Carers' Views on the Impact of the Adult Social Care Outcomes Framework (ASCOF)

Healthwatch Hounslow



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Acknowledgements

On behalf of Healthwatch Hounslow (HWH), I would like to thank all those who helped in the completion of this review.

From the very beginning, we received help from Davina Pandya, Joint Commissioning Manager, Carers & Learning Disability Services, London Borough of Hounslow (LBH) and her team member, Rebecca Smith. They assisted us in reaching out to some relevant organisations to widen our information base. We were also actively helped by John Morgan, Head of Prevention & Care Management, Children's & Adults' Services, LBH who linked us to his team who provided us with their insights and feedback on the Adult Social Care Outcomes Framework (ASCOF).

In the local community, we were also helped by some community/ voluntary organisations including the Disability Community Forum (DCF), the Parents' Carer's Forum (PCF) and the Centre for Armenian Information & Advice (CAIA). Individuals who were prominent in helping us were: Scarlet Sarksan, Health & Care Support Worker CAIA who went out of her way to contact relevant Armenian carers known to her for our review, Lisa Gatward, Services Manager and her colleague Anuradha from the Alzheimer's Society who enabled us to meet some users and carers of their Singing for the Brain sessions in Hounslow; Samattar from Hounslow's Somali Social Enterprise Centre who offered to obtain feedback from some Somali carers; Lyn Hammond, Care Navigator Manager, Integrated Neurological Services (INS) and Jackie Batten also from INS and Sarfraz Kherdin Principal Equalities Officer, Corporate Resources, LBH who provided links with other local groups. Additionally, I have no words to express my gratitude and admiration for one of the borough's most outspoken, indefatigable and conscientious of carers, Barbara Rhodes.

Within HWH, I am most thankful to our CEO, Tim Spilsbury. He not only helped me with completing a number of feedback questionnaires but also read through and commented on the content of this report, thereby enhancing its value. Finally, I thank Sangnuma Rai, HWH's Research Assistant for working at the grassroots for reaching out and collating data and HWH's able Engagement & Volunteers' Coordinator, Mystica Burridge for helping with the proofreading and layout of the document.

I hope this piece of work will help towards improving support and services and also raise the quality of life of carers in Hounslow who, though they generally go unspoken, "unhonoured and unsung", are the silent heroes and heroines who quietly and steadily perform a sterling role by looking after some of the most vulnerable people in our local communities.

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Introduction

Healthwatch Hounslow (HWH) undertook a review of the situation and experiences of residential carers in the local community of Hounslow in November 2016. As defined by Hounslow CCG[1] and the London Borough of Hounslow (LBH), we took a Carer to mean "anyone who spends a significant proportion of their life providing unpaid support to anyone who could be unable to not manage without their help. They could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems."

We started our work on the survey when we were asked to take up the investigation by the Joint Commissioning Team Manager of the London Borough of Hounslow's (LBH's) Carers & Learning Disability Services.

The Adult Social Care Outcomes Framework (ASCOF)[2] was adhered to as a guiding standard for our survey. As described by the Department of Health: "The ASCOF is a key mechanism by which the Government sets national priorities for adult social care, and measures national progress against those priorities."[3]

After taking this decision, we included a series of exploratory questions for gathering our data and enabling ourselves to make appropriate practical recommendations to improve the performance of the local Social Services team in their aim to inform, support and assist residential carers in the difficult task they perform.

Our focus was on non-paid residential carers, aged 18 years and above, who are looking after someone who is 18 years and above and who have been assessed or reviewed, either separately or jointly with the cared for person by the local Social Services during the past 12 months prior to the sample being extracted. We decided to target older carers and include young carers and those from so-called emerging and hard to reach ethnic groups in the community.

We aimed to review residential carers from the Hounslow community to compare our findings with those of the previous ASCOF report and to find out Hounslow's present performance in certain key areas. While doing so we made it a point to include some open-ended qualitative questions to provide opportunities to our sample of local carer respondents to provide rich qualitative data and insights so that we could explore and understand if, why, where and how carers struggle while performing their caring role.

[1] For the CCG's definition see: http://www.hounslowccg.nhs.uk/your- services/carers.aspx

[2] The ASCOF, first published in March 2011, is updated annually in partnership with local government. It focuses on measuring the success of the adult social care system in delivering high-quality care and support in a way that is of use both nationally and locally.

[3] The Adult Social Care Outcomes Framework, 2015/16, Handbook of Definitions, March 2015.

Background

ASCOF is the Department of Health's main tool for setting direction and strengthening transparency in adult social care. First published in March 2011, it is an important benchmarking tool as it helps measure performance of residential carers in five important areas:

- The quality of life of carers;
- The social contact available to carers;
- The overall satisfaction of carers with Social Services;
- Whether carers are included or consulted in discussions about the person they care for; and
- If carers think it is easy to find information about services relevant for them or those they are caring for.

This framework enables identification of areas where services are falling short whilst recognising their achievements at all levels.

The ASCOF survey takes place every two years. Unfortunately, over the years, Hounslow has consecutively scored well below the national average.

Hounslow borough has many residential carers that, per the Census of 2011, stood at 22,000. Hounslow not only has areas of deprivation within its boundaries, it is also one of the most ethnically diverse boroughs in London. Alongside parents and under 50s carers, it can be argued that groups such as older carers, young carers and carers whose first language is not English and who struggle with language barriers must be included among the most vulnerable of the borough's local residents.

Objectives

The aim of this review of residential carers in the community has the following objectives:

- To provide a comparison between performances from current and previous reports and to highlight strengths and weaknesses.
- To engage with carers to produce rich qualitative data from feedback to draw a clearer picture on why carers are struggling.
- To identify if there are any gaps or barriers to accessing help from services or the information to the service.

- To engage with Social Services to find out if they can identify gaps and barriers that might prevent their access to help.
- Are there any improvements to be made in the information resources and how are they being produced to increase public understanding, remove barriers and cater for diverse and underrepresented groups. If there is efficient communication between the care services and the carers.
- Make suitable and appropriate recommendation for improvements.

Scope

We targeted carers in the community, ensuring we included carers from diverse ethnicities as well as from hard to reach ethnic groups. Carers eligible for inclusion in the survey were those aged 18 and over who looked after someone aged 18 or over and who had been assessed or reviewed, either separately or jointly with the cared for person by Social Services during the past 12 months. To gain an idea of how providers look upon carers and to understand their point of view and the circumstances they face while trying to help, inform and support carers, we also engaged with representatives from Hounslow Social Services.

Chief Tools

We prepared **2 Questionnaires** for gathering data for our survey:

- One questionnaire was for collecting information from residential carers in Hounslow; and

- the other questionnaire was for collating data and views about Carers and the services and support provided to them from staff from Hounslow Social Services.

To reach out to diverse carers in the borough, we contacted various local voluntary and community organisations for help. These included Hounslow's Disability Community Forum (DCF), the Armenian Carers, the Parent Carers Forum (PCF), the Somali ... and vulnerable adults and their carers attending various support groups in the Heart of Hounslow.

To collate data from staff in Hounslow Social Services we managed to arrange a meeting with key staff and also requested them to complete our questionnaire for providers.

Limitations

Due to issues of confidentiality, we were unable to access the LBH's list of registered carers in the borough. Though we accessed carers from diverse ethnicities, we would have liked to have accessed a larger number of carers, including younger carers. It might also have been helpful had we had the time to collate data in a way that would have enabled us to compare, contrast and differentiate the experience of those carers who look after people with a lower level of care with those who are carers for those with a far higher level of such need such as patients with advanced Alzheimer's, cancer or multiple progressive health conditions. This would have enabled us to get a more complete picture of the life and experience of carers in the borough. Having more feedback from staff in Social Services would have also added to the richness of our data.

Our Respondents

We managed to obtain feedback from 84 carers in the borough. Regarding feedback from providers, we received responses to our questionnaire for staff from 5. We were also allowed to attend an Operational Managers and Deputies' meeting of staff from LBH Social Services organised by John Morgan, Head of Prevention & Care Management, Children's & Adults' Services.

Table 1: RESPONDENTS TO OUR REVIEW

Responses from Carers	84
Hounslow Social Service Staff	Questionnaires: 5

The responses received to the above-mentioned questionnaires from both Carers and staff from Social Services, are presented below separately:

Table 2: QUESTIONNAIRE FOR USERS AND A SUMMARY OF THEIR RESPONSES

A summary of our questions and a breakdown of the total of 84 responses received to the questions we asked them, are given below:

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
1.In the last 12 months, has it been easy or difficult to find information and advice about support, services or benefits?	**1.** Haven't tried to find information or advice in the last 12 months;	9	11
	2. Very easy to find;	4	5
	3. Fairly easy to find;	21	25
	4. Fairly difficult to find;	27	32
	5. Very difficult to find.	23	27
2. In the last 12 months, do you feel you have been involved or consulted as much as you wanted in discussions about the support or services provided to the person you care for?	**1.** I'm not aware of any discussions in the last 12 months;	11	13
	2. I always felt involved or consulted;	6	7
	3. I have usually been involved and consulted;	16	19
	4. I sometimes felt involved or consulted;	19	23
	5. I never felt involved or consulted.	27	32
		Did Not Answer (or DNA) 5	6
3. Overall, how satisfied/ dissatisfied are you with support or services you and the person you care	**1.** We haven't received any support or services from Social Services in the last 12 months;	8	10
			0

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
for have received from Social Services in the last 12 months?	**2.** I'm extremely satisfied;	0	4
	3. I am very satisfied;	3	6
	4. I am quite satisfied;	5	27
	5. I am neither satisfied nor dissatisfied;	23	12
	6. I am quite dissatisfied;	10	19
	7. I am very dissatisfied;	16	15
	8. I am extremely dissatisfied.	13	7
		DNA 6	
4a. Thinking about the positive and negative aspects that make up your quality of life, how would you rate the quality of your life as a whole?	**1.** So good, it could not be better;	0	0
	2. Very good;	0	0
	3. Good;	10	12
	4. All right;	29	35
	5. Bad;	19	23
	6. Very bad;	15	18
	7. So bad, it couldn't be worse.	10	12
		DNA 1	1

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
4b. Do care and support services help you to have a better quality of life?	Yes/ No	Yes 17 No 57 DNA 10	20 68 12
5a. Which statement best describes your level of control over your daily life?	**1.**I have as much control over my daily life as I want; **2.**I have adequate control over my daily life; **3.**I have some control over my daily life but not enough; **4.** I have no control over my daily life.	10 25 25 20 DNA 4	12 30 30 23 5
5b. Do care and support services help you to have control over your daily life?	Yes/ No	Yes: 9 No: 56 DNA: 19	11 66 23
6. Thinking about the food and drink you get, which statement best describes your situation?	**1.** I get all the food and drink I like when I want; **2.** I get adequate food and drink at OK times; **3.** I don't always get adequate or timely	36 22 9	42 26 11

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
	food and drink; **4.** I don't always get adequate or timely food and drink, and I think there is a risk to my health.	11 DNA: 6	13 7
7. As a Carer, do you face any difficulties if you want to attend events such as meetings, Forums, training sessions, etc.?	Yes/ No	Yes: 51 No: 14 DNA: 19	61 17 22
8. Thinking about how much contact you've had with people you like, which statement best describes your social situation?	**1.** I have as much social contact as I want with people I like; **2.** I have some social contact with people, but not enough; **3.** I have little social contact with people and feel socially isolated.	23 29 28 DNA: 4	27 35 33 5

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
9. Which statement best describes how you spend your time?	**1.** I'm able to spend my time as I want, doing things I value or enjoy;	9	11
	2. I'm able to do enough of the things I value or enjoy with my time;	9	11
	3. I do some of the things I value or enjoy with my time but not enough;	43	51
	4. I don't do anything I value or enjoy with my time.	22	26
		DNA: 1	1

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
10. Which statement best describes how having help to do things makes you think and feel about yourself?	**1.** Having help makes me think and feel better about myself;	36	43
	2. Having help does not affect the way I think or feel about myself;	17	20
	3. Having help sometimes undermines the way I think and feel about myself;	9	11
	4. Having help completely undermines the way I think and feel about myself.	9	11
		DNA: 13	15
11.Which statement best describes how the way you are helped and treated makes you think and feel about yourself?	**1.** The way I'm helped and treated makes me think and feel better about myself;	21	25
	2. The way I'm helped and treated does not affect the way I think or feel about myself;	28	33
	3. The way I'm helped and treated sometimes undermines the way I	14	17

LIST OF QUESTIONS	LIST OF OPTIONS	TOTALS PER OPTION	Approximate %
	think and feel about myself; **4.** The way I'm helped and treated completely undermines the way I think and feel about myself.	10 DNA: 11	12 13
12. How is your health in general?	**1.** Very good; **2.** Good; **3.** Fair; **4.** Bad; **5.** Very bad.	6 22 21 19 15 DNA: 1	7 26 25 23 18 1

CONCLUSIONS EVIDENT FROM RESPONSES RECEIVED FROM CARERS

1. **EASE OF ACCESS TO INFORMATION & ADVICE ABOUT SUPPORT, SERVICES & BENEFITS**:

   It is evident from responses to **Q.1** that only 5% said it was very easy to find information and advice about support, services or benefits and 25% said it was fairly easy to do so. **This takes the percentage of those who can be said to have found it easy to 30%.**

   On the other hand, 32% of our respondents said they found it fairly difficult to access such information and advice and another 27% said it had been very difficult. This **takes the total of those who can be said to have found it difficult to 59%.**

   We also came across instances of **problems of accessing information experienced by people from some ethnic minorities whose first language isn't English**. A Nepalese respondent, for instance, complained that: "there is lack of information." Another ethnic minority respondent went so far as to admit that they did not know what Social Services are and what Social Workers were supposed to do.

   It is, therefore, clear from our sample that, **in the past 12 months, the majority of carers (59%) in Hounslow did not find it easy to access information and advice about support, services or benefits.**

   Here it must also be added that although 11% of our respondents said they had not tried to find information/ advice in the past 12 months, some of them said that they had encountered difficulties when they had done so earlier. **This adds strength to our conclusion that accessing information has not been easy for carers in Hounslow.**

2. **INVOLVEMENT /CONSULTATION IN DISCUSSIONS ABOUT SUPPORT OR SERVICES TO THE ONE BEING CARED FOR:**

   Statistical data on carers' responses to **Q. 2** indicates that the performance of Social Services regarding their involving/ consulting carers about support services for those they care for in the past 12 months has been fairly good. Thus, we have 7% of our respondents saying they always felt involved and consulted, 19% saying they have been usually involved/ consulted and 23% reporting being consulted sometimes.

   It is, however, a cause for concern that 32% or our respondents said they felt they were never involved/ consulted. Additionally, it is evident from additional information provided by some carers that they are discontent with the way they are not being involved/ consulted. The following remarks will help illustrate our point and also indicate the lack of control and powerlessness experienced by carers:

"Only if I look at websites I know how carers lack consultation. [I]thought the Care Act was to give us more help/ support;

- Care, support is without our consultation;
  No assessment. No Social Worker, inadequate Care Plan, lack of support /communication;

- Am tired. Most carers are left to fend for themselves;
- Always have to fight;
- Have been involved but not given the support I need;
- Mostly I don't feel fully involved and even consulted. When I have another opinion, it is overlooked and I'm told to get counselling from GP.

3. OVERALL SATIFACTION/ DISSATISFACTION WITH SUPPORT/ SERVICES RECEIVED FROM SOCIAL SERVICES

Responses to **Q.3** indicate that only 10% of respondents said they were satisfied with support/ services received from Social Services and 27% said they were neither satisfied nor dissatisfied; the total of those who said they were quite dissatisfied, very dissatisfied, and extremely dissatisfied adds up to a high of 46%. **It is, therefore, obvious that a higher % of our respondents were dissatisfied with the services/support they had received than those who were satisfied with them.**

Dissatisfaction of respondents with services/ support received and carers' low estimation of Social Services and Social Workers were also evident from respondent comments such as the following:

- Social Workers are not easy to get hold of;
  Social Services don't meet my needs;
- Hounslow Social Services' telephone number is never received within 10 minutes;
- Social Workers have no idea of what they can and can't do. No idea of services in the area;
- [They're] not there when needed;
- Never listened to me. Not given support needed;
- Say my kids don't qualify for support;
- Safeguarding issues raised, but [they] failed to act;
- Referral takes [too long] like 18 months;
- Even when assessed a decision took a long time and contacting social services to ask for an update was not an easy process.
- They don't care for me, don't believe me, and have no damage limits

4. CARERS' RATING OF THEIR QUALITY OF LIFE

Responses to **Q.4a,** where **carers were asked to rate their quality of life, reveal that the majority of our respondents do not rate their quality of life as high.** Thus, while 0% rated their quality of life as "So good, it couldn't be better" and again 0% rated it as "Very Good", **only a small minority (12%) rated their quality of life as**

"Good" and 35% as "All right".

On the other hand, the majority of respondents (53%), rated their quality of life as "Bad" (23%), Very bad (18%) and "So bad, it couldn't be worse" (12%).

We are listing some respondents' comments to showcase their state of mind and situation to highlight their perception of their quality of life. The situation of full time carers seems to be particularly stressful[4]:

- Life is generally very restricted now. Mom needs support care during day and safety equipment, but we're waiting for an OT (Occupational Therapist's) assessment since three months.

- Being a carer is non-stop – day and night.

- [Am] very stressed and overwhelmed by my son's care needs. Its 24/7 caring, no time out and never used respite care for not enough information is there.

- Being a full- time carer, I've no time for myself, I must keep healthy but have health problems and hardly any family support.

- Manager decides what support you get regarding Respite Care.

- Progressively worse, so there is always scope for worse.

- As budgets tighten, get less advice/ help and it impacts on my anxiety and depressions sometimes.

- Feel suicidal[5]

5. CARE & SUPPORT SERVICES AND THEIR HELP TOWARDS IMPROVING CARERS' QUALITY OF LIFE

While responding to **Q.4b**, **the majority of our respondents (68%) said that care and support from Social Services did not help to better their quality of life; a much smaller minority (20%) said they did and 12% did not respond to this question.** Some respondents gave additional information about care and support and how it impacts on their quality of life some of which are listed below:

- Care is not available always when needed. Carers come and go when they like, not according to the cared for or carer's needs.

[4]Respondents who were FT carers felt they needed more support. This is a common call as all people want more support. However, the attitude of some social workers was looked upon as lacking in flexibility and just saying: "Well, that's all you're going to get! Instead of trying to look for possible options."

[5] In some instances such as this, there could be concerns about their safety, i.e., safeguarding issues.

- [They're' not there for me - feel emotionally and physically drained. No support offered.
- Because I have very little input I'm very discontent. I also need to manage all the care I am offered.

6. CARERS' LEVEL OF CONTROL OVER THEIR DAILY LIFE:

Responses to **Q.5a reveal that a high percentage of respondents (42%) said they had control over their daily life. This was made of 12% of those who said they had as much control as they want over their life and another 30% who said they had adequate control over their daily life.**

Despite this, since 30% said they have some control but not enough and an additional 23% said they have no control over their daily life, **the majority of respondents (53%) consisted of those who were either not fully satisfied or were dissatisfied with their situation as far as their control over their daily life was concerned.**

The following statements illustrate the lack of control experienced by some of our respondents:

- My life revolves around being a full- time carer.
  Have trouble with cleaning. Always have to fight with social workers.
- I get little support from them.
- Stressed.
- Mostly have no control. Life revolves around paperwork and responsibility.

7. CARE AND SUPPORT SERVICES AND THEIR HELPING CARERS HAVE CONTROL OVER THEIR DAILY LIFE

Responding to **Q.5b**, **most our respondents (66%) said that care and support services did not help them to have control over their daily life. A small minority (11%) said they did help and 23% did not respond to this question.**

Some respondents gave additional information about care and support and how it impacts negatively on their quality of life. Some of these are listed below:

They would help if there were enough resources and they made themselves known and available.

- Council is run badly.
- Have very bad experience with Social Services. Carer assessment takes four months to assess.

- Get little support from them.
- No support from any service.

8. ADEQUACY OF FOOD & DRINK AVAILABLE TO CARERS & THEIR TIMELY AVAILABILITY

Responses to **Q.6 reveal that the majority of respondents (68%) indicated that this was not a problem area. This is because 42% said they got all their food and drink when wanted and an additional 26% said they got adequate food and drink at OK times.**

There was, however, a smaller minority (24%) 11% of whom said they didn't always get adequate or timely food and drink and an additional 13% who said they didn't always get adequate or timely food and drink, and think there is a risk to their health. **Despite this group being relatively smaller in number, they are a vulnerable group of people who perform vital services for vulnerable local people whose needs cannot be treated lightly.**

9. CARERS AND DIFFICULTIES THEY MIGHT FACE IF THEY WANT TO ATTEND EVENTS/ MEETINGS/ TRAINING SESSIONS ETC.

Responding to **Q.7**, **the majority of our respondents (61%) said that thy faced difficulties if they wanted to attend events, etc. A small minority (17%) said they did not face difficulties and 22% did not respond to this question.**

Some respondents provided additional information to explain their difficulties some of which are given below:

- "It's not easy";
- "Costs extra - Taxi fare"[6];
- "Parking for disabled carers isn't available";
- "Are a couple so we're managing";
- "[It's a] problem getting cared for person ready for appointments with GP, etc.";
- "I'm in a wheelchair and it's hard to get by";
- "[Difficult] because my two children who I care for are young and fall ill suddenly. They need constant supervision during their illness."

[6] Local authorities do not have responsibility for providing NHS services such as patient transport, but they should consider needs for support when the adult is attending healthcare appointments.

10. CARERS' ASSESSMENT OF THEIR LEVEL OF SOCIAL CONTACT

Responses to **Q.8** reveal that **27% of our respondents felt they had as much social contact as they want. However, 35% said they had social contact but not enough and 33% said they had little social contact with people and felt socially isolated.**

Consequently, it seems that the majority of respondents (68%) was made up of those who were either not fully satisfied with their level of social contact (35%) or were clearly dissatisfied with their level of social contact and also felt they were socially isolated (33%)[7].

Those carers who were satisfied with their social contact made statements such as:
"Friends visit";
"Wife takes me to temple"; and
"Relative visits".

The viewpoint, sentiments and social isolation of other carers in diverse situations who viewed their social situation in a far less positive light, is evident from some stark and poignant statements like the following made by some of them:

- "I feel physically and mentally weak to socialise";
- "No one tells you what is out there even if you ask for places to go to visit or activities";
- "Life changes completely when you become a carer";
- "[I'm] immobile, can't go out and people don't come to visit me";
- "Could go to … [my community] Club but no bus, no funding, so can't be collected by them";
- "Friends of carers drop out. No confidence. Lost friends as carer"; and
- When you have a disabled child, you have no friends or relatives."

11. CARERS' DESCRIPTION OF HOW THEY SPEND THEIR TIME

Carers' responses to **Q. 9** reveal that **11% of our respondents felt they are able to spend their time as they want and do things they value or enjoy and another 11% said they are able to do enough of the things they value or enjoy. This takes the total of those who seem to think they were satisfied with how they spend their time to 22%. However, 51% of our respondents said they were able to do**

[7] We received considerable feedback from carers from which it is apparent that what many of them needed was not necessarily professional support, but more informal support – just someone to talk to and offer an alternative to structured programmes or activities, such as some peer support from a volunteer who may have been a carer and can understand what they are going through.

some of the things they value or enjoy with their time but not enough and another 26% said they don't do anything they value or enjoy. Consequently, it seems that the majority of respondents (77%) were either not fully satisfied or were definitely dissatisfied with how they were spending their time.

12. CARERS' DESCRIPTION OF HOW HAVING HELP TO DO THINGS IMPACTS ON HOW THEY THINK AND FEEL ABOUT THEMSELF

Carers' responses to **Q. 10** reveal that **43% of our respondents said they felt that having help makes them think and feel better about themselves; 20% said having help does not affect the way they think and feel about themselves; 11% said it sometimes undermines the way they think and feel about themselves; another 11% said it completely undermines the way they think and feel about themselves. 15% of our respondents did not respond to this question.**

Since the level of satisfaction of our carer respondents with information/ support/ services does not seem to be high, it seems unlikely that the fairly high 43% of those who are recorded as having said that receiving help makes them think and feel better about themselves, is a reflection of their approval/ appreciation of what they have received from service providers. We would, therefore, tend to think that it is rather a general recognition on their part that receiving help does impact on how ***anyone*** would feel and think about themselves, rather than their saying that what ***they*** have received from local, social services has helped ***them*** to feel and think better about themselves.

13. CARERS' DESCRIPTION OF HOW THE WAY THEY ARE HELPED AND TREATED IMPACTS ON HOW THEY THINK AND FEEL ABOUT THEMSELVES

Carers' responses to **Q. 11** reveal **that 25% of our respondents said they felt that how they are helped and treated affects how they think and feel about themselves; 33% said having that it does not affect the way they think and feel about themselves; 17% said it sometimes undermines the way they think and feel about themselves; 12% said it completely undermines the way they think and feel about themselves. 13% of our respondents did not respond to this question.**

14. CARERS' RATING OF THEIR GENERAL HEALTH

Carers' responses to **Q. 12 reveal that although a very small % (7%) said they enjoyed very good health, 26% said their general health was "Good" and another 25% described it as "Fair. On the other hand, 23% said their general health was "Bad" and another 18% said it was "Very Bad".**

It can, therefore, be said that 33% had a positive view of about the state of their general health, 25% felt it was fair or average but a greater proportion of our respondents (41%), reported their general health as not being in good shape.

The following responses are being listed to highlight how carers perceive their general health. One of those who said they had “Very good” health added: “I have no choice but to be healthy.”

Some of those who said their health was “Bad” or “Very Bad” made statements saying they had various health conditions. One of them said: [Have] health problems myself but just have to get on with it, that's what all carers do.” Others said they suffered from Blood Pressure or Diabetes or suspected Thyroid Cancer. Bemoaning the negative impact of having to look after her two disabled children, a female carer said: “Have physical issues related to a genetic condition and all issues with my children have created my anxiety and depression.” Another respondent, a full-time carer of her elderly mother, said she herself had chronic health issues but could often hardly sleep because of caring and worrying about her mother. Emphasising how this impacted on her health she said: “[I’m] scared it will get worse – If [she] can’t sleep I can’t sleep – but I have to be healthy.” Similarly, one carer rated his/ her level of emotional wellbeing to be as low as 2/10 and another frustrated carer remarked: “Social Services have let us down. No help [is] offered – filling in stupid forms is time waste, nothing ever changes for carers – physically, emotionally, mentally.”

CONCLUSIONS EVIDENT FROM RESPONSES FROM PROVIDERS WITHIN SOCIAL SERVICES

As mentioned earlier, we received five responses from staff within Hounslow Social services and also held a meeting with some of them in December. The main conclusions, evident from the data we gathered from them, are summarised below:

1. **Regarding registered carers in Hounslow,** our respondents from within Hounslow Social Services informed us that their Carers’ Directory included all local, registered carers. From information provided by them, we gathered that across the Hounslow Recovery Team East and Hounslow Recovery Team West, there are 255 Carers currently open; and that from April to October 2016, staff have managed to successfully complete 729 carers’ assessments.

   Though the general view of our staff respondents was that carers from various groups in Hounslow were represented among registered carers, one member of staff said they felt Black Somalis were under represented

2. **There was lack of unanimity in their views on local awareness about support available to carers.** While two members of staff said there was awareness, one said there wasn’t and one was unsure, yet another member of staff gave a substantial explanation of the strenuous efforts that were being made in Hounslow to reach out to carers for raising their awareness about services and support, including hard to reach groups.

   As far as information about support and services was concerned, almost all members of staff pointed out that the main information resource for local carers was Careplace viz., http://www.careplace.org.uk or http://www.hounslow.gove.uk/carers

3. **Regarding carers' assessments**, staff explained clearly that they were reviewed when those they cared were reviewed or separately. As far as referrals were concerned, carers could be referred by health and social care professionals or make self- referrals.

4. Regarding their views on the **Personal Care Framework,** most of our respondents viewed it as a useful tool for standardising and assessing the care provided to those who needed it.

5. Regarding their feedback on what works **effectively with healthcare professionals as well as with voluntary/ community organisations in supporting carers**, we would like to highlight the following responses:

    - Collaborative working with partner agencies, including health care professionals and voluntary organisations;
    - Carer's Champions; and
    - Support groups for Carers.

    Regarding what **acts as a barrier in the provision of support to carers**, the most significant response we received was: "The main barrier is services for carers available in the Borough and LA [Local Authority] budgets."

6. From feedback received about **what works well in the provision of services to carers**, we received a variety of responses. These were as follows:

    - Respite care to give carers a break from their caring role and prevent relationships breaking down;
    - Overnight respite (away from the home);
    - Support by INS such as with benefits, e.g. Direct Payments, Carers' Trust Support;
    - The Carers' Support Group offers an invaluable space and time for carers – this is irreplaceable and has become a central hub for carers to meet new people, share their experiences, socialise and enjoy time for themselves.
    - Being accessible is also very important to ensure that we are able to reach all of those who need us. I believe having at least one Carers Champion within each team, is central to keeping a focus on Carers needs.
    - A person-centred approach … valuing carers and treating them with the respect they so much deserve.

7. **Highlighting service gaps in the provision of help/ support to carers**, the majority of our respondents supported the following:

   - More Respite Care including overnight respite for young people;
   - More flexible creative Day Care for the 'cared for'.

8. In response to the question about **what changes they would like to see in the provision of support services for carers, t**he responses we received were varied and included the following:
   - More services and provision for carers;
   - More Respite care;
   - Greater uptake of Direct Payments: and
   - … more education around Carers needs with some practical considerations as to how best to support them … is important that all professionals are able to recognise this and consider how best they can be met, for both themselves and the cared for.

Recommendations

1. **Plugging the information gap**
   Carers need to be enabled to easily access all the information they need about their rights, services, support and benefits from one single point or source. We received some user feedback that Careplace was not providing this and, therefore, needs to be made more user-friendly.

   Besides providing training through Age UK to carers and others, e.g. older people on how to access Careplace, it is essential to understand that there are some sections in the local community who are simply not computer and internet savvy. They need to have access to hard copies. Some voluntary/ community organisations such as INS, are already successfully reaching out to carers to provide support/ information/ services. Likewise, some BMEs such as Armenians[8] are being informed through their community/ voluntary organisations. Thus, a positive way forward might be for Social Services to link up with carers through well-connected local community/ voluntary/ religious any other groups, including religious organisations. Doing so would also help increase uptake of benefits such as Direct Payments[9] which has been identified as something useful for carers by staff within Hounslow Social services.

2. **Professionals to be made more aware of the support/ information/ service needs of Carers and how best to support them**
   Likewise, health and social care staff, including social workers must understand carer needs and also be continuously updated with the latest changes in services/ rights/ benefits for carers. Due to the valuable services being performed by voluntary/ community organisations as well as BME groups, they must also have the latest information about the rise and fall of all such organisations in and around the borough.

   Echoing the need for health and social care providers to become aware of the needs of carers and how to support them, a staff member from within Hounslow social services said: “I would like to see more education around carers needs with some practical considerations as to how best to support them. The needs of carers are distinct and it is important that all professionals are able to recognise this and consider how best they can be met, for both themselves and the cared for.”

   Stressing the need to make GPs more conscious of the need of local carers, another provider said: “**Greater awareness, particularly amongst GPs needs** to be improved.”

[8] Feedback from users of the Centre for Armenian Information and Advice (CAIA) indicates that the organisation is providing a valuable service by informing and supporting carers who admit being, earlier, quite clueless about services and how to access them.

[9] Direct payments are available from Health and Social Care Trusts for someone who is assessed as needing help from social services. A carer can usually receive a direct payment if they are aged 16 or over. Direct payments can be generally used by a carer to: (1.) buy services from an organisation and (2) employ someone to provide help.

3. **Breaking down barriers and providing truly joined up services**
   Cultural barriers that have kept providers in various sectors apart for so long, will need to be further broken down to enable wider dissemination of information about services/ care/ support and activities for carers across the board including via community/ voluntary/ religious organisations. Collaborative working was also upheld as useful by staff within Social Services, one of whom remarked: "I believe that co-production is essential."

4. **Providing more services/ support and at appropriate times for carers**
   To reduce the stress level of carers and help to keep them more healthy and help to raise the quality of their life, it will be imperative (as recognised by providers as well), to provide carers with more services and support that is appropriate for them and is provided to them at a time or times that are suited to their convenience and those they care for, rather than in accordance with the ability and convenience of providers.

   An initiative that could perhaps be replicated is that of recruiting **Care Support Volunteers to give support to local carers looking after one or more of their relatives** that is presently being run by Your Voice in Health and Social Care (YVHSC). Such projects centred on helping carers to continue playing their crucial caring role are bound to raise funding issues which will need to be tackled by health and social care providers.

   Media reports state that the Government have suggested Councils can raise Council Tax to raise funds to provide care to those who need them. It is, however, apparent that richer councils will be in a better position to do so than less affluent ones. Moreover, it is reported that Councils need funds ***now***, whereas they will be able to raise taxes only by 2020. LBH will need to surmount the financial hurdle to be able to provide more and more appropriate services to its local carers.

5. **Reducing avoidable delays in making assessments and responding to other needs of carers**
   To reduce stress of carers[10], it will be beneficial to investigate what delays some assessments and try to reduce delays in making assessments for persons being cared for, especially in cases where safeguarding issues are involved. Also, there is need to reduce the time it takes to provide updates or respond to any other issues raised by carers.

6. **Increasing provision of and access to Respite Care for carers, Day Care for the cared for and Overnight Respite for young people coming through transition**
   As evident from feedback from carers and providers, increase in the provision of Respite Care for carers is a prime necessity. More funding is crucial for this to happen and the present climate of government cuts is not conducive towards fulfilling this caring need. Nevertheless, it is clear that respite care will help bring down stress levels of local carers and contribute towards their quality of life and wellbeing.

[10] There were many respondents who felt the time to be seen and assessed was disproportionate to their need and the needs of the person they care for; in other words they were desperate and felt it took far too long to be assessed and to respond to issues or provide updates.

Similarly, Overnight Respite care for young people and provision of Day Care services for the cared for would also help reduce the burden of work and responsibility felt by carers and give them some relief.

7. **Organising more informal and easily accessible support for Carers with a publicity boost to raise awareness of its existence**
   It was apparent from feedback from many of our carer respondents that besides, formal support and care, they would benefit from informal support from people who could empathise with their situation such as volunteers or those who had been carers themselves. We were informed by Hounslow Social Services staff that in Hounslow they do have Carers' Champions, Carers' representatives and Support Groups for Carers. These need to be developed further and given wider publicity so that carers in Hounslow are able to benefit from them.

8. **Empowering Carers to become Rights Aware and Rights Assertive**
   Valuable feedback from some local carers illustrates that for carers, to find the right information and then to put up a dignified fight or struggle for one's dues, is the prerequisite to get appropriate services/ care. This illustrates the prime importance of the need to firstly empower carers by providing them with information and then to also urge them to assert and stand up for themselves.

9. **Need for Advocacy Services to speak for disempowered carers**
   Despite the need for empowering carers, many a carer needs support. Due to their vulnerability, carers, (especially some parent carers), feel disempowered, powerless, unsupported by services, lost. They, therefore, need someone to stand up and speak and even fight for them. From feedback we received, it seems that in Hounslow an advocacy service is not easily available to carers. According to one of our carer respondents: "People say: 'Go to the Citizen's Advice Bureau, but it's not that easy to go there when you're feeling you're at the end of your tether. [Moreover,] the CAB can also turn around and say: 'Sorry! You don't qualify for services!'"

10. **Need to make sure Hounslow Social Services supports/ informs even those carers who do not qualify to receive services from them**
    It came across from some local carers, that those among them who don't qualify for services from Social Services, are not adequately helped. However, since Social Services must make sure that they provide information and advice on whatever support in the community that is available to carers even if they do not meet the national eligibility criteria, Hounslow Social Services must ensure that they do not fail such carers.

Conclusion

It is apparent that there is a large volume of negative feedback from carers in Hounslow. However, there is a high level of awareness of the important role played by carers and empathy with them among staff within Hounslow Social Services. This is evident from statements such as:

“[Carers need] to be listened to. [Need] breaks via various options. A person-centred approach by valuing carers and treating them with the respect they so much deserve.”

“Carers have vast experience and it is essential that as services, we respect that.”

They also have considerable awareness of the need for more services and provision of services and the lack of and strong support of the need for developing specific services such as Respite Care for carers and Day care for the cared to support them.

Thus, when asked to pinpoint what prevents carers from receiving the support they need, one of them said categorically: “The main barrier is services for carers available in the Borough and LA budgets.”

We are, therefore, confident that our recommendations will resonate with the general view of staff within Social Services instead of striking a discordant note.

Appendices

QUESTIONNAIRE FOR CARERS

Your Social Care & Support Services

The aim of this Survey is to include your invaluable feedback so that we can help the Department of Health monitor the performance of the care and support services provided to Patients and their Carers and see how far they are meeting Patient or User and Carer needs.

A "Carer" is anyone who spends a significant proportion of their life providing unpaid support to anyone who is unable to manage without their help. They could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. You are invited to respond to this Survey if you are aged 18 or over and helping or looking after someone aged 18 or over or who have been assessed or reviewed, either separately or jointly with the cared for person by Social Services during the past 12 months.

1. **In the last 12 months, has it been easy or difficult to find information and advice about support, services or benefits?** *[To answer this question, please think of information/ advice from different sources, such as voluntary groups, private agencies as well as Social Services and pick the statement that best describes what you think.]* **(*Please tick (✓) ONE box only*)**

☐	I have not tried to find information or advice in the last 12 months
☐	Very easy to find
☐	Fairly easy to find
☐	Fairly difficult to find
☐	Very difficult to find

Please briefly explain why.

_____

---

2. **In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for? (*Please tick (✓) ONE box only)***

☐	There have been no discussions that I am aware of, in the last 12 months
☐	I always felt involved or consulted
☐	I usually felt involved or consulted

	I sometimes felt involved or consulted
	I never felt involved or consulted

Please briefly explain why.

_____

_____

3. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months? (*Please tick (✓) ONE box only)*

	We haven't received any support or services from Social Services in the last 12 months
	I am extremely satisfied
	I am very satisfied
	I am quite satisfied
	I am neither satisfied nor dissatisfied
	I am quite dissatisfied
	I am very dissatisfied
	I am extremely dissatisfied

Please briefly explain why.

_____

4a. Thinking about the positive and negative aspects that make up your quality of life, how would you rate the quality of your life as a whole? [*Think about the quality of life as a whole and include help you get from Social Services and others*]. ***(Please tick (✓) ONE box only)***

	So good, it could not be better
	Very good

☐	Good
☐	All right
☐	Bad
☐	Very bad
☐	So bad, it could not be worse

Please briefly explain why.

_____

_____

4b. Do care and support services help you to have a better quality of life? Yes/ No. Please briefly explain why.

_____

_____

5a. From the statements given below, please choose the statement that best describes the level of control you have over your daily life? [*'Control over daily life' means having the choice to do things or have things done for you as you like and when you want.*] (***Please tick (✓) ONE box only***)

☐	I have as much control over my daily life as I want
☐	I have adequate control over my daily life
☐	I have some control over my daily life but not enough
☐	I have no control over my daily life

Please briefly explain why.

_____

_____

5b. Is there any area or aspect in your daily life that you would like to change?

Please briefly explain why.

_____

……

5c. Do care and support services help you to have control over your daily life?
Yes/ No

Please briefly explain why.

_____

_____

6. Do care and support services help you to keep clean and look presentable?
Yes/ No

Please briefly explain why.

_____

_____

7. Thinking about the food and drink you get, please indicate which of the following statements best describes your situation? (*Please tick ONE box only)*

	I get all the food and drink I like when I want
	I get adequate food and drink at OK times
	I don't always get adequate or timely food and drink
	I don't always get adequate or timely food and drink, and I think there is a risk to my health

Please briefly explain why.

_____

_____

8a. From the statements below, please tick the statement that best describes how safe you feel. *[By 'feeling safe' we mean how safe you feel*

both inside and outside the home. This includes fear of abuse, falling or other physical harm.] ***(Please tick (✓) ONE box only)***

	I feel as safe as I want
	Generally I feel adequately safe, but not as safe as I would like
	I feel less than adequately safe
	I don't feel at all safe

Please briefly explain why.

_____

_____

8b. Do care and support services help you in feeling safe? ***Yes/ No.***

Please briefly explain why.

_____

_____

9. Thinking about how much contact you've had with people you like, please tick the statement that best describes your social situation? (*Please tick (✓) ONE box only)*

	I have as much social contact as I want with people I like
	I have some social contact with people, but not enough
	I have little social contact with people and feel socially isolated

Please briefly explain why.

_____

_____

10. From the statements below, please tick the statement that best describes how you spend your time? (When thinking about how you spend your

time, please include whatever you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others). **(Please tick (✓) ONE box only)**

	I'm able to spend my time as I want, doing things I value or enjoy
	I'm able to do enough of the things I value or enjoy with my time
	I do some of the things I value or enjoy with my time but not enough
	I don't do anything I value or enjoy with my time

Please briefly explain why.

_____

_____

11. Which of these statements best describes how <u>having help to do things</u> makes you think and feel about yourself? (*Please tick (✓) ONE box only)*

	Having help makes me think and feel better about myself
	Having help does not affect the way I think or feel about myself
	Having help sometimes undermines the way I think and feel about myself
	Having help completely undermines the way I think and feel about myself

Please briefly explain why.

_____

_____

12. From the statements below please tick the statement that best describes how <u>the way you are helped and treated</u> makes you think and feel about yourself. *(Please tick (✓) ONE box only)*

	The way I'm helped and treated makes me think and feel better about myself
	The way I'm helped and treated does not affect the way I think or feel about myself
	The way I'm helped and treated sometimes undermines the way I think and feel about myself
	The way I'm helped and treated completely undermines the way I think and feel about myself

Please briefly explain why.

---

13. How is your health in general?

(*Please tick (✓) ONE box only)*

	Very good
	Good
	Fair
	Bad
	Very bad

Please briefly explain why.

_____

_____

14. Please indicate which statement best describes the state of your own health today. (*Please tick (✓) ONE box only)*

	I have no pain or discomfort
	I have moderate pain or discomfort
	I have extreme pain or discomfort

Please explain briefly why.

QUESTIONS FOR INTEREVIEWER

1. During this interview, did the service user have help from someone else? Choose ONE option only - Interviewer to code as appropriate

	No, they did not have help
	They had help from a care worker
	They had help from someone living in their household
	They had help from someone living outside their household

2. What type of help did they have? Choose as many options as apply – Interviewer to code as appropriate

	They didn't have any help
	Someone else read questions to them
	Someone else translated the questions to them
	Someone else wrote down the answers for them
	They talked though the questions with someone else
	Someone else answered for them, without asking them the questions

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QUESTIONS FOR PROVIDERS IN SOCIAL SERVICES

1. How many registered carers do you have in your records?
   Are there groups you feel are underrepresented?

2. Are the services and support you provide to local carers adequately known among people in the local community?

Can you provide us with any publicity material or link that is available to the local people in Hounslow to inform or reach out to those who might need your services and support?

3. How do you identify and assess the needs of local carers in Hounslow?

4. Do you think the Personal Care Framework is effective? Please explain why.

5. Do you think you work effectively with healthcare professionals as well as with voluntary/community organisations to support carers?
If yes, please explain briefly how. If not, please say what acts as a barrier.

6. What do you feel works well in the provision of services to carers?

7. Where do you feel the gaps in provision are?

8. What changes would you like to see in the provision of support services to carers?

Thank you!

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