

EQUAL, EXPERT and VALUED

Enhancing Carer Representative involvement on Integration Joint Boards

SECOND EDITION:

Update Report, February 2018







Background

The Carers Collaborative is a project that seeks to evaluate, support and improve carer representation on Integrated Joint Boards (IJBs). The Collaborative has gathered evidence and facilitated events since March 2016, involving 46 Carer Reps from 29 local authority areas. The first 'Equal Expert and Valued' report was published in February 2017. It identified good practice and set out recommendations to enhance carer involvement on IJBs. This update report is based on a further year's research, revisiting evidence and presenting new resources to improve carer representation.

AIM

This update report, published while IJBs are making plans for the Carers (Scotland) Act 2016, aims to:

- Contribute constructive insights and recommendations
- Provide resources and ideas for improving carers' involvement on IJBs
- Help Integration Authorities benchmark and continue improving their practice
- Start conversations and stimulate further progress.

Methodology

The Carers Collaborative met four times between January and November 2017, providing a forum for Carer Representatives to explore evidence and practice. Representatives and other IJB members also completed self-assessments against the 'Equal and Expert' best practice standards, with a comprehensive scoping exercise also being conducted by an independent researcher. The scoping exercise reviewed every Integration Authority's most recent strategic plan, annual report, committee papers and minutes for references to carers, carer outcomes, carer involvement and the Carers Act.

Note on language: The report typically uses the words 'Carer Reps' or 'representatives' to refer to Carer Representatives. These are usually unpaid carers (or former carers), but in some areas staff from local carers centres fulfil the role.

Introduction

The requirement for carer representation in planning and commissioning public services is increasing. The Public Bodies (Joint Working) Scotland Act 2014 requires Integration Authorities to include a Carer Representative on their IJB¹. The Carers (Scotland) Act 2016² extends the expectation of carer engagement to other areas of Health and Social Care planning. Scottish Government guidance on Health and Social Care commissioning states that services should be

"Planned and led locally in a way which is engaged with the community (including those who look after service users and those who are involved in the provision of health and social care)". 3

In 2013 the Coalition of Carers in Scotland developed 'Equal and Expert: 3 Best Practice Standards for Carer Engagement'.⁴ While good practice is evident in some areas, the standards have not been consistently applied. In 2017 the Scottish Government's Health and Sport Committee described this as a 'piecemeal' approach.⁵

This report offers positive and practical insights to help improve standards and consistency. It begins by defining Carer Representatives' role and purpose before examining evidence for the three Equal and Expert standards. The three standards are:

STANDARD ONE: Carer engagement is fully resourced

STANDARD TWO: Carers on strategic planning groups represent the views of local carers

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

A national overview of involvement practices is followed by local good practice examples. The report concludes with a review of progress towards the recommendations made in 2017, with straightforward suggestions for improving involvement.









- 1. Public Bodies (Joint Working) Scotland Act 2014
- http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/Carers-scotland-act-2016
- 3. Scottish Government (2015) Strategic Commissioning Plans Guidance
- 4. http://www.carersnet.org/policy-legislation/best-practice-standards-for-carer-engagement/
- . Are they involving us? Integration Authorities' engagement with stakeholders Scottish
 Parliament Health and Sport Committee Published 12 September 2017 SP Paper 188

Defining the Role: who are Carer Representatives and what do they do?

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.

The first 'Equal, Expert and Valued' report identified that although the Public Bodies Act requires Integration Authorities to involve 'a person who the integration authority considers to be representative of' carers6, the purpose of doing so is not specified. This led to the requirement being interpreted and implemented in quite different ways. The report recommended that Carer Reps have a clear remit, roles and expectations. A draft role description is now available, identifying three main functions, the principles behind them, and the resources required to support them:

CONTRIBUTE TO GOOD GOVERNANCE

- Contribute to discussions and provide advice and scrutiny from carers' perspective.
- Contribute to ensuring that Integration Authorities implement their statutory obligations.
- Add relevant items to the meeting agenda, to be discussed and minuted. Mechanisms should be in place for this.
- Be prepared to raise relevant points and question meeting papers and accompanying evidence appropriately, for example about the extent to which the recommendations are inclusive of, or impact on, carers.

REPRESENT CARERS – AND THE IJB

- Champion carers' involvement as Equal and Expert⁸ partners at all levels and link in with other champions and carers to enlarge the pool of views being collected and represented locally.
- Access their 'constituency' of carers via carer networks, local forums (including social media where appropriate) to encourage and maintain links with the IJB.
- Nominate a Depute to represent the role in the case of absence.
- Ensure their involvement is reflective of the views of the widest range of carers by engaging as fully as possible with other carer representatives.

HAVE ROLES OUTWITH IJB MEETINGS

- Join one or more sub committees/working groups (such as Audit and compliance committees), where appropriate and where carer capacity allows. IJBs should be upfront about expected time commitment, to enable planning and informed decisions.
- Take part in appropriate training and induction.
- Play an active role in IIB & HSCP events.
- Be active in local carers group(s)

- Public Bodies (Joint Working) Scotland Act 2014
- http://www.carersnet.org/wp-content/uploads/2018/01/ Download-the-Role-Description-Here.pdf
- http://www.carersnet.org/policy-legislation/best-practicestandards-for-carer-engagement/









Equal and Expert: Overview of evidence

This section presents an overview of the 'Equal and Expert' Carer Engagement standards, and the extent to which they were evident in IJB practice from the Collaborative's work and research.

STANDARD ONE: CARER ENGAGEMENT IS FULLY RESOURCED

IJBs vary in their commitment to resourcing engagement. Good practice examples include IJBs providing full-Board development sessions, paying out of pocket expenses and providing replacement care. Practice appears to be improving in giving Representatives time to read and prepare meeting papers, but in many areas still falls short.

KEY:

Several good examples – overall practice is good

Some good examples exist - but experience is mixed

Limited examples – some local good practice may exist but overall practice is poor

STANDARD ONE: CARER ENGAGEMENT IS FULLY RESOURCED

Outcomes

- 1. Carer Representatives will feel confident in undertaking the responsibilities of their role and be able to express clearly and fully the views of other carers.
- 2. The strategic groups will benefit from the views of carers being regularly and directly represented and will produce work which address the needs and meets the aspirations of carers more fully.

Evidence of implementation Carers in representative roles will:

Receive training and a full induction.	Some areas involve Carer Reps in IJB Development sessions and others arrange regular support meetings before IJB meetings to allow discussion of agenda items (East Renfrewshire, Midlothian). However, most Carer Reps still report that they receive no training or induction.
2. Be supplied with the information they require timeously.	Only a third of Carer Reps report receiving papers 7 days in advance. Getting 300+ page papers within 2-3 days of meetings is still common, as is the practice of issuing previous meeting minutes only days ahead of the next one.
3. Be mentored.	More than two thirds of Carer Reps have not been mentored. In our research, two IJBs provide mentoring through an Engagement Officer (Midlothian; Perth and Kinross). Carers Centres sometimes provide informal mentoring.
4. Be able to obtain the views of other carers via a strong network of carers.	Carer Reps in all but one area reported having access to networks like carer forums, Carers Voice Groups and Carer Reference Groups. Time is more of an issue than opportunity.
5. Have the full costs of their work in and for the strategic groups met – this includes the costs of any substitutionary care that is required.	From 20 self-assessments, only 5 areas have a written expenses policy. 4 do not pay expenses. 5 cover travel and parking costs, 6 provide additional resources such as subsistence, tea and coffee but only two reportedly provide lunch (Moray; Perth & Kinross) or printing costs (Angus; Midlothian). Five areas provide replacement care.

CHANGES SINCE 2016/17 REPORT:

Several areas have made efforts to issue meeting papers in a timelier way. More Carer Reps appear to be better connected to local networks. The common absence of induction and training is a concern: Carer Rep posts were unfilled in five IJBs at the time of writing, an increase on 2016 (three vacant posts). There is concern among Carer Reps about potential difficulty in recruiting (and retaining) their replacements without improvements in resourcing.

Spotlight on expenses

'I have never been asked about expenses...No-one has ever asked about who is caring for my daughter when I am at meetings.'

Carer Representative

'We expect the integration authorities to ensure that those who participate in the process can do so without detriment.'

Cabinet Secretary for Health and Sport

[Are they involving us? Integration Authorities' engagement with stakeholders Scottish Parliament Health and Sport Committee Published 12 September 2017 SP Paper 188]

There are costs involved for any member of an IJB. To avoid being worse off, they and Carer Reps should receive out-of-pocket expenses such as travel and printing costs. However, there are additional costs in being a Carer Rep:

- Time away from the caring role (preparing for, travelling to and attending meetings)
- Replacement care the stress and cost of finding and/or paying someone else to provide care. (Some Carer Reps use Direct Payments to purchase replacement care to attend IJB meetings, leaving less for proper breaks from caring)
- Time and cost of consulting and communicating with other carers
- Loss of income and time off work (or other commitments)

There are positive signs of improvement since 2016, but carer involvement is still under-resourced by most Integration Authorities. Sometimes this is due to limited budgets, sometimes to do with limited understanding of carers' lives, and occasionally both. The true costs of involvement are only rarely understood or provided for. Whatever the reasons, lack of appropriate expenses is becoming an impediment to involvement. It is also an equalities issue, excluding carers who cannot afford to finance the public duties they carry out on behalf of Integration Authorities.







STANDARD TWO: CARERS ON STRATEGIC PLANNING GROUPS REPRESENT THE VIEWS OF LOCAL CARERS

In 2016/17, this was the best evidenced of the three standards. There is still good evidence that Carer Reps receive quality resources and support from carers' centres, including access to local carer networks. Local engagement is growing, but in some areas Representatives struggle to reach carers, and to encourage more carers to take on representative roles.

STANDARD TWO: CARERS ON STRATEGIC PLANNING GROUPS REPRESENT THE VIEWS OF LOCAL CARERS

Outcomes

- 1. Carers on strategic groups will be:
 - (a) representative of the various communities of carers
 - (b) able to express in informed ways the views of a range of carers
- 2. The other partners on the strategic groups will know with confidence that they are learning of the views of a range of carers.
- 3. The work produced by the strategic groups will fully take into account the views of carers

Evidence of implementation

Carer organisations will be properly resourced to establish and support a strong carer network, which offers a variety of ways for carers to get involved	Some Carers Centres are funded to support Carer Reps and facilitate access to carer networks. Changes in funding have increased support in some areas (e.g. Argyll and Bute; Shetland) but reduced it in others (e.g. Inverclyde).
The number of carers involved in exchanging views through the network will grow.	Local carer engagement is growing but progress is slow. Carer Reps are often seeking new ways of reaching carers. Midlothian, for example, use social media and online videos for this.
3. The diversity of carers involved in the network will be broad.	Experience is mixed, with some Carer Reps reaching diverse groups but others struggling to engage new or different audiences.
There will be a continual emergence of new carers willing to undertake representative roles.	All areas report difficulty in attracting potential Carer Reps or deputies, listing time, expense, workload and 'tokenism' as barriers.
5. The information provided through and by the supported network will be of a high quality.	Carer Reps value the information they get from carer networks, though experience of having it recognised by IJBs is mixed. Some Carer Reps are known to have stepped down in the last year because of the demands of the role.

CHANGES SINCE 2016/17 REPORT:

The most significant challenge is in the lack of new carers emerging who are willing to undertake representative roles. As with Standard One, resourcing is identified as the primary obstacle. The last year has also seen changes in the funding environment. Some Carers Centres have increased resource for carer outreach and engagement, others are reviewing services due to changes in commissioning or funding.

STANDARD THREE: THE INVOLVEMENT OF CARERS ON STRATEGIC PLANNING GROUPS IS MEANINGFUL AND EFFECTIVE

There are signs that Carer Reps's expertise (and equality) are becoming better recognised, with some structures and meetings becoming more inclusive. Challenges persist in contributing to agenda setting. Carer Awareness Training has not taken place to the extent that was anticipated in 2016. Overall, Integration Authorities continue to overlook the importance of measuring the impact of policies – and involvement – on carers.

STANDARD THREE: The involvement of carers on strategic planning groups is meaningful and effective (This standard was written before the emergence of IJB 'Strategic Planning Groups'. It should be taken to mean any strategic forum, including the IJB itself.)

Outcomes

- 1. Carers will be treated as equal and expert partners in strategic groups.
- 2. The views of Carer Representatives will be evident in the strategic decisions taken and the plans that are developed.
- 3. Carers will be treated as equal and expert partners in the provision of care.

Evidence of implementation

Carers will be placed on the right strategic planning groups including at the top level of governance structures.	Carer Reps are generally well involved in Strategic Planning Groups and IJB sub-committees. Some Carer Reps chair committees (e.g. in Argyll and Bute and Midlothian, Carer Reps chair the Audit Committees). But several have had limited opportunities to join SPGs, and some are unable to give more time to join extra committees. Best practice would feature different carers at different levels, with good structures for communication and involvement.
2. Other partners in strategic groups will have had Carer Awareness training so that the perspectives brought by carers are understood and accepted as the statements of people who are "equal and expert" partners.	Several areas planned to provide Carer Awareness training, but few have. Good practice examples include Carer Reps delivering Carers Awareness Sessions to the IJB (Argyll & Bute; East Lothian); Carer Reps briefing on carer issues during business meetings; and an IJB (Fife) whose agenda features a regular 'Personal Story', including carers' experiences.
3. Meetings will be open and inclusive, allowing time for discussion and contributions from all members of the group. Language will be accessible and jargon will be avoided.	Although agendas are still reported to be full, and meetings full of jargon, Carer Reps appear to have more opportunities to contribute. One IJB uses support group meetings to ask Reps for feedback and include this as a standing item on the agenda (Midlothian).
4. Sufficient time will be given for preparation. Papers will be sent out in advance in a timely fashion and Carer Representatives will have the opportunity to clarify any information in advance.	See above — some improvements in receiving IJB papers, but SPG and other papers are often last-minute. Some areas welcome contact with authors or Integration Manager to clarify information.
5. The agenda will be jointly owned with all group members having the opportunity to place items on it or raise issues of concern.	Most IJBs still lack processes for contributing to agendas, and/or transparency about how agendas are set. Good practice examples include East Dunbartonshire, where there is a set item on IJB board agendas for service users and carers; and Shetland, where weekly sub-committee meetings consider items raised by members.
6. All plans and policies produced by strategic groups will be 'carer proofed' so that the impact on carers is explicitly stated to ensure that carers needs and aspirations have been fully considered.	There was very little evidence of this. Some IJBs require report authors to note the consideration of (and impact on) carers, but this is perceived as cursory.
7. Through their network carers will be supplied with information about the opportunities for participation in strategic planning groups.	Carer Reps remain very knowledgeable about the systems and structures in which their work takes place. With the move to Locality planning and Carers Act implementation, some areas are stepping up actions to inform, recruit and train more carers.
8. The outcomes of carer engagement will be evaluated.	No evidence of IJBs measuring the outcomes of carer involvement. In a small number of areas, other carer engagements are evaluated (e.g. following community consultations). See below for more information on carer outcomes.

CHANGES SINCE 2016/17 REPORT:

Carer Reps appear to be more integrated in IJBs and their associated Planning Groups and committees (see below). Further change may follow as IJBs adjust to locality planning, the Carers Act and the Community Empowerment Act, albeit that the structural and resource barriers identified above may still need to be removed.

Spotlight: Strategic Planning Group involvement

'I am on all the relevant groups - for all the difference it makes.'

Carer Representative

The 2016/17 report identified that Carer Representative effectiveness was improved when they were included in Strategic Planning Groups. SPGs were perceived as the place where agendas were set and decisions made.

Over the last year, Carers have had some modest success in being represented on these groups. At a Carer Collaborative meeting in 2017, five out of 13 participants were on an SPG. Four of these could suggest agenda items. Carer Representative's independence and experience has also been recognised in some areas, for example by being invited to Chair their Finance, Audit and Risk committees. Reasons posited for increased involvement included changes in IJB membership and personnel; Joint Inspection from the Care Inspectorate; and anticipation of the Carers Act.

However, changes are underway which might again change the level and nature of Carer Rep involvement. The move to locality planning is likely to require IJBs to review their structures and representation. As noted in the 2016/17 report, local networks of carers 'underneath' and around the IJB will help Carer Reps' ability to represent carers more effectively.

In some areas SPGs appear to be in abeyance, with no meetings having taken place for several months. And in the Carer Collaborative meeting mentioned above, only one of the 13 Representatives felt that communication between their SPG and IJB was effective. SPG involvement may not live up to the hopes Carer Reps had for it.







Scoping carer inclusion: IJB plans, reports and outcomes

As with the 2016/17 report, a scoping exercise sought to create a picture of national practice, analysing every Integration Authority's Strategic Plan; Annual Report; and IJB meeting minutes. References to carers (and Carer Representatives) were used as simple indicators of the extent to which carers and carers' outcomes had been identified and prioritised by Integration Authorities.

Year	Strategic Plans available	Annual Reports available	Meeting minutes available	IJB minutes referencing carers	IJB meeting dates available
2016	30	n/a	28	17 IJBs — with 29 total references to carers	26
2017	31	31	31	30 IJBs - with 89 references to carers	31

OBSERVATIONS

All Integration Authorities now have publicly available Strategic Plans and records of meetings. This is useful for Carer Rep involvement, allowing time for meeting preparation, carer engagement etc. The increase in minutes referencing carers is mainly due to preparations for the Carers Act (23 areas record planning for the Carers Act - 8 do not).

All annual reports measure progress towards National Health and Wellbeing Outcome Six⁹, comparing local achievement with the Scotland-wide result of 41% carer satisfaction¹⁰. 18 areas report achievements above 41% (two areas claim 99% carer satisfaction), with 10 below, and three at exactly 41%. These figures raise questions as to whether reporting is accurate, consistent and meaningful. The usefulness and validity of the 41% benchmark is also doubtful. 41% hardly represents 'success' - and Outcome 6 is the lowest performing outcome in the National Health and Wellbeing survey.

Some areas appear to use additional measures to Outcome Six. Scottish Government guidance on data collection for the Carers Act¹¹ may encourage IJBs to use additional indicators, allowing for a more rounded picture of carer outcomes to emerge. As noted above, no Integration Authorities measure the outcomes of carer involvement, though the three Standards above provide a useful template should they wish to do so.

- 9. 'People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being' www.gov.scot\Topics\Health\Policy\Health-Social-Care-Integration\National-Health-WellbeingOutcomes
- Health and Care Experience Survey 2015/16 National Results, A National
 Statistics Publication for Scotland published by the Scottish Government, May
 2016 http://www.gov.scot/Resource/0050/00500340.pdf
- 11. Carers Census Data Specification, Scottish Government, 2017 http://www.gov.scot/Topics/Statistics/Browse/Health/DataSupplier/CarersData







Recommendations to improve Carer Representation

This section reviews progress towards the recommendations in the 2016/17 report and identifies next steps for improving carer representation.

2017 Recommendation	Progress	Next steps - 2018+	
Include Carers' Representatives in decision making I.1 Find ways to involve carers in consultation and decision-making I.2 Include Carer Reps in different IJB groups	Carers appear to be better represented and consulted within IJB structures, but still lack decision-making authority and opportunities to contribute to agendas.	IJBs can continue to improve carer involvement in SPGs, locality groups and carer networks. However, recruiting and retaining Carer Reps will require improving practice regarding training and expenses.	
2. Increase awareness and profile 2.1 Raise profile of Carer Reps 2.2 Raise IJB awareness of carers	IJBs have generally not followed through on intentions to run Carer Aware training. The profile of Carer Reps has increased, with better access to carer networks.	As noted in our previous report, good practice would involve providing Carer Reps with email addresses and publicising these for easy contact. The benefits and outcomes of carer involvement can be measured using 'Equal and Expert'.	
 3. Value and resource Carer Representatives 3.1 Value Carers Representatives and their contributions 3.2 Train and support Carer Representatives 3.3 Resource representation 3.4 Ensure Carer Representatives have a clear remit 	Training, induction and expenses remain absent for Carer Reps in most IJBs. This now affecting retention and recruitment.	Develop and publish expenses policies for IJB Representatives. Improve practice regarding providing subsistence and replacement care. Use or adapt the suggested role description to provide clarity on roles, remits and expectations.	
4. Share practice and learning4.1 Share practice between IJBs4.2 Improve communication	IJB networks now explore similar issues to those in the Carer Collaborative (e.g. Chief Officers' Ministerial Group). Agendas and minutes are more publicly available than 2016/17. Papers remain lengthy and often last-minute.	Continue with efforts to issue papers sufficiently in advance to allow Carer Reps to read and prepare, particularly minutes of previous meetings. Develop clearer links between IJBs and their sub-committees, including Locality Planning as it develops. Improve transparency as to how agendas are formed and create opportunities for Representatives to contribute. Some IJBs use 'Any other business' to do this.	
5. Make meetings better5.1 Create structures to allow agenda items to be raised5.2 Make meetings, minutes and papers accessible	Some IJB meetings have become more accessible, with less jargon and more opportunities for carers to contribute. Links between SPGs and IJBs remain unclear, as does the process for tabling agenda items.		







SPOTLIGHT: LOCAL PRACTICE – INVOLVING CARERS IN PREPARATIONS FOR THE CARERS ACT IN EAST LOTHIAN

East Lothian HSCP has set up a Carers Strategic Group as one of seven groups leading work towards achieving its strategic outcomes. The Group will lead the development of a Carers Strategy and workplan in line Carers Act requirements. In the East Lothian IJB Annual Report 2016/17 the HSCP Director David Small commented that.

> 'The planning groups give us the opportunity to make sure that stakeholders are equal partners in planning, enabling us to develop innovative, flexible and responsive answers that really meet the health and social care needs of people in East Lothian.'

Local preparations for the Carers Act have also been informed by carers and carers' organisations. For example, a Carers Strategy Team worked with Carers of East Lothian to develop a new outcomefocused, strengths-based tool to pilot the new Adult Carer Support Plans. Feedback from a carer engagement event was used to develop the Eligibility Criteria Framework, based the National Carer Organisations framework contained in the Draft Statutory Guidance¹².

The IJB chair also met individually with the IJB Carer Representative. This led to an IJB development session, organised by the Carer Representative, to increase understanding of issues affecting carers, and to inform IJB members of the provisions of the Carers Act.

SPOTLIGHT: LOCAL PRACTICE - 'CARER AWARE' IN DUMFRIES & **GALLOWAY**

Dumfries and Galloway HSCP provide Carer Aware training to help staff understand who carers are, what they do and the support available for to them. The aim of this training is to help staff to identify carers and be better informed about issues impacting on their lives. NHS D&G and D&G Council have also achieved Carer Positive status, a Scottish Government funded initiative to recognise employers who offer the best support to carers, for demonstrating a genuine commitment to supporting staff who have to balance work with a caring role.

A recent development day also helped IJB members to get to know each other, beyond just their day jobs. It also helped IJB members recognise each other's expertise and to agree some simple actions that would improve the Board's functioning. A 'buddying' session as part of the day proved so popular that a buddying away day is now being considered.

SPOTLIGHT: LOCAL PRACTICE - ACHIEVING AND MEASURING CARER **OUTCOMES IN ARGYLL & BUTE**

Improving the support to unpaid carers is one of six priority areas for Argyll and Bute HSCP. In turn, every Locality Planning Group has a section in their action plan focusing on unpaid carers. Argyll and Bute's 2016/17 Annual Report¹³ notes that only one Health & Wellbeing outcome (Outcome 6) is being used to measure carers' experience. Although local results are in line with the Scottish average, the report acknowledges that more needs to be done. The IJB is therefore working with Carer Reps and the local carers' network to develop additional performance measures to supplement the existing Outcome 6 measure.

In developing their annual report, the HSCP asked a range of people who may have an interest to give feedback as 'critical friend reviewers' (e.g. on content, readability, etc). In 2016/17 two of these reviewers were unpaid/family carers.

- 12. Carers (Scotland) Act 2016 Draft Statutory Guidance: Local eligibility criteria, Appendix A. Scottish Government, 2017
- https://www.argyll-bute.gov.uk/sites/default/files/ab_hscp_annual_ performance report 21072017 5.pdf









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