Sandwell
Metropolitan Borough Council

Appendix:

The Carers Support Service: Engagement Report

Introduction

1.1 The purpose of this report is to present the consultation and engagement that took place for the design of the new Carers Support Service. The report will set out the approach, timescales, methods, dates, venues, participant numbers, findings and recommendations.

Consultation Activity

1.3 The aims of the engagement were to:

- Collate the views of people about the new service, including carers, potential service users, stakeholders, and professionals.
- Create opportunities for dialogue in focus groups.
- Facilitate the participation of stakeholders in service specification development, where relevant.
- Ensure that the service consultation was transparent and meaningful to participants.

Consultation Timescale

1.4 The consultation was carried out over a period of approximately a year and follow good practice guidelines as set out by Government in ‘The Consultation Principles’ issued by Cabinet Office 2016 and further work by SCIE, and ADASS in 2022. It also follows principles set out by the Council and involved the use of the Citizenspace tool.

1.5 A stakeholder map was prepared to categorise all stakeholders by level of influence and by level of interest. This was to drive engagement.

Influence Level

Keep Completely Informed	**Manage**
Commissioning Leads/Board Procurement Leads Managers and Teams in Social Care and Management	Current Grantees for Carer Support Services Finance leads Current carers People who are unidentified carers Current providers in carers support market SCT, ICB

Regular Contact	**Anticipate and Meet Needs**
ADASS Carers Leads Network Staff in ASC and SCT who are not involved in Carer Support Health partners Healthwatch SCVO/Voluntary Sector	Cabinet Member Director/Senior Management Legal Equality Democratic services Risk and Information Governance teams

Engagement activity

1.6 Various engagement activities took place to collate the views of a variety of stakeholders. The table at the end of the report lists date and activity, audience, method of engagement. Over 200 people took part in the engagement.

2 Engagement Findings – The Online Survey:

2.1 Response rate

157 responses were received from the Citizen space survey – which can be accessed – https://www.sandwell.gov.uk/carers/shaping-new-carer-support-service-sandwell. Of these responses 132 (84%) were from carers, and the rest were from residents or staff who know or support them. Of the 157 respondents:

- 77% were women.
- 5.7% were from young or young adults aged under 30.
- 24% were aged 64 or older.
- 70% from people aged 30- 64.
- 28% were from people from BAME groups (11 were Asian, 11 Dual Heritage, 13 African- Caribbean/Black British)
- 20.4% were people with disabilities.

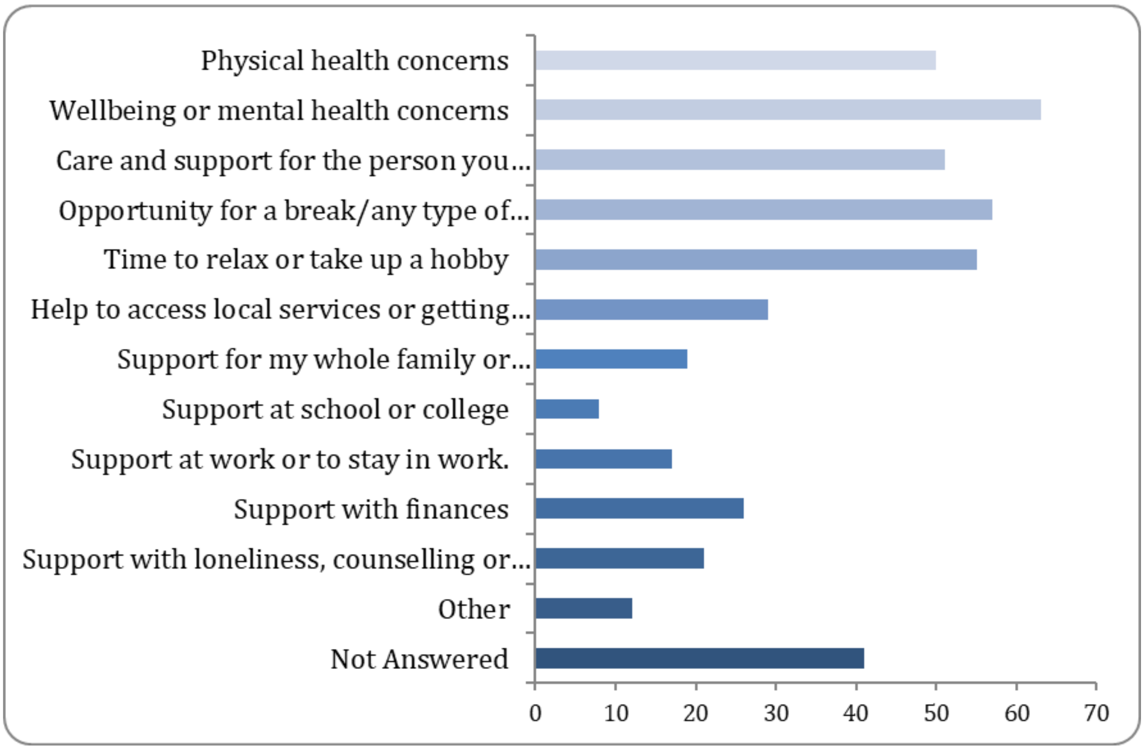
2.2 The needs of carers

Of the 132 carers who responded:

- All were caring for people with a wide variety of conditions – most commonly physical health conditions (32%) or disability (27%), learning disability (20%), dementia (19%) and mental health conditions (28%), and autism (18%).
- Most carers were caring for close family: 30% were caring for parent, 27% for spouse and 13% their child, 10% were caring for adult son/daughter.
- 43% were caring all the time, and 37% were caring every day.
- All were performing a wide variety of tasks - shopping, housework, medication, taking cared for person out etc. The only task completed

by less than 50% of carers was help with learning/homework (most of these were caring for child).

- Carers had various needs, as shown below:

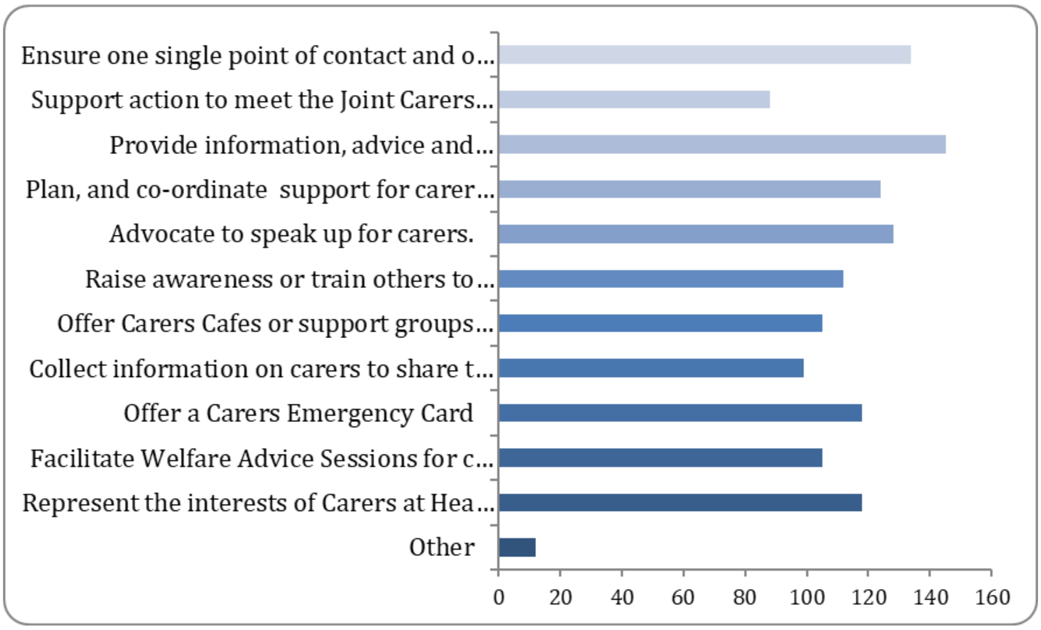


2.4 The need for a Carers Support Service

All respondents answered this question, 92.3% agreed there was a need for the new service, and of 153 responses to this question, 96% said they would use the new service. Most frequent reasons given:
“Carers need to know they are not alone, carers need companionship”.
“Overwhelmed, and some are dealing with complex needs, and need a break to prevent a breakdown, or cared for needing to go to hospital”.

2.5 Delivery

All respondents listed many deliverables, and they are listed below:

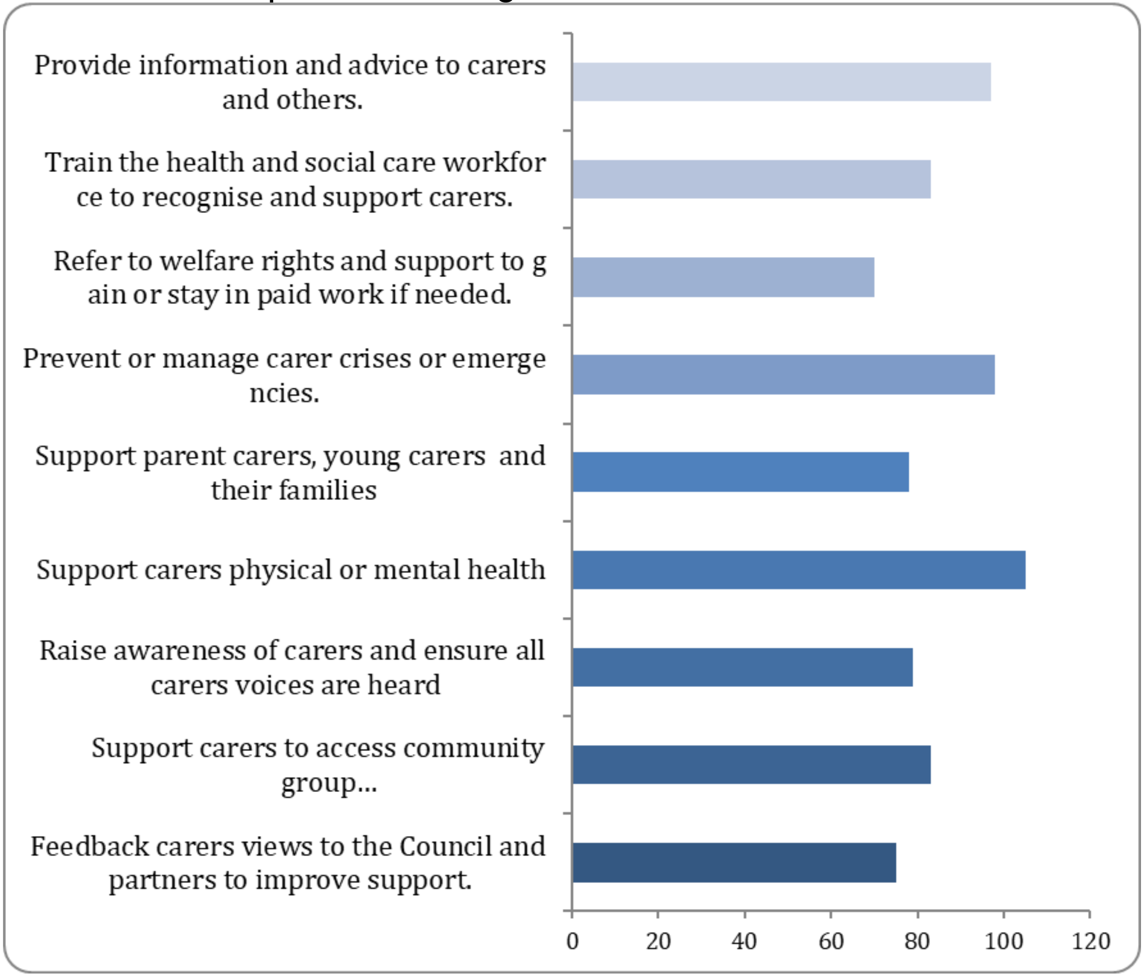


2.6 When asked to rate the three most important deliverables, the rankings were as follows (with 50% of 109 respondents ranking the single point of contact at number 1):

3 Item	**Ranking**
Ensure one single point of contact and one clear offer for carers	1.84
Supply information, advice and guidance to carers on available health and social care systems	1.47
Plan, and co-ordinate support for carers	0.76
Advocate to speak up for carers	0.47
Offer Carers Cafes or support groups across 6 Towns	0.44
Raise awareness or train others to understand caring	0.29
Facilitate Welfare Advice Sessions for carers benefits	0.24
Offer a Carers Emergency Card	0.17
Support action to meet the Joint Carers Strategy	0.17
Represent the interests of Carers at Health and Wellbeing Board and other local forums	0.08
collect information on carers to share trends on carers needs	0.04
Other – counselling, emotional support	0.03

3.5 Themes

When asked which themes in the Joint Carers Strategy the new service should prioritise, most frequent were health and wellbeing, information and advice and prevent/manage crises.

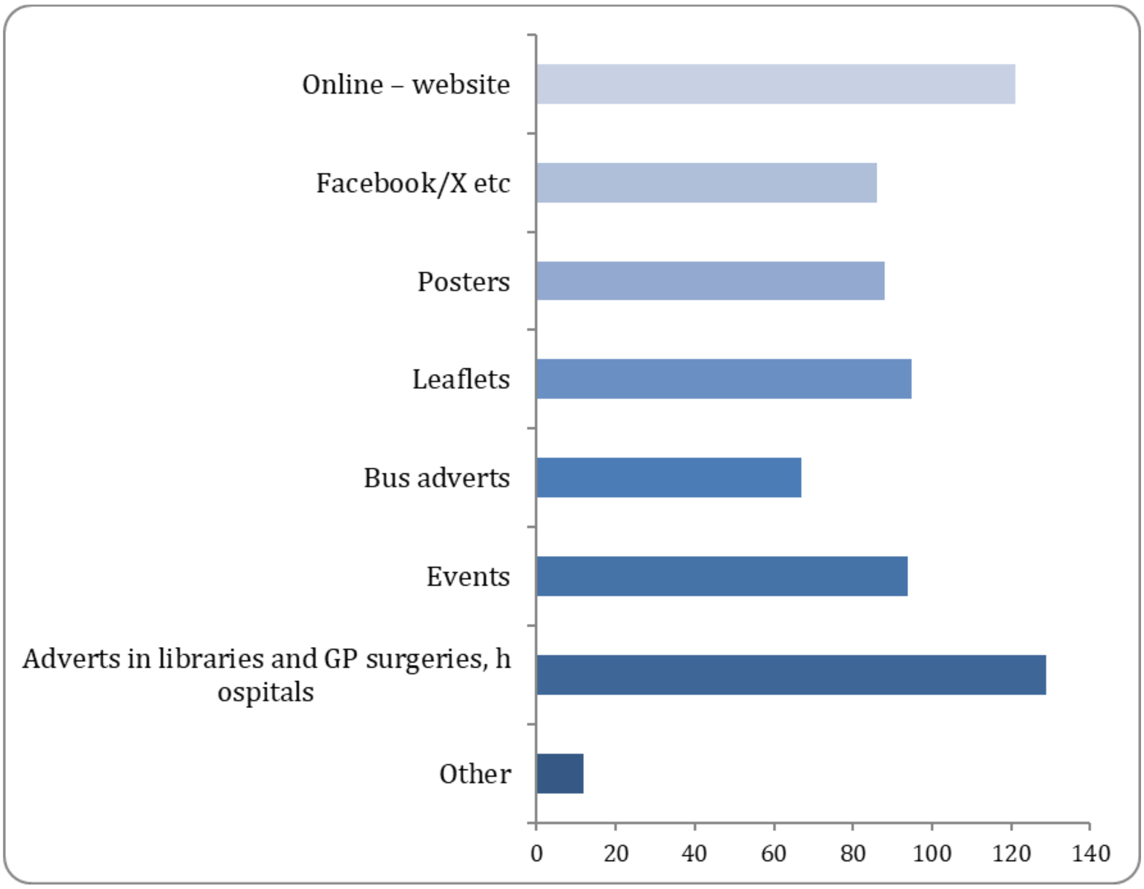


3.5 Access to the service

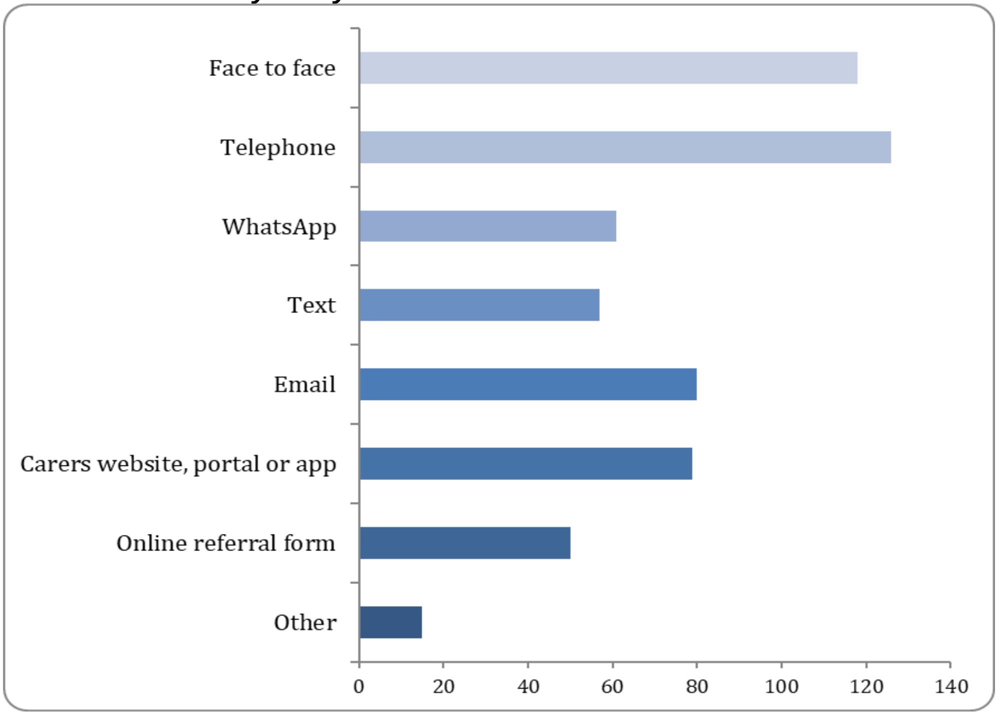
Of the 157 responses, 63.7% said that a central building, a base in each of the 6 towns, and online/telephone access were all important. 15% wanted a central building, these were mainly carers who already used a central building. 68.8% said that the service should be open in evenings and weekends in addition to normal office hours, for working carers, carers at school/college and for crises.

3.6 Promotion and Communication

Respondents said there were various ways to promote – most frequent were online (77%), social media and advertisements in health and community centres, hospitals (82%) and young carers included schools and shops. Events, posters and leaflets were slightly less popular. The preferred methods of communication were as follows:



To contact the service, most respondents preferred telephone or face to face. Mental Health carers preferred these due to sensitive nature of information they may share.



Of the respondents:

- 75% would use a 24/7 telephone line for crises.
- 65% would use a telephone line for normal office hours.
- 48% would use an app for carers.
- 34% would use WhatsApp texts.
- 16% were not confident to use IT, however. Main reasons given were age and lack of experience or access to laptop at home.

3.2 Other Comments

68 respondents commented – including most often:
“Carers go above and beyond in their job as they care”.
“There are no perks, we are paid pennies for the risk we take”.
“It’s quite difficult to navigate social services”.

4 Focus Groups

4.1 There were 7 focus groups to ensure that under- represented groups of carers and others were given the opportunity to have their say, or because the carers at the venue requested a group discussion. There was a short presentation outlining the plans for the new service and asking about what the new service should deliver, and how, followed by a group discussion. The main themes from the focus groups to the questions in the presentation were:

4.2 What should the new service deliver?

All or most groups said the following:

- **Single point of Contact -** The service should be a first point of access service for all carers and assess and plan carer support in other organisations, as low access to social workers or only speak to duty social worker, and they feel passed around /too much signposting. A one-stop shop for accessible information and added support for carers who don’t have access or may not be comfortable using telephones or online.
- **Carers need a range or package of support** including:
    - **Planning and Navigation.** Carers are confused over next steps in contacting services/support so need clear guidance. They are exhausted and tired especially chasing services.
    - Need for **quick, effective support** for cared for person and solution to their presenting issue. They get exhausted from caring and navigating the health and care system – they don’t know who to contact or next step.

- Carers need correct, clear and timely **information and advice**, especially about respite and availability of respite, and legal rights. by newsletter, social media, face to face, as some don't access IT. This needs to be concise and simple.
- **Signposting** – "It would be helpful if there was an information, advice, and guidance information sheet on key contact numbers". There is a lack of awareness of what activities are available within the local area, especially around sports and physical activity, "If you are a carer, you are not aware of what's going on".
- **Advocacy** with health and care "As carers feel out of their depth when dealing with professionals" and if crisis hits, the service needs to be familiar with the pathways into adults and children's services.
- **Peer Support** Carers are lonely and need peer support and face to face chats/drop ins. Peer support groups in each town, and different groups for different ages, genders etc.
- **Mental health support**, training, relaxation and counselling.
- **Promote awareness of caring** and find hidden carers in Sandwell. There is a need for awareness that they are a carer and what care, and support is available for cared for person at early stage in caring (and before hospital admission or other crisis) to prevent carer burnout and access the right care for cared for person.
- **Raise awareness/empathy for carers** by staff in health and social care. Empathy was an ask especially of older and BAME carers.
- **Financial Support** Provide or signpost to welfare rights or practical support such as grants for equipment or breaks, warm packs etc. There is a need for information on carers allowance, and other benefits, nor care and support for cared for people: "Nobody knows what they can claim and what they are entitled to, no one claims anything".
- **Regular and updated training** to carers on tasks for caring – medicine management, hoist use etc, to refresh and update carer's knowledge on any changes in legislation and practice.
- **Shorter carers assessments**
- Offer a **Carers Identification and collate a carer's Register**, and report on carers trends.
- **Emergency card and quick emergency responses** so that carer feels reassured.

How should the service be delivered?

Two themes were raised:

Effective leisure and respite –

- Respite should offer a real break from caring in way carer needs, so carers feel refreshed, and prevent carer breakdown.
- Replacement care needs to meet health/disability needs of cared for the service should refer to specialist care providers, to prevent crises.
- The support plan needs to be clear on respite.
- The service should have a flexible approach to respite, so carers get break they need– for nature, duration, whether cared for or carer together or separate: sitting service for appointments, day services for few hours, shared lives, wellbeing activities, leisure passes, outings, ‘short’ and longer breaks for carers, and good replacement care.

- **Waiting times for Council and NHS Support**

- The service needs to address the issues of long waits for assessments, diagnoses, support/treatment and reviews of care and support by the Council and NHS. There is a long wait for cared for people to get funded day care, and to see Mental health professionals for diagnosis, so carers can get informed, a break and enable them to cope and keep on caring or working in jobs. Waiting times and feeling that health and social care staff not doing jobs properly can both impact on mental health of carers.
- The service needs to give carers the information about waiting times and manage their expectations while they wait, especially for carers assessments, and signpost to or deliver the right support whilst waiting for these eligible support – including practical and mental health support and befriending.
- The service should know about demand for support or capacity of other providers to make easier for the carer to navigate services and what and when to expect support.
- The service needs to explain the Social Care financial assessment as well as Care Act assessments, to manage expectations. “If you have savings you have to self-fund or contribute to care, which discourages carers from accessing support for them and people they care for”.

Other themes included:

- **Carers must be experts by experience** and shape or co-design their service and influence what the carers support offer looks like in Sandwell. They must be listened to, involved in care and support of cared for person, and respected.

- **A carer needs to have somebody they can speak to face to face if they need it and have time to listen to and assess all their needs,** including their mental health and how to support that.
- **There must be a variety of ways for carers to engage with the service.** There must be a digital offer and telephone and face to face support especially for those not confident with IT or want a more personal and warm approach - especially the case with older and BAME carers. Technology and other ways to communicate because most information is and should be online, but not all can access it. Suggestions included a WhatsApp group for carers peer support.
- **There must be local support hubs for carers,** and use of the existing buildings for easy access by carers in all 6 towns and join up existing carers activities. Most carers would prefer face-to-face meetings. Some would be open to online, and talks from experts on LPA, benefits, mental health etc.
- **There needs to be staff with diverse language skills and staff who understand and empathise with the different support need of carers from different cultures** and that need so that they are able to communicate with carers in various ways.
- **The service needs to be 24/7** for working carers or emergencies.
- **This service to be overarching** and will signpost to more specialist organisations.

Where should service be delivered?

- A physical building as a hub is needed with social media, phone access for local carers and an attractive venue with space for many carers to meet in groups.
- There should be a Carers Centre where carers can walk in to have support face to face.
- There should be multidisciplinary teams so the carers can get all the up-to-date information and guidance from relevant staff.
- The service needs to deliver bespoke support at the different stages of caring.
- There were lots of ideas about a peripatetic model, voluntary sector staff suggested having a presence across all six towns using existing services.
- Examples of staff being in a base for 3 months will allow people to access easier.
- Carers are limited on time; the service needs to be accessed and ‘go to people’.

- Social workers agreed with a mobile service as cares may not be able to travel across towns.

Feedback by Stakeholder Group

In addition to the surveys and focus groups, the following groups of carers expressed their needs and preferences:

1. Partners in Joint Carers Strategy Group

There were approximately 30 professionals and volunteers working for the Council, NHS, Healthwatch and local carers organisations at a workshop in September 2023, who met again in April 2024, and attended a focus group in May 2024. The main themes were:

- Access to the service should be dependent on presenting carers needs and on the impact of caring on individual wellbeing, not dependent on medical diagnosis of cared for person. The eligibility criteria for a carer needs to be clear so all know who can access the support.
- The service should deliver an assessment of presenting needs of each carer, and plan/triage support.
- The service should link in and co-ordinate local support and services around carer's needs.
- Diverse groups of carers may need a different approach – so refer to specialist services for parent, young and BAME carers.
- The service must be independent
- Support must be sustainable.
- Sandwell Herald and the local press to promote the local carers offer.
- The new service could share funds to other charities who supply specialist support – for example young carers charities so they can identify the hidden young carers. Funding for carers support needs to increase.

2. Adult carers of people with mental health conditions, learning disabilities or parent cares of children using CAMHS

There were 28 carers of various ages and ethnic groups who discussed the following:

- The need for carers to feel valued as they save others money.

- The need for single point of contact as carers feel confused about talking to many different professionals and “being passed on”.
- Their need for emotional and peer support and own health and wellbeing needs, including stress and loneliness.
- The need for face to face and telephone support, which is confidential and “talking”, as they may share sensitive information.
- Preference for one building as a respite from caring and meet staff and carers who they can confide in over “sensitive” issues.

3. African Caribbean and Dual Heritage Carers using African Caribbean led Voluntary Organisations

Approximately 15 carers and staff who support carers held a group discussion. The themes were:

- In 2023, 48% of Sandwell were BAME. The carers don’t access universal services due to their cultural and language differences, so there is an increasing need for specialist support.
- To future proof services, the service needs to consider the barriers seldom heard carers face when trying to assess services to reduce health inequalities. Experiences of bias led to less trust and access.
- The service needs to work with specialist targeted trusted BAME led organisations. They need information/navigation, respite, end of life and bereavement services from a black led organisation who they trust and who share similar lived experiences.
- An Advocacy service to support carers mental health is useful
- A single point of contact for carers is crucial to improve communication between the care provider for the cared for person and carers.
- Who would replace the support for the cared for person whilst carer on a break, and would they be meet cultural needs? Good day care and trusted staff for cared for helps carer’s wellbeing.
- The carers direct payment was important due to low income.
- Mental or physical health care is not in place until a crisis happens, and it is difficult to access mental health care for the cared for after hospital discharge.

4 Parent carers.

- There is a rise in Autism/ADHD and number of parent carers. They need support both pre, during and post diagnosis.
- Parent carers often don't understand the difference between being a parent and a carer. They need time for the defences to come down so that they feel listened to in a confidential way.

- Parent carers need to have a better understanding of the cared for persons conditions: especially autism and mental health needs earlier.
- Services care for life limited children but there is a need for support for end-of-life carers and bereavement support for parents.
- There needs to be clarity around expectations of assessments for parent carers, as children with needs don't qualify for some services and that leads to frustration.
- There needs to be clarity about who can support with the cared for adult and clear pathways for parent carers and young carers into Sandwell children's trust and Sandwell children's services as there are long waiting lists.
- Parents need to easily go to one point of access to carers support.
- The new service should signpost to contracted short breaks for parent carers.

5 Young Carers

9 carers responded to the survey and held a focus group at a local organisation for young carers. 44% had disabilities/long term conditions.

- Their top needs were around health, respite and help with school or college. They wanted the Service to deliver Information and advice, train the health and social care workforce, plan support and Advocate for carers.
- Top themes: Support Health, train workforce, raise awareness of caring.
- 66% felt building/online/telephone all important, most wanted evening and weekend opening. 88% wanted online promotion, 66% wanted posters, and events in schools.
- 88% wanted 24/7 a telephone line for crises, 55% wanted an app, some wanted a separate space for young carers and information/forms for children.
- Their main need was not to feel alone, and that crises support was there promptly.

Staff from a local organisation supporting young carers explained:

- they are unidentified due to stigma and lack of understanding of what a carer is or does. Some young carers (and their families) fear that telling others of caring or parents/cared for condition may have consequences for family. The existing young carers services normally picks up these carers through other young people’s services where they present with mental health needs. Young carers services in schools need to build relationships with young carers and gain their trust.

- Young carers take up of carers assessment is low.

6 Older carers (aged over 60).

15 carers stated that:

- There is a lack of awareness or signposting of support groups and information, advice, and guidance (IAG), and support for carers to attend talks and sessions. So, they need a sitting service or better transport.
- Overwhelming Information and Advice when at crisis point – this needs to be concise and simple.
- The costs of transport prevent some older carers from attending events or accessing services.
- Carers need bespoke support at the different stages of their care.
- They need a one-stop shop for accessible information and added support for carers who don't have access to digital technology or may not be comfortable using phones etc. Carers are confused about service offers and are less likely to be It literate or confident.
- Older carers are very lonely and need support and empathy from staff.
- Financial assessment can be off-putting for some families.

7 **Employed carers** are juggling caring, job and life.

- The service needs to be flexible to be able to support them at a time when they need, when they have the time to access the information. These carers need to access local carers support outside normal office hours for information, advice and peer support.
- They need awareness raising to educate employers to be carer friendly and offer carers paid leave. Employed carers were having to reduce working hours to support cared for and need awareness raising of caring and more understanding by employers, and others.

8 Social Workers and Managers

- Agreed with the functions of the service, however stated that consideration to the location is important. All favoured bases in each town, thus being cost effective and more accessible.
- Discussion around the emergency card and understanding of implications if ownership changes.
- Carers DP- discussion around how social work can utilise support to meet the needs and issues. Carers DP as a one-off payment

does not allow for sustainable support as raised in this engagement.

- Support for social workers to understand wider offer and incorporate into assessment.

Date	Activity	Audience	Purpose and Method
29 Sept 2023	Stakeholder map by Power and Interest	All stakeholders	Visual diagram drawn up by Commissioner
29 Sept 2023	Joint Carers Strategy Engagement workshop	Representatives of various organisations, including providers of Carers Support, Adult Social Care, NHS trust and Healthwatch attended	Workshop to review Joint Carers Strategy which included a discussion of what the new Carers Support Service should deliver.
Spring 2024	Dept of Health and Social Care Carers biannual survey	Survey sent to cares who had contacted Adult Social Care in last 12 months	Survey for carers to feedback on satisfaction with social care and quality of life.
March – May 2024	Monthly online meetings	Carers Engagement Project team – commissioners, Care Management leads, NHS leads, Healthwatch, Voluntary Sector support team and public health, Digital Inclusion lead	To update and discuss progress of engagement and promote take up of engagement activities. Sharing of online survey with Share Lives carers, Carers of people using LD pathway, and all grant funded voluntary organisations in Sandwell. Link shared on SCVO newsletter
15 march – 15 May	Online Survey	Current commissioners of Carers Support in 14 West Midlands Councils	Online survey developed to compare commissioning arrangements.
20 March – 15 May	Online Survey on Citizen space	Carers and people who knew or worked with carers in Sandwell	Online Survey, and paper survey delivered by hand during focus groups and drop ins.
March	Presentation on Carers Support Service, posters and emails	For all stakeholders	
21 March	Tipton Library Drop in	Carers of people with dementia and people who knew or worked with carers	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
4 April	West Bromwich Central Library Drop in	Carers of people with dementia and people who knew or worked with carers	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
11 April	Drop in Portway Lifestyle Centre:	Carers and people who knew or worked with carers	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
16 April	South Staffs Water Company, Wednesbury:	Carers and people who knew or worked with carers	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
18April	Oldbury Library:	Carers of people with dementia	Face to face drop in for carers and people who knew carers or worked with them, using online survey above

22 April	Drop in Wednesbury Library	Carers of people with dementia	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
23 April	Drop in Harvest View, Rowley Regis	Carers and people who knew or worked with carers, using/visiting Harvest View	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
24 April	Drop-in Brass house Centre, Smethwick	Carers and people who knew or worked with carers, using the Centre	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
29 April	Focus Group African Caribbean Resource Centre	African Caribbean, Dual Heritage Carers and people who know or worked with them	Focus group with short presentation to ask: • What should new service deliver? • How should it run?
30 April	Focus Group Cradley Heath Community Centre	For women over 60 who are/have been carers using the Centre	As above
30 April	Drop in Council House	For carers who are employees of Sandwell Council	As above
2 May	Sandwell Aquatics Centre	Carers including parent carers	Face to face drop in for carers and people who knew carers or worked with them, using online survey above
3 May	Online meeting with staff who work with carers	Council and Voluntary Sector	Focus group with short presentation to ask: • What should new service deliver? • How should it run?
4 May	Focus Group Sandwell Young Carers	Young Carers aged 13 -18	Focus group with short presentation to ask: • What should new service deliver? • How should it run?
9 May	Drop in Portway Lifestyle Centre		
10 May	Focus Group Jubilee Community Centre, Tipton:	For carers in Tipton using the centre	Focus group with short presentation to ask: • What should new service deliver? • How should it run?
July x 2	TEAMS	Social workers and managers	Review feedback. Obtain views on the service offer Explain/identify issues such as carers emergency card