

Adult Carers' Support & Services Consultation

Summary of Responses & Key Findings



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Cardiff Council Adult Services
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Contents

	Page
1 Background	2
2 Summary of responses	
Entitlement and Access to a Carers Assessment	3
Completing a Carers Assessment	4
Eligibility Criteria for carers to access services	5
Charging for services	6
Direct Payments	7
Carers Emergency Card	8
Respite & Carers Breaks	8
Information, Advice and Advocacy for Carers	10
Alternative Carers' Services	11
3 Current service providers	11
4 Key Findings	11
List of respondents (organisations) - Appendix A	14
List of Stakeholder event attendees – Appendix B	15
Current Service Providers – Appendix C	16

1 BACKGROUND

This document presents a summary of the responses of the Adult Carers Support & Services consultation and the key findings.

The consultation was issued on 19 November 2012 with responses required by 8 February 2013. Written responses were received from 25 carers and 9 organisations (listed at Appendix A).

Feedback was also received from 20 carers who met with the Carers Policy & Development Officer. A stakeholder event was also held and attendees are listed at Appendix B.

The consultation document focussed on specific areas that Cardiff Council Adult Services felt needed to be reviewed or improved on, based on feedback from carers taken from previous consultations, surveys etc.

For the purposes of this document, responses have been summarised. In some cases, the responses did not relate to the question and therefore may not have been included or have been placed in the relevant sections.

2 SUMMARY OF RESPONSES

The following is a summary of responses received from both carers and from professionals on behalf of organisations. Responses have been taken from the consultation response forms, carers who met with the Carers Policy & Development Officer and the stakeholder event.

Responses have been set out to reflect the layout of the consultation response form.

Section 3.1 - Entitlement and Access to a Carers' Assessment

Q1 Do you agree that a carers assessment should be open to anyone who is identified as providing a caring role in some capacity?

21 carers agreed with this proposal. One carer felt there should be boundaries to ensure that resources were preserved for carers with more onerous caring roles.

Of the 6 professionals who commented, 5 agreed to the proposal. One disagreed and thought it should be expanded to include people who care on a voluntary basis.

From the feedback received entitlement is not necessarily the issue that needs addressing at this stage. Lack of awareness or understanding of Carers Assessments is priority. Some carers have been refused access at the point of enquiry, or through problems with allocating a carer to a team.

Q2 What do you think about having a form so carers can request a carers' assessment via the internet?

On analysing the comments, it highlighted that a number of respondents misunderstood this question and thought it was suggesting completing the Carers Assessment via internet.

However, the comments do show a lack of support for completing a Carers Assessment on-line if that was being considered as an option.

Seven of the 13 carers who responded to the question agreed with the proposal. On the whole, carers wanted to see this as an option and not the only way to make a request. Two carers suggested having copies made available at places such as GP surgeries.

4 of the 5 professionals who commented were in agreement to this proposal, but only as an option.

Q3 Are you aware of any other good or innovative practice that we should be looking at in this area?

- Carers should be contacted at regular intervals if they are refused a Carers Assessment to see if their situation had changed, and not expect the carer to keep contacting social services.
- This is an area where a 'one stop shop' would be helpful.
- Use social media such as Facebook.
- Third sector organisations should be better briefed on Carers Assessments.
- Get Health more involved.
- Refusal at enquiry stage needs to stop.
- Timing of the offer. Carer has overload at beginning of caring role and sometimes an offer at this point is not appropriate.
- Importance of the Carers Assessment needs to be highlighted.
- Literacy and comprehension issues, especially for BME carers, must be considered.
- Term "assessment" is off-putting – perhaps include "needs" in title.
- Need more positivity from professionals.

Section 3.2 - Completing a Carers Assessment

Q1 Do you agree that it would be helpful to have the option of a carers self assessment for those who prefer to complete it themselves?

Of the 22 carers who commented, most were not in full agreement, but thought it was ok to have choice. However, a large number emphasised that this should be a choice and not a way of social service staff reducing their workloads. There were a smaller number who felt that it was not a good option at all mostly because human contact and face to face meetings are considered more beneficial.

Carers at the meetings were more in favour of having someone complete the Carers Assessment with them and not self-assessment. They felt that you need a professional who knows how to complete the assessment and what services may be available.

Six professionals commented. One was in agreement of self-assessments, while 2 were opposed. Three organisations stated that they were in agreement but only as an option and that it must be followed up with a professional.

In the stakeholder event the idea of self-assessments were clearly unpopular. On the whole they agree that a professional with relevant expertise should help with the completion.

The practice of social services sending out Carers Assessments to carers, who then don't complete them was discussed and considered bad practice.

Professionals raised the issue of trust and suggested carers do not want to get social services involved. However, this was not raised as an issue with carers.

Q2 What are your views on providing the option of completing or discussing carers assessments by telephone with social services?

Eight carers thought this could work, again only as an option and only if it was the carer's choice.

Carers at the meetings weren't in favour but agreed it might work for some. They had concerns that both parties could be distracted and importance was taken away from the carers assessment.

This was not seen as a positive change with the majority of professionals.

Q3 Are you aware of any other good or innovative practice that we should be looking at in this area? In particular, good practice around carers from Black and Minority Ethnic communities, and carers who cannot access social services during normal working hours.

- Use of interpreters for Black and Minority Ethnic carers.
- Option of completing a Carers Assessment with a professional outside normal office hours.
- Practice needs to be standardised so it won't matter which social worker completes the Carers Assessment.
- Don't complete it in front of the cared for person.
- Currently the Carers Assessment is too long. Make it a quick, basic format – don't go into detail that won't be used and dredge up emotions unnecessarily.
- Carers Assessment must be followed up and not go into a 'black hole'.
- If possible, use 3rd sector organisations to complete the Carers Assessments.

Section 4.1 - Eligibility criteria for carers to access services

Q1 What do you think of the proposal to put in place eligibility criteria to provide equity for all carers?

The majority of carers were in favour of this as long as it led to equity and was not a way to save costs.

Professionals for the most part, also agreed that eligibility criteria is a good idea, if used for the intention of providing equity and not to cut services.

However, a couple felt that regardless of the criteria put in place, there will always be an element of subjectivity.

There were stronger views shared at the stakeholder event with one group describing this as “sneaky and weasley”. On a positive note, some felt that at least it was a benchmarking tool and a framework for social workers to work to. Issues of subjectivity were also raised.

Q2 Do you think the eligibility criteria set out by the Department of Health is suitable?

Some carers did not feel able to comment on this. Those that did, the majority thought they were suitable. One issue that was raised was that the eligibility criteria focused on illness and physical caring, and this is a concern for carers of people with mental health issues.

Those professionals who responded to this question were split evenly. Some felt it was comprehensive and a good approach, while others felt it was too subjective and open to interpretation.

At the stakeholder event it was generally felt that the criteria was still open to subjectivity and should have more of a carer focus.

Q3 Are you aware of any other good or innovative practice that we should be looking at in this area?

Comments related to how to support carers and not eligibility criteria and therefore are not included in this section, but have been included in other sections.

Section 4.2 - Charging for services

Q1 What are your views on providing free short breaks to carers who meet eligibility criteria?

A large proportion of carers agreed with this option but there were also some concerns raised around sustainability and cost.

On the whole carers felt that breaks for carers are an excellent idea and if there is a way of providing some level of free breaks, this should be considered.

Generally professionals stated it was a good idea, dependant on what the eligibility criteria would be. Two organisations felt that it should be available to all carers, regardless of eligibility.

Q2 What are your views on the definition that is proposed to define a break for a carer?

On the whole carers agreed with the definition. Two carers felt that a break for them meant they must be away from the person they care for. One carer wanted to know what was meant by 'short break'. One carer suggested that "has made a choice to" is deleted as carers do not necessarily choose to be carers.

For carers at the meetings respite meant different things and for some included being with the person they cared for. They also stated that having the person they care for engaged in activities was a break for them.

Professionals had similar views, with 2 stating that a break has to mean away from the cared for person and/or residential care.

Q3 Do you agree with the proposal that the level of breaks should be determined by the assessed needs of both the carer and cared for person?

The majority of carers agreed with this proposal. Three were not in agreement and felt that the carer and cared for person should be considered separately.

Of the 6 professionals that commented, 4 agreed, but with some caveats such as weighting in favour of the carer.

Q4 Are you aware of any other good or innovative practice that we should be looking at in this area?

Most suggestions were based around type of services and respite and not in response to charging or eligibility, and therefore have not been included in this section.

Section 4.3 - Direct Payments

Q1 Do you think Direct Payments are easily accessible for carers? What might we do to promote greater take up of Direct Payments?

It was clear from the consultation response forms and the carers meetings that carers did not know about Direct Payments, and those that did considered them too complicated to consider. At one meeting the carers stated that they had no idea Direct Payments existed until they saw the consultation document. No positive responses were received.

From the response forms, some professionals stated Direct Payments were accessible but not enough carers know about them. Others thought

differently and didn't feel they were accessible and are difficult for carers to understand and manage.

It was considered that promotion had to be much better with information more widely available. There was also concern that social care staff who were not keen on Direct Payments were discouraging carers.

Comments from the stakeholder event reiterated that Direct Payments are seen as complicated for both carers and professionals. There is also the difficulty of differentiating between a Direct Payment for a service user and for the carer.

Q2 Do you think there should be a way for carers to access small amounts of funding for one off items or support? Are you aware of any good practice or innovative ideas that could be considered?

On the whole carers agreed with just a couple of reservations, mostly around managing the system.

Most professionals were in favour of carers having access to this type of support for things such as white goods. One suggested that a third party should hold monies and order on behalf of carer or provide vouchers for major suppliers, when authorised by social services.

At the stakeholder event it was clear that this type of support would be useful, but the current practice of retrospective payments was of no use to carers, especially those on low incomes.

Section 4.4 – Carers Emergency Card

Q1 Do you agree with the proposal to open the Carers Emergency Card scheme to all carers, without the need for a Carers Assessment?

The majority of carers agreed with this proposal. Two had concerns about misuse and fraud. Another carer did not agree with the proposal, but stated that they were already registered on the scheme.

Professionals who commented agreed to this proposal, with one stating that it should not include formal carers such as foster carers and support workers.

Section 7 - Respite & Carers Breaks

Q1 Do you agree that current respite services funded through the carers budget should be reviewed to ensure equity across all client groups and that they continue to meet the needs of carers?

The majority of carers agreed that services should be reviewed with one carer stating respite should be more weighted to carers of people with mental health issues.

All professionals agreed that there should be equity. Concerns were raised about taking services off one group to support another or rationing services if funding was not increased. One stated that appropriate services should be provided for BME carers. One stated that it was important to review services to ensure that they continue to meet need.

Q2 What do you think about the 3 types of breaks indicated as the most requested by carers? Would you consider other types of breaks more appropriate?

At one carers meeting it was very clear what type of respite they feel is most appropriate as carers of people with mental health issues. They would prefer to have the person they care for involved in activities outside of the home as that would be far more beneficial for them both. As with all types of respite, the service has to be good quality and reliable. The most important factor is consistency as a level of trust must be built up between the cared for person and support worker.

Some responses raised the issue of lack of emergency care or ability to take breaks at short notice. One carer mentioned overnight stays.

Some carers weren't keen on 'sitting services' in the home. It's their home and they want to spend time there alone or to get on with others things around the house.

One professional was surprised overnight stays were not considered a priority and another felt it didn't show the whole picture.

One organisation felt that if the 3 types of respite mentioned are what is most frequently requested, then funding should focus on that. One organisation suggested week long breaks for the carer with the cared for being looked after in their own home.

From both carers and professionals it is clear that any respite should be a valuable and enjoyable break for the cared for person.

A few professionals and some carers felt that the carer and cared for do not necessarily have to be separated but have support to go out together.

For one respondent it was felt that the 3 types would not adequately meet the needs of carers and more bespoke services were needed.

Q3 What do you think of the current provision of emergency breaks, and how can this be improved?

It was clear from all carers responses that they had no knowledge of emergency break provision.

Professionals were also unaware of provision of emergency breaks. One stated that planning of respite needs to improve and that may even lead to reduction in crisis. One organisation is currently looking to develop a marketplace for respite similar to a 'travel agent'.

8 - Information, Advice & Advocacy

Q1 What do you think about the idea of a 'one stop shop' for carers in Cardiff & the Vale of Glamorgan?

Of the 19 carers who commented, 17 agreed with this and thought it was a good idea. Two carers questioned the location and accessibility.

At the carers meetings, all carers were in favour of this idea, with some wanting somewhere where all information could be provided, and others wanting a more generic service and signposted onto specialists.

Most professionals had a very different response with only 2 saying it was a good idea outright. For the majority of the professionals it was the impact of funding for specialist services that was of most concern and lack of personal, expert service.

A few suggested looking at what is currently available and consider expansion, and not start up a new one-stop shop.

One organisation stated that research has found that one-stop shops are not cost effective and do not deliver.

Q2 What are your thoughts on the services this type of project could provide? Do you think the scope is too large or too limited?

Carers had a very mixed response relating to this question. Some carers thought it should be all encompassing, while others thought general information and advice and signposting to specialist services would be the best approach.

Information provision and telephone helpline seemed most important to carers.

Most of the professionals reiterated their comments based on the first question but not on the type of services that could be provided.

There seemed to be a presumption that funding of specialist services would be withdrawn and therefore the scope would be too large if specialist services no longer existed.

One organisation with the same concerns as others did suggest it was an idea to aspire to but should enhance and not undermine what was already available.

One organisation suggested up to date information on carers rights, information on the full range of respite options and how to access them could be available.

Section 9 - Alternative Carers Services

Q1 Has this consultation document captured the needs of carers accurately? If no, what would you consider the top 3 priorities for carers?

Most of the comments were around respite and information which had already been captured, and only two carers identified 3 priorities, which mainly related to process than services.

Feedback from the carers meetings stated cleaning and gardening as being useful to them. Gardening was also mentioned in 2 response forms and 2 mentioned advocacy services.

At 2 carers meetings, they felt that having somewhere to meet with other carers was important. At one meeting, training for carers was clearly important eg how to reduce risk of injury when moving someone.

Professionals mostly reiterated certain elements of the consultation document such as improved respite. Other suggestions were:

- The need for carers to meet each other to socialise, have peer support and share experiences.
- Transport to hospital and GP appointments.
- Reduced rate as Leisure Centres.
- Support with finances.

3 Current Service Providers

One objective of the consultation was to identify if the projects currently funded through the carers budget met carers requests and needs. A list of the current projects are at Appendix C.

The majority of those that are funded do meet the needs of carers. These are predominantly carers breaks, welfare and benefits advice, advocacy and gardening and should continue with some agreed changes. Most of the changes will be to ensure that carers of all client groups are able to access the majority of these services and this will be discussed with each organisation separately.

4 Key Findings

- Barriers still remain when carers try to access Carers Assessments. There is some inconsistency with professionals when informing, explaining or offering the Carers Assessment. Some of the biggest

issues seem to be met by those who care for people with mental health issues or autism.

- Carers and professionals feel that the Carers Assessment is essential to support carers but that the current form needs to be simpler, less bureaucratic and intrusive. It was clear that it is important for carers to be supported to complete the Carers Assessment and not leave the form for them to complete alone.
- There has been a significant improvement in partnership working with Health because of the Carers Strategies (Wales) Measure. However, more work needs to be done, especially within primary care. Lack of information and support remains to be a problem that needs addressing with GP surgeries.
- The issue of eligibility showed that as long as it is well thought out and used for the purpose of ensuring equity amongst carers and consistency between professionals, it was considered a positive move. However, comments suggested that eligibility should not be used as a way of reducing or removing services.
- Consideration should be given to some provision of limited free breaks, but it needs to be sustainable given the current economic climate.
- Carers' awareness of Direct Payments was very low. The process for Direct Payments is seen as overly complicated and bureaucratic by professionals. There seems to be frustration that carers are not able to have Direct Payments for respite, but until legislation is changed, this is something outside the control of local authorities.
- The idea of extending the Carers Emergency Card to carers without the need of a Carers Assessment was popular.
- Although not a part of the consultation, confidentiality was raised on a number of occasions, especially by carers of people with mental health issues. Carers feel that professionals hide behind confidentiality as a reason to not share information with the carer, or listen to the carer's views. Carers need to understand when and why it is not possible for information to be shared.
- Breaks for carers remain one of the biggest issues for carers. Carers and professionals still see respite as being inflexible, inconsistent and low quality. Although we only had feedback from a small number of carers, traditional type services no longer seem to be what is wanted. It was clear that sitting services are no longer popular as the carer wants to know that the person they care for is being engaged in activities either inside or outside the home.
- Emergency respite is an area of anxiety for carers. A large number of carers, especially older carers worry about what will happen if they are

no longer able to care, either short term or long term and they don't feel that these concerns are being taken into account.

- There was a clear difference of opinion on the idea of a 'one stop shop' for carers to access for general carer advice. Carers were mostly in favour of this type of support and wanted it literally to be one place where they could obtain all the information they needed without the need to go elsewhere. Whereas professionals did not agree with the concept as their main concern seemed to be an assumption that this would impact on specialist services and therefore provide a lesser service to carers in the longer term. There is no intention to cease specialist services in favour of any adoption of a one-stop shop, but hope that it will enhance them by signposting and increasing referrals.

List of respondents (written response)

Age Concern

Ategi Shared Lives Scheme

Cardiff & Vale Mental Health Forum

Carers Centre (including Ethnic Minorities project)

Hafal

Nexus

Parents Federation

Riverside Advice

Stroke Association

Stakeholder Event - Attendees

Fateha Ahmed	Carers Centre
Posy Akande	Carers UK Cardiff Branch
Sapna Bibi	Carers Centre
Sue Campbell	Age Concern
John Cushen	Parents Federation
Nicola Hale	Vale of Glamorgan Council
Phil Harding	Parents Federation
Sheila Harrison	Cardiff & Vale UHB
Allyson Hughes	Crossroads Care
Junaid Iqbal	Hafal
Barbara Kerridge	Riverside Advice
Sophie Lewis	Hafal
Margaret McLaughlin	Cardiff & Vale UHB
Judith Parry	Nexus
Kim Pena	Alzheimer's Society
Julia Preece	Carers Centre
Linda Pritchard	VCVS
Sue Schelewa	Cardiff Council
Debbie Shanahan	Riverside Advice
Paul Underwood	Stroke Association
Ian Weaver	British Red Cross
Gavin Williams	Hafal
Terri Williams	Stroke Association

Current Services funded through Cardiff Council

Provider	Description & Annual Funding
Age Concern	Specialist income advice for carers of older people with mental health conditions, including dementia - £17,832
Alzheimer's Society	<ul style="list-style-type: none"> • Dementia Support Project - £42,092 • 10 hourly sessions are provided to give carers a break while the person they care for with dementia is undertaking activities with a support worker - £10,271 • Time limited fortnightly sessions to give carers a break - £12,076
British Red Cross	Sitting service to give carers of older people or those with physical disability a break - £71,388
Cardiff Carers Branch	Support group for carers in Cardiff. They also have a monthly information stall at University Hospital of Wales - £1,000
Carers Centre	<ul style="list-style-type: none"> • Fortnightly community based service for carers from Black and Ethnic Minority communities - £15,000 • Support worker phones carers who have completed a Carers Assessment - £30,000 • Support workers provide advice and advocacy to carers from Black and Ethnic Minority communities - £44,000
Crossroads	Sitting service for carers of people with mental health conditions, including dementia and some emergency respite provision - £64,824
Hafal	<ul style="list-style-type: none"> • Advice and advocacy to carers of people with mental health conditions - £29,475 • A gardening services for carers of people with mental health conditions - £18,446 • Sitting service or community activities for people with mental health conditions to give their carers a break - £36,316
Riverside Advice	Advice and information to carers of people with mental health conditions. This includes benefits advice - £35,584
Stroke Association	Home visiting service which provides advice, information and emotional support to carers who care for someone who has recently had a stroke – £33,936