



Independent Review of Adult Social Care

Evidence and written submissions

People at the Centre – Open Call



Angus Carers Voice Network

Angus Carers Association

A company limited by guarantee and a charity

Registered Charity Number: SC 026052 Company Number: SC 212062

A poem written by unpaid carer in Angus which sums up why investing in unpaid carers is a national priority.

Just for one day

*Being a carer tough and hard
A different life I've never had
One of blessings and of joy
One of sadness and destroy
Helplessly trying to do your best
Strength and sorrow, a mighty test*

*On your knees and battling hard
Reaching out for something they've never had
Trying to give them all you can
Only to be stolen by the misinformed man
Fighting every basic need
In a world caught up in shameful greed
A care system that is caving in
Only love will conquer and seize a win*

*Snared in a trap, that's lost direction
What happened to love and mutual affection?
Barriers that are often all man made
Oh how I wish that they would all just fade
Shining bright are those that need us most
Humanity, love, they do not cost
You can't put a price on life and wellbeing
If only our politicians would all start agreeing
Why can't they see what we are all seeing?*

*At the heart of it all are the people no less
The ones that survive this shameful mess
Those who deserve so much more
They are the ones that pick you up off the floor
They are the loved ones that ensure you don't give up
Even when they're down on their luck*

*A developed county that's broken and bruised
Leaving people hurt, lonely, lost and confused
A right to life, health and well being
If only everyone could see what a Carer is seeing*

*Walk in my shoes just for one day
Then you will see cuts and reform don't pay
Lives shattered and relying on desperate hope
It is no wonder carers and the cared for just can't cope*

Let's make a stance now and stand up and fight Carers.....and those we care for - we all have a RIGHT

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Introduction

Angus Carers Voice Network (ACVN) is a network of unpaid carers in Angus, founded in 2016, who are registered with Angus Carers Centre. This is a generic carer's support service provided on behalf of Angus Health & Social Care Partnership.

(Please find more information on this network at the end of this submission).

ACVN considered putting together local engagement events, in the short 'consultation window' in response to the call out for their views. However, they concluded that the engagement work they have recently completed with local carers including; the development of Eligibility Criteria; the development of the Adult Care Support Plan and the Young Carers Statement; and the development of the Angus Carers Strategy 2019 – 2022, (see attachment) thus bringing together the voices of over 200 carers, aged over 18 living in Angus, would be representative.

Priorities

At most recent ACVNs' meeting in October & November 2020 carers highlighted the main areas they wanted to feed back to the Review Board

3) the second sentence under the barriers section could possibly be written to be more concise? (in decision in making)

Barriers to a Life Outside of Caring & Access to Short Breaks

Replacement Care

- Paid care workers should complete pre and post qualifying training which better values the job they do within agreed qualification frameworks.
- Paid care work should not be provided by companies who operate a 'for profit' business
- Paid care workers should have a remuneration package which is commensurate with the responsibility of their role.

Barriers to Carers having choice

Self-Directed Support

- The bureaucracy involved in accessing and maintaining SDS Budgets adds to carers stress and anxiety.
- The bureaucracy and inconstancy in decision making exacerbates carers stress and anxiety significantly. Different teams across the local authority interpret operational guidance inconsistently resulting in confusing and conflicting decisions on how SDS budgets, both for Supported People Budgets and Carers Budgets are made.

Quote form carer: "My feelings are that carers must be listened to when they are asked what would help you to continue in their caring role with regards to carers budget. Not told, their request isn't possible".

- Continued lack of clarity on what is included in "Waiving of Charges" for Carers and the lack of consistency of how statutory guidance is interpreted at a local level, is a source of frustration for carers, carer support staff and their colleagues who are trying to support them.

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- The way to resolve this is to completely retrain front-line, social care staff and management, all the way up to Strategic Planning Groups and IJB's and ensure outcomes based SDS is a major element of pre - qualifying training.

Information Sharing

Carers having to share the same information multiple times

- An independent national database of carer information should be developed, perhaps based on the NHS CHI (Community Health Index) number based on the principles of GDPR "Legitimate Interest" with input, managed, and controlled by, carers. This would ensure that it should always be current, and it would avoid carers having to fill in form after form, often on an annual basis for the same department particularly when the condition of the cared-for person is permanent, or when benefit names and allowances, or Government departments, change.
- This would also increase awareness/legitimise the role of unpaid carers within the wider health & social care system.

A National Care Service/National Care Standards

Right to Independent Appeal

- At present unpaid carers are the only population who do not have the legal right to an independent tribunal or access to an ombudsman in the event of a deadlock with their HSCP or Local Authority. This relates to the services and support provided for the person they care for as well as the support of their own caring role. This should be a core principle of National Care Standards.

Carers Conversations

Carers views gathered at 'Carers Conversations' events in 2018 and 2019 hosted by ACVN, supported by Angus Carers Strategic Partnership, have been used for responses to the "Experiences" & "Priorities" questions posed in the People at the Centre – Open Call.

Overall principles

It was agreed that the following principles which should be included in Carers Impact Assessments completed.

- All reports and policies, when planning & delivering services with Health & Social Care, should be checked for carer impact under the Equalities Act.
- Income Support for those who are not able to work because of caring role and GP support and understanding should be fundamental in Adult Social Care
- The rights of the person being cared and the rights of the carer need to consider together.
- Consistent and up to date information to meet the needs of both carer and cared for person should be available by phone.
- Employers need to recognise carers, allowing them to do their job, realising personal needs, and supporting them to keep them in employment by offering flexible working hours and making it safe for workers to talk about their caring responsibilities with their employer without feeling they will be punishment or disadvantaged for doing so.

This next section re-presents the conclusions of the work completed at our annual Carers Conversation events in 2018 & 2019, building on the agreed outcomes for carers in Angus and are provided as a response to the following questions in the Open Call:

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Experiences

What are your experiences and/ or of those you represent in accessing social care support?
 What are the things that work well currently for you or for the people you represent?
 What are the key barriers or issues?
 How do you/people want to access social care support?
 How do you/ people define person centred care in social care support?

Priorities

What are the things you would like to keep and that work well?
 What changes need to occur within social care?
 How do we make those changes?

Carers are recognised and supported as key partners in the planning and delivery of care.

1. Greater focus on quality of life and supporting carers to continue in their role.
2. Sympathetic assessment and timely action to meet physical and mental wellbeing.
3. Discharge from hospital; carers need to be a part of the conversation; communicating the diagnosis with the carer.
4. Easier access to advocacy
5. Carers should be recognised as a diverse population and the role suitably rewarded.
6. The future should be planned for earlier to avoid crises, there is a need to work ahead of time on the emergency plan.

Carer's needs are fully assessed, and ongoing support offered.

1. Greater focus on quality of life and supporting carers to continue in their role.
2. Sympathetic action as and when physical adaptations are needed.
3. Planning for the future for individuals and for the wider picture.
4. Emergency planning needs to include post bereavement support and what happens when the carer is ill.
5. Diversity of caring role – whose needs are we meeting – children and young people do not come under the Integrated Joint Board and there needs to be effective transitions put into place.
6. Caring for young; planning for the future, changing carer roles – can be caring for the elderly and young at the same time.
7. Opportunity to enhance support through adult support; a safety net provided (and groups like men's shed, University of the 3rd Age, etc. need to be encouraged to provide activities and wellbeing)
8. Discharge at hospital; carers need to be part of the conversation; diagnosis needs to be communicated with carers and families.
9. Regular reviews of assessments / support plans (with support offered if needed) and carer integral to process.

Carer's financial needs are addressed

1. Carers should be suitably recompensed for the extra expense and reduction in their income associated with their caring role
2. Planning for the future – for individuals and for the wider family prior to reaching crisis point
3. Information needs to be available and consistent
4. Caring for young people /adult children – planning for the future, changing role
5. Greater focus on quality of life and supporting carers to continue in their role

6 Young Adult carer's transitions into adult life should include information on benefits

Carers are supported to have a life outside caring

1. Greater focus on quality of life and supporting carers to continue in their role
2. Reframe the myth that a break from caring is a 'reward'! It is about wellbeing and allows the carer to continue in their caring role.
3. Respite from caring is something to look forward to. There needs to be a desire to provide it from those who design service
4. Lack of availability of suitable facilities for the cared for
5. Information needs to be clear and available to carers
- 6 . Registered carers need to access available services
- 7 Not only should information be available, but it should targeted to help those who do not identify themselves as a carer. (NB the National Carer Awareness Campaign starting in Nov 2020 is cited as an excellent response to this issue)
8. Carers need time away from caring role, social outings are necessary for mental and physical wellbeing
9. Carers need friends outside of the caring role and the carer's support service environment
10. Carers need time away from caring role out with paid work
11. Full time employees are entitled to 28 days paid leave annually – why not full time Carers?

Carers wellbeing and mental health is improved

1. Mental health of carers needs to be taken as seriously as the carer's physical health. This is still not happening.
2. It is vital to have Emergency Plans in place in order to relieve stress and worry for carer and cared for person.
3. Support for families to have more open conversations about the future and their wishes and aspirations
4. Need to have pro-active engagement with carers opposed to crisis management.
5. Employers need to be more supportive to carers to keep them in employment

What is Angus Carers Voice Network?

Meeting every 6 weeks, ACVN offers all carers in Angus a genuine opportunity to ensure that their voices are heard and that their views influence the ongoing strategic development of the Health & Social Care Partnership.

Driving adherence to best practice and transparency in care-practice, any Angus-based carer is welcome to come to the Angus Carers' Voice Network.

Why get involved in ACVN?

- ACVN influences local & national strategic and policy development of the Health & Social Care Partnership which affects carers
- ACVN assists in the design and delivery of workforce development plans in partnership with colleagues from statutory services
- ACVN ensures that all staff in the Health & Social Care Partnership are aware of the “Equal and Expert – 3 Best practice standards for Carer Engagement” developed by the Coalition of Carers
- ACVN ensures that all strategic activity and plans in the Health & Social Care Partnership evidence the “Equal and Expert – 3 Best practice standards for Carer Engagement” developed by the Coalition of Carers in their work
- ACVN ensures that the communities represented by carers are represented at relevant groups and meetings both locally and nationally.
- ACVN ensures that work produced by the Health & Social Care Partnership is developed through dialogue with communities of carers
- We always provide clear and concise information and feedback to carers as outlined in a Communication Plan, which includes a timetable and minute of all meetings
- Carers are recognised & supported as key partners in the planning & delivery of care. Through ACVN, Carers' needs are fully assessed before ongoing support is offered.