

The RPB’s Living Well Programme has established excellent links with people who have a learning disability and they have had a great deal of input into developments in this area e.g. Smart House design. This will continue as our work progresses.

The Social Model of Disability will be used,</td>
<td></td>
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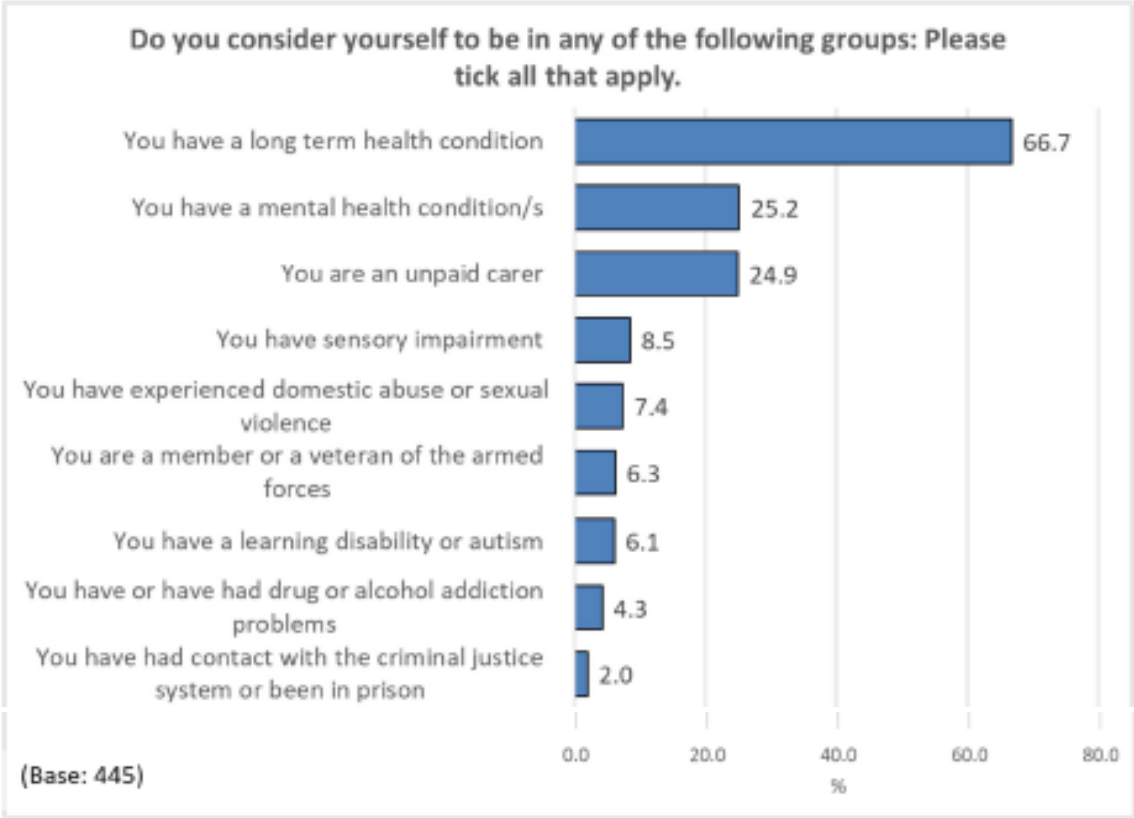
	Through articulating the needs identified in these population groups, services can consider how they can best meet these needs: a positive impact. Examples of key needs identified by people with a long term condition or a physical disability include: • Countering the disproportionate impact of COVID-19 on disabled people (direct harm from COVID-19 as well as difficulty accessing health services; mental health and well-being impacts of COVID-19 and restrictions) • Service access for people with mental health disorders and homelessness Examples of key needs identified by people with learning disability or autism include: • Independence, supported autonomy, and co-production • Transport Examples of key needs identified by people with a mental health condition or cognitive impairment including dementia include: • Timely access to services and treating physical and mental health conditions holistically • Caring for unpaid carers Examples of key needs identified by people with sensory loss or impairment include: • Availability of suitable communication mechanisms to access services equitably (for example, hearing loop availability and BSL interpreters) • Education and employment opportunities Examples of key needs identified by people with substance misuse include: • Specialist medical care including mental health • Prevention and management of homelessness	in accordance with feedback received. Each chapter in the PNA has developed recommendations based on the key needs identified. Future plans and assessments should consider the findings of the PNA in their development.	

Engagement findings

General survey respondents stated they considered themselves in the following groups. Two thirds (66.7%) of respondents indicated they had a long-term health condition; this was followed by one in four that considered themselves to have a mental health condition and/or to be an unpaid carer (25.2% and 24.9% respectively).



(NB. Percentages do not total 100% as respondents could select multiple options)

Three Easy Read surveys were returned. In view of small numbers, no further disaggregation is provided.

	A number of focus groups were held to identify the views of people with disabilities: • Adults with a long term condition (n=5) • Adults with a disability (n=8) • Adults with learning disability x3 (n=7; n=5; n=8) • Autistic adults (n=1; considered an interview rather than a focus group) • Adults with a mental health illness (n=4) • Adults with cognitive impairment/dementia (n=7) • Adults with sight loss (n=6) • Adults from the D/deaf community (n=4) • Adults with substance misuse (n=2) Some focus groups were very small, and so views garnered cannot be said to be representative; however, they have gained depth of insight.		
6.3 People of different genders: Consider men, women, people undergoing gender reassignment **NB** Gender-reassignment is anyone who proposes to, starts, is going through or who has completed a process to change his or her gender with or without going through any medical	No negative impact of the PNA on people of different genders was identified. There may be some positive impact as gender is considered in some of the chapters; through articulating the needs of people of different genders. Trans people may be underrepresented, with fewer than 3 respondents identifying as trans in the public survey. Gender including gender reassignment was not an explicit theme within the PNA, however, gender was considered within the Secure Estate and Violence Against Women, Domestic Abuse, and Sexual Violence (VAWDASV) chapters. Inequalities in the management of prisoners was identified in the **Secure Estate** chapter (chapter 19) as HMP Cardiff only accepts men. No female prisoners are resident in HMP Cardiff; they are instead imprisoned in England, most often HMP Eastwood Park. Increasing distance between an individual's residence prior to prison, and the location of their prison is known to be associated with decreased professional visits, therefore putting women at a disadvantage (4). It is recognised that there have been challenges with TB management for Welsh individuals imprisoned in England in terms of timeliness	Men and women may experience different barriers when accessing social care and it is important that their needs are met when redesigning services. People who have had gender reassignment will need to use our services and we will need to understand how to make them	

procedures. Sometimes referred to as Trans or Transgender	of care, with some reports that treatment is delayed until transfer to Wales (5). This will disproportionately disadvantage women. The **Violence Against Women, Domestic Abuse, and Sexual Violence (VAWDASV)** chapter (chapter 17) is predominantly focussed on women, however, men can be victims of domestic abuse and sexual violence also. This is discussed in the chapter. Examples of needs identified in the VAWDASV chapter include: • Gynaecological and maternity services **Engagement findings** General public survey respondents reported their gender as follows: 59% female, 38% male, 3% non-binary / other / prefer not to say. In response to the question, “Are you trans”, most responded “no” (487/510; 95.5%). Fewer than 3 stated they were trans. Adults responding to the Easy Read survey were all female, and did not consider themselves trans. Children and young people reported their gender as follows: 58% female, 35% male. Most (88%) did not describe themselves as trans, with others preferring to self-describe or preferring not to say.	welcoming and inclusive. Each chapter in the PNA has developed recommendations based on the key needs identified. Future plans and assessments should consider the findings of the PNA in their development.	
6.4 People who are married or who have a civil partner.	No impacts identified of the PNA on marriage or civil partnership. This protected characteristic was not considered an explicit theme within the PNA. **Engagement findings**	People who are married or who have a civil partnership may need to access our	

<table>
<tr>
<td></td>
<td>Survey respondents to the public survey were predominantly married (55%), with 19% responding they were single.

<table>
<tr><th></th><th>No.</th><th>%</th></tr>
<tr><td>Single</td><td>96</td><td>18.5</td></tr>
<tr><td>In a same-sex Civil Partnership</td><td>4</td><td>0.8</td></tr>
<tr><td>Married</td><td>283</td><td>54.6</td></tr>
<tr><td>Living together/Co-habiting</td><td>40</td><td>7.7</td></tr>
<tr><td>Separated/divorced or legally separated if formerly in a same-sex Civil Partnership</td><td>36</td><td>6.9</td></tr>
<tr><td>Widowed</td><td>52</td><td>10.0</td></tr>
<tr><td>Other</td><td>7</td><td>1.4</td></tr>
<tr><td>Table</td><td>518</td><td>100.0</td></tr>
</table>

Three Easy Read surveys were returned. In view of small numbers, no further disaggregation is provided.</td>
<td>services and the RPB will have to understand how to make them welcoming and inclusive. Future plans and assessments using the PNA should consider the findings of the PNA in their development.</td>
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<tr>
<td>6.5 Women who are expecting a baby, who are on a break from work after having a baby, or who are breastfeeding. They are protected for 26 weeks after having a baby whether or not they are on maternity leave.</td>
<td>No impacts identified of the PNA on women who are expecting a baby, who are on a break from work after having a baby, or who are breastfeeding. These protected characteristics were not an explicit theme in the PNA. They are underrepresented in our engagement work.

Engagement findings
A minority of survey respondents to the public survey responded that they were expecting a baby (3/57 who responded to the question); three were on a break from work after having a baby or currently breastfeeding.</td>
<td>People who are pregnant or have just had a baby may need to access our services and the RPB will have to understand how to make them welcoming and inclusive. Future plans and assessments using the PNA should consider the findings of the PNA in their development.</td>
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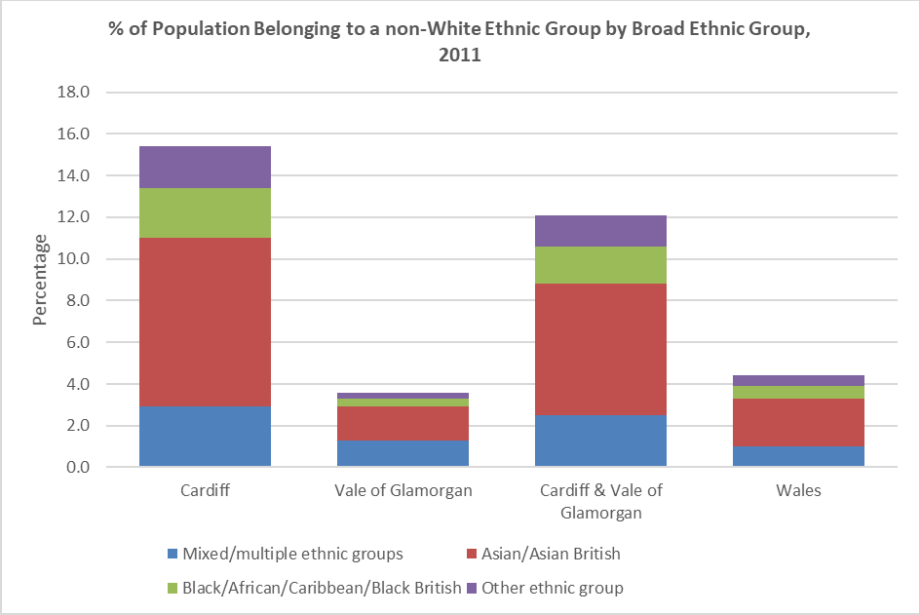
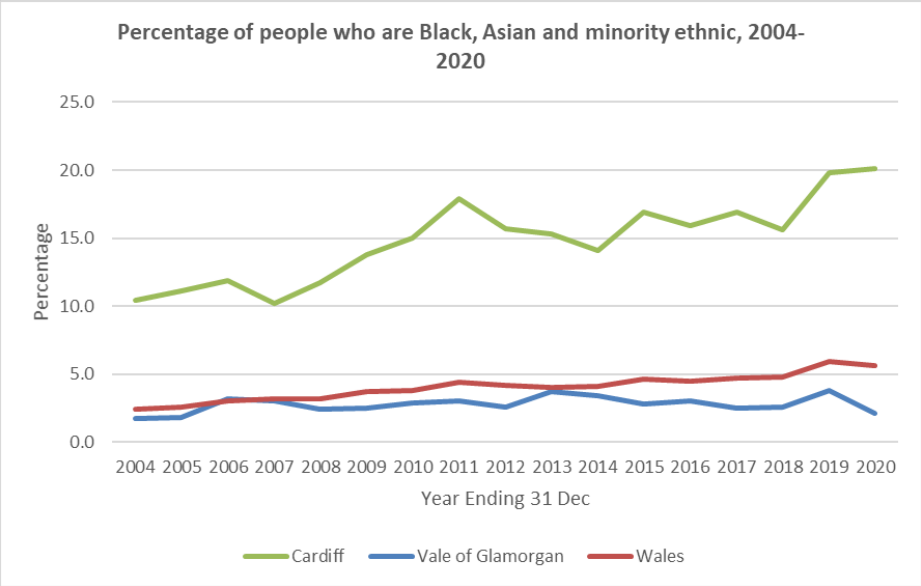
6.6 People of a different race, nationality, colour, culture or ethnic origin including non-English speakers, gypsies/travellers, migrant workers	No negative impact identified of the PNA on people of a different race, nationality, colour, culture or ethnic origin including non-English speakers, gypsies/travellers, migrant workers. This protected characteristic was not an explicit theme within the PNA. Unfortunately the planned focus group with gypsies and travellers could not take place. Future work should seek to identify the view of these communities. People who are of a different ethnicity are underrepresented in the engagement work for the PNA. The PNA includes a chapter on **Asylum Seekers and Refugees** (Chapter 20), which details the needs and services required for this population group. By articulating the needs of asylum seekers and refugees, their needs for care and support can be better designed. Examples of key needs of asylum seekers and refugees identified by the PNA include: • Variation in medical needs based on the person's background • Mental health and support for long term conditions • Understanding the NHS system including access to services Data gaps identified included the numbers and needs of undocumented migrants. Welsh Government have recently published a report on the association of ethnicity with impact of COVID-19 (6). Wales Governance Centre in their report identified that people from a Black, Asian, or Mixed Ethnic group experienced higher custody rates, compared to White defendants. Additionally, custodial sentence length was longer for Black, Asian, and Minority Ethnic groups (4). The 2011 Census identified that around one-sixth (15.3%) of Cardiff's population belongs to a non-white ethnic group, which is higher than the proportion across Wales of 4.4%. In the Vale of Glamorgan, 3.6% of the population belongs to a non-white ethnic group (7).	The RPB understands that people may experience barriers to accessing health and social care because of their race. The RPB has allocated funding to explore this specific area in phase 1 of our engagement plan. The PNA recommends all agencies working with asylum seekers, refugees, and undocumented migrants to improve data collection in order to address data gaps.	



Source: 2011 Census (7)

The Annual Population Survey identified an increase from 10.4% in 2004 to 20.1% in 2020 of people in Cardiff who are Black, Asian, or from a minority ethnic group. The Vale of Glamorgan has seen only a small increase in people who are Black, Asian, or from a minority ethnic group over the same time period (8).



Source: Annual Population Survey (8)

Nationally, children from Black, Asian, and Minority Ethnic groups are overrepresented amongst Children Looked After (CLA): 8.6%, despite making up 6.6% of the population (9). The majority of children looked after in 2020 were of white ethnicity (715/955 in Cardiff; 215/260 in Vale of Glamorgan). In Cardiff, 55 CLA are Black, African, Caribbean or Black British; 65 Asian or Asian British; 90 from mixed ethnic groups. In the Vale of Glamorgan, 40 were from other ethnic groups; and small numbers were suppressed for other responses (10).

Engagement findings

General public survey respondents were mostly White: 92.5%; n=482 of 521 who responded to the question. Fourteen were Asian (2.7%); 9 people identified as Mixed / Multiple Ethnic groups (1.7%). Adults responding to the Easy Read survey all reported their ethnicity as White (n=3).

6.7 People with a religion or belief or with no religion or belief. The term ‘religion’ includes a religious or philosophical belief	No negative impact identified of the PNA on people with a religion or belied, or no religion or belief. This protected characteristic was not an explicit theme within the PNA. Across many of the chapters of the PNA, religion and church were frequently identified as a community asset to support well-being. One respondent to the survey in HMP Cardiff stated: *"I would like a gypsy meal at least once a month, you're allowed Ramadan so why not food from my culture."* Increased awareness of the role of religion – or lack of religion – on well-being may have a positive impact. The views of people who practice Buddhism, Hinduism, Judaism, Islam, or Sikhism may be underrepresented. The 2011 Census states 57.6% of the population of Wales is Christian, with 32.1% of people having no religion (2001 data: 71.9% and 18.5% respectively) (11). Updated Census data is awaited in 2022. **Engagement findings** Respondents to the general public survey regarded themselves as belonging to the following religion: 54% no religion, 41% Christian, 1% Buddhist. Adults responding to the Easy Read survey all stated their religion as Christian (n=3).	The RPB understands that people may experience barriers to accessing health and social care because of their religion. The RPB plans to explore this in more detail before deciding the best way to collect people’s views. The PNA recommends in many chapters that a culture of person-centred services, with increased voice for the person, is developed, or continued in order to ensure services are welcoming to people of all beliefs and cultures.	

<table>
<tr>
<td>6.8 People who are attracted to other people of:
• the opposite sex (heterosexual);
• the same sex (lesbian or gay);
• both sexes (bisexual)</td>
<td>No negative impacts identified of the PNA on people who are heterosexual, lesbian, gay, or bisexual. The PNA identified that some services need to develop accessibility to Lesbian, Gay, Bisexual, Transgender, and Queer individuals, for example, in the VAWDASV chapter (chapter 11), and Older People (chapter 16), where a gap in knowledge was identified. This may have a positive impact as their needs can be proactively sought and articulated for future consideration.

Engagement findings
Respondents to the general survey described their sexual orientation as follows:
<table><tr><th></th><th>No</th><th>%</th></tr><tr><td>Bisexual</td><td>25</td><td>4.8</td></tr><tr><td>Gay Woman/ Lesbian</td><td>5</td><td>1.0</td></tr><tr><td>Gay Man</td><td>15</td><td>2.9</td></tr><tr><td>Heterosexual/ Straight</td><td>434</td><td>83.9</td></tr><tr><td>Other</td><td>5</td><td>1.0</td></tr><tr><td>Prefer not to answer</td><td>33</td><td>6.4</td></tr><tr><td>Total</td><td>517</td><td>100.0</td></tr></table>The Office for National Statistics report that 2.7% of the population in the UK identified as lesbian, gay, or bisexual in 2019 (12).

Adults responding to the Easy Read survey all identified as heterosexual (n=3).</td>
<td>The RPB understands that people may experience barriers to accessing health and social care because of their sexual orientation; and plans to undertake specific engagement with people who are LGBTQ+ in phase 2.</td>
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<tr>
<td>6.9 People who communicate using the Welsh language in terms of correspondence, information leaflets, or service plans and design</td>
<td>No negative impacts identified of the PNA on people who communicate using the Welsh language. PNA surveys were available in Welsh and English. Focus groups were held using the participants' desired communication method, for example, the D/deaf community conducted their focus group in British Sign Language.

An assessment of Welsh language / English as a second language and other communication needs is provided within each chapter of the PNA, and many data gaps are identified across the chapters of the PNA. By highlighting key needs and data gaps,</td>
<td>RPB engagement resources will be available bilingually. The RPB will ask people's language preferences on registration to any events to ensure our</td>
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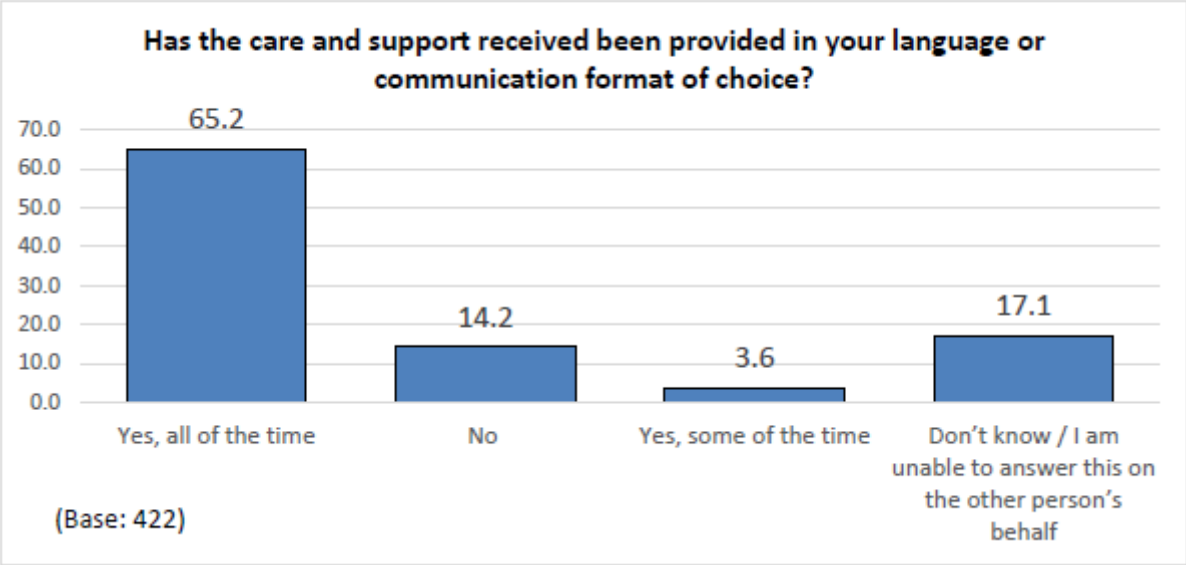
Well-being Goal – A Wales of vibrant culture and thriving Welsh language	future work can seek to address these so that services can be better developed to meet the language and communication needs of the population. This will be a positive impact. The National Survey for Wales reports that 11% of respondents in Cardiff and Vale were given the choice to receive treatment in Welsh or English (range 11-24% across Wales). Amongst Welsh speakers across Wales, 24% chose to receive treatment in Welsh (113). Social Care Wales report that only 2% of domiciliary care workers are fluent in Welsh, 15% have some Welsh in the Vale of Glamorgan, for Cardiff the figures are 3% and 27% (114). Chapter 16 discusses **sensory loss and impairment**. A prominent component of the chapter is around communication appropriate to the individual; including normalising use of British Sign Language and hearing loops. The 2011 Census identified that most (98.4%) of residents in the Vale of Glamorgan have English or Welsh as their main language. This is higher than the Wales average (97.1%). Cardiff has the lowest proportion of people speaking English or Welsh as their first language at 91.7%. **Engagement Findings** Respondents to the general public survey mostly spoke English at home (97.1%) with 2.2% speaking Welsh, and 1.5% speaking another language. The survey for the general public asked whether respondents have received care and support in the language or communication format of their choice. Responses were as	engagement plans are fully inclusive to Welsh speakers. Future plans and assessments should consider the PNA findings in their development.	

follows:



When considered by theme, adult unpaid carers were most satisfied with services being provided in a format of their choice (81.7%) compared to other groups.

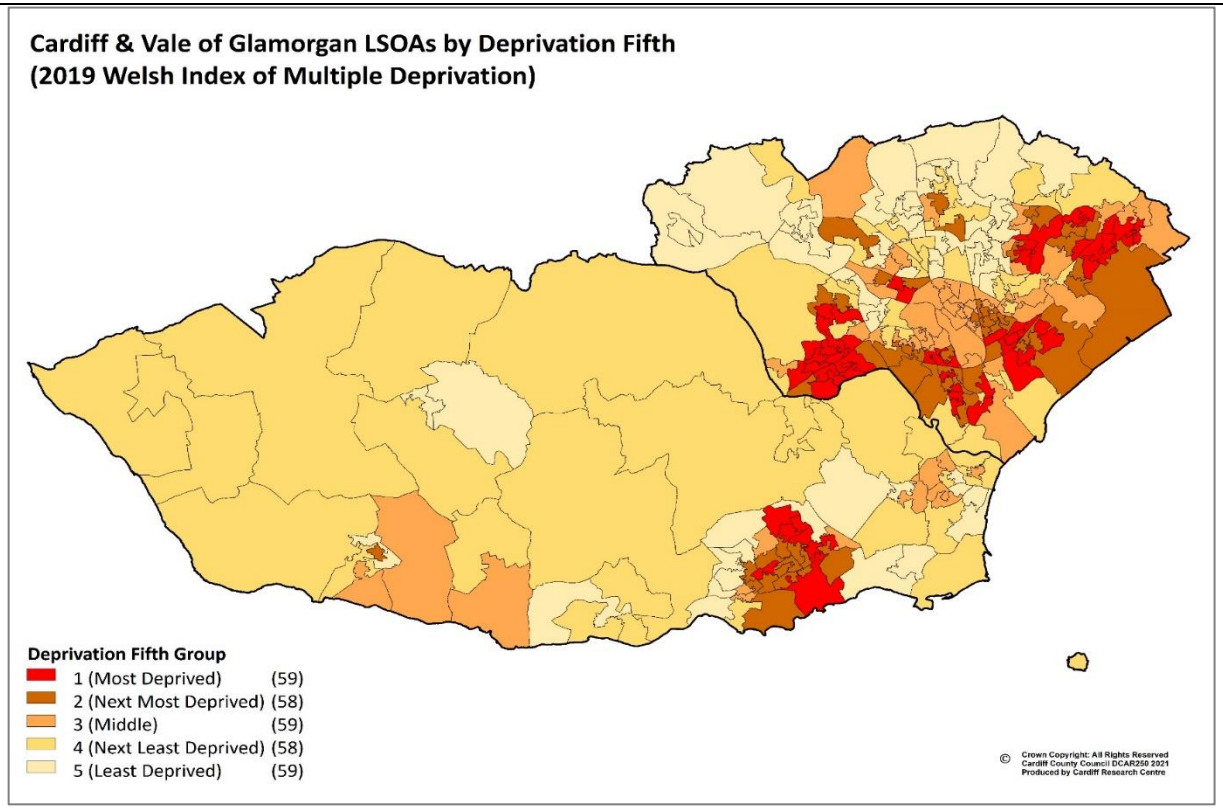
	Adult mental health		Adult unpaid carers		Older people		Health and physical disability	
	No	%	No	%	No	%	No	%
Yes, all of the time	63	*71.6*	67	*81.7*	126	*71.6*	140	*71.1*
Yes, some of the time	3	*3.4*	4	*4.9*	1	*0.6*	6	*3.0*
No	12	*13.6*	5	*6.1*	28	*15.9*	24	*12.2*
Don't know / I am unable to answer this on the other person's behalf	10	*11.4*	6	*7.3*	21	*11.9*	27	*13.7*
Total Respondents	**88**	***100.0***	**82**	***100.0***	**176**	***100.0***	**197**	***100.0***

Around one in seven (13.4%) speak a second language at home.

	Regarding whether respondents would like to see any improvements in language and communication provision: of the 152 respondents that left feedback to this question, three in five (59.2%) were either happy with the service or indicated that the service didn't apply to them. 7.9% would like to see better bilingual services, whilst a further 7.2% would like to more plain language / less jargon. Free text comments in the general public survey stated the following regarding Welsh language: • *"I get everything bilingually/am happy with that, I've more serious things on my mind."* • *"More Welsh signage and options when seeking phone advice."* • *"Less forced usage of the Welsh Language."* • *"Focus on 1 language. Resources are too stretched to accommodate all languages"* One respondent wanted increased access to interpreters (although it was not clear which language was desired) • More interpreters for young people in care (and their families). A number of comments were made regarding the use of language, and finding the balance between simple and clear communication, whilst not patronising the patient. • *"I'd like my husband's oncologist to learn how to be open and explain things. We are not stupid!"* • *"More support/understanding of non-verbal communication"* • *"We should all speak our own language"* • *"More simple, easy to read, jargon free communication."*		

	All three respondents to the Easy Read survey spoke English most at home, and reported that they received care and support in the language of their choice. Respondents wanted service providers to "*speak calmly*", "*speak plainly*, *no jargon*", Most children and young people spoke English at home (84.6%; 22/27), with 2 speaking English using Augmented and Alternative Communication (AAC). There was one response each for Welsh, Gujurati, and Romanian.		
6.10 People according to their income related group: Consider people on low income, economically inactive, unemployed/workless, people who are unable to work due to ill-health	No negative impacts identified of the PNA on people according to their income related group. The Socio-economic duty, inequalities and deprivation are discussed with each population group in the PNA, and so by articulating key issues and data gaps, it is hoped that the PNA will have a positive impact as service leads, commissioners, and others can consider how their services can reduce the identified inequalities. People who are digitally isolated are likely to be under-represented in engagement work, due to a focus on online distribution and communication methods relating to COVID-19. Therefore, their views may not have been comprehensively captured in the PNA. A focus group discussion with people who are homeless was conducted. Key needs identified included the following: • The need for an address in order to gain employment • Tension between accommodation rules (for example, needing to vacate by 9am) and shift work **Children and young people** An evidence review of the human rights of children in Wales identified differential outcomes in health risk factors and outcomes, education, and wellbeing depending on socio-economic background (13). Children aged 4-5 years in the most deprived decile were 76% more likely to be obese than those in the least deprived decile. Low birth weight and educational deprivation were also associated with income deprivation (14).	The Socio-Economic Duty was implemented in March 2021, and requires public bodies "to have due regard to the need to reduce the inequalities of outcome resulting from socio-economic disadvantage" (17). The Socio-Economic Duty will therefore be incorporated into the work of the Regional Partnership Board, as well as by plans and assessments utilising the PNA findings.	

	The most recent Welsh Index of Multiple Deprivation report uses 2016/17 data, and finds that 28% of children aged 0-4 lived in income deprivation (range 17%-30%). This is the highest proportion by age group. Cardiff has the highest number of 0-4 year olds living in income deprivation (6,600 children) but sits just above the Welsh average at 29%; the Vale of Glamorgan has nearly 2,000 children in income deprivation (23%). Cardiff has both the most and least deprived middle super output areas in Wales, with income deprivation rates between 3% in Rhiwbina and Pantmawr, to 67% in Ely East. In both local authorities, this represents a decrease from 2012/13: Cardiff had 33% and Vale of Glamorgan 27% of 0-4 year olds living in income deprivation (14). Further details can be found in Chapter 5, 6, and 7 which focus on **Children and young people** **Adults** A summary of Cardiff and the Vale of Glamorgan is given in the demography chapter (Chapter 4). The Welsh Index of Multiple Deprivation (WIMD) 2019 suggests that there are areas of established inequalities across the Cardiff and Vale region; with areas in the 'Southern Arc' in Cardiff and areas in the East of Barry ranked as more deprived against WIMD. In Cardiff, 39 LSOAs are included in top 10% most deprived in Wales, while 3 LSOAs in the Vale of Glamorgan are ranked in the top 10% most deprived area in Wales. In Cardiff, around one-fifth of residents live in the most deprived 10% of lower super output areas (LSOAs) in Wales. Approximately 50% of Cardiff's population live in the 50% least deprived LSOAs, while for the Vale of Glamorgan, 65% live in the 50% least deprived areas (15).		

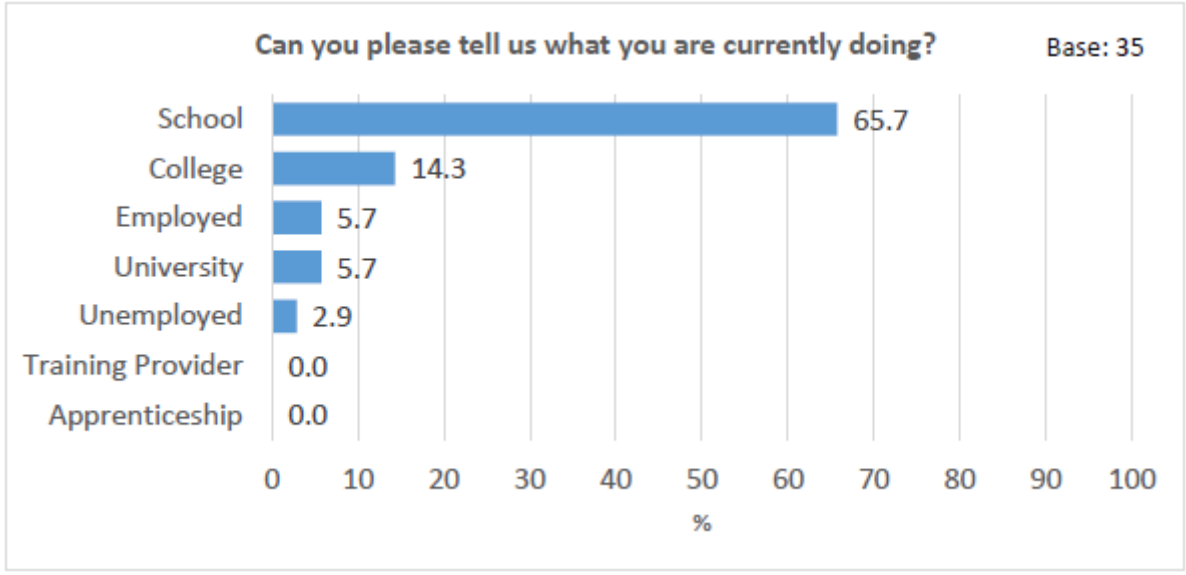


Respondents to engagement work, and existing reports and documents have described the desire for many people to have high quality, secure employment. Benefits include financial security, as well as the sense of purpose, and protective effects on mental health and well-being that employment brings. Examples of these findings can be found across the PNA, but is featured particularly prominently in the following chapters: healthy lifestyles and long term conditions (chapter 9), physical disability (chapter 10); learning disability (chapter 11), autism (chapter 12); sensory loss (chapter 16); secure estate (chapter 19); asylum seekers and refugees (chapter 20).

Welsh Government have published a report on COVID-19 and employment, an analysis of protected characteristics (16).

Engagement findings

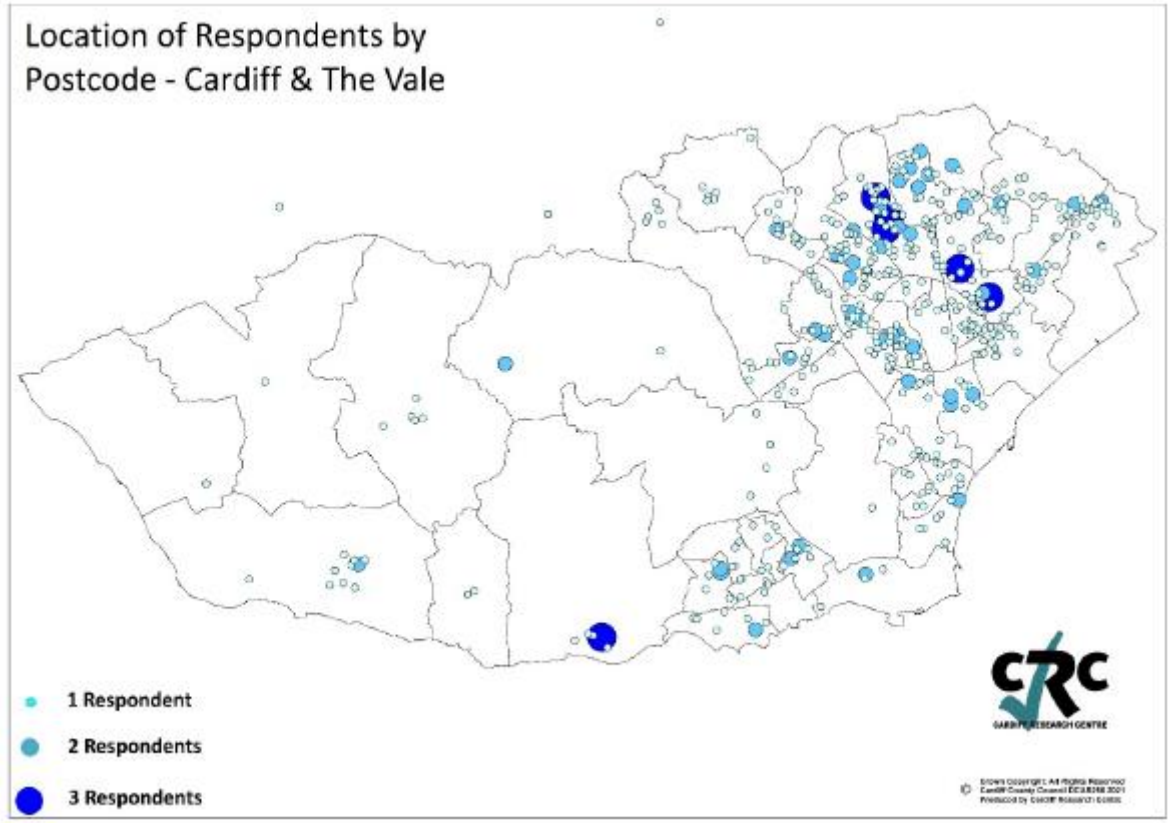
Respondents to the children and young people's survey were mostly in school. A minority (2.9%) were unemployed and not in training, education, or employment.



Twenty-six respondents of the survey answered questions relating to the Family Affluence Scale, also used by the School Health Research Network (29). Questions include whether the individual has their own bedroom; the number of computers/smart phones in the home; and the presence of a dishwasher. The Scale identified 7/26 respondents as low affluence, 14 as middle, and 5 as high affluence.

It was beyond the scope of the general public survey to formally assess deprivation/affluence, and so questions were chosen to provide an informal measure.

	A total of 482 of 661 participants stated they had a small amount of money to spend each week on themselves; 517 were able to keep up with bills and regular debt repayments; 461 were able to afford to keep their house in a decent state of repair; and 478 were able to keep their house warm in winter. Overall, 367 respondents (56%) reported being able to afford all four of these.		
6.11 People according to where they live: Consider people living in areas known to exhibit poor economic and/or health indicators, people unable to access services and facilities	No negative impacts identified of the PNA on where people live. Inequalities and deprivation are discussed with each population group in the PNA, and so by articulating key issues, it is hoped that the PNA will have a positive impact as service leads, commissioners, and others can consider how their services can reduce the identified inequalities. Some people including professional leads identified the move to online / telephone service provision as helpful for people living in more rural locations, as it made accessing services easier (see, for example, chapter 8: adult mental health and cognitive impairment). It should be noted, that many respondents observed difficulties with accessing services online/via the telephone – for example, those with sensory loss or impairment (chapter 16). **Engagement findings** Responses from the Children and Young Person's survey identified that 17/23 who answered the question lived in Cardiff, with 6 from the Vale of Glamorgan. Responses for the general public survey were mostly from Cardiff: of postcode data available, 402 were from Cardiff and 105 from the Vale of Glamorgan.	The RPB plans to redesign services to bring them closer to home. They will be seamless and be able to share information. These developments should all help people navigate the system more easily and save time travelling and repeating information.	

	 Two respondents for the Easy Read public survey answered regarding housing: due to small numbers, no disaggregated results are reported. Respondents reported having a small amount of money to spend on themselves each week, able to pay their bills and debts on time, and able to keep their house warm.		
6.12 Consider any other groups and risk factors relevant	No negative impacts identified of the PNA on other groups.	Unfortunately some planned focus groups did not take place. We	

to this strategy, policy, plan, procedure and/or service	The PNA explicitly and proactively sought the views of people who identified as being in one of the following themes: • Children and young people • Older people • Health / physical disabilities • Learning disability / autism • Mental health • Sensory impairment • Carers who need support; and • Violence against women, domestic abuse and sexual violence • Secure estate • Asylum seekers and refugees • Substance misuse • Armed Forces Service Leavers (Veterans) It is recognised that the findings are not comprehensive or exhaustive, but instead form the basis of an ongoing conversation between the Regional Partnership Board, and the residents of Cardiff and the Vale of Glamorgan.	were unable to gain an understanding of Gypsies and Travellers' views, for example. Further work should consider these gaps in our understanding of care and support needs of marginalised communities and seek to address them. We welcome comments and feedback on the PNA and the EHIA, as we seek to improve. Please send these to Hsc.Integration@wales.nhs.uk	

7. HIA / How will the strategy, policy, plan, procedure and/or service impact on the health and well-being of our population and help address inequalities in health?

Questions in this section relate to the impact on the overall health of individual people and on the impact on our population. Specific alignment with the 7 goals of the Well-being of Future Generations (Wales) Act 2015 is included against the relevant sections.

How will the strategy, policy, plan, procedure and/or service impact on:-	**Potential positive and/or negative impacts and any particular groups affected**	**Recommendations for improvement/ mitigation**	**Action taken by Clinical Board / Corporate Directorate** Make reference to where the mitigation is included in the document, as appropriate
7.1 People being able to access the service offered: Consider access for those living in areas of deprivation and/or those experiencing health inequalities Well-being Goal - A more equal Wales	Those who do not have internet access may not be able to access the online version of the PNA report. Two versions of the PNA report will be published: one for the general public with key findings, and one more detailed report for professionals, which will be available as downloadable individual chapters, or as the full report. This will increase access for all, to a report of the appropriate level of detail. Accessibility for those with sensory loss or impairment has been considered during the formatting of the document. Font, text size, and layout has	Communications regarding the publication of the PNA will be disseminated widely including through health and social care organisations and third sector organisations so that they can inform their service users. The PNA report will be available as an online, lay-friendly format, with downloadable chapters for those who prefer increased detail. Hard copies of both versions (for general public and professionals) will be available on request. Formatting (both the public and professionals version) will be accessible for screen-readers, and alt text boxes	

How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
	been decided upon in line with guidance on accessibility.	will be added for all graphs and figures.	
7.2 People being able to improve /maintain healthy lifestyles: Consider the impact on healthy lifestyles, including healthy eating, being active, no smoking /smoking cessation, reducing the harm caused by alcohol and /or non-prescribed drugs plus access to services that support disease prevention (e.g. immunisation and vaccination, falls prevention). Also consider impact on access to supportive services including smoking cessation services, weight management services etc Well-being Goal – A healthier Wales	The PNA has identified care and support needs; range and level of services including prevention for each population group.	These PNA findings will form the basis for further research and planning to further develop and improve services, and contribute to people being able to improve or maintain healthy lifestyles.	

How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
7.3 People in terms of their income and employment status: Consider the impact on the availability and accessibility of work, paid/ unpaid employment, wage levels, job security, working conditions Well-being Goal – A prosperous Wales	Deprivation, inequalities, and the Socio-Economic Duty has been considered for all population groups in the PNA. Data gaps have been identified. Respondents in engagement work identified their desire to find high quality, secure employment, and recommendations are made for more inclusive recruitment.	Recommendations in each chapter include addressing data gaps, and supporting inclusive recruitment and reasonable adjustments to promote employment. The Socio-Economic Duty was implemented in March 2021, and requires public bodies "*to have due regard to the need to reduce the inequalities of outcome resulting from socio-economic disadvantage*" (17). The Socio-Economic Duty will therefore be incorporated into the work of the Regional Partnership Board, as well as by plans and assessments utilising the PNA findings.	
7.4 People in terms of their use of the physical environment: Consider the impact on the availability and accessibility of transport, healthy food, leisure	Access to services was identified by the PNA as a key need by many of the population groups. The PNA recommends improved access to services, which will require an	The PNA will be one source of information contributing to future plans, for example, the Area Plan, or local commissioning decisions. In this way, relevant information	

How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
activities, green spaces; of the design of the built environment on the physical and mental health of patients, staff and visitors; on air quality, exposure to pollutants; safety of neighbourhoods, exposure to crime; road safety and preventing injuries/accidents; quality and safety of play areas and open spaces Well-being Goal – A resilient Wales	understanding of the barriers facing each group. Some of this detail is provided within each chapter.	from the PNA can be built upon. Some recommendations are relatively specific in terms of how information from the PNA can be used; however, the recommendations are not exhaustive and so information	
7.5 People in terms of social and community influences on their health: Consider the impact on family organisation and roles; social support and social networks; neighbourliness and sense of belonging; social isolation; peer pressure; community identity; cultural and spiritual ethos Well-being Goal – A Wales of cohesive communities	For each population group, the PNA has identified assets at an individual, community and population level which make a positive benefit to people's well-being.	Future plans including Area Plan and commissioning decisions can build upon the information contained in the PNA. For example, through promoting assets, reducing barriers, and addressing service gaps identified within the PNA in order to work towards a Wales of cohesive communities.	

How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
7.6 People in terms of macro-economic, environmental and sustainability factors: Consider the impact of government policies; gross domestic product; economic development; biological diversity; climate Well-being Goal – A globally responsible Wales	The PNA has identified key overarching factors such as the "*triple challenge*" of Brexit, climate change, and COVID-19. Each chapter in the PNA contains a section on overarching national considerations (for example, new legislation, or guidance). However, international context has not routinely been included within the PNA.	The PNA recommends that policy makers should use the Triple Challenge lens to inform policies and strategies around issues impacted by Brexit, COVID-19 and climate change, such as food systems and diet (18) Future plans and strategic decisions should contextualise the information within this PNA and align findings with overarching macro-economic, environmental, and sustainability factors.	

Please answer question 8.1 following the completion of the EHIA and complete the action plan

8.1 Please summarise the potential positive and/or negative impacts of the strategy, policy, plan or service	No negative impacts of the PNA on any of the protected or health characteristics were identified. However, people with some characteristics were underrepresented within engagement work in this iteration of the PNA, and so their views may not have been captured. These gaps in the completeness of the engagement work should be borne in mind when findings from the PNA are utilised within local plans and decisions. Future engagement work conducted by the Regional Partnership Board will build upon these beginnings and proactively consider how to most appropriately hear seldom heard voices. The PNA has identified a number of novel findings and data gaps compared to the previous publication. These findings can now be further investigated and data gaps addressed in order to plan the care and support services for Cardiff and the Vale of Glamorgan now, and in the future. Future iterations of the Population Needs Assessment will take a hybrid approach, so that the information contained within it can be more up to date. This will comprise a rolling update of quantitative data, and periodic refresh of qualitative data from engagement work. Therefore, this PNA report and Equality & Health Impact Assessment (EHIA) should be considered a first iteration; the beginning of an ongoing conversation between the Regional Partnership Board, and the residents of Cardiff and the Vale of Glamorgan. **We welcome comments and feedback on the PNA and the EHIA, as we seek to learn, improve, and develop. Please send these to Hsc.Integration@wales.nhs.uk**

Action Plan for Mitigation / Improvement and Implementation

	Action	Lead	Timescale	Action taken by Clinical Board / Corporate Directorate
8.2 What are the key actions identified as a result of completing the EHIA?	There is a real commitment and enthusiasm in the RPB to ensure that diverse voices are reflected in all we do. Areas of under-representation in terms of engagement work have been identified. Future engagement work will proactively consider how best to hear seldom heard voices so that their needs can be understood and met.	Senior Communications and Engagement Officer; Cardiff and Vale Regional Partnership Board	To commence by March 2022	
8.3 Is a more comprehensive Equalities Impact Assessment or Health Impact Assessment required? This means thinking about relevance and proportionality to the Equality Act and asking: is the impact significant enough that a more formal and full consultation is required?	No, however, plans, strategies, and other decisions developed from information contained within the PNA will require an Equalities Health Impact Assessment to be conducted	Leads of individual assessments and plans	According to timescale of the individual assessments and plans	

8.4 What are the next steps? Some suggestions:- • Decide whether the strategy policy, plan, procedure and/ service proposal: ○ continues unchanged as there are no significant negative impacts ○ adjusts to account for the negative impacts ○ continues despite potential for adverse impact or missed opportunities to advance equality (set out the justifications for doing so) ○ stops. • Have your strategy, policy, plan, procedure and/or service proposal approved • Publish your report of this impact assessment • Monitor and review	Use results of PNA as a basis to undertake further engagements where we are developing plans and making decisions Support the RPB's overarching communications and engagement strategy, which includes the following outcomes: 1. A citizen's panel that can help represent and reflect the diverse voices of older people 2. Ensuring adults with disabilities coproduce and drive our work in this area (this will often use existing forums) 3. Resources and engagements that give children and young people a voice and a way to directly influence the policies and decisions that affect them.	Senior Communications and Engagement Officer; Cardiff and Vale Regional Partnership Board	To commence by March 2022	

References

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