



Consultation on The Integration of Health and Social Care Messages from Carers - Summary Paper

Background to our Consultation Process

In partnership with Carers Scotland, the Coalition produced a briefing paper on the Government's proposals, which was circulated to carers and local carer organisations through our membership. In addition, we facilitated several consultation events with carers and stakeholders at both a national and local level.

At each of these consultation meetings the proposals were outlined and views from participants were sought on the implications of the proposals for carers.

These events included:

- A national meeting of our members on the 29th of February
- A joint meeting on the 26th of June with the Scottish Health Council and Highland Community Care Forum. This event brought together health and local authority practitioners and carers from across Scotland
- A local meeting of carers in Edinburgh on the 13th of August
- A local meeting of carers in Renfrewshire on the 24th of August
- A discussion group with our members on the 29th of August

At each of the meetings a series of questions were posed, both through open discussion, workshops and also through carers writing their views on message boards. The responses are detailed below:

1. Do you think the greater integration of health and social care services will lead to an improvement in the recognition and support of unpaid carers?

Yes a big improvement: 0%

A bit of an improvement:	33%
Things will stay the same	52%
Things will get worse:	14%

2. How will integrating health and social care change things for the better, or for the worse for unpaid carers?

- Great need to stop layer after layer of bureaucracy / ladder to climb when wanting help.
- Simplify processes, communication with carers to take part.
- Be open about what councils do with their budget.
- Changes are finance based and have little or nothing to do with quality provision for carers. The service user is left behind in all of this.
- If it is done properly it could make a huge difference – with a focus on early intervention rather than crisis management. However, partnerships must not be allowed to create new bloated management structures in order to save their own jobs.
- If integration embraces carers it should get better but it won't if it is an afterthought.
- It will only make things better if they listen to and implement carers issues whether integrated or separate health and social care.
- If you live in Glasgow I feel we will be left behind because of politics.
- Should be one door approach – one assessment.
- At the beginning I doubt the two bodies will be capable of integrating working practice. However, new staff brought up in the new ways might.
- If the powers that be listen to service users and carers and process the information this could lead to better services.
- Integrated services will lead to more people supported in their own homes which will require greater input from unpaid carers. They must be properly supported!
- Things should change for the better
- Hopefully for the better, by working with one another and alleviating stress on carers Working together towards the same outcomes should improve services, no doubling up
- It must not result in higher charging for services. Carers should not be charged for any services as they are providing a service. If charges increase, people will stop using services'

3. Should carers have a guaranteed place around the table in the new integrated structures?

YES 100%

NO 0%

- YES, YES, YES, YES, YES.
- YES, YES, YES.
- Yes and be recognised and treated as an expert.
- Consult before legislation.
- Good to talk but more important to be listened to.
- Decisions made behind closed door are no use or telling carers what is to be, after decisions are made.
- Edinburgh had a Strategic development Group for Carers which included carers, it has now disbanded. The new group is the Scottish Planning Group for Carers which has no seats for carers.
- Unpaid carers are saving the government millions why aren't they recognised for this.
- Listening to carers who are supposed to be 'equal' providing the care. Often they know the most practical solutions
- When carers sit on panels it tends to always be the same ones who may be confident speakers but don't always have the best things to say. Should consider use of advocacy services to give the views of other carers.
- Carers should have a guaranteed place but only if it a fully supported place so that it can be meaningful.
- Different types of carers (rural/mental health/learning disability/dementia/young carers etc) all have different experiences/ needs specific to them. A balance of 'types' of carers is needed on all consultation groups/committees.
- Carers are key partners in care!
- Carers are indispensable. I know – I am one.
- Use of independent advocates for carers to express the views of several 'types of carer at one meeting.
- Yes supported by Secondary legislation (Guidance, directions etc to NHS Boards and councils) The omission of carers in membership of Health and Social Care

Partnerships etc – if explained in terms of ‘not having caught up with CEL6’ – would demonstrate carers are not really being valued. Behavior reflects beliefs!

- This does happen in my region but some officers treat you as an individual and not as a representative.
- Carers being on commissioning and planning (strategic) groups either ‘on their own account’ or ‘as a representative’ is a key issue, but so too is the process of identifying and selecting a carer to fulfill the role. To often its simply down to who is ‘willing and able’ and this is often the ‘well kent face’.
- Carers should have a voting right at board level
- Carers often know more than the professionals and should be treated as such
- Carers need to be recognised, valued + heard
- Carers should have a guaranteed place around the table in the new integrated structure
- Must be carer rep in committee national as well as local

4. What are the barriers to integration working well and producing improvements in health and social care?

- Ignorance, bad attitudes, carers experiences being disregarded.
- Not taking carers seriously – Tokenism.
- The independent sector often provides what the NHS and local authorities don’t want. Usually it’s the staff that cost ‘too much’ It’s not a level playing field. Often it’s the independent provide that can provide integrated health and social care.
- Lack of training, loss of identity, loss of specialism, lack of knowledge as NHS takes a lead and stamps over social work, paranoia over stats, rather than qualifying quality service provision for carers.
- I think that there is a danger that as the paid workers jostle for recognition of their role, the role of carers may be overlooked.
- Ignorance of the consequences of caring for someone leads to carers becoming service users – anxiety, stress, depression, lack of resources.
- Workers are bogged down with change and recent loss of specialist identity and carers needs are left behind.
- It is people not systems which will make or break integration.
- An attitude of mind.

- Communication pathways between health and social care must be clear and simple, especially between departments and specialist areas within both.
- Thoughtlessness on the part of statutory bodies.
- Too many patients/people are 'defaulting' to NHS continuing care eg/spinal injury and head injury. Patients who have completed specialist rehab and are medically stable, simply because statutory authorities can't fund care packages.
- Budgets – Managers not wanting to share in delegation of responsibility.
- Providers of services – talking down, not listening.
- Health and Social Work still looking after their own corners and no one looking after the cross over areas and grey areas in the middle.
- Neither one taking a holistic view of an individual
- Budgets are the barriers. Each organisation wanting to hold in to their own budget and not wishing to share.
- The detail of services needs to be regarded with the highest importance. The outcome for carers support has to include the efficiency and effectiveness of services from a carers perspective
- Too much bureaucracy
- Aimed at older people, lack of focus on learning disabilities etc – others could lose out
- If Social Work and Health are joined; will it lead to more bureaucracy, fighting amongst each other?
- Will this result in job losses at a time when we need more?
- Could be conflict due to resistance to change information, communication must be bottom-up

5. What contributes to services working better together?

- Constructive dialogue, lack of suspicion.
- Carers must have rights. The right to be listened to, the right for good services, the right for help.
- A genuine understanding of each others roles and responsibilities, including carers. To work this needs to be invested in.
- Communication.
- Willingness of doctors/nurses to engage fully with families/carers of patients and work on collaboration with carer's groups.

- The right people in the right jobs should not be lost – keep what is already good.
- Trust, openness and mutual respect for other people's issues. But beware that integration sets up new barriers somewhere else.
- There is frustration about over/underspend of NHS/LA budgets and how these are distributed as a result. Underspend doesn't necessarily mean lack of need for services, often lack of awareness.
- Please find a way to get G.P's involved directly, not Practice Managers who don't pass things on.
- Need consultations to be done locally and specific carer consultation events
- Open and honest dialogue.
- Outcomes for carers are: To be recognised as an important component to after/long-term care. To be able to get services when needed.
- Money – budgets for carers must be ring fenced. Monitoring is a must for any new developments to social care.
- It would (lead to improvement) if service managers support it and make it happen.
- If important carer pathways are identified early within new structures.
- There should be a better understanding of needs of carers, more equality of funding
- Listening, communicating and taking on board the needs of care in the community and providing a good service
- Carers must be respected as equal partners – legality and parity
- Improve G.P /Community nurse focus on carers
- Both NHS and social work services need major culture shifts to make integration work
- Needs to be a joined up I.T system inclusive of all services to improve information sharing
- Making and strengthening - outcomes all carers being involved

6. The government is asking 'How can you help us make it work?' What can carers and local carer organisations do to help achieve better integration between the different sectors?

- Help to facilitate carer awareness training for all professionals who come into contact with carers.

- Why do we always look to creating incentives for GPs within their contracts to endure their participation? We could instead impose financial penalties if they fail to demonstrate participation.
- For it to be make clear to professionals that carers are equal partners.
- On the closure of hospitals or wards – the staff released must be fully trained for local community work. I believe that hospital and community nurses are on different wavelengths.
- As a unpaid carer I provide over 138 hours of free care a week. What else am I expected to do.
- Basically the movement of carer from hospital to the community means that information from the hospital and G.P must be perfect and complete.
- For carer involvement to work at all in an integrated structure there has to be a basis of supported, informed carers contributing to local support organisations, which in turn feed into higher level governance and decision making bodies. This is undermined when funding is withdrawn from carer organisations.
- GP practices have to be on board. GPs are the first port of call, or should be, for carers. They must be pulled into the system.
- Monitoring of services is key.
- Carer representatives should be limited to 4 years, to ensure other views are heard.
- Everyone on planning and commissioning groups need to be empowered to take decisions. It is not just carers who currently lack decision-making authority. Often the real decision makers sit behind the scenes where the real decisions are taken.
- Day care centres play a vital part for carers, respite care and well run agency care services
- It is vital that 24hour a day carers have a voice in helping to make change
- Looking better at the circumstances of individuals (Edinburgh Care 4 Carers)
- Communication with various groups. Important that they all reach the same conclusions

Submission to the consultation on the Integration of Adult Health and Social Care in Scotland

We write on behalf of the Coalition of Carers in Scotland in response to the consultation on the government's proposals for the integration of Adult Health and Social Care Services.

1. Information on the Coalition of Carers in Scotland

1.1 The Coalition was established in 1998 and represents over 80 local carer organisations . Through our members we reach and inform over 60,000 carers in Scotland.

2. Background Information

2.2 There are over 660,000 unpaid carers in Scotland¹ who save the government £10.3 billion pounds every year, equivalent to more than three quarters of the entire budget of NHS Scotland². Of these, 115,000 care full time, without pay, for over 50 hours a week – roughly equivalent to Scotland's total paid care workforce³. With our increasingly ageing population, the number of unpaid carers is set to grow, with society becoming ever more dependent on their contribution to health and social care delivery.

2.2 With the current move towards shifting the balance of care to care at home, family members, relatives and friends will play an increasingly central role in the care and treatment of people who are frail or live with long term conditions, illnesses and disabilities. Unpaid carers are the primary providers of personal and social care in Scotland, with more unpaid carers providing support than the entire health and social care workforce combined. The government's proposals to further integrate health and

¹ Scottish Household Survey 2007/2008

² Valuing Carers, Carers UK. 2011

³ Census 2001

social care needs to take account of the invaluable contribution carers make. A specific objective of Integration must be to strengthen support of unpaid carers, and their full participation in the new structures as equal and expert partners.

3. How we consulted on the proposals

3.1 In partnership with Carers Scotland, the Coalition produced a briefing paper on the proposals which was circulated to carers and local carer organisations through our membership. In addition, we facilitated several consultation events with carers and stakeholders at both a national and local level.

3.2 At each of these consultation meetings the proposals were outlined and views from participants were sought on the implications of the proposals for carers. The key messages from these events have been summarised and included as a separate report with this submission. We have also analysed the responses and used these in developing key recommendations relating to the development and implementation of the government's plans for integration.

4. Positive Outcomes leading from Integration

4.1 Carers and other stakeholders generally had many positive things to say about a move towards more integrated services. Most expressed the view that, provided the proposals are implemented successfully and achieve their vision, they have the potential to bring about the following positive outcomes for carers and the people they care for:

- More resources directed towards preventative community services
- People able to live independently at home with support for longer
- Better recognition and services for unpaid carers
- Better communication and shared outcomes between health and social care
- Increased role for the voluntary sector
- Potential for better engagement with carers in relation to decision making
- A better experience for service users and carers at critical times, such as hospital discharge.

5. Negative Outcomes leading from Integration

5.1 Carers also identified the potential for negative outcomes leading from integration which would be likely to impact on their caring role and could potentially make things worse, rather than better for them and the people they care for. These included:

- Shifting the balance of care leading to a greater burden on carers.
- Less investment in acute services leading to problems at times of crisis.
- A step back in terms of carer engagement with a failure to recognise carers as equal partners in care and a failure to include carers at the highest level of decision making within the new structures.
- Re-organisation taking the focus away from frontline services, resulting in carers needs being left behind
- The new structures being equally bureaucratic, with resources being wasted in setting them up thereby widening the gap between policy and the reality of carers' lives

6. Key Recommendations

6.1 While carers were on the whole positive towards the proposals many of their criticisms focused on the design of the new structures, the delivery of services and the need for all key stakeholders to be fully engaged and to embrace the changes. The following recommendations were developed as a means of strengthening the proposals in these areas:

7. Ensuring carers are well supported

7.1 Many carers expressed a concern that shifting the balance of care is effectively a shift from statutory care support, to unpaid family care. This already places a greater expectation and burden of care upon them – at the same time as resources are diminishing and eligibility criteria for community care support are tightened. Carers fear this situation will worsen:

‘Integrated services will lead to more people supported in their own homes which will require greater input from unpaid carers. They must be properly supported!’

7.2 *Caring Together* reflects the need for improved resources for carers centres:

‘The sustainability of these services and ability to cope with an increasing demand is an important issue, and one which should be addressed by funding provided, where possible, by local authorities, Health Boards and others’.

7.3 The outcome of integration must be a shift of the balance of resources, not just the balance of care, to support the sustainability and growth of core services and support, not just a proliferation of new projects and pilots.

7.4 In order to protect carers health and wellbeing and to ensure carers receive appropriate, preventative and personalised support, more resources must be directed to direct and person-centred services for carer.

7.5 A major threat of integration and merger of budgets and remits is that little of the benefit will be felt at the frontline of carer support. For Integration to deliver improved outcomes for carers, the Scottish Government should set out a framework of criteria and standards for universally accessible, free local carer support in Scotland's integrated authorities.

7.6 In the context of demographic projections, such a framework must deliver a sustainable local infrastructure for early carer identification and preventative support for all of Scotland's geographical and identity communities.

Recommendations

1. As resources shift from acute services to services within a community setting, a proportion must be directed towards direct carer support, building on the progress made through the allocation of 20% of the Change Fund to supporting carers in their caring role.
2. Parallel to the process of integration, the government should set out a future commitment and framework for improved universal carer support across all authorities.

8. Carer Engagement and Governance

8.1 Since 2002 carers have been recognised in legislation as 'key partners in providing care'⁴. The introduction of the term 'key partners' was to recognise carers as being different from the other partners in the care-giving system in respect to their status and contribution.

8.2 This was further strengthened in 2010 when carers were recognised for the first time as 'equal partners in care' in *Caring Together*, The Carers Strategy for Scotland. The introduction of the term 'equal partners' was to recognise that carers are

⁴ Community Care and Health (Scotland) Act

inherently disadvantaged within society by their caring role so require certain rights and entitlements to mitigate this.

“Carers are equal partners in the planning and delivery of care and support. There is a strong case on human rights, economic, efficiency and quality of care grounds for supporting carers. Without the valuable contribution of carers, the health and social care system would not be sustained.”⁵

8.3 While the central role carers play in the delivery of health and social care services has now been recognised in policy and legislation, this has not always translated into meaningful engagement with carers and their inclusion on key strategic planning groups.

8.4 To address this, in 2011 NHS Boards were required to strengthen carer engagement through the inclusion of carer representatives on Community Health Partnership committees.⁶

8.5 Many of the responses we received focused on the need to engage meaningfully with carers and to take their views into account:

‘Carers are key partners in care!’

‘Everyone on planning and commissioning groups need to be empowered to take decisions. It is not just carers who currently lack decision-making authority. Often the real decision makers sit behind the scenes where the real decisions are taken.’

8.6 At all our consultation events strong disappointment was expressed at the omission of carers within the proposed integrated structures at committee level. This was seen as a failure to include carers as equal partners and a backward step from recent advances in carer engagement through CEL6.

8.7 There is a pressing need to ensure carer engagement is embedded in the new emerging structures and that engagement is meaningful and has an impact for carers. We therefore recommend the following in relation to carer engagement;

Recommendations

⁵ Shona Robison MSP, Minister for Public Health, 26th July 2010

⁶ Reference: CEL 6, 2011

1. Carers are included in the new integrated structures at partnership committee level and key partners, including carers, service users and third sector representatives have voting rights.
2. The new partnerships adopt the Best Practice Standards for Carer Engagement⁷ to ensure engagement is meaningful, reflects the principles of co-production and has a measurable positive impact for carers.
3. The Jointly Accountable Officer should have a duty to consult with carers in relation to the monitoring of activities.

9. The Need for Clear Guidance and Transparent Systems

9.1 Many of the concerns around the proposals related to its implementation and the need for clear, simple and transparent systems. There were fears that current institutions and systems would be replaced with equally complicated and bureaucratic structures. The purpose must be to simplify systems and forge better methods of communication, involving all key stakeholders:

‘Communication pathways between health and social care must be clear and simple, especially between departments and specialist areas within both.’

Recommendations

1. Clear guidance must be developed to ensure all partners understand their individual and collective roles and are working to a set of guiding principles based on Human Rights (this recommendation also reflects those set out by the Long Term Conditions Alliance)
2. A carer pathway must be established to ensure that carers are recognised and supported in the new integrated structures. This should be outlined in the guidance.

10. Culture Change within organisations

10.1 Carers identified one of the main barriers to successful integration as the reluctance of workers to embrace the changes and adapt to a different way of working. They feared that workers will be resistant to working in different settings, or aligning themselves with other organisations and this will derail the integration process:

⁷ The Best Practice Standards for Carer Engagement have been produced by The Coalition of Carers in Scotland (August 2012)

'It is people not systems which will make or break integration.'

'I think that there is a danger that as the paid workers jostle for recognition of their role, the role of carers may be overlooked.'

10.2 It is essential that there is strong leadership from staff in all sectors and at all levels to drive the changes. The priority must be viewed as producing better outcomes for service users and carers, Scarce resources must not be wasted on the process of re-structuring and attempts to retain power bases.

11. More Personalised services and a greater role for the Third Sector

11.1 Several carers at our consultation events expressed their frustration at not being able to access appropriate support for the person they cared for. This was owing to various factors, such as the difficulty of accessing services in rural and remote areas, services being offered at the wrong times or in the wrong settings and a high turnover of staff and lack of training, causing additional stress. As a result some people refused support and others told us that lack of appropriate support had resulted in avoidable admissions to hospital or residential care.

11.2 If integration is to be successful at shifting the balance of care, there needs to be a greater emphasis on the development of preventative, personalised services within the community. This is not only an issue of resources, but of ensuring services are responsive to people's needs:

'If it is done properly it could make a huge difference – with a focus on early intervention rather than crisis management'

Recommendations

1. Carers, service users and the Third Sector must be involved in the development of Joint Commissioning Strategies
2. The Third Sector 's expertise in developing user and carer-led services and driving the personalisation agenda, must be recognised. They must be viewed as an equal partner within the new planning structures and must be properly resourced.

3. The specific challenges of building community capacity within rural and remote areas must be recognised and resourced. These include additional costs of transport and service provision and challenges around recruitment of staff.

12. A Joint Budget and Joint Outcomes

12.1 The success of integration is reliant on the sharing of resources and having a single vision and joint outcomes:

‘Budgets are the barriers. Each organisation wanting to hold in to their own budget and not wishing to share. ‘

‘Monitoring is a must for any new developments to social care’

12.2 The role of the Jointly Accountable Officer was felt to be key to this process. However wherever possible decisions on resource allocation should be made through a process of co-production with all partners, including carers.

12.3 The inclusion of a specific outcome for carers was welcomed. There needs to be a Performance Framework underpinning the outcomes approach, The continuation of existing outcomes and targets, such as HEAT Targets and Single Outcome Agreements was not seen as helpful as it will work against successful integration. All outcomes, targets and indicators should be joint, supporting a shared vision.

Recommendations

1. Joint outcomes need to be underpinned by a performance framework. All outcomes, targets and indicators should be shared.

13. Charging

13.1 Concerns were expressed by carers about how integration will affect charging for services and whether services which are currently provided by the health service at no cost will be subject to charges following integration:

‘It must not result in higher charging for services. Carers should not be charged for any services as they are providing a service. If charges increase, people will stop using services’

13.2 The Guidance on the Community Care and Health Act 2002:⁸ states:

“local authorities should recognise that carers are care-providers, and support of any kind which enables a carer to continue caring should be regarded as a resource enabling the carer to care, not as a service provided to the carer.”

Since carers are recognised as equal partners and care providers, any service supporting their caring role should be exempt from charges. Carers are often financially affected by charges for services provided to the person they care for, as these impact on family income. Furthermore, they often give up employment as a result of their caring role and it is essential that they are not further disadvantaged financially through direct charges for the services they require to enable them to continue to care.

Recommendations

1. The government must ensure, through legislation and clear guidance, that service users are not financially disadvantaged through increased charges, following integration
2. Carers must be recognised as equal partners and service providers and must be exempt from charges for any services supporting them in their caring role.

14. Summary of Recommendations

1. As resources shift from acute services to services within a community setting, a proportion must be directed towards direct carer support, building on the progress made through the allocation of 20% of the Change Fund to supporting carers in their caring role.
2. Parallel to the process of integration, the government should set out a future commitment and framework for improved universal carer support across all authorities
3. Carers are included in the new integrated structures at partnership committee level and key partners, including carers, service users and third sector representatives have voting rights.

⁸Circular No CCD 2/2003, New Statutory Rights for Carers

4. The new partnerships adopt the Best Practice Standards for Carer Engagement⁹ to ensure engagement is meaningful, reflects the principles of co-production and has a measurable positive impact for carers.
5. The Jointly Accountable Officer should have a duty to consult with carers in relation to the monitoring of activities.
6. Clear guidance must be developed to ensure all partners understand their individual and collective roles and are working to a set of guiding principles based on Human Rights (this recommendation also reflects those set out by the Long Term Conditions Alliance)
7. A carer pathway must be established to ensure that carers are recognised and supported in the new integrated structures. This should be outlined in the guidance.
8. Carers, service users and the Third Sector must be involved in the development of Joint Commissioning Strategies
9. The Third Sector 's expertise in developing user and carer-led services and driving the personalisation agenda, must be recognised. They must be viewed as an equal partner within the new planning structures and must be properly resourced.
10. The specific challenges of building community capacity within rural and remote areas must be recognised and resourced. These include additional costs of transport and service provision and challenges around recruitment of staff.
11. Joint outcomes need to be underpinned by a performance framework. All outcomes, targets and indicators should be shared.
12. The government must ensure, through legislation and clear guidance, that service users are not financially disadvantaged through increased charges, following integration
13. Carers must be recognised as equal partners and service providers and must be exempt from charges for any services supporting them in their caring role.

If you require any further information, supporting evidence or wish to consult with our members in relation to any of these issues, please don't hesitate to get in touch.

Yours sincerely

⁹ The Best Practice Standards for Carer Engagement have been produced by The Coalition of Carers in Scotland (August 2012)

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