The National Carer Organisations

The National Carer Organisations welcome the opportunity to provide evidence on Integration Authorities’ approach to engagement with stakeholders. We are pleased that the Health and Sport Committee are looking into this important issue.

In this submission we have focussed on how Integration Authorities have engaged with unpaid carers. In doing so we have drawn on evidence gathered from the Carers Collaborative project.

**Background**

The Carers Collaborative is a project facilitated by the Coalition of Carers in Scotland that seeks to

- Research the current landscape in relation to Carer Representation on Integration Joint Boards (IJBs)
- Develop and facilitate a forum for Carer Representatives on IJBs
- Make recommendations for future work in relation to ongoing support and training of Carer Representatives, and support for local Integration Authorities in relation our Equal and Expert Best Practice Standards for Carer Engagement.

The Collaborative ran events and research activities between March and October 2016, involving 38 Carer Reps from 27 local authority areas, leading to the report ‘Equal, Expert and Valued’. A copy of the report is included with this submission.

**Q1. How carers are involved with the Integration Authorities to influence decision making?**

Carer Reps have worked hard to be ‘representative’, but their visibility to other carers remains an issue. Some carers' centres support Carer Reps to represent local carer networks. Some areas struggle to engage carers, and most would like more carers in networks ‘underneath’ IJB board level. Where carers have been able to make contributions these appear to be valued (writing strategies, supporting consultations, improving governance, assisting inspections, contributing to commissioning etc.). It is important to note that strategic plans should reflect the issues which have been identified as priorities by Carers, not just carers’ responses to consultation on pre-determined issues.

**Examples of good practice**

| Some areas have good support structures to encourage different levels of involvement and coordination of carers’ views. Carers Reference Groups and Carers Voice Networks have been particularly helpful, as have pre-Board meetings with other public representatives. |
| These are often facilitated by Carer Centres or Third Sector Interfaces, but not always resourced by Integration Authorities. |

| ‘Carer forums’ can help ensure Carer Reps hear and represent the wider views of carers. Some IJBs raise Carer Representatives' profiles by including their photos, biographies and an IJB email address on their websites. |
| Some areas do not have good carer networks to connect carers at different levels. |

| Some areas are further ahead in ensuring carers are represented at Strategic Planning Groups ‘underneath’ the IJB and at a locality level and that there are good lines of communication between the different planning structures and the IJB |
| This work is still developing in some areas and carers are not fully involved at a strategic planning level and locality level |

**Q2. Involvement of carers in the preparation of strategic plans**

Carer Rep effectiveness appears to increase when they are included on Strategic Planning Groups, Carer Forums and IJB Agenda groups. Those with access to agenda-setting meetings report feeling more included and
productive. There are some good examples of IJBs being trained in Carer Awareness (e.g. Dumfries and Galloway, North Ayrshire). However across Scotland Carer Reps’ equality and expertise are still far from universally accepted.

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<th>Examples of good practice</th>
<th>Examples of practice to be improved</th>
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<td>Some IJBs are actively preparing for the Carers Act, for example discussing it at Board level; reviewing their Strategic Plans in readiness; scheduling development days on the Act; and asking Carer Reps to prepare Board papers or presentations on the Act.</td>
<td>Several IJBs have not discussed or begun preparing for the Carers Act.</td>
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<td>A small number of Strategic Plans use several indicators for National Health and Wellbeing Outcome 6, giving a rounded measure of carer outcomes. Some IJBs have worked with Carer Reps and carer centres to develop appropriate indicators.</td>
<td>Most areas use just the one indicator (“I feel supported to continue caring”).</td>
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**Q4. How have carers been involved with the work of the localities what involvement are they likely to have?**

The localities are at different stages of development. Some areas are further ahead and have carers represented at locality level. In other areas localities are still being established.

One of the current issues experienced by Integration Authorities is recruiting and supporting enough carer representatives to populate the IJB, strategic planning groups and localities. Local carer centres are often asked to identify and support carers to take on this role, but few areas provide sufficient resources to adequately reimburse carer representatives for the full costs of their involvement and to provide an adequate framework of support to ensure they can be effective in their role.

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<td>In some areas, carers are provided with travel expenses for attending meetings. In others, replacement care is provided for time spent in meetings.</td>
<td>Some areas do not provide travel expenses or replacement care. Where replacement care is provided, this does not cover time spent reading papers and preparing for meetings.</td>
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<td>Some IJBs identify a Carers’ Champion or lead officer who can work directly with Carer Reps and Carer Centres.</td>
<td>It is not always known who the local Carer Lead is, or what their role is.</td>
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<td>Carer Reps find IJB development sessions beneficial – some IJBs schedule these every other month, between formal Board meetings.</td>
<td>Some Carer Reps have received no induction or training.</td>
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In addition, many carers are put-off from becoming involved in strategic planning groups and localities because of the time-commitment and number of meetings. At a recent Carers Collaborative meeting one carer representative said she already had 40 meetings in her diary relating to her involvement in the work of the Integration Authority. All of this is provided on a voluntary basis.

**Q5. Has carer involvement had an impact on decision making?**

As part of the work of the Carers Collaborative we undertook scoping work between May and October 2016, sourcing and analysing the three most recently available sets of minutes from each IJB or shadow board (pre April 2016).

References to Carer Representatives’ inputs were used as indicators of the nature and level of carer
involvement in meetings and their impact on decision making (though this is a relatively crude measure, as carers commonly reported having more of a voice in other meetings and didn’t necessarily expect these to be recorded in IJB minutes). Each area’s Strategic Plan was also searched for references to unpaid carers. This was used as an indicator of the extent to which carers and carers’ outcomes had been identified and prioritised.

The findings show that at October 2016, 30 Strategic Plans were publicly available, 27 of which included outcomes for carers. 26 areas had made their meeting dates available, and 28 had published their minutes. Carers were referenced in the minutes of 17 IJBs.

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<th>Strategic Plans available</th>
<th>Carer outcomes included</th>
<th>Meeting minutes available</th>
<th># IJBs minuting references to carers</th>
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<tbody>
<tr>
<td>30 plans</td>
<td>27 plans</td>
<td>28 areas</td>
<td>17 IJBs. (Total number of mentions: 29)</td>
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We found that one of the barriers to carers having an impact on decision making is the way in which IJB meetings are conducted. There are some examples of good practice where meetings are felt to be inclusive and carers feel they are viewed as equal partners in decision making. Other carer reps report that they feel they are not able to contribute to meetings effectively, as communication is often poor, they do not have any influence over the agenda or content of the meetings and often the meetings are taken up by organisational issues.

**Examples of good practice**
- Meetings are made accessible to Carer Reps. For example, one rural area rotates its meetings around the region. Video links can help, but need careful planning and facilitation.
- Papers are made accessible by being provided in time to let carer prepare, in electronic and paper versions. In one area papers can be collected from a local access point. One IJB provides Carer Reps with I-pads. In some areas, Carer Reps receive confidential ‘green papers’ including financial information, which helps them fulfil their governance role.
- Carer Representatives are able to request agenda items and submit papers via Agenda Committees, SPG Chairs, IJB Committee Services, pre-Board meetings or under ‘Any Other Business’.

**Examples of practice to be improved**
- Barriers to involvement include long or unfocused meetings; jargon; meetings being conducted at high speed; and an emphasis on process.
- Papers are frequently lengthy and sent too late to allow Carer Reps to prepare. Several Carer Reps are not included in ‘green paper’ circulation.
- Several Carer Reps have no way to influence or contribute to agendas.

**Q6 What could be done to improve the communication from the IAs? & Q7 What could be done to ensure greater collaboration and engagement in the decision making process of Integration Authorities?**

We have developed five recommendations and 12 straightforward suggestions for improving carer involvement, all drawn from real life experience of what works for Carer Representatives across the country. Most of these recommendations would also improve the experience of other stakeholder groups who are experiencing the same issues.

**Include Carers’ Representatives in decision making**

1.1 **Find ways to involve carers in consultation and decision-making:** It is important to recognise the demands on carers’ time. Frequent or formal meetings can be a barrier to attracting or retaining carers. IJBs would benefit from sessions that enable carers to contribute more effectively, such as ideas exchanges. They should also consider ways to provide appropriate recognition and reward for Carer Reps.

1.2 **Include Carer Reps in different groups:** Ensure carers are represented on different groups within the wider structures of the Integration Authority, particularly groups that set agendas or agree decisions. Arrange
collective voice meetings for service user reps, service provider reps, Carer Reps, and third sector reps – before agenda deadline dates. If you don’t have one, establish a carers’ advisory group.

1. Increase awareness and profile
2.1 Raise profile of Carer Reps: Ensure that the Carer Rep’s identity and role are clearly signposted on relevant websites, with contact details so other carers can get in touch. Give Reps an email address so they don’t have to use their own. Business cards are a nice touch. Use locality groups to ensure carer issues are accessed and represented.

2.2 Raise IJB awareness of carers: Chairs, Chief Officers and other partnership staff can learn a lot about the impact of their decisions by attending carers’ centres and meetings. Making Carers Awareness Training available for all IJB members has also been a popular and effective way to do this.

2. Value and resource Carer Representatives
3.1 Value Carers Representatives and their contributions: Valuing Carer Reps can be as simple as inviting, minuting and acknowledging their contribution to meetings. The real test is then to listen, act and follow through.

3.2 Train and support Carer Representatives: Carer and User Representative training is essential to good involvement – and governance. Arrange regular training or development days for the whole IJB. Arrange inductions for new members, for example meetings with key officials. Supportive mentoring increases confidence.

3.3 Resource representation: Take steps to make sure Carer Representatives are not worse off as a result of contributing to the IJB’s work. Provide travel costs and replacement care for the time they spend carrying out their IJB duties.

3.4 Ensure Carer Representatives have a clear remit: Agree clear roles for and with Carer Representatives. Make sure everyone knows what is expected of them.

3. Share practice and learning
3.1 Share practice between IJBs: Arrange exchanges with other IJBs to improve each other’s practice. Support IJB Carer Reps to meet up to share ideas from different areas (it’s where everything in this report came from!).

4. Improve communication: Ask what Carer Reps need. Make sure your agendas and minutes are publicly available. Carers can be fantastic conduits for ‘bottom up’ and ‘top down’ communication when supported by the right networks and structures.

4. Make meetings better
5.1 Create structures to allow agenda items to be raised: If you don’t already, establish a pathway for agenda items to be raised. Set clear deadlines, establish an agenda setting meeting, committee or process. Join the dots between IJB and SPG meetings.

5.2 Make meetings, minutes and papers accessible: Produce minutes, agendas and meeting papers as promptly as possible. This lets representatives get feedback to and from their carer networks. It’s especially helpful when officers identify issues affecting carers and seek advice before papers are tabled.

About the National Carer Organisations
The National Carer Organisations are brought together by a shared vision that all Scotland’s unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Scotland, the Coalition of Carers in Scotland, Minority Ethnic Carers of Older
People Project (MECOPP), Carers Trust Scotland, the Scottish Young Carers Services Alliance, Crossroads Caring Scotland and Shared Care Scotland.