

COFNOD O BENDERFYNIAD WEDI'I DDIRPRWYO GAN SWYDDOG
RECORD OF DELEGATED OFFICER DECISION

Penderfyniad Allweddol | Key Decision ✓

Mae'r Penderfyniad Wedi'i Ddirprwyo hwn wedi'i bennu yn 'Benderfyniad Allweddol' gan ei fod yn debygol o:

This Delegated Decision has been established as a 'Key Decision' as it is likely:

a) arwain at y Cyngor yn ysgwyddo gwariant sylweddol neu wneud arbedion sylweddol; to result in the Council incurring expenditure which is, or the making of savings which are, significant; ☐

neu / or:

b) fod yn arwyddocaol o ran sut mae'n effeithio ar gymunedau sy'n byw neu'n gweithio mewn ardal sy'n cynnwys dwy etholaeth neu adran etholiadol neu ragor. to be significant in terms of its effects on Communities living or working in an area comprising two or more electoral wards. ☒

c) Eraill / Other:

PWNC | SUBJECT: PROPOSED NEW OFFER AND MODEL OF SUPPORT FOR UNPAID CARERS

DIBEN YR ADRODDIAD | PURPOSE OF THE REPORT:

The purpose of this report is to seek approval to consult on proposed changes to the current offer and model of support for unpaid carers across the County Borough.

PENDERFYNIAD WEDI'I DDIRPRWYO | DELEGATED DECISION:

It was **AGREED:**

1. To initiate an 8-week targeted consultation starting on 11th August 2025 on the proposed new offer and model of support for unpaid carers, as set out in Section 5 of the report; and
2. That a further report is considered by Cabinet detailing the outcome of the proposed targeted consultation prior to any final decision being made regarding proposed service changes.

Llofnod y Prif Swyddog

Chief Officer Signature



Neil Elliott

Director of Social Services

24th July 2025

Enw (priflythrennau)

Name (Print Name)

Swydd

Designation


Dyddiad

Date

Mae'r penderfyniad yn cael ei wneud yn unol ag Adran 15 o Ddeddf Llywodraeth Leol 2000 (Swyddogaethau'r Corff Gweithredol) ac yn y cylch gorchwyl sy wedi'i nodi yn Adran 5 o Ran 3 o Gyfansoddiad y Cyngor.

The decision is taken in accordance with Section 15 of the Local Government Act, 2000 (Executive Functions) and in the terms set out in Section 5 of Part 3 of the Council's Constitution.

YMGYNGHORI | CONSULTATION

	Councillor Gareth Caple Cabinet Member for Health and Social Care	24/07/25
LLOFNOD YR AELOD YMGYNGHOROL O'R CABINET CONSULTEE CABINET MEMBER SIGNATURE	ENW A SWYDD NAME AND DESIGNATION	DYDDIAD DATE

LLOFNODSWYDDOG YMGYNGHOROL CONSULTEE OFFICER SIGNATURE	ENW A SWYDD NAME AND DESIGNATION	DYDDIAD DATE

A FYDD Y PENDERFYNIAD YMA'N CAEL EFFAITH AR Y WARD?
WILL THIS DECISION HAVE AN IMPACT ON THE WARD?

BYDD | YES ✓ **NA FYDD | NO**

Unrhyw sylwadau pellach/Oes angen rhoi gwybod i'r Aelod Lleol: ✓
Any further comments/Need for Local Member to be informed:

RHEOLAU'R WEITHDREFN GALW-I-MEWN | CALL IN PROCEDURE RULES.

A YW'R PENDERFYNIAD YN UN BRYN A HEB FOD YN DESTUN PROSES GALW-I-MEWN GAN Y PWYLLGOR TROSOLWG A CHRAFFU?:

IS THE DECISION DEEMED URGENT AND NOT SUBJECT TO CALL-IN BY THE OVERVIEW AND SCRUTINY COMMITTEE:

YDY | YES

NAC YDY | NO ✓

Rheswm dros fod yn fater brys | Reason for Urgency:

Os yw'n cael ei ystyried yn fater brys - llofnod y Llywydd, y Dirprwy Lywydd neu Bennaeth y Gwasanaeth Cyflogedig yn cadarnhau cytundeb fod y penderfyniad arfaethedig yn rhesymol yn yr holl amgylchiadau iddo gael ei drin fel mater brys, yn unol â rheol gweithdrefn trosolwg a chraffu 17.2:

If deemed urgent - signature of Presiding Member or Deputy Presiding Member or Head of Paid Service confirming agreement that the proposed decision is reasonable in all the circumstances for it being treated as a matter of urgency, in accordance with the overview and scrutiny procedure rule 17.2:

.....
(Llywydd | Presiding Member)

.....
(Dyddiad | Date)

DS - Os yw hwn yn benderfyniad sy'n cael ei ail-ystyried yna does dim modd galw'r penderfyniad i mewn a bydd y penderfyniad yn dod i rym o'r dyddiad mae'r penderfyniad wedi'i lofnodi.

NB - If this is a reconsidered decision then the decision Cannot be Called In and the decision will take effect from the date the decision is signed.

DYDDIADAU CYHOEDDI A GWEITHREDU | PUBLICATION & IMPLEMENTATION DATES

CYHOEDDI | PUBLICATION

Cyhoeddi ar Wefan y Cyngor | Publication on the Council's Website:- ____28.07.25____

DYDDIAD | DATE

GWEITHREDU'R PENDERFYNIAD | IMPLEMENTATION OF THE DECISION

Nodwch: Fydd y penderfyniad hwn ddim yn dod i rym nac yn cael ei weithredu'n llawn nes cyn pen 3 diwrnod gwaith ar ôl ei gyhoeddi. Nod hyn yw ei alluogi i gael ei "Alw i Mewn" yn unol â Rheol 17.1, Rheolau Gweithdrefn Trosolwg a Chraffu.

Note: This decision will not come into force and may not be implemented until the expiry of 3 clear working days after its publication to enable it to be the subject to the Call-In Procedure in Rule 17.1 of the Overview and Scrutiny Procedure Rules.

Yn amodol ar y drefn "Galw i Mewn", caiff y penderfyniad ei roi ar waith ar:

Subject to Call In the implementation date will be:

____01.08.25____
DYDDIAD / DATE

WEDI'I GYMERADWYO I'W GYHOEDDI: | APPROVED FOR PUBLICATION :

Rhagor o wybodaeth | Further Information:

Cyfadrn Directorate:	Social Services
Enw'r Person Cyswllt Contact Name:	Beth May
Swydd Designation:	Head of Safeguarding, Care and Support
Rhif Ffôn Telephone Number:	07786523638



KEY OFFICER DELEGATED DECISION

RHONDDA CYNON TAF COUNTY BOROUGH COUNCIL

REPORT TO ACCOMPANY A DECISION OF THE OFFICER

24TH JULY 2025

PROPOSED NEW OFFER AND MODEL OF SUPPORT FOR UNPAID CARERS

AUTHOR(s): Beth May, Head of Safeguarding, Care and Support
Caroline O'Neill, Head of Arts, Culture and Libraries

1. PURPOSE OF THE REPORT

- 1.1 The purpose of this report is to seek approval to consult on proposed changes to the current offer and model of support for unpaid carers across the County Borough.

2. RECOMMENDATIONS

It is recommended that:

- 2.1 Agreement is given to initiate an 8-week targeted consultation starting on 11th August 2025 on the proposed new offer and model of support for unpaid carers, as set out in Section 5 of this report.
- 2.2 Subject to 2.1 above, that a further report is considered by Cabinet detailing the outcome of the proposed targeted consultation prior to any final decision being made regarding proposed service changes.

3. REASONS FOR RECOMMENDATIONS

- 3.1 The Council's existing non-statutory offer to unpaid carers consists primarily of the Carers Support Project (CSP), based in Pontypridd. Although well regarded by some unpaid carers, the Project supports only a minority of unpaid carers living in the Borough. The aim of the proposed model is to enhance the accessibility of Information and advice to unpaid carers across Rhondda Cynon Taf, and to provide an escalation pathway for those carers who require a statutory response from adult services.
- 3.2 Of the seven [Community Resilience Hubs](#) identified by the Council, there is a library at each, and an ever-evolving role for our libraries has been that of providing information, advice and assistance to the public. Libraries also provide a safe, inclusive and warm space for residents to attend and access services within their communities. The proposed model would further enhance the libraries role as a local provider of information, advice and assistance, that supports communities to be more resilient. This is also a step in creating a 'one front door' for our residents that can provide an improved public facing

Information, Advice and Assistance (IAA) Service, enabling the Council to use specialist staff in a smarter way.

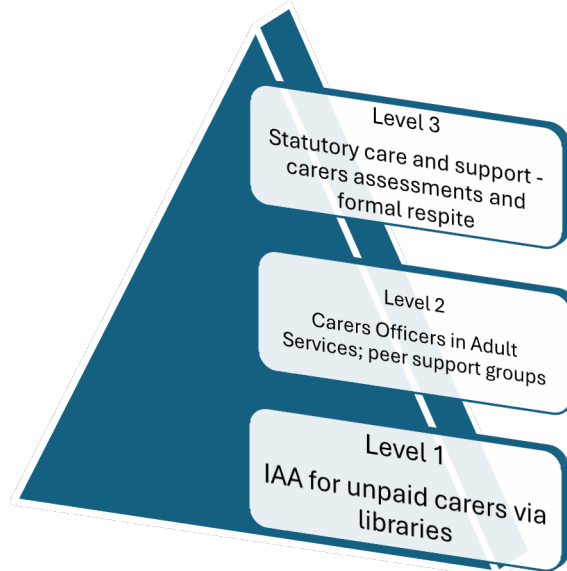
- 3.3 Proposals to make changes to the current offer and model of support for unpaid carers requires consultation to ensure that their views can be considered when a final decision is made.
- 3.4 A further report following the conclusion of the consultation, if agreed, is recommended to ensure that the Cabinet is fully informed of the outcome of the consultation, when it decides on the future of the Council's offer and model of support for unpaid carers.

4. BACKGROUND

- 4.1 Adult Services have worked alongside the Community Development Team (CDT) and Library Services to develop a proposed new offer and model of support for adult unpaid carer support, which is based on engagement work completed in 2021 and 2024, and the Adult Services Strategy which was agreed by Cabinet in September 2024.
- 4.2 The Social Services and Wellbeing (Wales) Act 2014 sets out the Council's responsibilities for improving the wellbeing of people who need care and support, and unpaid carers who need support, and for transforming social services in Wales. Statutory support for unpaid carers in terms of formal Carer Conversations (Carers Assessments) and formal respite support are facilitated via the Council's Social Work teams, whilst the Single Point of Access in Adult Services provides the statutory IAA function to unpaid carers, and others navigating the social care system.
- 4.3 For many years the CSP has formed the main part of the Council's non-statutory offer to unpaid carers. The small staff team delivers low-level open access support to unpaid carers in Rhondda Cynon Taf through a variety of activities, training, individual counselling and group support, as well as a quarterly newsletter. However, it is acknowledged that, whilst well regarded by some unpaid carers, the numbers that access the in-person sessions delivered by the CSP represents a minority of the registered unpaid carers.
- 4.4 Some insight into this disparity might be found in the outcomes of the engagement work, which sought the views of unpaid carers registered with the CSP, to understand what matters most to them. A copy of The engagement findings are included in Section 8 below and in Appendix 1 attached. The engagement identified that, whilst a small number of people benefit from the CSP, due to its location, the activities are not universally available for unpaid carers outside of Pontypridd.
- 4.5 The engagement also identified that the majority of unpaid carers require information and advice that is particularly relevant to what is available in their own local community. Whilst recognising a statutory carers assessment is of value, many unpaid carers expressed a need for something less formal at an earlier stage in their unpaid caring role.

5. OUR PROPOSED NEW OFFER AND MODEL OF SUPPORT FOR UNPAID CARERS

- 5.1 It is proposed the new offer and model of support for unpaid carers should have the following key elements as illustrated in the diagram below:



Level 1

- 5.2 There are two elements to Level 1 support:

Libraries

- 5.3 The Library Service will provide community space for Adult Services Officers to promote the CSP in locations across the Rhondda Cynon Taf and as well as being great places to meet people and borrow books they provide activities that may be of interest to carers including, for example:

- Knit and Natter groups.
- Reading Groups
- IT classes
- Welsh Classes
- Coffee mornings

- 5.4 The Council's libraries are often carer aware and this amendment would ensure that our libraries can provide targeted information and advice to unpaid carers, direct them to support within their community, and refer them where necessary to the Rhondda Cynon Taf Resident Support Pathway Partners via the online form [Resident Support | Rhondda Cynon Taf County Borough Council](#), where many offers of support are available from a variety of specialist services and third sector organisations. They will also have a direct referral route to Adult Services via the Level 2 Carers Officers if a statutory Carers Assessment is required, and

to the dedicated Peer Support Groups (see Level 2). Libraries will keep a directory of local support up to date and will need to be able to signpost people to national or local helplines relevant to their caring role for more specific support or a “listening ear”.

- 5.5 Libraries working in partnership with the CDT Community Coordinators and Resident Support Pathway Partners could offer further support including a non-statutory wellbeing assessment and food or fuel vouchers. Libraries will also through the Council’s At Home Library Service be able to extend this provision to people in the community who are unable to physically visit a static library.

CDT

- 5.6 The Council’s CDT Community Co-ordinators are present in the three Area Libraries once a week (Aberdare, Pontypridd and Treorchy). The Rhondda Cynon Taf Resident Support Pathway, mentioned in paragraph 5.4, continues to grow in relation to additional Community and Council Service Partners, and there are benefits for unpaid carers with regards to their inclusion. Under this proposal, this current commitment would continue.

Level 2

- 5.7 There are two elements to Level 2 support:
- 5.8 Specialist Officers within the Adult Services Short Term Intervention Service will be responsible for the provision of guidance and advice to social work teams and other professionals around good practice and effective statutory assessments for unpaid carers whilst also providing practical support to the Single Point of Access Team to progress requests directly from unpaid carers for information, advice and assistance.
- 5.9 In addition, peer support groups and other activities for unpaid carers, focused on enhancing and facilitating local opportunities will be facilitated. This support is likely to include peer support groups, practical training, workshops and activities that have been identified as valued by unpaid carers to support them in their caring role and to provide a life alongside caring. Our intention will be to involve unpaid carers in the commissioning of this support via a process of coproduction.

Level 3

- 5.10 This level of the model refers to the statutory services the Council is responsible for, including the formal Carer Conversation (Statutory Carers Assessment) and the provision of respite. This level of provision will be facilitated by the Council’s Social Work Teams for eligible unpaid carers.
- 5.11 The Council’s Adult Social Care Strategy (2024-2030) is centred around striving to make Rhondda Cynon Taf a great place for everyone, including those with care needs or unpaid carers. The proposed new offer and model of support aims to provide more widely available information and advice for unpaid carers in their

local communities and compliment the resources, networks and strengths people already have. It fits well with the aims of our Adult Services Strategy to move towards a model of care that:

- Encourages people to help themselves.
- Supports people when they need it.
- Supports people to live a good life.

5.12 By delivering more support for people to find solutions in their local community, the Council and Adult Services can focus on delivering direct support to people who need it whilst facilitating community support to intervene early and prevent escalation of need. The accessibility of information and advice could be significantly enhanced under the proposed new offer and model of support, with Adult Services resources focused on the statutory functions.

6. EQUALITY AND DIVERSITY IMPLICATIONS INCLUDING SOCIO ECONOMIC DUTY

6.1 There are no immediate Equality and Diversity/Socio-Economic Duty implications relating to the recommendations in this report.

6.2 An Equality Impact Assessment - pre-screening exercise has been completed with no negative impact identified at this stage and the indication is that this will be a positive development. However, it is recognised that a review of an existing service may affect a small number of unpaid carers and staff and so their contribution to the development of the model will be critical. The proposed engagement and consultation will be designed to ensure that unpaid carers and staff are able to engage effectively to ensure their voices are heard and influence the outcome. A copy of the pre-screening report is available on request

7. WELSH LANGUAGE IMPLICATIONS

7.1 A Welsh Language Impact Assessment has been completed, and the main findings are as follows:

- The policy emphasises a strength-based approach with people connecting with their communities and a focus on what matters to them which would include connecting to their cultural heritage and using their language of choice.
- This policy and the consultation will have a positive impact on the Welsh Language. Opportunities for the service to continue to promote the language and upskill Welsh speaking staff to participate in public engagement and Individual assessment will remain a priority.

7.2 Mwy Na Geiriau 2022 -2027 ('More than Just Words') is the Welsh Government's strategic framework for improving and promoting Welsh language services in health, social services and social care. The aim of the framework is to ensure that organisations recognise that language is an intrinsic part of people's care and the offer of Welsh language services to people is so important. Ensuring

positive well-being outcomes for individuals, is something which underpins the Social Services and Well Being (Wales) Act 2014. The Codes of Practice under the Act require local authorities to ensure Welsh language services are built into service planning and delivery and that services are offered in Welsh, to Welsh speakers, without them having to request it, as required by the 'Active Offer'.

8. CONSULTATION / INVOLVEMENT

8.1 The Council has engaged with unpaid carers regarding what is important to them in maintaining their caring role. This engagement has taken place over an extensive period, have been offered in different formats both face-to-face and virtually.

8.2 In 2021 we asked unpaid carers across Rhondda Cynon Taf and the wider region, as well as our staff, to tell us what mattered to them in their caring journey during an event in Pontypridd. The key findings from this engagement were:

- Knowing where to go to find suitable support
- Early support at the point of becoming an unpaid carer
- A single point of contact for all carer queries, offering specialist information and advice
- Having someone or somewhere to turn when feeling overwhelmed
- Knowledgeable social care staff who understand the role of an unpaid carer
- Assessments for unpaid carers that focus on them with clear outcomes
- Professionals using carer friendly language and terminology
- Practical support for unpaid carers
- Emotional, wellbeing and/or mental health support for unpaid carers
- Financial advice and support for unpaid carers
- Training/advice sessions for unpaid carers
- Accessing social, leisure, culture and fun activities and having a life outside caring
- Regular and flexible breaks from the caring role
- Peer support groups with other unpaid carers who understand the caring role
- Receiving regular news and updates in a newsletter for unpaid carers

8.3 In April 2024 a further consultation survey was issued with unpaid carers to check the findings from 2021 were still valid, and 6 engagement events at various locations across the borough were also facilitated for this purpose. Around 50 people attended the events and more than 250 people returned the survey. A summary report of the findings is attached as appendix 1. The key findings were:

- Knowing where to go to find suitable support.
- Wellbeing support and somewhere to turn when feeling overwhelmed.
- A point of contact for information and advice.
- Effective assessment by knowledgeable staff.
- Regular and flexible breaks from the caring role.
- Preventative and early support for unpaid carers.

- 8.4 It is proposed that a further and more targeted consultation exercise is now undertaken in respect of the proposed new offer and model of support for unpaid carer. This will consist of on-line and postal surveys and in person engagement events across the County Borough. A consultation document will be made available, in accessible formats, meeting Welsh language requirements.
- 8.5 A proportion of unpaid carers value the support they receive from the CSP. Changes to this offer, as a result of the review of the existing service, may cause disappointment for some people. It will be important to ensure that everyone is able to make a meaningful contribution to the outcome of the consultation to reflect a wide range of views.

9. FINANCIAL IMPLICATION(S)

- 9.1 The proposed new offer and model of support has been developed within the existing core budget attributed to the CSP and is anticipated to be cost neutral in the long term.

10. LEGAL IMPLICATIONS OR LEGISLATION CONSIDERED

- 10.1 The proposed new offer and model of support for unpaid carers has been developed in accordance with the Social Services and Wellbeing (Wales) Act 2014 as set out in this report.

11. LINKS TO THE COUNCILS CORPORATE PLAN / OTHER CORPORATE PRIORITIES/ SIP.

- 11.1 The proposed new offer and model of support for unpaid carers align with the Council's new corporate well-being objectives outlined in Working with Our Communities and in particular the people and Communities objective. Subject to approval, they will allow the Council to meet the requirements of the Social Services and Wellbeing (Wales) Act 2014 and the Wellbeing of Future Generations (Wales) Act 2015. They meet the needs of an ageing population, are more sustainable and support achievement of a healthier Wales and more equal Wales wellbeing goals and five ways of working.

12. CONCLUSIONS

- 12.1 The proposed new offer and model of support for unpaid carers sets out how we intend to extend the reach of existing funding to improve the support available to all unpaid carers and address some of the issues raised in our previous engagement activity.
- 12.2 The proposal also recognises the role of libraries in providing information, advice and assistance to residents within their communities, supporting their resilience and, furthermore, providing a step to creating a 'one front door' that can provide an improved public facing IAA Service, enabling the Council to use specialist staff in a smarter way.

Unpaid Carer Consultation 2024 Summary and Findings

Introduction

This document summarises the consultation themes of the Unpaid Carer Survey on 'What matters to Carers'.

In November 2017, WG made a commitment to unpaid carers and announced four priorities they wanted to achieve moving forward:

- Identifying and valuing unpaid carers
- Providing information, advice, and assistance.
- Supporting life alongside caring
- Supporting unpaid carers in education and the workplace

We have been working hard to achieve many of these priorities, however, we realise we still need to improve in some areas. Consultation and co-production has been at the heart of the changes so far, and as we move forward we will continue to involve as many unpaid carers as possible.

Previous consultations

The 2024 consultation developed the themes identified from consultation exercises conducted in 2019 and 2021, when unpaid carers spoke to us about what mattered to them. Key themes included:

- Availability of relevant information and advice, knowing where to go and having someone to help them navigate systems
- Feeling isolated and lonely, and needing to connect with others who understand the difficulties of caring
- Someone to talk to about problems, who can listen and understand
- Time to be themselves, time away from home, financial support for a break from caring

Methodology

The 2024 consultation process involved several methods, which included, on-line and paper surveys as well as face to face engagement events.

The approach used, and the range of views captured, provides unpaid carers to share their views. The overriding message is that all our unpaid carers are individuals. Although they share the challenges of caring, they are all experiencing a very different journey. What matters to them is that they are understood, they have support when they need it, and they can maximise their life outside caring.

The consultation was conducted by officers of the local authority. The consultation period ran between 1st April – 8th May.

The approach included the following activities:

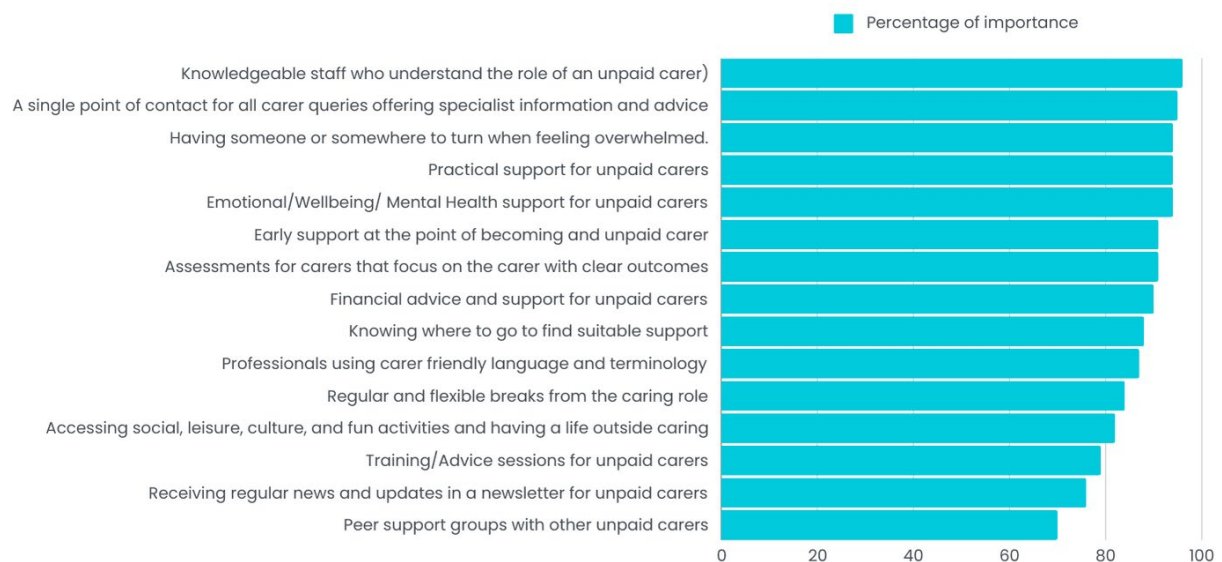
- A targeted survey for unpaid carers.
- 6 engagement events for unpaid carers at various times and locations throughout Rhondda Cynon Taf

The Council provided a variety of methods through which residents could complete the survey. The survey was available to complete on-line. However, to consider hard-to-reach groups, those having reduced or no access to the internet, and those who prefer to engage through traditional methods, an option to complete a paper survey was provided.

An option to complete the survey by telephone was available on request and was undertaken by members of the team. This option allows people to discuss their views in more depth.

50 unpaid carers attended the in-person consultation events. 269 unpaid carer surveys were completed.

The survey looked at a variety of factors to find out what is important to unpaid carers. The following have been ordered in order of importance:



The themes that were found from the survey and workshops can be identified below:

1. Information, Advice and Assistance:

Summary of themes from the comments provided include:

- Challenges in accessing support and services for both carers and individuals in need of care.
- Struggles with communication and coordination between different services and professionals.
- Importance of having a supportive and understanding network of individuals in the caregiving journey.
- Concerns about future planning and ensuring the safety and well-being of the cared for individual.

- Need for information, guidance, and resources to navigate the complex caregiving system effectively.
- Impact of financial pressures and lack of clarity on entitlements for carers.
- Recognition of the unique needs and individuality of both carers and those receiving care.
- Importance of peer support, respite care, and specialist training for caregivers.
- Frustrations with delays in accessing services, waiting lists, and lack of timely responses from support systems.
- Desire for improved communication, consistency, and transparency in the caregiving process.

Themes	Example Quotes	
Carer Support from Local Authority	Mental and Physical Disability support for carer and cared for	<i>To help support me as a carer and ease the unbearable pressure that I am constantly under, is for RCT to help and provide support for my son who suffers with serious mental health issues and has physical disabilities.</i>
	Recognition	<i>Being recognised professionally / local authority as being unpaid carer. Having support / discounts for being able to be unpaid carer.</i>
	Social Services Support	<i>Reablement Team RCT- did not find this supportive as they underestimated levels of difficulties – if model/approach doesn't work then limited what they can do.</i>
Carer's Support Project	Signposting	<i>Carers project is where we go for our information and advice</i>
	Offer of support	<i>If we have a problem, we would phone CSP – they would get us an answer</i>
	Carers news	<i>Carers news is a good resource and reassures that there is someone to contact if there is a query</i>
	Correspondence	<i>Better correspondence/more notice for events</i>
Point of Contact	Named Social Worker/Care Manager	<i>No named worker is emotionally draining</i>
	More regular Visits/contact	<i>A visit or phone call occasionally from Social Services to ask if I was still coping on my own. I have not been contacted since 2009.</i>
Knowing how and where to access support and opportunities	Where to access?	<i>Never know what support is out there and what it contains.</i> <i>How do you know where to go</i>
	Financial Advice & Support	<i>Financial info/support, leaving careers- us households are in poverty. Carers aren't sure what they are entitled to.</i> <i>Carer's allowance stops at 66 but caring doesn't stop. Carer's allowance needs to meet minimum wage.</i>
Accessibility of Information	Terminology	<i>Social worker terms put people off</i> <i>The terminology changes all the time-hard to keep up</i>
	Ease of access	<i>accessibility of information - e.g., people with dyslexia</i>

		<i>'Duty' system can be frustrating – repeated conversations especially in crisis.</i> <i>telephone contact is hard- menu of option.</i>
	Target Information	<i>Online info not accessible to everyone – need to target information for those who aren't computer literate.</i> <i>Computer literacy- digital sessions e.g., social media</i> <i>How to share information with people who aren't involved in groups</i>
	Need to publicize support routes	<i>Not easy finding out about benefits (everyone remembered GERDA)</i>
Lack of joint-up communication	Integrated systems	<i>Need an integrated system as its either mental health or learning disability</i>
	Joint professional/carer working	<i>Importance of school/family working together</i>
Peer Support	Other parents give more support than services.	<i>Peer support is important to carers.</i> <i>Other parents give more support than services.</i>
Future Planning	Future proof	<i>Contingency planning and future-proofing situation for cared for</i>
	Future planning for when a person can no longer care	<i>Its very worry about the future who or what will be available for our child when parents are not around (e.g. passed away).</i>
Carer Assessments	Waiting lists	<i>Waiting list for Carer's Assessments- only get one if at crisis</i>
	Knowledge of	<i>Not aware of Carer's Assessment</i> <i>Carers assessment not actively offered</i>

2. Assessments:

Summary of themes from the comments provided include:

- Challenges in accessing timely support and services- such as long waiting times for social workers and assessments, lack of active offer for carer assessments, and delays in receiving necessary aids and equipment.
- Lack of recognition and appreciation for unpaid carers- highlighting the need for valuing, appreciating, and supporting unpaid carers who play a crucial role in caregiving.
- Issues with the assessment process- including concerns about the timing of assessments, lack of feedback on assessment outcomes, and feeling like assessments are merely 'tick box' exercises.
- Communication and information accessibility- difficulties with information sharing, challenges with confidentiality, and issues with telephone contact and menu options for accessing services.

- Need for contingency planning and future-proofing-emphasising the importance of future planning, contingency measures, and respite care for both carers and the cared-for individuals.
- Terminology and terminology barriers- addressing concerns about terminology used in social work, which can be off-putting and hinder effective communication.
- Emotional and practical challenges faced by carers- such as dealing with emotional strain from lack of emotional support, frustrations with the assessment process, and feeling overwhelmed by caregiving responsibilities.
- Inconsistencies in care provision- confusion arising from discrepancies between care hours provided because of assessments and what is included in the care plan.

Themes		Example Quotes
Waiting Lists/Times	Social Worker visits	<i>Takes 2 years to get a social worker to visit</i>
	Annual reviews	<i>Yearly assessments – these are not happening.</i>
	Autism diagnoses	<i>Awaiting autism diagnosis as a carer – I can't get support or recognition until diagnosis.</i>
Future Planning and Contingency	Timings of assessment	<i>Timing of assessment offer is important.</i> <i>Timing of assessment offer is important.</i>
	Unmet needs	<i>Carers project really recognise our caring situations; assessments should do the same.</i> <i>There is no responsive process for meeting these.</i>
Caring Situations	Value of Unpaid Carers	<i>Felt like a 'tick box' – didn't really do anything for us – we 'cope' but that can change.</i>
	Inspections	<i>Inspecting the house-why?</i> <i>Questioning measures in place, mattress on floor locks etc chores</i>
	Refusal of support	<i>cared-for person won't accept support</i>

3. Services & Support:

Summary of themes from the comments provided include:

- Challenges and barriers in accessing services for individuals with autism and their caregivers.
- Lack of coordination and communication among different service providers.
- Emotional and mental health impact on caregivers.
- Uncertainty and fear regarding the future of support services.
- Need for consistent and integrated support systems for autism.
- Importance of peer support groups and community resources.

- Struggles with transitions, especially in terms of housing and care arrangements.
- Concerns about the diminishing availability and quality of services.
- Issues with care continuity, support during emergencies, and flexibility in care arrangements.
- Frustrations with processes and lack of clarity in care plans.
- Emotional toll on caregivers and the need for self-care and respite options.
- Appreciation for specific support services and professionals who have made a positive impact.
- Advocacy for more specialised workshops, talks, and counselling services.
- Feeling overwhelmed by the constant need to advocate and choose between different professionals.
- Worries about the future of care services and the well-being of both caregivers and care recipients.

Themes		Example Quotes
Knowing how and where to access services and support		<i>Knowing where to turn, didn't know who to turn to when I'm in hospital.</i>
Gap In Services	Adults with Autism	<i>Gap in services for adults with autism</i> <i>Services need to offer extra support for adults with autism instead of offering alternative options.</i>
	Links between services	<i>Link between Council departments.</i> <i>Noone speaks to each other – lack of links with services.</i>
Respite	Planning	<i>No planning is possible with respite – can't plan too far ahead but also need notice.</i>
	Consistency	<i>Respite makes it possible to carry on, but it needs to be booked and consistent (supports our mental health).</i>
	Preventative role of respite	<i>Respite needs to be a focus</i>
Carers Support Project	Uncertainty	<i>Have good family support and carers project support but the uncertainty of the future of the project scares me as this is our well needed time out and support.</i> <i>Upsetting to see CSP getting smaller and doing less – if we lose you, we have nothing.</i>
	Location	<i>Ponty is difficult to get to</i>
Support System	Importance of Support Groups	<i>Carer groups allow each other to offer support to each other</i> <i>A WhatsApp support group has been helpful</i>
	Family support network	<i>Feel unsupported as a carer as no family network- who do I rely on when I am unwell?</i>
Community Resources	Availability	<i>ALN sessions are not available or frequent enough e.g., swimming.</i>

	Day Centre	<i>There is a great demand for Day Centres for those in care which would help greatly the Carer and those being cared for. Activities and just a hot meal/Tea break/Bingo/Crafts one afternoon a week would help everyone's well-being and workloads. Part of being a carer is the guilt I have for not taking them out anywhere weekly other than appointments which of course are very demanding in their own way. I can't fault any of the help I have received so far but this is something I feel really needs investigating as it seems there used to be much more help regarding day centres years ago and those in care and their carers would really appreciate something like a Day centre. This gives the Carer some time out but also stimulates those in Care who are pretty housebound at the moment.</i>
Transition	Concerns around future	<i>Getting harder due to lack of care as cared for person gets older.</i> <i>Gets harder as older and care health deteriorates. Just because people turn 65 it does not mean they are no longer a carer.</i>
Service cutbacks	Worries about future and cutbacks to services	<i>Services are diminishing - day services -> less facilities, less activities. Replacing with PA's won't solve all this and brings issues of cost, resilience, continuity, availability.</i>
Continuity	Of carers/staff	<i>Continuity of workers & flexible arrangements for calls as they don't meet the needs of the individuals.</i>
Communication	Lack of communication	<i>Some services will mean more restrictions for us due to lack of consistency and communication.</i> <i>Communication needs to be improved across all services.</i>
	Jargon	<i>Communication can be poor & s/w using jargon. Families not clear what is on care plans/ options for them.</i>
Specialist Services/Support	Specialist Experts	<i>Talks from specialist experts, e.g., legal, wills, benefits.</i> <i>Specialist workshops are no longer as available as they were.</i>
	Dementia	<i>Lack of dementia nursing carer in RCT – had to go out of area (although it was a positive experience).</i>
	Mental Health	<i>Mental Health matters</i> <i>Counselling</i>
Direct Payments		<i>Direct Payments – PA for years – difficult to recruit</i>

4. A Life Outside Caring:

Summary of themes from the comments provided include:

- Challenges of balancing personal activities with care responsibilities
- Impact of inflexible care hours on personal freedom
- Struggles with planning and enjoying leisure activities.
- Emotional and physical exhaustion of caregiving
- Financial strain and managing family needs.
- Lack of support and services for carers
- Importance of social connections and community support
- Need for respite and breaks for carers' well-being.
- Identity and self-care struggles for carers
- Isolation and loneliness in the caregiving role
- Difficulty in seeking help and support.
- Impact of caring responsibilities on Health and Well-being
- Frustrations with system failures and lack of services
- Uncertainty and concerns about the future of caregiving

Themes		Example Quotes
Flexibility	Carer Hours	<i>The times of carers arriving does not suit meaning I can't get out to do my activities (hours to adhere)</i> <i>More freedom not being restricted by carers hours.</i>
	Employment	<i>Employment- no flexibility for carer friend roles even if they have the energy to look for work.</i> <i>Had disciplinary because of demands of caring role.</i>
	Events/Groups	Events/sessions need to offer time flexibility.
Planning in advance		<i>Can't plan my life outside care too far in advance e.g. watch motorsport or go to concerts</i>
Carers Support Project		<i>Enjoy meeting friends in carers support project.</i>

		<p><i>The only thing we have left is carers support project, we look forward to the newsletter.</i></p> <p><i>The trips and events provide peer support (respite, food, company, nice setting something I wouldn't do normally)</i></p>
Respite	Cancellations	<i>Respite can be planned but cancelled last minute for emergency – you could be holding out for that break as you're on your knees</i>
Carers Health	Physical and Emotional Wellbeing	<p><i>Unseen impact of caring -> sleep, own health, time for chores.</i></p> <p><i>Too physically exhausted (& emotionally) to have a life outside caring.</i></p> <p><i>Don't feel like I have lost my identity now that I am no longer a carer as I now have more time to take care of myself.</i></p>
	Isolation	<p><i>Carers are independent & don't like asking for support.</i></p> <p><i>It is very isolating.</i></p> <p><i>Loneliness is hard</i></p>
Breaks from Caring Roles	<i>Caring Commitments</i>	<i>Want opportunities to get outdoors, walks etc but no time due to caring commitments</i>
	opportunities to meet others in similar situation.	<i>The trips and events provide peer support (respite, food, company, nice setting something I wouldn't do normally)</i>
	Relief for carers	<i>Regular day sits to enable carer to have a life.</i>
Concerns about the future	-	<p><i>Cared for do not want to go into a home and its not their choice, so as their carers it puts pressure on them again as it not 'our culture' to give up and put them in a home.</i></p> <p><i>caring gets harder with age/ own health concerns.</i></p> <p><i>peace of mind that cared for will be adequately looked after and happy.</i></p>
Financial Situation		<i>Money is tight- it's difficult to manage needs of whole family including other children.</i>
Personalised support for Carers/individuals	Joint activities with cared for person	<p><i>Helpful when cared for could come on trips.</i></p> <p><i>not all have same interests.</i></p>