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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 Alltwn 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.