

Agenda – Health, Social Care and Sport Committee

Meeting Venue:

For further information contact:

Committee Room 2 – Senedd

Claire Morris

Meeting date: 21 November 2018

Committee Clerk

Meeting time: 09.00

0300 200 6355

SeneddHealth@assembly.wales

At its meeting on 15 November, the Committee agreed a motion under Standing Order 17.42 (vi) to exclude the public for item 1 of today's meeting

1 Autism (Wales) Bill: Consideration of draft report

(09:00–09:30)

(Pages 1 – 56)

Autism (Wales) Bill: Draft report

2 Introductions, apologies, substitutions and declarations of interest

(09:30)

3 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with children's organisations

(09:30–10:30)

(Pages 57 – 90)

Sarah Crawley, Director, Barnardo's Cymru

Lynne Hill, Policy Director, Children in Wales

Geraint Turner, Project Co-ordinator, YMCA

Research Brief

Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Focus Group Summary



Paper 1 – Barnardo’s Cymru

Paper 2 – Children in Wales

Paper 3 – YMCA Swansea

Break (10:30–10:35)

4 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with Alzheimer's Society

Cymru

(10:35–11:15)

(Pages 91 – 95)

Huw Owen, Policy Officer, Alzheimer’s Society Cymru

Dawn Walters, Advocate, Alzheimer’s Society Cymru

Jayne Goodrick, Carer of a person living with dementia

Ceri Higgins, Carer of a person living with dementia

Paper 4 – Alzheimer’s Society Cymru

Break (11:15–11:20)

5 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with Association of Directors of Social Services Cymru and Welsh Local Government Association

(11:20–12:10)

(Pages 96 – 109)

Damien McCann, Corporate Director for Social Services in Blaenau Gwent,
Association of Directors of Social Services Cymru

Kim Sparrey, Carers Services Development Manager, Monmouthshire County
Council and Chair of the Carers Officers Learning and Improvement Network,
Welsh Local Government Association

Cllr Susan Elsmore, Deputy Spokesperson for Social Care and Health, Welsh
Local Government Association

Naomi Alleyne, Director, Social Services and Housing, Welsh Local Government Association

Paper 5 – Association of Directors of Social Services Cymru and Welsh Local Government Association

6 Paper(s) to note

6.1 Autism (Wales) Bill: Additional Information from the Welsh Local Government Association

(Pages 110 – 113)

6.2 Autism (Wales) Bill: Letter from Paul Davies, Member in Charge, to Chair of Finance Committee

(Pages 114 – 121)

7 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the remainder of this meeting

(12:10)

8 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Consideration of evidence

(12:10–12:15)

9 Scrutiny of the Welsh Government Draft Budget 2019–20: Consideration of draft report

(12:15–12:20)

(Pages 122 – 156)

Scrutiny of the Welsh Government Draft Budget 2019–20 – draft report

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By virtue of paragraph(s) vi of Standing Order 17.42

Document is Restricted



Written Submission – 9th November 2018
Health, Social Care and Sport Committee Inquiry:
Impact of Social Services and Well-being (Wales) Act 2014 in
relation to Carers

Barnardo's Cymru delivers four specific Young Carer Services. We support parent carers at four services for disabled children and their families; we also support carers of all ages within nineteen other services. Furthermore, within our 27 family support services, we will be supporting carers.

Our organisation has experienced closures and reductions in services for carers in recent years; this can be attributed to the move towards more individualised support and an encouragement to engage carers in mainstream activities. This change, although welcomed in terms of a person-centred approach, has inevitably also had negative consequences for some of the carers we support, as specified later.

This evidence represents the views of managers from services commissioned to support carers, the majority being from the young carer services.

Impact of the Act

Overall the picture is mixed in terms of the impact of the Social Services and Well-being (Wales) Act on carers we support. Although there are positives in terms of an increasing awareness of rights for carers in some cases, many of our services report a lack of funding which can undermine the positive intentions of the Act. Others are reporting no significant change in the lives of carers since the introduction of the Act. There seems to be an inconsistency in recognition of, and provision for, carers across, and at times within local authorities, depending on issues such as local priorities, workforce experience and levels of awareness.

Some of the negative consequences of the Act, or changes reported by our services include:

- Significant reductions in the length of interventions, which has implications on the types of support offered and a move away from relational services
- Less support available overall, leading to a perception that there is an increased need for families to fight and provide more justification for their requests for support
- Loss of peer support opportunities in the case of young carers
- Inaccessible provision in some areas
- An impression that young carers' issues are being overlooked, or diluted, with the introduction of a whole population approach
- Staff shortages
- Burgeoning waiting lists for services in some areas, leading to higher thresholds for support and increases in incidents of crisis
- A reduction in respite care options for parent carers and an absence of opportunities for respite for young carers.

Assessment of need

Again there were reports of inconsistencies in experiences of assessment according to locality and individual professionals. When a thorough assessment had been conducted by an experienced professional with a personable approach and an awareness of the needs of carers, our services reported positively in terms of good information sharing, and families being put at ease in talking about their issues.

However, there are examples of poor experiences of families being assessed. These include intrusive and negative processes, which lead the carer to feel compelled to admit they are failing or cannot cope, which is particularly an issue for parent carers. Other experiences of assessments have led to carers feeling judged or not feeling valued, or supported.

Provision of support, including respite care

Closures and a reduction of services, has had an impact on the provision of support available, leading to increasing caseloads, reduced staff numbers and increasing waiting lists. Budget and staff shortages are resulting in a reduction in the amount and type of support available for those with caring responsibilities.

Although, as an organisation, we welcome a person centred approach, one of the unintended consequences of the Act for young carers, is that they are missing out on opportunities to socialise and make relationships with other young carers – those with whom they share

similar lived experiences. This was always a particularly important, and valued, aspect of young carer specific support services.

That young carers miss out on ordinary leisure, sport and hobby time as well as ordinary, out of school, social lives is well documented.¹ Whilst some young people can take advantage of opportunities available within their communities, assuming they have time freed up through respite care provision for those they care for, others find this more difficult. Opportunities to make relationships with other young carers, to share experiences and build their confidence is an important, sometimes essential, step for children who often experience loneliness, isolation and depression as a consequence of their caring responsibilities.

In some areas the contracted amount of time allocated to supporting carers has reduced from 12 months to six weeks. Although many families may only require shorter timeframes for support, a lack of flexibility in terms of how long a family can receive support, will inevitably lead to some families not receiving the support they require. This limited time frame also reduces opportunities for young carers to take part in development and influencing work, or to feel that their voices are being heard by people who make decisions about them.

Our services report a drastic cut to respite care, which can lead to increasing rates of crisis. Particular issues identified by our service staff, include a lack of availability of respite care for young carers, along with a diminishing provision for adult carers.

Provision of information, advice and assistance

The introduction of Information, Advice and Assistance Officers has in many cases had a positive impact on families with caring responsibilities, as it gives them a point of contact and can improve their access to services. This offer is especially positive when multiagency working is properly embedded, so that communications between organisations are effective and support can be provided earlier. However, again the quality of support is too often dependent on the expertise of the individual and the approach of the local authority. In some areas there is no central point of contact for carers. It has been our experience that although the statutory obligation to provide information, advice and assistance has been positive, funding

¹ <https://carers.org/news-item/research-reveals-80-young-carers-miss-out-childhood-experiences>

shortages mean that there are sometimes limited services to refer into or support that can be offered.

Information collected by local authorities and Local Health Boards on carers and their needs

Although as a third sector organisation, we would not always be party to information collected by local authorities and health boards, our service managers did raise concerns relating to the way data is collected and used, as follows:

- Funding restraints have led to a perception that local authorities may be more protective of the scarce provision available, leading to assessment processes which might be preventing families from requesting support
- Outcomes are not readily shared with families across the board
- An increased emphasis on collecting statistics, has led some to believe there is less of a focus on providing support
- Young carers continue to be overlooked, particularly when the widening criteria for classification as a carer across the population, inevitably leads to more people being identified. Although we would welcome more identification of carers, we are concerned when the funding does not match increasing demand
- Although there is agreement that mainstream and universal provision has a key role to play in early intervention and ultimately better outcomes for carers, these mainstream providers are not yet at a stage where they are equipped to work in this way, leading to concerns that young carers will be missed
- In some areas it has been reported that there has been no increase in awareness and identification of young carers

Additional comments

Below are some quotes from our service managers on the impact of the Social Services and Well-being (Wales) Act on parent carers, young carers and young adult carers:

“I do not think local authorities have adequate funding to meet the expectations set out in the Act. This money should be ring fenced to ensure carers are properly supported.”

“More support for young carers is needed.”

"Young carers money used to be ring-fenced, maybe this needs to happen again."

"Currently, I personally don't feel the Act has offered any improvements to the lives/support offered to young carers or young adult carers within our local authority."

"I feel that it [the Act] has let young carers down in a major way."

"those whose voices are part of the Act have since stated that they feel let down."

Children in Wales:

Evidence on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers.

Children in Wales has been carrying out work relating to young carers since 2002, when we were invited to join the Welsh Governments Carers Strategy Advisory group, to look at how young carers could be actively engaged in the Carers Strategy. Children in Wales believes that work to support young carers is vital as these young people are often hidden. Many young carers may not recognise that their role within the family is different to other children and young people, but they often carry significant physical and psychological burdens. Young carers often have little or no “me time” and can appear to lose their childhood.

Children in Wales’ current work in this area includes:

- Facilitating a Young Carers Network.
- Sitting on Welsh Government working groups to represent young carers.
- Supporting projects to work together to develop activities for young carers.
- Undertaking consultation work for Welsh Government and ensuring that young carers’ views are reflected in consultations that are relevant to children and young people.

Children in Wales welcomes the opportunity to give evidence to the Health, Social Care and Sport Committee.

The evidence presented was gathered from members of the Young Carers network.

There is a Young Carers service in every local authority, but services are delivered by a range of providers. While all young carers referred to a service will receive an assessment, these may vary dependent on the provider.

Torfaen services for young carers employs a social worker to work with young carers in an in-house social services young carers' service. The worker operates within the guidelines of the Social Services and Wellbeing Act.

The young carer's assessment is undertaken in the same way as any other assessment for a child or young person and recorded on the same paperwork, and is delivered to meet timescale of 42 working days.

All young carers have a care and support plan, which is reviewed every 6 months.

Torfaen has close contact with the other young carer's services in the area, Monmouthshire, Caerphilly, Blaenau Gwent and Newport. Each of these services works differently and none of them work in the way that Torfaen does.

Evidence gathered from the Cardiff and the Vale service, indicated that they have not seen any change in support to Young Carers' since the Act came into place. There was a recent example of a young carer being assessed by social services and then referred to the young Carers service.

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Policy Director Children in Wales.

YMCA Swansea works with over 150 young carers and their families in Swansea. We are part of the all Wales young carers forum and have been working with politicians and ministers in Wales to lobby the views and voices of young carers in Wales. The legislation looks at carers of all ages.

- To assess the impact of the **Social Services and Well-being (Wales) Act 2014 [Opens in a new browser window]** on carers of all ages in Wales, including:

- **Assessments of need;**

Local authorities across Wales have adopted different methods for ensuring they are completing assessments of need for young carers. Whilst adult carers regularly get assessments, young carers are often missed out across Wales. Some local authorities complete their own assessments of need and share information with organisations that can support young people and their families. Some local authorities commission third sector organisations to develop and implement assessments of need and create action plans to work with the families to reduce the impact of caring on a young carer. Unfortunately, there are examples where local authorities don't provide or complete any assessments of need. Therefore organisations working with and supporting young carers have developed their own assessments to provide support.

There needs to be a national standard for a Young Carers assessment where it links into the SSWA and future generations of Wales act. Local Authorities need to be held accountable for completing assessments or commissioning services that do this role for them.

- **Provision of support, including respite care;**

- Respite care for young carers is usually provided by the third sector organisations that support them. They are opportunities that don't get funded by Local Authorities and tend to be trust funds or grant funds that organisations have to apply for.

- **Provision of information, advice and assistance;**

- Local Health Boards have created and adopted Carers Strategies that include the provision of providing information, advice and assistance. Whilst this is a great start, far too often young people's views and experiences are not thought about. Many of the events that are hosted by local authorities or voluntary services are hosted during the day time on weekdays to cater for adult carers. This is then not accessible for young carers as the aim of the services supporting young carers is to ensure they are attending school.

- **Information collected by local authorities and Local Health Boards on carers and their needs.**

- The number of identified young carers used to be collated and reported on a yearly basis. This stopped in 2015/16

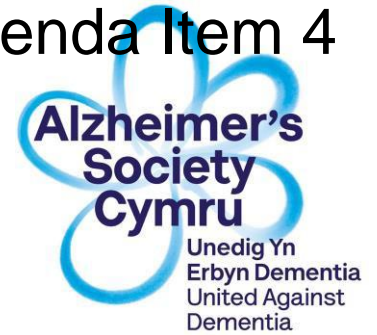
<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Childrens-Services/Service-Provision/Prior-to-April-2016/youngcarers-by-localauthority-measure>

- **To consider broader Welsh Government policy on carers.**

more needs to be done to support young carers in school. When a young carer leaves primary school their secondary school should be informed of their caring role. Similarly when young carers leave secondary school they should be able to tell the college on application that they are a young carer. Only recently universities have created a box where applicants can declare they are a carers.

Agenda Item 4

Dr Dai Lloyd
Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff
CF99 1NA
SeneddHealth@assembly.wales



18 September 2018

Ref: Health, Social Care and Sport Committee inquiry into the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers: Alzheimer's Society Cymru response

Alzheimer's Society Cymru



Website

alzheimers.org.uk

Dear Dr Lloyd,

I am pleased to respond on behalf of Alzheimer's Society Cymru to the [Health, Social Care and Sport Committee inquiry into the Impact of the Social Services and Wellbeing \(Wales\) Act 2014 in relation to Carers](#). Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia. Alzheimer's Society Cymru welcomes the Committee's interest in the impact of the Social Services and Wellbeing (Wales) Act 2014 on Carers. Evidence for this document was collected by a mixture of desk based research and anecdotal evidence collected from Alzheimer's Society frontline staff in the period 13 August to 10 September 2018. The evidence was collected from across Wales.

Overview

- 1.1 The evidence provided by staff suggests that Carer's Assessments are seen as inconsistent and tokenistic.
- 1.2 The well-publicised issues around funding continue to persist in Wales.
- 1.3 Statutory Service staff and unpaid carers are doing the best job possible in the current climate.
- 1.4 The sharing of information between Local Health Boards, local authorities and third sector organisations is poor and in need of improvement.
- 1.5 Guidance from Local Health Boards, local authorities and third sector is in need of standardisation to prevent confusion.
- 1.6 There are not enough services, and those services do not have enough resource.

Assessments of Need

- 2.1 The Adults receiving care and support in Wales Report, 2016-17 from Statistics Wales reported that 6864 carers refused an assessment.¹
- 2.2 Further discussion with Statistics Wales revealed the reasons for these refusals were not reported on, or not recorded.

¹ Adults receiving care and support in Wales, 2016-17 (Experimental statistics), Statistics Wales, 31 October 2017. First Accessed August 2018

2.3 Anecdotal evidence from Alzheimer's Society frontline staff revealed that most local authorities have a long waiting list, and it is often a case of "take a ticket and wait for your number to be called."

2.4 Evidence also suggested that the assessments are being done over the telephone as opposed to face to face, meaning that the assessor is not getting the full picture and situation of the carer being assessed.

2.5 Staff also reported that often carers are asked what they want out of an assessment and that carers often come away with a carer's passport or carer's card.

2.6 Reasons given by staff for this included the stigma of talking to Social Services; the fear that Social Services will remove the person being cared for if the carer cannot cope and that Social Services are seen as an extension of a figure of authority and carers are afraid to question or fight for something they need.

2.7 This has been echoed by staff across Wales who have commented that Social Services have passed the responsibility onto the carer. One example came from North Wales where staff commented that Social Services are asking carers to complete the 'What Matters' form, something that Social Services used to do themselves. Staff reported that this has led to an inconsistent service and inequitable access.

2.8 Evidence from staff also suggested that the new system has put greater expectation on carers to meet the needs of the person being cared for themselves.

2.9 However, comments from other staff indicated that Social Services have become easier to deal with and there has been an attitude change towards making things easier for the carer to be assessed and access the support needed.

2.10 Overall, staff expressed concern that whilst the new system has led to some improvements, it is patchy at best, and often feels inconsistent and tokenistic to the person being assessed.

2.11 Staff were also concerned that the Carer's Assessments only focussed on the immediate position of the carer and not any potential needs in the future.

Provision of support, including respite care

3.1 The overarching thread that emerged from evidence given by staff and from desk research is that Social Services staff are doing all they can to support carers and the people they care for in a challenging situation.

3.2 Evidence from staff indicated that in theory everyone understands the need for the community to do what it can before statutory services step in, but in practice people generally only ask for help when they are really in need and cannot do any more.

3.3 An example was given where respite wasn't approved for a Carer of a Person with Dementia who is prone to violent outbursts as the Council and carer were unable to fund the respite place despite the chosen facility having space and the service user wanting to go there due to past positive experiences.

3.4 An example was also given of Denbighshire cutting their respite care provision to half, with the Council outlining that the full eight weeks are only available in exceptional circumstances.

3.5 This has led to a situation where volunteer led services are attempting to fill in the gaps in the care, with befriending services asked to go in and provide respite care. Staff have said that there is an over reliance on this.

3.6 Concerns have also been raised about making sure that respite care is age appropriate. What is considered appropriate for older people living with dementia is not always appropriate for those living with early onset dementia.

3.7 Worries have also been raised on the accessibility of respite care, particularly in rural areas; with our report 'Dementia in rural Wales: The lived experiences' highlighting the issue, with one carer saying that: 'They say he can go to a residential setting for respite, but that I need to take him to it and pick him up. By the time I've driven there and back, it's not really giving me a break or for the purpose it's intended.'²

3.8 Anecdotal evidence on taking respite together was also heard, with staff commenting that often, carers and the people they care for would like to have a holiday or break together, but are unable to do so due to a lack of options or availability of help whilst on the break.

3.9 Evidence from staff suggested that this gap is growing due to funding pressures on local authorities, with suggestions that those who can afford to pay for respite care are getting a more comprehensive service than those who cannot.

3.10 Issues were also raised with the state of respite facilities available to carers and people they care for, with staff giving examples of carers refusing to take up respite due to negative experiences in respite homes.

3.11 This has led to safeguarding issues coming to the fore in discussions around respite, with concerns that care plans are not being put in place and followed for respite care.

3.12 There were also concerns raised with the speed of response to advance requests for respite care, with an example given of a carer who had put in a request for respite for a pre-planned trip, but not hearing if respite was granted until 48 hours before the trip, adding to concerns about the person being cared for.

3.13 Finally, staff expressed bewilderment that self-neglect is not recognised as a form of abuse in Wales, and expressed a wish that this should be recognised as soon as possible.

Provision of information, advice and assistance

4.1 Staff reported that the information that exists currently is of good quality, but the people trying to either provide it out or make use of the information are being hamstrung by systems, regulations or funding.

4.2 An example of this was given whereby an assessor asked for signposting advice from the third sector as they didn't know what services were available in their area. Whilst the information was available, joined up access to it was not, leading to this confusion.

4.3 A further example was given of trying to contact the C1V service in the Vale of Glamorgan. The caller wished to report a safeguarding issue, but was faced with a 15 minute wait and a staff member, who, whilst trying their best, were unable to understand the full issues due to a lack of information.

4.4 Evidence from staff suggested that this lack of information, and joined up access to it, has led to a much deeper questioning of the carer's ability to provide care and the carers wider support network.

4.5 This line of questioning simply adds to their burden. People feel obliged to agree to providing support which they are not able to fulfil and get closer to crisis, despite information about helpful services existing.

4.6 Where this information exists, but is held by the third sector, staff evidenced that whilst there was a need to show a connection with the third Sector, it felt like a tick-box exercise as consultations with potentially valuable allies were going on after the majority of a plan or assessment had been finalised.

² Alzheimer's Society Cymru – Dementia in rural Wales The lived experiences - https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_in_rural_wales_the_lived_experiences.pdf - First Accessed September 2018

4.7 Finally, staff also evidenced that there have been occasions when safeguarding complaints have not been upheld as they have been told that “carers can just walk away.” This comment was echoed by staff working in various local authorities.

Information collected by local authorities and Local Health Boards on carers and their needs

5.1 The overwhelming evidence given by staff here is that third sector organisations and Local Health Boards & local authority services are speaking different languages. Staff evidenced that this includes different policies and different structures and suggested that there is a need for some form of standardisation.

5.2 Evidence also emerged that there is a lack of signposting and that it of ten seems that services are talked about and offered to people on a ‘need to know basis.’

5.3 An example of this was given of a multi-disciplinary team meeting where each person at the meeting had their own agenda and were actually arguing amongst themselves to fight for their own services, as opposed to offering and producing the best services for the person in need.

5.4 A further example of this disconnect came from Rhondda Cynon Taf where people who have been diagnosed with dementia don’t know the type of dementia they have been diagnosed with. Staff commented that this lack of sharing of information leads to increased service pressures.

Broader Welsh Government Carers Policy

6.1 Evidence from staff suggested that carers are struggling to have their caring for the elderly or people living with dementia taken as seriously as childcare by employers. Staff also commented that they felt there is a need to destigmatise care for those living with dementia, with one comment suggesting that “there is more understanding of caring for a child than of caring for an elderly person.”

6.2 Comments suggested that there should be a push to enshrine carer’s rights in workplaces to attempt to combat the problem outlined above.

6.3 Staff then suggested that the definition of a dependent needed to be expanded to ensure that people living with dementia or other unseen disabilities can fit into the category to allow their carers access to the same right as those who fit into the current definition.

6.4 Evidence from staff also suggested that unpaid carers are effectively taking on a full time job with no training, and that a programme of training in skills such as manual handling, medication, finances and other useful skills should be created and rolled out nationwide.

6.5 Evidence from staff also suggested that there seems to be a system of “crisis management, not crisis prevention” meaning that local authorities and Local Health Boards were willing to let people reach crisis point before intervening rather than fix it in advance.

6.7 Comments suggested that the majority of policy on dementia focuses on the individual with dementia, rather than the team around the person. We believe that this needs to change, and the carers need to be brought more into focus in order to improve the care received by people living with dementia, both in the home, and in more formal settings such as hospitals or care homes.

6.8 Finally, concerns were raised about people with dementia who are also carers in their own right. This group of carers are often overlooked in the wider carer’s policy, and we believe that this needs to be rectified.

Recommendations

- 7.1 Alzheimer's Society recommends the creation of new guidelines to be rolled out nationwide to standardise and futureproof Carers Assessments.
- 7.2 The Welsh Government should consider issuing guidance recognising self-neglect as a form of abuse, as is the case in England.³
- 7.3 The expansion of the definition of dependent to include those living with dementia and other unseen disabilities to allow their carers to access the same help and support in the workplace.
- 7.4 The creation of a training programme for carers to equip them with the skills necessary to provide the best possible care for as long as possible to those they care for.
- 7.5 The implementation of a social care levy as outlined by Professor Holtham in order to boost the ailing finances of the social care sector in Wales.
- 7.6 The inclusion of people living with dementia as carers in all carer's policy and thinking going forward.

Conclusion

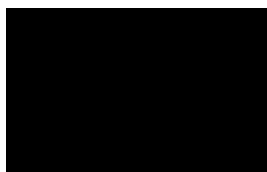
We welcome the Health, Social Care and Sport Committee's interest in the important topic of the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers. Whilst the evidence outlined above may seem overly negative, we are aware that there is plenty of good practice undertaken by carers; those who work with them; those who provide information, support and advice; and those who offer services to carers.

What we have sought to achieve with this evidential submission is to outline to the committee where there are areas for improvement and to try and offer solutions to these issues. We are acutely aware of the issues that surround the funding of Health and Social Care in Wales and have aimed to provide solutions to these issues that fit into the current funding structures.

We hope that evidence contained in this document is informative and will help the committee accurately examine the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers.

If you require any other information, please do not hesitate to contact me.

Kind regards



Country Director, Alzheimer's Society Cymru

³ <https://www.scie.org.uk/safeguarding/adults/introduction/types-and-indicators-of-abuse#self-neglect>

WLGA AND ADSS CYMRU EVIDENCE TO THE HEALTH, SOCIAL CARE & SPORT COMMITTEE'S INQUIRY INTO THE IMPACT OF THE SOCIAL SERVICES AND WELLBEING (WALES) ACT 2014 IN RELATION TO CARERS



CLILC • WLGA

SEPTEMBER 2018



ADSS Cymru

Leading Social Services in Wales

Yn arwain Gwasanaethau Cymdeithasol yng Nghymru

About Us

1. The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.
2. The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.
3. The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.
4. As the national leadership organisation for social services in Wales, the role of the Association of Directors of Social Services (ADSS Cymru) is to represent the collective, authoritative voice of Directors of Social Services, Heads of Adult Services, Children's Services and Business Services, together with professionals who support vulnerable children and adults, their families and communities, on a range of national and regional issues of social care policy, practice and resourcing.

The important role of carers

5. According to Carers Wales, there are 370,000 people caring, unpaid, for a family member or friend, and 3 in 5 of us will be carers in our lifetime. This is the highest proportionate figure of all

UK countries, with 103,594 people in Wales providing over 50 hours of unpaid care per week. It is estimated that the care provided by unpaid carers in Wales is worth an estimated £8.1 billion a year. The number of carers continues to rise and it is estimated that by 2037 there will be over half a million carers in Wales - a 40% rise. Many do not define themselves as 'carers', but a family member, friend or neighbour – however the act of caring, the time it involves, the physical and emotional expenditure, the impact on working life and social networks can significantly affect the carer's health and wellbeing, financial security and ability to meet their own life-time's goals.

6. The demographic changes being seen across the UK will also have an impact on unpaid carers. An ageing population with improved life expectancy for people with long term conditions or complex disabilities means the need for more high level care provided for longer. We are likely to see more older people in a caring role, with the number of carers over 85 predicted to double in the next 20 years. Increasing hours of care often results in the general health of carers deteriorating incrementally. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities. Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care, placing further pressure on our already over-stretched system.
7. Supporting and improving the wellbeing and rights of unpaid carers is important for councils who fully recognise the vital role and the significant contribution carers make to people with social care needs, and the wider health and care economy. Without these vital informal carers, the safety net of care and support they provide to thousands of people every day would collapse.
8. As a society, we need to do more to ensure the role of a carer is seen as a positive, rather than a stigma, and we are keen to work with Welsh Government, carers and carers organisations to make sure that carers are fully supported and signposted to services to avoid them and families reaching crisis point and care breakdown. It is fundamentally important for society as a whole that carers have the support they need to maintain their own wellbeing and to be able to lead fulfilling lives; to maintain social relationships; undertake education and training; maintain employment; and be active community members.

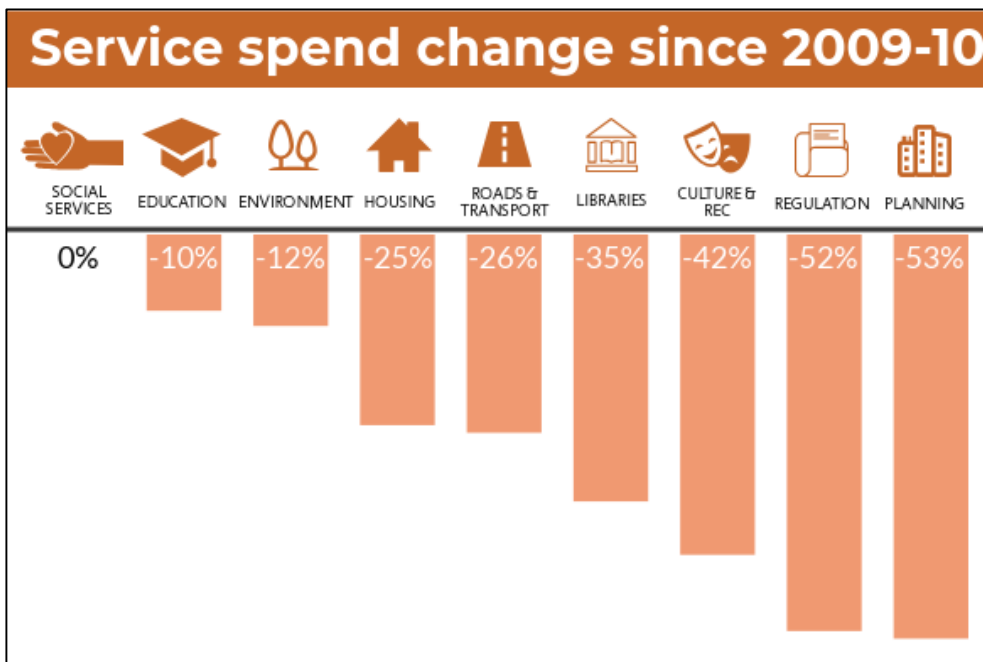
Local government funding

9. Councils' ability to provide this well-being support is however undermined by the continued cuts to council budgets. If we are to achieve our aspirations for all carers - who are needed in increasing numbers to address the rise in those needing care - and fulfil the ambition and intent of the Social Services and Wellbeing (Wales) Act, Welsh Government needs to ensure that local authorities are adequately funded to meet the requirements that are being placed upon them.

10. Local government provides more than 700 local services, a significant proportion of which help improve wellbeing and tackle the social determinants of health. This includes housing, employment, welfare, leisure and transport and these help support the health and wellbeing of carers.

11. However, over the last 8 years Council’s core grant funding has reduced by 22% after adjusting for inflation. If you take schools funding out, core funding has fallen by 35%. Figure 1 below shows how this reduction in funding has impacted on individual local government service areas.

Figure 1 – Service Spend Change



12. The statutory services of social services and education have been protected as far as possible by local government. This has meant that other non-statutory preventative community based services, such as leisure, parks, adult education, housing, transport and community facilities, all of which support carer’s wellbeing and health, have faced the brunt of cuts to local authority budgets out of necessity. The report by Wales Public Services 2025, ‘Austerity and Local Government in Wales: an analysis of income and spending priorities, 2009-10 to 2016-17’, highlighted the significant impact that eight years of austerity have had on local public services. Cuts in the smaller but vital services have been deep, with question marks over their future sustainability if a further period of cuts were to continue.

13. Local government has kept the worst consequences of austerity at bay in recent years but its impact is now catching up with councils, threatening services that improve our lives and our communities, including services vital to supporting carers. We know that the cumulative financial pressures will continue to mount for local government over the next four years. Just to stand still on providing current services, local government would need a revenue increase of £264m (5% of

net spend) in 2019-20 and 4% the year after. During this period unavoidable workforce costs will increasingly drive inflationary pressures and in 2021-22 and the year after, the overall inflationary pressures will run at around 3% in each year. Despite the best efforts of local government against the scale of the reduction outlined, these efforts can only go so far. Without a more fundamental review of how we fund services there is little wriggle room for further cuts. The current model is not sustainable, annual incremental budgeting just stores up problems for the future.

14. Further information on the financial pressures facing local authorities in Wales can be found in the WLGA's publication 'Fair and Sustainable Funding for Essential Local Services'¹
15. In our evidence to the Health, Social Care and Sport Committee's scrutiny of the Welsh Government's draft budget we were clear that the local government funding position has serious consequences for wellbeing. It constrains social care which, in turn, constrains the voluntary sector and care providers. This all points to the need to urgently reform our current arrangements and take on the complex task of developing a long term sustainable funding framework for social care.
16. It is therefore welcomed that the new long-term plan for health and social care, *A Healthier Wales*, identifies the need to achieve a sustainable funding model for health and social care, recognising that health and social care currently consume a growing proportion of the Welsh Government's budget, at the expense of other public service areas, which also have a great influence on the health and wellbeing of the people of Wales. There is a desperate need for this work to lead to the provision of an additional source of funding for local government as part of an overall settlement that provides sustainable funding for all the vital services that councils deliver. All funding options to tackle the social care crisis must be on the table given the scale of the current crisis.
17. The recent announcement of additional consequential funding coming into Wales as a result of the UK Government's decision to provide an extra £20bn a year by 2023 to the NHS in England also provides Welsh Government with an opportunity to look at providing much needed additional funding to local government which would enable Welsh councils to plan with some surety over the next three years and provide local authorities flexibility to best meet local demand and needs, focussed on improving outcomes for their citizens and communities. Recent funding made available for social services from Welsh Government has only been for specific pieces of work and to support new initiatives rather than to be able to meet increasing demand and current pressures.

How councils support carers

¹ Available at: <https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1754>

18. Both the WLGA and ADSS Cymru welcomed the principles of the Social Services and Wellbeing (Wales) Act, but we need to recognise the increasing expectations that are being placed on local authorities at a time of reducing resources. Working alongside Welsh Government, we have played (and continue to play) a key role in supporting the implementation of the legislation. The Social Services and Wellbeing (Wales) Act sets out important legislative changes for carers, crucially giving them the same recognition and parity of esteem with those they support. Local authorities have a duty to offer assessments and support plans for carers, developed with them as equal partners, and with the goal of enabling carers to live the life they want to achieve.
19. These responsibilities that are specific to carers sit alongside other general provisions within the legislation, which are also relevant to carers. These include, for instance:
 - A duty to provide an information and advice service
 - A duty to ensure the provision of preventative services.
20. Under the Act all regions are also required to develop and publish Regional Population Needs Assessments, which provide an assessment of the care and support needs of their area, with carers being one of the core themes of the assessments. These assessments have now been completed and regions have also recently published their Population Area plans, another requirement of the Act. All identify the important and vital role that unpaid carers undertake and are committed to improving access to suitable breaks and respite that meet the varied, often complex needs of the people they care for. Regions recognise it is vital that all carers, young and old, need to have a break from their caring role, with a need for suitable and flexible respite opportunities to help support people to remain in their caring role. However, we also need to acknowledge the impact that funding cuts have placed on local authorities and their capacity to be able to continue to offer services such as these. Many regions are mapping or exploring more flexible options that meet specialist needs, such as autism or dementia. It is acknowledged that planning for carers services needs to consider the potential future needs of older carers and find ways of supporting older carers to plan ahead. Some regions have also highlighted concerns over the sustainability of carers services, which in many cases is provided through third sector support which is often reliant on short term grant funding.
21. The assessments identify that there are dedicated services for young carers linked to schools with additional one to one support and access to emotional support. There are examples of using social media to support young carers and involving young carers in service development. Respite and access to leisure opportunities are also available. A Team Around the Carer approach is also being utilised in one area. This supports the recent Care Inspectorate Wales (CIW) thematic review, 'In Support of Carers', which found that, "young carers generally are well supported", but warned that there are an increasing number with complex emotional needs and the lack of child mental health services means that workers supporting young carers are dealing with some challenging and complex issues.

22. A recent report by the Social Care Institute for Excellence (SCIE), 'Preventative support for adult carers in Wales' identified a number of examples in Wales of services that support carers, including:

Services to support better identification and recognition of carers

Blaenau Gwent ran a Carers Engagement Project based within GP surgeries and run by the third sector on behalf of the local authority. The project employed carers support workers to raise awareness of carer support, to offer signposting and referral services, facilitate access to assessments and respite, and provide broader support and counselling

Rhondda Cynon Taf Council employs carers' champions, volunteer members of council staff who act as the main contacts for carer information in the service department in which they work. The network of champions encourage other staff to complete carer awareness training and gather carer information to cascade internally and to carers.

Services providing information, advice and advocacy

The Welfare Benefits Service in Swansea is funded by Swansea Council to support carers, and prevent them from having to access higher tier and more expensive services. It offers benefits checks to maximise carer income, support with filling in forms and making claims, support with appeals and access to grants for carer support. Carers using the benefits service are also encouraged to make use of the full range of Swansea carers' centre services, which includes a local authority funded counselling service.

Dewis Cymru is a key information hub for carers looking for information or advice about their wellbeing. Funded and managed by Local Authorities across Wales so that information can be kept up to date and relevant. It acts as a signposting service for up to 6,000 local and national services across Wales.

Shared Lives Wales

There are 12 Shared Lives schemes in Wales, which is the first of the four UK nations to have Shared Lives services across almost every local authority area. Almost half (46 per cent) the people using Shared Lives in Wales in 2015 to 2016 enjoyed flexible, personalised short breaks and day support in a Shared Lives carers' home. Short breaks are an effective and affordable alternative to traditional respite care, particularly for families supporting people with dementia.

Caerphilly County Borough Council has addressed the emergency needs of carers through a range of measures, including advice on dealing with emergencies and an emergency card scheme together with a carers' time out service enabling carers to access time to attend their own appointments and health treatments.

23. SCIE has also published a series of practice examples which evidence the types of models of support available to carers in Wales (further details can be found in Appendix 1), with examples including:
- Programmes of support being designed to support emotional wellbeing and improve outcomes in relation to isolation, stress and identity. This includes access to free training, workshops, social events and support networks.
 - Introduction of carers' emergency cards - a credit card sized piece of plastic that denotes that the carrier is a carer and provides a number to contact in case of emergencies (24 hours per day). Ringing this number enables contingency support to be arranged.
 - Carers Support Services which help carers in managing their health and wellbeing needs, providing support and advice
 - Introduction of a dedicated carer's coordinator roles to oversee future developments and implementation of the Social Services and Well-being (Wales) Act 2014.
 - Carers Champions whose role is to act as a liaison point between carers and services. They provide advice and information to carers; lead on carer issues at a service level and cascade information to their colleagues about what carers need.
24. Whilst much work is ongoing the SCIE report, 'Preventative support for adult carers in Wales' identifies that considerable challenges remain in providing consistent support and better outcomes for carers across the UK. They found that the most effective services in both England and Wales have been developed in response to local priorities, shaped by a strong carer voice at local level, and supported by proactive partnership working between health, social care and the voluntary sector. They aim to provide person-centred, holistic support tailored to specific needs. One of the key messages of the research is that caring is more than a health and social care issue, and to develop caring communities, carers' rights need to be embedded within broader health, social and employment policies.
25. One of the overarching challenges is identification, both encouraging people to self-identify as a carer but also with health and care professionals identifying carers, so that carers are able to access the information and support that is available. When carers do not conceptualise or identify themselves as carers but see the support they provide as a natural part of their relationship with the cared-for person they may be reluctant to come forward and fail to access benefits or support services, which could improve their quality of life. According to a poll published by Carers UK on Carers Rights Day, "the public is unable to recognise friends and family that care" with 51 per cent of those polled underestimating the number of carers in their own family, friendship network or workplace. Carers UK's 'Missing Out' report noted that in Wales 55 per cent of carers took more than a year to recognise their caring role, while 24 per cent took more than five years to identify as a carer. Early intervention, identifying carers before they reach crisis point, is crucial, as is identifying priorities and outcomes for carers on an individual basis once they have come forward to provide the right level and type of support. This has shown to be particularly true in relation to

older carers (aged 80 years old or above) looking after a spouse or partner, BME carers, LGBT+ carers, and carers of people with dementia or mental health issues where there may be perceived to be an element of stigma and a wish to keep things private.

26. The challenge around identification and awareness is also evident from the recent figures which show that more than half of those offered a carers assessment refuse it, pointing to the need to increase our awareness raising efforts as part of an on-going process.
27. Issues of identification are compounded by those of accessibility. For example, carers living in remote or rural communities in Wales will have specific needs where social isolation, poverty, deprivation, lack of transport and long distances to travel to access health and care services mean that rural carers face additional challenges in accessing services. For example, if there are significant transport times this has an impact of the availability and length of time of respite care.
28. In Wales we need to have an overarching ambition to make being identified as a 'carer' a positive, with the support of our communities, so that more people can ask for support - and not just monetary help – to look after their own health, and ultimately benefit the whole of society, with a focus on encouraging people to self-identify as carers as a route to unlocking support from the community, public sector and businesses. This could include making it clearer that supporting the carer is supporting the one who is cared for, and that being a carer does not detract from being a husband, wife, sibling, daughter, son, friend, etc.
29. There is a need for practical recommendations on how to support carers who don't self-identify. The NHS and GPs are crucial in helping to identify carers, but there may also be more community-based or voluntary services adept at identifying and supporting carers. There may also be particular groups that are more difficult to identify. Working with other sectors, for instance faith groups, may open other avenues for engaging with these groups.
30. In our evidence to the Parliamentary Review we highlighted the importance of the workforce, and in particular the need to ensure that unpaid carers are recognised, valued and included as part of the workforce planning to ensure carers receive appropriate training and support for the roles they undertake. It is positive to see 'A Healthier Wales' identify the need to recognise and support the vital role played by the informal workforce of unpaid carers and the need for greater parity of esteem not just between health and care professionals, but with carers as well. The new long-term workforce strategy provides an opportunity to ensure that the workforce we have in Wales, including carers, feel valued and supported and are enabled to access relevant education, training and support opportunities.
31. There is also a need to recognise that the ability of councils to deliver any new ambitions is reliant on additional investment from Welsh Government. With a case for investment, whilst acknowledging that upfront investment to save money later requires that additional investment

money to be available in the first place. There is a clear case here around the early intervention and prevention agendas for carers.

Appendix 1 – Types of models of support available to carers

Carers Resilience and Wellbeing Programme - Ceredigion County Council Carers Unit

Since autumn 2016, Ceredigion County Council Carers Unit have been working to deliver and evaluate a programme of support for local carers designed to support emotional wellbeing and improve outcomes in relation to isolation, stress and identity. The ultimate goal is to enable carers to become more resilient so that they are better able to cope with their caring responsibilities and prevent crises from occurring. The programme was originally designed as a means of supporting the wellbeing of frontline care staff and to reduce the risks associated with the high levels of stress and burnout that can be a feature in the sector. However, recognition of the role that family and friends play 'on the frontline' when caring for a loved one suggested that the programme might have wider applications. In response to a commission from the Mid Wales Collaborative and Hywel Dda University Health Board the programme was adapted for carers.

The programme encourages carers to develop a 'situational awareness' of their own resilience (and regularly consider at what level this is), and motivates them to improve this by taking part in activities that can improve their wellbeing. Underpinning this is a theoretical model drawing on a range of approaches from the fields of psychology, neuroscience and pedagogy.

The first phase of the project ran for seven months and was designed as a pilot service in order to determine whether the programme could be adapted for use with carers and to measure the impact of the programme on carers' outcomes (in particular those aligned with the Social Services and Well-being (Wales) Act 2014).

Carers Support Service - Vale of Glamorgan

Carers support in the Vale of Glamorgan is being reviewed, with Cardiff Council, as part of their joint response to the Social Services and Well-being (Wales) Act 2014. This is part of the regional partnerships' work stream dedicated to carers. As the work stream is relatively new, the first objective is to conduct scoping work and map support for carers that is already in existence. This information is then fed in to a long-term strategy.

In terms of support for individual carers, a key piece of work has been the introduction of the carers' emergency card. This is a credit card sized piece of plastic that denotes that the carrier is a carer and provides a number to contact in case of emergencies (24 hours per day). Ringing this number enables contingency support to be arranged. The service is run jointly with Cardiff Council using existing record management systems and out of hours arrangements, and provides carers

with reassurance that the person that they look after will be cared for if anything should happen to them.

The service also provides help with carers in managing their health and wellbeing needs. For those with relatively low level needs, the service enables them to experience a range of alternative therapies such as massages and holistic treatments. These provide an immediate relief from stress but during the course of the treatment, the carer is also given practical tools that they can take away that will help them to take care of themselves, e.g. in relation to their sleep patterns, diets, and nutrition. The key is to help them to recognise the importance of looking after themselves. Where a carers needs appear to be more acute the service encourages them to seek medical advice.

The council also commissions Care and Repair, a tailored service designed to help carers with small maintenance problems such as fixing a broken lock or a broken tap. Services are commissioned on a local basis, using outcomes based contracts. These are monitored using a Results Based Accountability system (on a quarterly basis). This has demonstrated good results in terms of the number of carers supported and the added value provided by the service, for example by identifying other issues and risks (e.g. fuel poverty) that can be addressed either directly support or by signposting to other services.

Carers Project - Monmouthshire County Council and the Gwent Association of Voluntary Organisations (GAVO)

Monmouthshire Carers Project is an initiative run by Monmouthshire County Council and the Gwent Association of Voluntary Organisations (GAVO). The Monmouthshire Carers Project is the umbrella under which commissioned providers, the Monmouthshire Carers Strategy Group and carers work collaboratively in providing information, advice, events, training and support for each other, the third sector, social care, health and other organisations.

The programme provides free access and support for carers (via self-referral) including free training, social events, Carers Week events, Carers Rights Day (respite and transport can be provided so the carer can attend these events), the Carers Handbook, emergency and future planning booklet, carers emergency card and most importantly opportunities for carers to talk and be listened to. The goal is to be as responsive as possible and to ensure that services are designed with input from carers.

The initiative also places an emphasis on the role of GP surgeries in supporting carers with the Investment in Carers scheme (developed in collaboration with Hwyl Dda Health Board). The Investors in Carers scheme is a framework of good practice which GP practices can utilise to develop their carer awareness and ways of working to support carers on their patient register.

Another key strand to the project is the young carers strategy, which was developed in collaboration with a group of young carers and highlights the importance of working with providers to provide preventative support.

Carers Support Service - Caerphilly County Borough Council

Caerphilly County Borough Council carers support service is an inclusive support network that seeks to improve carer outcomes and promote the caring agenda. The service has been a long standing service, however it was significantly development through the introduction of a dedicated carer's coordinator role to oversee future developments and implementation of the Social Services and Well-being (Wales) Act 2014. This post was established in September 2016 and has resulted in the service being able to provide a wide range of support. This includes the organisation of frequent social events as well as activities during Carers' Week and Carers' Rights Day. The service also provides information through newsletters and mailing lists (both in print and electronically) and staff manage an online carer support group (using a closed Facebook page). The service has also worked in partnership with neighbouring local authorities and health board to establish the carers grant scheme. They have relaunched the carer's emergency card and the 'time out' respite service.

Team members also work hard to promote the importance of carers' assessments and ensure that all carers receive an assessment if they wish to do so. However the service is an inclusive one and will ensure carers have access to all necessary information and support groups even if they do not wish to have a carers assessment. The first task for staff was to identify what was important to carers and what barriers there were to achieving this by asking 'what matters to you?' The intention in asking this question is to ensure that the focus is upon the carer as an individual and not purely on their role as a carer. The assessment remains focused on identifying potential solutions rather than simply listing problems (a cultural shift in assessment practice). This approach has seen many benefits to carers, including carers being supported to access small breaks, education opportunities, and support to carers to meet their own personal outcomes and continue in their caring role.

Since its inception, the carers coordinator role has ensured the objectives of the service have expanded to become more strategic in outlook are underpinned by a recognition that to be effective the service must be responsive to the needs of the local carer population. This was in part informed by consultation on a carers rights day held in November 2016, where the emphasis on outcome focused, person-centred support that recognised the needs of the individual was identified.

Consequently, there is a significant focus on engagement with local carers to provide a clearer understanding of their needs, and to determine which aspects of support are working well and which are not. By doing so it is hoped that a more sustainable and responsive service can be provided which will prevent crises and reduce the need for intensive intervention, thereby meeting the requirements of the Social Services and Well-being (Wales) Act 2014. Over the next two years a

range of consultation events are planned to inform the development of the service strategy, including an event specifically for young carers.

The service is funded by the council, the integrated care fund and is staffed by a small team of four. A range of other organisations are also involved; for example the carers grant scheme is overseen by the Carers Trust and services for young carers are contracted to Barnardo's.

Carers Support Service - Rhondda Cynon Taf County Borough Council

Rhondda Cynon Taf (RCT) Borough Council's carers support project provides support and advice to individuals living in the area who care for a family member, friend or neighbour who is ill, frail, has a disability, suffering with a mental illness or substance misuse problem. The service has been running for twenty years and takes an early intervention and prevention approach to support aiming to meet low level needs of carers in order to prevent crises. The geographic profile of the area can make it difficult to co-ordinate support as the borough is relatively large and the towns often lie some distance from each other. As a result, the service has to be a little more creative in the way it works, with events being held in places such as local job and leisure centres.

The service is run by six members of staff working both full and part time. Referrals can be made from health and social care practitioners as well from the third sector professionals and from self-referrals. Support is provided through a range of projects. In addition to one to one assistance and signposting to carer's assessments and direct payments; the service also produces a carer's newsletter, an in house counselling and peer support service, advice regarding legal problems and facilitates access to local authority services. The service also regularly runs outreach services and coffee mornings as a means of informal support as well as working with the Past Carers group to support individuals whose caring roles have come to an end.

The Project has strong links with RCT leisure services and offer discounted access to carers to council run leisure facilities in RCT. A key piece of work that has proven very popular amongst local carers is the Carers Emergency card. This is a credit card sized card that carers carry with them and is used as source of identification in case they have an accident or are suddenly taken ill. By ringing the support line number on the card (staffed 24 hours per day and 365 days per year) help can be arranged for both the carer and the person whom they look after.

The Project provides a range of workshops, events and training to carers across RCT. These include anything from first aid, manual handling, stress busting and healthy eating, to family fun days, relaxed inclusive cinema screenings and the more social craft workshops and team building opportunities. All of this is provided to carers free of charge. The service also provides targeted support, with staff focusing on carer populations with more unique needs, for example, young adults (helping with work, education, etc.) and parent carers of children with additional needs (working closely with the Disabled Children Team). Staff also work with the Alzheimer's Society to

run the Carers Information and Support Programme (CRISP) which provides support to carers of people with dementia and empowers them to address their own wellbeing needs.

In addition to working with individual carers, the service also aims to help services to understand the needs of carers through the Carers Champion role. The role of a champion is to act as a liaison point between carers and services (their employer). They provide advice and information to carers; lead on carer issues at a service level and cascade information to their colleagues about what carers need. There are currently champions working in a range of settings such as day centres, children's services, colleges and schools, community teams, home care services, housing teams, job centres, leisure centres, social care teams, and welfare rights teams.

Agenda Item 6.1

Gofynnwch am/Please ask for:
Llinell uniongyrchol/Direct line:
Ebost/Email:

13 November 2018

[Redacted]
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Dr Dai Lloyd
Chair, Health, Social Care and Sport Committee
National Assembly for Wales
Ty Hwyl
Cardiff Bay
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Dear Dr Lloyd

Additional Information as Follow up to Evidence Session

Thank you for the opportunity to provide evidence on Thursday 11th October to the Health, Social Care and Sport Committee as part of the enquiry into the proposed Autism (Wales) Bill on behalf of the WLGA. I agreed to forward further supporting information in relation to the funding of the Integrated Autism Services (IASs) and the National ASD Development Team. I also include some further case studies in relation to the impact of Integrated Autism Services across Wales and support for autistic individuals provided through Local Authority ASD Lead Officers.

Funding

I would like to confirm the point I made at the meeting that the WLGA does not play any part in distributing the £13 million (over 5 years) that has been made available by Welsh Government through the Integrated Care Fund for the development of IASs across Wales. I was surprised to hear that the WLGA was thought to be the 'gatekeeper' of this funding and I can confirm that this is not the case.

Integrated Care Funding for autism is allocated regionally to each of the seven Regional Partnership Boards via the Health Boards. Where underspend occurs, limited amounts of ICF have been allocated to the WLGA to progress national approaches to training, for example: training for Community Mental Health Teams in gaining a greater understanding of autism and its impact on mental health, which is being rolled out nationally via each Integrated Autism Service team linking to the relevant CMHTs. The National ASD Development Team also provides a monitoring role in collating ICF information and performance returns to Welsh Government.

The WLGA hosts the National ASD Development Team, working in partnership with Public Health Wales. The team staffing and core activity is funded by Welsh Government through an annual

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Croesawn ohebiaeth yn y Gymraeg a'r Saesneg a byddwn yn ymateb i ohebiaeth yn yr un iaith.

Ni fydd defnyddio'r naill iaith na'r llall yn arwain at oedi.

We welcome correspondence in Welsh and English and will respond to correspondence in the same language.
Use of either language will not lead to a delay.

social services grant to deliver the team's Annual Work Plan ([link here](#)). The social services grant funding for 2018/19 in support of the team and their work is £607,000. The team have also secured a grant of £81,390 from WG's Education Directorate this year to develop resources and training programmes on autism for Further Education and Work Based Learning providers.

The National ASD Development Team supports the delivery of the Welsh Government's ASD Strategic Plan and Delivery Plan in conjunction with key stakeholders. The 2018/19 work plan is a consolidation of work in previous years and includes the ambition to rollout out the awareness raising and training resources across Wales in an effective way with the support of partners and stakeholders. The work plan builds on a foundation of a number of years of work among partners with a commitment to supporting and responding to the needs of autistic individuals and children and their parents and carers. The implementation of the Integrated Autism Service across Wales is a further key priority and the team works with the 7 Regional Partnership Boards (Social Care and Health) to support the effective establishment and delivery of these services for the benefit of autistic individuals, children with autism and their parents and carers in the context of existing services. The resources referenced above represent an important underpinning of the IAS delivery. The Annual Report detailing the activities and outcomes in relation to 2017/18 is available [here](#) and has been previously circulated to all Assembly Members.

Snapshot IAS Case Studies – Impact

Cardiff & Vale – Case Study A

A young man in his mid-twenties, very anxious and spent most of his time at home, unable to go anywhere without his dad. His theory of mind issues mean that he doesn't see why he should conform to any of the demands society places on him.

He has been unable to access services in the past and this is linked to a history of violence. He has been attending the IAS for some weeks having 1:1 sessions with psychology and with support staff.

When he first came he didn't say anything and would become angry if asked to do anything or make a decision. Now when he comes he is very responsive, offers information and he can complete whole sessions without a meltdown.

Staff are working to increase his independence and he has now asked to be referred to the Cardiff "Into Work" service (an employment support service with Cardiff Council). He wants to do voluntary conservation work in parks which is being facilitated for him. Internally to the IAS he will be taking part in the cooking skills course. To the delight of his family he is being helped to create a timetable for him to keep his own room clean and tidy (noting this is a person who didn't see why he should do anything for himself). This may not actually work because he's still a twenty something young man and untidy rooms aren't confined to people with a diagnosis but it's a step.

Progress of this nature is significant for this individual. The success of this case required a multiagency approach: the person would not have been able to access the work support staff can provide towards volunteering, employment etc without psychological input and that psychological input alone would not have moved him towards independence. It also highlights the vital contribution clinicians make outside the narrow bounds of diagnosis.

Croesawn ohebiaeth yn y Gymraeg a'r Saesneg a byddwn yn ymateb i ohebiaeth yn yr un iaith.

Ni fydd defnyddio'r naill iaith na'r llall yn arwain at oedi.

We welcome correspondence in Welsh and English and will respond to correspondence in the same language.
Use of either language will not lead to a delay.

Cardiff & Vale – Case Study B

Young woman was seen by the Community Mental Health Team but they couldn't get her to engage. Not a criticism of the CMHT but a simple acknowledgement that working with this young woman required a level of expertise in autism far beyond basic knowledge and it was wholly appropriate for the CMHT to seek support from the IAS team.

She presented as a person who would not speak at all, IAS involvement has included both speech and language therapy input and support staff. She is now talking and beginning to address issues in her home. This has included supporting mum to get a carers assessment. She is now attending the adult forum unsupported, it is very early days but she has turned a corner and is making progress. This person is supported by "services" but it needed the specialist knowledge and input that the IAS working with CMHT to achieve change.

This is another example of non-diagnostic clinical involvement which was essential in this case and provides an example of how services can and do work together for the benefit of the person concerned.

Cardiff & Vale – Case Study C

Young woman who had dropped out of university with psychosis and is under the care of the Community Mental Health Team. Integrated Autism Service is involved to address autism aspects. She has been recently diagnosed and was looking to grow in confidence and wanted opportunities to fill her days constructively.

IAS input and support has resulted in her doing Open University modules that help her move towards the academic aims she has. She will be attending the post diagnostic group and the Social Eyes social skills training group. She has been referred on to Peer Mentoring, this is a service for people with mental health issues but many adults with autism also have mental health conditions to some extent or another. Peer mentoring has provided her with a mentor and they will be doing some bee keeping. She is attending the adult forum and meeting other adults with the diagnosis. She has also been directed towards and is attending stress control courses provided by the Primary Mental Health Service. This is a young woman who was in a very dark place but she can now see some light.

Once again, provision of a care and support plan through social services would not have achieved the outcomes an integrated team approach has achieved.

Gwent – Case Study D

A sub-group of referrals received in the Gwent IAS demonstrated a need to support young, autistic women with understanding relationships as well keeping safe online. In many cases, these women were recognised to be vulnerable to potential abuse/exploitation etc.

One individual (SO) self-identified difficulties in managing inter-personal relationships as well as traumatic experiences related to sex. The IAS responded to this demand by connecting with a third sector partner to deliver support to these young women. The SAFE (Sexual Awareness for Everyone) Project has been commissioned (by the Big Lottery) to

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Ni fydd defnyddio'r naill iaith na'r llall yn arwain at oedi.

We welcome correspondence in Welsh and English and will respond to correspondence in the same language.
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deliver peer led sessions that support disabled young women to understand friendships, relationships and keeping safe online. This was delivered jointly with SAFE and the IAS in April/May 2018. SO attended three out of the four delivered sessions and responded positively to peer led approach.

SO said that she would like to share what she learned with other young women. The SAFE project offered SO a volunteering position and SO will help to deliver an upcoming group in the summer of 2018. SO will also be working towards achieving an accredited Millennium Volunteering award.

The National ASD Development Team has worked with IAS and Local Authority ASD Leads across Wales to produce a compendium of case studies which can be made available to the Committee on request. We have also noted that there has been some engagement with autistic people by the Committee to date. The National ASD team has forged a number of contacts with autistic people who we have been encouraging to feed their views into the Committee. If there are opportunities for the National ASD team to support you in this, within your timescales, we would be pleased to do so.

I hope this additional information is helpful in better understanding the role of the National ASD Development Team and the value and benefits being gained through the IASs. Please do not hesitate to contact me if you require further information.

Yours sincerely



Director of Social Services and Housing

Agenda Item 6.2

Paul Davies AM/AC

Aelod Y Ceidwadwyr Cymreig dros Preseli Penfro
Conservative Member for Preseli Pembrokeshire

Llyr Gruffydd AM
Chair, Finance Committee
National Assembly for Wales

16 November 2018

Dear Llyr,

Autism (Wales) Bill

Further to the Cabinet Secretary for Health and Social Services' appearance before the Finance Committee to give evidence on the Autism (Wales) Bill, I would like to respond to some of the issues raised during the session and the views expressed by the Cabinet Secretary.

Costs provided in the Regulatory Impact Assessment

In relation to costs outlined in the Regulatory Impact Assessment (RIA), you will be aware that the Cabinet Secretary did not provide me with important financial information I requested relating to the current costs of Autism Spectrum Disorder (ASD) services. Throughout I have sought to make every possible effort to provide comprehensive financial data in the impact assessment and, notwithstanding the lack of data from the government, respectfully submit that the financial analysis set out in the impact assessment is a fair reflection of the costs and savings.

I note the Cabinet Secretary's suggestion of engaging a health economist to assist in this process. It is clear from my evidence that I sought robust expert advice on the available data. It is concerning to note the difficulties the Cabinet Secretary outlined to you in apportioning ASD specific spend from wider spend on neurological development conditions, as one would expect the government to be capturing this data as part of its existing ASD activities. Further, if this information is not readily available, I'm unsure as to how a health economist could have assisted in this instance.

Despite the lack of information available to me, the RIA sets out the best estimates of the cost impact of the options. To help inform detailed costings I engaged with a number of health economists, academics and organisations delivering services. As has been discussed in scrutiny of this Bill in the Health, Social Care and Sport Committee, there is still no data published on ASD waiting times, so I performed my own research by contacting local health boards directly for waiting times data, Dr Dawn Wimpory at Betsi Cadwaladr University Health Board and her colleagues at Bangor University who manage a current database for detailed discussions on how a data collection system could work and what it could cost (as well as information on the current processes) and validation of our methodology.

In the absence of any data on number of people with ASD diagnosis, services provided or the wider impact on carers, Professor Tommy MacKay and his team of experts, from the University of Strathclyde and London School of Economics, who worked on the The Microsegmentation of the Autism Spectrum: Economic and research implications for Scotland report, helped me with my approach to estimating the costs of ASD in Wales. I am grateful for figures that ASD Info Wales provided when I approached them for information on ASD specific training developed and provided in Wales.

The official supporting the Cabinet Secretary at the Finance Committee session acknowledged that the methodology used in estimating costs under option 1 followed the same approach as would have been adopted by the Welsh Government. However, the official reported there were points of detail around some “fundamental flaws”. As an example, the official cited the costs outlined on page 57 of the RIA and Table 5, querying whether these were 2013–14 or 2017–18 prices. Table 5 sets out an extract from the report, ‘The Microsegmentation of the Autism Strategy’, which are in 2013–14 prices. However, paragraph 299 of the Explanatory Memorandum notes the resulting costs were discounted back to the present value (PV) using the discount rate of 3.5%, which is the HM Treasury’s central rate (to which paragraph 245 of the Explanatory Memorandum refers).

Diagnosis focused approach

I would like to refute the view continuously expressed by the Cabinet Secretary that the sole focus of the legislation is to achieve a diagnosis of ASD. As I explained in my evidence to the Health, Social Care and Sport Committee, the claim that the Bill is overly focused on diagnosis is misleading. The Bill is not solely concerned with diagnosis, but instead puts forward an overarching regime that

seeks to address all the needs of a person with ASD, both pre and post diagnosis. It is concerned with the range of services which people with ASD may access, including healthcare, education, employment, housing, Welsh language, and advocacy.

The Cabinet Secretary has asserted his belief that resources would be diverted from support services in order to meet the demands of an increase in demand for diagnosis. I would like to emphasise that is not the intention of this Bill. I have identified that additional resources will be needed to achieve the 3 month timescale, including staffing resources, and I have set this out in the Explanatory Memorandum. Introducing timescales will have the effect of concentrating effort, but if the necessary resources are put in place there should be no detrimental effect on other service areas. Further, I have received considerable evidence that giving children and adults an earlier diagnosis and having trained staff to deliver services appropriate to their needs will result in better outcomes, including longer term savings.

As noted at paragraph 411 of the Explanatory Memorandum, there is a growing body of evidence to suggest that early intervention programmes can improve overall functioning, social communication, language, cognition and adaptive behaviour in children with ASD. Examples of the benefits of timely diagnostic assessment of children and adults are set out at paragraph 422. These note that supported employment can be both effective and (strongly) cost-effective from a societal perspective, and has important economic benefits for people with ASD. The National Institute for Health and Care Excellence (NICE) reports¹:

A systematic review (11 studies, n= 67,251) examined the costs, benefits and the cost-benefit ratio of employing adults with ASD, from a societal perspective and from the perspective of employers. The results indicated that enhancing the opportunities for adults with ASD to join the workforce is beneficial from a societal perspective, not only from an inclusiveness viewpoint, but also from a strict economic standpoint.

¹ 4 year surveillance (2016) Autism in Adults (2012) NICE guideline CG142. National Institute for Health and Care Excellence. Available at <https://www.nice.org.uk/guidance/cg142/evidence/appendix-a-decision-matrix-pdf-2600145326>

In its clinical guidance in respect of children and young people², NICE states ‘there are benefits in establishing the nature of any developmental or behavioural disorder. Many families and carers find the process helpful, and early recognition can avoid delayed diagnosis’. It also states:

No evidence was identified that addressed the cost effectiveness of recognising signs and symptoms of autism.... If it was decided that the child did not have autism but another differential diagnosis, the initial referral could still lead to earlier identification of the child’s other developmental or communication needs, which is likely to be a cost-effective use of resources ...The additional benefit of correctly identifying and referring on children with autism needs to be weighed up against the added cost to the NHS and stress to the family of over-assessing children and young people who do not have the condition. There was no data to help the GDG [the Guideline Development Group] in making its considerations, but the GDG consensus was that the benefits would outweigh the costs.

The Welsh Government has chosen to pursue a specific strategy for ASD, based on diagnosis, and has also indicated that the proposed code seeks to cover much of what the Bill does, so clearly it thinks that such an approach can work symbiotically with the existing legislation. The Refreshed [Autistic Spectrum Disorder Strategic Action Plan](#) has assessment and diagnosis as one its three key priority areas. It states:

Timely access to assessment services is vital for families so that each child’s needs are understood and appropriate services are put in place to support them to lead fulfilling lives. An early diagnosis will also enable parents to understand their child’s needs and to seek appropriate support in their caring role. Some adults with autism are not identified or diagnosed during childhood but may be helped by having access to assessment services as adults. (p9)

The lack of information on the services that are currently provided makes it difficult to make precise estimates of the additional costs for support services and the cost and other savings in terms of having an understanding of a person’s needs earlier and the preventative benefits of providing appropriate rather than potentially inappropriate needs to people with ASD and their carers. Paragraph 422

² Autism: recognition, referral and diagnosis of children and young people on the autism spectrum, National Collaborating Centre for Women’s and Children’s Health, Commissioned by the National Institute for Health and Care Excellence, September 2011. Available at <https://www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447>

of the Explanatory Memorandum provides further details on benefits of timely diagnosis. My approach was to look at the costs of supporting people with ASD and their carers as a whole in Wales. This was based on the latest in-depth research provided in the Microsegmentation report, which was applied to Wales and the methodology checked with the authors of that report.

Increase in demand

I note that the Welsh Government official also commented to you that the RIA is “silent” on costs beyond eradicating the diagnosis “waiting list”, and on the increased demand on services. He cited Northern Ireland, which had seen an increase in demand and pressure on diagnosis as a result of increasing awareness.

Wales also experienced an increase in demand for diagnosis following the introduction of the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP). In February 2016, the Welsh Government published the outcome of the external evaluation of the ASD SAP, which had been undertaken by the People and Work Unit³. This reported that the original ASD SAP, which had been published by the Welsh Government in April 2008, and the implementation of national and local infrastructure have ‘helped raise the policy profile of ASD, empowered individuals to develop and improve services and provided a focus for developments across Wales’⁴. It noted the outcome:

Increased awareness of ASD has contributed to increased rates of identification. This in turn has contributed to sharply increased rates of diagnosis among school age pupils in Wales, from approximately 0.2 per cent in 2003/2004 to 1 per cent by 2012/13 (Holtom et al., forthcoming).

This increased rate of diagnosis is broadly consistent with the most accurate prevalence estimates available. As noted at paragraph 291 of the Explanatory Memorandum, these are based on the Microsegmentation report’s recommendation that 103.5 per 10,000 population be used. Paragraph 366

³ Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan, Welsh Government, February 2016. Available at <https://gov.wales/statistics-and-research/outcome-evaluation-autism-spectrum-disorder-strategic-action-plan/?lang=en>

⁴ Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Executive Summary, Welsh Government. Available at <https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-summary-en.pdf>

demonstrates that we have assumed diagnoses will be above the prevalence rate to allow for some growth in demand. As highlighted in Dr Dawn Wimpory's evidence to the Health, Social Care and Sport Committee, better training should lead to better referrals and reduced incidence of repeat GP visits for people with undiagnosed ASD.

The significantly lower diagnosis rate prior to the ASD SAP suggests there were high levels of unmet need. It is important that people with ASD are identified and provided with any support they may need, and it is not a sustainable or acceptable position to take the view that persons with ASD should go undiagnosed. To support this, the provisions in the Bill for data collection would facilitate a comparison of diagnostic rates for each local health board in Wales against the expected prevalence.

Workforce capacity

I am aware of the workforce pressures that exist in ASD services, and indeed across wider health and social care services, and I acknowledge that workforce issues need to be addressed in order that ASD services can be improved. The Royal colleges responded to my consultations on the Bill and highlighted the workforce pressures ASD services face. While it would not be appropriate to include detailed workforce provisions in an autism Bill, I have taken account of staffing resources in the cost estimates. Paragraphs 393 and 394 of the Explanatory Memorandum detail how these costs have been estimated.

I accept that increasing workforce capacity will not happen overnight but it is an issue which needs to be addressed if we are serious about improving services for people with ASD. The Explanatory Memorandum does highlight additional funding needed to implement this Bill. The Impact Assessment also suggests that investment will be needed over a number of years to reflect the time needed to identify resources to reduce waiting times and provide training to relevant staffing. The Bill does not seek to duplicate or conflict with organisations current staff and resource planning, such as the current 3 year NHS planning regime. It would be expected that public organisations would include plans to implement this Bill into their current workforce planning.

Welsh Government proposed code of practice

Throughout the Stage 1 process, the Cabinet Secretary has referred to the ASD code of practice which he proposes to issue, as being able to do everything my Bill

sets out to achieve. Whilst it is difficult to comment on the proposed code without seeing it, it is possible to highlight a number of important differences between the code and the Bill. The code for example, will not:

- Introduce a waiting time target from referral to start of diagnosis in line with the NICE Quality Standard (currently 3 months);
- Require NHS bodies to collect data to enable them to improve the planning and delivery of services.

These are two of the areas of the Bill where I have undertaken the most detailed research, in conjunction with leading academics and health economists to provide cost estimates for the RIA.

The Cabinet Secretary told you that the code had already been budgeted for and that the Welsh Government is investing £13 million to underpin the delivery of the ASD strategy.

It is perhaps worth noting that many of the issues the Welsh Government is planning to address in the code are the same as those in the Bill (e.g. assessment and diagnosis; accessing care and support; staff training; planning, and stakeholder engagement in service planning and delivery).

I note that the Cabinet Secretary has agreed to provide you with approximate costs for the development and implementation of the code. This suggests that the Cabinet Secretary does have access to specific ASD data, rather than general unsegmented neurodevelopmental data. If this is not the case, then one has to ask how the government can properly plan for and cost its ASD related activities, and this further strengthens the need for the collection of valid data, such as that proposed under section 6 of my Bill.

Working with the Welsh Government

I note that the Cabinet Secretary told you that he had offered me the opportunity to be involved in the development of the code, but that I decided to pursue my Bill. I would like to make it absolutely clear that I have sought to work with the Welsh Government from the outset, and indicated early on that I would consider withdrawing my Bill, subject to specified improvements to ASD services being achieved across Wales. Early in the process I proactively provided Milestones to the Welsh Government, setting out where I believed gaps that exist in services and

support for autistic children and adults in Wales could be filled but, after some delay, received responses which did not provide sufficient detail or assurance that these Milestones would be met. Thereafter, I was given sight of early proposals for a code but I did not believe that these would achieve the objectives I set for my Bill. As I have still not had sight of the content of the code, despite indications that it would be available before introduction of my Bill, it is difficult to judge whether it will meet the aims of my Bill, and it would not have been appropriate to withhold introduction of the Bill on that basis.

Finally may I express my thanks in advance for your consideration of this further evidence, and I hope you will find the information I have provided useful. I am copying this letter to the Chair of the Health, Social Care and Sport Committee.

Yours sincerely,

A handwritten signature in grey ink that reads "Paul Davies". The signature is written in a cursive style with a large initial 'P' and 'D'.

Paul Davies AM
Preseli Pembrokeshire
Leader of the Welsh Conservative Assembly Group

Agenda Item 9

By virtue of paragraph(s) vi of Standing Order 17.42

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