Question 4

Current service and assets
(and what could we do better/gaps in services)
Contents

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Question 4: Current service and assets (and what could we do better/gaps in services)

Too much and inconsistent information

The issue of information is a key point raised, by the vast majority of carers, in the questionnaires, focus groups and 1-2-1 interviews. Many feel that there is too much information available from a wide and varied range of sources and agencies. New carers are ‘overwhelmed’ by the amount of information on offer, and some had contacted multiple statutory and third sector support services as they were unsure where to go to for assistance. Carers say it’s difficult to know who to contact first and that they want a simpler way to get help. There is a clear need for:

- Clear guidance information
- Legal advice
- Financial advice (particularly to mitigate carer assumptions that they will not be eligible so do not investigate financial support)

Carers comments include:

“It’s all down to the carers to find out, you get passed from pillar to post. Very disjointed communication between organisations. It's draining, you don’t want to chase up, you just want some help.”

“It’s as if they want to make it difficult.”

“Don’t make forms more difficult than they already are.”

“Focal point for information – too many organisations contacting me, got very confusing. Overwhelmed.”

“The biggest problem is getting the right information and asking the right question.”

“If you’re a carer, you’ve enough on your plate without having to look things up.”

“Information on tap – Livewell [Website] not promoted to communities. No-one knows it is there. Need it to be up to date. Not just relying on website, need a paper version. Have a hub in the library with all up to date services.”

“I’ve been doing this for 43 years now. It’s been a struggle doing all this on my own.”

“Everything is online now, which makes a problem.”

“Stop assuming that everyone is online and can access services.”

Conversely, a large number of respondents to the adult survey said lack of awareness of services available was a big issue. For example; 73% of survey respondents were unaware of the support available at short notice or in a crisis; 55% were unaware of respite bed provision, and 57% of respondents were unaware of the emergency support scheme which contacts named people in the event of an emergency.

The findings suggest that each adult carer has different support in place - dependent upon what they have discovered for themselves, or what they have been made aware of. There were many instances of support packages widely varying from one carer to another – for example in one focus group of 10 carers no two people had the same support or had the same experience.

Some carers reported that they were happy with the formal pathways they had taken to access support, others felt that information given had been very inconsistent (both from different organisations and even from different people at the same organisations) and they often found out about support services through informal channels e.g. peer support groups.
“I contacted all i.e. doctor, district nurse, carers, Macmillan and OT. Must be a simpler way to get help rather than having to contact everyone!”

In some cases, carers struggled to identify which organisation provided which support, and others mentioned that organisations (statutory and VCFS) didn’t always work well with each other, leading to gaps in support or delays in providing assistance:

“There have been a couple of occasions where it has been disjointed and confusion about whose responsibility it is to do something.”

35% of respondents in the Cheshire East Council survey (left) who had struggled with finding information, experienced the same issues with very similar comments being made:

“Information is very scattered between different organisations who do not work together.”

“Very, very exhausting trying to find out information – no central point. You are busy enough caring without having to search the internet/make phone calls/have interviews/visit care homes etc.”

“Having to access different agencies and have to give the same information over again.”

Opportunities for improvement:

Carers want to be signposted to specific organisations that will suit their individual needs, rather than a list of providers to work through:

“Better advice from social services on suitable providers for your specific needs, rather than just being given a list of all providers and being told it’s your decision, without suitable information upon which to make a decision.”

Option to speak to someone face-to-face - several carers stressed that not everyone is online, and that some people will always value having a person to speak to.

- Carers want information to be consistent e.g. a checklist of options and support provided to all carers, whichever pathway they have taken.
- Stronger partnership-working between support organisations.
- The development of a one-stop-shop for information and advice.
- Tailored support for the specific needs of the carer.
Mental Health and Emotional Support

A number of adult carers felt that there was not enough support for mental health and that carers have to be at breaking point before being offered mental health support:

“It’s not geared for mental health, you have no help from social services unless you have a crisis.”

“Being offered counselling in the first place instead of until breakdown point and instead of self-funding it all.”

Cheshire East Parent Carer Forum Members’ Survey (2017) also found that being a carer could impact upon the parent carer’s mental health. As well as the physical and mental strain of being a carer, it was reported that this can be made worse by feeling “doubted/blamed” by professionals, and also by the “constant battling for support” for the person they care for.

Opportunities for improvement:

- Provide access to counselling at the point of need and help carers work through issues around guilt and self-care.
- Fast track carers to health services.

Difficulties securing support for the cared-for person

One carer felt that there was limited support for Aspergers’, especially newly diagnosed as an adult and in females. A large number of adult respondents also commented that they would particularly value support that was more tailored to specific conditions and it was commented more than once that condition-specific training for medical and care staff would be helpful (most often raised in relation to those caring for people with autism and dementia, but also for Huntington’s disease and challenging behaviour).

More generally, 55% of the adult survey respondents said that they would welcome support to help them understand the condition of the person they cared for and 73% of respondents to the adult survey would most value support from medical professionals and services.

From a dementia focus group, a number of attendees agreed that they would have an improved quality of life if they could rely upon the standard of external care provided for their cared-for person.

From focus groups held at specific condition peer support groups, attendees said that they particularly valued the opportunity to share experiences and information with other people who understood the needs of the person they care for. From the adult survey, it emerged that 67% would welcome support from others in similar situations. The following comments were made about peer support groups:

“Carers want a space to have a ‘rant’ and speak to others who understand.”

“People are under serious and distressing circumstances and they can come to these groups and have a laugh and share advice and experiences.”

“We need more support groups, more regularly than once a fortnight.”

More than one adult carer said that they “felt stupid” and “like they were part of the problem” by asking medical professionals questions about their cared-for person’s condition.

One carer described the lack of communication and cohesion between NHS services when their cared-for person was discharged from hospital:

“We were just sent home with 2 Zimmer frames and told to get on with it.”

The Cheshire East Parent Carer Forum Members’ Survey (2017) noted that members had raised concerns about communication between support organisations: “poor transitions – having to repeat everything”, with “information not passed on/provision not carried over to a new setting.”
Carers had the following suggestions and comments to make:

**Awareness of carer status:**

"It took a while to come around to realising that I wasn’t just being a mum, I was a carer too."

"Even though I did voluntary work with Young Carers, I had to email the session coordinator to ask if I was a carer as I thought I was just a daughter. There are problems with identification."

"When mum had dementia, I didn’t think I was a carer, we were just her children."

"It’s not something that sits easy with me, because she’s my daughter. But with the problems she has and all the appointments, I suppose I am."

**Barriers to carers getting support:**

"Some people can’t leave their cared-for person at all. They need to take that into account."

"They used to be able to provide transport to meetings, but that’s stopped."

**Eligibility for support:**

"There needs to be eligibility and criteria for funding. I felt the Wellbeing Fund was too ambiguous, I felt a 1-10 grading wasn’t fair. If you’re caring for somebody 24/7, that should be enough to mean you’re eligible for the fund. Sometimes the facts should speak for themselves."

**Befriending services for their cared-for person:**

"Befriending, set up by the Reablement Team. They were really good. They take your cared-for person to the pub for a meal or for a walk and it really works. It makes such a difference. You pay the outing expenses. But it needs funding."

Opportunities for improvement

- Develop portal to access suitably qualified, high quality paid carers with information about their experiences of working with people with specific conditions. Investigate whether this can be included as part of the Live Well directory.

- Add Healthwatch enter and view reports of care homes to the Live Well directory.

- Provide condition-specific training for medical and care staff (e.g. for autism, dementia, Huntington’s and challenging behaviour).

- Awareness raising for adults to recognise their caring role.

What has been your experience of support provided by your doctor, district nurse or local hospital?

The majority of adults spoken to, had registered as their cared-for person’s carer at their GP surgery. A large number felt that this had not made any difference; however, others mentioned flexibility with appointments (times and double appointments), home visits and additional support.

"Doctors register you as a carer to “make things easier” but I think it’s just to tick a box."

Being able to attend medical appointments at a time of day that suited them was another issue for carers. Some said they struggled to phone their GP surgery at a designated time of day, particularly when needing to make an emergency appointment, because of the needs and daily routine of their cared-for person.
Similarly, it could be difficult when needing to attend appointments at GP surgeries or hospital. There appeared to be limited use of online booking of appointments or online prescription renewals, possibly due to lack of awareness.

A large number of adult participants have said that they have received a good level of support and assistance from their GPs with their situations and caring roles. At least one GP surgery runs its own carer support group. However, there have been instances where support has not been provided:

“I told my GP I sometimes feel like walking out of the house, getting in my car and driving off and calling social services to say I’ve left my cared-for person. The doctor’s response was, well I recommend that if you do that you do it in the morning and not the afternoon so that they have more time to arrange care.”

Others have mentioned the issue of confidentiality when dealing with a family member cared-for person, and the difficulties of overcoming patient confidentiality e.g. permission from the person they care for/Power of Health Attorney etc.

A small number of adult carers felt unsupported by the GP of the person they care for, with at least two carers suggesting that being given better support and signposting at point of diagnosis would be very helpful (one carer had been left for six weeks following diagnosis without any support or signposting at all):

“They don’t listen – make me feel little”

“... [information] at point of diagnosis would be better ie same as cancer services”

“Would have been helpful for GP at diagnosis to have provided Cheshire and Warrington Carers Trust information at that appointment, instead of having to wait 6 weeks.”

The above delay resulted in a significant negative impact upon the carer’s mental health, before they became aware that support was available.

Young carers’ experiences of doctors and hospitals

The young carers at the two support groups did not have much to say about their experiences of doctors and hospitals, aside from a number of young carers who felt that they had not been asked about their caring role by medical professionals or offered support e.g. at doctor appointments with their cared-for person or at hospital.

They were more forthcoming about support from social workers and schools. The following comments were made:

“I haven’t had much support from my doctor. My dad said at the hospital that I was a carer at home, I wasn’t even asked by anyone. I wasn’t referred for any more support.”

“I was asked if I had any roles to do at home. I filled in a survey but nothing happened after that.”

Some service providers have said that they get their lowest number of referrals from GPs, despite GPs being most likely to see large numbers of carers, and to see those who may not know where else to go.

Focus group discussions suggest that it would greatly benefit carers to be asked about their own health and wellbeing when attending health appointments with their cared-for person.

“They don’t understand carers’ needs”

“They don’t ask how we are”
Regarding social workers, the young carers who referred to them commented that they were provided with support from their social worker (or 'link worker') and that they could talk to them if they needed to talk about issues.

**Opportunities for improvement:**

- More information and advice and guidance regarding online booking and the ordering and collection of prescriptions.
- Provision of post-diagnosis support for carers quickly and not having to wait weeks for information.
- Provision for home visits from the GP when the cared-for person is unable to go out, for either the cared-for person or the carer.
- Flexible appointments offered to those who are limited by when they can leave the house.
- Development of a clear offer for carers that is promoted to the public and professionals, especially GPs.
- Flagging to GP and other health professionals the importance of being aware of, and recognising the needs of the carer who is attending with the person that they care for. Improving understanding of current barriers to doing this and identifying ways of overcoming them e.g. booking double appointments when the carer will also be attending.
- Encourage referrals from GPs.
- Instructing health professionals to consider if the cared-for person will need help taking medication, and how this could best be provided (taking into account the presence of young carers).
- Provision of more information to young carers about their cared-for person's medical condition.

**Limited awareness of crisis and out of hours support**

A number use a crisis support scheme which gives some carers peace of mind – but only 42% of respondents were aware of this scheme (which alerts named contacts in the event of an emergency). Out of 20 carers interviewed, a few of the people they care for had a pendant alarm system, and two had contact details for relevant crisis teams.

73% of adult respondents were unaware of the short notice/emergency break support available, and the majority of carers had no crisis plans in place, and would use 999 in an emergency.

Only 54% of 31 young carers were aware that there is support enabling them to take a break at short notice or in an emergency. 67% of the young carers were unaware of the emergency contact scheme.

Of those who have had a crisis, the vast majority would call 999 for an ambulance or for the police. One young carer has been to Accident and Emergency at Leighton Hospital on three separate occasions with their cared-for person. A small minority would rely upon family and friends.

Two young carers mentioned that they used assistive technology, with one young carer using an alarm pendant for their cared-for person, and the other young carer explained about a falls alert bracelet.

The issue of out of working hours support could be problematic for carers. Some felt they needed to know there was still someone available on the phone to speak to, whilst others said they struggled at weekends to find support in a crisis:

"Weekends are a nightmare for carers as there isn't the same service there"
Opportunities for improvement:

- Raise awareness of what support is available in an emergency.
- Raise awareness of crisis support schemes which alert named contacts in the event of an emergency.
- Raise awareness of short notice/emergency break support available.

Experience of social care

A number of respondents to the survey felt that they had not received sufficient support from social care:

“It would be nice to get support and understanding from the Local Authority staff. Cheshire East have been very unsupportive.”

“I have been promised so much over the years, but it just never happened, so now I just go it alone. It’s less stressful.”

“The Wellbeing Fund is so important. I just feel that there’s no support from social services and nobody there to call.”

However, a number of respondents stated that they received support from social services. This input was mainly valued by the carers, however, a common response was that social workers could be hard to contact, that carers had to deal with too many different social workers, and that support could take some time to arrange:

“I work for social services and know the system, but even so struggled to gain a service without involving my work contacts.”

“It would be useful not to have everything so difficult to communicate and chase up, don’t need any other help. Care plan waiting on and direct payments linked. Phoned 4 times.”

A number of carers were also concerned about ‘getting things wrong’ and ‘using the correct terminology’ to clearly convey their situation when filling in documentation and responding to social care workers.

A large workload was suggested by one carer as the presumed reason why they struggled to contact their social care contact:

“I often spend hours or days waiting for a call back. Cancelled appointments. She has an enormous workload and it shows.”

From 1-2-1 interviews, parent carers also expressed concern about the transition of their cared-for person into adult social care, and this was particularly the case for parents of children with an autism spectrum condition.

From the Cheshire East Council survey of autumn 2016 ‘Survey of carers of Adults in Cheshire East 2016/17’, ‘Support from social work staff and good social work practice was listed both in the top 5 of services and support most valued by carers, as well as the top 5 areas of support that could be improved.

Similar responses to the Community JSNA findings above were also made through the Cheshire East Council Survey:

“Social services promised to send information out but never did. I had to do my own internet research.”

“Getting a response from services can take a while and I need to keep phoning to chase it up.”

“Continuity in having one single permanent social worker at Cheshire East Council, we have had several since they were first involved.”

“Had a number of social workers and each one had to visit and ask the same questions which was quite disruptive for a person with dementia.”
Inconsistent experiences of Carer’s Assessments

There was a wide disparity between carers who were aware of the Carer’s Assessment, and those who were not. There did not appear to be any consistent approach, and carers had found out about the assessments through different pathways.

“It’s very rare that someone asks you about a Carer’s Assessment.”

“I had to get a Carer’s Assessment before I could receive a service. The assessment was only provided when I asked for it, not as a matter of process.”

Of those who had had a Carer’s Assessment, a number felt that it had not helped them at all and they felt there was little point in having one. However, some felt that the assessment had been an important gateway to accessing other services:

“My initial Carer’s Assessment was several years ago, I had to fight for my right to an assessment and ended up waiting over 2 years! However, my carer’s assessment earlier this year was taken more seriously and an action plan devised which helps enormously.”

More than one carer had reported a significant wait between requesting an assessment and receiving one (more than one had been waiting for up to 2 years). However, others reported a quick turnaround time, which highlights again inconsistent experiences between carers.

Case Study: Cheshire and Warrington Carers Trust

CARER (83) cares for his wife, (81) who suffers from chronic pain... They had no family or help and CARER himself was finding jobs around the house physically demanding and had no time to himself as his wife needed constant attention.

CARER received a home visit from a Carer Support Worker and was at first reluctant to talk, especially about benefits and help. With support CARER agreed to let us help him apply for attendance allowance for his wife and to have a Carers Assessment. His wife was awarded attendance at the higher level (currently £82.30 per week) and CARER’s Carers Assessment highlighted the need for help.

CARER received 3 hours help per week, arising from the Carers Assessment, with the household chores. They used the attendance allowance money to buy in extra care for his wife, allowing CARER to have time to himself. With support, he began attending one of our support groups and was able to meet with friends on Tuesdays and joined a group that made farming tools for developing countries.

CARER told us that we had helped him to get his life back and no matter how things got with his cared-for person he had help and knew that on Tuesday, he would have the day to himself and that this meant the world to him. He also knew that we were there to help him and stayed in touch via the group. His only regret was that he hadn’t known he was a carer earlier and got in touch.

Opportunities for improvement:

- One point of contact for social care and be aware of the difficulties in contacting social care
- Develop an interface between the Carer’s Hub and social care teams
- Investigate the transition process for individuals from Children’s Services to Adult Social Care
- Raise awareness of the Carer’s Assessment with all carers and organisations
- Develop, implement and evaluate a clear process for offering Carer’s Assessments and clearly publicise this, together with the benefits of having an assessment.
Respite: increase opportunities for taking a break from caring

Residential respite

The information below applies to adult carers only. 55% of 86 adult carers were not aware of residential respite and several presumed that if payment was required they would be unable to afford it or that they would not be eligible.

It was mentioned more than once that some respite care could not be booked more than a fortnight in advance, which made planning a trip or break well in advance an impossibility. Others, however, said that they can book in advance, so there appears to be variation in experience.

The cost of residential respite can be prohibitive; one carer reported that the cost of residential respite was three times the cost of their holiday break.

The impact residential respite can have on carers was outlined as follows:

“It had massive impact, I slept better and I didn’t feel as if I was the one with dementia. At times I feel like I’m losing the plot and I didn’t feel like a hamster on a wheel. I didn’t have to think about someone else…”

“People in different financial circumstances can’t afford to pay for respite to go for a weekend. People who can’t afford to pay, it’s really difficult for them. We have savings, so we can manage for now. I don’t want money, I just want to go away one weekend in a year.”

Most who used residential respite appeared to be happy with the care home/facility used to provide the care, with only occasional mentions that sometimes the facility provided wasn’t entirely appropriate e.g. a cared-for person with a stroke staying in a care home primarily housing dementia patients, or a young woman being offered respite care with elderly dementia patients. This concurs with the Cheshire East Parent Carer Forum Members’ Survey from Autumn 2017 which found that some of their members reported that they were unable to find suitable provision, with respite not being suitable for the person they care for, or that it was too hard to find provision that met the EHIPS/Direct Payments criteria.

Another issue raised was that there was limited support available for cared-for people with challenging behaviour in Cheshire East, particularly the lack of respite beds.

The majority of those carers who could arrange residential respite found that it made a significant difference to their own health and wellbeing. This is a finding which is supported by the Cheshire East Parent Carer Forum Members’ Survey (2017), which found that “respite is very highly valued by those that get it – supporting a child with additional needs can impact on the whole family”. However, they also found that “many respondents were unsure about what is available, where and when”.

Some carers of adults talked about feelings of guilt at leaving or “abandoning” the person they cared for, which prevented them from accessing much needed residential respite care. The Cheshire East Parent Carer Forum survey also found that some of their members found it hard to use respite as the needs of the person they cared for made it hard for them to take time away.

Taking a break during the day or evening

From the Cheshire East Council ‘Survey of Carers of Adults in Cheshire East 2016/17’ (autumn 2016), ‘provision of breaks for the carer’ and ‘help to have a life outside of caring’ were in the top 5 of services and support that carers most valued.

This was reflected in the findings of the Community JSNA work:

“With dementia, there’s no doubt about it, the friends and family go away. But all you need sometimes is 30 minutes for a break.”

“Seeing the family smile again. To have support to be able to breathe. I feel like running away.”
A number of carers who responded to the Community JSNA adult survey, paid for private carer breaks during the week to enable them to have some time to themselves and to leave the house. Some carers reported that they had difficulty in persuading the person they cared for to accept ‘strangers’ coming into their home to allow them to have a break. Another carer whose cared-for person had complex needs was told that they did not have sufficiently skilled staff available to provide for their carer breaks.

A carer had the following suggestion to make:

"I’ve had a letter saying that respite beds are not being utilised properly so they are considering closing them. I’m surprised if they’re not used more. They could do with revitalising places, having respite homes where disabled people go and they do things and activities."

Young carers

When asked about residential respite, none of the 29 Young Carers were aware of this support provision.

Young carers were asked what would make their life easier. The two most popular responses to this question were:

- More frequent group sessions
- More trips and residential

Young carers said they would find it really helpful to have longer trips away from home, so they could switch off and have a proper break from their caring duties.

There was split opinion about the need for more group/peer support sessions during the daytime at weekends. The main benefit would be to go to the shops or go for a coffee, which they would not be able to do during the usual week night group sessions.

A suggestion was made that more age relevant activities would be welcome at group support sessions - some of the sessions cater for a wide variety of ages and there can be a significant age difference between the youngest and oldest attendees.

The groups would also welcome more indoor resources at the support group sessions, with some requests including: new art equipment for craft sessions, a table tennis table, and a facility whereby they could safely leave their own equipment at the venues.
Case study: Cheshire Young Carers: Child C

Reason for referral:

Child C is 8 years old. She was referred in by her school teacher because she supports her older brother who has severe Autism and ADHD and her mother who suffers with Depression. In the referral, school mentioned that child C lacked confidence in everything she tried. She often appeared emotional and tearful in school, with a total lack of confidence in herself. Child C also struggled to maintain friendships and often worries that her friends are talking about her. Her mother mentioned that every time she tried something new, she would quickly lose hope and give up. Due to her brother’s behaviour, the family are unable to go out and enjoy time together. Her anxieties are having a negative impact on her education, her social and her emotional wellbeing. Child C stated that she feels that professionals don’t listen to what she has to say.

Support given:

Child C started her first session in September. She walked through the doors, hiding behind her own hands and clinging to her mother’s side. Within 10 minutes, she had been introduced to the group, was joining in with the activities and had not even noticed her mother’s departure. She has attended every session since that date. Initially, she refrained from engaging with group activities and preferred to help the adults or just to observe. With time, she began to engage more as her confidence grew. The Link Worker attended the CAF meeting held at school, to make sure that Child C’s voice was heard. At these meetings the Link Worker was able to share Child C’s concerns about school and anxieties regarding her friends.

Outcome:

Since starting sessions, Child C has made huge advances in terms of her confidence and self-esteem. During a recent session, she organised and explained her own game to the rest of the group. She has made a number of strong friendships within the group and mixes well with the rest. She has demonstrated her ability to empathise in how she makes an extra effort to make new starters feel welcome. She repeatedly tells volunteers how much she enjoys her time at Cheshire Young Carers and is always sad to leave at home time. As a result of the referral to CYC, Child C now has a consistent form of social outlet, where she can rely on peers and staff for support.

Effective communication through telephone calls and contribution to professional meetings means that Child C’s school is kept up to date with how she is getting on at sessions. Child C knows that the Link Worker is a person she can trust, independent from both school and home, to turn to if the emotional strain becomes too much.

Opportunities for improvement:

- Develop options for providing stimulation for the cared-for person outside or inside the home, especially for housebound people (e.g. befrienders).
- Raise awareness of respite options and eligibility and costs involved.
- Provide residential respite for cared-for people with challenging behaviour within Cheshire East with appropriately skilled staff.
- Ensure that staff on the Personal Assistants (PA) register are sufficiently skilled and that their experience is detailed on the register e.g. experience of Alzheimer’s.
- Consider hosting a user rating system on the Live Well directory of available care support services, as well as adding the Healthwatch enter and view reports for care homes.
- Raise awareness of short-notice care available in an emergency.
- Ensure carers are made aware of relaxation therapies.
• Carer’s Hub to support carers and the person that they care for to identify options that both are happy with to enable carers to take a break, including telecare and assistive technology as an option for support or advice on home adaptations and equipment. [See the Technology support to improve health and wellbeing JSNA]

• Develop consistent respite offer for self-funders and those on direct payments.

• Ensure age-relevant activities at young carer group support sessions and explore options for indoor resources and longer trips away from home.

Work-related support

Cheshire East Council commissioned a service to provide careers advice and improve employment opportunities and life chances for both young and adult carers. In the last 12 months they supported 200 people in Cheshire East in total into work (this figure includes carers - the precise number of carers included in the total is recorded via their KPIs).

Case Study: Cheshire and Warrington Carers Trust

CARER looks after her teenage son who suffers from extreme anxiety. When the situation with her son became more acute she sought... help from 'listening support' and carried on attending the group where she has made many friends.

Recently, CARER has been feeling better and the situation with her son is improving. CARER was starting to feel that she could return to work but still felt that her confidence was low, she needed a CV and help to look for work that would be suitable for her. She wasn’t sure what she wanted to do or (her words) or if she had any skills, but knew that she wanted to ease herself into employment again gently.

With encouragement and support, CARER contacted her previous employer and was offered a job as a midday assistant. She says that she would like to do something else but feels this is a good gentle start. Cheshire and Warrington Carers Trust explained the services offered and contacted the provider to explain CARER’s situation and some of the help she may benefit from.

CARER came along to the support group for the last time in December (due to her new job) and explained that she had met with the careers advice and support service and was thrilled with the work they have done together. She looks happier and much more confident and although they will be sorry not to see her, the group wished her well and all commented on her wellbeing. She’s looking forward to new challenges in 2017.

How young carers access support

The two main agencies that support young carers in Cheshire East are: Cheshire Young Carers and Carers’ Trust 4 All.

Young carers were asked how they found out about young carer support. The main signposters to the Cheshire Young Carer service were:

• Schools and teachers
• Friends already attending
• Social workers

66% of 29 young carers who responded to the survey, said that they had accessed ‘help or support for their caring role’. This was intended to cover support from VCFS organisations and schools, however, the majority of those respondents were attending young carer sessions with Cheshire Young Carers and had not all felt that they were accessing support: and so it may be that the respondents interpreted this question as ‘do you get help with your caring role’, rather than ‘do you get the opportunity to have a carer break’. 27% of 30 young carers said that they did not know where to go if they needed help.
Young carers said that they accessed support from the following:

- Cheshire Young Carers
- CarersTrust4All
- Family
- Support in school
- School Young Carers Group
- Therapist
- Social Workers
- Cleaners at home

The main issue raised by service-providers about the needs of young carers was their transition at age 18 from being young carers to adult carers. There were reports by some service-providers that young carers could be left “high and dry” during the transition process. It was felt that the preparation of young carers to go through the transition should start well before the age of 18, to enable the young person to be as prepared and supported as possible.

“Consider the handover services instead of an abrupt stop.”

“Transitional services need looking at, there are definite gaps here.”

School

The vast majority of young carers felt that it would be helpful for their schools and teachers to be aware of their caring roles. In some cases, just the head teacher or specific teachers were aware of the young carer’s home situation. During discussion, some felt it would be helpful if all teachers were aware of their situation, but of those who felt this way, they felt strongly they would not want to be questioned about their situation, they just wanted teachers to be aware:

“I think it would be good to spread awareness, but not too much as I don’t want to be mithered. I’d still want my privacy.”

“It would be good to have people to speak to if you need to.”

Only one young carer felt that they did not want anyone at school to be aware of their situation.

There was a discussion about one of the young carer groups at Sandbach Girls School. There was some interest in this disclosure, with one young carer commenting:

“I wish they had groups like that at other schools.”

A number of young carers felt that they needed more support at school because of their caring roles at home, with some struggling with homework and tiredness:

“I can’t do the homework. It’s difficult as a young carer because you’ve got someone to look after. School could be more supportive. I’ve been given detention because of my caring responsibilities.”

“I wish they’d give us a bit of slack, and be a bit more understanding about our home situation.”

“I feel tired all the time, it’d be nice to have a place to catch up.”

At least two of the young carers would value a designated space at school to have respite and be able to catch up with work:

“It’d be good to have respite in school.”

“It would be good to have a place in school to go and get on with things.”

74% of 31 young carers felt that they could attend after school clubs or activities if they wanted to, with the comment being made that it would be helpful to have some clubs at lunchtimes for those who had to go home at the end of the school day.

Opportunities for improvement:

- Formalise a transition process for young carers that starts in advance of their turning 18.
- Improve school identification of young carers.
• Awareness-raising for school staff and young people to recognise their caring role

• Build links into Kooth.

Geography

“I’m on the border with Staffordshire, so I’m stuck within boundaries. Cross-county stuff would be helpful, as I could have gone over to North Staffs for some things that are much nearer than travelling up to, say, Macclesfield.”

Co-production/consultation and carers

From the autumn 2016 Cheshire East Council’s ‘Survey of Carers of Adults in Cheshire East 2016/17 Report’ (which surveyed adult carers who have had a social care assessment or who have accessed commissioned support in the previous 12 months) 6.8% of the 279 respondents felt that they were never involved or consulted, with a fifth (21.9%) saying that they felt involved or consulted sometimes and 71.3% saying that always or usually felt involved or consulted in discussions about support or services for the person they care for (see below).

It was raised during the Community JSNA engagement process, by a large number of respondents that they felt that there was a negative impact on the consistency and continuity of services by decisions made without consultation with service-users e.g. the ending of contracts.

“It feels like changes are made without consulting us.”

“Stop ‘consulting and engaging’ and start genuine co-production. Have conversations about how people can get a life that’s worth living. Give us free choice of what will work for us.”

The issue of funding cuts and services that had been commissioned but were no longer available was also raised by members in the Cheshire East Parent Carer Forum Members’ Survey (2017).

Opportunities for improvement:

• Provide feedback to carers and engagement participants to show how their input has been valued and listened to prior to any decisions being made, even if difficult decisions still have to be made.

• Ensure co-production around Equality Impact Assessments and encourage a consistent approach.
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