

PEOPLE WHO HELP OTHERS

Report

Unpaid Carers

Scrutiny Investigation

January - February 2017

Members

Councillors:

R.H. Wyn Williams (Chairman)

E. Selwyn Griffiths

Siân Wyn Hughes

Linda Ann Jones

Eryl Jones-Williams

Ann Williams

Eirwyn Williams

Officers

Gareth James

Bethan Adams

Introduction

We have only just started to unveil the work that's under way in Gwynedd to support those key people who work quietly and without pay to look after someone.

The general public, people like ourselves, but special people who ensure that their loved ones, friends and acquaintances are given encouragement, a service and care to help them live healthier and happy lives.

The topic of this Investigation is the way in which we help these people who help others.

It became clear to us early on that the Council, the Health Board and the third sector organisations who operate in this field succeed in providing excellent support to support unpaid carers in Gwynedd; But there is increasing strain on the services. Savings and cuts have had a detrimental effect on the ability to maintain key preventative services and the level of service that is expected to carers.

There is always room for improvement, and the aim of the brief work undertaken by this investigation was to support the developmental work that the Cabinet Member is carrying out to see whether our arrangements and the current situation are suitable considering the expectations imposed by the Social Services and Well-being (Wales) Act 2014.

This investigation, whilst acknowledging the excellent work that is taking place, nevertheless, focuses on ways of improving.

Our thanks are extended to all officers who have contributed sincerely to the work and our requests (tiresome at times, I'm sure!) for data and information.

Councillor R. H. Wyn Williams (Chairman)

Recommendations

Recommendation 1 – Identifying Carers

That the Cabinet Member commissions detailed work with our partners to agree how to identify and to keep a record of 'hidden' carers in Gwynedd.

Recommendation 2 – Assessments and Records

That the Cabinet Member undertakes work with our partners in care across the North in order to standardise methods of holding assessments and records.

Recommendation 3 – Response from Carers

That the Cabinet Member makes use of the information gathered in the Questionnaires returned by Carers to identify strengths, weaknesses and opportunities for improvement.

Recommendation 4 – Information and Advice

- Develop co-ordinated Information, Advice and Assessment (IAA) arrangements across the County without delay.
- Raise awareness of Members and front line officers and staff of the support services for carers
- Chemists to distribute carer leaflets with medicine
- Surgeries to distribute leaflets when issuing prescriptions
- Schools to distribute leaflets to pupils

Recommendation 5 – Respite

- Hold a detailed review to find out how many instances of lack of respite opportunities occur
- Create a policy to support Council employees who are carers with respite periods

Recommendation 6 – Effect of Savings and Cuts

That the Cabinet Member holds a detailed assessment of the effect that the reduction in spending on support services for un-paid carers/ people who help others.

Recommendation 7 – Third Sector and Community Businesses

Plan core and preventative services with the Third Sector and Community Businesses

Recommendation 8 – Mental Health

That the Cabinet Member holds an urgent review to assess the situation in full.

Recommendation 9 – Welsh Language

That the Language Committee undertakes specific work to monitor and support services to provide bilingual services for carers.

1. Background

- 1.1 One of the priorities of the Council's work programme for the 2016-17 year (as part of the Council's Strategic Plan 2013-17) is to review the effectiveness of our current arrangements of supporting unpaid carers (Priority Project G7). [Link to the Strategic Plan](#)
- 1.2 The Project aims to carry out a detailed review of the existing provision for unpaid carer support, implement short term arrangements where possible to support and develop the support and make plans to set out robust and sustainable arrangements for the medium and long term.
- 1.3 To support this developmental work, some members of the Services Scrutiny Committee agreed to conduct an Investigation to consider:
 - What support is available for unpaid carers who support individuals voluntarily?
 - How can that support be improved?
 - How does the Council communicate the information about the available support?
- 1.4 The main questions to address are: 'How sustainable is the provision for supporting carers in Gwynedd today and in future? And how do we communicate the provision?'
- 1.5 We attempted to answer these questions by gathering evidence on the three following elements:
 - That public services plan and provide sufficient support for carers.
 - That Gwynedd Council, the Health Board and their partners collaborate to sustain and improve support services for carers.
 - That Gwynedd Council and the Health Board consider the opinion of carers when providing and planning services.

2. Methodology

- 2.1 Five meetings of the Scrutiny Working Groups were held in order to gather information by Public Sector and Voluntary Sector representatives, and evidence was submitted in writing by some organisations. (See Appendix 1)

- 2.2 Observations received from some Members were considered. These observations had been conveyed by individuals in the community about their experiences of being carers and about the support provided by the services.
- 2.3 Consideration was given to performance reports, and measures and documents used by the Adults, Children and Health Services to identify and record the information about carers.
- 2.4 Council websites were looked at, as were Third Sector organisations and publications, from the point of view of the older and younger carer.
- 2.5 It is timely that the Council's Carer Support Service has carried out a Questionnaire which was distributed to over a thousand carers in September 2016 and that the analysis of the results had just been received (February 2017). This gives Investigation Members a good indication of the opinions of service users.

3. **Who is a Carer?**

Recommendation 1

That the Cabinet Member commissions detailed work with our partners to agree on how to identify and record 'hidden' carers in Gwynedd.

- 3.1 Understanding the significance of who is a carer is vital. The Council used to ensure that support was provided to carers; now, the Council's first responsibility is to assess the need and refer for support.
- 3.2 *The Social Services and Well-being Act (Wales) 2014 defines carer as 'an individual who is providing or who intends to provide care for an adult or child... local authorities can treat a person as a carer even if he/she would be otherwise considered a carer, if it believes it would be appropriate to do so in the context of a caring relationship.'*

The vision of the Gwynedd Carers Partnership (now called the Gwynedd and Anglesey Carers Partnership) defines a carer as '*a person who looks after a relative or friend who is unwell, fragile or disabled, and who is unable to live at home without unpaid practical or emotional support from you...*'

One of the features of carers is that a number of them do not call themselves carers.

The situation of being a carer is unique to each carer.

A lack of support can have a very negative effect on the health of carers and on their ability to care.

4. **How many Carers are there in Gwynedd? (see Appendix 2)**

4.1 According to the 2011 Census, there were 12,433 people in Gwynedd who identified themselves as carers.

4.2 This figure is likely to be far lower than the actual number as many do not identify themselves as carers.

4.3 The latest data from the Council (up to December 2016) notes

- The number of Carers on RAISE (the Council's record keeping system) - 165
- The number of Carers identified from the Core Data form - 114
- The number of Carers according to the definition of the Social Services and Well-being Act - 90

4.4 A further analysis is provided on the 165 recorded by RAISE:

Age	Number
18-64	60
65-74	24
75-84	42
85+	30
Total	165

4.5 The Report on Carers Questionnaires by the *Gwynedd Council Carer Support Officer* notes that over 1000 questionnaires were sent to carers in Gwynedd who have registered with the *Carers Outreach Service* or *Hafal*.

4.6 A difference is also observed in the distribution of carer numbers across Gwynedd.

An analysis of the 2011 Census figures shows the ranges as follows:

a) Working Areas - Percentage of the Population who are Carers (round figures)

Bangor	8%
Caernarfon	11%
Central (Port-Blaenau-Harlech)	11%
Pen Llŷn	10%
South Meirionnydd	12%

b) LSOA (Lower Super Output Area) Areas - Percentage of the Population who are Carers (rounded figures)

Highest Percentile	Dyffryn Ardudwy (South Meirionnydd)	15%
Lowest Percentile	Menai (Bangor)	3%

- 4.7 A significant difference can be seen between the areas of Bangor and South Meirionnydd in general and even more so between specific wards/LSOAs.
- 4.8 In addition, it appears from the information submitted and from discussions with officers and practitioners in the Focus Groups that the Council does not have reliable information on the number of carers who live in the County.
- 4.9 The situation seems to be no clearer in other counties, and the Cabinet Member is encouraged to work with our partners on a county, regional and national level (including Welsh Government) to address this vital issue.
- 4.10 Without knowing the extent of the need, it is not possible to address it.

5. **Assessments, Records and Measures**

Recommendation 2

That the Cabinet Member commissions detailed work with our partners in care across north Wales to co-ordinate the work of conducting assessments and record keeping

- 5.1 One of the reasons for setting up the investigation was to discover the reason why, in 2014-15, Gwynedd fared worse than anywhere else in Wales on the national measure:
- How many carers of adults were offered their own assessments?
- 5.2 The performance had fallen from 100% in 2012-13 to 58% in 2014-15. The 2015-16 performance shows improvement with a figure of 70%, but the performance remains the worst but one in Wales.
- 5.3 Though there is a small improvement in performance, it is not clear to Members why this measure continues to perform badly, but a few possible reasons are as follows:
- The system for gathering and recording data varies across Wales
 - Although assessments are carried out, they are not being recorded.
 - Officers prioritise other more important work.
 - Officers lack time to record information

- The record keeping arrangements and methods are unclear
- Are the number of assessments per officer consistent across north Wales

5.4 Once more, there are no clear answers, but here are some suggestions:

- In the case of an adjoining council (Anglesey) which performs at a level of 95%, there is a self-referral form on the Council's website which enables individuals to request a health and care assessment on-line.
- There may be inconsistencies between the way in which assessments are conducted in Gwynedd compared with other counties; that these assessments are more thorough and take longer to complete.
- Work pressures may mean that more assessments are carried out per officer.
- Lack of consistency and clarity in the way in which information is relayed and reported on between Council officers.

5.5 During the Focus Group held on 10 January 2017, the Health Board's first Annual Review of the way in which the Board and its partners operate and monitor the North Wales Carers Consultation and Information Strategy for the period of 1 April 2015 and 31 March 2016 was considered.

5.6 Observations and information were provided by the Head of Service User Experience at the Betsi Cadwaladr University Health Board. Some observations are quoted below:

The Carers Strategy Measure (Wales) 2010 was introduced to impose a statutory duty on the National Health Service (NHS) and Local Authorities in Wales to work together to prepare, publish and implement an Information and Consultation Strategy for Carers. The main purpose of this strategy was to ensure that:

- *Carers are identified early*
- *Carers receive more ordered assistance and at an earlier stage*
- *Change of culture, so that carers are empowered in all decision-making processes relating to care management*
- *Matters involving carers are main-streamed to **the National Health Service's (NHS)*** day to day work practices*

The Local Health Boards were designated as the lead authorities in developing the Information and Consultation Strategy for Carers. This strategy was developed in partnership with the six local authorities and third sector organisations and was approved by Welsh Government in 2012.

***It is suggested that 'and the Local Authorities and other partners' be added here.**

5.7 It is, therefore, clear that the national framework is in place to promote collaboration on a strategic level nationally and, as a dedicated partner, the Council must ensure it contributes fully to this work.

5.8 It is suggested that the North Wales Carers Strategy Group needs to address methods of registering, recording, assessing and monitoring carers in order to standardise arrangements across north Wales.

5.9 Although some progress has been made to achieve the strategy, the Report highlights a number of challenges which include:

- *Retaining a Carers Project Manager and administrative assistance remains a challenge because of the temporary nature of the budget. There are two empty posts at present.*
- *It has been difficult to obtain reliable performance measures. Work continues with carers outreach organisations to develop reliable indicators*

5.10 It will be difficult for the Partnership to develop effectively without, first of all, dealing with the above.

6. **What do Carers tell us?**

Recommendation 3

That the Cabinet Member uses the information in the Questionnaires to identify strengths, weaknesses and obstacles, and opportunities to improve.

6.1 Over 1000 questionnaires were sent to Gwynedd residents who are on the Carers Outreach Service and Hafal information systems. 227 questionnaires were returned and the main messages from the responses are as follows. (See Appendix 3)

Here is a summary of the results:

Type of care provided:

- Over 150 carers provide emotional support, personal care and general support.
- Between 100-150 provide support with mobility and medication
- Between 50-100 provide financial support

The challenges facing carers in their daily lives:

Tiredness/stress	50+
Lack of 'me time'	40
Loneliness/Isolation	25
Disability / illness	25
Working and caring	10
Concern about the future	5

7. Information and Advice

Recommendation 4

- **Develop co-ordinated Information, Advice and Assessment (IAA) arrangements across the County as a priority.**
- **Raise awareness among Council Members, officers and front line staff about support services for carers**
- **Pharmacist to give out a carer's leaflet when dispensing medication**
- **Surgeries to give out leaflets with prescriptions**
- **Schools to distribute leaflets to pupils**

- 7.1 The commissioners, providers and users provided evidence that the support services available to carers in Gwynedd were of a high standard.
- 7.2 Local Authorities are required under the Social Services and Well-being Act (Wales) 2014 to provide a bilingual Information, Advice and Help service as part of their preventative services.
- 7.3 In Gwynedd the Advice and Assessment Team has operated for 8 years as a Single Point of Access and can direct carers swiftly to the most suitable place for service. Residents in the Cricieth and Porthmadog area are referred to Alltwen Hospital as part of the Ffordd Gwynedd pilot scheme. It's an area of work that is currently receiving attention by the Adults, Health and Wellbeing Department with the view to further develop the provision in order to address the requirements of the Act in terms of Information, Advice and Assessment (IAA).
- 7.4 The Gwynedd Carers Partnership (Gwynedd and Môn now) is effective in gathering information about support that's available locally. The work is coordinated by the Part-time Adults and Children Carer Support Officer for Gwynedd who is employed by the Gwynedd Council Adults, Health and Well-being Department.
- 7.5 A comprehensive leaflet is published (electronically and on paper) with information about the organisations that support carers. ([Do you look after someone?](#)). Paper copies are available at libraries, surgeries and hospitals. There is useful advice on a range of issues, including:
- Health and Leisure
 - Work, training and courses
 - Financial Matters
 - Legal Matters
 - Maintaining and adapting your home
 - Transportation
 - Care to the end
 - Complaints

- 7.6 In addition, there is a detailed reference book of 99 organisations with a summary of what is available and useful contacts.
- 7.7 A national scheme, DEWIS, also provides information in electronic format.
(<https://www.dewis.wales/>)
- 7.8 The officers and practitioners interviewed noted that the information available through the Council's link was useful, but the same enthusiasm was not there for DEWIS.
- 7.9 The point was made that the value of the information depended on the quality of the information inputted, and the information from Gwynedd on the DEWIS website tended to be lacking in parts and the information needed to be maintained and updated. This is the responsibility of individual organisations, not the Council.
- 7.10 In addition, observations were made that gathering, sharing and updating information about more local events such as club and society activities could be highly valuable for carers and those they look after, but that it was difficult to deliver this effectively.
- 7.11 Despite the existence of the above information, the Carers Outreach Officer told us that there was clear evidence that the majority of carers had been given the most useful information from another person - sometimes social services, sometimes health services and often the third sector, and specifically Carers Outreach Services, Hafal and Action for Children.
- 7.12 Getting hold of the right information at the right time is vital for the well-being of carers.
- 7.13 The problem is how to let carers know about the provision. This is a substantial problem if one considers that there are, roughly, 2,000 carers in Gwynedd who are in touch with a third sector organisation or the Council or the Health Board. This leaves 10,000 who have no contact. (Taking the 2011 Census figures, namely 12,433 carers)
- 7.14 The Adults, Health and Well-being Department provides one to one information for carers through the Advice and Assessment Team and the adults team, and the Children and Supporting Families Department provides the same service for young carers and parent carers. Third sector organisations do likewise.
- 7.15 Despite this, it is considered that there is room for improving the availability of information across the County e.g. in leisure centres, schools and surgeries. There was no opportunity to air these ideas in detail in these areas during this investigation.

- 7.16 One of the difficulties in sharing information with carers is that carers, often, do not identify themselves as carers. Often, the first contact will take place with the health services in an emergency situation. It is, therefore, vitally important that the information be available in these places.
- 7.17 In the first national survey by Wales Carers - Follow the Act which was published in November 2016, it is noted that: *82% of unpaid carers said that they had not seen any published information by their local authority which would help them in their role as carer.*

8. Respite

Recommendation 5

- **Conduct a detailed survey to see the extent of the lack of respite opportunities**
- **Create a policy to support Council employees who are carers with respite periods**

- 8.1 In accordance with the requirements of the Social Services and Well-being Act (Wales) 2014, when carrying out assessments, carers' needs of respite must be considered. This is vital in order that carers may maintain their own health and well-being and in order for her/him to have a life beyond their role as carer.
- 8.2 A period of respite could mean a few hours, days or weeks. Having someone clean the house for a couple of hours could mean a period of respite for the carer. The respite period helps the carer continue with the role of carer as well as being important for health and well-being.
- 8.3 Respite can be provided by statutory services, third sector, friends and families.
- 8.4 Evidence was provided by the Carer Support Officer that the resources available are insufficient to meet the identified need among the, approximately, 2,000 carers we know about in Gwynedd, the other 10,000 notwithstanding. Although many carers are able to carry on, unfortunately, in reality their health is likely to suffer before they are identified.
- 8.5 A range of respite periods are provided in Gwynedd:
- The care-recipient attends a day centre, or one of the Council or private sector Carers call by to give the carer some respite
 - Friends and family
 - The care-recipient receives a Continuous Health Care Package with which the Health board can arrange a respite period for the carer and support to maintain the health of the carer

- Third Sector Organisations - transportation, sitting services, activities for carers and their families
- Private Sector - either as part of a care package or paid for themselves.

8.6 Although the respite periods on offer are important and very valuable, there are a number of problems:

- Local Authorities and Health Boards lack financial resources to commission and maintain the service
- The care-recipient unwilling to release the carer
- Lack of care workers, especially in Meirionnydd
- Lack of Welsh speakers
- Lack of flexibility at short notice e.g. to enable the carer to attend a funeral.
- Specific lack in the ability to release carers who support patients with Dementia and Mental Health.

9 Services Budgets

Recommendation 6

That the Cabinet Member conduct a detailed assessment of the impact of the spending cuts on support services for unpaid carers / people who look after someone.

- 9.1 Members of the Investigation are concerned that the Council could create serious financial problems in future by not investing strategically in preventative work in the field of carers.
- 9.2 In the 'Gwynedd Parent Carers Social Return on Investment Evaluation Report' created by Social Value Wales on behalf of Gwynedd Parent Carers, it states that each £1 spent on supporting carers would equate to spending £5.82 if the service provided by unpaid carers were paid for. (See appendix 4)
- 9.3 It's worth pausing for a minute to consider the implication of this.
- 9.4 If Gwynedd Council and Betsi Cadwaladr University Health Board provided these services, for every £1,000,000 of current expenditure, they would actually have to spend £5,820,000.
- 9.5 In the current economic climate, it is highly unlikely that the Council will be in a position to fund this level of service in future, but Members are concerned that there are signs that this already happens.
- 9.6 As a result of the reduction in the Council's funds and the implementation of Savings Strategy since 2007, it is possible that difficult decisions have been taken to reduce

expenditure in Adults and Children Services and which have led to increased spending by the Council.

- 9.7 A Third Quarter Review of Revenue Budget 2016/17 considered by the Cabinet shows an overspend of £226,000 by the Children and Families Department and £88,000 by the Adults, Health and Well-being Department. (see Appendix 5)
- 9.8 In the same report, it was noted that Specialist Services/Derwen achieved an under expenditure of £34,000 – this due to being unable to appoint temporary staff to cover maternity leave. In addition Derwen had to make a saving of £50,000 in 2015-16, a further reduction in their budget of £75,000 this year and a further cut is anticipated for next year. Officers from the service say that this is having a negative effect on un-paid carers; and they are concerned that this may lead to a detrimental effect on their health and increased costs for the Council.
- 9.9 Furthermore, the Cabinet has agreed, in principle (depending on the detailed work) to spend an additional £40,000 next year on the 'Early Intervention/Preventative Programme for groups of vulnerable children and young people in Gwynedd'.
- 9.10 It is suggested that the impact of reducing preventative budgets in the field of unpaid carers and the increase to Council expenditure and the effect on un-paid carers should be considered in more detail and assessed comprehensively.

10. Other matters requiring attention

- 10.1 Members of the Investigation feel that further work is urgently required to assess the risks to carer support services in more detail, but because of the constraints of local government democratic regulations and the May election, there was no time to test these fully. They are, therefore, noted below as matters that need to remain on the carer support development agenda:

10.2 Third Sector and Social Enterprises

There is a great deal of emphasis in the Social Services and Well-being (Wales) Act 2014 for local authorities to work with the Third Sector and to promote social enterprises in order to deliver the requirements of the Act:

“Local authorities must promote the involvement of people who receive care and support, in the design and delivery of services, along with alternative delivery models including: social enterprises, co-operatives, user-led services and the voluntary sector.”

The majority of services noted on the Council website as support services for carers, are services provided by social enterprises and the third sector.

There was some opportunity during the investigation to receive feedback from a small number of them and, although those interviewed stated that they were able to continue to provide services for the carers for the time being, it is clear to Members of the Investigation that the pressure they are under is remarkably great and some noted their concern that they would not be able to satisfy the need at times.

This is true of some core services and preventative services.

Although Members have an awareness of the financial pressures facing us as a Council, they are concerned that insufficient attention is placed on the strategic planning of services.

10.3 Mental Health

Officers of the Council, the Health Board and other organisations stated specific concerns about extreme pressures and suggested that the Cabinet Member conduct an urgent enquiry to fully assess the situation

10.4 The Welsh Language

Members expressed by concern that some services commissioned by the Council were lacking in their bilingual service provision and suggested that the Language Committee carry out specific work to monitor and support services to deliver bilingual services.