

EQUAL, EXPERT *and* VALUED

Enhancing Carer Representative involvement on
Integration Joint Boards

REPORT SUMMARY



Background

The Carers Collaborative is a project 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 this report.

AIM

The report offers positive and constructive insights in order to:

- Help improve carers' involvement in IJBs
- Help planning officers and commissioners to move from good intentions to better practice
- Start conversations and stimulate further progress by sharing good practice.

Equal and Expert?

In 2013 The Coalition of Carers developed 'Equal and Expert' 3 best practice standards for carer engagement. The standards were co-produced by carers and local carer support organisations, with support from the Scottish Government and the Scottish Health Council.

The report assesses evidence for the extent to which the three 'Equal and Expert' carer involvement standards have been met by IJBs to date:

STANDARD ONE:

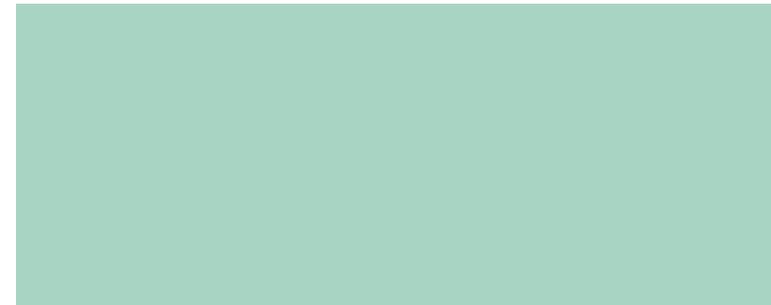
Carer engagement is fully resourced

Practice varies. Carer Reps have found training and induction beneficial, particularly where it involves the full Board. Meeting papers are rarely sent in time to allow proper preparation. Where replacement care is provided for carers, it tends not to include time spent preparing for meetings.

STANDARD TWO:

Carers on strategic planning groups represent the views of local carers

This was the best evidenced of the three standards. 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.



STANDARD THREE:

The involvement of carers on strategic planning groups is meaningful and effective

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.

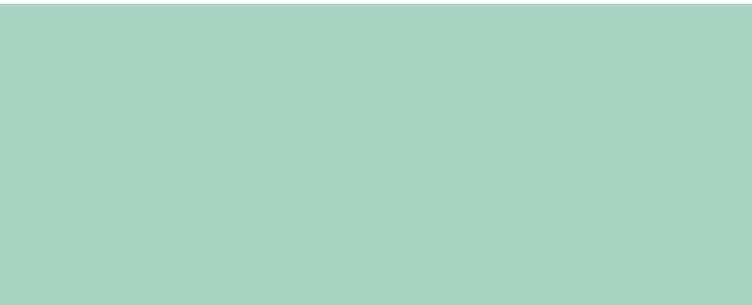
Experience so far

Between May and October 2016 we analysed IJB Strategies and meeting minutes to determine how easily accessible information was and to identify any references to unpaid carers. 27 out of 30 Strategies include carer outcomes. 28 IJBs make their meeting minutes publicly available, and 26 publish meeting dates in advance. Between April and October 2016, 17 IJBs discussed carers or carer-specific issues.

Carers Collaborative meetings shared more detailed information on local practice. Although these focused on good practice examples, they highlighted some common gaps:

- Being listened to
- Agenda setting
- Consultation on plans
- Paperwork
- Power
- Process
- Voting
- Resourcing
- Engagement

The report gives more detail on these, and of good practice from around the country, leading to the recommendations listed below.



Sharing experience: Good practice notes from around the country

This section of the report is based on mapping and scoping activities carried out during the three Carer Collaborative meetings. It aims to put a spotlight on good practice and to draw attention to practice that can be improved.

RECRUITMENT, INDUCTION AND ROLES	
Examples of good practice	Examples of practice to be improved
Several Carer Reps were appointed after an application process and interview. In one example this was carried out by the Carers' Centre, meaning this was a more open process and the representative role of the Carer Rep was clearly established from the outset. Unsuccessful applicants now form a consultation group, which means their expertise and willingness to engage has not been lost.	Some areas do not yet have a Carer Representative, or have appointed on an interim basis. This risks losing continuity of 'the carer's voice'.
Many IJBs allow for two Carer Representatives. This helps to share the workload and the pressures. If the Carer Rep can't make a meeting, a substitute can be agreed with the IJB Chair.	Some IJBs only allow for one Carer Representative. Others do not allow deputies to take part in meetings, only observe them, sometime without access to all the papers.
A few areas have provided Carer Reps with a role description. A small number of IJB Chairs have given helpful guidance on the Carer Rep's role. For example, about their right to comment on, or challenge, issues that are raised at meetings.	Most IJBs appear not to have identified a description of the Carer Rep's role or purpose.

SUPPORT AND RESOURCES	
Examples of good practice	Examples of practice to be improved
In some areas, carers are provided with travel expenses for attending meetings. In others, replacement care is provided for time spent in meetings.	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.
Some IJBs identify a Carers' Champion or lead officer who can work directly with Carer Reps and Carer Centres.	It is not always know who the local Carer Lead is, or what their role is.
Carer Reps find IJB development sessions beneficial – some IJBs schedule these every other month, between formal Board meetings.	Some Carer Reps have received no induction or training.

STRUCTURES FOR INCLUSION AND REPRESENTATION

Examples of good practice	Examples of practice to be improved
Several Integration Authorities have run 'carer aware' training for members of IJBs and other key partners	In some areas carer reps report a lack of understanding of the contribution of unpaid carers and the value carer reps bring to IJBs through their lived experience.
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

MEETINGS AND PAPERS

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

STRATEGY

Examples of good practice	Examples of practice to be improved
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.	Several IJBs have not discussed or begun preparing for the Carers Act.
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.	Most areas use just the one indicator (“I feel supported to continue caring”).

Work in Progress

It became evident during both the scoping activity and the group events that progress was being made. During early scoping (May-June) for example, only 17 IJBs had published meeting minutes, and carers had been mentioned just four times in these. However by October, 28 had minutes available and carers had been mentioned 29 times.

The tone of conversation had also changed. At the first Collaborative meeting in May, there was some frustration about lack of training, level of involvement, quality of governance etc. But by October, positive improvements were being reported. For example, some Carer Reps had been able to ensure that the Carers Act appeared on the agenda.



Recommendations to improve Carer Representation

The report shares 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.

1. 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.

2. 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.

3. 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.



4. SHARE PRACTICE AND LEARNING

4.1 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!).

4.2 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.

5. 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 Strategic Planning Group 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.

Spotlight: SHETLAND

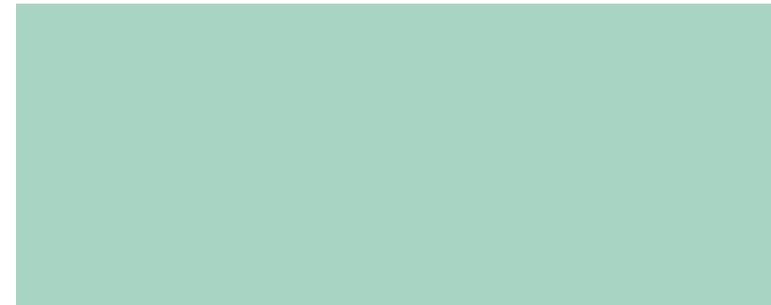
A Carers Forum facilitated by a carers support worker gives carers the opportunity to voice individual concerns

Spotlight: FIFE

Carer Rep was appointed through interview by the Carers' Centre. Others applicants now form a consultation group.

Spotlight: MORAY

issues papers 7-10 days ahead of meetings, giving carers time to prepare.



Spotlight:
on best practice:
HIGHLAND

The role of Carer Voice Coordinator in Highland was created as a self-employed consultant role to be carried out by a carer. The ethos behind the role being self-employed was to allow the carer to have complete flexibility to fit the requirements of the role around their caring responsibilities.

The remit is to increase the engagement and involvement of carers in the planning and delivery of services that affect their lives and the lives of the people they care for.

‘The vision for Highland to have carers involved in the planning and delivery of all services that affect their lives is a work in progress, however with the creation of this role, we now have someone who has that ambition at the core of their role and is dedicated to making the vision a reality.’

Karen Anderson, Carer Voice Co-ordinator



In North Ayrshire, carers were on the shadow board and helped to establish how the IJB structures and meetings would operate. All board members received the same training, which reinforced the feeling of equality among partners. Councillors also received carer awareness training.

STRATEGY

The IJB Strategy has an accessible summary, and includes a section on carers, which was approved by carers before going to print. The Carers Strategy sits underneath this, written with carers.

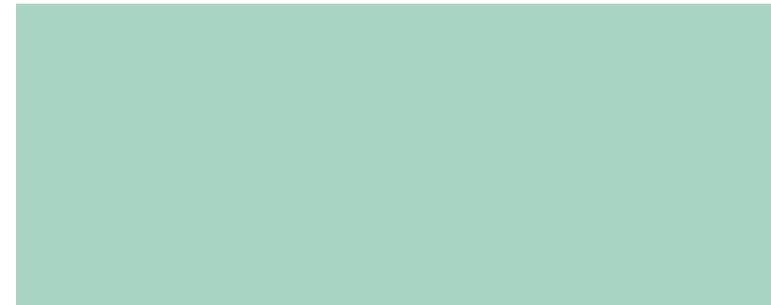
STRUCTURE

To provide a link between communities and the IJB, a Carers Advisory Group brings carers together from different localities and carer groups. It is chaired by a 'Carer Champion', a councillor with a remit for social work. Carers from the Carers Advisory Group populate other strategic planning groups, which helps provide a network of support underneath the IJB Board. In these and other ways, community members can raise issues and get items on the agenda.

SUCCESS FACTORS

Marie McWaters, a Carers Rep, puts these successes down to the positivity of councillors and council leaders towards involving carers. Other carers could see the benefits that involvement was having, so more signed up.

'Once you make the pathway it's easy – you just keep using the same path.'



NEXT STEPS

Members would like to continue the Collaborative's work, though providing regional events alongside national ones would be an improvement for several members. The practice-sharing format has built Carer Reps' confidence and their ability to understand their IJB's practice in the context of developments elsewhere. However a next step might be to explore whether a common or agreed role specification for Carer Reps would be useful.

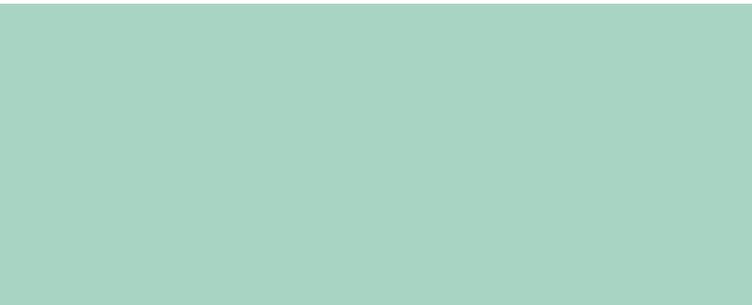
Thanks and acknowledgements

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