

Reading Mencap LD Carer's Survey

At the end of the summer we undertook a survey of the family carers on our mailing list to inform the work of the Carer's Steering Group and also to inform our own response to the families of people with learning disability who use our services. 27 carers responded, 22 of which were Reading Borough Council area and 5 of which were from the greater Reading area.

Some things that jump out are:

- that there could have been a policy decision made, and guidance issued, about flexible use of Direct Payments, and better communication from the Council Direct Payments Team to carers.
- There could have been more carer targeted communication generally, with acknowledgement that a lot of carers had lost all their normal care for a variety of reasons beyond their control.
- Consideration could have been given to the issue of a carer's card to help with reasonable adjustments for carers around shopping.

These were the findings:

About carers and the cared for

- 77.8% were carers of sons or daughters
- 59.3% were carers aged between 50-70 and 25% were over 70 with 11% age 25-50
- 44.4% of cared for people were age 25-50, 37% were age 18-25, & 11% were 50 plus, and 7.4% were 11-17

About what care has been lost during the pandemic

- 56% of respondents had lost all their care, 33.3% some care, & 14.8% none

What were the reasons for loss of care

(Some respondents had a combination of care and the % therefore adds up to over 100%)

- 60/9% the day service was closed
- 30.4% didn't want agency carers coming into the house
- 30.4% had lost overnight respite
- 21.7% The college was closed
- 17.4% were shielding
- 17.24 PA couldn't continue caring
- 13% Care agency couldn't continue to provide care

Other reasons were, medical vulnerability meant return to college not advisable, charity activities closed, school was closed.

Personal Budgets

- 74.1 % of respondents had a personal budget for their cared for person 25.9% did not
- 65% had their PB as a Direct Payment, 15% had notional budgets and 20% had a mix

- 50% knew they could use Direct Payments flexibly and 50% didn't
- Of the 50% who knew they could use them flexibly, 36.4% found out for 'the Council', 28.2% from a social worker, 27.3% from other sources and 9.1% from the Direct Payments Team
- 44% said it was difficult to find the right person or phone number to ask about flexible use of DPs, 33% couldn't get a response and 22% said it was easy to find out.
- 50% were still waiting were still waiting to hear if they could use the DP to buy what they needed, 25% they didn't get what they needed and 25% said I got what I needed.

Who has been in touch during the pandemic and what for

(Some respondents had a combination of care and the % therefore adds up to over 100%)

- 52% said a charity had been in touch to check on welfare, 44% a social worker, 28% the Council, 24% said other
- 52% had activity packs delivered, 28.6% had food deliveries and 9.5% had on-line services
- 37.5% people said the contact/delivery services were very helpful, 43.7% said they were a little helpful.

How have carers managed their health & wellbeing during the pandemic

- 40.7% said they felt OK for only some of the time, 29.6% said they were struggling to cope and 28% said they were OK
- 80% said they hadn't needed to contact a health professional during the pandemic and 20% said they had.
- Only 3 people answered that their contact with a health professional was helpful, 1 said it wasn't, 2 said they thought it was and 1 said that it was difficult to make an appointment
- 59% of carers said that they hadn't managed to get as much exercise as they wanted while 40.7% said they had.
- 37% said they felt isolated or lonely during this time, 33.3% said they felt a bit lonely and 29.6% said they didn't feel isolated or lonely

Carer's Assessments

- 26 people said they hadn't had a Carer's Assessment during the pandemic and only one said they had, and they had used the Berkshire Carer's Hub, but they didn't get a service that helped them to manage

We Asked Carers what more could their Council have done to help then during this period

We got a huge variety of answers from "I don't know" to "make more effort", "I don't know what is available", "Rather trapped" to: -

- "Could have told us we could use the Direct Payment package more flexibly and provided examples"
- "They could arrange for family members to take on the role of support worker and be paid as we have had to disrupt our own jobs and do night shifts as well leaving our own family and homes"
- "Support more, set up on-line activities"

- “We felt ignored and left behind, I bought a laptop for my son with his direct payments which is for activities, and they want him to pay it back. the laptop is very helpful for him”
- “Opened residential respite even if only for short daytime breaks. Still not opened!!!”
- “It's been difficult to get hold of our social worker, especially when we are moving on to college”
- “The Council Tax office could have been a lot more helpful. Others did a good job but didn't 'go the extra mile' to avoid more stress put on me - WITH THE EXCEPTION of sheltered housing, Liz Wilks - excellent! The Social Worker did more than I expected”
- “At the beginning we had one call from Social Services. That is all”
- “Frequently at contacting”
- “RBC need to make it easier to complete their forms”
- “Shown an interest”
- “They could have contacted us a bit more”
- “Contact with RBC and a policy for the return to Day Activities”
- “Since I am not the full-time carer it is difficult to answer many of these questions. I am the LPA for my brother who has 24 hr care, but I manage all his care issues, his finance & health issues. I also have my brother here as often as possible (at least weekly) & make all decisions for/with him. Therefore it would have been useful for the Council to have contacted me about his care needs. They have not, even though they know I am his point of contact”

Lastly we asked carers what other comments they wanted to make about their experience of caring during the pandemic.

1. “Scared for our son’s safety .. v anxious. Reading Mencap quiz was brilliant - helped our son so much and lifted all our Tuesdays .. THANK YOU SO MUCH :).”
2. Trying at times, no flexibility from shops or services when you are stuck at home caring.
3. Stressful. Don’t know what is out there for carers without getting exposed to virus.
4. It has been very stressful as along with my 44-year-old severely disabled daughter, I also care for a 50-year-old significantly disabled and autistic son who can be very difficult at times and it just seems that nobody really cares or is interested. It is made really tough as I am disabled myself and in constant pain so doing housework is challenging.
5. It has focused my mind on sorting out the transition to adulthood to ensure my son doesn't live at home full time after leaving school in 2022. It has been an exhausting time.
6. I have worked SO hard, learning and implementing SO much, ... and am fed up with stories of people finding time for new hobbies!! I have been busier than ever.
7. My husband and I have managed caring for our disabled daughter, who is 46, but although she has been very good, I am 73 and my husband is 74. Physically and mentally it has been a bit difficult as we have to do everything for her, and it has been 7 months with no respite. We have no other family available. However I would rather she is home safe with us. I have been shielding as I have COPD and asthma.
8. You’re on your own basically.
9. Lock down was challenging as we didn’t want to have anyone in the house. When lockdown finished we then had our daughter’s carer back in the home which made a huge difference to mental health of daughter as she was able to go out to more places and enjoyed being with her carer

10. Being told to pay back monies used on DP even though it was used to help during the pandemic and told to pay it back, this needs to be reviewed.
11. The constant and repetitive questions and statements from our daughter have become very wearing. She has become more anxious during this pandemic period.
12. You realise how alone you are in caring for someone, no one cares if you get sick, or plans anything to cover that, no one cares if you are coping for a special needs person who does not understand, it's been very hard
13. During this time, I emailed the social worker and asked for her help to sort out the problem, got a response with an email about the direct payments, and it was passed to manager's attention. No calls or support.
14. I lost both parents to Covid19 so has been a difficult time getting support from my doctor.
15. Though SW tried nothing was available. Adult social care said "didn't realise how families were affected" by closure of respite service. Despite being classed as vulnerable, myself and daughter had to make a rota between us to enable the 24/7 care needed. 2 or 3 phone calls only in 6 months. Situation ongoing though college hopefully starts next week. Adult social care a disgrace for complex physical and learning disability.
16. I am also caring for wife with Dementia, so it has been challenging and other daughters have to assist in caring for daughter, supporting by having her stay with them. Only possible as they were off work due to lockdown.
17. As the sister of a person who has been cared for, due to her service day centre closed during pandemic it has been challenging to keep her occupied and to understand why she can't go out. Her day centre staff have been supportive in enquiring her welfare or taking her out, now lockdown lifted slightly. I have taken my sister to stay with me during a week to give Dad the much-needed time out as we also care for Mum with Dementia. This has helped a lot. Behaviours have been a real challenge.
18. Our care agency worked well with us.
19. Continuity of guidance to Carers for those with Learning Disability.
20. As per above, it has been very difficult during lockdown in particular, when we were not allowed to see one another. My brother found it very difficult and his mental health suffered terribly. We did communicate via WhatsApp video, but it is not the same as being with family that you know and trust in such worrying times. His full-time carers were great, but it is only part of what was needed, since I pick up on much more than what he verbalises to his carers. He felt very lonely & isolated at times, and I just didn't know what to do to help since we were not able to see one another because of protecting him. Consequently, I felt guilty that he was not staying here throughout the crisis, but since it happened quite suddenly this could not be arranged. Since he has complex medical needs which I always provide support for, this added another layer of challenge"