

Equal, expert and valued Six years on

Enhancing carer representation on Integration Joint Boards Fourth report from the Carer Collaborative of IJB Carer Representatives

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Introduction and summary

The Carers Collaborative is a project that supports, evaluates and improves carer representation on Integration Joint Boards (IJBs). This is the Collaborative's fourth scoping report.



This report is published during the on-going Couid-19 pandemic. It is recognised that the impact of Couid-19 has brought significant and unprecedented pressures within health and social care, and for unpaid carers. Despite this, there have been a number of highprofile developments in health and social care during 2020/21, building on previous developments noted in the 2019 Equal, Expert and Valued report.

Following two reviews of Health and Social Care Integration (by Audit Scotland and the Ministerial Strategic Group for Health and Community Care) during 2018/19, in 2020/21 the Independent Review of Adult Social Care was conducted. The Review report and recommendations, published in February 2021, have led to a range of recent developments, including the proposal for, and consultation on, the formation of a National Care Service for Scotland.

This report focuses on carer involvement on IJBs, reflecting on progress against report recommendations from 2019.

In summary

- Recruiting and retaining new carers who are willing to undertake representative roles remains a challenge for IJBs.
- Whilst there have been improvements in areas providing out of pocket expenses, and to an extent, replacement care costs, many areas still do not have (or do not share), written expenses policies with Carer Reps. The template expenses policy produced by the Carer Collaborative seeks to help with the development and consistency of expenses policies.
- Involvement in agenda-setting and decisionmaking has improved in some areas, but Carer Reps are still excluded in many others, particularly during emergency governance measures implemented in response to Covid-19.

The report then reviews evidence of effective involvement, using the 'Equal, Expert and Valued best practice standards',¹ and concludes with an updated set of straightforward recommendations.

¹ https://carersnet.org/wp-content/uploads/2021/10/Standards-for-Carer-Engagment.pdf

The Carers Collaborative recommendations

| Rec | ommendation | Progress | Next steps – 2022+ |
|-------------------------|---|--|--|
| 1. 1.1 1.2 | Include Carers' Reps in decision making Carer Reps are involved in IJB strategic groups. Carer Reps are seen as 'equal, expert and valued' partners. | Carers are better represented within IJB structures, with more opportunities to get involved in a range of locality and strategic groups. Emergency measures implemented by IJBs during Covid-19 have impacted on carer involvement in decision-making. The Independent Review of Adult Social Care recommends Carer Reps are full partners on the IJB. | Continue to support carer involvement in key governance and decision- making processes, particularly as IJBs return from emergency measures implemented in response to Covid-19. Processes to support implementation of the recommendations from the Review of Adult Social Care should be developed by IJBs. |
| 2. 2.1 2.2 | Increase awareness and profile of carers and Carer Reps Provide formal Carer Awareness training to IJB strategic partners. Undertake 'carer proofing' of policies and strategies. | Most areas note a high level of carers awareness and understanding of the importance of carer involvement within the IJB and other strategic groups. However, more still needs to be done to increase awareness and understanding of carer issues. | Carer Awareness training for IJB strategic partners should be prioritised to ensure Carer Reps experiences and expertise is seen as equally valuable. Prioritise and involve carers to 'carer proof' policies, linking these with Equality Impact Assessments. The Carer Collaborative Briefing Paper on Carers and Equality Impact Assessments can help. ² |
| | Build capacity in Carer networks Prioritise the development of succession planning processes. Develop systematic recruitment and induction processes. Expand the pool of Carers Reps to support sustainable representation. Increase the diversity of Carers Reps to ensure representativeness. | Recruitment and retention remain a concern, particularly in relation to succession planning and the representation of carers on the broad range of IJB/HSCP strategy groups. Carer Reps are increasingly invited to become involved in strategic groups and meetings, however responsibility often lies with one or two Carer Reps. | Succession planning processes for Carer Rep roles must developed as a matter of priority. IJBs should ensure sufficient time and resources for: Exit interviews and handovers from existing Reps. Structured induction and training for new Reps to build confidence and capacity to engage. Capacity across carer networks should be proactively built to: Identify carers who wish to become involved and provide them with training and support to participate. Increase the number of Carer Reps in each area so that one or two Reps don't have to attend multiple planning groups. Support increased diversity of Carer Reps, ensuring those who face barriers to engagement are supported to be involved. |

Continued...

² https://carersnet.org/wp-content/uploads/2021/10/Carers-and-EQIA.pdf

The Carers Collaborative recommendations:

| Recommendation | Progress | Next steps – 2022+ |
|--|--|---|
| Value and resource Carer Reps Ensure Carer Representatives have a clear remit. Train and support Carer Representatives. Provide the expenses and resources necessary to perform the role. | The provision of role descriptions and mentoring support / training for Carer Reps shows a slight improvement. Most IJBs now provide expenses for IJB and other strategic meetings, however, reimbursement of other costs such as printing, replacement care and preparation time is still mixed. The number of written expenses policies remains low and where these are available they are not being shared consistently with Carer Reps. | Use or adapt the Carer Collaborative role description ³ to provide mutual clarity on roles, remits and expectations. Continue to develop structured training and mentoring opportunities for Carer Reps. Use or adapt the Carer Collaborative template expenses policy ⁴ to develop and implement an expenses process that acknowledges and meets the full costs of carer contributions to IJBs and other strategic groups. Proactively share expenses policies with Carer Reps. Explore the provision of remuneration for Carer Reps to acknowledge their time and expertise. |
| Make meetings better Continue supporting Carer Reps to contribute to agendas. Continue to improve the accessibility of meetings, minutes and papers. Allow time in meetings for discussion and questions. | IJB meetings have become more accessible, with more opportunities for carers to contribute and an increased focus on using jargon- free language. Access to agenda-setting varies across the country with many areas feeling the agenda still 'belongs' to IJB officers. Over the last two years meetings have mostly been held online (which has had benefits and challenges). Almost half of IJBs now either livestream or have publicly available recordings of their meetings. | Continue to issue papers sufficiently in advance to allow Carer Reps to read, consult and prepare. Provide more consistent access to agenda-setting, whether through Strategic Planning Groups, pre-IJB meetings or structured contact with Chairs and officials. Ensure Carer Rep involvement is meaningful and is having an impact (e.g. in decision-making) and allow time in meetings for discussion and questions. Ensure online meetings are accessible, for example with the provision of IT equipment and digital training for Carer Reps. |

³ https://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf

⁴ https://carersnet.org/wp-content/uploads/2021/10/Carer-Expenses-Policy.pdf

Background



The Carers Collaborative

The Carers Collaborative is a project that supports, evaluates and improves carer representation on Integration Joint Boards (IJBs). The Collaborative has gathered evidence and facilitated events since March 2016, involving 55 Carer Reps from 30 authority areas.

Three 'Equal, Expert and Valued' reports have been published to date, in 2017,⁵ 2018⁶ and 2019.⁷ They identified good practice and set out recommendations to support and improve carer involvement on IJBs. During 2019/20 research was undertaken to produce the fourth Equal, Expert and Valued report, which was due to be released in April 2020. However, due to the emergence of Covid-19 publication was postponed. Where appropriate, this fourth update report therefore includes data covering the years 2019/20 and 2020/21.

It is recognised that 2020 and 2021 were exceptional years, with health and social care services and unpaid carers being impacted by unprecedented pressures and challenges due to the Covid-19 pandemic. Specific mentions are made within this report where it is felt the pandemic has impacted significantly on the data presented.

Aim

This fourth Equal, Expert and Valued report is published four years into implementation of the Carers (Scotland) Act 2016 and six years into the Public Bodies (Joint Working) (Scotland) Act 2014. It aims to:

- Build on the constructive insights and recommendations offered in our previous reports
- Provide ideas and signpost to resources for improving carers' involvement on IJBs
- Help Integration Authorities
 benchmark their practice
- Support the proposals outlined by the Ministerial Strategic Group for Health and Community Care in their Review of Progress with Integration for Health and Social Care Final Report⁸ and the recommendations outlined in the Independent Review of Adult Social Care Report⁹
- Support continued practice improvement.

⁵ https://carersnet.org/wp-content/uploads/2021/10/Equal-Expert-and-Valued-2017.pdf

⁶ https://carersnet.org/wp-content/uploads/2021/10/Equal-Expert-and-Valued-2018.pdf

⁷ https://carersnet.org/wp-content/uploads/2021/10/Equal-Expert-and-Valued-2019.pdf

⁸ https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/

⁹ https://www.gov.scot/publications/independent-review-adult-social-care-scotland/

Methodology

The Carers Collaborative normally meets four times each year. However, to keep pace with the impacts of Covid-19 on IJBs and unpaid carers, during 2020/21 the Collaborative met more frequently, with six meetings taking place between May 2020 and January 2021. The normal schedule of quarterly meetings was resumed during 2021/22, with four meetings taking place from May 2021 to January 2022.

These meetings provide a forum for Carer Representatives to receive mutual support, share their experiences as carer reps, develop best practice tools and scope current practice. This forum has proved particularly vital to assess the impact of the Covid-19 pandemic. Alongside this, the Carers Collaborative has regular inputs from external stakeholders, and Carer Reps were also asked to provide expert views for the Independent Review of Adult Social Care. During 2020/21 this has included meetings with:

- Equality and Human Rights Commission
- Scottish Government Integration and Policy Support Team and Carer Policy Team
- Derek Feeley, Chair of the Independent Review of Adult Social Care

In 2021, 15 Carer Representatives (and other IJB members) completed self-assessments against the 'Equal and Expert' best practice standards, with a comprehensive scoping exercise also being conducted by an independent researcher. Broadly consistent with previous years, the scoping exercise reviewed every Integration Authority's most recent annual performance report and minutes for references to carers, carer outcomes, carer involvement and the Carers Act.

Achievement of National Health and Wellbeing Outcome Six¹⁰ was assessed for each area via annual performance reports and data from the 2019/20 Health and Care Experience Survey.¹¹ In this fourth update report, Integration Authority Annual Accounts (2020/21) were also included in the scoping exercise, to assess allocation of resources for carer support, including funding for the Carers (Scotland) Act 2016.

What we mean by 'Carer Representative'

The report typically uses the words 'Carer Reps' or 'Representatives' to refer to Carer Representatives. These are usually unpaid carers (or former carers). Every effort should be made to recruit and, importantly, retain Carer Representatives on IJBs. As our 2019 report noted, and as we expand upon in this updated report, this is becoming harder as demands of the role grow and while many IJBs do not have structured induction, support and succession plans in place.



¹⁰ 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. https://www.gov.scot/publications/national-health-wellbeing-outcomes-framework/pages/5/

¹¹ https://publichealthscotland.scot/publications/health-and-care-experience-survey/health-and-care-experience-survey-2020/ introduction/

The Policy Context for carer involvement

The requirement for carer representation in planning and commissioning public services is set out by the Public Bodies (Joint Working) (Scotland) Act 2014, which requires Integration Authorities to include a Carer Representative on their IJB.¹² The Carers (Scotland) Act 2016¹³ extended the expectation of carer engagement to other areas of Health and Social Care. Furthermore, 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)."¹⁴

More recently in 2021, the Independent Review of Adult Social Care made recommendations about the involvement of, and support for, unpaid carers on IJBs and within health and social care decision-making processes, noting that:

"Carers must be represented as full partners on the Integration Joint Boards and on the Board of the National Care Service...Integration Joint Boards and locality planners need to do a better job of building the user voice into their considerations. People with lived experience must be partners in the commissioning process and integral to decisionmaking and prioritisation, monitoring progress and making improvements...Every member of the Integration Joint Board should have a vote. Membership should include but not be limited to representation of the workforce, people who use services, carers, providers, professionals, localities and local communities. Careful thought will need to be given to the workable size of Integration Joint Board and appropriate support will need to be provided to enable participants to fulfil their responsibilities." 15

Since 2016, the Carers Collaborative has used the 'Equal and Expert' best practice standards¹⁶ to assess the effectiveness of carer representation in health and social care integration. Our previous reports highlighted good practice from some areas of the country. This year's report follows this theme and notes that, whilst approaches to carer involvement seem to be improving, they remain inconsistent across the country, in what the Scottish Government's Health and Sport Committee described in 2017 as a 'piecemeal' approach.¹⁷

This report offers positive and practical insights to help improve standards and consistency. It begins with a reflection on the changing policy context for integration and involvement. A review of progress against previous years' recommendations is then presented, before examining updated evidence for the three Equal and Expert standards:

The three Equal and Expert standards

Carer engagement is fully resourced

Carers on strategic planning groups represent the views of local carers

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

13 http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/Carers-scotland-act-2016

¹² Public Bodies (Joint Working) (Scotland) Act 2014: https://www.legislation.gov.uk/asp/2014/9/pdfs/asp_20140009_en.pdf

¹⁴ Scottish Government (2015) Strategic Commissioning Plans Guidance: https://www.gov.scot/publications/strategic-commissioning-plans-guidance/

¹⁵ https://www.gov.scot/publications/independent-review-adult-social-care-scotland/documents/

¹⁶ https://www.carersnet.org/carers-collaborative/

¹⁷ Are they involving us? Integration Authorities' engagement with stakeholders Scottish Parliament Health and Sport Committee Published 12 September 2017 SP Paper 188

The changing context

In 2018/19, two reviews of Health and Social Integration were carried out, by Audit Scotland and the Ministerial Strategic Group for Health and Community Care.

In 2019, Integration Authorities assessed their progress towards integration, followed by formal reviews of their Integration Schemes in 2021.

In early 2021, the Independent Review of Adult Social Care made a series of recommendations about the involvement of carers in health and social care design and decision-making.

The Ministerial Strategic Group for Health and Community Care

As detailed in its final report on Integration¹⁸ in 2019, the Ministerial Strategic Group for Health and Community Care proposed a number of steps to ensure the 'meaningful and sustained engagement' of carers and Carer Reps on IJBs:

6. (iii) We will support carers and representatives of people using services better to enable their full involvement in integration. Carers and representatives of people using health and social care services will be supported by partnerships to enable meaningful engagement with their constituencies. This will support their input to Integration Joint Boards, strategic planning groups and locality arrangements for integration. This would include, for example, receipt of IJB papers with enough time to engage other carers and people using services in responding to issues raised. It would also include paying reasonable expenses for attending meetings.

Assessment of progress towards integration

During 2019 a new self-assessment process for Integration Authorities was introduced to evaluate progress against the six key features that Audit Scotland define as central to the success of integration (see Figure 1 below). The results of this first self-assessment process were released in June 2019.



¹⁸ https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/

Progress towards Key feature six: Meaningful and sustained engagement is key to the involvement of carers as equal and expert partners.

Integration Authorities assessment results were discussed at Carer Collaborative meetings in 2019

and 2021, where Carer Reps conducted comparator assessments of progress towards Key feature six (see Appendix for assessments). In summer 2021, IJBs began conducting formal reviews of their Integration Schemes many of which have now been published.

Features central to the success of integration

Six areas must be addressed if integration is to make a meaningful difference to the people of Scotland



Independent Review of Adult Social Care

More recently in early 2021, the Independent Review of Adult Social Care¹⁹ made a series of recommendations about the contribution and involvement of carers within health and social care redesign and decisionmaking noting that:

...we need to support and enable unpaid carers to continue to be a cornerstone of social care support. The contribution they make is invaluable. Their commitment and compassion is humbling. We need to provide them with a stronger voice and with the networks, support and respite they need to continue in their vital role...it is vital that we amplify the voice of lived experience at every level in our redesign. We have a duty to co-produce our new system with the people who it is designed to support, both individually and collectively.



Significantly the Review further considered the role of Carer Representatives on IJBs, recommending that:

Carers must be represented as full partners on the Integration Joint Boards...They already have a nonvoting seat around the Integration Joint Board table, but they should be full partners...Every member of the Integration Joint Board should have a vote.

¹⁹ https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/

Progress with previous Equal, Expert and Valued themes

In the sections that follow, we review progress against some of the core themes and recommendations from the previous Equal, Expert and Valued reports in more depth.

New themes have also been added, to reflect succession planning challenges; the need to ensure sustainability and equity of carer representation on IJBs; and recovery from Covid-19. Feedback from Carer Reps on progress this year is noted alongside each of these recommendations

Carer Rep recruitment and retention



Recruiting and retaining new carers who are willing to undertake representative roles continues to be a challenge for IJBs. At the time of writing we are aware of four IJB areas without Carer Reps, and a further three which are in the process of recruitment. More encouragingly, five areas recruited new Carer Reps to the IJB in 2021 and early 2022. Some IJBs work with or delegate their local Carers Centres to carry out recruitment and selection. Carers Centres and established carer involvement groups continue to be the most productive source of potential applicants.

IJBs can encourage members of existing fora to become IJB Carer Reps by promoting the importance of the role, giving clear information about mutual expectations and commitments, resourcing induction and involvement, including providing training, expenses and resources necessary for carrying out the role.

Equal, Expert and Valued and our template role description²⁰ can help with recruitment. The Scottish Government, the Improvement Service and NHS Education for Scotland have also produced national induction materials²¹ which can be used to support local approaches.

Carer Rep feedback:

Five areas are using the Carer Collaborative template role description to support recruitment. Clear role descriptions, full induction and mentoring are essential to helping new Reps not only be recruited but supported to undertake the role (see below).



²⁰ https://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf

²¹ https://learn.nes.nhs.scot/17538/board-development/induction

Succession planning



Carer Reps are typically appointed for a three-year term, with variance between areas as to the number of terms Reps can remain in office. Succession planning is therefore crucial to support positive exits, continuity and renewal of carer representation. However, whilst some areas are now considering how best to plan for succession, many do not have succession plans or handover processes in place. As a result, as noted in the 2019 Report, some Carer Reps have been asked to stay on in the role beyond their initial tenure or to continue for a second, or even third, term.

- "My planned summer 2022 exit [was] delayed for 12 months to ease succession and also...to help remobilisation."
- "I am now seven months into my third three-year term."
- "We struggle to recruit to the group which makes succession planning difficult, although we have very recently recruited some new members."
- "I was voted in for a second term and have asked the Chair to note we need to work on succession planning for my exit."

At the time of writing six Carer Reps have, or are about to, step down, resulting in the loss of extensive Carer Rep experience and succession challenges in some areas. IJBs should have a formal succession planning process, identifying when tenures end and allowing sufficient time to recruit and train replacements. Of course, existing Carer Reps can, and in a few areas do, assist these processes.

Carer Rep feedback:

Carer Reps note that succession planning remains a significant challenge (and has been exacerbated by Covid-19), with the time commitment required to be involved a challenge for many carers.

Most areas do not have a structured succession planning process in place. This puts unsustainable pressure on existing Carer Reps, some of whom have been in their role for several years.

"I am close to the end of my second 3-year term, and should not be continuing beyond April 2022, but I cannot see a successor being in place by that time. Succession planning is being actively considered, but nobody is champing at the bit to take over from me, and I do not wish to put people off who might like to be involved by throwing them in at the deep end. I rather suspect I shall have to negotiate an extra year in order to affect the handover."



Supporting Carer Reps



Carer Reps bring significant personal and professional experience, but IJBs can help new or prospective Reps by providing structured induction and ongoing training. Newly appointed Reps report benefitting from shadowing and handover with existing Carer Reps and from having facilitated introductions to their fellow board members.

Carer Rep feedback:

There is an improvement in the provision of induction and mentoring support and in some areas existing Carer Reps have been involved in providing this support. However, the picture remains mixed across the country with other areas still in the process of developing structured induction and mentoring support.

Sustainability and equity



Building on the points above, the scale and scope of the Carer Rep role is significant and has expanded in many areas due to increased awareness of the importance of involving carers. However, most areas have only one or two Carer Reps who attend a broad range of strategic groups, sub-groups, locality groups and so on. To ensure the sustainability of Carer Rep engagement it is crucial to have a pool of carers who can support engagement across the broad range of groups and meetings. Moreover, the time commitment required, and the timing of meetings create barriers to engagement for carers who have full-time commitments (working; studying), reducing opportunities to get involved and creating inequity of access for some carers.

'I thought the commitment would be 6 to 8 days a year, but it is far more than that. I am not able to commit that much time as I work full time and have an active caring role'.



Carer Rep feedback:

Many Carer Reps report that their role has turned into a full-time job, due there only being one or two Reps to fulfil multiple roles on the IJB, Strategic Planning Group (SPG) and locality or working groups. Whilst opportunities for increased involvement across a range of groups are hugely welcomed, work must be undertaken to expand and diversify the pool of carers to ensure unsustainable pressure is not put on one or two Reps.

"When I first took on the role as IJB rep we were only ever allowed to go the IJB board meetings. But we pushed to be able to attend more meetings and this, along with a change in leadership...led to us being invited to almost every meeting that involved decisions around support for carers. The downside is that the HSCP have made no efforts to widen the pool of carers who attend these additional meetings and groups, and it all falls on the carer reps. It is definitely not sustainable long term, and I am concerned that new carer reps will end up dropping out...overwhelmed by what is expected of them."

"I am currently involved in 22 groups. Eight of these are long-term groups and the rest are short-term working groups."

Good practice spotlights:

As with previous years, we seek and share examples to encourage good practice



Increasing carer representation in West Lothian

Following completion of the Equal, Expert and Valued self-assessment for this report, **West Lothian** HSCP CEO, IJB and SPG Chairs met with the Carer Rep to discuss the responses. This has led to an agreement to introduce new ways to improve carer representation, including identifying and removing barriers to support more carers to become involved.

Training for Carer Reps

The Coalition of Carers in Scotland and Carers Scotland were funded by the Health and Social Care Alliance to develop and facilitate training for carers in 5 HSCP areas. The project was delayed due to Covid–19 with the training subsequently adapted for delivery online from January to August 2021. The training has increased the number of carer representatives across the five areas and has also increased the confidence and ability of the participants to contribute meaningfully to meetings and to influence local developments.

Resourcing carer involvement in Fife

In **Fife**, the Change and Improvement Manager for unpaid carers has consulted with members of the Carers Strategy Group to ensure that funding for carers is effectively spent. In 2019 Fife Voluntary Action was commissioned to create and support a carers representative group to increase the voice and views from carers to aid policy and strategy development and provide the IJB member with a constituency of views for improved participation. Access to the Carers Scotland Digital Resource for carers in Fife was purchased.

In late 2020 a Participation and Engagement Team was created to support greater involvement of carers and others in shaping policy and influencing strategic direction, including leading the engagement activities for the refresh of the carers strategies. Fife Carers Centre is well resourced and has a very strong relationship with carers. The Carers Strategy Group has recently begun meeting again (online) after a considerable hiatus over the pandemic period. A Carer Support Worker has been appointed to work with carers in each locality.

Expenses policies and renumeration



Previous Equal, Expert and Valued reports highlighted that most Carer Reps were required to subsidise the public duties they carry out on behalf of Integration Authorities because expenses and replacement care were not being covered. It is a basic point of principle and good practice that people should not be financially worse off for undertaking voluntary public duties, and people should not be excluded by the need to subsidise their role. This was affirmed by the Cabinet Secretary for Health and Sport in 2017:

'We expect the integration authorities to ensure that those who participate in the process can do so without detriment.'²²

and by the Scottish Human Rights Commission in their 2021 report on paid participation:

'Create a clear policy for paid participation, detailing all stages and necessary documentation, that can be shared with participants and partner organisations. This policy should be available in a range of formats that respond to any accessibility needs. The policy should detail all relevant processes and the documentation required to produce a robust audit trail.'

The Coalition of Carers in Scotland also made a series of suggestions for renumeration of Carer Reps in their submission to the National Care Service consultation.²³

Written expenses policies are essential for processes to work effectively and equitably, and the table below shows that there has been a slight improvement in IJB practice over the last year.

| | 2020/21 (15 Carer Rep/ IJB returns) | 2019/20 (16 Carer Rep/ IJB returns) | 2018/19 (20 Carer Rep/ IJB returns) | 2017/18 (17 Carer Rep/ IJB returns) |
|--|--|--|--|--|
| Does your IJB | Yes: 7 | Yes: 6 | Yes: 6 | Yes: 5 |
| have a written expenses policy? | No: 1 | No: 5 | No: 5 | No: 9 |
| | I'm not aware of it: 6 | I'm not aware of it: 5 | I'm not aware of it: 7 | I'm not aware of it: 3 |
| Have you been | Yes: 7* | Yes: 5 | Yes: 5 | Yes: 4 |
| given a copy? | No: 5 | No: 11 | No: 14 | No: 13 |
| Is replacement | Yes: 6 | Yes: 4 | Yes: 5 | Yes: 5 |
| care included? | No: 5 | No: 1 | No: 3 | No: 3 |
| | Don't know / no policy: 2 | Don't know / no policy: 6 | Don't know: 2 | Don't know: 5 |
| | N/A to me: 2 | N/A to me: 5 | N/A to me: 3 | N/A to me: 1 |
| Are expenses only | All meetings: 7 | All meetings: 10 | All meetings: 7 | All meetings: 12 |
| for IJB meetings, or for other meetings | Only IJB: 3 | Only IJB: 1 | Only IJB: 3 | Only IJB: O |
| and preparation? | None: 0 | None: 0 | None: 2 | None: 3 |
| | Don't know/ no policy: 1 | Don't know / no policy: 5 | Don't know: 3 | Don't know: 2 |

*Two further areas noted that they were aware of the policy but had not seen it for several years

²² Are they involving us? Integration Authorities' engagement with stakeholders Scottish Parliament Health and Sport Committee Published 12 September 2017 SP Paper 188

²³ https://carersnet.org/wp-content/uploads/2021/11/National-Care-Service-Response.pdf

However, from 15 self-assessment returns received, only seven IJBs have a visible expenses policy and five Carer Reps have never received a copy. Moreover, three Carer Reps note that they use their existing care package or SDS budget to enable them to undertake their role, which means they have less resource to enable them to have a break from caring. The Carers Collaborative has produced a template expenses policy²⁴ which IJBs can adapt and use, with four IJBs already having made use of this.



Agenda setting



The ability of Carer Representatives to contribute agenda items still varies depending between areas, and whilst this showed an improvement in the 2019 report, over the last two years this has declined. It is recognised that this may relate in part to the emergency governance measures put in place to respond to Covid-19, however as the Independent Review of Adult Social Care affirms, 'carers must be represented as full partners on the IJB' and more therefore needs to be done to ensure joint ownership when setting agendas.

Carer Rep feedback:

In some areas Carer Reps report that IJB discussions and decision-making are not 'back to normal' following the implementation emergency governance measures during Covid-19.

Recovery from Couid–19



It is recognised that 2020/21 was an exceptional year, with health and social care services and unpaid carers, being impacted by unprecedented pressures and challenges due to the Covid–19 pandemic. These included the closure of many health and social care services; the initial suspension of IJB and associated meetings; the introduction of emergency governance measures; the transfer to online support from carers centres; access to PPE; flexibility in the use of SDS; and the vaccination programme, to name but a few.

To ensure a fair and sustainable recovery from Covid-19, and to realise the ambitions for system change set out in the Independent Review of Adult Social Care, the involvement of carers as equal and expert partners on IJBs and associated strategic groups is critical. Resourcing and supporting carers, who have been and continue to be under additional strain due to Covid-19, is therefore paramount in the coming year.

Carer Rep feedback:

As we have moved through the pandemic, Carer Reps have had on-going concerns about the resumption of services, including respite and day care; the flexibility of SDS; and the pressures faced by unpaid carers. However, several Reps note that there has been an increased appreciation of the role carers and the voluntary sector play in their area, and many also feel information sharing by the HSCP has been done well.

²⁴ https://carersnet.org/wp-content/uploads/2021/10/Carer-Expenses-Policy.pdf

Equal and Expert: Overview of evidence

This section presents an overview of the 'Equal and Expert' carer engagement standards and shows the extent to which they were evident in selfassessments received from 15 Carer Representatives or their IJB colleagues. Eight indicators show improvements since the third update Report in early 2019, however a further three show a decline over the last year. One new indicator was included in the 2020 and 2021 self-assessment (under Standard One).



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 addresses the needs and meets the aspirations of carers more fully.

Evidence of implementation Carers in representative roles will:

| 1. Receive training and a full induction | Self-assessment feedback shows structured or semi-structured induction to board roles and operations was provided by 9 out of 15 areas. In some areas, induction consists largely of introductions to senior HSCP staff. Ongoing training commonly takes the form of development sessions or seminars, with some areas noting they contribute to the development of the training programme or can request training on specific topics. 2 out of 15 Carer Reps report receiving no induction or training. | Met: 9 Partially Met: 4 Not Met: 2 Improvement on 2019 |
|--|--|--|
| 2. Be supplied with the information they require timeously | Electronic mailings and posting papers online are now commonplace, however two areas noted that they can request papers in whatever format they find most accessible (e.g. paper copy). 11 out of 15 Carer Reps report receiving papers at least a week before meetings, with two noting this process had greatly improved in their area. One area mentioned Reps also have a support meeting with Partnership staff and voluntary sector partners before the IJB to discuss papers. However lengthy papers (300+ pages) remain an issue which affects the time available to review and consult with carers. | Met: 11 Partially Met: 1 Not Met: 3 Similar to 2019 |
| 3. Be mentored | Seven areas noted mentoring opportunities in their areas, which is a marked improvement compared to 2019. Of these, one existing Carer Rep has provided mentoring support to new 'lay members' on the IJB; others are provided support from senior officers or from Carers Centres. Three others noted that mentoring would be available, but they would need to request this as there is no structured mentoring process in place. | Met: 7 Partially Met: 5 Not Met: 3 Improvement on 2019 |
| 4. Be able to obtain the views of other carers via a strong network of carers | Most Carer Reps have good access to carer networks, forums and reference groups. However, six areas noted that Covid-19 had meant meetings for many of these groups were paused, with most only having recently resumed. Carers Centres and carer strategy or partnership groups are mentioned by most areas as playing a key role in connecting with a network of carers to ensure information is shared and input on areas for discussion is sought. One area mentioned having dedicated Partnership engagement workers to support involvement. Three areas noted that more needs to be done to proactively increase both the number and diversity of carers involved in IJB sub-groups. | Met: 13 Partially Met: 2 Not Met: 0 Improvement on 2019 |

Standard One (continued)

Evidence of implementation Carers in representative roles will:

| 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 | Despite only seven of the IJBs in our research having a written expenses policy, most Reps report that all travel, IT / printing costs are covered in their area. Six areas provide replacement care, with a further three Reps unsure as they do not need this. Three Carer Reps noted that they would use their existing care packages or SDS Option One to provide replacement care. Whilst there is an overall improvement in the provision of expenses to cover full costs, in three areas this was not the case, and it appears more still needs to be done to ensure consistency of approach across all IJB areas. The Collaborative carer expenses policy template ²⁵ and recommendations in the 'Paid Participation' report ²⁶ from the Scottish Human Rights Council can help. | Met: 11 Partially met: 1 Not met: 3 Improvement on 2019 |
|--|---|--|
| 6. Be supported to leave their role through succession planning processes, including exit interviews | This new indicator aims to review the succession challenges being experienced (as noted in the 2019 report). Only three areas report that succession planning was being undertaken, one of whom notes this is being progressed in a joint project between the HSCP, Carers Centre, Coalition of Carers and Carers Scotland. Challenges in recruitment of new carers to the role means that many existing Reps are now into their second or even third term of office. Meanwhile, despite the welcome appointment of new Carer Reps in three areas, the Carer Reps who vacated these roles were not offered exit interviews. Six areas report no succession planning takes place in their area. Overall feedback indicates this is an area which requires focussed attention and development. | Met: 3 Partially Met: 6 Not Met: 6 New indicator in 2020/21 |

²⁵ https://carersnet.org/wp-content/uploads/2021/10/Carer-Expenses-Policy.pdf

²⁶ https://www.scottishhumanrights.com/media/2251/paid-participation-report-vfinal.pdf

Standard Two: Carers on strategic planning groups represent the views of local carers

Outcomes:

- 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 1. Carer Eight areas report that their Carers Centres provide support to organisations establish and support carers networks as well as a range of ways will be properly to enable carers to get involved. Two areas report developments resourced to underway to strengthen this in their area, with a further two noting Met: 9 establish and that whilst support is resourced improvements could be made. Two Partially Met: 4 support a strong areas mentioned funding, tendering and procurement as a challenge. Not Met: 2 carer network, Decline on 2019 which offers a variety of ways for carers to get involved 2. The number Nine areas report that numbers have increased, albeit slowly and carers within carer networks. Initiatives to increase involvement include Met: 9 involved in engaging with carers via Carers Centres and other carer networks; exchanging HSCPs encouraging carers to get involved via recruitment videos Partially Met: 5 views through and messages on social media; support from the HSCP and Carers Not Met: **0** the network will Centre to set up carer involvement groups; the use of creative online Unsure: 1 grow approaches to support involvement. However, many areas report that Covid-19 has interrupted or adversely impacted participation, Similar to 2019 noting the increased pressures on unpaid carers as result of the pandemic. 3. The diversity Increasing the diversity of carers is an active and on-going area of of carers development in most areas. Six areas note that proactive attempts to Met: 6 increase representation of the diversity of caring roles are underway, involved in the Partially Met: 9 network will be via Carer Centres and other carer forums or networks. One area noted that engagement with the local third sector interface aims to Not Met: 0 broad increase engagement with those from BAME communities. However, Similar to 2019 nine areas report that whilst networks are open to all carers, more needs to be done to engage with currently underrepresented groups.

Standard Two (continued)

Evidence of implementation

| 4. There will be a continual emergence of new carers willing to undertake representative roles | Five areas report that proactive work is underway to encourage the emergence of new carers to undertake representative roles. Examples include the establishment of carer forums or groups; carer surveys; meetings with HSCP officers on specific carer issues; recruitment campaign with the Carers Centre and TSI. However, again many areas notes that Covid-19 has adversely impacted progress, for example previously planned engagement projects were paused; and many carers are unable to take on additional responsibilities due to the loss of services / increased caring responsibilities. Three areas mentioned the need to ensure additional support and training is available to carers to enable them to undertake what are challenging and time-consuming representative roles. | Met: 5 Partially Met: 8 Not Met: 1 Improvement on 2019 |
|---|--|---|
| 5. The information provided through and by the supported network will be of a high quality | Almost all areas report that the sharing of local and national information is working well, with examples of increased collaboration / information sharing between the IJB and third sector; high quality information being shared by Carers Centres and carer networks/ forums; the use of social media platforms to share information with carers more widely. However, four areas felt that there was a need to increase consistency and alignment of information which is shared. | Met: 11 Partially Met: 4 Not Met: 0 Similar to 2019 |

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

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

| 1. Carers will be placed on the right strategic planning groups including at the top level of governance structures | on the right strategicremained stable since the 2019 report. Carer Reps reportolanning groupsrepresentation on a broad range of strategic groups, includingoncluding at the toplocality planning groups; strategic commissioning groups; carerevel of governancestrategy groups; issue-specific steering groups; as well as the | |
|---|---|--|
| 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 | Most areas note a high level of carers awareness and understanding of the importance of carer involvement within the IJB and other strategic groups. However, on-going formal carer awareness training was only mentioned by five areas, with two of these having paused due to Covid-19. Four areas were unsure if carer awareness training had happened, and one area noted that no training was available. Three Carer Reps felt that they were not always seen as equal and expert partners. | Met: 8 Partially met: 5 Not met: 2 Improvement on 2019 |
| expert" partners3. 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 avoidedThere has been an improvement since 2019 in Carer Reps feeling meetings are more open and inclusive. Some examples include, Carer Rep input as a standing item on the SPG agenda; discussions about language, equalities and human rights; the development of Co-production Charter; meetings being open to the public / media; improvements because of the use of 'hands- up' function in MS Teams. Seven areas noted there are still challenges with the use of jargon, however proactive attempts are being made to address this, for example Carer Reps asking for clarification or pre-IJB support meetings to discuss papers. However, one area noted that the use of jargon had led to the loss of Carer Reps. One area felt Carer Reps still had to push to get their voices heard, as their opinions were not actively sought. | | Met: 14 Partially met: 1 Not met: 0 Improvement on 2019 |

Standard Three (continued)

Evidence of implementation

| 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 | As noted in the 2019 report, electronic publication and circulation have made a difference to the timely receipt of papers. Four areas note that support is also available to discuss the papers, if needed. However, three areas note that at times papers are sent later than planned, and in further four areas papers are sent less than seven days before the meeting. This affects the time available to: seek clarity on any information contained in the papers; discuss the papers with other carers; and prepare/submit questions/comments. This is an on-going challenge, particularly due to the length and complexity of IJB papers, and it affects Carer Reps' capacity to engage more widely to gather carer views. | Met: 8 Partially met: 3 Not met: 4 Decline from 2019 |
|---|--|---|
| 5. The agenda will be jointly owned with all group members having the opportunity to place items on it or raise issues of concern | There has been a decline since 2019 in progress towards this indicator. In five areas Carer Reps note that they feel they are, or would be, able to put items on the IJB agenda. This can involve a request to include a specific point of discussion or asking for items to be included in AOCB. However, in most other areas experience is mixed, with some mentioning other mechanisms being more effective, such as placing items on the SPG agenda, making comments on specific papers, or using the rolling IJB Workplan as a way to make suggestions. In five areas there is no ability to put items on the agenda, with one area commenting that there is no feeling of joint ownership. | Met: 5 Partially met: 5 Not met: 5 Decline from 2019 |
| 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 | Progress towards this indicator has improved since 2019. Six areas note that plans and policies are discussed with cares to gather views and assess their impact – encouragingly two of these areas mention this is done as part of formal Equality Impact Assessments. However, in other areas experience is mixed, with five areas noting this is either done informally at the moment or that not all plans are assessed for carer impact. Three areas note that carer-proofing is not consistently or systematically prioritised. | Met: 6 Partially met: 6 Not met: 3 Similar to 2019 |
| 7. Through their network carers will be supplied with information about the opportunities for participation in strategic planning groups | Carer networks are being actively used to identify and promote opportunities for participation – primarily through Carers Centres and carer networks/forums. In one area the HSCP use social media to advertise opportunities and in another work is underway to increase diversity of involvement. One further area notes a collaboration between the Carers Centre and local authority to develop of capacity building approaches to support carers to become involved. However three areas note that recruitment remains a significant challenge. | Met: 7 Partially met: 5 Not met: 3 Decline from 2019 |
| 8. The outcomes of carer engagement will be evaluated | Five areas note that they have an evaluation process in place to measure the outcomes of carer involvement, with a further two mentioning that this happens informally in their area. It is noted however, that where the outcomes of carer engagement are evaluated, this tends to relate to the impact of carer involvement in policy development and consultation, rather than IJB board membership. Seven areas note that evaluation either does not happen or that they are unsure if any process is in place. | Met: 5 Partially met: 3 Not met: 7 Decline from 2019 |

Summary of scoping results and good practice spotlights

Alongside the Carer Rep/IJB self-assessment each year, the Carers Collaborative undertakes desk-based research to assess the visibility of carers in IJBs plans and processes.

References to carers (and Carer Representatives) in meeting minutes are used as simple indicators of the extent to which carers and carers' outcomes are identified and prioritised by Integration Authorities. This year, the scoping exercise continued to review references to carers in Annual Reports and was broadened to include scoping of Annual Accounts.

Meeting minutes were available for all 31 areas (in 14 areas IJB meetings are now also livestreamed and/or online recordings are publicly available). Encouragingly, during both 2019/20 and 2020/21, there was a significant increase in the number of references to carers in IJB minutes. In 2019/20 this was mainly due to work underway to support implementation of the Carers (Scotland) Act. In 2020/21, discussions related to a broader range of issues, most prominently around the Independent Review of Adult Social Care and the impact of Covid-19, but also Carers Strategies (which many areas are updating); updates on progress with implementation of the Carers Act; Carer Investment Plans; strategic commissioning plans; carer support and short breaks.

Annual Reports were available for 30 areas (although two of these were for 2019/20). There was a slight reduction in the number of references to carers in the annual reports for 2020/21. Most annual reports report progress towards National Health and Wellbeing Outcome Six²⁷ (this information is also available for all HSCP areas on Public Health Scotland's website).²⁸ Most areas compare local achievement against the Scottish average reported in the biennial Health and Social Care Experience survey.



This survey was updated in 2019/20²⁹ and shows the Scottish average of 'carers who feel supported to continue caring' at 34%, down from the previous national average of 37% in the 2017/18 survey (and from 40% in the 2015/16 survey). In 2020/21, 18 areas achieved above the national average, with the remaining 13 areas achieving 34% or less. However, performance (as compared to the previous year) only improved in five areas, five areas remained the same and performance dropped in the remaining 21 areas.

We continue to believe that comparison with a low - and ever reducing - national benchmark is not a useful measure of success.

²⁷ People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of https://www.gov.scot/policies/social-care/health-and-social-care-integration/

²⁸ https://publichealthscotland.scot/publications/health-and-care-experience-survey/health-and-care-experience-survey-2020/detailedexperience-ratings-results/

²⁹ Health and Care Experience Survey 2019/2020: https://www.gov.scot/publications/health-care-experience-survey-2019-20/pages/8/

Annual Accounts 2018/19 were included the scoping for this year's Report to assess reporting on spend of funding allocated to support implementation of the Carers Act. The Carers (Scotland) Act 2016 Statutory Guidance³⁰ states that:

5.1.44. The performance management framework for integration authorities under the Public Bodies (Joint Working) (Scotland) Act 2014 requires integration authorities to publish certain financial information on an annual basis. The detail of this is set out in The Public Bodies (Joint Working) (Content of Performance Reports) (Scotland) Regulations 2014108. Regulation 4(1), read with regulation 4(2)(d) of those regulations requires an integration authority to publish, in an Annual Financial Statement, the total amount and proportion of funds which have been spent in each reporting year on 'social care services provided in pursuance of integration functions to support unpaid carers in relation to needs arising from their caring role'.

Annual Accounts were available for 30 Integration Authorities (four of these were unaudited versions). Perhaps unsurprisingly (as Carers Act funding is not ringfenced) there were only four areas which detailed any figures for the Carers Act funding in their accounts. All four of these areas mention Carers Act figures in the 'usable reserves' notes to the accounts. No other areas detailed Carers Act monies in any of their figures, however 13 areas did make mention of the Carers Act, or support for unpaid carers more generally, in their introductory or contextual commentary.

| Year | Meeting minutes available | IJB minutes referencing carers (total references to carers) | Annual Reports (AR) available | AR refs to carers | Annual accounts available | Carer sup- port/Carers Act monies detailed in figures | Carers support/ Carers Act mentioned in accounts commen- tary |
|---------|---------------------------------|--|--|--|---------------------------------|---|---|
| 2020/21 | 31 | 30 IJBs 570 references to carers | 30 | 1468 Average per area: 50 | 30 | 4 | 13 |
| 2019/20 | 29 | 27 IJBs 366 references to carers | 31 | 1754 Average per area: 57 | 30 | 3 | 21 |
| 2018/19 | 29 | 20 IJBs 79 references to carers | 31 | 1648 Average per area: 53 | - | - | - |
| 2017/18 | 31 | 30 IJBs 89 references to carers | 31 | n/a | - | - | - |
| 2016/17 | 28 | 17 IJBs 29 references to carers | n/a | n/a | - | - | - |

³⁰ https://www.gov.scot/publications/carers-scotland-act-2016-statutory-guidance/

Good practice spotlights:

As with previous years, we seek and share examples to encourage good practice



Training and support for carers

East Dunbartonshire have established a Public Service Users and Carers (PSUC) group. Carer Reps are part of this group which provides a range of support and training for carers. This includes regular awareness sessions, and carers can request training on specific topics when they need more information to help them contribute to discussions in meetings. The PSUC group also have a full expenses policy in place which includes all travel and carer expenses, including replacement care.

Mentoring support to extend engagement

In **Edinburgh** the existing Carer Rep has been involved in the recruitment and mentoring of one new Carer Representative and two new Citizen Representatives who have joined the IJB. These Reps have pre-meetings together prior to the IJB, and the two Carer Reps also have pan-Lothian Carer Rep meetings to share perspectives across the four IJBs that are involved with NHS Lothian. In **Falkirk** mentoring is provided initially by the IJB Senior Service Manager and Carer Reps also have access to support from the Carers Centre.

Strengthening carer involvement networks

Carer Centres and other local carer forums play a key role in ensuring carers can engage and contribute their views to local policy and practice developments. In Midlothian, VOCAL Midlothian organise and facilitate meetings of Carers Action Midlothian (CAM). This group explores how to involve more carers, including ideas to involve and include carers from a wide range of caring circumstances. In **South Lanarkshire** the numbers of carers being supported by Lanarkshire Carers service has grown due to the pandemic. Carers are supported by the Carers Centre and Carers Connected Group to ensure they can exchange their views through the network. **East Renfrewshire** has setup a Carers Collective with support of the HSCP Carers Lead and the local Carers Centre in order to hear from carers directly. Scottish Borders has four Carer Reps on the Carers Workstream. These Reps are elected by members of Carers First to represent the wider views of carers and to identify issues and raise concerns.

Proactively supporting recruitment

Recruitment of Carer Representatives has been identified as a significant challenge within this, and previous years' reports. It is therefore encouraging to highlight good practice now taking place to proactively address recruitment and succession. East Dunbartonshire HSCP has produced recruitment videos and posts messages on social media encouraging local people to contribute to shaping local services. There is an ongoing recruitment process in place, with the HSCP working alongside the local Carers Centre, the TSI, local authority and other third sector partners. **Falkirk** aim to recommence their carer engagement project (which was paused due to Couid-19). This project is a collaboration between the Coalition of Carers, Carers Scotland, Falkirk Carers Centre and HSCP Carers Lead, and aims to support the recruitment, training and on-going support of Carer Representatives. In Fife training is being carried out by Fife Voluntary Action, and a new recruiter is aiming to form a constituency of carers. An induction pack has also been prepared with input from the existing Carer Rep to prepare for their upcoming end of tenure.

Building diversity

Engaging with a diverse range of carers is key to ensuring equality and representativeness of carer views. North Lanarkshire Carers Together have increased their engagement with those from BAME communities and have found their online engagement has helped reach more diverse audiences. West Dunbartonshire have actively engaged with those who have different caring roles, for example caring for people with Alzheimer's; long term conditions; as well as young carers. West Lothian report that diversity is growing with concerted efforts being made by the Carer Centre and the IJB Carer Rep. to ensure this is the case. **Edinburgh** are engaging with carers from black and minority ethnic communities via Edinburgh Voluntary Organisations Council (EVOC) forums; East Renfrewshire are actively expanding the Carers Collective group so all types of carers are equally represented; and **Falkirk** Carers Centre is creating carer sub-groups for specific carer roles, e.g. parent carers, carers for those with dementia.



Carer involvement in strategic groups

In **North Lanarkshire** Carer Representatives are members of a range of strategic groups including the IJB; Performance Finance and Audit Committee; Carers Strategy Implementation Group; Integrated Care Fund Steering Group; Community Capacity Building Subgroup. The local authority has recently established 12 locality planning groups (LPG's) focusing on the needs of the two major care groups (Frail, Elderly and Long-Term Conditions and Addictions, Learning Disability and Mental Health). North Lanarkshire Carers Together and CL&D have developed a programme of training to equip carers to participate at this level.

Carer proofing policies

In Shetland the IJB Carer Rep leads on carer proofing new policies and strategies which has led to amendments being made based on Carer Rep feedback. In Clackmannanshire & Stirling this has been discussed at the IJB and carers are included in Equality Impact Assessments and in Scottish Borders the Carers Centre leads on carer proofing. In **East Dunbartonshire** all strategic plans are shared with the SPG for comments and the lead officer for new strategic plans attends the Public Service Users and Carers group to allow discussion about the plan and to gather views from the group. In Midlothian new policies within the council/partnership require to be assessed against an Inequalities Impact Assessment (IIA), checking if there are any issues which impact detrimentally against a particular group of people. Carer representatives at strategic groups can comment and feedback on papers and proposals before approval.

Making a difference

The Carers Collaborative follows the Equal and Expert standards in its own work. In 2019/20 and 2020/21, Carer Reps reviewed the collective contribution the Collaborative's work has made and the individual impact of their involvement in local IJBs.

Over the period 2019 – 2021 key areas of work included:

- Developing a template expenses policy (shared with Scottish Government)
- Reviewing IJB self-assessments of progress towards integration
- Meeting with Minister for Public Health, Sport and Wellbeing
- Meetings with Scottish Government Carer Policy Team and Integration & policy Support Team
- Developing a Briefing Paper on Carers & Equality Impact Assessments (endorsed by COSLA and shared with Scottish Government)
- Producing Equal, Expert & Valued Year Four Report.

Carer Reps also considered what they valued from their involvement with the Collaborative. Key areas of feedback showed Reps felt that having the opportunity to meet and discuss different experiences, practice and perspectives from around the country was extremely beneficial to building their knowledge and supporting their work on their IJBs.

- "Knowing good/bad practice elsewhere helps get the balance to 'praise' for what we have that is good, but information to try to influence the 'bad'!"
- "The intelligence we gain at meetings means we have more authority and are more able to ask the right questions and challenge more effectively."

Carer Reps also felt that being members of the Carers Collaborative has helped strengthen their collective voice to better influence both local and national policy and practice.

"Individually our voices can be quiet but together we are strong. We use our collective voice to influence policy and practice locally and nationally, for example with IJBs, Scottish Government and COSLA."



- "On our own we have very little chance of being equal. Being a member of the Collaborative restores some of the power imbalance."
- "We now have a seat at the table in other decisionmaking forums. We have also met with key decisionmakers to influence important legislative and policy developments, such as the Independent Review of Adult Social Care and the NCS consultation."

Alongside this the Collaborative gives Carer Reps the opportunity to keep abreast of regional and national policy and practice developments. During 2019 meetings involved the Minister for Public Health, Sport and Wellbeing and the Self-Directed Support Team at Scottish Government. During 2020/21 it included meetings with Derek Feeley, Chair of the Independent Review of Adult Social Care, Carer Policy Team and Integration and Policy Support Team at Scottish Government and the Equality & Human Rights Commission.

- "Keeping up to date with regional and national policies. The speakers/ presentations are always very informative."
- "Information is power and we need as much power as we can get."

When Carer Reps were asked what they value about being involved in their IJB, overwhelming feedback focussed on the ability to ensure carers rights and needs were considered within decision-making. Some areas also noted that carer involvement had improved in their area.

- "The opportunity to ensure carers are thought about and dealt with properly in decision–making."
- "Actually making a difference to carers on two occasions [through the] reversal of decisions impacting on specific carer groups."
- "There has been an improvement in carer involvement over the last year – a shift in culture and an increased recognition of carers as partners."

However, as the following feedback shows, more needs to be done in some areas to ensure Carer Reps are seen as equal and expert partners on IJBs. More support is required to ensure carers can carry out their role, that their views are heard and that they have influence over discussions and decision-making. Recruitment, succession and properly resourcing and embedding involvement were again raised as key challenges.

"I am an Unpaid Carer Rep. Actually, I'm an unpaid, Unpaid Carer Rep. No, in fact, I'm an unpaid, Unpaid Carer Rep, with no voting rights."

"Although carer involvement has improved, much of this is because Carer Reps have pushed for this to happen and have built relationships with key people. However, carer involvement processes haven't been embedded and when existing Carer Reps finish their term of office these gains could be lost."

"We are being invited to join different groups in our area – and nationally. But recruitment and succession challenges, and the lack of dedicated resources to support carer involvement, mean this is putting unsustainable pressure on Carer Reps. Carer involvement has to be more than a tick box – it must be properly resourced and meaningful."

We therefore conclude this report by revisiting our recommendations for continuing improvements in Carer Representation.

Recommendations to improve Carer Representation

This section updates the recommendations from our previous reports and identifies next steps for improving carer representation.

| Rec | ommendation | Progress | Next steps – 2022+ |
|-------------------------|---|--|--|
| 1. 1.1 1.2 | Include Carers' Reps in decision making Carer Reps are involved in IJB strategic groups. Carer Reps are seen as 'equal, expert and valued' partners. | Carers are better represented within IJB structures, with more opportunities to get involved in a range of locality and strategic groups. Emergency measures implemented by IJBs during Covid-19 have impacted on carer involvement in decision-making. The Independent Review of Adult Social Care recommends Carer Reps are full partners on the IJB. | Continue to support carer involvement in key governance and decision-making processes, particularly as IJBs return from emergency measures implemented in response to Covid-19. Processes to support implementation of the recommendations from the Review of Adult Social Care should be developed by IJBs. |
| 2. 2.1 2.2 | Increase awareness and profile of carers and Carer Reps Provide formal Carer Awareness training to IJB strategic partners. Undertake 'carer proofing' of policies and strategies. | Most areas note a high level of carers awareness and understanding of the importance of carer involvement within the IJB and other strategic groups. However, more still needs to be done to increase awareness and understanding of carer issues. | Carer Awareness training for IJB strategic partners should be prioritised to ensure Carer Reps experiences and expertise is seen as equally valuable. Prioritise and involve carers to 'carer proof' policies, linking these with Equality Impact Assessments. The Carer Collaborative Briefing Paper on Carers and Equality Impact Assessments can help. ³¹ |
| | Build capacity in Carer networks Prioritise the development of succession planning processes. Develop systematic recruitment and induction processes. Expand the pool of Carers Reps to support sustainable representation. Increase the diversity of Carers Reps to ensure representativeness. | Recruitment and retention remain a concern, particularly in relation to succession planning and the representation of carers on the broad range of IJB/HSCP strategy groups. Carer Reps are increasingly invited to become involved in strategic groups and meetings, however responsibility often lies with one or two Carer Reps. | Succession planning processes for Carer Rep roles must developed as a matter of priority. IJBs should ensure sufficient time and resources for: Exit interviews and handovers from existing Reps. Structured induction and training for new Reps to build confidence and capacity to engage. Capacity across carer networks should be proactively built to: Identify carers who wish to become involved and provide them with training and support to participate. |

31 https://carersnet.org/wp-content/uploads/2021/10/Carers-and-EQIA.pdf

| Rec | ommendation | Progress | Next steps – 2022+ |
|---------------------------------|--|--|--|
| | | | Increase the number of Carer Reps in each area so that one or two Reps don't have to attend multiple planning groups. Support increased diversity of Carer Reps, ensuring those who face barriers to engagement are supported to be involved. |
| | Value and resource Carer Reps Ensure Carer Representatives have a clear remit. Train and support Carer Representatives. Provide the expenses and resources necessary to perform the role. | The provision of role descriptions and mentoring support / training for Carer Reps shows a slight improvement. Most IJBs now provide expenses for IJB and other strategic meetings, however, reimbursement of other costs such as printing, replacement care and preparation time is still mixed. The number of written expenses policies remains low and where these are available they are not being shared consistently with Carer Reps. | Use or adapt the Carer Collaborative role description ³² to provide mutual clarity on roles, remits and expectations. Continue to develop structured training and mentoring opportunities for Carer Reps. Use or adapt the Carer Collaborative template expenses policy ³³ to develop and implement an expenses process that acknowledges and meets the full costs of carer contributions to IJBs and other strategic groups. Proactively share expenses policies with Carer Reps. Explore the provision of remuneration for Carer Reps to acknowledge their time and expertise. |
| 5 . 5.1 5.2 5.3 | Make meetings better Continue supporting Carer Reps to contribute to agendas. Continue to improve the accessibility of meetings, minutes and papers. Allow time in meetings for discussion and questions. | IJB meetings have become more accessible, with more opportunities for carers to contribute and an increased focus on using jargon-free language. Access to agenda-setting varies across the country with many areas feeling the agenda still 'belongs' to IJB officers. Over the last two years meetings have mostly been held online (which has had benefits and challenges). Almost half of IJBs now either livestream or have publicly available recordings of their meetings. | Continue to issue papers sufficiently in advance to allow Carer Reps to read, consult and prepare. Provide more consistent access to agenda- setting, whether through Strategic Planning Groups, pre-IJB meetings or structured contact with Chairs and officials. Ensure Carer Rep involvement is meaningful and is having an impact (e.g. in decision- making) and allow time in meetings for discussion and questions. Ensure online meetings are accessible, for example with the provision of IT equipment and digital training for Carer Reps. |

³² https://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf

³³ https://carersnet.org/wp-content/uploads/2021/10/Carer-Expenses-Policy.pdf

Appendix

Integration Authorities assessment of progress towards Key feature 6

(as reported to the Integration Leadership Group, June 2019)

| Proposal | Not yet established | Partly established | Established | Exemplary |
|--|------------------------|--|---|--|
| Effective approaches for community engagement and participation must be put in place for integration. | | 8 IAs: Argyll & Bute, Dumfries & Galloway, Edinburgh City, Fife, Orkney, Perth & Kinross, Scottish Borders, Shetland. | 18 IAs: Aberdeen City, Aberdeenshire, Clackmannanshire and Stirling, Dundee, East Dunbartonshire, East Lothian, East Renfrewshire, Falkirk, Glasgow City, Highland, Inverclyde, Midlothian, Moray, North Lanarkshire, Renfrewshire, West Dunbartonshire, West Lothian, Western Isles. | 5 IAs: Angus, East Ayrshire, North Ayrshire, South Ayrshire, South Lanarkshire. |
| Improved understanding of effective working relationships with carers and people using services and local communities is required. | | 10 IAs: Argyll & Bute, Dumfries & Galloway, Edinburgh City, Fife, Orkney, Perth & Kinross, Renfrewshire, Shetland, West Dunbartonshire, Western Isles. | 18 IAs: Aberdeen City, Aberdeenshire, Angus, Clackmannanshire and Stirling, Dundee, East Dunbartonshire, East Lothian, East Renfrewshire, Falkirk, Glasgow City, Highland, Inverclyde, Midlothian, Moray, North Lanarkshire, Scottish Borders, South Lanarkshire, West Lothian. | 3 IAs: East Ayrshire, North Ayrshire, South Ayrshire. |
| We will support carers and representatives of people using services better to enable their full involvement with integration. | | 14 IAs: Aberdeenshire, Argyll & Bute, Clackmannanshire and Stirling, Dumfries & Galloway, East Lothian, Edinburgh City, Falkirk, Glasgow City, Highland, Moray, Perth & Kinross, Scottish Borders, Shetland, Western Isles. | 14 IAs: Angus, Dundee, East Dunbartonshire, East Renfrewshire, Fife, Inverclyde, Midlothian, North Lanarkshire, Orkney, Renfrewshire, South Ayrshire, South Lanarkshire, West Dunbartonshire, West Lothian. | 3 IAs: Aberdeen City, East Ayrshire, North Ayrshire. |

Carer Rep comparator assessment of progress towards Key feature 6

(completed by Carer Reps from 20 IA areas in 2019)

| Proposal | Not yet established | Partly established | Established | Exemplary |
|--|------------------------------|---|--|---|
| Effective approaches for community engagement and participation must be put in place for integration. | | 12 IAs: Argyll & Bute; Clacks & Stirling; Edinburgh; Falkirk; Fife; North Lanarkshire; Perth & Kinross; Renfrewshire; Shetland; South Ayrshire; West Lothian; West Dunbartonshire. | 5 IAs: Dundee; East Dunbartonshire; East Lothian; East Renfrewshire: Scottish Borders. | 3 IAs: Angus; D&G North Ayrshire. |
| Improved understanding of effective working relationships with carers and people using services and local communities is required. | 11A: Argyll & Bute | 12 IAs: Clacks & Stirling; Edinburgh; East Lothian; East Renfrewshire; Falkirk; Fife; North Lanarkshire; Perth & Kinross; Renfrewshire; Shetland; South Ayrshire; West Lothian. | 6 IAs: Angus; D&G Dundee; East Dunbartonshire; Scottish Borders; West Dunbartonshire | 11A: North Ayrshire. |
| We will support carers and representatives of people using services better to enable their full involvement with integration. | | 15 IAs: Angus; Argyll & Bute; Clacks & Stirling; East Lothian; Edinburgh; Falkirk; Fife; North Lanarkshire; Perth & Kinross; Renfrewshire; Scottish Borders; Shetland; South Ayrshire; West Dunbartonshire; West Lothian. | 5 IAs: D&G Dundee; East Dunbartonshire; East Renfrewshire; North Ayrshire. | |

Update on progress towards Key feature 6 – January 2021

The Carers Collaborative met on the 12 January 2021 and provided an update on progress in relation to Key feature 6 from March 2020 to January 2021.

Carer representatives from 17 local authority areas were present.

Q1 Effective approaches for community engagement and participation

This has improved – 31%

This has stayed the same – 54%

This has declined - 15%

Q2 Improved understanding of effective working relationships

This has improved – 35% This has stayed the same – 53% This has declined – 12%

Q3 We will support carers and representatives of people using services better

This has improved – 43% This has stayed the same – 51% This has declined – 6%







Thanks and acknowledgments

This report was produced by the Coalition of Carers in Scotland, authored by Jen Curran of The Lasting Difference.

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The Coalition of Carers in Scotland, PO Box 21624, Stirling FK7 1EF T 01786 850 247 • E coalition@carersnet.org www.carersnet.org



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