

Learning Disability Carers Survey 2022

Report

Introduction

In May and June 2022, Torbay Carers Service undertook a survey of Carers of adults with learning disabilities in Torbay. The focus of the survey was to understand what these Carers need to support them in their caring role, including the impact of the specialist support service for people caring for an adult with a learning disability, provided by Mencap. In total 114 responses were received: 87 online, 17 returned by mail and 10 completed over the phone supported by Carer Evaluators¹. The survey had a response rate of 19.2% from the 593 Carers who were originally contacted.

Key findings

1. Carers listed the top three things they need, and the most popular responses were:
 - *Information / knowing what's out there / signposting* (34% of responses)
 - *Support* (32%)
 - *Someone to talk to who understands / listens* (25%)
 - *A break from the caring role* (23%)
2. The greatest level of unmet need was around help to plan future support for the person they care for (49%). 42% would like to improve their knowledge of their rights as a Carer. Open-ended responses to unmet needs focused on *finances* (4 responses), *meeting isolation, loneliness and social needs* (4 responses) and *services for the cared for person* (4 responses).
3. Carers using Mencap's service seemed to have a considerably lower level of unmet needs in most areas compared to those responses from Carers who weren't receiving this specialist support, eg only 12% of the level of unmet need when referring to needing to join Torbay Carers, and 18% of the level of unmet need of needing help to set up an emergency back-up plan. NB It was difficult to accurately attribute responses as respondents were not always clear on whether or not they had received support from Mencap's Family Carers Service. Where they mentioned 'Mencap' the responses were attributed to the Family Carers Service, but it is possible they are referring to Torbay Mencap, who provide support to people with a learning disability.
4. People who received Mencap's support valued *information / advice / knowledge* the most (46%), but *being there / responsiveness / approachability* was highlighted by 38% and *listening / empathy* was most important to 29%.
5. The main barriers to people getting the support they needed were *not knowing what is available* (9 responses), and *services they accessed not being helpful* (8). These responses referred to a number of issues, but it is unclear whether people are talking about services for Carers or the people they care for. Carers suggested solutions to the barriers, with four people saying that *services that listen* would help, and four people also said that *improved availability of information* would make the difference. Again, it is unclear if respondents are referring to services for Carers or the people they care for.

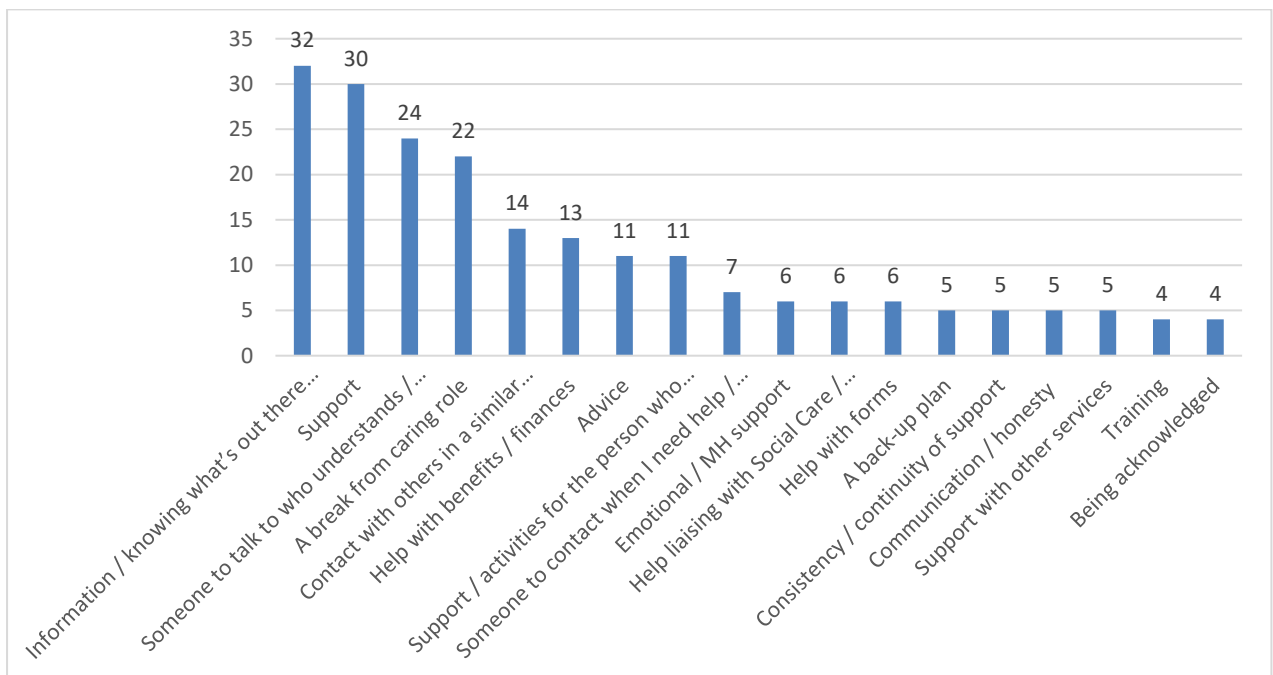
¹ Carer Evaluators are a group of Carers / former Carers who have been trained to evaluate services.

6. Online meetings, as introduced by Mencap in response to COVID-19, were used by 42% of people using Mencap’s service, but 44% do not want to attend them and 14% would like to but are unable to.

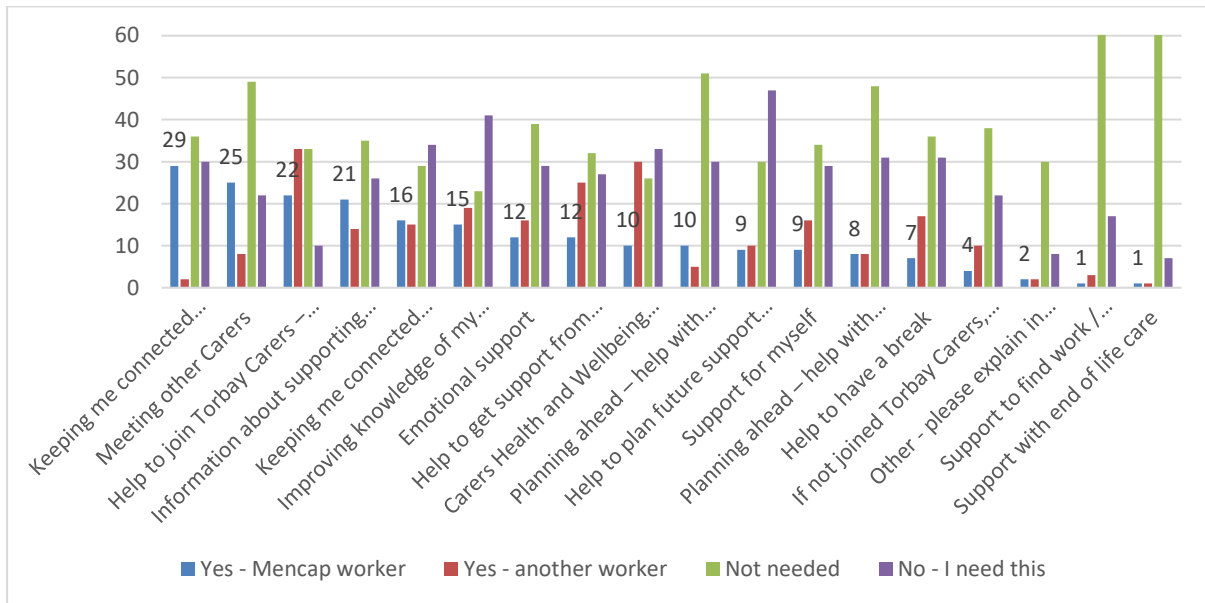
Summary responses from all questions

Question 1: What are the top three things that Carers of adults with a learning disability in Torbay need from Carers’ Services? (Responses were written in free text, and are themed below).

- As can be seen in the following table, the greatest number of responses refer to the need for information, awareness about available support, and signposting, with 32 out of 95 (34%) having this theme. Other common themes were ‘support’ with 30 responses (32%), ‘someone to talk to who understands / listens’ with 24 (25%) and ‘a break from the caring role’ with 22 (23%).
- Other popular themes focused on ‘contacting others in a similar situation / socialising with other Carers’ (14, 15%), ‘help with benefits / finances’ (13, 14%), ‘advice’ (11, 12%) and ‘support / activities for the person who they care for’ (11, 12%).



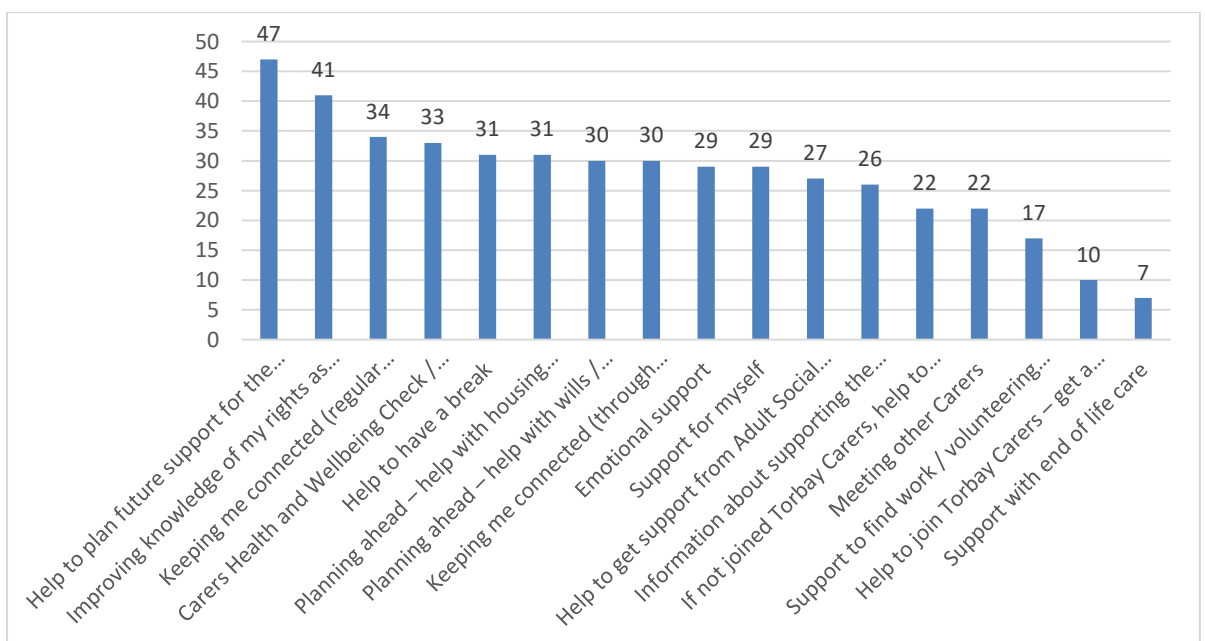
Question 2: Most of the services provided by Torbay’s Carers Services do not specialise in learning disability. However, Mencap’s Family Carers Service does. Please tick any Carer support you have used and whether or not that was from the Mencap Service (tick all that apply).



The Mencap mailing list is the service that most Carers use (29 responses – 53% of the people who have used Mencap services), followed by meeting other Carers (25), help to join Torbay Carers (22), and information about supporting the person I care for (21).

The greatest level of unmet need is clear (from the tallest purple line) that 49% of respondents said they did not have help to plan future support for the person they care for, but need this. 42% would like to improve their knowledge of their rights as a Carer. The chart below shows the number of people with unmet needs in each category.

Unmet needs identified by Carers



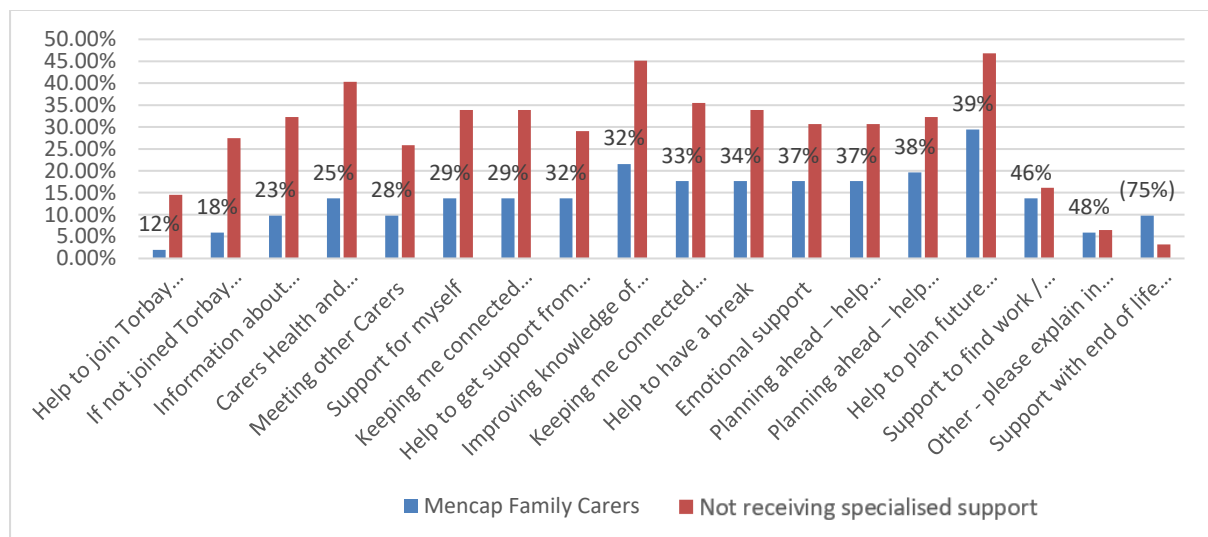
The wide breadth of unmet need shows that different elements of support are required by Carers who completed this survey.

To compare unmet needs between the Carers who are supported by Mencap’s Family Carers Service with those who receive only general Carer support, the graph below shows that in all but one area Mencap’s service has a lower level of unmet need. This area is around support with end of life care.

Carers accessing Mencap’s service have a considerably lower level of unmet needs compared to those who do not access their specialist support in most areas, including:

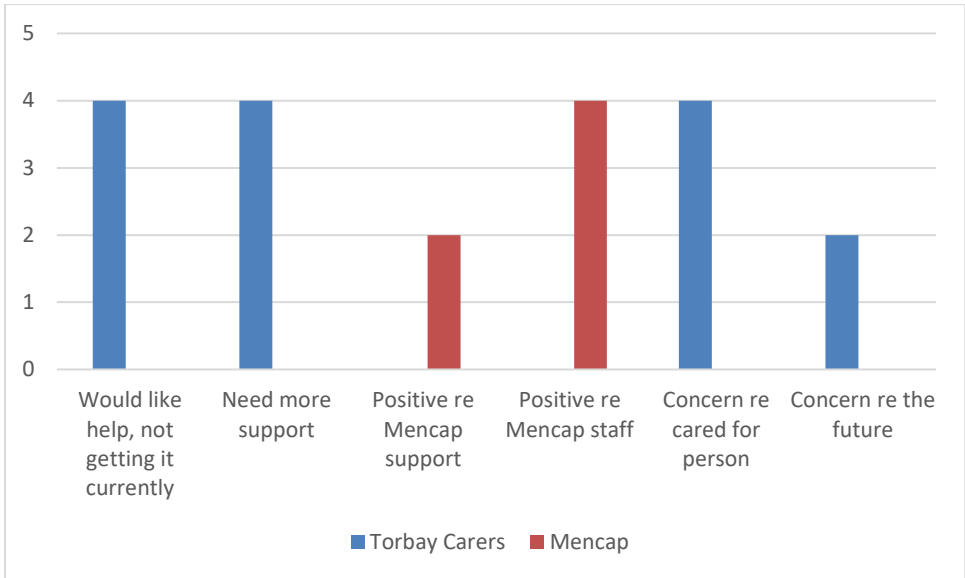
- Unmet need relating to joining Torbay Carers (12% of total unmet need were from people supported by Mencap)
- Unmet need of having help to make an emergency back-up plan (18%)
- Unmet need of having information to support the person I care for (23%)
- Unmet need of having a Carers Health and Wellbeing Check / Assessment (25%)
- Unmet need of meeting other Carers (28%)

Unmet needs for people supported by Mencap as a percentage of total unmet needs



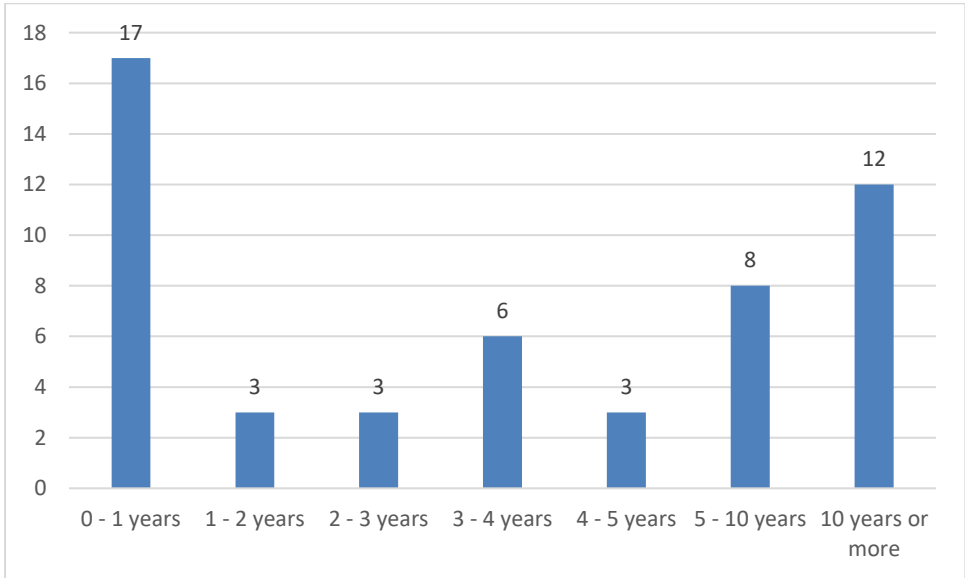
Comments

There were open-ended comments from 49 respondents. Many responses did not form a theme, but from what could be themed there were a number of positive reflections on the Mencap service and staff and those needing more support tended to be those who were not accessing support from Mencap.



Other comments referred to the need to have one person to speak to, and one person said they had never been offered the support set out in the question.

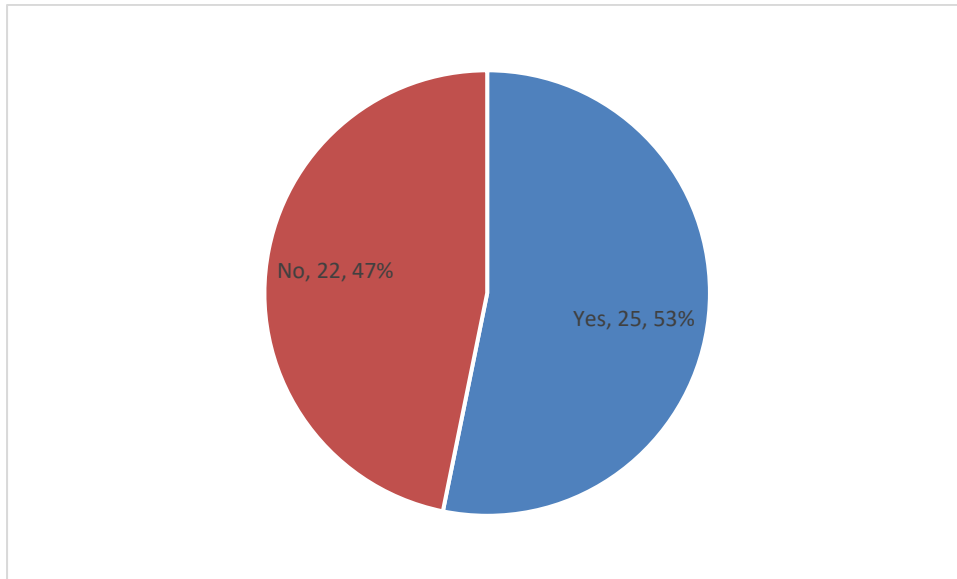
Question 3a: For how long have you been receiving support from Mencap’s Family Carers Service?



The greatest number of responses from the 52 people who are supported by Mencap’s Family Carers Service were from people who are relatively new to the service, and those who have been long-standing recipients of the service.

Respondents were not always clear on whether they have received support from Mencap’s Family Carers Service. This meant that it was necessary to interpret whether they had received this support from their answers in some cases. We have put people who have mentioned Mencap in their responses in the Mencap group, but this is likely to be imperfect as it is possible they are referring to Torbay Mencap, who provide support to people with a learning disability.

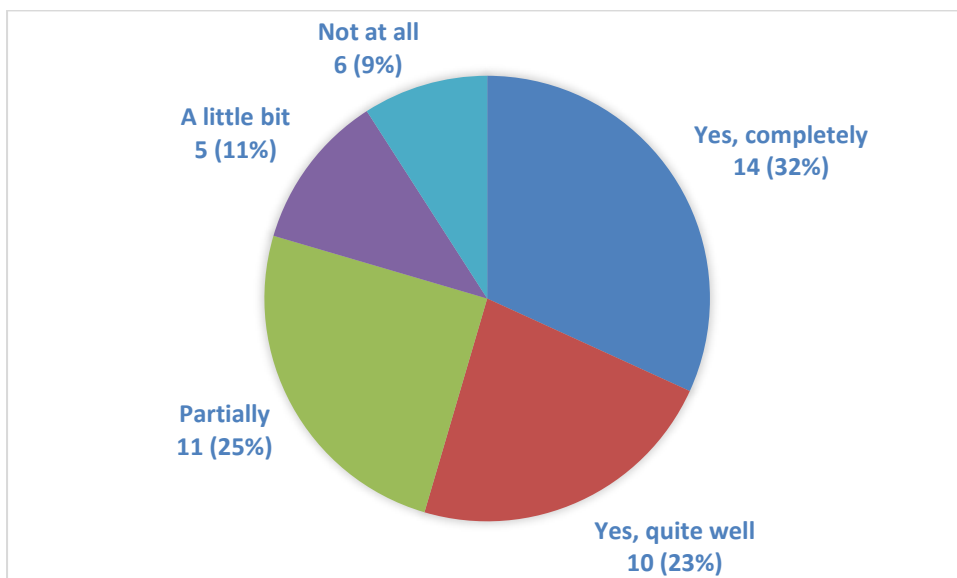
Question 3b: Have you received support from Mencap's Family Carers Service within the last year?



53% of the people who have been supported by Mencap's Family Carers Service had received support from them within the last year.

Question 3c: Has Mencap's Family Carers Service met your needs?

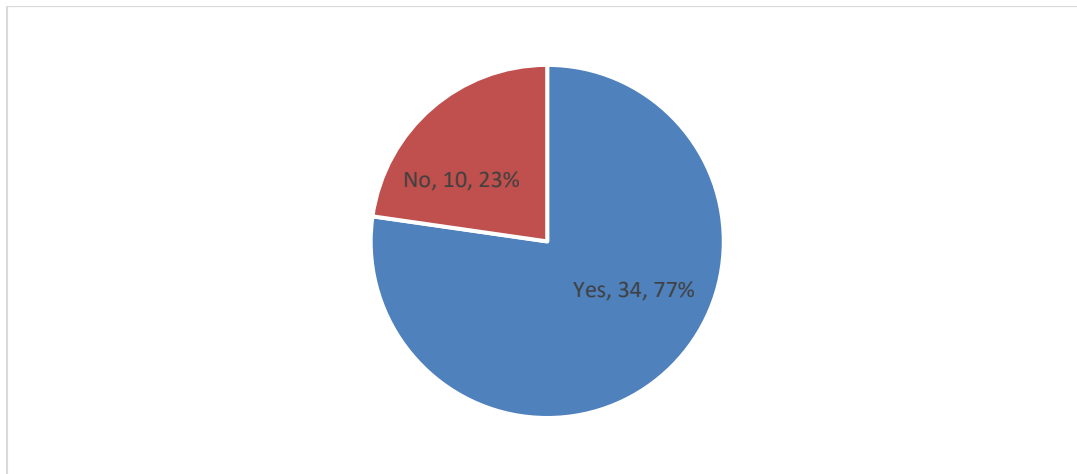
For those who indicated they received support from Mencap's Family Carers Service, 32% said they had met their needs completely, 23% answered 'yes, quite well' and a further 25% answered 'Partially'. 11% said they met their needs 'a little bit' and 9% answered 'not at all'.



Comments:

- Issues with IT / connectivity / video calls were raised by two people.
- Positive reflections on interactions with the team from were seen in four comments.
- There were no comments that elaborated when the respondents answered 'not at all'.

Question 3d: COVID-19 has forced Mencap Family Carers Service to change the way it communicates with Carers. Are you still able to get the support you need from the service?



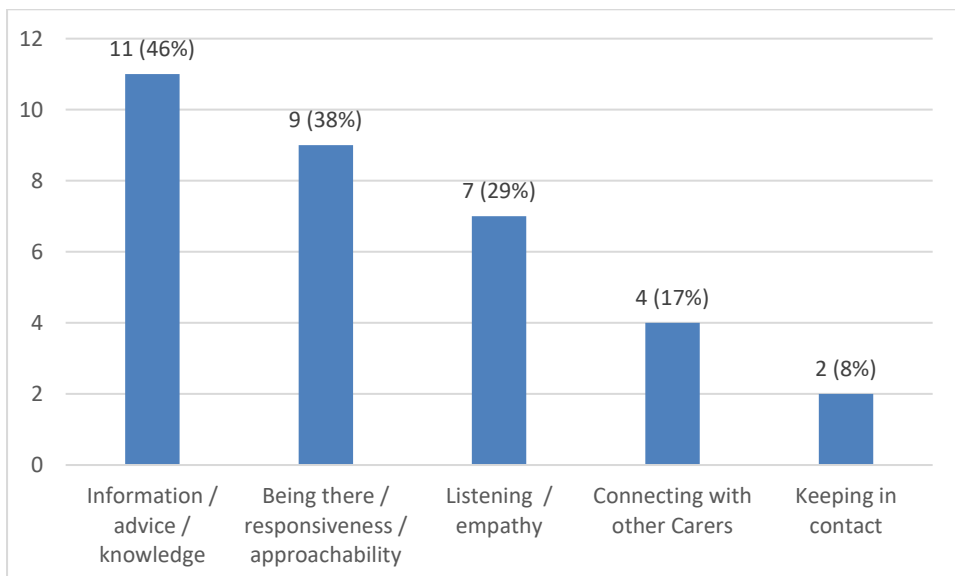
Over three quarters of respondents are still able to access the support they need, but 10 (23%) are not. Comments reflecting on this had the following themes:

- Two people are not being kept informed.
- Two referred to difficulty accessing the internet being a barrier.
- Two were happy with accessing the service using video calls and phone calls.

Question 3e: Is there anything that you would like Mencap’s Family Carers Service to do that it does not at present?

Thirteen people (26%) would like to see changes to what Mencap offer, with the largest number (four) saying they would like to see face-to-face meetings, and others referring to needing support with finances, legal issues, housing and Social Care. With an end to COVID-19 restrictions the service now offers face-to-face meetings again, meeting this need for some respondents.

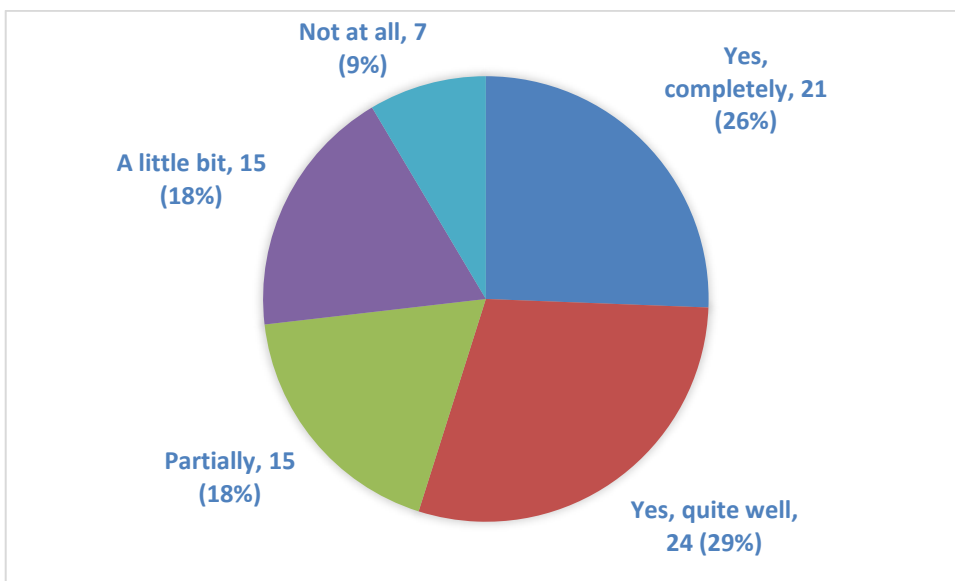
Question 3f: What is it about Mencap’s Family Carers Service that is most helpful in supporting you as a Carer?



Responses were concentrated on the personal interactions offered by the service , such as knowledge, quality of information and advice receiving eleven comments and a further nine focusing on being there / responsiveness and approachability. Nine people felt that listening and empathy was most helpful to them. Four people appreciated the ability to connect with other Carers and two appreciated how the service keeps in contact with them.

Question 4: If you have received support from Torbay Carers Service, have they met your needs?

55% of respondents who had received support from Torbay Carers Service either had their needs met completely (26%) or quite well (29%). 9% had not had their needs met at all, however, and a further 18% said the needs were met a little bit.

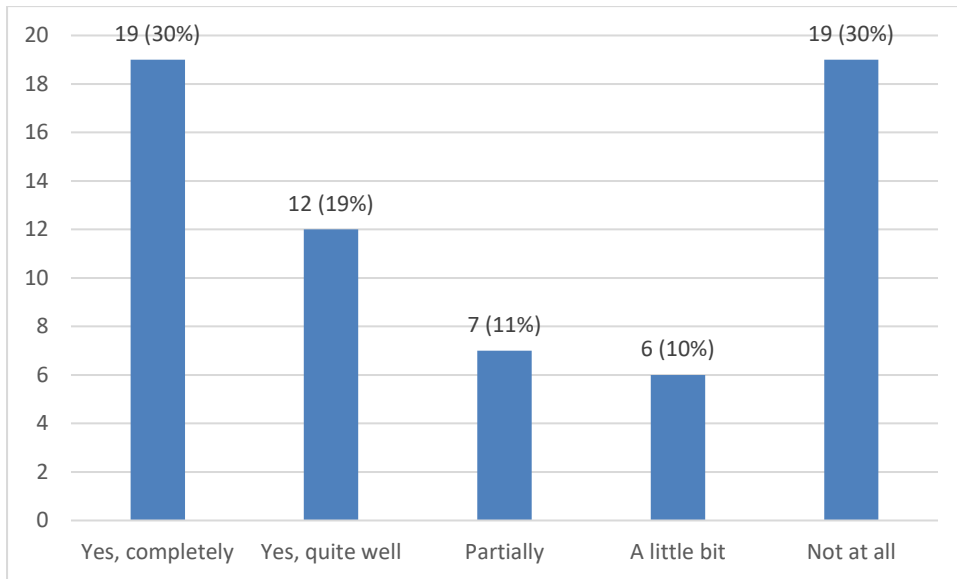


From the responses saying that the non-specialist support had not met their needs at all, three elaborated on their answer, with two saying that they still needed to sort problems out themselves - one not receiving the response they were offered and another being signposted on to other services. The third respondent said that they were not happy to attend the group as they didn't want to spend their time listening to "negative, whinging people". However as the only group for Carers of people with learning disability is the one run by Mencap, this person should possibly be in the other dataset.

Positive responses referred to the positive impact of counselling and direct payment at a difficult time, how the Carers Phone Line is appreciated, and two people referred to the value of receiving Signposts Newsletter.

Comparing this chart with that for Mencap, it is clear that the specialist service meets more of Carers' needs than the non-specialised service.

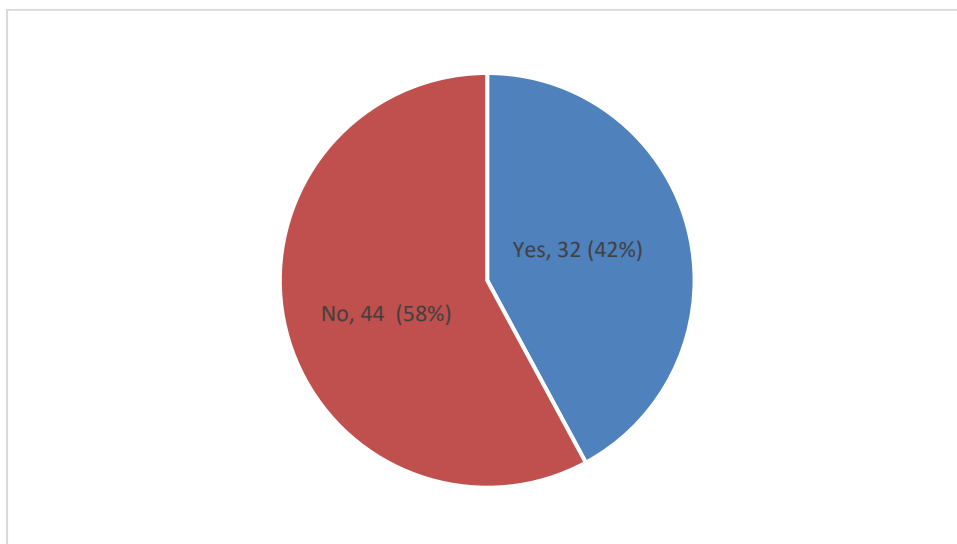
Question 5: If you have received support from any other workers, who were they and have they met your needs?



Responses to this question are mixed, with the same number of very positive and very negative answers. The positive responses (those who replied 'yes, completely') referred to Carer Support Workers in GP surgeries (three responses), Carers Aid Torbay, the Transitions Service and Summon Bonum² (each with two responses).

Very few people expanded on their negative responses, but one referred to their experience with a social worker and another tried Adult Social Care, South Devon College and SPACE without success.

Question 6: Is there any support you require that you are not receiving?



32 people (42%) require support that they were not receiving at the time of the survey, with more detail in Q6a.

² A service for people with a learning disability

Question 6a: If yes, what support do you need?

This question was answered by 32 Carers, and the responses were often quite individual to personal circumstances, but key themes were:

- Financial help (4 responses)
- Help with isolation / loneliness / meeting social needs (4 responses)
- Services for the cared for person (4 responses)
- Information (2 responses)
- Planning ahead (2 responses)

Two quotes from answers to this question follow, summing up the particular unmet needs of Carers:

“I need help in managing/planning transition. My daughter will need to move into long term care in a few years as we are getting older. We have been trying to start planning for this but the council / NHS seem unwilling to engage unless the move is happening tomorrow. Basically, they appear to only be able to fire fight, rather than plan ahead, which is both inefficient for them and frustrating for us as carers”

“We need support to carry on caring as we age... We’ve never been so close to throwing in the towel as now. We need the freedom to use his Social Care budget in a less restricted way. We do not have enough Enablers yet that is all I can spend budget on... let us use it for a much-needed break away as a family etc.”

Question 6b: What barriers have you experienced to getting the support that you need?

The 40 responses to this question were themed as follows:

- Not knowing what is available (9 responses)
- Services accessed have not been helpful (8 responses)
- Working hours get in the way (3 responses)
- Carer’s own health is a barrier (2 responses)
- No-one will help (2 responses)

“Our young person (in their 20s) with LD does not want to be different, or receive any help other than from family members. Does not like attending anything to do with disabilities. Nor access any services.”

“I was told by the social worker the most outside support they can offer is 5 hours (as I am classed as full-time support). I am doing 80-90hrs a week for less than £70. I am not meeting my bills and need to return to paid work or be paid a living wage as a carer! But the council will not put anyone in to cover me if I go out to work and the gentleman with Severe Learning Disabilities & Autistic Spectrum Disorder can't be left alone all day / night.”

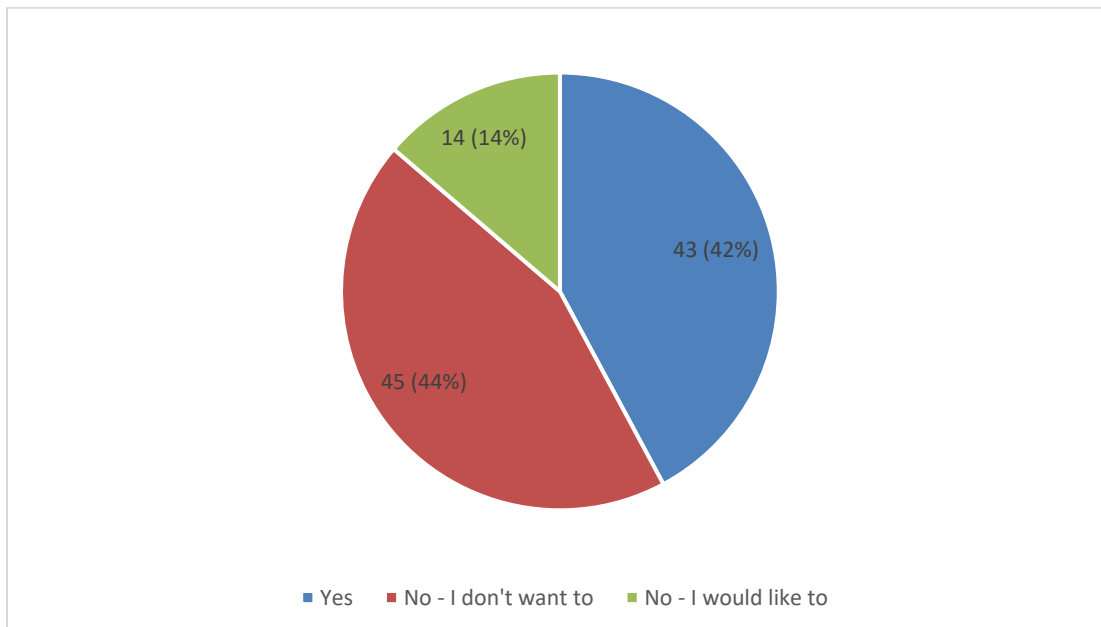
Question 6c: How do you think these barriers could be overcome?

Themes from responses to this question follow:

- Services that listen (4 responses)
- Improved availability of information (4 responses)
- One central information hub (2 responses)
- Improved communication (2 responses)
- Named support worker / key worker (2 responses)

Question 7: Are you able to access online groups / meetings?

Online groups have developed as a key communication method for support services over the last couple of years. From those who replied to this question 42% could access the groups / meetings, 44% do not want to, and 14% cannot access them but would like to.

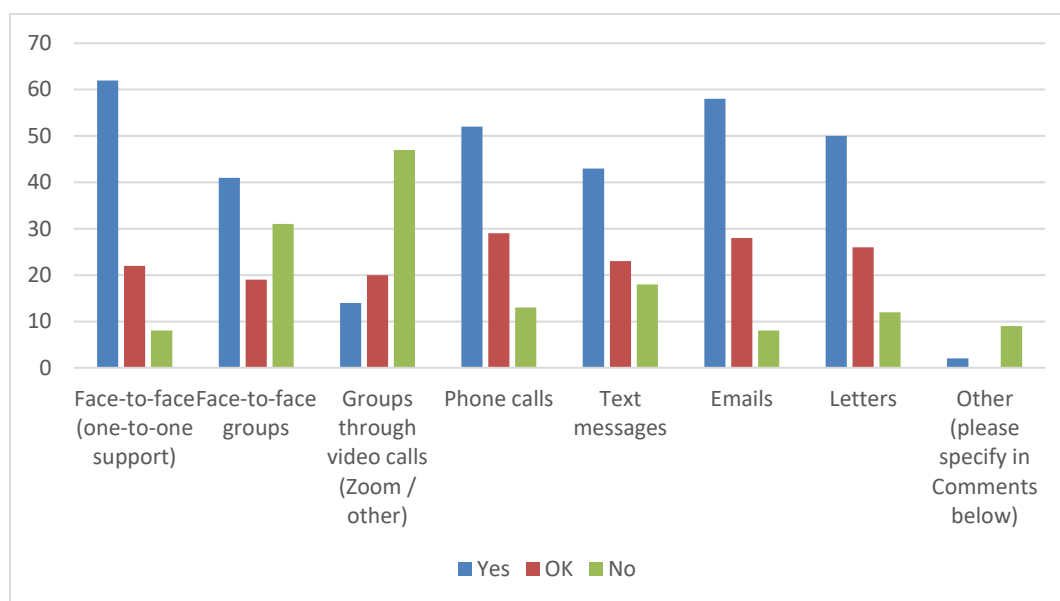


Of those who received support from Mencap, 22 (46%) were able to access online groups / meetings, with a further 19 (40%) who did not want to. Seven (15%) would like to but had not, either because they were unable to, or because they did not know about the meetings.

From those who did not access Mencap's Family Carers Service, 20 (38%) accessed groups / meetings, 26 (50%) did not want to, and 7 (13%) did not but would like to.

Whilst the majority of people who did not access online services did not want to, there was still a large number (14) who would like to access the groups / meetings. Further work is required to ensure that people are aware of what is available and how to access it. Furthermore, if there are technical issues, Carers Services will help to enable them to use or access the technology required.

Question 8: What methods of communication do you like to have with a service?



Emails are the most popular method (81% of respondents to the question answered yes or OK to this method), followed by face-to-face communication with 79%, phone calls with 76%, letters with 72%, text messages with 62% and face-to-face groups with 57%. Respondents were, however, most enthusiastic about face-to-face communication, with the greatest percentage answering yes to this question (67%).

People are least keen to attend groups through video calls (44% did not like this method). Face-to-face groups also had a large number of negative responses, with 29% saying they don't like this type of communication, but there were also a fair number of positive responses (50% said they like this type of communication).

Conclusion

Carers of adults with a learning disability were clear in terms of what they need from Carers Services to manage their caring role. A specialist service that can provide information and support, having someone to talk to who understands and listens, along with creating the opportunity to take a break from the caring role would meet the bulk of needs highlighted by Carers.

When Carers were asked about their unmet needs, they raised the need for help with planning ahead, and knowing one's rights as a Carer, so particular attention must be paid to ensuring these needs are met as services to support this group of Carers develop into the future.

There is a far lower level of unmet need among the people accessing Mencap's services compared to generic Carer support. The need to know their rights as a Carer was only half as common among people supported by Mencap than if they hadn't received this support. Seventeen out of eighteen areas of support were met more effectively by Carers supported by Mencap than those who weren't accessing the service. These findings give a strong message around the value of accessing specialist support for the specific caring role where people support a family member with a learning disability.

Carers using Mencap's support most valued being able to access information, advice and knowledge. Knowing that someone approachable is there who listens and understands what it is like to care for an adult with a learning disability was also highly valued. This gives a picture of what is required to provide the service that the people who use it need.

Findings from this evaluation have helped to focus attention on what really matters to Carers of adults with a learning disability. It is clear that a specialist service is required and that the Mencap service meets many of these Carers' needs. There is a need for improving information and awareness about support, so that Carers who need it can access it.

Carers need to be aware of their rights so that they are confident and able to ensure they get the support they are entitled to. Digital support to Carers should also be promoted so that those who wish to use on-line support feel confident to do so. There must be support to enable Carers to plan ahead so that they are confident measures have been put into place if they are no longer able to provide care for their relative. In order for this to be done well, and at a suitable pace for the person with a learning disability and their carer, this process should be started at the earliest opportunity.