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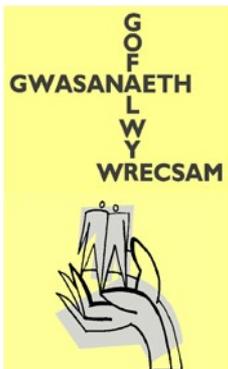
NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE



North Wales Carers' Strategy

- A strategy for carers of all ages

June 2018



North Wales Regional Partnership Board

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Ffion Johnstone



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Introduction

The North Wales Regional Partnership Board recognises the key role that carers of all ages have in the health and social care environment and that they need to be valued for the support they provide. The partnership also recognises that they need to be supported in this vital role. This strategy acknowledges the importance of working in partnership with carers throughout their contact with services and is based on the principles of the Triangle of Care model developed originally as a guide to best practice in mental health care in England.

This is also in line with the Social Services and Well Being (Wales) Act 2014 (SSWBA) which legislates for enhanced rights for carers of all ages and simplifies and consolidates the law, giving them for the first time equivalent rights to the person they care for. The act also gives carers the absolute right to choose whether and to what extent they are or remain carers. Carers have the right to say no to taking on a carer's role as well as a right not to continue in their role as carer, and to be supported in this.

When referring to carers, we mean unpaid carers of all ages (including young carers and young adult carers) and background who look after a relative or friend who is ill, frail or is a disabled person, who cannot manage to live at home without the carer's practical or emotional unpaid support. Whilst acknowledging that carers will have different responsibilities, such as carers of people with long term conditions, carers of people with dementia, carers of individuals with mental health problems or carers of substance misusers, it is acknowledged that a carer's needs are unique to the individual and can differ substantially from the needs of the person cared for.

The Social Services and Well Being (Wales) Act 2014 defines a carer as a person who provides or intends to provide care for an adult or child. This definition includes carers of all ages.

Young carers are defined as carers who are under the age of 18, and young adult carers as being aged 16-25.

Carers often do not see themselves as carers. They will describe themselves as a parent, husband, wife, partner, son, daughter, brother, sister, friend or neighbour, but not as a carer.

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

Carers of all ages in North Wales currently benefit from a range of services including information, advice and support. These services include one to one support, support groups, forums, cafes, emotional support, counselling, training, therapies, benefits advice, carer breaks, peer support, activities, advocacy, support for carers of people with long term conditions as well as direct payments, support budgets and one off grants. Carers are also supported by third sector organisations to access life-long learning, employment and volunteering opportunities. Carers services also provide carer awareness training for professionals, e.g. student nurses, social work staff and GPs and are able to attract sources of external funding to support the work that they do.

Whilst there is quantitative data available on services available for carers, this report focuses on looking through the eyes of carers to understand what matters to them and what will contribute to the well-being and improving their circumstances. Partners have talked to carers of all ages about what helps them to be a carer, to continue being a carer and to live their life the way they want to.

The scope of this work has included:

1. Understanding where we are at and what success looks like.
2. Understanding our priorities should be in terms of getting there.
3. Being clear on funding and the sustainability of services for the future.
4. Understanding added value of working together regionally as well as collaboratively.

It has not included an evaluation of current services, nor has it undertaken a cost benefit analysis or a return on investment assessment of those services that are currently delivered.

Carers of all ages have told us that good quality reliable support for the person cared for is of paramount importance and contributes to their well-being as carers. They've also said that they really value the range of support provided by third sector organisations. Importantly also, they've said that they appreciate being listened to, being recognised, respected and heard by people responsible for designing and providing services for them and the person they care for.

This has enabled us to work together as partners to produce our vision for carers' services in North Wales which is to:

- Think carer

- Involve carers of all groups and communities in decision-making and planning
- Work in partnership to design and co-produce services around the carer

Partners' vision for carers' services in North Wales has led to the development and co-production of the offer for carers in North Wales which incorporates standards of service that partners are committed to achieving.

North Wales Carers' Strategy - Summary

The offer for carers in North Wales

Partners' vision for carers' services in North Wales has led to the development and co-production of the offer for carers in North Wales by the following groups:

- North Wales Carers' Strategic Group
- North Wales Carers' Operational Group
- North Wales Young Carers' Operational Group
- Carers Reference Group

Personal well-being outcomes for carers

Partners want to achieve the following personal well-being outcomes for all carers in North Wales, with the needs of the carer depending on the needs of the person cared for:

- That individual carers' needs, including language needs are met in the best way
- That carers come to mind as soon as the person cared for

In doing this, we also want to make sure that:

- We provide services that are consistent
- There is added value by working collaboratively
- Services and funding are not duplicated
- We adhere to best practice

To achieve this, partners will commit to:

- **Promote general awareness** of carers and caring to the wider population and to all relevant staff in the health and care sector
- **Think carer** in commissioning and assessing needs, with attention to rurality and those furthest from services for other reasons
- **Involve carers** of all groups and communities in decision-making and planning processes
- **The early identification** of carers at first contact with services

Also, as employers, partners will:

- Identify carers in the organisation
- Adopt a carer friendly infrastructure
- Commit to equitable provision for carers
- Provide opportunities to hear the voice of carers in the workplace
- Allow flexible working practices, where reasonable and practicable

Standards of service

The following standards were adopted from the Triangle of Care and are particularly relevant to local authorities and BCUHB. Partners agreed these standards provide a

strong base on which to develop services, with and for carer, across the region.

- Carers' views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies are co-produced
 - Staff are carer aware and trained in carer engagement strategies from the outset
 - Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers' own needs
- Staff need knowledge, training and support to become carer aware
 - A carer focused introduction to the service and staff are available, with a relevant range of information across the care pathway
- Carers and the essential role they play are identified at first contact or as soon as possible thereafter
- Policy and practice protocols on confidentiality and sharing information are in place
- Defined post(s) responsible for carers are in place (carers leads)
- A range of carer support services is available

These standards will have implications for all partners when services for carers are commissioned and delivered:

- Local, sub-regional and regional commissioning:
 - agencies designed to give carers a voice in local decision-making and make sure that all services in the area become more carer-aware and carer-friendly
 - services with carer expertise able to raise the carer awareness of all agencies in an area
 - services designed to find carers and help them to identify their needs and entitlements
 - support services for carers with particular support needs and/or entitlements
- Ready access to information and advice (and where appropriate formal advocacy) services tailored to the needs of carers in different life stages (e.g. young carers, parent carers, carers of adults), circumstances and conditions, and stages of the caring journey
- Access to training on the new skills carers may need when they begin or adapt to their new caring role and to peer support when appropriate
- The right to an assessment (what matters conversation) as a carer in your own right:
 - to develop a general care and support plan
 - signpost to appropriate services; and
 - determine eligibility for support to them to care
- For eligible carers:
 - A support plan centred on personal well-being outcomes they have identified themselves.
 - It will set out the support to help them achieve the personal well-being outcomes identified.
 - Support plans will be subject to regular reviews by local authorities, and re-assessment of needs if their circumstances change.

In accordance with the standards agreed, the following headline plan outlines the actions and lead responsibility for implementation.

No	Standards	Action	Regional responsibility for action	Local responsibility
1.	Engagement with carers and carers voice	Carers views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies take shape.	NWCSG	All partners
		Agencies designed to give carers a voice in local decision making and make sure all services in the area become more carer-aware and carer-friendly	NWCSG	All partners
2.	Induction and training for carers and staff	A carer focused introduction to the service and staff are available, with a relevant range of information across the care pathway	NWCOG, in collaboration with NWYCOG	All partners
		Staff are trained in carer awareness and engagement strategies.	NWCOG, in collaboration with NWYCOG	All partners
		Carers need access to training on the new skills they may need when they begin or adapt to their new caring role and to peer support when appropriate	NWCOG/NWYCOG	All partners
3.	Assessment and support for all carers	Carers to be part of an assessment (what matters) conversation in their own right	NWCOG/NWYCOG	Local authorities
		A support plan centred on personal well-being outcomes they have identified themselves to achieve the personal well-being outcomes identified and subject to regular reviews and re-assessment of needs if circumstances change	NWCOG/NWYCOG	Local authorities working with partners
		Ready access to information, advice and peer support (and where appropriate formal	NWCOG, in collaboration with NWYCOG	All partners

No	Standards	Action	Regional responsibility for action	Local responsibility
		advocacy) services tailored to the needs of carers in different life stages, circumstances and conditions and stages of the caring journey		
		A range of flexible carer breaks is available	NWCSG	Local authorities working with partners
		Specialist advocacy, including for Continuing Health Care and for young carers	NWCSG	Local authorities, BCUHB working with partners
4.	Policy and practice protocols	Policy and practice protocols on confidentiality and sharing information are in place.	NWCSG	All partners
5.	Adopt employer standards	<ul style="list-style-type: none"> • Identifying carers in the organisation • Adopting a carer friendly infrastructure • Committing to equitable provision for carers • Providing opportunities to hear the voice of carers in the workplace • Allow flexible working practices, where reasonable and practicable 	NWCOG	All partners
6.	Carer leads	Defined posts responsible for carers are in place	Local authorities, BCUHB	
7.	Develop success measures and data collection arrangements	Performance measures agreed	NWCSG	All partners
		Data collection arrangements agreed and underway	NWCOG/NWYCOG	All partners

Noted below are the proposed headline success measures as agreed by partners. These will be collated by the NWCOG and progress monitored by the NWCSG to improve services and inform future planning. Two of the measures are the same as those in the Welsh Government Outcomes Measures Framework, with the others considered to be important to measure the progress of our strategy in North Wales. These success measures place a strong focus on improving the life circumstances of carers, listening to their views and involving them in the design of services.

- Carers of all ages report satisfaction with the assessments and personalised support they receive, have access to the services they need and have an understanding of their rights under the Social Services & Wellbeing (Wales) Act.
- Social workers and other care practitioners can evidence that they are applying the well-being principle in all their adult social care decisions.
- The number of assessments in 2018 has increased in line with the Regional Partnership's own estimate.
- Carers reporting they felt involved in designing the care and support plan for the person that they care for (Welsh Government, 2015)
- Carers reporting they feel supported to continue in their caring role
- If a carer is facing a crisis, they know how to access a rapid response service to assess and respond to their need.

Taken together, the vision, standards and delivery by partners of good quality services for carers of all ages in North Wales will contribute to improving their circumstances and well-being.



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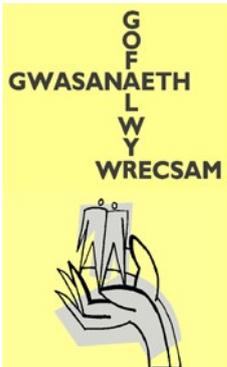
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1.0 Context and background

Carers of all ages have a key role in the health and social care environment; the North Wales Regional Partnership Board places great value on this and also recognises that it needs to act to ensure that carers are well supported in all circumstances. This strategy acknowledges the importance of working in partnership with carers throughout their contact with services and is based on the principles of the Triangle of Care model developed originally as a guide to best practice in mental health care in England.

When referring to carers, we mean unpaid carers of all ages (including young carers and young adult carers) and background who look after a relative or friend who is ill, frail or is a disabled person, who cannot manage to live at home without the carer's practical or emotional unpaid support. Whilst acknowledging that carers will have different responsibilities, such as carers of people with long term conditions, carers of people with dementia, carers of individuals with mental health problems or carers of substance misusers, it is acknowledged that a carer's needs are unique to the individual and can differ substantially from the needs of the person cared for.

2.0 The Social Services and Well Being (Wales) Act 2014

The importance of supporting carers is also aligned with the Social Services and Well Being (Wales) Act 2014 (SSWBA) which legislates for enhanced rights for carers of all ages and simplifies and consolidates the law, giving them for the first time equivalent rights to the person they care for. The act also gives carers the absolute right to choose whether and to what extent they are or remain carers. The Act re-defines the responsibility of individuals and families for maintaining their own health and wellbeing, and requires a change in culture that provides a greater focus on promoting resilience, independence, self-care and community support. The Act recognises that carers have a key role in the preventative service approach and local authorities should therefore help ensure that carers are able to live their own lives as independently as possible. Carers have the right to say no to taking on a carer's role as well as a right not to continue in their role as carer and to be supported in this. These requirements are stated both in Part 9 of the Act as well as throughout all other parts of the Act.

The Act defines a carer as a person who provides or intends to provide care for an adult or child. This definition includes carers of all ages.

Young carers are defined as carers who are under the age of 18, and young adult carers as being aged 16-25.

Carers often do not see themselves as carers. They will describe themselves as a parent, husband, wife, partner, son, daughter, brother, sister, friend or neighbour, but not as a carer.

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

The Act:

- Ensures that carers can access a wider range of appropriate services in a more flexible way, including access to comprehensive information in relation to all types of support and services that can be accessed without a need for formal assessment.
- Creates a duty for local authorities to carry out carers' needs assessments where a carer appears to have support needs. The assessment of need of the individual in their own right is central as well as their capacity to carry on caring.
- Requires assessments to be proportionate to ensure that more energy is focused on delivering community-based support, and support from third sector organisations.
- Requires local authorities to provide advocacy support for individuals including carers. This provision will include independent professional advocacy as well as informal advocacy.

The Act also sets out a new national eligibility framework to determine whether assessed carers with greater support needs will meet the criteria for services as set out in the new framework. Carers with eligible needs will have a support plan centered on personal well-being outcomes they have identified themselves. It will also set out the support to help them achieve the personal well-being outcomes identified. Support plans will be subject to regular reviews by local authorities, and re-assessment of needs if their circumstances change.

3.0 National priorities

On 24 November 2017, Carers Rights Day, the Minister for Children and Social Care announced an allocation of £1m in 2018-19 for health boards and trusts to work collaboratively with all partners to enhance the lives of carers in line with the national priorities, which are:

- Supporting life alongside caring – all carers must have reasonable breaks from

their caring role to enable them to maintain their capacity to care, and to have a life beyond caring

- Identifying and recognising carers – fundamental to the success of delivering improved personal well-being outcomes for carers is the need to improve carers' recognition of their role and to ensure they can access the necessary support
- Providing information, advice and assistance – it is important that carers receive the appropriate information and advice where and when they need it

4.0 About carers in North Wales

The Population Needs Assessment published on 1 April 2017 states that carers provide a crucial role in the provision of care and support and it is estimated that they provide between 75% and 95% of care, saving £7.72 billion every year in Wales (Yeandle and Buckner, 2015; Welsh Government 2016).

The main findings from the needs assessment were that:

- The number of carers in North Wales is increasing, particularly in north-west Wales
- People aged 50 to 64 are the most likely to provide unpaid care
- Half of all carers in North Wales are in employment: for carers in employment the support of their employer and colleagues is vital to helping them continue in their caring role
- The increase in need for social care identified in other chapters of the population assessment report is likely to lead to greater numbers of people providing unpaid care and providing care for longer
- There are over 1,000 young carers identified across North Wales, which is an increase over the past few years

5.0 Priorities for carers in North Wales

Evidence from the Population Needs Assessment, what carers have told us and the resource mapping considered by partners have led us to the following priorities. If carers are appropriately supported by society then the vast majority of negative consequences can be avoided proactively. Further work on these will be reflected in the work programmes of the partnership's North Wales carers' groups:

5.1 Engagement with carers and carers' voice

Listening to carers and hearing their voice provides a valuable insight into their lives and circumstances, and demonstrates the importance of engaging with them. This section highlights some of the issues carers have raised to demonstrate how they need to influence the planning and delivery of services.

The main findings from engagement activities carried out for the population needs assessment and from previous consultations carried out by each local council and health demonstrated that the needs of the carer could be supported by better meeting the needs of the cared for person:

- Equipment and adaptations and assistive technology can provide valuable services, although issues can include training needs and waiting lists
- Carer breaks (respite), including short-term carer breaks
- Continuing Health Care (CHC) assessments to include short term breaks for carers
- More activities for people cared-for, particularly individuals with dementia
- Good quality reliable support for person cared for
- Support when carer is ill, both in emergency and planned treatment
- Reliable hospital transport that includes transport for the carer. Carers need equal access to transport even when the cared for person is not with them to enable them to collect prescriptions for example
- Health and social care workers – having workers that can help with medication as well as personal care

Other aspects of support specifically for carers which are valued are:

- Accessible information and advice (preferably in one place)
- Local information surgeries, hubs, single point of access (SPOA), talking points and drop-in services
- Advocacy for the carer
- One to one support for the carer, such as a listening ear and telephone support 24 hours a day
- Socialising and carer groups in local community
- Access to leisure activities
- Volunteering opportunities
- Education, skills and employment
- Recognition and respect, consultation as partners in care, including when a person enters long-term care
- Better communication between all parties included in providing support for carers and the person cared for
- Third sector support – carers really value the range of support provided by the third sector organisations
- Support for the carer when their caring role comes to an end, including employment, benefit and housing issues

Mapping carers journeys has told us that a single point of access to services can work well for carers, in enabling some carers to refer themselves to services, holding the initial what matters conversation, signposting carers to information and carer support services, and understanding the circumstances and unique situation of the carer.

Carers' stories demonstrate that care giving, as well as being a practical function, is also an emotive role, with carers reporting feelings of guilt, loneliness, anxiety, worry, distress, isolation, fear, frustration, difficulty in dealing with change and transition. These will occur at different times within the carer's timeline of experience, and each carer will require bespoke support.

The main themes arising from carers' stories and case studies can be summarised as follows:

- The isolation of the caring role
- Stress experienced by carers of all ages
- The value carers of all ages place on the support of third sector organisations and local authorities
- The impact of the person cared for's well-being on the carer's well-being
- Carers' need for breaks
- Carers' need for information
- The need to be employed, or to return to employment
- Rural issues

The things that matter to **young carers** are often the same things that would matter to any young person. Their situation as a young carer however can at times have an effect on the way that they live their lives, and opportunities that are taken for granted by young people without caring responsibilities can be difficult to access for young carers. Findings from the consultation and engagement with young carers as part of the North Wales Population Needs Assessment found that areas that young carers found challenging were: concentrating, communicating, being confident and making friends.

In addition to this, young carers have told us that the health and well-being of the person for whom they are caring is important to them, e.g. not wanting their parent to start drinking again. Also important for young carers is acceptance both by their peer group and by teachers. Whilst what people think of them can be important for many young people, the impact that their caring responsibilities can have on their lives mean that this issue is sometimes heightened for young carers, e.g. attitudes that people might have towards them because of them not being able to join in social activities, or not being able to complete homework. One young carer said that whilst other young people messed around in class, that he strived to get all his work done at school as he wouldn't be able to do so at home.

"If my mum got better. If I had better memory. If I was faster at doing work. If I could see my friends out of school more often." Young carer, Anglesey.

Young carers' ability to concentrate amidst other responsibilities and concerns is an issue, e.g. whilst the person for whom they are caring is ill. Also, the need to talk to others about their problems and feelings, e.g. family, friends, neighbours, other young carers as well as professionals in the public and third sector.

Play and recreation facilities have also been voiced by young carers as important. In the same way as young people without caring responsibilities, young carers enjoy contributing to the development of services, and are looking for a positive attitude and an openness to new ideas from community leaders to support them to do this.

Parent carers report that they often have to battle to ensure that their child's condition is acknowledged, and also to receive attention afterwards e.g. from schools. This can lead to feelings of frustration and a perception that the system is not there to facilitate matters for them. This can also have an impact on sibling carers.

"The pressure that is put upon me as a carer to make decisions that I am not always comfortable with them and if I object the feeling that I am judged." Parent carer, Gwynedd.

Many carers will say that they do not need support, and that if the person cared for's needs are met, that they also feel that they are supported as carers. This highlights the importance of ensuring that the carer's views are sought as part of the person cared for's needs assessment.

5.2 Induction and training

If carers' experiences and stories are listened to, they will provide a sound basis from which to deliver day to day services and support for carers. One important element to underpin this is staff induction and training. Supporting staff with a good introduction to carers' needs, raising their awareness of carers and their role will contribute greatly to influencing the way that carers are treated as part of the culture of organisations responsible for services to carers of all ages. Good peer support and mentoring from more experienced members of staff and strong leadership will also be vital to support a carer aware culture.

Carers themselves need to be supported with training on the new skills they may need when they begin or adapt to their new caring role or when that role evolves. This may involve training on caring for specific conditions, e.g. administering medication (young carers) dementia, moving and handling, interpersonal skills, financial issues, delivering personal care, as well as other skills to support the person cared for's well-being. Third sector organisations already provide this training which is based on what carers say that they need and is highly valued by them.

5.3 Assessment and support for all carers

Local Councils have a new duty to offer an assessment to any carer where it appears to the local authority that a carer may have needs for support. If the local council determines that a carer's needs meet the eligibility criteria then they must consider what could be done to meet those needs. Previously, it was the responsibility of the carer to request an assessment.

A carer's needs meet eligibility criteria for support if:

- a) The need arises as a result of providing care for either an adult or child
- b) The carer cannot meet the need whether
 - Alone
 - With the support of others who are willing to provide that support, or
 - With the assistance of services in the community to which the carer has

- access, and
- c) The carer is unlikely to achieve one or more of their personal well-being outcomes which relate to the specified outcomes in part 3 of the act

The local council may now carry out a joint assessment, where an assessment of the cared for person and the carer is carried out at the same time if both parties are willing and it would be beneficial to do so. This is good practice although there are concerns that the assessment of the carer may be compromised by focussing on what the carer can and can't do for the cared for person rather than looking at their desired personal well-being outcomes in their own right.

The carer's element of the assessment needs to focus on 'what matters' to the carer and the carer's needs in their own right, for example, their employment, education and training needs.

The local council must involve the carer in the assessment and include:

- The extent to which the carer is willing to provide the care and to continue to provide the care
- The personal well-being outcomes the carer wishes to achieve

An assessment of a carer must also have regard to whether the carer wishes to work and whether they are participating or wish to participate in education, training or leisure activities.

Carers will need to be very clear about what they can and can't do and any differences between their expectations and that of the person cared for. The people carrying out the assessments will need to be skilled in drawing out this information. The act says carers need to be asked what they can do, so this will need to be monitored to make sure it happens in practice and is included in the assessment. It is important that the individual feels that they are an equal partner in their relationship with professionals.

With regard to **young carers**, the Code of Practice relating to the act includes a range of examples relating to young carers including:

- The child is unlikely to achieve development goals
- The individual is/will be unable to access and engage in work, training, education, volunteering or recreational activities

In assessing, the council must have regard to the importance of promoting the upbringing of the child by the child's family, in so far as doing so is consistent with promoting the well-being of the child.

Where the carer is a child the council must have regard to his or her developmental needs and the extent to which it is appropriate for the child to provide the care. This should lead to consideration by the council of whether a child carer is actually a child with care and support needs in his or her own right.

Providers of support services for young carers report that short term funding, lack of resources for transport, money for trips places constraints on the support and breaks that they can offer young carers. Ensuring that young carers are provided

with support according to their age-related needs is also a challenge.

The act sets out a new national 'eligibility framework' to determine whether or not a carer who has been assessed and who has support needs will meet the criteria for service. Carers with eligible needs will have a support plan centered on personal well-being outcomes they have identified themselves. It will also set out the support to help them achieve the personal well-being outcomes identified. Support plans will be subject to regular reviews by local councils, and re-assessment of their needs if circumstances change.

5.4 Information, advice and assistance

The Population Needs Assessment engagement demonstrated that accessible information and advice (preferably in one place) matter to carers as well as local information surgeries, hubs, talking points and drop-in services.

Evidence from carers' stories and 'what matters' conversations suggests that many carers are unaware of their rights and also unaware of the information and support services that are available to them.

"The family never accessed any statutory services and she was never aware of any services to support Carers. Her main contact was always with the GP but he never informed her of any services available to her, or her right to a Carer Assessment." Case Study, Denbighshire.

Lack of information on financial issues can also lead to carer anxiety:

"Mr A was not in receipt of any benefits and was not aware that he could claim Carers Allowance. He didn't know of the support available to Carers in Denbighshire." Case Study, Denbighshire.

A parent of a child with Down's Syndrome told us that she had not received sufficient information:

"When looking back at the early period I did not receive information about organisations such as "Down Syndrome Association" or the Carers Outreach Service which could have been of assistance for me as a parent." Parent Carer's Story, Gwynedd.

Young carers also need information, which sometimes needs to come from people they know:

"Would like to be told more about brother's condition."

"Would like support from an autism charity – want a better understanding of the condition." Young carer, Anglesey

Carer breaks have traditionally been referred to as 'respite', and it is worth noting at the outset that there is no real national definition for 'respite'. The term has also been associated with respite from something that is a burden. For the purpose of this strategy, the term 'carer breaks' will be used.

Local authorities and BCUHB invest significantly in carers' services that provide short term breaks in the form of sitting services and/or replacement care. Although there are services delivered to the cared for person, they are sometimes regarded as carers' services. Some third sector organisations also draw in external funding for these types of services.

The population needs assessment identified insufficient range, availability and flexibility of respite and short breaks for carers.

This is supported by the resource mapping which tells us that carer break services are provided in the field of older people, learning disability and mental health. In older people's and learning disability services the carer break is delivered in the form of a sitting service or replacement care. In mental health services, the service offers a mental break, support and skills development for the carer. However, following discussions by partners at the workshop, the amount invested of £1.25m depicted in the resource mapping is not thought to be an accurate reflection of carer breaks. The resource mapping encountered challenges as:

- All carer breaks could not be identified, as monies paid to independent domiciliary care providers could not be separated out
- Differentiating between a break for the carer and the person cared for was not a simple task
- Whether the carer break provides the carer with a complete break or not, e.g. are they using their time to catch up on household chores
- Carer breaks in all service areas may not be accurately reflected

The main message that carers are telling us is that the break they need from caring is in response to their needs, situation and home environment. They want to be listened to, and each carer will have different needs. They do not appreciate being told what service can be provided to them, do not necessarily need a regular carer break service which sometimes causes overprescribing of services, leading to wastage.

In a situation where in-home respite is being provided, carers have told us that it is important that the person cared for is familiar with the individual providing the care, otherwise it may not be worthwhile. In situations where the individual providing the sitting service is on holiday, the person cared for or carer may decide to delay the arrangement until the individual who usually provides the carer break is available. Consistency and continuity of service is therefore of paramount importance to both the carer and person cared for.

Continuing Health Care (CHC) is a sensitive area in terms of carer breaks. Carers have told us that when an individual becomes eligible for CHC funding, then this can lead to changes in the support that both the carer and person cared for can expect to receive. For example, BCUHB will be contracting with different

providers to those providing care through local authority commissioning arrangements, therefore resulting in a change in the care giver.

If the person cared for is CHC funded, the health service recognises that carers need a break and places value on the support that the carer offers in meeting the person cared for's needs. The health service recognises its duty to meet all of the person cared for's needs, particularly in the absence of the carer being able to care for them. This could involve the care co-ordinator developing an application for 'additional funding'.

It is also important that carer breaks can be provided on a flexible and short notice basis in order for the carer to continue to live their lives the way they want to, e.g. joining social gatherings at short notice, and not having to make arrangements too long before hand.

Voucher schemes are in operation in some areas of North Wales to facilitate flexibility for carers. Eligible carers, upon completion of a carer's needs assessment, are provided with a time-limited voucher for flexible short-term breaks. Whilst the development of innovative flexible schemes such as this is positive, it is important also that regular evaluations are carried out to ensure that lessons are learnt.

Young carers would like to spend time apart from the person they care for doing the activities that they enjoy with their peers, e.g. activities in leisure centres, making use of local amenities such as parks, cycle pathways, and participating in sports.

Carers living in **rural areas** wish to receive the same level of service as carers living in towns.

Carers report that living in rural areas creates problems for them in terms of:

- Accessing support or carer breaks
- Travel time being taken out of the time allocated for direct service
- Isolation

"There are no learning disability facilities, support group activities for my daughter to attend in Llangollen although there appears to be far more in Denbigh and some in Ruthin, but she is unable to get transport to these places." Carer, Denbighshire

Some carers want to receive **services in Welsh**, in the language of their choice. Consultation and engagement as part of the Population Needs Assessment highlighted the importance of care and support services being available in Welsh. Services should ensure Welsh language services are built into service planning and delivery and that services are offered in Welsh to Welsh speakers without them having to request it. Although information from the service mapping exercise suggests that services are available in both Welsh and English for carers, it is unclear whether services reach the 'More than just words' standards,

whether they are instantly available or whether arrangements need to be made before hand to arrange the services.

5.5 Policy and practice

Partners need to ensure that standard policy and practice protocols are in place with relation to confidentiality and the sharing of information. The piloting of the Triangle of Care model in mental health rehabilitation services within BCUHB has enabled discussions to take place around consent and confidentiality when working with carers.

Staff recognise the importance of carer inclusion but admit that they struggle when there is no consent from the cared for or consent fluctuates depending on situation or mood. Guiding principles endorsed by the Triangle of Care Lead for England, as well as the BCUHB Carers Lead Officer are that staff:

1. Talk about what they are aware of.
2. Provide carers with non-sensitive information in a form which helps the carer to understand. For example: condition specific information, or information around medicines management.
3. Signpost carers to sources of information and support.
4. You can receive third part information from carers.
5. Tell carers information for themselves.
6. Carers are entitled to confidentiality for themselves.

Staff have welcomed these guiding principles and also welcome bespoke training on carers and confidentiality.

5.6 Employer standards

All partners involved in the design and delivery of carers services in North Wales will want to ensure that their organisations commit to the following:

- Identifying carers in the organisation
- Adopting a carer friendly infrastructure
- Committing to equitable provision for carers
- Providing opportunities to hear the voice of carers in the workplace
- Allow flexible working practices, where reasonable and practicable

5.7 Carer Leads

Carer lead posts in the North Wales six local authorities and in BCUHB are of significant importance particularly with regard to developing and promoting carers services locally, working with community teams to engage with carers and understanding what matters locally, collating and analysing data, understanding service needs and identifying gaps in services. These officers can also facilitate teams to develop and pilot new models of working with carers, as well as providing training. They will also support corporate leads to ensure that employer standards are met. Carers leads will also be working with their local carers

partnership to implement the carers offer as well as working regionally to design services and contribute to learning and improvement work nationally.

Where the carer lead officer is not also the lead officer for young carers, the organisation will need to be clear how the development and promotion of carers services happens in children's services.

These posts can influence and impact the perception of carers within organisations and facilitate working towards 'think carer' and raising carer awareness.

6.0 How services for carers are currently funded

Funding for carers services have been unstructured, with allocations for carer breaks accounted for, for example, in core budgets. The Carers' Transitional Grant received by BCUHB from Welsh Government to manage the transition from the Carers Strategies (Wales) Measure 2010 (Carers Measure) to the SSWBA has been allocated on a short term annual basis.

On 24 November 2017, Carers Rights Day, the Minister for Children and Social Care announced an allocation of £1m in 2018-19 for health boards and trusts to work collaboratively with all partners to enhance the lives of carers in line with the national priorities. A decision was taken by the Regional Partnership Board on the expenditure of the grant following consideration to the carers' work stream and the offer for carers in North Wales.

Local authorities have received an allocation for respite (carer breaks) for carers of all ages during 2018-19 through their Revenue Support Grant (RSG), and Integrated Care Fund (ICF) guidance refers to the national priorities for carers.

The resource mapping demonstrates that funding is received from a variety of sources:

- Local authority
- Third sector
- Welsh Government
- Health Board
- Chargeable services

The resource mapping also reflects the unsustainability of funding with providers not knowing whether funding streams will be available from one year to the next, creating uncertainty amongst the workforce and staff turnover, which in turn affects the continuity of service to the carers. The mapping also tells us that third sector providers have been successful in attracting external sources of funding as well as sponsorship.

Providers have reported on the inefficiency of preparing more than one performance report for the same commissioner, as well as having to report on management data, rather than focusing on the real personal well-being outcomes for carers.

Providers also mentioned the need for security for a skilled and specialist workforce in the field. This would then support what is agreed as part of the carers offer relating to being carer aware. Providers report that 3+2=5 years contracts are valued and provide stability for the service as well as an opportunity to plan and develop services for the future.

Whilst Direct Payments provide a personalised form for individuals to access services, take up by carers is understood to be low. The effective delivery of Direct Payments services is essential to the implementation of the Social Services and Well-being (Wales) Act 2014.

The explanatory memorandum to the regulations that accompany the Act¹ underlines this:

“Direct Payments are crucial to achieving the Welsh Government’s aim of improving the well-being of people who need care and support to achieve their well-being outcomes and carers who need support to achieve their well-being outcomes. They provide the mechanism to increase independence, choice and control, and are an enabler of co- production in care planning which affords individuals the freedom to plan flexible and innovative ways to maximise their well-being outcomes.”

Whilst the main impetus for increasing take-up generally is likely to come through the work done with individuals when they are first assessed for services and begin discussing care and support plans with the staff doing those assessments, therefore, work would need to be undertaken regionally and locally to look at the possibility of increasing the take-up of Direct Payments.

There are positive examples of adult carers taking up Direct Payments to provide them with flexibility in their caring role in North Wales. Further discussions on the possibility of Direct Payments as an enabler to facilitate flexibility in carer services are needed.

7.0 The offer for carers in North Wales

The partners’ offer to carers in North Wales has been developed and co-produced by the following groups:

- North Wales Carers’ Strategic Group
- North Wales Carers’ Operational Group
- North Wales Young Carers’ Operational Group
- Carers Reference Group

Partners want to achieve the following personal well-being outcomes for all carers in North Wales:

- That individual carers’ needs, including language needs are met in the best way

¹ Explanatory Memorandum to the Care and Support (Direct Payment) (Wales) Regulations 2015
Welsh Government 2015

- That carers come to mind as soon as the person cared for
- Services that are consistent

In doing this, we also want to make sure that:

- There is added value by working collaboratively
- Services and funding are not duplicated
- We adhere to best practice

Partners will commit to:

- **Promote general awareness** of carers and caring to the wider population and to all relevant staff in the health and care sector
- **Think carer** in commissioning and assessing needs, with attention to rurality and those furthest from services for other reasons
- **Involve carers** of all groups and communities in decision-making and planning processes
- **The early identification** of carers at first contact with services

What partners will do as employers

- Identify carers in the organisation
- Adopt a carer friendly infrastructure
- Commit to equitable provision for carers
- Provide opportunities to hear the voice of carers in the workplace
- Allow flexible working practices, where reasonable and practicable

8.0 Standards of service

The following standards were adopted from the Triangle of Care and are particularly relevant to local authorities and BCUHB. Partners agreed these standards provide a strong base on which to develop services, with and for carer, across the region.

- Carers' views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies are co-produced
 - Staff are carer aware and trained in carer engagement strategies from the outset
 - Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers' own needs
- Staff need knowledge, training and support to become carer aware
 - A carer focused introduction to the service and staff are available, with a relevant range of information across the care pathway
- Carers and the essential role they play are identified at first contact or as soon as possible thereafter and help is available to them in the simplest and quickest way possible
- Policy and practice protocols on confidentiality and sharing information are in place
- Defined post(s) responsible for carers are in place (carers leads)
- A range of carer support services is available

These standards will have implications for all partners when services for carers are commissioned and delivered:

- For local, sub-regional and regional commissioning:
 - agencies designed to give carers a voice in local decision-making and make sure that all services in the area become more carer-aware and carer-friendly
 - services with carer expertise able to raise the carer awareness of all agencies in an area
 - services designed to find carers and help them to identify their needs and entitlements
 - support services for carers with particular support needs and/or entitlements
 - Direct Payments are offered to those who want them
- Ready access to information and advice (and where appropriate formal or independent advocacy) services tailored to the needs of carers in different life stages (e.g. young carers, parent carers, carers of adults), circumstances and conditions, and stages of the caring journey
- Access to training on the new skills carers may need when they begin or adapt to their new caring role and to peer support when appropriate
- The right to an assessment (what matters conversation) as a carer in your own right:
 - to develop a general care and support plan
 - signpost to appropriate services; and
 - determine eligibility for support to them to care
- For eligible carers:
 - A support plan centred on personal well-being outcomes they have identified themselves.
 - It will set out the support to help them achieve the personal well-being outcomes identified.
 - Support plans will be subject to regular reviews by local authorities, and re-assessment of needs if their circumstances change

In accordance with the standards agreed, the following headline plan outlines the actions and lead responsibility.

No	Standards	Action	Regional responsibility for action	Local responsibility
1.	Engagement with carers and carers voice	Carers views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies take shape.	NWCSG	All partners
		Agencies designed to give carers a voice in local decision making and make sure all services in the area become more carer-aware and carer-friendly	NWCSG	All partners
2.	Induction and training for carers and staff	A carer focused introduction to the service and staff are available, with a relevant range of information across the care pathway	NWCOG, in collaboration with NWYCOG	All partners
		Staff are trained in carer awareness and engagement strategies.	NWCOG, in collaboration with NWYCOG	All partners
		Carers need access to training on the new skills they may need when they begin or adapt to their new caring role and to peer support when appropriate	NWCOG/NWYCOG	All partners
3.	Assessment and support for all carers	Carers to be part of an assessment (what matters) conversation in their own right	NWCOG/NWYCOG	Local authorities
		A support plan centred on personal well-being outcomes they have identified themselves to achieve the personal well-being outcomes identified and subject to regular reviews and re-assessment of needs if circumstances change	NWCOG/NWYCOG	Local authorities working with partners
		Ready access to information, advice and peer support (and where appropriate formal	NWCOG, in collaboration with NWYCOG	All partners

No	Standards	Action	Regional responsibility for action	Local responsibility
		advocacy) services tailored to the needs of carers in different life stages, circumstances and conditions and stages of the caring journey		
		A range of flexible carer breaks is available	NWCSG	Local authorities working with partners
		Specialist advocacy, including for Continuing Health Care and for young carers	NWCSG	Local authorities, BCUHB working with partners
4.	Policy and practice protocols	Policy and practice protocols on confidentiality and sharing information are in place.	NWCSG	All partners
5.	Adopt employer standards	<ul style="list-style-type: none"> • Identifying carers in the organisation • Adopting a carer friendly infrastructure • Committing to equitable provision for carers • Providing opportunities to hear the voice of carers in the workplace • Allow flexible working practices, where reasonable and practicable 	NWCOG	All partners
6.	Carer leads	Defined posts responsible for carers are in place	Local authorities, BCUHB	
7.	Develop success measures and data collection arrangements	Performance measures agreed	NWCSG	All partners
		Data collection arrangements agreed and underway	NWCOG/NWYCOG	All partners

9.0 Success measures

Noted below are the proposed headline success measures as agreed by partners. These will be collated by the NWCOG and NWYCOG and progress monitored by the NWCSG to inform future planning. Two of the measures are the same as those in the Welsh Government Outcomes Measures Framework, with the others considered to be important to measure the progress of our strategy in North Wales. These success measures place a strong focus on improving the life circumstances of carers, listening to their views and involving them in the design of services.

- Carers of all ages report satisfaction with the assessments and personalised support they receive, have access to the services they need and have an understanding of their rights under the Social Services & Wellbeing (Wales) Act
- Social workers and other care practitioners can evidence that they are applying the well-being principle in all their adult social care decisions.
- The number of assessments in 2018 has increased in line with the Regional Partnership's own estimate
- Carers reporting they felt involved in designing the care and support plan for the person that they care for (Welsh Government)
- Carers reporting they feel supported to continue in their caring role (Welsh Government)
- If a carer is facing a crisis, they know how to access a rapid response service to assess and respond to their need

10.0 Conclusion

Listening to what carers of all ages have to say about their experiences has shown that there is a high quality level of provision available for carers in North Wales, and that when things go right, that this is greatly appreciated. What carers have also told us is that services provided by knowledgeable and informed staff can make all the difference to their well-being and circumstances.

Whilst there are numerous good practice examples of support for carers in North Wales, those responsible for implementing this strategy and its related action plans will work to ensure that those services become more consistent across the region and that local provision in all areas will reflect the regional standards which have been agreed.

Those firstly coming into contact with carers, possibly in primary health care, schools or local authorities need to listen to carers, think carer and encourage them to be aware of their role and understand that they can access the information and support that's available for them.

Appendices:

Appendix 1: What matters to carers

Appendix 2: Carer pathways

Appendix 3: Resource mapping

Appendix 4: North Wales Carers Strategic Group (NWCSG) Action Plan

Appendix 5: North Wales Carers Operational Group (NWCOG) Action Plan

Appendix 6: North Wales Young Carers Operational Group (NWYCOG) Action Plan

Appendix 7: Carers Reference Group (CRG) Action Plan

Draft



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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

Carers' strategy: What matters to carers report

June 2018

Introduction

Carers' stories and experiences provide an useful snapshot of what matters to them, what helps them to carry on in their caring role and what aspects challenge them. The main themes arising from carers stories and case studies can be summarised as follows:

- The isolation of the caring role
- Stress experienced by carers
- The value carers place on the support of third sector organisations and local authorities
- The impact of the person cared for's well-being on the carer's well-being
- Carers' need for breaks
- Carers' need for information
- The need to be employed, or to return to employment
- Rural issues

The stories and case studies below are only some examples of those which have been offered by third sector organisations, BCUHB and local authorities.

Isolation of caring role and stress experienced by carers

"Feeling of isolation at times and would find it less stressful if I had more social time for myself" Carer, Anglesey

"Mrs B is unable to return to work since her husband's operation, and sometimes finds it difficult to cope with life. They have a bungalow in rural Wales, 9 miles away from the nearest supermarket. Mrs B feels isolated, and misses her old life where she was able to socialise and spend time with friends and family. Mrs B told me that she feels she is "existing not living" and at times feels so low that life doesn't seem worth living." Case Study, Conwy

"During a conversation with a parent carer of an adult with learning disabilities, carer broke down explaining that she was under tremendous pressure. Her daughter had not been able to attend day care for over a month as she had been ill. Carer was not

getting any sleep because of this and her partner had his own health issues and she herself was waiting to have an operation on her knee.

At the end of the telephone call, carer stated that being able to talk to someone about her worries with someone she could trust made her feel that the weight of the world had been lifted from her shoulders. Carer explained that she doesn't get the opportunity to talk about her worries as she doesn't feel comfortable talking to others. It was decided that I would phone her on a regular basis during this difficult time. Carer feels so much better knowing that she can share all her worries with me. Emotional support continuing with carer." Case study, Carers Outreach

The things that matter to young carers are often the same things that would matter to any young person. Their situation as a young carer however can at times have an effect on the way that they live their lives, and opportunities that are taken for granted by young people without caring responsibilities can be difficult to access for young carers. Findings from the consultation and engagement with young carers as part of the North Wales Population Needs Assessment found that areas that young carers found challenging were: concentrating, communicating, being confident and making friends.

Young carers and young adult carers also talk of the pressure that they are under at times:

"Remember everything (e.g. chores, being told to do things like put rubbish out). Work fast.

"Mr A is a young adult carer caring for his father with multiple health conditions and significant mobility problems. Mr A was having problems with moving and handling. Father was a wheelchair user. He had become very isolated because of his caring role. He had not pursued any further education since leaving school and had never been in employment.

Mr A also had his own health issues and was experiencing acute anxiety attacks. He had neglected his own health and had not visited his GP for some considerable time" Case study, Denbighshire

Young carers' ability to concentrate amidst other responsibilities and concerns is an issue, e.g. whilst the person for whom they are caring is ill. Also, the need to talk to others about their problems and feelings, e.g. family, friends, neighbours, other young carers as well as professionals in the public and third sector.

The value carers place on the support of third sector organisations and local authorities

Carers are telling us that they value the support services that they receive, that they do not appreciate services that are working well with them being taken from them, particularly at short notice. If it hasn't been communicated to them why the service is ceasing, they feel frustrated and do not have an understanding of why it has happened.

"I saw a NEWCIS brochure at the GP surgery and decided to contact them. One of the staff came out to meet us both. Over the years we have received lots of support and without them I don't think I could have gone on. They helped us to go to CAB for financial help and supported us to gain aids. I now meet other carers at NEWCIS carer group and it gets me out of the house and I meet people in similar situations." Case study, NEWCIS

"My learning has all been from accidental apart from Carer's Outreach and when I did need to go and get a carer's assessment I went to Dinerth Road, she was very good the Social Worker there and organised crossroads sitting service for me, which was very good. It was the best service ever, brilliant I can't praise them enough."
Carer's story, Conwy

"Carer is looking after his wife who has dementia; she has deteriorated rapidly in the past 6 months. He finds the situation immensely stressful and is struggling to cope with her questions etc. He contacted the office to request help with coping strategies for managing stress.

I have been supporting the carer for the last 2 months and he is very appreciative of having someone understanding to talk to. I have visited him at his home where we discussed different ways of coping and responding to the situation to minimise the effects on himself. He said this was very helpful and gave him ideas for different things he could try to deal with the situation without getting tense and worked up. I also gave him a Dementia Red key fob to show discreetly when out with his wife, so that he does not have to explain anything verbally or feel embarrassed or apologetic for her behaviour. I subsequently referred him to the Alzheimer society to request a dementia support worker to help and advise him. I followed this up with a couple of phone calls to encourage him, offer support, and see what else I can help with. Increased respite hours are being put in place through SS, and a visiting clinical psychologist is offering to help him with anxiety. Recently I sent him information regarding the Snowdon train trip organised by Awyr Las for those diagnosed with dementia and their carers, and the dementia support day at Alltwen hospital. He is immensely grateful for all the support and information and I have offered to keep in touch with him for the foreseeable future." Carer's story, Carer's Outreach.

"Referral received from Specialist Nurse at the hospital. Patient carer requiring support as she is the sole carer for her husband who has dementia. He requires 24/7 care and for several months the carer has been sleeping downstairs next to her husband as there is no heating upstairs and her husband is unable to manage the stairs due to his poor mobility.

She has been told that she requires treatment and she is concerned how this is possible as she cannot leave her husband alone and will not be physically capable of caring for her husband following the operation and chemotherapy treatment.

Emotional Support- discussed the concerns of Carer

Contact made with CPN and What Matters conversation completed to review care needs and respite services available- for Carer needs support for her husband whilst she is having treatment.

Benefit check completed- No Attendance Allowance (AA) in payment for cared for and he is totally reliant on Carer. DWP referral for AA1, Pension Credit (PC) (calculations completed with carer) and Council Tax Exemption applicable once PC awarded. Once this is awarded referral via Nest Heating scheme

Funding- Health and Social funding explained re cared for if admitted into a Care Home.

Blue Badge application completed

At 4 week review following meeting with carer at YG

-“I would not have known about any of the above without the help of Carers’ Support Officer, Ysbyty Gwynedd” Case study, Carers Outreach.

“Mrs D cares for her mum and now her husband, leaving her feeling very isolated with no time for anything else – “being a carer is what my whole life now consisted of.

Visiting the Centre with my husband is the first time that I have felt my carer role being acknowledged. The staff are caring and responsible, if they know that you are having any difficulty at all they are keen to help, as they recognise that the health and welfare of the carer is just as important.” Carer’s story, Denbighshire

Some carers want to receive services in Welsh, in the language of their choice. Consultation and engagement as part of the Population Needs Assessment highlighted the importance of care and support services being available in Welsh. Services should ensure Welsh language services are built into service planning and delivery and that services are offered in Welsh to Welsh speakers without them having to request it. Although information from the service mapping exercise suggests that services are available in both Welsh and English for carers, it is unclear whether services reach the ‘More than just words’ standards, whether they are instantly available or whether arrangements need to be made before hand to arrange the services.

Carers’ need for information

Evidence from carers’ stories and What Matters conversations suggests that at times carers are unaware of their rights and also unaware of the information and support services that are available to them.

“The family never accessed any statutory services and she was never aware of any services to support Carers. Her main contact was always with the GP but he never informed her of any services available to her, or her right to a Carer Assessment.” Case Study, Denbighshire.

It is also important for carers to be given relevant information at the most appropriate time,

“I just think it’s the memory clinic for me would have been the place to give a pack or information to me and say go home and when you get a minute do this and once you have done this everything will be so much better for you.” Carer, Conwy

Lack of information on financial issues can also lead to carer anxiety:

“Mr A was not in receipt of any benefits and was not aware that he could claim Carers Allowance. He didn’t know of the support available to Carers in Denbighshire.” Case Study, Denbighshire.

A parent of a child with Down’s Syndrome told us that she had not received sufficient information through the health service:

“When looking back at the early period I did not receive information about organisations such as “Down Syndrome Association” or the Carers Outreach Service which could have been of assistance for me as a parent.” Parent Carer’s Story, Gwynedd.

The impact of the person cared for’s well-being on the carer’s well-being

Carers will often say that they do not need support, and that if the person cared for’s needs are met, that they also feel that they are supported as carers.

“Son was taken ill and I cared for him on my own. He received services from the Community Mental Health Team. There is far too much talk and not enough action. The support worker takes him for regular blood tests. On Tuesdays, he goes on a ‘walk and talk’, which is only for an hour, but it gives breathing space. I’ve been asking for that for years, but there’s far too much talking. Support for the cared for is also indirect support for carers...

...I’ve had to cancel a holiday offered by my other son. You worry while you’re away, and the cared for would have had to go somewhere else...

...The support worker is the most productive and alleviates the stress for the carer.” Carer’s story, Gwynedd

Young carers have told us that the health and well-being of the person for whom they are caring is important to them, e.g. not wanting their parent to start drinking again, and that their family is important, *“because I can talk to them all the time”*. Also important for young carers is acceptance both by their peer group and by teachers. Whilst what people think of them can be important for many young people, the impact that their caring responsibilities can have on their lives mean that this issue is sometimes heightened for young carers, e.g. attitudes that people might

have towards them because of them not being able to join in social activities, or not being able to complete homework. One young carer said that whilst other young people messed around in class, that he strived to get all his work done at school as he wouldn't be able to do so at home.

"If my mum got better. If I had better memory. If I was faster at doing work. If I could see my friends out of school more often." Young carer, Anglesey.

Carers' need for breaks

The main message that carers are telling us is that the break they need from caring is in response to their needs, situation and home environment. They want to be listened to, and each carer will have different needs. They do not appreciate being told what service can be provided to them, do not necessarily need a regular carer break service and sometimes there is overprescribing of services, leading to wastage.

In a situation where in-home replacement care or a sitting service is being provided, carers have told us that it is important that the person cared for is familiar with the individual providing the care, otherwise it may not be worthwhile. In situations where the individual providing the service is on holiday, the person cared for or carer may decide to delay the arrangement until the individual who usually provides the service is available.

It is also important that carer breaks can be provided on a flexible and short notice basis in order for the carer to continue to live their lives the way they want to, e.g. joining social gatherings at short notice, and not having to make arrangements too long before hand. Another issue also is the need for enough flexibility in the care available to allow for care in emergency situations and in out of hours situations.

"There is nowhere that you could phone and get emergency or pre planned care for a couple of hours for a young person with dementia where you know that you would be leaving them with someone they know and trust if you have no family or friends that can help." Carer, Anglesey

"It's just a shame because often there is a choice and things on at the same time as well during the week but nothing at the weekend and I understand it's the weekend but that is a big thing for a lot of people." Carer, Conwy.

Carer breaks also need to be tailored to the needs of the individual,

"Assessment completed, Carer A has had a discussion with her family over the Christmas period about wanting respite from her caring role. This was declined by her husband and he stated he is happy for his wife to go to her groups in the evenings as he feels capable of managing his own medication. Carer A is now attending evening groups and using this as her respite. Carer A has also used this time to attend church and seek support through her faith." Carer, Conwy.

At times, the carer will want to have the carer break outside the home environment. At other times, they will want someone to provide replacement care. Another option would be to have a break for the carer and person cared for together.

“Miss C is a carer for mum who is also supported by another family member..Miss C’s mum requested day care in order to regain community connections and increase activity and stimulation.

Both carers attended the day centre to support a period of settlement but the centre staff were able to focus on both the carers and Miss C to allow all three individuals to have some respite and attend and partake in some meaningful activities...

..The centre affords both carers to have time away from mum, safe in the knowledge that any personal care needs required in their absence will be delivered by well trained staff.” Carer’s story, Denbighshire.

“I cannot believe NEWCIS have given us the opportunity to have a break away with other carers and supportive NEWCIS staff. Being away with other carers and their loved ones, who are in a similar situation to ourselves enabled us to enjoy comfortable surroundings, with good company and feel less isolated. I could relax as I knew there was someone there for me and my wife, to support us if we needed help”.

“We have not had a break away from home and I have not had a break from my caring role for many years. This is due to our financial situation and because I would be frightened to take my wife away without support”.

“This break has allowed me to rest, clear my head, not think about cooking or cleaning and has given us time together to make memories. I love her so much and we enjoyed spending quality time together. Thank you”. Carer’s story, NEWCIS.

Parent carers also have specific needs for a break:

“What keeps me going?...Family and friends but also what is important to me is time away from caring, I sometimes row but opportunities for the “golden time” as I call it are very few and far between, nobody to babysit I for example. I would also like to spend “golden time” with T (I’s little brother) and as a parent I worry if he is given fair play as out days out as a family tend to be around I’s needs.” Parent Carer’s story, Gwynedd.

The need to be employed, or to return to employment

Carers’ stories about trying to return to work or balancing work with caring responsibilities feature often. Carers need to build their confidence in order to do this and they benefit from the support that they are given to achieve what is important to them in the world of work.

“One of the concerns the carer has about moving her mother into a residential home is whether or not she will have her own identity after she’s lost her caring role. During a home visit, we talked about getting back into paid employment. The carer

shared her worries about not having the confidence or skills to jump back into the workplace

We decided to have a discussion, focusing on what skills she has gained from her caring role. The patience, the commitment, the sacrifices. All good personal attributes that can be included in her CV and application forms. The carer agreed and acknowledged that her skills could be just as valuable, or even more valuable than those who have studies and learnt from books.” Carer’s story, Conwy.

“After the initial phone call, a home visit was arranged and a Carers’ Needs Assessment (CNA) was conducted. The CNA was to identify the full carers’ situation. The CNA identified that the Carer needed support around her rights in the workplace and knowing what her options were. The Carers UK Carers Rights booklet was passed to the Carer and options was discussed with her about how employers can help – flexible working, job share, time off for emergencies etc. The Carer was signposted to look at her employers Carers policy and if she wanted to, she could discuss her situation with her employer. Her employer already knew she was a Carer.

Direct Payments and Penderels Trust was discussed and Carer wanted to know more information regarding this. It was discussed that a Social Worker was needed for her to access Direct Payments.

Social Services agreed direct payments at panel and the Carer is now looking for a care worker through Penderels to entitle her to have regular breaks from her caring role.” Case study, Third sector organisation.

“Someone’s life can change within seconds...from being an industrious person who has travelled the world to be a mother with a child with additional needs – I can no longer work full time since I have so many medical appointments – Audiology, Cardiology, Language Therapy, Paediatrics etc, I have attended so many hospital appointments with I that I have lost count, this in turn having a Financial effect on me...Working part time can be a struggle...particularly if I am unwell (lack of sleep)...but as a parent the “Carer’s Allowance” is far from sufficient and I feel that there is no other option but to work. It can also be difficult to find work since I am dependent on my employer to have an understanding of my situation as a carer.” Parent *Carer’s story, Gwynedd.*

Rural issues

Carers living in rural areas wish to receive the same level of service as carers living in towns.

Carers report that living in rural areas creates problems for them in terms of:

- Accessing support or carer breaks
- Travel time being taken out of the time allocated for direct service
- Isolation

“There are no learning disability facilities, support group activities for my daughter to attend in Llangollen although there appears to be far more in Denbigh and some in Ruthin, but she is unable to get transport to these places.” Carer, Denbighshire

Carers have noted that travel time when replacement care is arranged is not factored in. Replacement care maybe arranged for three hours, but in rural locations it may take the carer a large proportion of time to travel to the closest shops/activities etc and they then only get a short amount of time to do what they want to do. Problems are compounded in rural areas; simple tasks such as picking up prescriptions, appointments, travelling can be very difficult for the carer. Carers contributing to this work in North Wales discussed the possibility of a rural carers’ assessment component and that a premium for rural replacement care is reflected. Contingency planning in rural areas can be particularly difficult.

Conclusion

Carers’ stories demonstrate that care giving, as well as being a practical function, is also an emotive role, with carers reporting feelings of guilt, loneliness, anxiety, worry, distress, isolation, fear, frustration, difficulty in dealing with change and transition. Some carers may also experience feelings of denial surrounding their cared for person’s condition. These feelings will occur at different times within the carer’s timeline of experience, and each carer will require bespoke support.

Listening to carers’ stories and experiences provides an insight into their lives, demonstrates the importance of support, and emphasises issues involved with the caring role. This work has helped partners ensure that services are designed with the carer at the centre.

Work needs to continue to listen to carers and to gather their stories. This will help us measure what progress we are making and understand about what works well, what is appreciated and what we need to do change or improve services.

The contribution of carer stories and case studies is greatly valued and appreciated and many thanks are extended to all carers and professionals who have been involved.



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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

Carers' strategy: mapping carers journeys report

June 2018

Introduction

As part of the discussions on the North Wales Regional Partnership's Carers Work stream, it became apparent that in order to understand better what carers' experiences of current services are, that it would be useful to map their journeys.

The purpose of mapping carers' journeys was to:

- Establish to what extent the carers' experiences are different to the process
- Identify who in the process can support carers
- Understand what needs to change and improve

Method

In order to complete this work, we worked with our local authority and health partners to look at carers' cases. This work focused on carer journeys through statutory services including how well services worked with the third sector to provide what matters to carers.

The time available meant that only a small number of cases could be looked at.

Conwy: 3 cases – carers of older people

Denbighshire: 1 case – carer of individual with learning disability

Wrexham: 1 case – carer of an older person

BCUHB – 1 case – mental health rehabilitation patient, Llanfairfechan

In Gwynedd, we looked at the support service for mental health service user in one area of the county and understood its impact on a small number of cases.

The journey mapping task had two aspects to it:

- 1) Mapping the process
- 2) Mapping how the individual goes through the process (the carer's journey)

Working with relevant professionals in local authorities and health, we understood from their experiences and from case files and notes how things are for carers. As discussions took place, the process and carer's involvement was documented on paper, leading to a discussion on how things could be improved. An example is included below.

What the journey mapping tells us

The work demonstrates individual carers' journeys and has been useful to add to the qualitative evidence partners have already drawn together in the carers' stories and case studies.

From this work we have been able to understand better how things are for carers and learn what's working well, what could work better, and what needs to change. All of this has been considered alongside other things that we have learnt from carers.

Although the journey mapping work looked at a small number of carers' cases across the region, it reflected the following:

About the carer:

- That many carers refuse a carers assessment. This may be partly because many carers consider themselves a parent, husband, wife, partner, son, daughter, brother, sister, friend or neighbour, rather than as a carer.
- That carers tend to wait until they reach crisis point until they contact social services
- That carers are grateful for the support that they do receive and do not tend to ask for more
- That carers are ready to provide their feedback and opinion on the sufficiency of the service that they receive when invited to do so
- That person centred reviews focusing on what's going well, and what's not going well are beneficial to the carer
- That there are examples of carers making self-referrals to the Single Point of Access Service (SPOA)
- That carer involvement may at times lead to carer overwhelm
- That carers need emotional support

About local authority and health services:

- There are examples of SPOA services and GPs working well in identifying carers and having 'what matters' conversations with them
- That there is good practice in terms of carer engagement within BCUHB, e.g. treating the carer as an equal partner, welcoming the carer, providing information, documenting family circumstances, inviting the carer to talk, involving the carer in discharge planning, carer viewing of the person cared for's accommodation, involving the carer in the person cared for's treatment planning

- That it is important in some cases to meet the carer outside of the home environment and to ask their preferred method of communication
- That Direct Payments work well to offer flexibility to carers and in avoiding over prescribing of carer breaks (i.e. a set number of hours delivered by a contracted provider)
- That getting the right support for the person with learning disabilities can be crucial to the well-being of the carer. In one case the person cared for was eligible for an integrated care and support plan. Once that was in place the carers' well-being outcomes were able to be met with some support from the third sector and by signposting to other support in the local community.
- That advocacy is important to make sure the wishes and needs of the carer and the person being cared for are fully considered
- That there are examples of 'sitting' services providing additional services for the person cared for, e.g. taking them on outings, making the most of the time with the person cared for
- That there is a gap in carer break 'sitting' services for mental health service users
- The term 'sitting service' may be misleading; whilst a sitting service is not the same as replacement care, it does however refer to a service that regularly offers more than sitting with the person cared for
- That group support in mental health services cannot work in areas where the population is more dispersed and depends on one to one support services
- That carers are referred for expert information and assistance to the third sector organisations

About our workforce:

- That good quality services are provided by carer aware professionals who are committed to their work and to thinking creatively to tailor the service around the person cared for and carer
- That committed and dedicated professionals can add value to services and think outside 'process pathways' in order to create a pathway that suits the individual carer and person cared for
- That there are several points along the person cared for's journey where practitioners need to consider the carer, offer a carers assessment and check how the carer is coping or whether anything has changed. We saw good examples of this.
- That auditable formal carer pathways supported by the guiding principle of placing the carer at the centre of the service may facilitate culture change

- Although professionals can work to ensure that the carer pathway is a smooth one within their service, the carer may not have had a positive experience prior to their encounter with that service, or after their encounter with that service
- That good communication between the professional who is supporting the carer and professionals who are supporting the person cared for is crucial
- That supporting the carer to become more confident, promote their independence, maintain their identity and maintain and build resilience is important
- That social services link with third sector support services and other services (e.g. OPUS) where it's been identified that that is useful but that professionals need to be reminded and updated of third sector support that is available

To what extent are the carers' experiences different to the process?

Whilst there are clear processes within health and social services to establish what matters to carers and to support them, the work undertaken suggests that the most important aspect is to be carer aware, to be guided by the needs of the carer and to work together with the carer and person cared for, placing them at the centre of the service.

Who in the process can support carers?

Different areas of service may be providing good quality services for carers, however, it is important that the experience of the carer is consistent throughout their journey. This may mean looking at the consistency of the carer's experience within one organisation as well as along a journey where the carer will be coming into contact with different organisations.

What do we need to do to change and improve?

- Further work needs to take place to understand the reasons why individuals with caring responsibilities refuse carer assessments
- Look at the possibilities of Direct Payment to enable flexibility in carer break services for carers
- Work in partnership to ensure that the carer journey is a smooth and seamless one from their first encounter with services that might be able to support them
- Ensure that carers are supported in their involvement with services, e.g. through briefings and de-briefings, and staff prompts where appropriate
- Consider whether carer champions within organisations would be helpful
- Consider the possibility of extending the principles of Triangle of Care (which have been piloted in BCUHB mental health services) to other service areas
- Ensuring that professionals are aware of third sector and other support services available to carers

- Consider how well the processes work when people move from one local authority to another.



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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

Carers' strategy: resource mapping

May 2018

Introduction

This resource mapping was carried out as part of the Regional Partnership Board's carers work stream. The aim was to identify the services available for carers in North Wales, the main funders and an estimate of the amount of investment.

The project scope was to include services provided specifically for carers, although we know that many of the services that are provided for the person cared for also have beneficial personal well-being outcomes for carers.

The mapping gives us a snapshot of the resources available at the time the data was collected.

What the mapping can tell us

- It can provide an overview of the services available for carers in North Wales and an estimate of the investment in those services.
- It can facilitate an understanding of how current investments support what carers are telling us that matter to them.
- It can be used alongside the agreed 'offer for carers in North Wales' to highlight gaps where more provision may be needed to provide consistent services for carers in North Wales.
- It can help to identify opportunities to better co-ordinate services supported by different organisations.
- It can highlight areas we need to investigate further.

What the mapping can't tell us

- It can't tell us whether there is enough provision or investment in each area to align with what carers are telling us that matter to them.
- It can't tell us whether there is duplication between services. It can highlight areas to investigate but similar services in the same location may be reaching different groups of people or with different preferences or slightly different needs.

- It doesn't give us an up-to-the-minute picture of carers' services. Due to the constantly changing nature of services we have provided a snapshot at a particular point in time.
- It can't give us a full picture of the investment in carers' services. The way some services are funded made it difficult to identify exactly what funding was supporting carers directly, so there will be some undercounting.
- It can't tell us what should change as a result. This data only forms part of the picture and needs to be considered alongside carers' stories, feedback from the workshops, commissioners, the population assessment findings and so on. The analysis needs to involve all partners to co-produce recommendations.

Methods

A form was circulated to partners in North Wales during 2017 asking what services were available in the area (see [Appendix \(i\)](#)). This information was then collated into a spreadsheet and circulated to local authority and health commissioners and service providers including third sector organisations for checking. A draft version was discussed at the carer's workshop on 19 March which included members of the Carers Strategic Group, Carers Operational Group, Young Carers and young adult carers sub group and Carers Reference Group. There was an opportunity to make further amendments after the event until 30 March 2018.

Findings

[Appendix \(ii\)](#) shows an overview of services in North Wales. This shows a wide range of information, advice and assistance available across North Wales to support carers. It also identified gaps, including the lack of a hospital liaison post at Ysbyty Glan Clwyd and that employment support projects for carers are available across North Wales apart from in Wrexham. While there are generic services for carers of individuals with substance misuse problems, the resource mapping didn't demonstrate that there were specific services for these carers. There were also a number of different projects offering information and advice to carers of people living with dementia across North Wales, which may mean a risk of duplication.

Analysis of the investment in services found over £5 million of investment into services for carers across North Wales as shown in table 1. The funding comes from both statutory and third sector organisations (see table 3). This is an underestimate of the total funding available due to the difficulty of separating out the funding directly supporting carers in some contracts.

Table 1: Investment in carers services by service type

Service type	Service Cost (£ each year)
Assistance and support	2,100,000
Carer breaks	1,400,000
Young carers	1,000,000
Carers information and advice	660,000
Total	5,200,000

Data has been rounded so may not sum

Table 2 shows that around half of the funding identified is available to support all carers. Just over £1 million is available to support young carers and £600,000 is available to support parent carers. The majority of investment in services based on specific conditions is to carers of people with dementia, followed by mental health.

Table 2: Investment in carers services by carer group (needs of the person cared for)

Carer group	Service Cost (£ each year)
All carers	2,600,000
Young carers	1,000,000
Carers of people with a specific condition	930,000
Dementia	550,000
Mental health	370,000
Neurological conditions	12,000
Parent carers	600,000
Total	5,200,000

Data has been rounded so may not sum

The majority of funding comes from local authorities as shown in table 3, with a significant amount raised by third sector partners through grants and other fundraising. Funding from Welsh Government includes funds distributed through local authorities and the health board such as Carers Transitional Funding, Families First, ICF and Welsh Government.

Table 3: Investment in carers services by type of funder

Type of funder	Total
Local authority	3,000,000
Third sector grants and fundraising	800,000
Welsh Government	580,000
Health Board	520,000
Chargeable services	65,000
Total	5,200,000

Data has been rounded so may not sum

The data collection included end dates of contracts where known which highlighted the insecurity of much of the funding. The full spreadsheet has been made available to local authority and health commissioners to support local commissioning.

Appendix i: Resources for carers questionnaire

Gwasanaeth/ Service	
Darparwr/ Provider	
Disgrifiad byr o'r gwasanaeth/ Brief description of the service	
Canllawiau mynediad i'r gwasanaeth/ Eligibility criteria	
Sut i gyfeirio i'r gwasanaeth/ How to refer to the service	
Oriau gwasanaeth/ Hours of service	
Lleoliad y gwasanaeth/ Location of service	
Iaith/ Language	
Lefelau Staffio/ Staffing Levels	
Cyfyngiadau/ Constraints	
Cost Gwasanaeth/ Service Cost	
Dyddiad diwedd y cytundeb/ Expiry date of contract	
Incwm a ffynhonnell / Income and source	
Unrhyw fater arall/ Any other issues	
Darparwyd yr wybodaeth gan/ Information provided by	

Appendix ii: Overview of carers' services in North Wales

Type of support	Services available	Summary/gaps	Anglesey	Gwynedd	Conwy	Denbighshire	Flintshire	Wrexham
Information	Local authority: websites, leaflets	Information provided on local authority websites, and through leaflets for carers	Available	Available	Available	Available	Available	Available
	Carers organisations: leaflets, packs, specialist information	General information as well as information on specific conditions provided by third sector organisations.	Available	Available	Available	Available	Available	Available
	Dewis Cymru	Information about well-being and local services.	Available	Available	Available	Available	Available	Available
	Specialist organisations: information on specific conditions	Information provided by specialist organisations on specific conditions, with general information available on websites, with some local projects providing additional support.	Available	Available	Available	Available	Available	Available
	Dementia carer information	National and local information as well as coping strategies provided to improve family, friends' and carers understanding of dementia.	Available	Available	Available	Available	Available	Available
	Hospital liaison posts	Hospital liaison posts in Ysbyty Gwynedd and Wrexham Maelor. No post at Ysbyty Glan Clwyd. Access to the service is determined by which hospital people attend rather than where they live e.g. someone from Conwy attending Ysbyty Gwynedd could still access the service.	Available	Available			Available	Available
	GP Liaison and hospital discharge: social prescribing; local area coordination	Service provided to facilitate the early identification of carers, carer support at the point of discharge. Also, community based services provided for carers to access support and well-being services locally. These services may be known under different names locally, and also have different models of delivery.	Available	Available	Available	Available	Available	Available
Advice	Single Points of Access to health and social care	Provided by local authorities/health across North Wales together with third sector organisations.	Available	Available	Available	Available	Available	Available

	Carers advice and information projects	Provided by third sector organisations as well as in-house teams.	Available	Available	Available	Available	Available	Available
	Money and benefits advice	Welfare advice for carers provided either through local authorities, carer third sector organisations or by signposting to other providers of welfare rights services.	Available	Available	Available	Available	Available	Available
Assistance and support	Advocacy	Advocacy provided through specialist advocacy services for carers. Third sector organisations also provide informal advocacy for carers. Advocacy covers a range through from informal to formal advocacy, with a service available specifically for young carers.	Available	Available	Available	Available	Available	Available
	Assessment of carers' needs	Local authorities, with one local authority commissioning a third sector organisation. Although third sector organisations may also be providing informal assessments of carers' needs, which may reduce the demand for formal local authority needs assessments, these are not included in the needs assessment data.	Available	Available	Available	Available	Available	Available
	Direct payments, support budgets	Offered by local authorities. The way they are promoted and used varies across counties.	Available	Available	Available	Available	Available	Available
	Carers' emergency support	Type of emergency support may vary across counties. It is unclear to what extent contingency arrangements are in place in various areas when carers fall ill or are no longer able to care.	Available	Available	Available	Available	Available	Available
	Carers grants	Provided through third sector organisations across the region. Third sector organisations also can provide access to other sources of grant funding.	Available	Available	Available	Available	Available	Available
	Carer breaks	Provided by third sector organisations and/or domiciliary care providers, across North Wales.	Available	Available	Available	Available	Available	Available
	Carer peer support and networking	Provided by third sector carer organisations and condition specific organisations, also providing an element of respite.	Available	Available	Available	Available	Available	Available

Training	Provided by third sector carer organisations and condition specific organisations.	Available	Available	Available	Available	Available	Available
Emotional support and counselling	Third sector carer organisations and condition specific organisations offer emotional support across North Wales. Counselling is offered through carer organisations in some areas. Counselling is also available for young carers.	Partly available	Partly available	Partly available	Available	Available	Available
Changes and transitions	Local authorities, third sector carer organisations and condition specific organisations. Type of support may vary across counties and could involve emotional support and counselling. Peer support and networking will also support carers in times of transition.	Available	Available	Available	Available	Available	Available
Support to access employment	Provided through an European Funded project in some areas, as well as through a third sector organisation. Support to access employment is unavailable in Wrexham.	Available	Available	Available	Available	Available	
Support to access social/leisure activity	Could include discounted leisure membership, support with costs, information about informal social/leisure activities. Provided by local authorities, third sector carer organisations and condition specific organisations. Type of support may vary across counties and based on 'what matters' conversation.	Available	Available	Available	Available	Available	Available
Health and well-being	Whilst carers' well-being will be an integral part of their needs assessment, services recognised as services to support well-being will vary. One local authority area employs an officer to support the local authority's duty to focus on the well being of carers. The lottery funded project in the North East places an emphasis on supporting carers' well-being.	Available	Available	Available	Available	Available	Available
Whole family support	Local authorities, third sector carer organisations and condition specific organisations. Type of	Available	Available	Available	Available	Available	Available

		support may vary across counties and based on 'what matters' conversation.							
	Housing support	Not aware of direct housing support but carers' organisations will signpost to other organisations.							
	Support to access / maintain attendance at school (young carers)	Provided by third sector organisations working with young carers. Pilot project underway with some schools in North Wales.	Available						
	Support for young carers	Provided by third sector organisations across North Wales.	Available						
Carers shaping policy and services	Opportunities to be involved in shaping policy and services	Regional carers reference group. Local opportunities through local partnerships, local authorities and health and third sector organisations. Type of opportunities vary across counties.	Available						



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NORTH WALES SOCIAL CARE AND WELL-BEING
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North Wales Carers Strategic Group Action Plan – June 2018

Carers have a key role in the health the health and social care environment in Wales and need to be recognised and valued for the support they provide. They themselves also need support in this vital role, and local authorities should therefore help ensure that carers are able to live their own lives as independently as possible. This is also in line with the Social Services and Well Being (Wales) Act 2014 (SSWBA) which legislates for enhanced rights for carers and simplifies and consolidates the law, giving them for the first time equivalent rights to the person they care for.

The action plan is based on:

The offer for carers in North Wales as agreed at the Workshop on 19 March 2018 – Regional standards, local commissioning

- i) The Welsh Government's national priorities for carers:
 - Supporting life alongside caring – all carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring
 - Identifying and recognising carers – fundamental to the success of delivering improved personal well-being outcomes for carers is the need to improve carers' recognition of their role and to ensure they can access the necessary support
 - Providing information, advice and assistance – it is important that carers receive the appropriate information and advice where and when they need it
- ii) The North Wales Population Assessment Regional Plan 2018-2023

The action plan reflects the regional standards, local commissioning approach involved in the offer for carers. The carers offer has been aged as a region, with much of the delivery happening on a local level led by local organisations. This group will have a role in monitoring progress, providing support and facilitating joint work where appropriate, with the North Wales Carers Operational Group collaborating to deliver services which meet the offer for carers and identifying opportunities to work better together.

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
	The offer for carers					
1.	Carers views and knowledge are sought to co-produce plans and strategies	For carers to be involved in the design of services	All partners	WG survey undertaken by local authorities Patient satisfaction survey undertaken by BCUHB Case studies collected as part of monitoring services	Information from case studies and surveys to be reviewed and used to inform the carers strategy in North Wales.	
2.	Carers being involved in local decision making	Agencies designed to give carers a voice in local decision making and make sure all services in the area become more carer-aware and carer-friendly	All partners	Evidence needed to establish current situation	Links to be made with Public Service Boards and their Well-being plans	
3.	Policy and Practice Protocols	Policy and practice protocols on	All partners	Confirmation needed of current situation and sharing of		

		confidentiality and sharing information are in place.		information arrangements		
4.	Success measures	Success measures are available to inform the progress of the carers strategy	All partners		Carers strategy measures to be adopted	
Social Services and Well Being Act 2014						
5.	Specialist advocacy available	All carers in North Wales to be able to access specialist advocacy, including for Continuing Health Care and for young carers	Local authorities, BCUHB	Informal advocacy available, with need to ensure that formal advocacy support is available across the region	Increased understanding needed of why carers need advocacy, with a view to learning and improving the way services are provided, which could lead in reduced demand for advocacy. To consider the possibilities of support for self-advocacy.	

Population Needs Assessment						
6.	Flexible carer break provision	The need for carers to access flexible and bespoke breaks in accordance to what matters to them	Local authorities Health Third sector	<p>Discussion held with NASH regarding the possibilities of more innovative use of Direct Payments to support carer breaks.</p> <p>NWCOG work programme in action: Contributing to National Carers Officers Learning and Improvement Network work stream on alternative carer breaks.</p> <p>Third sector innovative carer break projects.</p> <p>Local initiatives as part of third sector led projects</p>	Local discussions needed to build business cases locally for using Direct Payments to facilitate flexible carer breaks.	

				Social prescribing/community navigators		
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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Carers Operational Group Action Plan – April 2018

Carers have a key role in the health the health and social care environment in Wales and need to be recognised and valued for the support they provide. They themselves also need support in this vital role, and local authorities should therefore help ensure that carers are able to live their own lives as independently as possible. This is also in line with the Social Services and Well Being (Wales) Act 2014 (SSWBA) which legislates for enhanced rights for carers and simplifies and consolidates the law, giving them for the first time equivalent rights to the person they care for.

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- i) The Welsh Government's national priorities for carers:
 - Supporting life alongside caring – all carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring
 - Identifying and recognising carers – fundamental to the success of delivering improved personal well-being outcomes for carers is the need to improve carers' recognition of their role and to ensure they can access the necessary support
 - Providing information, advice and assistance – it is important that carers receive the appropriate information and advice where and when they need it
- ii) The North Wales Population Assessment Regional Plan 2018-2023

The action plan reflects the regional standards, local commissioning approach involved in the offer for carers. The carers offer has been aged as a region, with much of the delivery happening on a local level led by local organisations. The North Wales Strategic Group will have a role in monitoring progress, providing support and facilitating joint work where appropriate, with the North Wales Carers Operational Group collaborating to deliver services which meet the offer for carers and identifying opportunities to work better together.

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
	The offer for carers					
1	Carers and the essential role they play are identified at first contact or as soon as possible thereafter	Need to identify, support and signpost carers at the earliest point	Local authorities Health	Unclear whether all carers are identified. Some carers do not wish to be identified. Mapping carer pathways Triangle of care work incorporates this and is implemented in mental health services (BCUHB)	Extension of Triangle of Care work to Acute services, Community Mental Health services and Dementia services.	

Appendix 5 Carers: NWCOG Action Plan

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
				<p>Acute hospital discharge support has been strengthened with support available in all 3 hospital sites</p> <p>GP facilitator work under review</p>	<p>Exit strategy needed</p> <p>Data needed on GP/community hospital model under pilot in NEWCIS</p> <p>Synergy in outcomes and outputs.</p> <p>Royal College of General Practitioner resources to be looked at as well as the possibility of designing</p>	

Appendix 5 Carers: NWCOG Action Plan

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
					<p>posters to be displayed in GP surgeries. Need to work towards standards for GPs.</p> <p>Letter to be drafted from the RPB to GPs from the partnership board stating what the offer for carers from the primary carer needs to be and what the benefits to them are. Copy to staff.</p> <p>A statement to be made to carers stating what they can expect.</p>	

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
2	<p>Carers' views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies take shape</p>	<p>Need to involve carers in the planning of services, also as part of the evaluation of locally run projects</p>	<p>Local authorities</p> <p>Health</p> <p>Third sector organisations</p>	<p>Local partnerships, local engagement and strategy development work involves carers</p> <p>Partnership Carers Reference Group meets regularly</p> <p>Case studies are collated</p> <p>Surveys – Partnership and local authorities for WG statistics</p>		

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
3i)	<p>Staff are 'carer aware' and trained in carer engagement strategies</p>	<p>Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers' own needs. Staff need knowledge, training and support to become carer aware.</p>	<p>Local authorities Health</p>	<p>Training available, but unclear as to whether this is consistent across services.</p> <p>Triangle of care incorporates training needs</p> <p>Social Care Wales have commissioned Carers Wales to co-produce a new national online carers awareness training which will be appropriate for health, local authority and third sector workers.</p>	<p>Training needs analyses needed.</p>	

Appendix 5 Carers: NWCOG Action Plan

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
3ii)	Carers' training needs are being addressed	Training needs of carers to be fed into the Social Care Workforce Development Plan (SCWDP).	Local authorities	Training delivered for carers by third sector organisations. Carers have access to SCWDP training.	Carer training needs should be incorporated into SCWDP, with consideration given to training already provided by third sector	
4	Policy and practice protocols on confidentiality and sharing information are in place.	Staff need to be confident in sharing of information with carer	Local authorities Health	Triangle of care incorporates understanding of confidentiality and sharing of information.		
5	Defined post(s) responsible for carers are in place (carers leads)	Role of carer lead officer needs to be able to influence discussions on strategic direction within organisations.	Local authorities Health	Each local authority has a carers lead officer post. Responsibilities vary from area to area.	Post of BCUHB lead officer needs to be funded from core budget.	
6	A carer focused introduction to the service and staff is available, with a relevant	Carers need to be thought of on an equal basis	Local authorities Health	Carer leaflets available from local authorities.	Understanding needed of gaps in provision.	

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
	range of information across the care pathway.	as the person cared for		Triangle of care incorporates a standard for introductory materials	Audit needed, as part of Triangle of care work where possible.	
7	A range of carer support services is available.	Capacity to provide bespoke services to carers according to what matters	Local authorities Health Third sector	A range is available across North Wales, with differences from area to area in terms of how service is delivered.	Local partnerships to work together to ensure that support services are commissioned in response to what matters to carers.	
Social Services and Well Being Act 2014						
8	Carers' needs assessments	To carry out needs assessments where a carer appears to have support needs and to conduct regular reviews	Local authorities	Needs assessments carried out, but lack of clarity and consistency in data. One authority commissions a third sector provider to carry out assessments on its behalf	Link to carer surveys. What are carers telling us about the sustainability of their caring role.	

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
9	Advocacy	Independent professional advocacy as well as informal advocacy	Local authorities	A range of advocacy services are available.		
Population Needs Assessment						
10	Flexible carer break provision	The need for carers to access flexible and bespoke breaks in accordance to what matters to them	Local authorities Health Third sector	Contributing to National Carers Officers Learning and Improvement Network work stream on alternative carer breaks. Third sector innovative carer break projects. Local initiatives as part of third sector led projects		

Appendix 5 Carers: NWCOG Action Plan

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
				Social prescribing/community navigators		
11	Supporting carers in employment	Employers to develop	Local authorities Health Third Sector Carers Wales	Carers Wales Employers for Carers scheme underway. BCUHB policy for carer absences adopted but not implemented. NEWCIS Carer Friendly Employment Recognition Standards available		
12	Young adult carers supported	Bespoke support needed for young adult carers	Third sector Local authorities Health	Gaps in services identified, namely more intensive and tailored support around employment, training, confidence building and housing.	Consider the possibility of a third sector led a regional bid to the People and Places lottery fund to improve services for	

Appendix 5 Carers: NWCOG Action Plan

	INDICATOR/RISK	NEED	LEAD/KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
					young adult carers.	

Draft



North Wales Young Carers Operational Group: Action Plan January 2018

Welsh Government defines young carers as carers who are under the age of 18. The Code of Practice for Part 3 of the SSWWA 2014 defines young adult carers as being ages 16 to 25. This action plan is inclusive of the needs of all young and young adult carers up to age 25 years.

The needs and indicators have been extracted from Annex 1 of Code of Practice on the exercise of social service functions in relation to Part 3 SSWWA 2014 (COP) <http://gov.wales/docs/dhss/publications/151218part3en.pdf> and from the North Wales Population Needs Assessment Carers Chapter <https://www.northwalescollaborative.wales/wp-content/uploads/2017/04/7-Carers-chapter.pdf> pages 223-230 (PNA).

Guiding Principles of the North Wales Young Carer Action Plan.

- That the action plan is based on what matters for young carers/young adult carers
- That we involve young carers/young adult carers in service design
- That we develop robust, sustainable and flexible services in partnership to support young adult carers

	INDICATOR / RISK	NEED	LEAD/ KEY PARTNER	WHERE ARE WE NOW?	FUTURE ACTION	PROGRESS R/A/G
1	The individual is/will be unable to access support to maintain or develop family or other significant personal relationships (COP)	Need for peer support, counselling and carer break services (PNA)	Local Authority Health Carer support services.	Additional carer break funding for LA`s. School counselling services do exist.	Strengthen link with CAMHS and ACEs leads. Link in with MH Primary Care and Well-Being pathway.	

Appendix 6 Carers: NWYCOG Action Plan

				<p>YC and schools based services re: peer support.</p> <p>Carer support services provide the majority of support.</p>	<p>Map how available formal counselling is.</p> <p>Query: Health Representative from Childrens Services.</p>	
2	<p>The individual experiences loss of control, or is likely to experience loss of control, over their immediate environment and/or day-to-day life including financial stability.(COP)</p>	<p>Young carers may feel insecure about their housing as they are not able to receive benefits or take on responsibility for paying council tax themselves (PNA)</p>	<p>Local Authority</p> <p>Carer support services.</p>	<p>Currently we don't know we need to explore: Links with housing, contingency planning YC services, access to benefits advice, welfare rights etc?</p>	<p>Work with L/A to research need and uptake for tenancy/housing related support for YC.</p> <p>Map what services are available and is there a need?</p>	
3	<p>The individual is unable to undertake, or is likely to be unable to undertake family and social roles and responsibilities that enable them to meet personal well-being outcomes for themselves or others (COP).</p>	<p>Need for carer breaks and opportunities to socialise (giving them time to be a child) (PNA)</p>	<p>Local Authority</p> <p>Carer support services.</p>	<p>YC services and LA provide these provisions.</p> <p>What is the current uptake of Carers Assessment? Carers assessments should identify and signpost to achieve these personal</p>	<p>YC Services to adopt regional Young Carer Assessment protocol currently being developed (Vicky Allen)</p>	

Appendix 6 Carers: NWYCOG Action Plan

				well-being outcomes.		
4	The individual's social support systems are or could be at risk (COP).	Preventative measures to prevent the social support systems becoming at risk (PNA)	Local Authority Carer support services.	Team Around the Family (TAF)/Team around Child (TAC); Family Group meetings; and YC services address these issues.	Further work to be done around community support and inclusion.	
5	The individual is unable to attain or experience good physical and/or mental health (COP).	Need for support to improve resilience, emotional wellbeing and self-esteem. Need for peer support networks with other young carers who understand. Counselling services and support with their own health needs (PNA)	Health Local Authority Support services.	YC Services and School based counselling. Some discounted leisure centre access.	Further work to be done with CAMHS, primary mental health services and GPs. Updated mapping of current leisure opportunities for YCs Training opportunities on-line re: Mental Health information and resilience. What else is available?	
6	The individual is/will be unable to access and engage in work, training, education, volunteering or	Need for support with education and learning Young adult carers miss or cut short on average 48 days of	Local Authority Education services. Carer support services.	YCiS programme. Pilot YCiS in primary schools from Transitional Funds.	Potential to work with Pupil Referral Service and Careers service to capture YC's in transition?	

Appendix 6 Carers: NWYCOG Action Plan

	recreational activities (COP)..	school each year (nearly 5 weeks). This among other factors can have a negative impact on achievement and future attainment (PNA).			Make links with Challenge Advisors. Need to establish links with Directors of Education and Cluster Leads to be involved in this work.	
7	Lack of awareness and respect by some professionals, particularly in health (PNA)	Need for advocacy, especially when dealing with professionals in order to have their voices heard (PNA).	Local Authority Health	YC Services National ID card being proposed by WG. Childrens Advocacy Service (unclear if this is open to YCs) Training and promotion in and for primary care health professionals ongoing. Medicines management Triangle of Care	Advocacy for YC as with adults? Potential to map Triangle of care approach for YC`s in MH WCPPE leading on work around training on medicines management for YCs	
8	Accessible user friendly information	Access to appropriate	All Partners.	YC services	SS&WB ACT General Functions	

Appendix 6 Carers: NWYCOG Action Plan

	<p>either online or one to one without using jargon (PNA).</p>	<p>information, advice and assistance (PNA)</p>		<p>Local Authority IAA systems</p> <p>Health support and further IAA internally.</p>	<p>350. In addition, alignment to the standards within the National Standards and Quality Assurance Framework for Information Services for Young People is recommended.</p> <p>http://www.promo-cymru.org/resources-2/national-standards-quality-assuranceframework</p> <p>Promote information for YC in the wider community.</p>	
<p>9</p>	<p>Problems making GP appointments and wider issues within primary care services (PNA)</p>	<p>Improve identification and understanding within primary care (PNA).</p>	<p>Health</p> <p>Carer support services.</p>	<p>Targeted interventions and GP facilitators work on-going.</p> <p>New model of primary care facilitators being assessed to see if this has a better impact.</p>	<p>Governance around accessible healthcare and how we can promote from this angle.</p> <p>Continued engagement with managed practices to show the benefit of engaging with YC`s.</p>	

Appendix 6 Carers: NWYCOG Action Plan

					Targeted campaigns for GP`s, checklist why beneficial to be inclusive.	
10	Very young carers, those under the age of eight, are at particular risk and have been excluded from some young carers' assessments and services in the past on the grounds that a child under eight shouldn't have any caring responsibilities (PNA).	Commissioners need to make sure there is support in place for these young people whether through young carers' services or other services for vulnerable children (PNA).	All Partners.	Work with primary schools via YCiS programme and YC services. YC services some working from age 5. Eligibility for care and support Part 3	Establish better and targeted links with Health visitors, school nurse and GPs. Map the discrepancies within YC services. Link with private nurseries who may not be linked in to wider work stream. Child in Need/ child at Risk; are their caring roles being capture if there is already a primary need?	



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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Carers Reference Group (CRG). Action Plan January 2018-January 2019

<i>Item</i>	<i>Action</i>	<i>Responsible</i>	<i>Deadline</i>	<i>Progress</i>
Regimentation and institutionalisation of support services offered to carers. Carers wish to be offered a personalised and bespoke package of wrap around care.	<ul style="list-style-type: none"> Inform the Regional Leadership board of case studies and examples highlighting this issue. Continue to challenge old behaviours within Local Authority and Health Boards. CRG members to bring issues to the attention of the CRG so that issues can be tackled in order to change culture and processes. 	ALL ALL	Ongoing.	<ul style="list-style-type: none"> Informed Regional Leadership Group of this issue at the CRG Workshop on 16th November 2017. This has also been completed by professionals in their engagement with the Regional Leadership Group. This has been captured by the Regional Business Manager and put forward in her mapping report. This has been captured within our collection of carer's stories to inform the Regional Leadership Group. Education around this is ongoing within the Health Board and Local Authority. CRG members bring specific issues to the group and ones that can be tackled are handed over to the appropriate person to be dealt with.
Encourage early identification and intervention for the carer and person cared for to take the pressure off carers. Good quality	<ul style="list-style-type: none"> Educate Health staff. Educate Local Authority staff. Develop a package of training for all health and social care staff to ensure consistency in awareness and provision. 	Health Board L/A's ALL	Ongoing Ongoing March 2018	<ul style="list-style-type: none"> Ongoing awareness raising and training being undertaken in BCUHB. Also looking at audits and opportunities for procedural change to improve identification of carers and what staff do with this information once captured. Mandatory training for LA staff on the SSWWA 2014 and ongoing training being delivered

<i>Item</i>	<i>Action</i>	<i>Responsible</i>	<i>Deadline</i>	<i>Progress</i>
education and training for health care professionals around carers issues.				<p>across the region. Still inconsistencies in each L/A.</p> <ul style="list-style-type: none"> • Social Care Wales are developing a National training package for all health, LA`s and social care workers to utilise. All partners have been collaborated with and a draft version is due to be circulated early next year.
Eliminate geographical barriers and information sharing barriers between services. In order to foster a climate of partnership and integration.	<ul style="list-style-type: none"> • Inform the Regional Leadership Group of this issue. • Promote consistency with services across geographical areas. • Allow LA`s and third sector organisations to work more closely together. 	<p>ALL</p> <p>ALL</p>	Ongoing	<ul style="list-style-type: none"> • Informed Regional Leadership Group of this issue at the CRG Workshop on 16th November 2017. • This has also been completed by professionals in their engagement with the Regional Leadership Group. • This has been captured by the Regional Business Manager and put forward in her mapping report. • The Regional Leadership Group has recommended that carer`s services budgets are pooled. Not only will this spread the funds we have further, but this will promote cross boundary working.

Item	Action	Responsible	Deadline	Progress
<p>Improve the experience for carers within the Continuing Health Care (CHC) process.</p>	<ul style="list-style-type: none"> • AD and DC to meet with Will Williams. • AD to work closely with CHC staff trainer Sian Kelbrick. • AD/DC/WW to look at capturing carer experiences in the CHC process and how to do this. • AD to meet with ASNEW around advocacy in the CHC process. 	<p>AD/DC LA`s. CHC</p>	<p>Ongoing</p>	<ul style="list-style-type: none"> • AD and DC met with WW on 17th October 2017 and committed to working more closely together. Very important to ensure that carers are supported and informed throughout the process. • Training for staff is very good and explicitly states what carer`s are entitled to and should be provided with. Carer friendly, however, this does not always happen in practice. AD will support trainer SK and explore carer issues in more depth with staff. • DC and WW looking at how to utilise carer survey in order to target poor practice and highlight good practice in the CHC process. • AD met with specialist CHC advisor on 12th October from ASNEW, very good however only available in some LA areas and long waiting lists. Advocacy to be promoted in the CHC process. • AD has met with Sian Kelbrick Interim Head of CHC Performance and Compliance on 9th March 2018, I have advise on their strategy and suggested future ways of improving carer inclusion and engagement. Ad provided Sian with the CRG action plan and fed back the comments received about the CHC. Sian has agreed to adopt out carers servey to drive

Item	Action	Responsible	Deadline	Progress
				improvement for carers and also will distribute out BCUHB Carers Leaflets to every new person cared for and family. They are also going to adopt their invitation letters to be more carer inclusive and advise carers of their rights and a right to an advocate. AD has provided the CHC with a map of carers` services and advocacy services.
Carers wish to be able to access expert advice and assistance when issues arise in relation to mental health and substance misuse carers.	<ul style="list-style-type: none"> • Feedback to the Mental Health Patient Experience Group. • Recommend a telephone support service/triage service for families and carers. • Encourage Triangle of Care (ToC) principles throughout all of MH division which will promote advice and assistance being offered to carers at the earliest opportunity preventing the need for emergency advice. 	AD BCUHB	March 2018	<ul style="list-style-type: none"> • ToC audits have been undertaken in all rehabilitation units and many CMHT`s. The audits have been analysed and in the process of feeding back to each unit with recommendations and support processes. • AD will start to compile report of final findings, developments to date and overarching recommendations in January 2018. • Working closely with third sector partners and carers to improve out services for MH carers. • (March 2018) The Rehabilitation Units have now adopted all of the changes highlighted by the ToC and a carer pathway has been created.

<i>Item</i>	<i>Action</i>	<i>Responsible</i>	<i>Deadline</i>	<i>Progress</i>
	<ul style="list-style-type: none"> AD to write and submit a report to the M/HPEG of the ToC finding and CRG findings. 			
<i>Item</i>	<i>Action</i>	<i>Responsible</i>	<i>Deadline</i>	<i>Progress</i>
Carers Week Plans Monday 11 th June to Sunday 17 th June 2018	<ul style="list-style-type: none"> The group to plan awareness raising activities for Carers Week 2018 	CRG members	May 2018	<ul style="list-style-type: none">