Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
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Health, Social Care and Sport Committee inquiry into the impact of the Social Services and Wellbeing Act 2014 in relation to carers

Contents

Introduction

Carers Trust Wales exists to improve support, services and recognition for unpaid carers in Wales. With our Network Partners – local services that deliver support to carers – we work to ensure that information, advice and practical support is available to carers across the country.

During 2017-2018 the Carers Trust Wales Network reached over 34,000 carers, employed 480 staff and was supported by 475 volunteers.

Carers Trust Wales delivers practical support and information to carers and to those who work with them, including: schools, social workers, nurses, pharmacists and physiotherapists. We also seek to influence decision-makers, the media and the public to promote, protect and recognise the contribution carers make, and the support they deserve.

We welcome the opportunity to contribute to the Health, Social Care and Sport Committee's inquiry into the impact of the Act. We recognise this inquiry as an opportunity to ensure that implementation meets the aspirations of the Act.

Key recommendations

Make carers services sustainable

Welsh Government must ensure a sustainable and proportionate funding base for generic carers services. This will ensure that more carers are able to access preventative support, rather than having to access their right to formal support under the Act once at crisis point.

Make carers needs assessments meaningful

Welsh Government must give clear direction to local authorities that once known to them, carers must be actively offered a Carers Needs Assessment. Welsh Government must also work with carers, professionals and the third sector to understand where this is not happening. Assessments must be delivered in a timely way by an appropriate professional with the intention of delivering a support package that enables carers to live healthy and connected lives in a way that is meaningful to them.

Make service provision equitable throughout Wales

Welsh Government must utilise Population Needs Assessments and ensure a strategic approach to creating sustainable and impactful means of supporting carers through Regional Partnership Boards and other joined-up commissioning processes.

Consistent and transparent monitoring and evaluation of commissioning processes, at a regional and national level, should be facilitated by the development of a national minimum suite of services for carers that should be in place within each local authority. Whilst models for delivery may vary, there are specific services that should always be available to carers.

Make a life alongside caring achievable

Many carers are unable to access appropriate breaks from caring, both to live healthy and fulfilling lives and to reach their potential in terms of education and employment. All carers should be entitled to minimum breaks during which the full cost of replacement or respite care is covered.

We would recommend that carers be entitled to a minimum amount of respite for rest and relaxation on top of any replacement care they may need to enable them to do the things that matter to them on a weekly basis, such as: employment, education or socialising. We believe strongly that Welsh Government should carefully review the barrier eligibility criteria currently present for carers achieving a life alongside their caring role.

Make every contact count

Education, health and social care professionals must all be up-skilled and empowered to identify carers and to refer them on for appropriate support, information and advice. Systems and processes must encourage and enable information sharing and, particularly in the case of young carers, a joined-up approach to understanding and meeting their needs. Building on up-coming Young Carer ID card pilot schemes, Welsh Government should consider encouraging all local authorities to adopt recognition schemes for carers of all ages to act as a facilitator for streamlined information-sharing between organisations and improvements in carer recognition amongst all professionals.

Make evidence-based decisions

At a national level, greater investment needs to be given to developing the evidence base to inform outcome focused commissioning of services. Welsh Government must commit to funding new Wales-based research around unpaid caring and the impact it is having on different groups in society. Additionally, Welsh Government should ensure that research priorities are aligned with more robust and transparent monitoring and evaluation processes to ensure that commissioning processes result in the most impactful services.

Make investment proportionate

Welsh Government must invest in developing appropriate capacity within the third sector and within Welsh Government to develop, scrutinise and utilise an appropriate evidence-base regarding the needs of carers and how they can best be met, to inform decision making at a national level.

It is essential that national third sector organisations are funded in a transparent and sustainable way to engage with professionals, carers and carers services to deliver practical solutions to overcoming the barriers to the successful implementation of the Act.

Delivering good services for carers

Carers Trust Wales has identified 6 common factors that contribute to the development and delivery of good services for carers, in keeping with obligations under the Act and the Ministerial priorities for carers:

1. **Involvement of carers in the design and development of provision to meet their needs -** Carers are experts in their own lives and they are key to identifying what will make the most difference to them and those they care for. It is vital that their involvement is meaningful and that they are fully supported to engage effectively.

2. **A diverse and sustainable funding base for carers services -** This model of funding ensures consistency and continuity of service provision for carers. It will also support the provision of a diverse range of services which are key to meeting the varied and often complex needs of carers.

3. **A clear focal point from which carers and professionals can access up to date information, advice and support -** Carers consistently state that, despite clear rights under the Social Services and Wellbeing (Wales) Act 2014, it can be difficult to access information and support. Our evidence shows that having an easily identifiable point of contact, whether that be a physical building, a main telephone line, an outreach worker or combination of these things, is key in ensuring carers are able to access the support they need. Additionally, these services help to facilitate access to the views of the carers they support helping to improve engagement, planning and service development.

4. **A proactive approach to identifying and supporting all carers and raising the profile of caring amongst professionals and communities -** The term carer is not a description with which all those with caring responsibilities identify. Many carers are harder to reach and therefore it is key that a proactive approach is adopted to reach out to carers - and those that work with them - to raise the profile of caring, improve identification and to ensure easy access to assessment and support.

5. **Parity of provision across geographical area served** - It can be more difficult for carers in remote or rural areas to access support. Parity of provision is key to ensure that all carers are able to access the support they need. Services must adapt their model to meet need and commissioners must factor in additional costs for service delivery in rural areas such as additional travel costs for domiciliary or respite care.

6. **Working collaboratively and in partnership -** Services must actively identify and develop partnerships and collaborative working with relevant organisations and existing services to promote a joined-up approach, reducing duplication and promoting choice. Clear pathways must be developed to ensure that the needs of carers are met by the most appropriate service in a streamlined manner.

Impact of the Act on carers

Strong legal rights delivered through the Social Services and Wellbeing (Wales) Act 2014 have yet to be consistently delivered to the spirit and letter of the law at the point of implementation.

Assessment of need

Carers Trust Wales and our local Network Partners, have been made aware of waiting lists for carers needs assessments, low levels of awareness amongst carers of their entitlement to an assessment or a clear understanding of when an assessment has been undertaken. Where carers are aware of their rights under the Act they often identify that this knowledge has been gained through peer-to-peer support rather than through formal engagement with statutory services.

The inconsistent interpretation of rights delivered by the Act and the processes that need to be developed and embedded to deliver against them, have negatively impacted on the quality and consistency of support available to carers. Some of our Network Partners report that even within a local authority, social workers can be using different forms and approaches to either delivering a Carers Needs Assessment or deciding upon whether an assessment is necessary.

We are particularly concerned that where councils are using “What Matters” conversations as an assessment process they may not be meeting their statutory duty to offer and undertake a Carer’s Needs Assessment’. The Act encourages relevant proportionate assessments, but councils may be acting unlawfully if carers do not know the legal basis of the conversations or assessments they are having.

Carers and carers services often report that when assessing need, social workers can reference limits to the amount of support available. For example, suggesting to carers that the nature of their caring role would only make them eligible for a specific amount of support. This approach is contrary to the intention of the Act in terms of enabling an approach that recognises the very individual nature of support each carer may require.

Some of our Network Partners, who are involved with the delivery of assessments, have strongly illustrated the value of involving third sector organisations in the process of assessments. Carers may be more comfortable speaking with a third sector professional about their needs and often third sector workers have a better knowledge of existing support services and groups. Whilst Carers Trust Wales does not recommend a specific approach to understanding and meeting carers needs, we would recommend that more needs to be done to ensure that the process is transparent, delivered in a way that empowers carers and undertaken by a professional that has adequate knowledge of carers rights and the services that may be most appropriate to meet carers’ needs.

Additionally, some carers have identified that the process of having needs assessed through a formal process, often involving a social worker who is involved with the person they care for, is a barrier to them accessing their rights. Many, particularly in the case of parent carers, will be reticent to discuss struggling with their caring role; fearing negative repercussions if they admit to needing additional support.

Whilst we recognise the relevance and importance of assessments as defined by the Act it is important to recognise that not all carers want an assessment – there are still concerns with the name ‘assessment’ and fears around getting involved with statutory services. If uptake of assessments is to be improved this needs to be addressed.

Additionally, not all carers will need an assessment, particularly if they access support via a local service as their needs have already been met. Therefore, it is important that the breadth of local carers services is fully understood as a mitigating factor for the creation of needs as defined under the Act. Reducing funding for preventative services will inevitably and unnecessarily create more needs that will have to be met more formally via assessment at the point of crisis. It is essential that investment and commissioning processes truly recognise the preventative value of carers services and avoid necessitating more formal approaches to identifying and meeting carers' needs.

Whilst some carer support workers report that the Act has helped to challenge and influence statutory decisions about the availability of support, many reflect that there remains a fundamental lack of support services. As a result of this we are aware that some social work teams are reticent to undertake assessments for carers when they know that there simply aren't services in their area to signpost them to. Carers Trust Wales is concerned that levels of unmet need may be significant and that current processes do not capture the number of carers discouraged or unable to access an assessment of their need.

The **Care and Support (Eligibility) (Wales) Regulations 2015**[1] sets out eligibility criteria and the requirement for a National Assessment and Eligibility Tool to ensure a consistent approach to assessments and recording information. Determination of eligibility flows from assessment. However, regulations make clear that in making a determination of eligibility there should not be an over-reliance on any voluntary caring arrangements. Local authorities must ensure that the ability of the carer to provide care is sustainable and that they comply with their general duty to promote the wellbeing of the carer and the person cared for.

In some parts of Wales, parent carers have found themselves ineligible for a carers needs assessment because their child is awaiting diagnosis or not currently in receipt of services. In these cases, parents are having to wait more than a year without being eligible to have a needs assessment. In some areas, once these carers become eligible, the waiting times for an assessment can be upwards of a year. We are aware of cases where some carers have been advised that the local authority has no suitable route for them to access a carers needs assessment unless their child is eligible for a specific type of local authority led support. Copies of correspondence to this effect can be provided confidentially to the committee.

This year we have seen examples from across Wales of eligibility criteria for services being set at critical and high-level need. This sets a high bar for when people with care needs can access services, which has a knock-on effect on the whole family, including carers.

We have also identified examples where criteria for services have changed with local authorities reducing the availability of specific services. For example, this includes no longer commissioning calls just to support the taking of medication. This type of call can be particularly useful for those in early stages of dementia and of course their carer.

Particular challenges for assessing the needs of young carers

There is a lack of clarity as to the extent to which assessments include consideration of whether the level of care provided by a young carer is appropriate.

The legislation is very clear in England[2] and Scotland[3] in stating that young carers should not be providing "inappropriate" levels of care. The Scottish statutory guidance provides more detail on how to identify whether the level of care provided by the young carer is inappropriate, and that care provided by statutory agencies on a more permanent basis to relieve the young carer of inappropriate caring responsibilities and ensure that the cared-for person's needs are being met would not be considered "replacement care".

In Wales this assessment of whether the young carer is providing inappropriate care is only provided for in the Code of Practice (part 3, Section 15): "the assessment must have regard to his

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[1] **http://www.legislation.gov.uk/wsi/2015/1578/pdfs/wsi_20151578_mi.pdf**
[2] Children and Families Act 2014, Section 96 (7)
[3] The Carers (Scotland) Act 2016, Section 15(c)

or her developmental needs and t the extent to which it is appropriate for the child to provide the care".

However, it is unclear what is deemed appropriate or what action should be taken to remove the responsibility for providing inappropriate care from young carers. There could be potential benefit from revising the Code of Practice to provide more clear guidance for Local Authorities in this regard.

It may be possible to remove inappropriate levels of care from young carers through joint assessments. Although the current statutory guidance allows for joint assessments, it is not clear to what extent these are combined for young carers and those they care for.

Professional awareness, information sharing and signposting

A key issue identified by carers and carers services is the continued lack of knowledge amongst a range of professionals, including social workers, those who work in schools and healthcare professionals, about carers' rights. Beyond a lack of ability to appropriately signpost for support, there is ongoing concern that too many professionals fail to identify carers or to have appropriate information-sharing mechanisms to ensure holistic packages of support are delivered for carers.

This is particularly apparent in the case of young carers. Our Young Carers in Schools pilot clearly demonstrates some excellent practice within school environments in Wales in identifying and supporting young carers to be successful and happy at school. However, even some of the most carer aware schools in Wales still do not have links with local carers services or mechanisms to signpost carers to preventative services or for a formal assessment of their wider support needs beyond an education setting.

Where carers services have engaged with schools, colleges, universities or in primary and secondary care environments, professionals' ability to identify and appropriately support carers are significantly improved. In particular, having specialist support workers for carers within hospitals is an efficient way to support clinical staff and carers alike. There is a need for funding to be given to support the roll out of resources available to support professionals to work with carers more effectively, such as:

- **The Triangle of Care, Carers Included: A Guide to Best Practice in Dementia Care, Wales Edition**
- **Supporting Young Carers in Schools: A Step-by-step Guide for Leaders,Teachers and Non-teaching Staff**
- **Supporting Students with Caring Responsibilities: A Resource for Further Education Providers to Help Young Adult Carers Succeed in Further Education in Wales**
- **Training resources for social care teams**

Additionally, the introduction of the Act has had some unintended consequences in terms of the level of responsibility various public-sector organisations consider themselves to have in relation to carers. Whilst Regional Partnership Boards potentially facilitate a step forward in joint-working it remains clear that in practice the Act has served to dilute what the Carers Measure had set out in terms of Health Board's responsibility for carers.

There is a genuine concern that highly-valued, carer-lead roles will not be prioritised within Health Boards once transitional monies come to an end.

Meeting carers' needs following assessment

Carers and some carers services report that where needs have been identified through an assessment, there are often not adequate resources to meet those needs. It is felt that in some cases inordinate pressure is put on carers to identify ways of meeting their own needs, such as through accessing paid for services or asking family or friends for support. In particular, carers identify that there can be a lack of joined-up thinking in terms of how needs are met. For example, where respite or replacement care is given to enable a carer to maintain employment they may find themselves unable to access additional respite or replacement care to facilitate rest and relaxation. In effect, carers are being asked to choose between their needs rather than have them all met.

Carers services report that when signposting carers for assessments they feel the need to manage carer's expectations. It can be challenging for services to encourage carers to have their needs formally assessed when they are aware that the types of support they may need are not available.

It is important to recognise that when considering how best to support carers the intrinsic link between the carer and cared for is fully recognised. Often, if the needs of the cared for are appropriately met, many of the challenges faced by carers will be significantly mitigated. It is important that the needs of carers are not considered in isolation of the individual that they care for. Often it is the lack of appropriate services for the cared for that increases the pressure on carers. For example, a lack of facilities for children with disabilities during weekends and school holidays will impact greatly on parent carers.

Linked to this is the fact that in many cases the cared for must agree to have a service (in order for the carer to have a break) and not all do. More frequently the cared for must agree to pay where charges have been implemented, which creates another barrier for carers.

Additionally, it is important that carer accreditation (as referenced in Prosperity for All) is delivered in a way that is ambitious for carers, recognising skills and opening up opportunities – guarding against pigeon-holing carers skills within a social care context. Whilst we recognise the importance of providing carers with opportunities to develop their skills and have them recognised, it is essential that no carer feels obliged to under-take training or to deliver types of care they are uncomfortable delivering.

Carers Wales' Track the Act briefing provides clear evidence to support our concerns regarding the extent to which the Social Services and Wellbeing (Wales) Act 2014 is ensuring that Carers' needs are being identified and met in all Local Authorities across Wales.[4]

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[4] https://www.carersuk.org/files/section/5763/track-the-act-briefing-2-final-draft-year-1.pdf

Wider provision of support for carers

Carers’ own health and wellbeing needs are often exacerbated or caused because of their caring role.[5] If a carers’ health continues to deteriorate it will have a negative impact on their own wellbeing, and also the wellbeing of the person or people they care for. It may also have an impact on health and social care services as they may be required to provide unplanned, emergency care to the people with care and support needs.

Despite the Act setting out clear responsibilities in terms of preventative services:

“Part 2, Section 15 places a duty on local authorities to provide or arrange for the provision of a range of preventative services to prevent or delay people’s needs for care and support.

“A relevant partner, such as an LHB, must comply with a request to cooperate in relation to the delivery of preventative services, unless to do so is incompatible with their own duties.”

There remains a lack of join-up in the commissioning of specialist and generic carers services and an expectation that the third sector will be able to innovate and sustain preventative services, upon which the statutory sector relies, without appropriate public-sector investment.

There are limited funding options for third sector organisations seeking to support carers, which consist of charitable trusts and foundations, European funding, lottery funding, and fundraising. All of these approaches require investing in appropriate resources and management to facilitate these funding approaches.

In terms of charitable trusts, there are very few that have a remit for carers. Outside of other, larger scale funders, i.e. Big Lottery Fund, Lloyds Bank Foundation and Triangle Trust, The Waterloo Foundation is one of the only funding foundations in Wales that has the remit specifically for carers and availability of funding for large scale projects.

Funding is highly competitive and can be a long process, taking months for a decision. This is an issue for any long-term planning within charities, where many do not have the time or capacity to complete the applications.

WCVA offers some of the information about the remits of funders, however it is usually up to the individual organisation to do this time-consuming research. There is no straight-forward list of trust and foundations identifying their remit for funding. Some local authorities have these available however, in most cases it will be up to the organisation to do this research.

Carers Trust Wales strongly recommends that Welsh Government has an accessible list of funding sources available for charitable organisations which identifies the funding opportunities along with funding remit.

The challenges facing unpaid carers in Wales are significant and have growing potential to impact on our public services if they are not robustly addressed. The demand on health and social care services is growing and is projected to grow further still. If just a small percentage of carers stopped caring, health and social care services could easily become unsustainable. Supporting our unpaid carers is the definition of a preventative integrated health and social care service.

We recognise the potential of Regional Partnership Boards (**addressed below**) however it is important to recognise the scale of support services provided for carers that are developed and funded solely by the third sector.

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[5] http://static.carers.org/files/in-poor-health-carers-uk-report-1674.pdf

Carers Services – delivering the preventative agenda

We are proud of the services provided across the Carers Trust Wales Network and their impact on carers and those that work with them. However, in order for carers services to have the most impact they need to be funded in sustainable ways that fully appreciate both the importance of innovation and the importance of funding long-term mainstream services. There is a clear and growing need for additional investment in social care across Wales with local authorities having felt the pressure of reducing budgets over many years.

Within our Network, we have recent examples of closures, mergers and the cessation of services as a result of the increasing local financial pressures. The particular challenges that have been faced are often as a result of commissioning processes that don't sufficiently prioritise achieving the wellbeing outcomes of those they are designed to support.

As employers, all of our Network Partners have seen rising salary costs in line with rises to the National Living Wage. Whilst fair and appropriate remuneration is, of course, important, this increase alongside the costs associated with training and developing the workforce has made the cost of delivering services substantially higher. This increase in cost has not been recognised by all commissioners, with many service providers themselves often facing real-term cuts year on year.

As providers, Network Partners have experienced a range of challenges to being commissioned in a way that enables them to continue to deliver a high-quality service for carers and those they care for in a way that is sustainable.

To develop appropriate and impactful services, it is important that when service specifications are developed the third sector are engaged as equal partners in determining what support is needed and how this can best be delivered to the individual. Many of the additional benefits that can be gained as a result of providing care within the home, such as signposting to other services, providing assurance and support to the family and delivering appropriate and compassionate care are often curtailed by seemingly arbitrary limits on call times.

Within our Network we have had examples where Partners have been commissioned by Local Authorities to deliver domiciliary care at a rate that is below what it costs to deliver the service. This has resulted in some Network Partners handing contracts back, with others facing significant financial difficulty as a result.

Other examples, in terms of financial disincentives to providing domiciliary care, include the cost of travel between calls in rural areas. This cost is both the pay for the care worker and the actual cost of travel, which can be prohibitive in some rural areas. We have numerous examples from within our Network where Partners have had to cease providing care to those in rural or remote areas because it is not financial viable to do so under the current system.

Local authorities can and have changed their method and timing of payments, sometimes moving from in advance to in arrears. One of our Network Partners reports that if they had not had sufficient reserves to withstand a short-term shortfall because of a change in payment methods and process they would have risked closure.

As more people with increasingly complex needs are choosing to live at home, the skills required to deliver this type of care are growing. Upskilling the workforce presents challenges, both the time and cost implications of doing so, and the challenge of retaining them within the social care sector once they have been trained. Training and recruitment costs can be significant for care providers and are often not accounted for in commissioning processes.

The regulations under the Regulation and Inspection of Social Care (Wales) Act 2016 are a welcome move towards the creation of a recognised and highly-skilled registered workforce. While our Network supports the professionalisation of the workforce, we are concerned by the potential to add pressure to the ability to recruit and retain the workforce on current terms and conditions. These measures will undoubtedly create additional costs for the sector in terms of training, administration and registration fees.

To deliver against legislative and policy obligations, and to ensure high-quality services for carers, commissioners must ensure that carers services are accessible, responsive and relevant. Developing and implementing integrated service delivery models that work with and across public, statutory and third sector organisations is essential to achieving these aims.

In England, commissioning of Integrated Carers Hubs has become **recognised** as good practice in enabling carers to access support through a single point of access, enabling councils to meet their statutory obligations under **section 4 of Care Act 2014**.

In Wales, the model of carer service delivery is still largely disaggregated, relying on goodwill within and between the main service providers. Many local authorities use the Single Point of Access (SPoA) to help meet obligations under the Act.

Consideration needs to be given to the cost benefit of properly mapping, commissioning and resourcing appropriate services throughout Wales.

Rural challenges

Meeting the needs of carers in rural Wales is particularly challenging. Those challenges were summarised in a recent **report** from the Welsh NHS Confederation that provided an insight into providing health and care services in rural parts of Wales and included:

- Achieving seamless access to services
- Overcoming challenges linked to small population bases
- Delivering services sustainably
- Addressing loneliness and isolation
- Recruiting and training the required workforce
- Ensuring provision of service in a person’s preferred language, can all relate equally to service provision for carers

There are increased costs when providing any services for a large, sparsely populated area, as it is more difficult to achieve economies of scale. Given that many carers tell us that they prefer face to face interaction, the need for a greater number of staff per head of the population in rural areas is clear.

The report by the Welsh NHS Confederation recommends the creation of generalist workers; frontline professionals with the skills and capabilities to take care of a persons’ health and social care needs. This has the benefit of reducing the number of professionals from separate agencies making repeat visits to a person’s home (or local community centre) for the same outcome. This needs forethought, training and closer working relationships between health and social care services to achieve, but it is an approach to meeting a growing carer need that is worth further consideration. It has the potential to reduce duplication and to offer a more seamless service delivery.

Respite care

As outlined above, we know that carers value a range of services provided by statutory and third sector organisations. However, it is apparent that carers particularly value flexible breaks and respite care. Breaks can help to ensure that the carer remains well and is able to continue to provide care.

Despite this, services across Wales that provide quality breaks and respite for carers have been squeezed, and commissioning has focused increasingly on price rather than quality. We have also seen a significant decrease in individuals accessing day services or respite care since 2012[6].

It is clear that further funding is needed for respite and short breaks. This must be ring-fenced to Local Authorities, and part of a long-term funding stream. Carers Trust Wales has been funded by Welsh Government to undertake a Wales-wide study to investigate the ways in which flexible support (including emergency support and short breaks) could best be provided longer term. It is important that these report findings are used to deliver a step-change in the funding and commissioning of appropriate respite services for carers across Wales.

In Scotland the local authority, when determining which support to provide to a carer, must consider in particular whether the support should take the form of, or include, a break from caring[7]. A local authority must also have regard to the desirability of breaks from caring being provided on a planned basis. There is also a specific requirement that the “Young Carer Statement” should contain information about whether support should be provided in the form of a break from caring. Each local authority is required to publish a ‘Short Breaks Services Statement’.

There is also a requirement for local authorities in Scotland to waive charges for services provided to carers under Section 24 of the Act[8]. This includes support in the form of a break from caring and “the charge to be waived covers the cost of all the element of the break the local authority has decided to provide to meet the carer’s identified needs (having considered its local eligibility criteria)”[9]. The statutory guidance sets out some complex considerations in terms of whether providing care so the carer can take a break constitutes chargeable “replacement care” or not chargeable, as it is integral to allowing the carer to take a break. There are also provisions for the carer and cared-for person to have a break together with additional support for the cared-for person and in such cases charges would only be waived for cost of the break for the carer.

In Wales there is no specific requirement for respite to be provided. There does not appear to be any specific provision for respite to be considered in the legislation or the associated guidance. The introduction of the Social Services and Wellbeing (Wales) Act 2014 resulted in the revocation of the only legislation specifically providing for breaks (for carers of disabled children)[10].

Commissioning to meet carers’ needs

Regional Partnership Boards and regional funding of services

Whilst Regional Partnership Boards and the Social Value Fora that sit alongside them are, in theory, well placed to ensure that support needs are identified and met in innovative and creative ways – there is still significant work to be done to make this aspiration a reality.

There are growing concerns relating to the lack of meaningful representation of the third sector and carers at regional partnership board level. Lack of support, limited financial autonomy and opportunity to strategically plan are all factors that contribute to a power imbalance that ultimately impacts on the quality and appropriateness of services commissioned.

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[6] https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

[7] The Carers (Scotland) Act 2016, Section 25, Section 15, Section 35

[8] The Carers (Waiving of Charges for Support) (Scotland) Amendment Regulations 2018

[9] Carers (Scotland) Act 2016 Statutory Guidance, Section 3.3

[10] The Breaks for Carers of Disabled Children Regulations 2011 were revoked under the 2014 Act by the Consequential Amendments) (Secondary Legislation) Regulations 2016

The fact the third sector are not budget holders in the same way as statutory services results in them not being treated as equal partners when it comes to commissioning and planning of services.

Whilst carers services are struggling to maintain services because of a lack of funding it remains that statutory services continue to rely on them as a main referral source to support carers.

Having met with a number of Regional Partnership Board carer representatives across Wales, Carers Trust Wales and Carers Wales identified a number of concerns including:

- there remains a very mixed level of support and engagement across Wales
- contributions by carer representatives are often hindered by regular use of jargon and acronyms
- meetings can be very formal, intimidating, high level and fast-paced
- the size and complexity of the Board papers can often be overwhelmingly with little preparation time
- It is difficult for one carer representative to be truly representative of different areas within a region

Delivering Transformation in Wales: Social Services and Wellbeing (Wales) Act (SSWBA) 2014 and the role of the Third Sector outlines experiences, issues and concerns from a third sector RPB representatives and County Voluntary Councils perspective with regard to how the Act is being implemented across Wales. Carers Trust Wales supports the key findings of this report.

Additionally, we are concerned that Regional Partnership Boards are failing to take an appropriately evidenced-based approach to planning carers services relying too greatly on national third sector organisations to provide the scrutiny needed to ensure the right decisions are made. An example of this occurred in Autumn 2017: Carers Trust Wales were given the opportunity, alongside other stakeholders, to provide feedback on a carers service mapping report that had been undertaken by the North Wales Collaborative on behalf of the Regional Partnership Board. The mapping exercise represented an important opportunity to understand current service provision, demand and options for the future.

Whilst we welcomed the opportunity to provide feedback following the initial draft report, we had significant concerns, which were shared by others within the third sector, about the accuracy, representativeness and scope of the mapping exercise.

The purpose of carers service mapping report was to facilitate discussions between partners organisations to ensure robust service arrangements were in place to meet the requirements and aspirations of the Act.

It was anticipated that significant weight would be placed on this report by the Regional Partnership Board and ultimately commissioning of future carers services. It was widely felt that had the mapping exercise involved the third sector in the design and planning process the data collected and presented would have been considerably more accurate.

The main concerns outlined were:

- The significant lack of insight reflected within the report regarding the range, breadth and depth of the generic carer service model, including regulated care, specialised tasks and information, advice and support services; the report provided no context or summary of the funding environment for carers and carers services across north Wales
- the findings set out in the North Wales Population Assessment (PNA), upon which this report was meant to build, had either been diluted or ignored
- Detailed information within the PNA on what services carers wanted was underutilised

- Contrary to the findings of the mapping report, the review of services outlined in the PNA concluded that there is provision in north Wales to meet many of the needs of carers although this is not consistent across the region
- Funding for carers services from local councils and health boards varies significantly from county to county resulting in varying levels of support for carers across the region, an issue the report fails to recognise

The report recommended one respite service contract across North Wales without sufficient evidence that this would deliver the best support to carers and the people that they care for. This went against the evidence provided within the PNA advocated an increase in range, availability and flexibility of respite and short breaks for carers.

Ultimately the report exposed a lack of depth, insight and knowledge from a statutory lead perspective when it came to accurately reporting the needs of carers and support services, emphasising the need for third sector inclusion at all stages of planning. As a result of our feedback the report was dismissed and a more collaborative method of engagement was adopted.

We would recommend that RPBs ought to issue a clear mandate as to how the third sector (specifically, local carer strategy or partnership boards) must be involved in the planning process. We would also suggest that consideration should be given as to whether the third sector could be directly delegated a budget, in the same way as statutory partners.

ICF and other carer-focused allocations

We remain concerned that the planning of ICF spending is rarely agreed with the third sector. Carers services are often the last to receive allocations and at best are provided only with limited opportunities to apply and draw down monies.

The variation in timing and distribution of allocated monies from Local Authorities and Local Health Boards varies widely and, as such, not all third sector organisations receive the same opportunities. As well as late funding confirmation, late guidance is also a cause for concern.

Given that the majority of preventative services are delivered by third sector and often developed in response to identified need, it is disappointing that planning for such services does not have sufficient third sector input.

There are no general functions directed at the third sector within Part 9 responsibilities and, as a result, they can often be overlooked as equal partners in the early strategic planning discussions which are critical to the long-term sustainability of preventative services.

Correspondence and notification of funding to the third sector, either directly or via CVCs, in many instances is very short, leaving just a few weeks for bid submissions and a limited window for service delivery.

According to the ICF guidance (point 23) “ICF capital and revenue funding is available for the financial year in which it is allocated by Welsh Government”. However, this only works effectively when allocations are timely - if there is a delay in the funding release date then this should be reflected in the date by which the monies need to be spent and extensions granted. In 2016/17 the second tranche of ICF funding wasn’t confirmed until September 2016 yet the spend deadline remained March 2017, leaving just 6 months for delivery. In some areas, to allow for expressions of interest and assessment panels to be established, service delivery was reduced to a period of just 4 months.

Whilst this has, in some instances, improved over the last year, there are ongoing issues. As a recent example of poor practice, in one region, ICF monies allocated under the Dementia Action Plan gave just 3 weeks for bid submissions and a 6 month window for service delivery. This is not an efficient method of ensuring that ICF monies are spent in the most coordinated and impactful way possible.

Another example of how the process of deciding on ICF funding can be unfair for the third sector is as follows (from a Network Partner of ours, edited to preserve anonymity at their request):

> “We have just been awarded some of the money for xxx in xxx, with hopefully more to follow, but this has been an amazingly long, difficult battle to have the bid heard. 1 hour before the meeting I was phoned to say that I was not allowed to attend the meeting, despite it being our bid, our evidence, our expertise, that wrote the bid. Their reason, because the CVC were there.
>
> The disproportionate nature comes in to play when a local authority or health board send the most appropriate team member to present their case, but the third sector are not able to.”

There are a number of areas that could be strengthened within the existing ICF guidance to help promote and improve third sector and carer involvement. For instance, the guidance suggests that Regional Partnership Boards should involve primary care clusters in developing and agreeing spending plans where appropriate to avoid duplication and to ensure investment from the ICF and the primary care fund is complementary. Carers Trust Wales would recommend that equally Regional Partnership Boards should also develop clear mechanisms to enable a similar process with carers services and carer strategy groups.

There is a need to strengthen and clarify regional forums and to give a clear mandate to facilitate meaningful partnership working. The Carers Officers Learning and Information Network (COLIN) is one such National mechanism that could be better utilised. Whilst currently open to Health Boards it remains largely a local authority-lead forum.

In our view, the carer focus at Regional Partnership Board level is at risk of being diluted due to the level, complexity and breadth of issues it needs to govern. Local Strategic Carers Partnership arrangements are working well but the impact of that is losing focus at Regional Partnership level.

Welsh Government need make full use of regional governance processes, i.e. The Regional Partnership Boards’ main function is to be a conduit for integrated working and pooled budgets for all carer services. It is unfortunate that the recent respite grant bypassed this process and was issued directly to local authorities.

Further clarity is urgently needed around the future of respite funding and how it will be managed. Our Network Partners have voiced concern that once taken into Revenue Support Grant this money will no longer be protected for carers.

There is a lack of clarity as to whether the formal Integrated Care Fund (ICF) agreements submitted by each region are made public. It is essential that there is a Wales-wide clear and transparent process relating to the publication of information regarding ICF spends.

Service models

Regardless of the service model used, it is important that the services commissioned to support carers:

- Meet obligations under the Social Services and Wellbeing (Wales) Act 2014
- Deliver the Wellbeing Objectives under the Wellbeing of Future Generations (Wales) Act 2015
- Deliver against the Ministerial priorities for carers

It is also important that services adequately reflect carers’ views, experiences and preferences.

We would advocate using the guidelines **outlined above** to assess the appropriateness of service design as they reflect legislative obligations, good and emerging practice and the views of carers.

The development of services within each region ought to be based on the needs identified through population needs assessments, reflecting on the thematic findings of the national needs assessments. However, commissioners and service providers must be mindful of the low levels of self-identification amongst carers and potential levels of unmet need that has yet to be identified.

When developing new service models, it is important that carers, the third sector and the public sector work together through Regional Partnership Boards to fully assess existing provision and to understand its effectiveness, including the sustainability challenges facing carers services themselves.

Building upon a clear understanding of existing provision and the extent to which it meets current and anticipated future need, services should be commissioned in a way that reflects the importance and value of:

- Investing in ensuring the appropriate support mechanisms are in place to enable carers to engage effectively with approaches to co-production
- Integrating new services with existing provisions and pathways
- Evolving a whole-system approach which is designed to ensure increased identification of carers at the earliest possible opportunity in their caring journey
- Developing support services that reflect the needs of carers
- Identifying clear and appropriate mechanisms for information sharing, both with the carer and the organisations and professionals that are best placed to support them
- Supporting a plurality of providers to have the skills to engage with tendering processes.
- Developing measurable targets and outcomes focused on providing high-quality and appropriate support to a significant proportion of carers and families, recognising the importance of adapting service provision to meet the needs of the most vulnerable carers
- Ensuring accountability by building in clear monitoring processes to assess whether the services and initiatives are effective in supporting carers and families

The importance of co-production and regional collaboration in service development

For services to be effective it is essential that they are co-produced with carers. It is important that carers are supported as key contributors to the development of service specifications and involved in commissioning processes.

The National Population Needs Assessment identifies that improvements must be made to the involvement of carers in service development. Our Network Partners strongly identify that involving carers in service design and development is essential. However, current processes for engagement are often tokenistic and repetitive.

To join-up carer engagement it is important that stronger relationships are built within each region between:

- Carers Services
- Carers representatives on Regional Partnership Boards, and relevant associated groups that sit under them
- Carers Leads within local authorities and local health boards
- Community Safety Partnerships
- Public Service Boards
- Local and national third sector organisations that support carers

Developing High-Quality Models of Service

It is important that commissioners better understand the breadth of carers needs and the skills and insight of carers services in identifying, understanding and meeting carer's needs.

It is important that the diversity of carers, both in terms of their needs and the barriers they face, is recognised and reflected in the types of services made available. It is essential that a range of services are commissioned which include links to both specialist and generic services. They must be delivered through flexible service models that are able to be proactive in meeting the needs of carers. It is essential that regardless of the service model used, support is integrated, coordinated and easy to navigate for carers.

Additionally, it is important that effort is made to understand which professionals are most likely to meet families and carers before they have been formally identified. To improve identification before points of crisis it is essential that support and training is given to appropriate staff to ensure that they can provide an active offer of support and signpost effectively.

Whilst teachers and medical professionals are likely to meet families and carers, it is unlikely that identifying and supporting carers is central to their role. Therefore, it is important that they receive clear training and guidance to enable them to refer to appropriate services easily and efficiently, regardless of which service model is used.

Additionally, it is essential that all services consistently monitor, evaluate and refine their service provision to ensure that they achieve successful outcomes for carers.

A variety of methods are currently used across carers services to monitor and evaluate their effectiveness, including:

- Recording "distance travelled" following a "what matters conversation" or "reflective listening"
- Capturing anecdotal feedback including quotes
- Evaluation forms, surveys and questionnaires
- Analysis of staff reports and assessment against intended outputs
- The Carers Star
- Pen pictures and case studies
- Social Return on Investment (SROI)

It is essential that services are designed and commissioned with a focus on utilising approaches that can be shown to demonstrate maximum impact for carers.

Wider Welsh Government Policy

In terms of wider Welsh Government policy, we remain concerned that there has been significant underinvestment in developing the evidence-base to inform decision-making at a national level. There remains a considerable lack of data in relation to carers and limited academic study of the experiences and outcomes of carers in Wales.

To ensure that carers' needs and experiences are understood and that carers are supported in the most impactful ways, more investment is needed in the collection and analysis of appropriate data at a national level. In particular, we would consider that there is insufficient investment in applied research to test new approaches and to enable fuller understanding of the approaches that are most likely to improve carers experiences, wellbeing and life outcomes.

Whilst Welsh Government has developed funding streams focused on facilitating locally determined solutions, insufficient investment has been made in wider-scale analysis and information sharing. There are insufficient platforms to identify, explore and share emerging practice creating inefficiencies in the development of recognised good practice.

More widely, national organisations, that are best placed to act both as a critical friend and as a facilitator of policy into practice, struggle to achieve funding for these much-needed areas of work. The sustainable social services grant is central to enabling organisations to support the implementation of the Act. However, in the last funding round organisations were unable to access funding for policy and development work. Currently, with less than 6 months to run on the current funding programme, organisations funded through this grant, including Carers Trust Wales, have had no notification regarding its continuation.

The Welsh Government team with responsibility for carers remains disproportionately small and this lack of capacity both for scrutiny and innovation will undoubtedly have an impact on the extent to which the Act is implemented effectively. Too often the expertise of the third sector is heavily relied upon without adequate funding to ensure the sustainability of policy, research and engagement expertise within the sector.

In order to embed the Act efficiently, in a way that maximises impact for carers, it is essential that national third sector organisations are funded in a transparent and sustainable way to engage with professionals, carers and carers services to deliver practical solutions to barriers to the successful implementation of the Act and the development of Welsh Government policy on carers more broadly.

Appendix 1: The importance of supporting carers

Supporting carers appropriately delivers benefits for carers and the people they care for. For example:

- supporting carers by providing breaks and emotional support helps to prevent burnout and keep carers caring for longer
- working to encourage carers into - or to continue in - education improves their emotional wellbeing and personal fulfilment as well as widening their options for future employment, education or training
- involving carers in hospital treatment and clinical decisions improves communication and planning which results in better outcomes for both patient and carer

However, too often carers are not supported in any of these ways.

The specific support individual carers need to thrive will be as diverse as their circumstances. In our experience, this can range from requiring better information on managing medicines to having access to reliable services to provide a much-needed break from caring[11]. However, the first step in delivering appropriate support will always stem from ensuring that more individuals and professionals are equipped with the information and tools they need to identify carers and to understand the barriers they face.

In order to deliver appropriate support for carers more investment is needed to:

- make local carers services sustainable
- support professional to identify carers, put in place appropriate support and information sharing systems and to signpost for more direct support (such as through an ID card or other recognition scheme)
- work with the third sector to identify, share and mainstream good practice and to support the commissioning of the most impactful services

Experts calculate that Welsh carers contributed the equivalent of £8.1bn of care during 2015[12], far exceeding the £1.7bn spent across Wales on social care during 2016-17[13]. Whilst providing unpaid care saves the Welsh economy around four times the amount spent on all forms of social care, this comes at a cost to the carers. The detrimental effect on carers' health, wellbeing and financial circumstances has been well documented, with older carers at higher risk than younger carers[14]. Around 65 percent of older carers - those aged 60 to 94 - have a long-term health problem or disability themselves and 68 per cent of carers say that being a carer has had an adverse effect on their mental health, with a third reporting that they have cancelled treatment or an operation for themselves because of their caring responsibilities[15].

In England, the Royal College of General Practitioners has worked with Baker Tilly to identify the social return on investment which can be made when CCGs invest in services which support carers. The study shows that this could equate to a saving of almost £4 for every £1 invested[16].

Additionally, an Impact Assessment published by the Department of Health in England in October 2014 makes an estimate of the "monetised health benefits" of additional support for carers. This estimates that an anticipated extra spend on carers for England of £293 million would save

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[11] **https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf**

[12] **https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf**

[13] **https://statswales.gov.wales/Catalogue/Local-Government/Finance/Revenue/Social-Services/socialservicesrevenueexpendituresubjectiveanalysis-by-authority**

[14] Mansell and Wilson 2009; Mullan et al 2011; O'Brien et al. 2012; Chapman 2014; Greenwood et al. 2017; Smith et al 2017

[15] **http://record.assembly.wales/Committee/4621**

[16] **http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx**

councils £429 million in replacement care costs and result in "monetised health benefits" of £2.3 bn. This suggests, as a ratio, that each pound spent on supporting carers could save councils £1.47 on replacement care costs and benefit the wider health system by £7.88[17].

The services carers receive and require are diverse and include a wide range of local and national services. Services include:

- information, advice and support
- short breaks
- replacement care
- palliative care
- employment support
- training
- benefit support.

The preventative value of these services, both in securing the well-being of individuals, and in avoiding additional costs to local authorities and local health boards, is well-established. For example:

A longitudinal study of 100 people with dementia found a 20-fold protective effect of having a co-resident carer when it comes to preventing or delaying residential care admissions[18].

One study found that problems associated with the carer contributed to readmission in 62% of cases[19].

Appendix 2: Background information: Young Carers, older carers and carers of people with mental ill health including dementia

3 in 5 of us will become a carer at some point in our lives. There are millions of unpaid carers providing support across the UK with the last census showing that there are at least 370,000 in Wales[20].

In almost every category, Wales has the highest proportion of carers in the UK – including the highest proportion of older carers and the highest proportion of carers providing over 50 hours of care a week.

- According to the 2011 census, in almost every category, Wales has the highest proportion of carers in the UK – including the highest proportion of older carers, young carers and of carers providing over 50 hours of care a week[21]
- 65% of older carers (aged 60–94) have long-term health problems or a disability themselves[22]
- 68.8% of older carers say that being a carer has an adverse effect on their mental health[23]
- One third of older carers say they have cancelled treatment or an operation for themselves because of their caring responsibilities[24]

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[17] Department of Health (2014) Impact Assessment (Carers) **http://www.legislation.gov.uk/ukia/2014/407/pdfs/ukia_20140407_en.pdf**

[18] Banerjee, S, Murray, J, Foley, B, Atkins, L, Schneider, J, Mann, A (2003) Predictors of institutionalisation in people with dementia, *Journal of Neurology, Neurosurgery & Psychiatry 2003*, 74,1315–1316.

[19] Williams, E, Fitton, F (1991) Survey of Carers of elderly patients discharged from hospital, *British Journal of General Practice*, 41, 105 –108.

[20] **https://carers.org/key-facts-about-carers-and-people-they-care**

[21] **https://www.ons.gov.uk/census/2011census**

[22] **https://carers.org/key-facts-about-carers-and-people-they-care**

[23] **https://carers.org/article/mental-health**

[24] **https://carers.org/key-facts-about-carers-and-people-they-care**

- 27% of young carers (aged 11–15) miss school or experience educational difficulties (this rises to 40% where children care for a relative with drug or alcohol problems)[25]
- Young carers on average cut short or miss 48 days of school a year[26]
- Young adult carers are more likely than the national average not to be in education, employment or training (NEET) between 16 and 19[27]
- A quarter of young carers say they are bullied at school because of their caring role[28]
- Carers provide 96% of care in the communities of Wales[29]
- Unpaid carers contribute £8.1 billion to the Welsh economy each year[30]

Young and Young Adult Carers

In Wales there are an estimated **370,000** unpaid carers, including **21,611** young adult carers (aged 16-24) and **7,544** young carers (aged under 16). Wales has the highest percentage of young carers in the UK.

Young carers are a vulnerable and disadvantaged group specifically mentioned in Estyn's School Inspection Guidance. Official figures show that there is at least one young carer in every class and research suggests that the real figure is closer to 4 in every class.

Despite pockets of good practice, our Young Adult Carers Council report that for many young carers, a lack of support and understanding at school had a detrimental impact not just on their ability to achieve academically, but also on their wider health and wellbeing.

More needs to be done to ensure that systems and structures are developed in a way that supports and empowers carers both to deliver good care and to prioritise their life alongside caring. This is particularly important for young and young adult carers who experience a range of barriers which can have a lasting detrimental impact on their life outcomes.

Welsh Government has acknowledged[31] that robust arrangements have to be in place locally so that professionals and organisations collaborate effectively in considering support and commissioning services, both within school and outside. It is evident that in many parts of Wales the support available to young and young adult carers is disjointed and inconsistent.

We know from young carers, schools, support workers and academic research that the current system is not delivering adequately or equitably for all young carers. For many young carers, the aspiration set out in Our National Mission of being "well-educated, safe and happy, to be treated fairly and benefit from high-levels of wellbeing" is one that is very far from being achieved.

Carers Trust Wales welcomes Welsh Government's focus on the importance of co-constructing policy and doing so based on evidence and research. However, to ensure evidence-based policy making and practice development, research regarding young carers must be improved upon significantly for this aspiration to be realised.

Problems with school attendance or attainment can impact on the future of young carers. It can be difficult for young carers to think about the future when their focus is on more immediate concerns.

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[25] **https://carers.org/young-carers-schools**

[26] **https://www.bbc.co.uk/news/uk-wales-44306700**

[27] Young adult carers are more likely than the national average not to be in education, employment or training (NEET) between 16 and 19

[28] **https://carers.org/content/anti-bullying-week-quarter-young-carers-are-bullied-school-because-their-caring-role**

[29] **https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf**

[30] **https://www.carersuk.org/news-and-campaigns/news/vale-of-unpaid-care-in-wales**

[31] **https://carers.org/welsh-government-supports-young-carers-schools**

Being tired or distracted when in school can adversely affect their educational attainment and young carers have significantly lower educational attainment at GCSE level[32]. There is a one in three chance that a young carer in year 9 will become NEET (not in education, employment or training) between the ages of 16 and 19, compared to a one in four risk for those without caring responsibilities. This often results in unemployment, reduced earnings, poor health and depression[33].

Caring responsibilities can be difficult and stressful at any age. Taking on the physical and emotional demands of supporting a family member or friend with a long-term sickness, disability, mental ill health or addiction is a lot for young minds to deal with.

For many young people, particularly those who go unidentified, caring can lead to a significant and long term negative impact on their physical and mental health and wellbeing.

Young carers often talk about feeling tired and under pressure. Many experience traumatic life changes such as bereavement, family break-up, losing income or housing, and seeing the effects of an illness or addiction on the person they care for[34]. All these things alongside the pressures of school or college and the social isolation experienced by many, can lead to stress, anxiety and depression.

Research by Carers Trust and the University of Nottingham[35] found that almost a third of young carers surveyed (29%), reported that their own physical health was 'just OK', and 38% reported having a mental health problem.

Young carers' physical health may also suffer. Financial pressures, time pressures, exhaustion as a result of interrupted sleep, physical injuries from repeatedly having to support or move someone with poor mobility.

The health of young carers may be affected for a variety of reasons and might not be addressed if their health appointments are missed, not prioritised or there is a distrust of health services.

Issues related to health and wellbeing can be broken down into several categories, including difficulty balancing young carers' responsibilities, the physical demands of caring, feelings of a lack of control and anger. Where young carers have shared their biggest worries and fears relating to their role, school has frequently emerged as a source of anxiety[36].

- Young carers are 1.5 times more likely than their peers to have a special educational need or a disability[37]
- "65% of those responding to the Nottingham University survey said they had one or more disability or health difficulty and 45% of those responding to the survey reported having a mental health problem, including anxiety, depression and eating disorders"
- Young adult carers are developing health problems, including high levels of mental ill health, at a much higher rate than other young people"[38]

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[32] Children's Society 2013, **https://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf**

[33] **http://www.education.gov.uk/childrenandyoungpeople/youngpeople/participation/neet**

[34] **https://professionals.carers.org/protecting-health-and-wellbeing-young-carers**

[35] **https://professionals.carers.org/sites/default/files/young_adult_carers_at_school-8_11_13-1_proof_4_final.pdf**

[36] Cascade report: "Young Carers Speak Out!" 2016. Dr. Jen Lyttleton-Smith, Children's Social Care Research and Development Centre. **Available online** [Accessed 8 February 2018].

[37] See reference 9.

[38] Time to be heard report (Wales) 2015**,** Carers Trust. **Available online** [Accessed 8 February 2018]

- 19% of young carers reported “Getting stressed”; 22% reported “Worrying about the person you care for” and 13% “Being depressed”[39]
- The 2011 Census shows that for young carers doing more than 50 hours of care a week they are five times more likely to report that their health is ‘not good’
- The **2011 census** also shows that young carers providing between 20 and 49 hours of care per week are over three times more likely to report their health as not good compared to other children without caring responsibilities.

Transport, or affordable transport, is an issue for many young carers whose families may rely on state funded financial support. Most young carers cannot drive, and this impacts on their ability to travel when the person who normally drives them is ill or not available.

Young carers have said that public transport is expensive and not all operatives, such as bus drivers, are understanding. Problems accessing suitable transport means that young carers can be isolated or excluded from social activities[40]. Young carers need to be identified when accompanying someone they care for on buses, trains or at airports/on flights in case of a medical or other incident[41].

An inability to access affordable public transport limits young carers ability to access education, leisure and other opportunities which are integral to maintaining good physical and mental health.

There are some key barriers which limit young and young adult carers ability to access opportunities for leisure and, in particular, physical activity.

Whilst there is a distinct lack of robust evidence regarding physical activity rates amongst young carers, anecdotal reports gained through our Young Adult Carers Council, suggest that young carers are less likely than their peers to undertake regular physical activity. This can be because of time pressures, access to replacement care or financial barriers.

Young and young adult carers are a marginalised group with numerous restrictions on their ability to engage in exercise and we believe that more research needs to be undertaken to fully understand these barriers and how best they might be overcome, including the potential use of Young Carers ID Cards to offer free access to local authority run leisure facilities.

We believe that young carers and young adult carers have an even greater need to be able to access regular activity than their peers to ensure their physical health and wellbeing. Whilst caring cannot be considered an Adverse Childhood Experience, we know that young carers are more likely than their peers to experience mental ill health[42]. Physical exercise has been clearly identified as a resilience factor in terms of young people’s mental health and therefore it should be a priority for Welsh Government to remove barriers to young carers accessing opportunities for regular physical activity.

Our Young Adult Carer Council, has identified 5 main barriers young carers face to accessing regular physical activity[43]:

- Time away from caring. This can be broken down into two different barriers: the first being that it is too difficult to have any time away from the person that they care for and the second being that having regular time away to attend a specific class or to

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[39] Caerphilly County Council. 2016. **Available online** [Accessed 8 February 2018].
[40] Caerphilly County Council. 2016. **Available online** [Accessed 8 February 2018].
[41] Barnardo’s report (2017). Greater Gwent Carers Programme Board: scoping a proposal to establish an ID Card Scheme for young carers and young adult carers Barnardo’s. 2017
[42] **www.wales.nhs.uk/sitesplus/documents/888/PHW%20ACEs%20Resilience%20infographic%20(Eng).pdf**
[43] **http://senedd.assembly.wales/documents/s67283/PACYP%2019%20Carers%20Trust%20Wales.pdf**

join a team is impossible to accommodate, even if respite / replacement care is in place
- The needs of the person they care for come first. Many young carers recognise the importance of regular exercise and leisure activities. However, they do not view its importance as being greater than undertaking their caring role
- Financial constraints. Many young and young adult carers report that they do not have the money for either appropriate sports equipment (including clothes) or to join a gym or team. This includes school-based teams where money is needed to go to away games
- A lack of appropriate / interesting activities available at convenient times in accessible locations
- Confidence. Evidence shows that a quarter of young carers report being bullied at school because of their caring roles. Many lack the confidence to participate in physical activities

Young carers' responsibilities can prevent them socialising with other children or young people. They may also experience poverty and social isolation or exclusion due to their family's financial circumstances.

- "77% of the young carers surveyed would like to do more exercise" and "79% of the young carers surveyed visited a sport's centre every week, every month or now and again"[44]
- 10% of students reported being unable to go to after school clubs due to their caring responsibilities[45]

Older Carers

The number of older carers is increasing with the number of those aged 85 and over growing by 128% in the last decade (Carers UK and Age UK, 2015).

Older carers have their own specific needs and have tended to be a forgotten group, often going unidentified because they do not recognise themselves as a carer or are not adequately recognised by professionals and services.

With an aging population and the increase in the life expectancy of people with learning disabilities; people are caring for longer and later in their lives[46].

Key issues for older carers include:
- Lack of recognition of their own health needs and the impact of caring on their own health and wellbeing
- Isolation and loneliness, especially in relation to unavailable, inappropriate or inaccessible transport
- Complex management and navigation models of health and social care systems with no support
- Lack of preparation including a lack of awareness of the likelihood for caring in later life, especially so for carers who have been caring for children with long term conditions

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[44] Full of Care report. "All Right Gov?". 2009. Children in Wales. **Available online** [Accessed 8 February 2018],
[45] Caerphilly County Council. 2016. **Available online** [Accessed 8 February 2018].and Barnardo's report (2017).
[46] Marks. L, Retirement on Hold, Carers Trust, 2016 (due to be published January 2017)

whose life expectancy meant they were previously unlikely to reach old age where increasing numbers now are
- Older carers have a strong sense of “duty to care”, this can be reinforced by health and social care professionals which means they may feel they have no choice or continue to do so longer than they are able
- Lack of information on financial planning, including information on lasting powers of attorney are not provided at an early enough point

Carers Trust has produced a number of reports looking in more detail at the challenges facing older carers across the UK[47&48].

Carers aged 60–69 often juggle caring with the demands of work and financial pressures while those aged over 70 may be more likely to find it difficult to cope with the physical demands of caring.

Over 16% of older carers in research in 2011[49] were caring for more than one person. This is more common for those aged 60–75 where significant numbers care for a parent as well as an adult son or daughter, grandchild or someone else with a disability or long-term health condition.

Additionally, this research found that:

- Two thirds of older carers have long-term health problems. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression
- One third of older carers report having cancelled treatment or an operation they needed due to their caring responsibilities
- 50% reported that their physical health had got worse in the last year, and 70% said specifically that their caring responsibilities had a negative impact on their physical health
- Across all of the older age groups, more than 40% said their mental health had deteriorated over the last year, with 75% of the 60–69 age-group saying that caring had a negative impact on their mental health
- Less than 50% of carers over 70 who had to lift the person they care for, think that they do this confidently or safely

Many older carers caring for a partner find themselves having to provide personal care alongside having to do all the household jobs that once were shared, resulting in high levels of stress and physical fatigue.

Tiredness is also a significant issue when a carer is on call for 24 hours a day and may be awake often in the night to attend to the needs of the person they care for. Dealing with challenging or unpredictable behaviour also causes particular stress and emotional strain, for example when then person being cared for has dementia.

Carers’ health deteriorates incrementally with increased hours of caring[50]. This is a concern as data shows that the oldest carers are more likely to spend more hours caring than those who are younger, particularly as this is compounded by the fact that age-related illness will be more likely.

There is a considerable body of evidence[51], to show that carer wellbeing is a key factor in hospital admissions, readmission and delays in the transfer of care. For example, a whole systems study

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[47] Fraser. M, Always on Call, Always Concerned, Carers Trust, 2011

[48] Caring about Older Carers: Providing Support for People Caring in Later Life, Carers Trust, 2015

[49] **https://professionals.carers.org/sites/default/files/caring_about_older_carers-finallo.pdf**

[50] **https://www.gov.uk/government/policies/carers-health**

[51] **http://static.carers.org/files/supporting-carers-the-case-for-change-5728.pdf, (Conochie, G, 2011)**

tracking a sample of people over 75 years old who had entered the health and social care system found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.

Supporting Carers: The Case for Change[52] also highlights that carer-related reasons for admission to nursing or residential care are common, with carer stress the reason for admission in 38% of cases[53]. This suggests that giving carers extra support to manage their caring role more effectively and maintain good health could reduce unwanted residential care admissions.

Deterioration in carer health and wellbeing therefore is likely to increase demand on health and social care services for both the carer and the person with care needs. Preventative interventions to support the carer may therefore reduce the likelihood of increased future health, social care or residential care needs of both parties.

To support older carers it is important that:

- Primary and secondary care services identify older carers as early as possible and ensure they are referred for a carers need assessment
- Planning for caring in later life should be considered as a public health priority and the public supported to plan for their own care needs and the potential for becoming a carer in later life
- Health and social care systems must be aligned and integrated to ensure older carers are not required to navigate the complex systems for both their own and the person they care for's health needs. This presents particular challenges when discharging an unpaid carer from hospital.

Carers of people with mental ill health including dementia

Carers Trust's research into the experiences and needs of carers of people with dementia, demonstrates clearly what the issues faced by this group of carers experience. A Road Less Rocky[54], sets ten key crisis points when carers of people with dementia need specific, information, advice and support in their own right to prepare for and cope with their caring journey. These are:

- When dementia is diagnosed
- When the carer takes on an “active” caring role
- When the capacity of the person with dementia declines
- When the carer needs emotional support and/or a break from caring
- When the person with dementia loses their mobility
- When the person with dementia has other health problems
- When the carer has to cope with behavioural problems
- When the carer's own circumstances change
- When the person with dementia becomes incontinent
- When decisions about residential care and end of life care have to be made

Carers are still going unidentified at an early enough point, meaning they reach crisis point at one of the later positions which has long term implications for their own health and wellbeing and often leads to the person they care for being admitted to residential care.

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[52] **http://static.carers.org/files/supporting-carers-the-case-for-change-5728.pdf, (Conochie, G, 2011)**
[53] Bebbington, A et al, 2001
[54] Newbronner. L, Chamberlain. R et al, A Road Less Rocky – Supporting Carers of People with Dementia, Carers Trust, 2013

Carers of people with dementia experience particular challenges that are in addition to the wider issues experienced by all carers. Often due to their age, the nature and complexity of dementia and their own health needs they are a particularly vulnerable group who need attention in their own right.

It is important that all hospitals in Wales develop their carer awareness to ensure that carers are included throughout the care pathway which would reduce poor discharge practices.

Additionally, Commissioners must ensure carers of people with dementia are included in commissioning decisions including ensuring their own needs (as identified in the Road Less Rocky) are taken into account when commissioning services.

The Triangle of Care - The Triangle of Care was originally developed by staff and carers to improve carer engagement in acute inpatient and home treatment services. Created in partnership with the National Mental Health Development Unit it aims to improve communication between those caring for people with a mental health problem and mental health professionals. Since its launch in 2010, the programme has been adapted for use across all mental health services, not only inpatient, and includes a universal self-assessment tool as well as guidance notes.

The Triangle of Care best practice guides and audit tools aim to build upon existing good practice to recognise and include carers as partners in care. It offers key standards and resources to support mental health service providers if incorporated in their everyday practice, policies and procedures. In Wales, 50% of health boards have shown an active interest in implementing a Triangle of Care model and support is growing within other health boards throughout Wales.

Betsi Cadwaladr Health Board is the most advanced in terms of actioning a Triangle of Care pilot and last year set up a steering group to take the work forward, with an initial pilot receiving positive feedback from staff and carers.

In 2018, with support from the RCN Foundation, Carers Trust Wales published **The Triangle of Care, Carers Included: A Guide to Best Practice in Dementia Care, Wales Edition** which sets out to ensure consistent carer involvement and support across all health and social care services irrespective of where and when a person is being treated.

Appendix 3: Summary of Carers Services in Wales

The majority of services for carers are delivered by third sector organisations commissioned by local authorities[55]. The tables below summarise the organisations that deliver these services across Wales as well as the regional approaches being taken to service delivery and commissioning. Whilst many more services for carers exist, this report focuses on the main adult carer service providers for advice, information assistance and respite, in each local authority area.

It is worth noting that since the introduction of the Social Services and Wellbeing (Wales) Act 2014 many local authorities and local health boards are developing a more integrated and collaborative approach to addressing the needs of carers. However, this is an ongoing process with varying levels of collaboration achieved within each region.

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[55] Carers services do receive funding from Local Health Boards and non-statutory funders, but this has traditionally been for specific or time-limited carer focused projects.

Local Authority: Bridgend

Bridgend carers service (advice, information and support)
Bridgend Crossroads Care (adult respite)

Local Authority: Neath Port Talbot

NPT Carers Service (advice, information and support for adult carers)

Local Authority: Swansea

Swansea Carers Service (advice, information, respite and support for adult carers and young adult carers)

Regional approach

Western Bay Carers Partnership Board has recently commissioned a carers mapping exercise to inform the development of more consistent approaches and services.

The Board is developing a new plan for 2018 - 2019 to address carers priorities highlighted in the **Area Plan** as well as the Ministerial priorities for carers.

Strategic Direction:
New Carers Partnership Action Plan 2018/19 (to be published)
Valuing Carers Transition Plan 2017-18

Local Authority: Torfaen

Carers Trust South East Wales (respite)
Torfaen CBC (adult carers)

Local Authority: Newport

Carers Trust South East Wales (advice, information, respite and support)
Age Cymru Gwent (respite carer service)

Local Authority: Blaenau Gwent

Carers Trust South East Wales (respite)
Age Cymru Gwent (advice, information and support for adult carers)

Local Authority: Monmouthshire

Carers Trust South East Wales (respite)
Age Cymru Gwent (respite care service)

Local Authority: Caerphilly

Carers Trust South East Wales (respite)
Caerphilly CBC (adult carers)

Regional approach

As part of their draft **Wellbeing Area Plan** in relation to carers, Greater Gwent Regional Partnership Board sets out the following actions:

- Coordination of consistent community based services such as community connectors / social prescribers to identify and support carers
- Accurate Information, Advice and Assistance through DEWIS and **Five Ways to Wellbeing**
- Consistent commissioning across health and social care to ensure equitable, region wide and effective models of carer support including flexible respite
- Ensure that the implementation of the **Care Closer to Home Strategy** increases the community level support for carers across Aneurin Bevan University Health Board (ABUHB)

Success will be measured by:

- Increase in number of befrienders providing flexible respite for carers
- Increase in the number of schools involved in the Young Carers awards scheme
- Increase in number of GP surgeries that are ‘Carers aware’

Local Authority: Anglesey

Carers Outreach Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite)

Local Authority: Wrexham

Wrexham Carers Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service

Local Authority: Flintshire

NEWCIS (advice, information, respite and support for adult carers and young adult carers)
Carers Trust North Wales Crossroads Care Service (respite for all ages)

Local Authority: Conwy

Carers Outreach Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite for all ages)

Local Authority: Denbighshire

NEWCIS (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite for all ages)

Local Authority: Gwynedd

Carers Outreach Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite for all ages)

Regional approach

As part of the **regional plan**, the **North Wales Regional Partnership Board** have set out a number of actions in relation to carers to support the integration of health and social care. The actions outlined are as follows:

- Map current provision and services and assess these against the requirements in the Social Services and Wellbeing (Wales) Act 2014
- Explore and develop approaches for integrated Carer's services and consider whether a pooled budget can be created to support these services

In response to this, the North Wales Social Care and Wellbeing Improvement Collaborative, which is advised by several groups (North Wales Strategic Carers Leads Group, North Wales Operational Carers Group and the North Wales Young Carer) are now in the process of developing **a regional offer for carers**:

- Understanding where they are at and what success looks like
- What the priorities should be
- Being clear on funding and the sustainability of services for the future

Current activities include resource mapping giving an overview of the services available for carers in North Wales and an estimate of the investment in those services, a mapping of carers journeys and workshops with multi-stakeholder engagement to help shape the regional carer offer.

Local Authority: Cardiff

N/A

Local Authority: Vale of Glamorgan

Crossroads Care in the Vale EMI (dementia respite for adults)

Regional approach

As part of the **Area Action Plan**, **Cardiff and Vale Regional Partnership Board** has committed to identify and implement a carer engagement model based on best practice. Work undertaken to date includes:

- Delivering Phase 1 of the Carers Engagement Project which considered potential carer forum models and barriers to engagement.
- Commissioning a Carer's Support services report to help shape a future offer to carers in Cardiff. This report will include a local carers voice and an analysis of best and emerging practice across Wales.

Local Authority: Merthyr Tydfil

Merthyr CBC
Carers Trust South East Wales (respite)

Local Authority: Rhondda Cynon Taff

Carers Support Project RCT (advice, information and support for adult carers)
Carers Trust South East Wales (respite)

Regional approach

As part of their **Area Plan**, **Cwm Taf Social Services and Wellbeing Partnership Board** commissioned the **Welsh Institute of Health and Social Care** to review current service model for carers and consider how more effective integrated services across the region could be provided.

As a result of this work an integrated service model for carers has been developed which will see the creation of an integrated, dedicated team (initially in-house) to provide a coordinated response to carers issues across the region. The team will operate from multiple places, implementing relevant elements of a 'blueprint' offer whilst scoping detailed implementation of more innovative model.

- Tier 1 - Universal and preventive services. Single point of entry providing advice, information and support on all aspect of caring
- Tier 2 - Early intervention and re-ablement (training, peer support, carer network etc.)
- Tier 3 - Specialist Services (respite, complex care needs, palliative care etc.)

Local Authority: Carmarthenshire

Carers Trust Carmarthenshire Crossroads Care (carers information service for adult carers)
Carers Trust Carmarthenshire Crossroads Care (respite for all ages)

Local Authority: Ceredigion

British Red Cross (adult carers)
Action for Children (young carers)
Hafal Crossroads (respite)

Local Authority: Pembrokeshire

Hafal Crossroads (carers information and support service for adult carers)
Hafal Crossroads (Respite)

Regional approach

West Wales Area Plan 2018-2023 - Delivering Change Together

The West Wales Carer Development Group has developed a Carers Delivery Plan, to address both the Welsh Government priorities as well as the gaps highlighted within the Population Needs Assessment. The following key workstreams have been established for adult carers:

- Investors in Carers (IiC) – to include evaluation of current schemes and development of proposals for long term sustainability across health, social care and community settings.
- Joint Commissioning of Carers Services (Outreach, Respite and Information Services) including review of current provision
- Information, Advice and Assistance (specific to the needs of Carers) – including the production of a Carers Communication Plan in line with the regional IAA framework
- Service improvement & integration (including Hospital Discharge and Transfers of Care, improving the wellbeing of Carers) – to include an audit of carer assessments, promotion of carer resilience models, review workforce carer policies and establishing a regional carers quality group
- Training & Development (including formal/informal training for Carers) – to audit and assess the Learning & Development opportunities for Carers and carer awareness training for staff.

Local Authority: Powys

Credu (adult carers, young carers and young adult carers)
Hafal Crossroads (respite)

Regional approach

Delivering the Vision – Joint Area Plan

Priorities identified within the plan include:

- Reviewing and updating the **Powys Carers Joint Commissioning Strategy** including Implement **The "Everybody's Business" Model for Carers**
- Focus on accelerating the integration of Health and Social Care Services work ongoing with integration of care teams for older people.

Appendix 4: Evidence of what is working well

In 2017 the Social Care Institute for Excellence (SCiE), on behalf of Social Care Wales, undertook a rapid review of carers services in Wales. The report **Preventative support for adult carers in Wales: a rapid review**[56] identifies some emerging good practice and new models in adult carers support, with a particular focus on prevention. However, the review doesn't go far enough to realise its intended aim of capturing emerging good practice in preventative services. Instead, it offers a snapshot of existing practice and carer issues.

It is pleasing that the report echoes the feedback we have received from our Network Partners which clearly demonstrates the importance of ensuring that carers services focus on the important impacts that can be achieved by improving identification and recognition, information, advice and advocacy, mechanisms to achieve a life alongside caring and appropriate and flexible respite.

From our experience, it is clear there are many emerging practices can be identified in Wales, particularly relating to: primary care, respite, hospital liaison, advocacy, mental health and palliative care. These examples provide a much richer and deeper narrative and help to provide a platform for some promising areas of work.

Similarly, **research** carried out by Care and Social Services Inspectorate Wales (2017) into carer engagement, identified many areas that support the **views of carers in Cardiff and the Vale of Glamorgan**, reaffirming that:

- carers want to have their stories heard and hold meaningful 'what matters' conversations with social workers
- carers value carer group meetings which offer peer support as well as an opportunity to receive good sources of information
- that multiple sources and entry points of information and support be simplified

Areas of good practice noted include:

- providing a diverse range of flexible and creative provision, including courses
- counselling and direct payments to enable carers to make their own arrangements
- statutory services adopting carer-friendly policies to support carers they employ and developing partnerships with job centres to support carers into employment

Many local authorities have developed successful initiatives with health boards and, notably, GP practices, which are often the first point of contact for carers. Others have extended this to hospital wards. This area of development has often been driven by NHS involvement, delivered in partnership with local third sector carer organisations.

A common thread throughout the report was the requirement of specialist support groups, such as those for mental health, substance misuse and learning disabilities (particularly parent carers for children with complex needs), which are less universally available for carers than those for older people for instance. It is important that service models and commissioners recognised the importance of ensuring access to appropriate specialist services within an integrated and easy-to-navigate care and support pathway.

This report also further emphasises the views of carers regarding the need for significant forward planning to enable effective use of short-break care. It noted that little help was available when

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[56] **https://socialcare.wales/cms_assets/file-uploads/Carers-Report.pdf**

short breaks were urgently needed, something that many of our Network Partners have identified as a priority.