



# **National Carer Organisations' response to the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill Consultation**

## **Introduction**

The National Carer Organisations welcome the opportunity to submit a response to Learning Disabilities, Autism and Neurodivergence (LDAN) Bill Consultation.

The National Carer Organisations are Carers Trust Scotland, Carers Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance.

Together we have a shared vision that all of Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The National Carer Organisations aim to achieve this through the representation of unpaid carers and amplifying their voices at a national level.

We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

Our response to the LDAN Bill consultation reflects what we heard from unpaid carers at our various consultation events and through our online polling. There will also be additional responses submitted from the Coalition of Carers in Scotland, Carers Trust Scotland, and MECOPP on behalf of their memberships and unpaid carers groups.

Our response to the LDAN Bill consultation will focus on the following questions as these were the areas that were identified as being a priority by unpaid carers and our members:

- Reach and definition: who should the LDAN Bill include?

- Statutory Strategies
- Mandatory Training
- Inclusive Communications
- Data
- Independent Advocacy
- Accountability

## Consultation Responses

### Reach and definitions: who should the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill include?

The Bill proposes 3 definitions of who the Bill should include:

**Proposal 1:** People who are Neurodiverse/Neurodiverse people

**Proposal 2:** People who are Neurodivergent/'Neurodivergent People'

**Proposal 3:** Including specific conditions only in the Bill

***Which of these proposals do you agree with (if any), please tell us why?***

We had some mixed views from unpaid carers about Proposal 2. Some unpaid carers were familiar with the term neurodivergent and felt that it was a useful way to group people who were autistic or had a learning disability or a learning difficulty. Carers Trust Scotland's consultation work with young carers (aged under 18) found that young carers agreed with Proposal 2, and many of the predominantly sibling young carers consulted had a good grasp of term neurodivergent.

However, adult unpaid carers (many of whom were autistic or identified as neurodivergent) that took part in the discussion groups hosted by the Coalition of Carers felt that neurodivergent was not a term that was commonly understood by the general public and did not think that the people that they cared for who had learning disabilities or Down's Syndrome would consider themselves to be neurodivergent.

*"Neurodivergent commonly applies to autism etc. You would have to re-educate every single person who has a disability along with their carers*

*and any profession that works with them. I very much doubt that the funding will be available to do it properly.” - Carer (Coalition of Carers discussion group)<sup>1</sup>*

*“My son has Down’s Syndrome. He will not understand his ‘proposed’ new identity.” - Carer (Coalition of Carers online discussion)*

We heard similar feedback from unpaid carers of people with multiple and profound learning disabilities and those caring for people with rare conditions.

*“my daughter has a rare chromosome condition. She is proud to be part of a very small community of people in the world who live with this condition. She does not see herself as neurodivergent and its not a label that I think she or we would ever use to describe her condition” - Carer (Coalition of Carers discussion group)*

We also share some of the concerns raised by unpaid carers about the term neurodivergent being used to group a range of different conditions together. This could have some unintended outcomes such as support and services not being tailored to meet the specific needs of people with different learning and support needs.

*“The problem with putting learning disabilities along side autism and neurodivergence is assuming they are the same thing and also suggests that neurodivergence and autism is around intelligence.” - Carer (Coalition of Carers discussion group)*

*“Just lumping together everyone as neurodivergent may highlight the different needs from neurotypical, but it doesn’t highlight the difference within the neurodivergent communities” – Carer (Coalition of Carers discussion group)*

We therefore think that a combination of Proposal 2 and Proposal 3 provides the best approach to defining who the LDAN Bill should be about. We know that some people prefer to be known as neurodivergent, but this is not a term that everyone will identify with, which is why we think individual conditions and diagnosis should also be included in the Bill. We agree that the Bill should name and define the different populations of people who will covered by the provisions in the

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<sup>1</sup> The carer quotes from the Coalition of Carers and the Carers Trust Scotland have been taken from the individual consultation responses that these organisations have submitted separately.

Bill. This would increase the visibility of these groups and more clearly state who the Bill applies to for the benefit of those people, as well as for practitioners.

We also think that people who do not have a formal diagnosis should be able to access the same rights included in LDAN Bill as those with a formal diagnosis.

We are aware that it can take years before someone receives a diagnosis for autism, learning disabilities, and other neurodivergent conditions. Whilst someone is awaiting formal diagnosis they should not be denied the opportunity to access support and services that may help them.

*“I don’t think people should have to wait ages to have a name for what’s wrong with them, they should be able to start getting help and so should their family. My brother was told he had one thing and then it was actually another thing.”* Young Carer, Secondary School Focus Group (Carers Trust Scotland).

***Which of these proposals do you not agree with (if any), please tell us why?***

We do not agree with Proposal 1 for the reasons already outlined in the consultation document. We agree that the term neurodiversity does not refer to a particular condition; it is a term used to describe a population that contains both neurodivergent and neurotypical people. Therefore, for the purpose of this Bill, we do not think neurodiversity is a useful term.

***Is there anything else that we should consider in relation to this topic?***

There needs to be a clear rationale behind why some conditions will or will not be included in the Bill. For example, unpaid carers in our consultation group queried why certain conditions were e.g. epilepsy were included, but other neurological conditions were excluded.

*“If you are autistic there is no medication for this, however something like epilepsy can be medicated. It will be unfair to view both of these conditions under the same lens.”* - Carer (Coalition of Carers discussion group)

We think that more consideration should be given to the intersectionality between being autistic or having a learning disability and other protected characteristics. For example, what difference will the LDAN Bill make to a Chinese woman with a learning disability that can't access any of the mainstream services for people with learning disabilities.

We also think consideration should be given to whether some of the aims of the LDAN Bill could be achieved through the Human Rights Bill in Scotland, which will incorporate elements of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) and impose positive obligations on the state to respect, protect and fulfil the human rights of disabled people, which will people with learning disabilities, autism and neurodivergence.

## **Statutory Strategies for Neurodivergence and Learning Disabilities**

**Proposal 1:** Introduce a requirement for a national strategy on neurodivergence and learning disabilities to be produced by the Scottish Government.

**Proposal 2:** Introduce a requirement for local strategies to be produced by some public bodies, for example health and social care partnerships, local authorities, and other public bodies.

**Proposal 3:** Introduce guidance that could cover a range of topics to be included in national and local strategies.

**Proposal 4:** Ensure that there is a requirement to review strategies, for example every 5 years for example.

**Proposal 5:** Ensure that people with lived experience have to be involved in the development of the strategies.

**Proposal 6:** Consider whether any new accountability mechanism introduced by the Bill should have a duty to review national and/or local strategies and their effectiveness.

***Which of these proposals do you agree with (if any), please tell us why?***

We partly agree with Proposal 1. We think that a national strategy on neurodivergence and learning disabilities will allow for Scottish Government to have an overview of the different policy areas that impact the lives of people who are neurodivergent or have a learning disability. However, unless the national strategy includes an implementation plan that is fully resourced and is monitored, we think it is unlikely to have any real impact on improving outcomes for people who are neurodivergent or have a learning disability.

*“Haven’t we seen this already with the Autism Strategy in 2011. What difference did that make. Unless the Government puts more money into it and actually makes sure that the actions in the strategy actually happen, its just a pointless piece of document” – Carer (Coalition of Carers discussion group)*

The evaluation of the national Autism Strategy in 2011 found that it did help to raise the profile of Autism in Scotland, but it’s impact was limited due to lack of resources, monitoring and accountability. For a national LDAN strategy to be successful these would need to be addressed.

We agree with Proposal 5. If there is to be a national strategy on neurodivergence and learning disabilities, it must be produced in partnership with people who are neurodivergent or have a learning disability. This must also include the views of people who have multiple and profound learning disabilities, or who use alternative augmentative communication. We also believe that the views of unpaid carers who support family members that are neurodivergent or have a learning disability should be included in the development of national strategy.

We partly agree with Proposal 6. Without an accountability mechanism in place, a national strategy will not help to improve outcomes for people who are neurodivergent or have a learning disability. We think that consideration should be given to whether the proposed National Care Board (under the NCS Bill) might be a mechanism for providing accountability and scrutiny of a national strategy on neurodivergence and learning disabilities. We also think the new Human Rights Bill for Scotland also presents opportunities for an accountability mechanism to be introduced that could help people with learning disabilities and neurodivergence to access their rights.

***Which of these proposals do you not agree with (if any), please tell us why?***

We do not fully agree with Proposal 2. We do not think that introducing a requirement for local authorities and Health and Social Care Partnerships (HSCPs) to produce separate local strategies for neurodivergence and learning disabilities will result in better outcomes for people who are neurodivergent or have a learning disability.

Local carer organisations and unpaid carers have frequently told us of the limited impact that local carer strategies have had in improving unpaid carer outcomes across Scotland.

The Carers (Scotland) Act 2016 included a requirement for local carer strategies to be produced in consultation with unpaid carers and stipulated what needs to be included in all local carer strategies. Various research carried out by the National Carer Organisations over the last few years has shown that local carer strategies have not included all of the statutory requirements and that there is very little accountability or monitoring of how well local carer strategies are being implemented. MECOPP for instance did some analysis of the local carers strategies that showed only 15 out of 30 contained equalities outcomes designed to support BME communities<sup>2</sup>.

We think that instead of producing local strategies specifically for neurodivergence and learning disabilities, the time and resources could be better utilised by requiring existing HSCP and local authority strategies to include references to neurodivergence and learning disabilities. For example, all HSCP strategic plans should be required to include information about how they will support people who are neurodivergent or have a learning disability and their unpaid carers.

***Is there anything else that we should consider in relation to this topic?***

Although we are in agreement with Proposal 5, we believe it should also include the lived experience of unpaid carers. Unpaid carers' experiences and insightful knowledge could be vital in helping to ensure the development of a sustainable and robust strategy.

It is also worth noting that unpaid carers often advocate on behalf of family members who have profound and complex learning disabilities.

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<sup>2</sup> MECOPP (2023), 'Local Authority Carers Strategies and Action Plans: A Review', <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/646f804e13cf995603e31f36/1685028943149/MECOPP+Briefing+Sheet+16.pdf>



Many of these young people and adults with multiple and profound learning disabilities may be unable to contribute their views without the support from their unpaid carers. It is therefore important to ensure that unpaid carers are also involved as advocates where it is needed.

## **Mandatory Training in the Public Sector**

**Proposal 1:** Mandatory training for public facing staff in health and social care

***Which of these proposals do you agree with (if any), please tell us why?***

We partly agree with the Proposal 1. We think that there should be training offered to all health and social care staff, but and that this training should be extended to all public sector staff who support or work with people who are neurodivergent or have a learning disability. In particular this should be extended to all staff who work in local authorities, including education and housing.

*“I believe mandatory training would help professionals know more about how to help my brother.”* Young Carer, Secondary School Focus Group (Carers Trust Scotland)

We think that the design of any mandatory training needs to include people with learning disabilities and people who are neurodivergent. The training needs to also reflect the diversity within the LDAN community and address the inequalities and discrimination that people with additional protected characteristics experience.

Unpaid carers in our focus groups (many of whom were also neurodivergent) suggested that any mandatory training in itself will not necessarily lead to a more empathetic workforce, and that more needs to be done to attract, recruit, and retain the right people into teaching, health, social care and justice.

*“Nobody should have to be taught how to treat people with dignity and respect. This should be a given, rather than have specific training on this.”* - Carer (Coalition of Carers discussion group)



*“We need to focus more training on how to communicate with someone who has a learning disability or is not a verbal communicator. Professionals should be able to understand if a person’s communication needs are not being met.” – Carer (Coalition of Carers discussion group)*

***Which of these proposals do you not agree with (if any), please tell us why?***

No further response.

***Is there anything else that we should consider in relation to this topic?***

No further response.

## **Inclusive Communications**

**Proposal 1:** Alternative means of communication for neurodivergent people and people with learning disabilities.

**Proposal 2:** Better access to easy-read versions of all public facing communications and documents made by public authorities.

**Proposal 3:** Neurodivergent and learning disabilities strategies should include information on how communication needs are met

**Proposal 4:** An enforceable Accessible Information Standard for Scotland

***Which of these proposals do you agree with (if any), please tell us why?***

We agree with Proposal 1. Alternative means of communication for neurodivergent people and people with learning disabilities should be made available by all public authorities and services that support people with learning disabilities and neurodivergent people. This includes health services, local authorities, social work, education, social security and justice services.

We believe that any request for alternative means of communication needs to be person led and not just person centred. What we mean by this is that people with learning disabilities and neurodivergent people should have a choice about the alternative means of communication they would like. Services and authorities should not make assumptions about what 'someone with a learning disability' would like and only offer one alternative, such as Easy Read.

We agree with Proposal 2, to some extent. Better access to easy read versions of all public facing communications and documents by public authorities will be very welcome. However, unpaid carers from ethnic minority communities have told us that any easy read version needs to also be made available in community languages to enable ethnic minority people with learning disabilities to understand the information.

As well as easy read versions, consideration needs to also be given to a range of other ways in which people with learning disabilities and neurodivergent people would like to access information and communicate with professionals in public authorities. For example, use of alternative augmentative communication (AAC), Plain English, translated materials and interpreters for non English speakers and for those who have sensory loss.

Young carers in our focus group consultations highlighted the use of technology and questioned why everything had to be in writing. They highlighted the need for videos and audio files that they could replay:

*"I tried to write down all the complicated words the Doctor used when talking about my brothers medical condition so I could google them at home. I think I spelt them wrong as it was difficult to find them. I get so frustrated when I don't understand how to help him, a video for me and my brother would have been so much easier." Young Carer, Secondary School Focus Group (Carers Trust Scotland).*

***Which of these proposals do you not agree with (if any), please tell us why?***

No further response.

***Is there anything else that we should consider in relation to this topic?***

No further response.

## **Data**

**Proposal 1:** Developing a commission(er) with responsibility for data collation

**Proposal 2:** Placing duties on some relevant public bodies to collect data on neurodivergent people and people with learning disabilities

**Proposal 3:** Placing duties on some relevant public bodies to provide returns to the Scottish Government regarding local data on people with learning disabilities and neurodivergent people.

**Proposal 4:** Consideration of the development of a Scottish version of the Learning Disability Mortality Review (LeDeR) programme.

***Which of these proposals do you agree with (if any), please tell us why?***

We agree with Proposal 2. We think that local authorities and health boards should be collecting better and meaningful data on the number of neurodivergent people and people with learning disabilities that access their services.

They should also be collecting data on the experiences (positive and negative) that neurodivergent people and people with learning disabilities have had with their services with a view to improving their services and making them more accessible and inclusive.

We also think that any collection of data about people with learning disabilities and people who are neurodivergent needs to take an intersectional approach. People with learning disabilities and neurodivergence can experience multiple and additional inequalities due to other protected characteristics such as ethnicity, age, and gender.

If the data being collected is not viewed through an intersectional lens there is a risk that some groups of people with learning disabilities or neurodivergence will continue to be further marginalised and excluded from services and support.

Unpaid carers in our focus groups also expressed views on ensuring the data collection process does not just become another tick box exercise

that public authorities complete in order to be ‘compliant’ – it is important that the purpose of collecting and recording data about the lives of people with learning disabilities and people who are neurodivergent is done in a meaningful and inclusive way.

*“Data collecting is important but we need to ensure we do not dehumanise people. The way you collect the data is very important, we have to remember their right to privacy and consent.” - Carer (Coalition of Carers discussion group)*

We partly agree with Proposal 3. We think there should be a duty on some public bodies, such as local authorities and health boards to provide returns to the Scottish Government regarding local data of people with learning disabilities and neurodivergent people. However, we think with this duty there needs to be clear guidance on the purpose of the data returns and how the data returns will be used as part of a quality improvement cycle at local and national level.

We agree with Proposal 4. The LeDeR programme in England has provided important data about premature deaths in adults with a learning disability, and has recently been extended to include autistic adults as well. The LeDeR data has highlighted that ethnic minority men with a learning disability have a lower life expectancy compared to white men with a learning disability. We currently do not have comparable data in Scotland so we cannot know for sure whether ethnicity, gender or other protected characteristics are leading to greater health inequalities for some adults with a learning disability.

We agree that investment in a research programme in Scotland similar to LeDeR would provide greater insight into the causes of death in adults with a learning disability and allow for measures to be considered and put in place to prevent untimely deaths.

***Which of these proposals do you not agree with (if any), please tell us why?***

No further response.

***Is there anything else that we should consider in relation to this topic?***

With the proposal to introduce a National Care Board as part of the NCS Bill, we think there is potential for this new National Care Board to

possibly have a role in collecting and scrutinising the data returns from local public bodies. We think this should be explored further.

We also think that there are lessons that could be learned from the experience of implementing the Carers Census which was a duty laid out in the Carers (Scotland) Act to collect data about unpaid carers in the Carers (Scotland) Act 2016.

The Carers Census collects a variety of information on unpaid carers, and the support they are provided with. Data is collected annually from across Scotland via HSCPs and local carer organisations.

Evaluation carried out by Healthcare Improvement Scotland<sup>3</sup> has shown that there continues to be significant gaps in data about unpaid carers in Scotland with the recent Carers Census report highlighting challenges around quality and variance of data being submitted from local areas. Concerns have also been raised that the requirement for data has impacted on local assessment practice and the experience of staff and unpaid carers.

## **Independent Advocacy**

**Proposal 1:** Strengthen and improve access to existing advocacy provisions

**Proposal 2:** Improve our Understanding of Independent Advocacy

***Which of these proposals do you agree with (if any), please tell us why?***

We agree with Proposal 1. The right to access independent advocacy already exists under the [Mental health \(Care and Treatment\)\(Scotland\) Act](#), which states that people who have a mental health issue, learning disability, autism or dementia have a legal right to independent advocacy. People are not always made aware that the role of the advocate is not restricted to mental health situations. We believe that more could be done to raise awareness of the right to independent advocacy for people with learning disabilities and autism. We also

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<sup>3</sup> <https://ihub.scot/media/9452/exploring-the-carers-census-discovery-report-v30.pdf>

believe that additional funding to secure this right to an independent advocate in any circumstances needs to be given more consideration.

We note that in another section of the LDAN Bill Consultation, there is a proposal to remove learning disability and autism from the scope of mental health and incapacity legislation. If that were to happen, it is vital that the right to independent advocacy for autistic people and people with learning disabilities is not lost.

***Which of these proposals do you not agree with (if any), please tell us why?***

No further response.

***Is there anything else that we should consider in relation to this topic?***

Carers in our focus group who were also neurodivergent told us about the difficulties they experienced in trying to get an independent advocate for themselves because an assumption was always made that it was only the person they were caring for who needed an advocate.

*“When I was first diagnosed with autism, I was told I couldn't be a carer and also be disabled” – Carer in focus group (Coalition of Carers in Scotland)*

Parent carers also told us that there needs to be a recognition of the role of the parent or primary carer in understanding some of the subtle cues and nuances of the behaviour or communication of their young person. Carers told us that their views are often dismissed or taken less seriously than the views of an independent advocate.

*“I can tell when my son is masking and trying to downplay the seriousness of how things are affecting him. If the advocate is just taking his word that things are OK and not realising that he is masking, then they are just failing my son.” - Carer in focus group (Coalition of Carers in Scotland)*

## **Accountability**

**Option 1:** A new Commission or Commissioner

**Option 2:** Better resourcing and additional duties for an existing body

**Option 3:** Champions and Advocates within Public Bodies

**Option 4:** Better resourcing for existing Disabled People's Organisations who support neurodivergent people and people with a learning disability

**Option 5:** Supporting good practice through standards, guidance and practical tools and investing in co-production

***Which of the 5 options set out above do you think would best protect, respect and champion the rights of people with learning disabilities and neurodivergent people? You can select multiple options if you wish. Please give the reason for your choice(s).***

There was some support for Option 1 from unpaid carers in some of our focus groups. However, during the discussions, it was apparent that unpaid carers viewed the role of a commissioner or commission as a body that could be set up immediately and would have the power to hold authorities to account in a way that does not currently exist.

Although we see some merit in setting up a new commission or commissioner for people with learning disabilities and people who are neurodivergent, we do not think that there is sufficient evidence to suggest that this would be the best option to protect, respect and champion the rights of people with learning disabilities and neurodivergent people.

The discussion paper on the future of commissioners and commissions in Scotland by the SHRC<sup>4</sup> and the recent call for views on Scotland's commissioner landscape by the Scottish Parliament Finance and Public Administration Committee<sup>5</sup> reflect some of the concerns we have about setting up of a new commission specifically for people with learning disabilities and people who are neurodivergent.

*“the process of setting up a new public body takes time, allowing for the proposal to be researched and scoped, set out, consulted upon, drawn up into legislative proposals, placed on the legislative timetable and*

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<sup>4</sup> [https://www.scottishhumanrights.com/media/2456/crossroads\\_what-next-for-human-rights-protection-in-scotland-shrc-june-2023.pdf](https://www.scottishhumanrights.com/media/2456/crossroads_what-next-for-human-rights-protection-in-scotland-shrc-june-2023.pdf)

<sup>5</sup> [https://www.parliament.scot/-/media/files/committees/finance-and-public-administration-committee/correspondence/2024/scotlandscomissonerlandscape\\_spicesummaryofevidence.pdf](https://www.parliament.scot/-/media/files/committees/finance-and-public-administration-committee/correspondence/2024/scotlandscomissonerlandscape_spicesummaryofevidence.pdf)



*passed through the parliamentary process, to set up the commission in operation. While some proposals are at a more advanced stage of this process, others may take a number of years to come to fruition.” – Quote from SHRC<sup>6</sup>*

We echo the concerns about costs and the time that it would take to set up a new commission. People with learning disabilities and people who are neurodivergent cannot be expected to wait for years to access justice and recourse for the lack of services and inequalities that they are currently experiencing.

We also have concerns that a new commission specifically for people with learning disabilities and people will not be able to serve the needs of people who have issues or identities that are intersectional. For example, a Black woman with a learning disability may experience multiple and additional inequalities due to her gender, ethnicity as well as her disability. Due to the indivisibility and interdependence of human rights, we believe that stronger consideration should be given to an intersectional approach to upholding human rights.

It is for these reasons that we think a combination of Option 2, Option 3, and Option 4 would best protect, respect and champion the rights of people with learning disabilities and neurodivergent people.

With the incorporation of the new Human Rights Bill in Scotland, we think there an opportunity to explore the option of expanding the powers that existing commissions such as SHRC have, and to consider whether this could include additional powers to hold authorities to account.

We are also mindful of the proposal to introduce a new Disability Commissioner in Scotland and think that a LDAN commissioner would be duplicating the role of a Disability Commissioner.

Unpaid carers have told us that there is a significant accountability gap in Scotland when it comes to services and support for people with learning disabilities and people who are neurodivergent. We are therefore supportive of Option 3 as a way of championing and ensuring the rights people with learning disabilities and neurodivergent people are included in decisions about people’s lives.

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<sup>6</sup> [https://www.scottishhumanrights.com/media/2456/crossroads\\_what-next-for-human-rights-protection-in-scotland-shrc-june-2023.pdf](https://www.scottishhumanrights.com/media/2456/crossroads_what-next-for-human-rights-protection-in-scotland-shrc-june-2023.pdf)

We agree that better resourcing for disabled people's organisation will enable people with learning disabilities and people who are neurodivergent to have an increased understand of their rights and to have the skills and confidence to challenge when those rights are not being upheld.

We also think that the additional resourcing should extend to carer organisations which support unpaid carers of people who are neurodivergent or have a learning disability, as well as supporting unpaid carers who are also neurodivergent.

***Are there any other options we should consider? Please give details***

No further response.

*Submitted by Shubhanna Hussain, Coalition of Carers in Scotland on behalf of the National Carer Organisations.*

**Contacts**

Shubhanna Hussain, Coalition of Carers in Scotland: [shubhanna@carersnet.org](mailto:shubhanna@carersnet.org)

Claire Cairns, Coalition of Carers in Scotland: [coalition@carersnet.org](mailto:coalition@carersnet.org)

Fiona Collie, Carers Scotland: [fiona.collie@carerscotland.org](mailto:fiona.collie@carerscotland.org)

James Calder, MECOPP: [james@mecopp.org.uk](mailto:james@mecopp.org.uk)

Paul Traynor, Carers Trust Scotland: [p Traynor@carers.org](mailto:p Traynor@carers.org)

Kate Hogarth, Shared Care Scotland: [kate.hogarth@sharedcarescotland.com](mailto:kate.hogarth@sharedcarescotland.com)