

COLLECTIVE ADVOCACY

Consultation paper and summary of responses

February 2022

Collective Advocacy: Consultation paper and summary of responses

Contents

Introduction	2
Collective Advocacy in Mental Health – Consultation Paper and Summary of Responses	3
What is collective advocacy?	3
What does a collective advocacy group do?	4
Questions on general description of collective advocacy	5
Strengths of collective advocacy	6
Questions on the strengths of collective advocacy	7
Weaknesses of collective advocacy	8
Questions on the weaknesses of collective advocacy	9
Opportunities for collective advocacy	14
Questions on the opportunities for collective advocacy	16
Threats to collective advocacy	21
Questions on the threats to collective advocacy	23
List of groups who responded:	27

Introduction

In July 2021, the Scottish Mental Health Law Review published its third interim report. It promised to 'seek views on how collective advocacy should be sustained, protected and developed in the future'. This followed agreement among the Executive Team Members that they should consider making recommendations about 'collective advocacy and the structures that allow it to flourish'.

Members of the Review's Economic, Cultural and Social Rights Group with experience of collective advocacy got together over the summer. They wrote a short paper on collective advocacy for a targeted consultation exercise. The aim of the consultation was to get feedback on collective advocacy generally and the Executive Team's ideas. The paper was structured around 21 questions on the strengths and weaknesses of collective advocacy, and its current threats and opportunities. There was an easy read version with 9 questions.

The paper was sent out to 12 mental health groups in August 2021. 11 other groups representing young people, autistic people, people with learning disabilities, older people, and some national representative bodies were also invited to respond. The deadline for responses was extended until 31 October 2021.

Fourteen responses were received. A number of organisations said they simply did not have sufficient resource to respond at this time. The list of the respondents can be found at the end of this report. No groups of specifically younger or older people responded. Some groups did not answer all the questions.

The information provided here will be used by the Review to help finalise any proposals for change.

The Review would like to thank everyone who took the time to respond.

The rest of this report is the Review's original paper on collective advocacy with a summary of the responses it received to each of the questions it asked.

Collective Advocacy in Mental Health – Consultation Paper and Summary of Responses

What is collective advocacy?

Collective advocacy is the voice of a community of people with a shared sense of identity on the issues that are important to them, expressed in whatever way they choose to express it. It brings people with a common interest or particular experience together, providing opportunities for everyone to be heard, especially marginalised individuals.

It provides opportunities for people to share their experiences and concerns. People share how they want their community to be viewed, treated and included in society. They then use their collective voice to try to improve and influence decisions and services that affect their lives. By doing this, collective advocacy supports people to make sure their human rights are respected.

In mental health, collective advocacy group members are generally people who have experienced mental distress and/or who have used mental health services. Its work is run and directed by people with lived experience.

Every collective advocacy groups is different as it responds to the needs and aims of its members. Groups cover any issue of importance to their members including social, community and health issues.

Many groups get support from independent advocacy providers. Others operate in a different way. The degree of formal structures for governance and accountability within groups varies. The amount of autonomy and funding they have also varies.

As a branch of independent advocacy, collective advocacy should be independent of services providers. The group decides on its vision, values and activities and much more. Groups can be run entirely by people with lived experience.

What does a collective advocacy group do?

The work of a collective advocacy group is directed by its membership.

- Collective advocacy groups support opportunities for people to share their views, preferences and concerns. The diverse range of experiences and viewpoints of its members are respected. Groups do not impose a consensus.
- They strengthen the voices of their members and seek to influence or campaign for positive change. This can be done in many ways. Groups give evidence at parliamentary inquiries and respond to consultations on issues that are of importance to their members. They express the opinions of members at meetings with service providers.
- They respect the rights and autonomy of their members. They promote, support and defend the views of their members. This process helps to empower people to speak out, identify they are not alone and helps to build confidence.
- They look for ways to help workers and the wider public better understand and learn from the experiences of people with lived experience.
- They are inclusive and value the diversity of people who join. They recognise the range of experiences, skills and backgrounds of their members and the different ways people can contribute.

Questions on general description of collective advocacy

1. Do you agree with the description of collective advocacy? Is there anything else you wish to highlight to the Review?

There were 13 responses. Overall, people felt the description 'caught the essence' of collective advocacy.

People also stressed that collective advocacy :

- is essential for a human rights based approach. It strengthens and champions human rights.
- works to change the balance of power between providers and users of services. It does this by increasing the 'agency and power' of members.
- keeps people informed of changes that impact on them (e.g. welfare reforms, self-directed support). This helps them to then 'act on an individual basis in their best interest'.
- does not necessarily mean being part of a group. Collective advocacy also works with individuals who may find it difficult or not want to join a group. This makes sure they can contribute to the collective voice.

2. How important is independence to collective advocacy? What is meant by 'independence'?

There were 13 responses. People were clear that independence underpins collective advocacy. Independence was said to be 'key', 'critical' and 'essential'.

This independence prevents conflicts of interest. It protects against influence or interference including unintentional bias and professional agendas. It is 'vitally important' in allowing trust and dialogue to develop. It also allows the 'power to be with the people who have the lived experience'.

One response suggested that when a group also provides a service for members, it is less likely to challenge existing ways of working. Another felt it was OK for a group to be part of an organisation that gave the group support.

Strengths of collective advocacy

One of the key strengths of collective advocacy is that the group voice can be louder and harder to ignore than a lone voice.

Collective advocacy groups are confident, proactive and accessible enough to reach out to people and communities who might not otherwise be heard. This means they present the full range of peoples' views on subjects of importance to them. This increases the information available about the diversity and reality of people's experiences. Services, the public and society then have the opportunity to grow in ways that reflect the needs of often marginalised and unheard communities.

Some people have told the Review that they do not feel able to question or complain about their care and treatment. They fear negative consequences and feel it is better to just keep their head down and comply. The Review has heard that some people have had their complaints dismissed or used as further evidence of their mental illness. It can take courage, resources or a knowledge of complaint systems for an individual to raise an issue. They can be left feeling vulnerable and isolated. Collective advocacy provides support and confidentiality for someone to share their concerns with others and have the group raise the issue on a collective level.

Frequently, the issues an individual is concerned about do not just apply to them. They are issues with the larger system. Collective advocacy is one way to reduce the burden on the individual to take on systemic issues.

Collective advocacy plays a crucial role in raising awareness among its members of their rights. People often do not know their rights. This makes it hard for them to exercise these rights and seek effective remedies when they are violated.

Other strengths of collective advocacy include its ability to:

- Identify gaps and issues in services and the early recognition of systemic issues.
- Identify services that are working well and should be protected or extended.

- Give people a sense of belonging and connection. The mutual support and inspiration that people find in collective advocacy groups promotes individual growth, feelings of empowerment and a mission for the future.
- Allow people to participate as much or as little as - and in whatever ways - they prefer.
- Give people the opportunity to think more deeply about their experiences in a shared space.
- Provide a space among peers. It is a place where people can be open about mental health issues without fear of judgement or retribution.
- Create a space where people's experiences are honoured and believed, and in which relationships of trust and solidarity are built.

Questions on the strengths of collective advocacy

3. Do you agree these are the key strengths and benefits of collective advocacy? Are there any others you want to highlight to the Review?

There were 11 responses. They agreed that these were some of the key strengths and benefits of collective advocacy. People felt, however, that the collective voice was 'stronger' rather than 'louder'. It presents a 'stronger case' through 'strength in numbers'. It also makes it harder for marginalised voices to keep being marginalised.

People mentioned collective advocacy's ability to drive change in systems and culture. It was said that groups 'can be very powerful, and that by connecting with each other and working together, we can make real change'. They create pressure to address failings in the system and have a role in holding services to account.

The benefits of being part of a collective advocacy group were also mentioned. People spoke of being more confident and less isolated. They feel they had more control and a greater sense of purpose. It helps with some people's recovery.

One group suggested one of collective advocacy's strengths was that you are not placed on a waiting list or assessed for eligibility in order to join.

Weaknesses of collective advocacy

There are ways that the effectiveness of collective advocacy groups can be reduced or compromised.

Critically, collective advocacy is not consistently available across Scotland.

Collective advocacy only has the power of its members' voices and the persuasive abilities of its members to get its views across. Collective advocacy groups have no formal mechanisms to contribute to service planning or policy. They have no right in law to participate in meetings or planning events where decisions about services that affect their membership are being discussed and made. Groups can be invited to these but more often they have to make the case for their inclusion.

A key strength of collective advocacy is its inclusion of the community it represents in its entirety. This can be weakened if a group becomes exclusionary or insular. A group may not be aware that there are experiences or viewpoints that are missing or silenced. It can become interested only in its own cause without learning from groups in other areas.

Groups can develop set ways of understanding mental health and mental health services, and so be less open to new ideas. They can also become so close-knit that the new members may struggle to become a part of it.

Collective advocacy groups require organisation and managing. While the purpose of these groups is to be inclusive, supportive and targeted at identifying concerns and experiences of their members and facilitating solutions, they need to be run properly. This is however not why most people join collective advocacy. Some

members may have some or all of these skills and experiences but many do not. Others will not be interested in these roles. A group may call on expertise outside of its membership. This can be invaluable but needs to be managed to ensure the membership remains the driving force of the group.

Collective advocacy groups can become confused with the services provided by a self-help or support group. The support and camaraderie which develops between members may lead the group to lose its way. For example, a group may take responsibility for delivering the solutions to the issues its members raise, e.g. by setting up a café or providing mainstream training such as Mental Health First Aid to its members. This turns the focus of the group from collective advocacy to service provision which compromises its own independent voice.

Other risks to the strengths of collective advocacy are:

- The governance set-up for some groups can see some of the responsibilities of an employer being done by another organisation. This has benefits for the group but may also lead to the culture of the other organisation compromising the group's independence and autonomy.
- There is currently no independent monitoring, evaluation or regulation of independent advocacy. This means there is no way to know the quality or impact of advocacy services provided to people.

Questions on the weaknesses of collective advocacy

4. Do you agree these are the potential weaknesses that can occur within collective advocacy groups? Are there any others you want to highlight to the Review?

There were 12 responses. Some people did not recognise the lack of inclusion in their groups. Others recognised this risk but felt it can be managed by trained and experience advocacy workers and members.

People felt groups lacked a statutory role or right to be included in discussions. They also spoke of the lack of feedback from services when groups had engaged in discussions. People spoke of not being heard and nothing ever changing.

One group said that the number of people who got to collective advocacy and peer support group remains unknown. They felt that the groups were therefore providing a 'hidden service' that concealed the true number of people with mental health needs across the country.

5. There are existing rights to accessing independent advocacy in the current mental health legislation. Are any changes needed specifically for collective advocacy in any new legislation?

There were 11 response. There was support for legislative change to strengthen and support collective advocacy. People were clear, however, that there was no point in having an increased right to collective advocacy without the required resources to make this a reality.

People wanted an explicit statutory right to collective advocacy. One group felt it must be available in places where adults' rights may be restricted (e.g. long stay hospitals and care homes).

People suggested a duty on local authorities/health boards to fund, support and report on the provision of collective advocacy. They felt this could help with the patchiness of provision across Scotland. It could also prevent providers considering collective advocacy as 'an afterthought'.

One response was that advocacy needed to be available for people not covered by the mental health act.

Another, was that carers should have a right to advocacy when statutory measures were being considered.

6. Who are/should collective advocacy groups be accountable to?

There were 11 responses. Everyone said that groups are accountable to their members first and foremost. Some people did not think they should be accountable to anyone else as it would compromise their independence.

Others did recognise other people who they felt their groups were accountable to.

These groups included:

- Funders / commissioners.
- Those affected by the proposals made by their groups.
- The wider public.
- The Scottish Charity Regulator.
- A collective body, e.g. Scottish Independent Advocacy Alliance.

7. Do you agree there should be more independent monitoring and regulation of independent advocacy? What are the pros and cons?

There were 12 responses. Most responses recognised that independent monitoring and regulation was important. It could also increase consistency of provision.

However, there was concern that without funding and investment in appropriate systems, it risked introducing more bureaucracy and barriers. It was noted that this, 'has not be forthcoming in the past'. Monitoring processes can take the focus away from a group's core task. They also need to be proportionate to avoid smaller groups being disadvantaged.

Any system, however, needs to be developed by people who understand the nature of collective advocacy. There was scepticism from one group that the Scottish Government could be trusted to do this. This was because of the different interpretation of independent advocacy the Scottish Government has used for the Scottish Social Security system.

8. Do you agree there should be more evaluation of collective advocacy?

How can the outcomes of collective advocacy be measured?

There were 12 responses. It was generally felt that it was good to evaluate collective advocacy. People thought that capturing the benefits it provides to both members and services could help increase awareness, funding and consistency.

It is currently up to groups to evaluate themselves. The Scottish Independent Advocacy Association's [toolkit for demonstrating impact](#) was mentioned positively by two groups. One response felt there should absolutely not be more evaluation as 'accountability and ownership lies with the membership'. Another felt that only the people receiving collective advocacy can evaluate it. They said 'it shouldn't be about professionals deciding what works and what doesn't'.

Aspects people suggested could be usefully evaluated included:

- the transparency of the groups' processes, e.g. whether groups are being members-led and are actively pursuing topics prioritised by their members.
- the amount of information and access to advocacy people are given.
- levels of participation and representation on networks and in groups.
- levels of engagement in the development and evaluation of services.
- members' feelings of belonging and empowerment.

One group warned against measuring changes as a result of collective advocacy. This was because they highlighted that the power to make these changes does not lie with them. Another, however, felt that measuring the impact of a group's work could increase pressure on services. They felt it would 'shine a light' on whether services engage meaningfully or merely pay 'lip service' to the collective voice.

One group said that bench-marking across organisations would be helpful.

9. The [United Nations Committee on the Rights of Persons with Disabilities Comment No. 7](#) says that governments should support people with disabilities and their representative bodies to get the skills and knowledge needed to independently advocate for their full and effective participation in society.

Do you think there should be more training available for collective advocacy workers and members? If so, what training would be most helpful?

11 responses were received. There were calls for investment in the personal development of credible, informed, peer leaders. It was stressed that effective advocates and peer leaders develop their skills and confidence over time and need support to do that. This is not something that can 'be bought off the shelf, pre-formed and ready to go'.

All would welcome access to good quality training. They explained most training currently was 'on the job' and experiential, or not specific to collective advocacy. People should be able to decide what training they wanted. They provided a range of ideas for what an opt-in advocacy-related learning programme could offer. It included:

- Basic research skills – including in participatory research.
- Facilitation of groups – including group dynamics, bias and creating safe spaces for people to talk about difficult things and be heard.
- Monitoring, evaluation and governance skills – including project management and report writing.

Some highlighted training opportunities would need to be supported by additional funding otherwise it would remain 'difficult to fit in'.

Opportunities for collective advocacy

There is momentum in Scotland for systemic changes to ensure the progressive realisation of all human rights for everyone. The Review is working within this wider context.

A key part of this is the Scottish Government's [commitment to incorporate four United Nations Human Rights Treaties into Scots Law](#). This commitment includes the incorporation of the [International Covenant on Economic, Social and Cultural Rights](#) (ICESCR) and the [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCPRD).¹

This commitment was made in response to the [final report](#) of the National Taskforce on Human Rights Leadership (the Taskforce) published in March 2021. The Taskforce emphasised the role scrutiny bodies had in making sure people's rights are upheld and that systemic shortcomings are identified. It stressed the need to ensure that rights-holders know their rights and have access to justice through a range of remedies when their rights are violated. It recommended allowing bodies with 'sufficient interest' to be able to bring proceedings on behalf of and with rights-holders.

The active and informed participation of people in decisions that affect their lives and rights is a critical part of any human rights based approach to decision making. UNCPRD obliges States to closely consult and actively involve people with disabilities in all decision making processes on issues that directly or indirectly impact the rights of people with disabilities.²

The UNCPRD's [Committee General Comment No. 7](#) (Comment No. 7) states the importance of organisations of disabled people (DPOs). It commits governments to

¹ The other treaties are the Convention on the Elimination of All Forms of Discrimination against Women; Convention on the Elimination of All Forms of Racial Discrimination. See the Scottish Government's press release on this available at: [New Human Rights Bill - gov.scot \(www.gov.scot\)](#). Legislation has already been passed to incorporate the Convention on the Rights of the Child (subject to a referral to the UK Supreme Court. More details can be found on the Scottish Parliament's website at: [United Nations Convention on the Rights of the Child Incorporation Scotland Bill – Bills \(proposed laws\) – Scottish Parliament | Scottish Parliament Website](#)

² The UNCPRD considers people with disabilities to include people with 'mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (see [Article 1](#)).

strengthening the capacity of DPOs. This is to allow them to participate in all phases of policy making. It states that resources should be prioritised for DPOs that focus on advocacy for disability rights.

Comment No. 7 defines certain characteristics of DPOs. These include that DPOs:

- are led, governed and directed by people with disabilities
- are predominantly established with the aim of collectively acting, expressing or pursuing the rights of people with disabilities
- are independent of public authorities and any other non-governmental organisations
- represent and reflect the diversity of backgrounds of people with disabilities.

Most collective advocacy groups will meet these criteria.

Comment No. 7 suggests that it is important that governments and stakeholders define the scope of DPOs, while recognising the different types of organisations that exist. The Scottish Independent Advocacy Alliance (SIAA) is membership organisation for advocacy providers. It has established 'Independent Advocacy Principles, Standards and Code of Best Practice' to support all types of independent advocacy.³ Not all collective advocacy groups are members of SIAA.

Comment 7 also encourages each country to establish a 'single, united and diverse representative coalition' of organisations of person with disabilities. This coalition should be involved and participate in the monitoring of the UNCPRD at national level. Inclusion Scotland is a national network of disabled people, their organisations and allies which are run by disabled people. VOX Scotland is a national organisation that represents the voice of people with mental health issues at a national level. It is run by services users for service users.

On the evidence it has already heard, the Review's Executive Team is looking at measures to increase access to effective remedies and accountability in mental

³ The SIAA, *Independent Advocacy Principles, Standards and Code of Best Practice (2019)* can be found at: [Independent Advocacy Principles, Standards & Code of Best Practice - Scottish Independent Advocacy Alliance \(siaa.org.uk\)](https://www.siaa.org.uk/independent-advocacy-principles-standards-and-code-of-best-practice)

health. It is also considering how to ensure the active and informed participation of people affected by the mental health legislation in Scotland. This presents an opportunity for collective advocacy groups.

Recommendations being considered by the Executive Team are:

- Include DPOs/collective advocacy groups within the bodies with 'sufficient interest' to bring proceedings on behalf of claimants which may include a power for DPOs/collective advocacy groups to raise court actions or refer issues to other scrutiny bodies.
- Greater support for DPOs/collective advocacy groups including a new duty to ensure that DPOs/collective advocacy groups are supported and resourced to allow both service users and unpaid carers a much greater role in service planning and oversight (see Threats section for questions on this).

Questions on the opportunities for collective advocacy

10. Do you agree these are the potential opportunities for collective advocacy groups? Are there any others you want to highlight to the Review?

There were 12 responses. People recognised these as potential opportunities for advocacy groups. They felt that UNCPRD requires collective advocacy to be embedded more systematically. People felt collective advocacy is key to empowering people to work with, understand, and access their human rights. They need support however to increase their capacity to do this.

But people doubted these opportunities would be realised. It would require significant commitment and cultural change among professional groups and service providers. The lack of understanding about the status of human rights in Scots law amongst decision-makers was said to be a major obstacle. One group explained how they have been highlighting the requirements in Comment 7 for years. But they are still excluded from decision-making processes. They said

participation is mainly limited to being consulted on already developed ideas. They felt the Review's own participatory processes were similarly limited.

11. Do you agree that collective advocacy groups in mental health are DPOs as defined by UNCRPD? What are the pros and cons to this?

There were 12 responses. Most of the responses felt collective advocacy groups met the definition of Disabled Persons Organisations (DPOs). One response felt it was not necessarily the case. Being recognised as a DPO (and within the scope of Comment 7) was generally welcomed.

People highlighted potential difficulties in achieving the levels of independence and representation across diverse populations that Comment 7 seemed to require. For example, reaching out to wider ranges of groups requires resources that some groups do not have.

People also stressed that the term 'disabled' may cause problems. Many people with mental health difficulties do not consider themselves to be disabled. The word 'disability' therefore could act as a barrier to people joining or increase stigma. However, one response said that society does not consider mental illness a disability as it does physical disability, and maybe this could start to address that inequality of esteem in a positive way.

12. Do you want a greater role in the service planning, decision making and oversight of mental health services? What would you need to make this happen? Can you see any downsides to this?

There were 12 responses. Everyone wanted a greater role in the service planning, decision making and oversight. The lack of full statutory recognition of collective advocacy's right to participate in public authority decision-making was said to be a problem.

People said that a 'right to be heard' should be built into the NHS. They wanted a duty on services to include collective advocacy in the development, planning,

commissioning and oversight of its services. They should not be allowed to do this as just a 'box ticking exercise'. They should be required to engage meaningfully with collective advocacy groups regularly. They must be part of processes from the start and on an ongoing basis. They must also be recognised as equal partners. One response suggested there should be 'standards for engagement' to make sure DPOs have 'a seat at the table'.

People agreed that it was important to be involved in the governance and oversight, including the monitoring and evaluation of services. One group felt this to be especially important for assessment and treatment units, long stay hospitals and care homes. They explained, 'we see time and time again the failings of these services but nothing has changed to make us any safer'. It was also suggested that collective advocacy groups could be called on to investigate specific issues.

People said that getting this greater role would require resources to allow advocacy workers to devote time to this. People felt funders, commissioners, policy makers and professionals needed a better understanding of collective advocacy. Groups are not user involvement groups and need to be able to set their own agendas. One response worried that involvement at too high a level may conflict with its independence.

13. Should collective advocacy groups be considered bodies of 'sufficient interest' as set down by the Taskforce? This would allow you to raise court actions for systemic issues or refer these issues to other scrutiny bodies. What would be required to support you to do this? Can you see any downsides to this?

There were 11 responses. The majority supported the ability to raise court actions. Two preferred the option to refer to a scrutiny body. Two did not know. People gave examples of the pros and cons to this.

Those welcoming the right to raise a court action were hopeful it could result in greater consequential change than they can currently achieve. They did not feel they needed non-disabled people advocating for them and have the 'passion and ability to do it for ourselves'. It was felt actions should not fall on advocacy

workers as it must be led and driven by members. This linked to a concern at the length of time cases took and the fluctuating membership of groups.

One group suggested groups may already hold this power looking at the approach being taken by courts on what 'sufficient interest' is. Either way, there would need to be greater awareness and training for groups on how they can demonstrate their 'interest' and the other questions they need to consider about taking action.⁴ They would also need relevant access to legal expertise and training.

Those who did not fully support court action were still interested in having a 'further place' to which they might refer issues. If the reference was to a scrutiny body, that body would need to be resourced and staff trained to take this on with guidance on the criteria for such referrals.

Some were concerned this role may change the nature of collective advocacy and its relationship with services. One group felt the responsibility and implications of taking a court case forward seemed inappropriate for collective advocacy groups.

14. How does collective advocacy work alongside less formal routes that people have to give feedback, for example complaints systems?

There were 9 responses. People explained that collective advocacy groups do not take on individual complex complaints. What they can do is look for common themes across individual issues brought to them. As such, they can be the first to identify when there is an issue in the system affecting multiple people.

People thought issues raised collectively should be taken as seriously as those raised by individuals. It would be helpful if organisations could, for example, take on collective complaints. Also, if organisations shared the topics of individual complaints they received, collective advocacy could consult and consider further on ways to make improvements in those areas.

People stressed the value of different ways to raise concerns and seek improvements. Some people feel able to challenge services directly. Other

⁴ One response gave as an example a series of questions that groups could usefully consider when considering such an action taken from: *A Practical Guide to Public Law and Litigation in Scotland (2020)* by Lorna Drummond, Frances McCartney and Anna Poole, p.106.

people choose to do this through advocacy or by presenting at a forum. Collective advocacy can often be a place people come to when they have been unsuccessful in effecting change in others ways.

15. The UNCRPD's Comment 7 encourages governments to set up a single, coalition of organisations of person with disabilities and ensure its involvement and participation in the UNCRPD at a national level. How should this work in practice for representing people with mental health issues?

There were eight responses. People highlighted that the disabled people's movement is not homogenous. Any coalition would need to represent all voices across a wide range of disability groups. There was concern that some people with mental health difficulties may be put off by a coalition that includes people with physical disabilities. Or that if everything was seen under the social model of disability this would exclude people who found a diagnosis helpful. It was felt that there would probably be a continued need for a collective advocacy voice with specialist mental health expertise and focus.

One group imagined such a coalition as 'regular meetings, regular networking opportunities and support for people to engage with it'. Another explained that coalition work has already been happening organically with different DPOs coming together on certain issues.

The Scottish Human Rights Commission (SHRC) was suggested by one group as a potential agency for this. The SHRC is already the body in Scotland identified by the UN to monitor the implementation of UNCRPD and DPOs. The ability to carry out these monitoring functions is already constrained by resources.

16. Do collective advocacy groups require any further rights or powers? What responsibilities would need to go alongside these?

There were 10 responses. As well as the rights mentioned in answers to previous questions, one group wanted to be able to challenge policies and legislation. Another wanted powers to hold private and public organisations to account.

One group felt it would be good to have champions of collective advocacy in the highest levels of NHS Boards, local councils and commissioning bodies. This could help to ensure that collective advocacy and the importance of participation is not forgotten.

One group felt that the focus of advocacy was to empower their advocacy partners not seek powers for itself.

Threats to collective advocacy

There are external factors which can place the work of collective advocacy at risk.

Factors around funding are key. The [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#) (Section 259) gives anyone with a mental disorder the right to access independent advocacy. It places duties on NHS Boards and local authorities to fund it.

The Review has been told that most independent advocacy organisations are funded locally through the NHS, local authorities or Integrated Joint Boards. This may lead to conflicts of interests which compromise the ability of advocacy to work independently without, for example, fear of contracts not being renewed. Or, funding may come with conditions about what groups can speak about which would undermine the autonomy and independence of the group.

Advocacy groups can also receive funding from the Scottish Government and trust/grant awarding bodies.

The different funding streams means there are inconsistencies in the advocacy services that are commissioned, the length of contracts and reporting requirements.

The Review has been told that advocacy services are 'chronically underfunded'.⁵

⁵ See the Health and Social Care Alliance Scotland's response to the Review's consultation available at: [Response 263196933 to Review of Mental Health Law in Scotland - Scottish Government - Citizen Space \(consult.gov.scot\)](#) . See also the Scottish Independent Advocacy Alliance's response to the Review's consultation at: [Response 492306794 to Review of Mental Health Law in Scotland - Scottish Government - Citizen Space \(consult.gov.scot\)](#) and their Report, *A Map of Advocacy across Scotland 2015-2016* edition available at: [SIAA Advocacy Map 2015-16-1.pdf \(kinstacdn.com\)](#) . They report that in 2015-16 advocacy organisations met an 11.5% increase in demand while statutory funding

The lack of sustainable or long-term funding for advocacy has also been brought to its attention. A lack of guaranteed funding means many advocacy groups work under the constant pressure of insecure funding and uncertain futures. This diverts focus away from advocacy work while groups look at ways to secure funding.

Smaller budgets impact on how proactive, accessible and inclusive groups can be. Where funding comes from may also compromise a group's activities. When groups reach a certain size they can also find that they need to participate in competitive tendering exercises to secure their continued existence.

Ultimately, lack of funding can lead to greater inequalities and loss of diversity within the collective voice.

Other threats to collective advocacy include a lack of understanding of collective advocacy by funders, decision makers and service providers. Collective advocacy can be confused with user involvement with people trying to use these groups as a mechanism to get feedback for their existing plans. These plans may not even address the issues that collective advocacy groups have identified as important to them.

There is also not always a full understanding or respect for the confidentiality that is critical to the work of collective advocacy. Collective advocates may be asked for further details on an issue which would risk identifying the specific circumstances or concerns of an individual and so undermining the collective advocacy process.

There is always the threat of tokenistic involvement on the part of decision makers and service providers. This is when collective advocacy groups are listened to but no consequent changes are made.

The validity of research done by collective advocacy groups can be questioned in the way that research done by others (e.g. academics or professionals) is not. Groups can feel pressure to change the way they present their message to conform to the standards of service of others before it is considered of value. Groups can be expected to 'quantify' their concerns or have their qualitative results seemingly

decreased by 4%. There was also reductions in the number of paid advocates and volunteer activities

dismissed as 'anecdotal'. This pressure to operate in 'standardised ways' can be at odds at what works for the group.

Questions on the threats to collective advocacy

17. Do you agree these are the potential threats to collective advocacy groups? Are there any others you want to highlight to the Review?

There were 11 responses. All agreed with the potential threats.

The need for appropriate funding had already been mentioned by people in responses to earlier questions. Here they gave more detail. They spoke of operating on 'shoe-string budgets' that were being cut or had not been increased in years. They pointed to short-term and uncertain funding. One group said they were on the 'point of not being able to function any more'. Carer advocacy groups were said to be 'vastly underfunded'. People stressed the need for collective advocacy to be fully resourced so that groups 'can do the job'. It would also ensure people have access to collective advocacy no matter where they are in Scotland.

People spoke of the impact of unstable funding. They said it weakens organisations. It requires time to be spent on funding activities that 'takes valuable time away from core activities'. It has an impact on staff retention. People also wanted it to be clear that less funding results in less of a service and this impacts on people's human rights.

People said that the lack of an explicit statutory basis for collective advocacy meant it was sometimes overlooked in favour of funding for individual advocacy. However, funders – including trusts that offer grants - will sometime not fund it either as they consider advocacy to be a statutory service.

18. Do you agree with that there should be greater support for collective advocacy groups/ DPOs? In practical terms what sort of support/resource would you want to see?

There were 11 responses. People felt there needed to be more awareness of groups so people knew they existed. But this costs money.

Support also needs to be made available to help people access collective advocacy. This could be free or arranged travel, or someone who can go along with a person to the meetings. Groups also need appropriate meeting places.

19. What would collective advocacy provision look like across Scotland if it was sufficiently and sustainably funded?

There were 9 responses. People spoke of what a sufficiently and sustainably funded collective advocacy landscape would look like.

There would be longer term funding and security of venues. They could have long and short term goals. They would be able to plan and report properly, be truly independent and able to focus on the priorities of their members. One group said that people would be 'better able to have their rights met and Scotland would be a better and more empowered society'.

Everyone in Scotland would have access to a collective advocacy group. There would be local and national groups. Groups would work together to have a strong national voice capturing local issues at a national level.

There would be a greater awareness of collective advocacy and understanding of its benefits. People would know where groups were in their area and how to join them. Services would recognise the benefits of meaningful partnership with collective advocacy groups. Collective advocacy would be seen as a necessary and respected voice in the development and evaluation of public services.

20. Where should collective advocacy be funded from? How should levels of funding be agreed?

There were 9 responses. Most groups felt that funding should come from a range of sources, so it was not all coming from one place. Most felt it should be a mixture of government, local authority and NHS funding. A couple suggested the Scottish Government or Third Sector Interfaces (TSIs) should provide funding to avoid any potential conflict of interest with statutory services. One group pointed out that getting funding from multiple sources can result in different provision being available to people from different local authorities within the same health board area.

People said funding should not be tied to activities or outcomes that could affect a group's independence.

The tender process that local authorities use to commission collective advocacy services was described by one group as a 'destabilising experience'. They felt that 'despite people saying that they value small, grass-roots and accountable organisations, funders prefer larger organisations who will bid for more than one contract'. One group wanted commissioners to be wary of simply commissioning the cheapest service. This could result in lower standards.

21. This paper has focused on collective advocacy groups working in mental health generally. Does collective advocacy look different for different communities – e.g. people with intellectual disability, autistic people, children and young people, people with dementia, carers?

There were 9 responses. There was a general agreement that each collective advocacy group knows best how to engage and work with its members. Groups have different needs and approaches. As such some people did not comment further.

Some felt that while collective advocacy may look different for different groups they worked from shared principles, with a 'common ethos'.

Some groups already have members from a wide range of different population groups. One such group explained that while it was important 'to make sure there was enough common ground for people to organise around', it was also 'important not to silo people'. Another group stressed the need for a better understanding of non-instructed collective advocacy.

22. Do you have any other feedback on the issues raised in this paper that you wish to Review to take account of?

There were 5 responses. One brought the Review's attention to the National Survivor User Network report on [What Do User-Led Groups Need](#) (2020). One thought collective advocacy needed to be made more widely available to 'all citizens of Scotland on an equitable basis'.

One group spoke of needing help, support and recognition to continue to fight against 'an unprecedented assault on the rights and livelihoods of disabled people'. The other responses welcomed the consultation and the opportunity for any further engagement.

List of groups who responded:

1. Advocard
2. ARGH
3. CAPS Independent Advocacy
4. Edinburgh Carers Council
5. Enable ACE
6. Law and Human Rights Group, People First (Scotland)
7. Member of the Review's Lived Experience Reference Group
8. Mental Health Advocacy Project
9. Mental Health Network (Greater Glasgow)
10. Royal Edinburgh Hospital Patients Council
11. Scottish Human Rights Committee
12. Spirit Advocacy
13. VOX (Scotland)