

# Notes of two Virtual Consultation sessions for carers held on 20 and 23 July 2020 Adult Care Services: 3 Year Plan Review, 2018 – 2021

Participants:

Carers: 19 carers and one service user took part  
 Carers in Herts: Maria Kiely, Roma Mills, Sharon Ruse, Will Davis  
 Guest: Helen Maneuf, Assistant Director Resource, Adult Care Services

<b>1</b>	<b>Welcome</b>
	<p>Roma welcomed everyone to each meeting and introduced Helen Maneuf who explained that she currently leads on Adult Care Services (ACS) finance and that she is currently also leading on the review of the ACS plan. However Helen is likely to be changing responsibilities to take on Chris Badger’s role as operational lead while he steps up as Interim ACS Director.</p>
<b>2</b>	<b>3 year plan, 2021-2024</b>
	<p>Helen explained that ACS is coming to the end of the 3-year service delivery plan for 2018-2021. She referred to the paper ‘Evaluation of the ACS 3 year plan 2021-24’ (attached) that sets out the timetable for the 2018-21 review and the publication of the new plan for 2021-24.</p> <p>The timetable is:</p> <ul style="list-style-type: none"> <li>• Review of the current plan – June/July/August 2020</li> <li>• Development of the next plan – September/October 2020</li> <li>• Draft plan agreed by HCC – December 2020</li> <li>• Consultation on draft plan – January/February 2021</li> <li>• Final plan agreed by HCC – March 2021</li> </ul> <p>Helen stated that ACS really wants to hear what carers think about the current plan as there was not enough done to involve them when it was drafted in 2018. This is why she has come to the meetings and she hopes that the carers who attend would also be willing to take part in the second round of discussions in the autumn.</p>
<b>3</b>	<b>Overview of the existing 3 year plan, 2018-2021</b>
	<p>Helen noted that the existing plan is the first stage in the delivery of the County Council’s Strategy the ‘15 Year Direction for Adult Social Care’. The plan includes a Vision statement for Adult Social Care, which is the first time that a vision statement had been made (see attached presentation).</p> <p>Helen explained that the current plan includes a section on each of the following four main themes:</p> <ul style="list-style-type: none"> <li>• Information and Advice</li> <li>• Connected Communities</li> <li>• Valuing Independence</li> <li>• Caring Well</li> </ul>

	<p>Each theme includes a set of aims for action during the three year period together with performance targets for each year. Roma noted that there was no information included to show whether the targets had been met. Helen agreed to forward the information that was available for 2018/19 and 2019/2020 but she acknowledged that the targets were more a measure of 'outputs' or activity and do not really assess what has been achieved in relation to the intended 'outcomes'. Helen said that she thought the conversations with service users and carers and the responses to the survey that has been sent out would be very useful feedback – there is also the opportunity to have a one-to-one telephone interview with an ACS member of staff.</p> <p>This section on the four themes is followed by a one page description of Connected Lives which underpins ACS and a one page description of Co-production which focusses on the involvement of people who use services and their families in service design, commissioning and delivery.</p> <p>Helen introduced each theme and invited comments.</p>
	<p><b>Information and Advice:</b> Carers' comments -</p> <ul style="list-style-type: none"> <li>• Information and advice offered in direct conversations with social work staff often does not reflect the needs of the individual and family but focuses on what the system currently offers – it's a more service-led than person- centred conversation. If staff worked with carers/ families to develop and agree the right support to meet their needs, the out-comes would be better. One carer described this as a 'work with us' rather than 'do to us' approach.</li> <li>• Some families had cared for their relative for many years without accessing support because they were simply unaware of what was available –, in one case the family were only referred or alerted to the opportunity to have a care needs assessment when their relative was in Stanmore.</li> <li>• A number of carers find it very difficult to contact ACS, leaving messages for social workers and not getting a reply, waiting for equipment replacement and getting no response or action etc. and most felt that the system is difficult to navigate.</li> <li>• Few carers reported being contacted to have an annual review either of a care package or of a carer's assessment.</li> <li>• Concern was expressed about capacity within services and what feels like a regular turnover of social workers and care co-ordinators that can leave people struggling and feeling alone – many carers value the 'named social worker/care co-ordinator' approach. This was coupled with concerns about changes in how the system operates.</li> <li>• Concern that people with enduring, long-term mental health problems are heavily reliant on family carers to alert services when/ if they need help, as they are unlikely/unable to initiate contact with crisis or emergency services themselves.</li> <li>• In mental health services the lack of a care co-ordinator means that the key link in service co-ordination is missing.</li> <li>• Only half of the carers who attended the two meetings had heard of Herts Help.</li> </ul>

	<ul style="list-style-type: none"> <li>• Carers commented that voluntary groups/ organisations/ other families are often the best source of information. However if carers don't identify themselves as 'carers' or are not linked in with local groups they can really struggle to know where to go.</li> <li>• A number of carers commented on being 'overwhelmed' by the amount of information given to them, for example after a diagnosis of dementia or following a stroke. They described having lots of information – an avalanche – but finding it too challenging to work out what was relevant or likely to be helpful.</li> <li>• Caring can be exhausting and people often don't have enough 'head space' or energy to work their way through the system – this can be particularly difficult for those juggling work and caring or those with more than one caring responsibility.</li> <li>• One carer described being signposted to services, put on a waiting list for a sitting service only to find that this was not available in his village, then signposted to another service – getting in touch only to find that it was unable to offer help. This all seemed disjointed with no obvious co-ordination between services.</li> <li>• Having 1:1 support to help families find their way through the system would help – particularly for those with limited or no online access. Helen asked if anyone had used the Community Navigator service – Will had received good feedback from carers who had used that service but there was some confusion about whether this is a county-wide service and how you access it.</li> <li>• Having a clear map or flowchart on HertsDirect that carers can use to find out what services are available and how to reach them would be helpful and would replace the need for a community navigator for some people. This should be in graphic form with clear links between services and explanations of what each service offers.</li> <li>• There needs to be a clear route into the system – the person on the front desk (or who is responsible for answering the telephone) should be able to sort the 'problem' out. The role of the 'gatekeeper' is critical.</li> <li>• It should be easier to contact ACS other than by using the call centre contact number – not everyone is confident in using the phone – can people have email addresses of, for example, the Direct Payments team. Please make it easier to contact ACS by the method of choice of the person using the service not of the service itself.</li> <li>• Carers in Hertfordshire is getting feedback from carers via 'Keeping in Touch' calls that they find it difficult to contact statutory services - long waits on the telephone and then they feel pushed from pillar to post.</li> <li>• Services appear reactive and not proactive so an adult with, for example PD or ASC who is unlikely to seek support, can end up just struggling without the necessary help.</li> </ul>
	<p><b>Connected Communities:</b> Carers' comments –</p> <ul style="list-style-type: none"> <li>• One carer referred to a church-led initiative in his village to promote a 'Dementia friendly' church – this did not prove successful so they moved on to a project called 'Linking Lives' which is a form of 1:1</li> </ul>

befriending and which had led to some really positive outcomes for lonely shy people.

- The surge in volunteers during the COVID-19 pandemic was welcomed and carers hoped that plans would be in place to maintain a healthy volunteer base in local communities. Some carers had felt supported locally but this did depend upon how far they already had well established networks.
- It would be good to see more done to promote 'Disability friendly' communities – in terms of good access, appropriate use of language, support when needed to use universal services, including statutory, voluntary and private sector, e.g. cinemas, sports centres, shops and restaurants. Offering a 9.00am slot at the local supermarket for people with dementia or autism might feel positive but the timing is inappropriate and consequently unhelpful. It was also not particularly useful for carers during the lockdown as they were often not able to leave the person they care for at that time of day.
- It was noted that some of the former local 'drop in' or 'open door' services for those with enduring mental health problems were no longer operating and their service users' needs for companionship or a 'listening' ear are not met in universal services.
- There was also some concern that 'service user' social or peer support groups are expected to become self-running – carers felt that such groups usually need a 'co-ordinator' or 'facilitator' if they are to be sustainable.
- If we want people with a physical disability to be able to access local community services, then ACS should involve the local District/Borough Councils – those using big wheelchairs often can't get access to shops/public transport/disabled parking places/other forms of transport to get out and about.
- A carer whose daughter has a learning disability and who lives in Supported Living accommodation supported by Mencap noted that she only seems to mix with other Mencap groups or specialist day services and the Gateway club. There doesn't seem to be any involvement with local community activities or even a local church.
- A carer of a young adult with complex health care needs and severe learning disability commented that there were few places that she was able to take him, outside of specialist services like Keech Cottage and the Aldenham Country Park adventure playground. She also asked what residential or overnight respite services were available in Hertfordshire for this client group as she was not aware of any.
- It was felt that while it is possible to access universal community facilities for younger children with severe learning disabilities and complex health needs or challenging behaviour, this becomes difficult by the time they are 14 or 15 years old, when families become increasingly housebound and isolated.
- During the pandemic with services becoming unavailable, a lot of carers have become isolated – particularly parent carers who became housebound with children with high care needs.

- A carer commented that he and his wife, who care for each other, had been in lock down since March, they had not even been outside the house – all the old boundaries and rules had fallen apart. Everything crumbled away. The best thing had been a monthly ‘phone call from Carers in Hertfordshire, as the person who phones comes across as someone who cares, they have an ordinary ‘non-professional’ conversation. He has also been taking part Viewpoint sessions 3 x a week via Zoom and is leading one.
- There is a feeling that carers are having to do more and more chasing up of services – GP/NHS/HCC – something that the social worker would have done for the client in the past. This suggests a lack of connection. There is also some concern about how the services provided to an individual by different agencies are recorded so that it is clear how a care plan is being delivered.
- One carer has moved from Barnet, where their equipment was provided by Millbrook, to Hertfordshire – which has the same provider. However there does not appear to be any co-ordination between the two branches and the carer finds themselves batted between both.
- Issues with getting the right equipment for a younger disabled adult were raised by another carer – however in the case of a service for an older person, a carer was satisfied with the provision of equipment which was timely and appropriate.
- A carer commented that a ‘connected’ approach is central to quality of support provided. His relative - an adult with a learning disability receives care and support from 3 different sources – the team at the Housing Association where they live, the day centre which they attend three days each week and the domiciliary carers who help them manage tasks at home. All good services but they not connected and do not work together, there is no co-ordination which leads to problems, e.g. the client is out when carers come, transport to the day service comes on the wrong day. Mutual objectives and outcomes are not co-ordinated. It used to work better when the social worker co-ordinated the care package but there is no longer a named social worker.
- However another carer who also supports an adult with a learning disability commented that their experience was of good communication between the supported living and day service. In that case, both services are provided by HCC. Carers queried whether the number of agencies involved in delivering a care package made co-ordination more difficult – given the focus on Direct Payments and buying your own services it is likely that providers will become more diverse and care packages will need some project management.
- Buddying or befriending schemes can be effective in supporting people to use community services, for example going for a coffee in a local café, a luncheon club, a social club or to the gym. This can work for vulnerable adults – people with ASC, a learning or physical disability, a mental health problem and for isolated elderly people.
- One carer noted how her foster mother had benefitted from attending a day centre for older people – this had made a really positive difference to her and helped to address her loneliness and isolation.

**Valuing Independence:** Carers commented as follows –

- It was noted that when a person become eligible for Continuing Healthcare (CHC) funding this is a completely different landscape - their previous care package can be disrupted – the CHC care manager from the Clinical Commissioning Group seems to require change of agencies etc. even if they have been using the same agency for some time. This approach does not seem person-centred nor does it promote choice.
- A major issue for many carers is the difficulty of recruiting skilled and reliable Personal Assistants of home care workers who are interested and have the aptitude to help people live independently – careers in care are not highly regarded or well-paid and until this is addressed the workforce capacity will continue to be challenging.
- One carer commented that his daughter has severe learning disabilities – she cannot easily join in group activities as she needs support with personal care, this is an area where it is even more difficult to find the right providers. Funding has to be available at the right rate and we need a range of providers who are able to offer the services that people need. How does HCC make sure that there are enough providers out there – what workforce planning is going on?
- Another carer reported problems with timekeeping by home care workers arriving late to get someone up in the morning – this can have a knock-on effect for the whole day and can make a service user feel like a burden to their family.
- Finding housing for someone to enable them to leave their parents' home is not easy with 10 different Housing Authorities in the county and numerous housing associations. Families need a flowchart to guide them through the process.
- One carer explained that his son, aged 49 years who has Asperger's Syndrome, has been living with him and his wife for 10 years – in one room in their house. He earns a good wage but not enough to pay rent or put down a deposit. He needs someone to help him with his finances – he doesn't want his parents involved in his financial matters but does need support and guidance.
- Contact with other people is key to developing and maintaining independence – buddying and befriending schemes are needed, even if only to get someone out for a coffee or shopping expedition.

**Caring Well:** Carers commented as follows –

- Only very few carers had been offered a Carers Assessment although some were aware that they are entitled to this and to an annual review.
- There was a general feeling that the 'buck stops' with the carer. As noted in the *Information and Advice* section – carers need help negotiating the system, they are often left 'project managing' their relative's care package and this can leave them tired and stressed. They need support at the right times and a social worker or community care worker who can pick up some tasks for them.
- One carer stated that help came to an end when the virus hit him and his wife, they were both considered high risk and while help was

available at the other end of the phone, he is not very confident on the phone and needed to be able to see the person's face. Zoom or Microsoft Teams would have worked better.

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- one carer commented that his daughter has severe learning disabilities – she cannot easily join in group activities as she needs support with personal care, this is an area where it is even more difficult to find the right providers.
- The point was made that while it is possible to recruit volunteers to run social groups and befriend people, those with complex needs required highly trained well paid staff.
- Domiciliary and day services don't meet the cultural needs of some older people, e.g. when one carer tried to take her mother, an Italian lady with vascular dementia, to groups the activities did not include any songs or music from in her language as it was all in English so her mother did not feel comfortable. Similarly an Asian elder was reluctant to accept personal care as she would have preferred a care worker who could speak to her in her own language.
- This concern was echoed by a carer who runs a support group for Polish families with disabled children – she felt that nationality groups need support; language can be a barrier to accessing support as can different culture and expectations. HCC need to know about specialist voluntary groups and support them.
- Carers did not consider it acceptable that people do not have a choice of the gender of the care worker who comes to provide personal care. Elderly women or women who live alone should have that choice – they may be very vulnerable.
- A carer reported problems in communication between statutory authorities when her son was placed in Haringey as the local services did not pick him up – his mental health deteriorated and he ended up being moved to a service in the west Midlands under 'section' and then to Notts. Poor communication appeared to be a trigger in his deterioration.
- A carer who had moved into extra care housing said that having access to carers onsite 24 hours each day makes life easier, provided they can be flexible and come when needed.
- One carer commented that he had moved his mother into his home when the lockdown started but when he asked for help for her to return home – a home care enablement type package – he was told that this was not possible. However she then developed a UTI and was admitted to hospital when an enablement package was provided to enable her discharge. The carer made the point that he had had his mother with him for 4 months to keep her safe and that where families have taken people in then they will need help to help elderly people to get back home. Families have done lots to help the system

	<p>cope, from carer's point of view – how does he return his mother home – sandwich carers need more thought and support to help them to cope.</p> <ul style="list-style-type: none"> <li>• Where a carer has two caring roles it can be difficult to get the support in place in a timely way when an emergency occurs. One carer had had to leave his disabled wife at home alone – except for some support from their church – when his grandson needed urgent support. She had no-one even to make a cup of tea or help her into a chair and they seemed to slip through the net.</li> <li>• The hourly rates available through Direct Payments were not felt to be sufficient.</li> <li>• There were also concerns about the hourly charges that domiciliary care agencies make, compared with the hourly rates of pay of the care workers.</li> <li>• A carer suggested that the County Council should set up a PA Pool website to help families who are using Direct Payments to find home care workers. This could include the option for providing feedback.</li> <li>• Some carers found the administrative requirements of managing a relative's Direct Payment burdensome. This was cited as a particular issue where the payments were being used to buy a homecare service from a local agency which could have been equally well commissioned by ACS.</li> <li>• There is also some confusion about how Attendance Allowance or Disability Living Allowance/Personal Independence Payment should be used.</li> <li>• It was noted that for some people who live near the county boundaries, it would be easier to attend a service provided in a neighbouring authority but there seems to be reluctance on the part of ACS to facilitate or fund this sort of arrangement – even when this would be the best solution for the person and their carer.</li> <li>• The final comment was a plea was made in respect of the next three year plan – ACS should get the basics right and not promise what cannot be achieved.</li> </ul>
<b>5</b>	<b>Next steps and close</b>
	<p>Helen referred to the timetable in the short Evaluation paper. She will be collating all the feedback from the survey which was sent out, from the individual telephone conversations and from meetings like those held with carers – one is due to be held with voluntary sector representatives on Monday 27th July. She will then draft out some proposals for the next three year plan which she will share with us in September/October 2020. The draft will then be finalised and submitted to the County Council Cabinet in December for agreement and will then go out for a formal consultation with the final plan agreed in March 2021.</p> <p>Roma confirmed that Carers in Hertfordshire will organise some meetings for carers to discuss the draft plan 2021/24 in the autumn and that all those who took part in the two meetings held in July would receive invitations.</p>