



Learning Disabilities, Autism and Neurodivergence (LDAN) Bill Consultation SIAA Response

April 2024



Scottish
Independent
Advocacy
Alliance



SIAA Consultation Response | April 2024

In brief - why should independent advocacy be strengthened for LDAN Bill?

Independent advocates are human rights defenders. For the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill to be effective in bringing about positive change for neurodivergent people and people with learning disabilities, independent advocacy must be included to enable rights to participation, access to justice and increase accountability.

Without clarity about the definition of independent advocacy and the resources available to provide independent advocacy to neurodivergent people and people with learning disabilities to have their voice heard, the Bill will not be effective. Independent advocacy is ready made to bring human rights to life. When sustainably resourced, independent advocacy expands understanding of human rights, enables accountability mechanisms and embeds participation creating the context for services to uphold rights and justice to be realised.

What is independent advocacy?

Independent advocacy is about speaking up for, and standing alongside individuals or groups, and not being influenced by the views of others. Fundamentally it is about everyone having the right to a voice: addressing barriers and imbalances of power, and ensuring that an individual's human rights are recognised, respected, and secured. Independent advocacy supports people to navigate public services/systems and acts as a catalyst for change in a situation.

Independent advocacy can have a preventative role and stop situations from escalating, and it can help individuals and groups being supported to develop the skills, confidence and understanding to advocate for themselves.

Scottish Independent Advocacy Alliance and our members

The [Scottish Independent Advocacy Alliance \(SIAA\)](#)

advocates for independent advocacy. As the only national organisation with a remit to promote, support and advocate for independent advocacy we have been examining the provision, quality, availability, and accessibility of independent advocacy for over two decades. Our aim is to raise awareness about the value and impact of independent advocacy, and influence decision makers with the aim of widening access to quality independent advocacy for all who need it in Scotland.

SIAA is a membership organisation that has members providing independent advocacy across Scotland. [SIAA members](#) are a diverse range of organisations and groups that provide independent advocacy to different people and groups in a variety of settings including:

- individual independent advocacy in the communities, hospitals, forensic mental health, and prison settings,
- organisations specialising in citizen advocacy,
- carers advocacy organisations,
- collective advocacy groups based in hospitals, care homes and the community, and
- organisations providing independent advocacy to remote and rural communities.

Each SIAA member works to the [Independent Advocacy Principles Standards and Code of Best Practice](#), which is the foundational document for independent advocacy in Scotland. The Principles and Standards are provided in Appendix 3. We will provide more detail on how independent advocacy, both individual and collective, works in practice in our response. The Independent Advocacy Principles Standards and Code of Best Practice are intrinsically linked to the principles of Participation, Accountability, Non-discrimination and equality, Empowerment and Legality (PANEL). Independent advocacy groups have a human rights-based approach that support individuals and groups to consider how human rights laws may apply to their specific circumstances.

Models of Independent Advocacy

Individual or one-to-one advocacy

This includes professional or issue-based advocacy. It can be provided by both paid and unpaid advocates. An independent advocate supports an individual to represent their own interests or represents the views of an individual if the person is unable to do so. Advocates provide support on specific issues and provide information, but not advice. This support can be short or long term.

Another model of individual advocacy is **citizen advocacy**. Citizen advocacy occurs when an ordinary citizen is encouraged to become involved with a person who might need support in the community. The citizen advocate is not paid. The relationship between the citizen advocate and the advocacy partner is on a one-to-one, long-term basis. It is based on trust between the partner and the citizen advocate and is supported, but not influenced, by the advocacy organisation. The citizen advocate supports the advocacy partner through natural skills and talents rather than being trained in the role. For many people their Citizen Advocate is the only person not paid to be in their life. Citizen Advocates provide essential support for local people at key times of vulnerability and need. A key part of many partnerships is the support citizen advocates provide, whether by ensuring their partner has the information they need to make choices, by sharing activities to widen opportunities and by ensuring their partner understands the legal processes they are part of.

Collective advocacy

Collective advocacy creates spaces for people to get together, support each other to explore shared issues and find common ground. It supports people to speak up about their experiences, values, and expectations. It enables people to find a stronger voice, to campaign and influence the agendas and decisions that shape and affect their lives. Collective advocacy also takes the onus off the individual to solely address a human rights issue, the collective voice means people do not have to continuously reshare difficult experiences to make change happen and improve systems.

Collective independent advocacy provides opportunities for people to have a meaningful voice in legislative processes, policy making and strategic planning, combating discrimination, inequality and enables people to take part as active citizens.

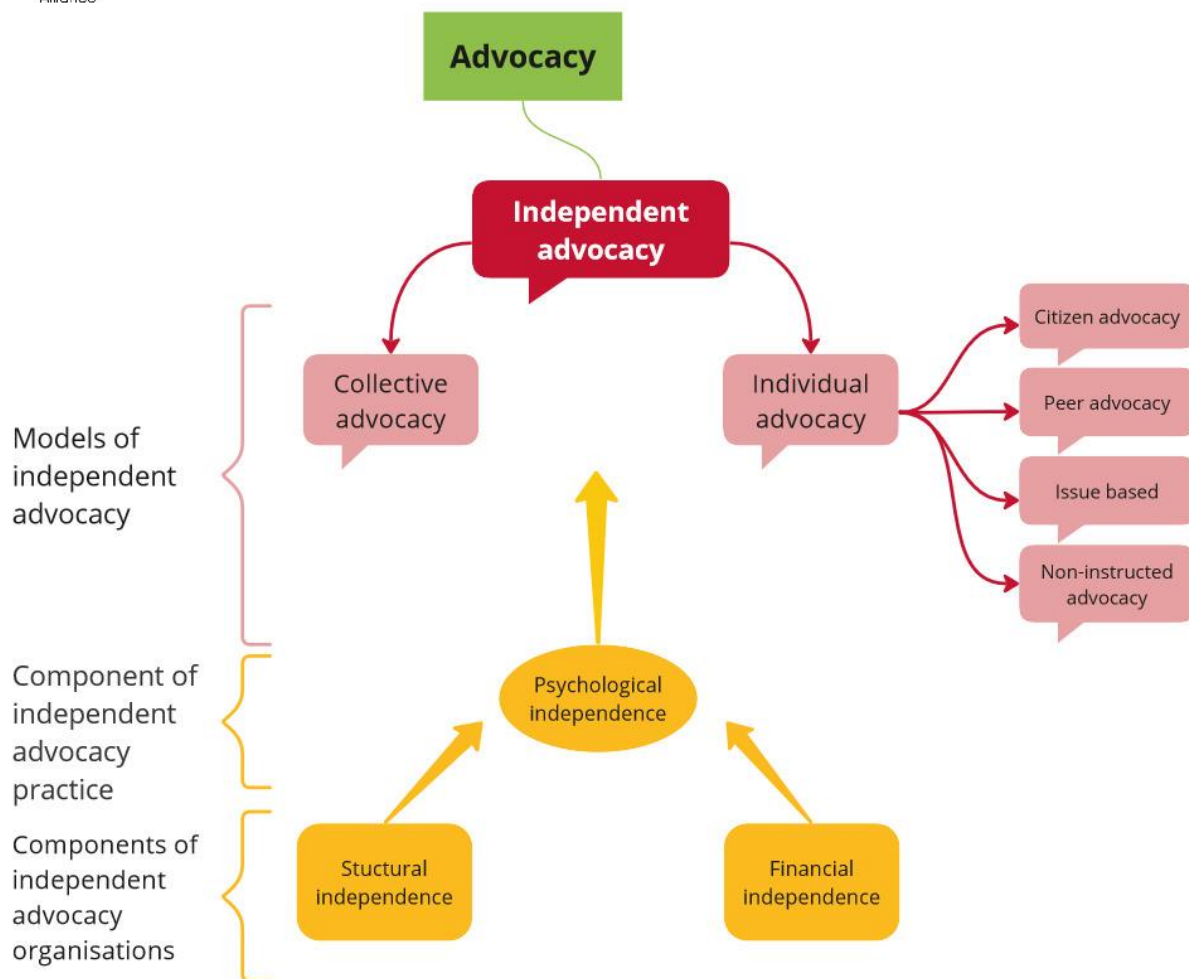
Collective advocacy can help planners, commissioners, service providers and researchers to know what is working well, where gaps are in services and how best to target resources. It helps

legislators and policy makers to create opportunities for people to challenge discrimination and inequality. Collective advocacy groups benefit from skilled help from an independent advocacy organisation and with the support of resources. However, it is important to note that collective advocacy groups cannot be 'mandated' into existence, they must continue to emerge from the needs, wants and views of their potential members. Collective advocacy groups are run by their members, who set their own agendas.¹

The below diagram illustrates the models of independent advocacy and contributing components that enable independence.



Independent advocacy models and components



¹ <https://webarchive.nrscotland.gov.uk/20230327160310/https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/09/SMHLR-FINAL-Report-.pdf>

Reach and definitions: who should the Bill include?

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

SIAA are supportive of Proposal 2. SIAA believe that the people that will be within the scope of the Bill, and therefore may be able to access any provision of independent advocacy linked to the Bill, should be clearly defined using the language preferred by those with lived experience.

As the consultation document states the approach that would follow Proposal 2 would allow definition with 'reference to common barriers or behaviours faced or expressed by various groups.' Referencing where common barriers exist would be valuable in allowing for people without formal diagnoses to be within scope of the Bill and therefore be more likely to gain access to any independent advocacy provision where their rights are at risk.

The Bill must clearly outline these common barriers, perhaps in terms of rights at risk. Implementation of this element of the Bill must be cognisant of the barriers that can be avoided and broken down through independent advocacy being utilised in early intervention and preventative approaches.

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

The approach outlined by Proposal 2 would go some way to address an issue that our member organisations have raised: people struggling to access independent advocacy due to lack of a diagnosis. The lack of a diagnosis can act as a barrier to accessing independent advocacy due to the complex web of independent advocacy provision in Scots law as well as the underfunding of independent advocacy organisations, then impacting the sustainability of organisations at a local level. Allowing people to access independent advocacy because they are experiencing a human rights issue would be a useful way to remove the need to have a formal diagnosis and help to avoid crisis situations that may escalate as access to other public services is diagnosis dependent.

SIAA are supportive of The ALLIANCE's call to explicitly embed a human rights based approach, and specifically align with the United Nations Convention on Rights of Persons with Disabilities (UNCRPD)². The UNCRPD imposes positive obligations on states to respect, protect and fulfil the human rights of people with learning disabilities, autism and neurodivergence.

² <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

SIAA recommend the Scottish Government carefully consider the LDAN Bill alongside proposals to incorporate the UNCRPD as part of the upcoming Human Rights Bill. In particular, the UNCRPD's focus on supported decision-making (moving away from current substitute decision-making that is most commonly practiced across service in Scotland) that is already been considered across future Scottish policy, see Scott Review, and internationally³. Supported decision-making is central to ensuring that disabled people can access the same rights as non-disabled people⁴. Supported decision-making, can be described as ensuring that a person's will and preferences are discerned and given effect. As noted by Professor Jill Stavert Article 12(3) CRPD requires states parties to provide access by persons with disabilities to the support they may require in exercising their legal capacity. This is to ensure that the rights, will and preferences of persons with disabilities are enjoyed on an equal basis with others [Articles 12(1)(2) and (4) CRPD].

Moreover, the Committee on the Rights of Persons with Disabilities has made it clear that supported decision-making must replace substitute decision-making arrangements as these are discriminatory and deny equal enjoyment of the right to exercise of legal capacity for persons.⁵ Independent advocacy enables supported decision-making and can support other forms of advanced planning when needed for example Advance Statements. It is therefore vital that independent advocacy is considered as a tool to help realise the substantive rights of UNCRPD and the other special protection treaties when implementation is planned. See answer to question 27 for more on this.

Independent Advocacy

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

SIAA welcomes the inclusion of independent advocacy as an overarching theme of the consultation. This acknowledges the fact that independent advocacy was frequently mentioned by LEAP as an important area that has been instrumental in upholding rights for neurodivergent people and people with learning disabilities.

³ <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-six-from-provisions-to-practice-implementing-the-convention-5.html>

⁴ <https://www.mwscot.org.uk/sites/default/files/2021-02/Supported%20Decision%20Making%202021.pdf>

⁵ <https://www.frontiersin.org/articles/10.3389/fpsy.2020.571005/full>

Below is a summary of our key asks of Scottish Government in relation to independent advocacy when drafting the LDAN Bill:

1. The Bill should guarantee access to independent advocacy for all people with a learning disability and neurodivergent people, ensuring that this provision is explicitly included in the LDAN Bill.
2. As the Bill is drafted and implementation work on the Bill begins, part of this must be a clear roadmap to increasing access to independent advocacy, this roadmap must;
 - Ensure that those with current rights to independent advocacy in Scots law can access it,
 - Utilize different models of independent advocacy including collective advocacy to support groups to address systemic human rights issues, and citizen advocacy to increase inclusion for people that have been excluded from their community,
 - Provide individual independent advocacy and citizen advocacy first to those who experience the greatest barriers to having their rights realised,
 - Progressive realisation of rights should be supported by sustainably increasing access to independent advocacy so that eventually it can be accessed by anyone with a human rights issue. This should be done in consultation with existing grassroots and local independent advocacy organisations and groups.
3. 'Independent advocacy' must have a clear definition in the Bill that aligns with the Independent Advocacy Principles, Standards and Code of Best Practice⁶. More explanation on the definition is included later in our response.

Specific themes

Independent advocacy is relevant across the 14 specific themes of the consultation document. In some cases, there are already independent advocacy organisations providing support to neurodivergent people and people with learning disabilities to have their voice heard within specific settings and systems related to the 14 themes. This may take the form providing accessible information to people about their human rights, supporting them to have their view heard in a statutory decision-making process related to mental health, accessing rights to education or sharing

⁶ <https://www.siaa.org.uk/wp-content/uploads/2021/02/SIAA-Principles-Final-2nd-print-run-with-ISBN.pdf>

views through collective advocacy on local transport accessibility. There is much scope for improving access to and provision of quality independent advocacy across the 14 themes.

SIAA broadly agree with the two proposals; however they do not go far enough and we would urge the Scottish Government to reconsider the significance of independent advocacy to the groups impacted by the Bill.

Terminology

As a comment on the section on independent advocacy as a whole, we urge the Scottish Government to discuss 'independent advocacy' rather than 'advocacy'. We know that there is a need for increased understanding around what independent advocacy is. As stated in the consultation, a shared and clear definition of independent advocacy is vital for progressing this work (which SIAA and our members are keen to support given the extensive work we have done in this area). Part of clarifying what independent advocacy is entails consistently using the term 'independent advocacy' instead of just advocacy. This helps to differentiate it from other types of advocacy that are not independent or provide different functions, for example advocacy work relevant to national campaigning or the law. SIAA fully recognise the value of advocacy in its different forms but suggest the value of different forms of advocacy cannot be recognised without being clear about what is being discussed.

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

SIAA somewhat supports the suggestions within Proposal 1.

SIAA and our members would value working with the Scottish Government, alongside those with lived experience, to help identify how best to strengthen rights and access to provision. SIAA are already working towards producing a clear definition of independent advocacy for primary legislation and beyond using our in depth knowledge of the structures, culture and practice that results in high quality independent advocacy.

Definition of independent advocacy

For independent advocacy to work well and be resourced effectively it needs to be clearly defined in law and policy and understood by funders and commissioners as well as the advocacy partners it is available to.

An independent advocacy group only provides independent advocacy. All the activities it undertakes are about providing, promoting, supporting, and advocating for independent advocacy. Independence means that it does not provide any other services and is structurally, financially, and psychologically separate from other organisations and interests.

‘Independent advocates’ or ‘advocacy workers’ work or volunteer for independent advocacy groups. Independent advocates help people to get the information they need to make real choices about their circumstances and support the person or ‘collective advocacy’ group to put their choices across to others. An independent advocate may speak on behalf of people who are unable to do so for themselves.

‘Independent advocacy’ must have a clear definition in the Bill that aligns with the Independent Advocacy Principles, Standards and Code of Best Practice⁷ as follows:

“Independent advocacy organisations or groups providing support and representation must have structural and financial independence from other organisations and services. An organisation providing independent advocacy must have structural and financial independence.

- Structural independence means an independent advocacy organisation or group is a separate organisation in its own right. For example, it is registered as a charity or company and has its own Management Committee or Board of Directors. An independent advocacy organisation only provides independent advocacy. The organisation must provide no other services, have no other interests, ties or links other than the delivery, promotion and support of independent advocacy.
- Financial independence means an independent advocacy organisation or group has its own source of funding that does not cause any conflict of interest and does not compromise the work it does.”

The above definition must be expanded upon in any regulations, standards and guidance following the primary legislation. SIAA recommend that this includes guidance on the practice of psychological independence that is vital for robust independent advocacy but is difficult to define in law. SIAA would recommend the Scottish Government consider the following for an expanded definition relevant for secondary legislation:

⁷ <https://www.siaa.org.uk/wp-content/uploads/2021/02/SIAA-Principles-Final-2nd-print-run-with-ISBN.pdf>

“In order to practice effective independent advocacy, an independent advocacy organisation or group must be structurally, financially and psychologically independent. Structural and financial independence are outlined in the Act.

The independent advocacy organisation or group should provide no other services, have no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy. Structural and financial independence support psychological independence. Independent advocates must have psychological independence through acting in the absence of undue influence and minimising conflict of interests. Psychological independence is fundamental to the practice of independent advocacy, meaning the primary loyalty and accountability of an independent advocate is to the advocacy partner and enables the independent advocate to better support a person to express their views. Psychological independence builds trust with an advocacy partner or group and shapes the nature of the advocacy being provided.”

This goes far beyond semantics - SIAA knows from our members how important the concept of independence is to people using independent advocacy and how critical the use of the word ‘independent’ is in positively shaping their perceptions of and engagement with independent advocacy. If people feel the advocacy is related to or attached in any way to another system or service they also use, this can erode the ability to build trust.

Proposal 2: Improve our Understanding of Independent Advocacy

SIAA agree with proposal 2 and would like to set out some of the context for current gaps in provision and help to identify groups that currently have rights of accesses but are not provided for. SIAA are supportive of the idea that those who have the greatest barriers to accessing their rights should be prioritised when resources are limited. However, we would like to emphasise that longer term planning to sustainably increase access to independent advocacy is essential to allow independent advocacy to be a preventative tool and allow people to navigate systems well from the outset. This approach would save money through utilising independent advocacy’s enabling of supported decision making and participation.

Only some people have the right to access independent advocacy dependent on the specific legislation. The Mental Health (Care and Treatment) (Scotland) Act 2003 gave people the most significant right to independent advocacy. Under Section 259 of the Mental Health (Care & Treatment) (Scotland) Act 2003 there is a legal right to access independent advocacy for everyone

with 'mental disorder' (as defined by the Act) as per s328 of the Act. However, as highlighted by the Mental Welfare Commission in The Right to Advocacy 2018 report, the way the funding has been distributed in Scotland often means people subject to statutory processes under this legislation are prioritised in their access to independent advocacy. Meaning people not subject to compulsory treatment may have to wait or may not even have access to independent advocacy.

For a full list of here and how independent advocacy has been written into Scots law and policy please see Appendix 2.

The way independent advocacy was written into the legislation, and has subsequently been resourced, has meant both a widening of access to independent advocacy but also a funnelling of independent advocacy provision, linking it to statutory processes (e.g. a Mental Health Tribunal) in the minds of both advocacy partners and public services. This has meant independent advocacy cannot fulfil its potential in the context of early intervention and prevention or enable participation and supported decision makings as fully as it could. In order to address this a clear definition of independent advocacy should be included in the Human Rights Bill and other upcoming legislation as well as addressing the underutilization of different models of advocacy, specifically collective advocacy and citizen advocacy. Finally human rights budgeting approach should be taken to funding grassroots independent advocacy.

The gaps and lack of access, despite the right in law was reinforced in the Independent Review of Learning Disabilities and Autism in the Mental Health Act⁸ which highlighted that although autistic people and those with an intellectual disability have the right to access independent advocacy under the Mental Health (Care and Treatment) (Scotland) Act 2003, the reality is that people do not have equal access to independent advocacy. SIAA research for The Advocacy Map⁹ shows there are significant gaps in the provision of independent advocacy across Scotland, including:

- children and young people
- people with dementia
- neurodivergent people
- people with learning disabilities
- people within the prison system

⁸ <https://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2020/02/IRMHA-easy-read-final-report-10-1-20.pdf>

⁹ <https://www.siaa.org.uk/information-hub/siaa-advocacy-map-sustainability-of-independent-advocacy-in-scotland/>

- unpaid carers.

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

SIAA are disappointed that the Scottish Government are not proposing a broad right within the Bill, particularly as a right of access to independent advocacy was recommended by LEAP. It is concerning to SIAA that not everyone that is likely to be included under the LDAN Bill will cross over with the group that has a right of access that exists under the Mental Health (Care and Treatment) Scotland Act 2003. The consultation paper itself reflects this but the explanation around the reasoning for not including a right to independent advocacy for those within scope of the LDAN Bill amounts to 'wait and see' what happens with upcoming legislation. SIAA would like to highlight that there is no timetable for reforming mental health and capacity law yet and therefore are deeply concerned that this misses a crucial opportunity to tangibly improve rights for neurodivergent people and people with learning disabilities. Including a right of access to independent advocacy would ensure those that fall out with the 2003 Act definitions can still access independent advocacy and create the context for increased supported decision-making. SIAA understand there are complexities around the scope of who will be included and how they will be defined in future mental health and capacity law, however, this should not impact on people with learning disabilities and neurodivergent people whose rights are at risk now.

SIAA would caution the Scottish Government on the proposal to place a duty on all public bodies to ensure independent advocacy information and signposting is provided without also looking at resourcing of independent advocacy organisations. SIAA's report on the Sustainability of Independent Advocacy in Scotland¹⁰ identified that 71% of respondents (independent advocacy organisations) identified groups with an unmet need for independent advocacy. This was identified by organisations who had people approach them asking for independent advocacy who did not meet the existing criteria for access. It is important to note that this does not necessarily mean that those not meeting existing criteria did not have a 'right of access' under the 2003 Act, the work that an independent advocacy organisation provides independent advocacy within are often limited to statutory processes due to their limited resources. However, the right of access in the 2003 Act is meant to be broader than just statutory processes. Increasing knowledge about independent

¹⁰ <https://www.siaa.org.uk/member-news/siaa-launch-sustainability-of-independent-advocacy-in-scotland-report/>

advocacy through a duty on public services to provide information without also increasing resources will likely result in more stress on organisations that are already struggling to meet demand due to underfunding.

SIAA support SCVO's work on Fair Funding¹¹ and call on the Scottish Government to commit to Fair Funding across the voluntary sector and consider the Fair Funding commitment in relation to independent advocacy before increasing signposting to independent advocacy organisations. Fair Funding means long-term, flexible, sustainable, and accessible approach to funding and procurement calling for consistent approaches and processes, unrestricted funding, transparency, and investment in the sector that keeps pace with inflation and supports Fair Work and at least the Living Wage.

Is there anything else that we should consider in relation to independent advocacy?

Independent advocacy and 'best interests'

As the Scottish Government develops its understanding of independent advocacy and develops legislation and policy for the LDAN Bill and beyond, SIAA would urge the Scottish Government to consider independent advocacy as a concept in and of itself and not discuss independent advocacy as a 'service'. Independent advocacy is a human rights tool, and its strength is often that it is not working in best interests and it is accountable solely to the advocacy partner and independent advocacy organisation. Human rights are all about power, and the sharing of that power between those impacted (rights holders) and those who are in a position to make decisions (duty bearers). Independent advocates work alongside marginalised people and groups, supporting them to be empowered to take part in decision-making about their lives, and about policy and law making, on an equal basis.

One of the guiding principles of the UNCRPD in Article 3 is the "Respect for [the] inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons"¹². Independent advocacy can support people to understand and make their own choices and develop their own personal autonomy independent from others who may have undue

¹¹ <https://scvo.scot/policy/fair-funding-procurement>

¹² <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html>

influence or conflicts of interest. This can include professionals that must work in best interests and family or carers that often must have other considerations as well as the individual's will, wishes and preferences. The SIAA Principles, which underpin independent advocacy in Scotland, are intrinsically linked to the principles of Participation, Accountability, Non-discrimination and equality, Empowerment and Legality (PANEL). Independent advocacy groups have a human rights-based approach that support individuals and groups to consider how human rights laws may apply to their specific circumstances.

Why should independent advocacy provision be strengthened?

SIAA would like to take this opportunity to provide some evidence around why independent advocacy should be strengthened. Independent advocacy has been a key feature of recent independent reviews and policy recommendations. Most importantly, when people with lived and living experience of barriers to having their rights realised are asked what has helped to break down those barriers, independent advocacy has frequently and consistently featured. Independent advocates who take a rights-based approach to their work are Human Rights Defenders. As such the UN states that:

“Implementation of international human rights standards within countries depends to a great extent on the contribution of individuals and groups (working inside as well as outside the State), and support to these human rights defenders is fundamental to achieving universal respect for human rights.”¹³

All Our Rights in Law¹⁴

The All Our Rights in Law project that brought together over 430 people for over 35 community conversations to talk about a new human rights law for Scotland concluded that one of the thirteen key recommendations to make rights reality was: “Independent advocacy services should be available to all”, independent advocacy also supports a number of the other thirteen recommendations in the following ways:

1. People need to know and understand their rights - a key part of independent advocates work is to provide impartial information about choices and raise people's awareness about their human rights.

¹³ <https://www.ohchr.org/sites/default/files/Documents/Publications/FactSheet29en.pdf>

¹⁴ <https://www.allourrightsinalaw.scot/>

3. Systemic change on human rights should not rely on individuals – collective advocacy creates space for groups to lead in creating change.

6. We need a human rights culture across public authorities – independent advocacy reminds services of their responsibilities and duties. Having an independent advocate in a room where decisions are made that will impact a person’s rights can be enough to shift the power dynamic and create change.

8. Voices of marginalised people should guide public decision-making – the independent advocacy movement, particularly collective advocacy, is rooted in and has grown from the voices of marginalised people, for example those with mental ill health¹⁵.

9. Mechanisms for public accountability should be built in – independent advocacy can act as a reminder of accountability mechanisms and provide information about what they are so people can make informed choices.

From the All Our Rights In Law report “It was marked that, whilst advocacy services were not highlighted particularly within the All Our Rights resources, many participants spoke about these services as being critical to making the new rights system work for marginalised people. Some spoke about advocacy services being currently patchy and available mainly to those in the mental health system. They also spoke about their concern around recent cuts in these services.”

Independent review recommendations

The Scottish Mental Health Law Review (SMHLR)¹⁶ chaired by John Scott gathered expertise from across Scotland including from those with lived and living experience. This is particularly relevant to assessing where independent advocacy can be improved and utilized as people that fall under current mental health and incapacity legislation have some of the strongest access to independent advocacy at present. Recommendations around independent advocacy, particularly around how it supports human rights, enables participation and allows for supported decision making, are a theme of the final report. SIAA urge the Scottish Government to consider the Scott Review recommendations on independent advocacy when looking at UNCRPD incorporation and to support

¹⁵ <https://capsadvocacy.org/collective-advocacy/oor-mad-history/>

¹⁶ <https://webarchive.nrscotland.gov.uk/20230327160310/https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/09/SMHLR-FINAL-Report-.pdf>

joined up policy making across Government including future proofing approaches that may be taken to mental health and capacity law.

Other reviews that have made recommendations to strengthen independent advocacy in Scotland are the Independent Review of Adult Social Care¹⁷ (Feeley Review) and the Independent Review of Learning Disability and Autism in the Mental Health Act¹⁸ (Rome Review). The Feeley Review report noted that “advocacy arrangements need to be improved, so that people with incapacity and others who are accessing supports and services have their needs, rights and preferences properly represented.”

Recommendations from the three independent reviews include:

- greater resource and right to access collective advocacy,
- individual and collective advocacy groups should have an explicit right to raise a court action for human right breaches,
- increased access to independent advocacy for infants, children, and young people,
- culturally appropriate independent individual and collective advocacy provision,
- developing a national training programme for independent advocates,
- an existing or new organisation should have responsibility for monitoring and continuing development of independent individual advocacy,
- align legislation and policy to ensure consistency regarding the definition of independent advocacy,
- independent individual and collective advocacy are sustainably funded,
- opt out access to independent advocacy for certain groups at risk of their rights not being met,
- increased independent advocacy for carers.

Independent advocacy in the Children’s Hearing System

Within the Children’s Hearing System, a child may be informed of the availability of independent advocacy by the Chair. The Hearings System Working Group's Redesign Report states that: “In the current Children’s Hearings System, independent advocacy workers play a crucial role in helping

¹⁷ <https://www.gov.scot/groups/independent-review-of-adult-social-care/>

¹⁸

https://www.researchgate.net/publication/342314047_Final_report_of_Scotland%27s_Independent_Review_of_Learning_Disability_and_Autism_in_the_Mental_Health_Act

children to tell the Children’s Hearing what they want—how they feel, what they think, and what they would like to happen. The aim of this is to give children the offer of support of an independent advocacy worker as and when they need one, in order for them to give their views clearly and definitely, and to have their voice magnified within the Children’s Hearing... The HSWG has heard that this provision is positive and recognises its significance for children.”

Care experienced people are a group that experience many barriers to having their rights realised and it is clear that independent advocacy is a vital component of ensuring some of those barriers are removed. The whole system approach Scottish Government has taken when introducing independent advocacy into the Children’s Hearings System has been widely praised by SIAA members and within wider analysis of the redesign of the system¹⁹. The systems change approach has been made possible through the joint work of Scottish Government, Children’s Hearings, Scottish Children’s Reporter Administration, independent advocacy organisations and others in the Expert Reference Forum working together to tackle barriers and affect system change. SIAA and members would encourage Scottish Government to identify key learnings from colleagues working on independent advocacy within the Children’s Hearing System and seek to understand how the approach they have taken to funding (that supports local, grassroots independent advocacy organisations) evaluation, monitoring and training, could be applied.

The recent scoping document published by The Promise Scotland²⁰ sets out plans and ambitions for lifelong independent advocacy for care experienced people. Independent advocacy is identified as being ‘distinctly different from other forms of advocacy and has developed in practice over the last thirty years in Scotland.’

Housing and Independent Living

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

SIAA partially supports Proposal 1.

¹⁹ <https://thepromise.scot/resources/2023/hearings-for-children-the-redesign-report.pdf>

²⁰ <https://thepromise.scot/the-promise-scotland/what-the-promise-scotland-does/change-projects/national-lifelong-advocacy-service/>

SIAA agree that increased independent advocacy provision for people with learning disabilities and neurodivergent people with housing and independent living issues would help address these rights issues. However, SIAA would strongly encourage the Scottish Government to carefully consider procurement around service or settings specific independent advocacy. Evidence from our member organisations suggests that when people access advocacy about a specific issue, they will often end up receiving support for more than one issue. For example, one of our member organisations told us that in the year 2022 to 2023 the difference between the number of people and the number of advocacy issues was an average of 1.3 per person within the year, showing people are accessing advocacy for multiple issues. An organisation in a different local authority area told SIAA that ‘it’s very rare for us to support only with a singular issue and that nearly everyone that accesses our service will receive support with multiple things’. Having local independent advocacy organisations support people across multiple issues is not only cost effective but provides consistency for the advocacy partner as they only have to explain their lived experience once and build trust with one provider that they know can provide information on the choices available to them in their local area.

Is there anything else that we should consider in relation to housing and independent living?

Independent advocacy and advice

As Proposal 1 mentions ‘advice, support, advocacy and guidance’ SIAA would like to take this opportunity to highlight that independent advocacy and advice are mutually supportive, but distinct, avenues of assistance. Independent advocacy and advice are not interchangeable - they fulfil different functions and provide different levels of support. In addition, it is a fundamental tenet of independent advocacy that people accessing it are “protected from undue pressure, advice or others’ agendas” (SIAA Principles, 2019). Independent advocacy does not give advice but supports people or groups to access information so they can make their own informed decision. This distinction is crucial when considering how independent advice and independent advocacy are set out in law.

Relationships

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

SIAA agree with Proposal 1. As we mentioned earlier in our response, we are supportive of independent advocacy being resourced to provide to the widest range of people, providing it can remain of high quality. Where budgets mean access is limited, focussing initially on those that have the greatest barriers to having their human rights realised could be a reasonable decision-making tool to adopt.

Justice

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

SIAA agrees that independent advocacy is essential for those involved in the justice system. However, we would like more clarity on how not providing a right of access to independent advocacy under the LDAN Bill holds back other work on independent advocacy across Scottish Government.

SIAA agrees that part of the justice systems improvement should be training for public bodies on independent advocacy. Particularly as we aim to see access to independent advocacy increased across policy areas in Scotland. SIAA have recently delivered awareness raising sessions about independent advocacy to Scottish Public Services Ombudsman (SPSO) staff and Independent Living Fund (ILF), among others. We support consistent and resourced training on independent advocacy for scrutiny and public bodies. Any training on independent advocacy should be co-designed with independent advocacy organisations and advocacy partners. Training should aim to provide a clear understanding of the principles, standards, practice and landscape of independent advocacy across Scotland.

SIAA recommend that consideration is given to how independent advocacy organisations and collective advocacy groups will be resourced to gather expertise on the changing landscape of justice systems, particularly as work on many new and potential commissions/commissioners is undertaken. Upskilling across independent advocacy will be required to ensure that they can provide accurate information to neurodivergent people and people with learning disabilities and

provide high quality independent advocacy to ensure people's voices are heard when interacting with the justice systems.

Is there anything else that we should consider in relation to justice?

Independent advocacy and Access to Justice

Independent advocacy can support access to justice and those interacting with the justice system by ensuring someone's voice is heard and providing information so a person can understand their rights. If resourced well, independent advocacy is;

Accessible – one of the three key principles of independent advocacy is 'independent advocacy stands up to injustice, discrimination and disempowerment'. In order to do this independent advocates work hard to make sure they work is as accessible as possible.

Affordable - it is always free at the point of access.

Timely – Independent advocacy, when resourced well, can be very effective in ensuring that decisions are explained by services, challenged and often prevented from escalating.

Effective – no matter the outcome, having independent advocacy involvement will ensure a person's voice has been heard, supported participation and will have provided information about their rights.

The independent advocacy relationship does not have the conflicts of interest inherent in other relationships with family, friends, service providers and professionals. People accessing independent advocacy are protected from undue pressure, advice or others' agendas. Often professionals and organisations make decisions that are in the best interests of an individual because they have a duty to do so. Independent advocacy does not have such a legal duty. Independent advocates do not have the same conflicts of interest as other professional workers who are expected to make judgements about who is in need, deserving or most eligible for a service. Because independent advocates do not have this sort of power over people and do not control access to resources, they are in a better position to see things from the person's point of view. From the outset of the advocacy relationship, they are more likely to have the trust of the people they are working with.

Although SIAA and our member organisations believe access to justice is a crucial part of how independent advocacy can support human rights, independent advocacy enables a range of

participation, is effective when used in an early intervention approach to breaches of human rights and can be particularly important for people and groups that experience the greatest barriers in having their rights realised.

Accountability mechanism - Independent advocacy can act as an 'everyday' accountability mechanism by providing information to advocacy partners about what duties public services have and what choices an individual has when accessing services, for example asking for a second medical opinion or asking for paperwork to evidence decision making. Advocacy workers can also help people to access complaints processes, courts and tribunals, often making the processes more participatory by shifting power dynamics.

Early intervention and prevention - When independent advocacy is accessed early when a person is experiencing a human rights issue, it can prevent things from escalating and leading to expensive statutory processes, complaints or legal processes. Sometimes people tolerate things in their lives because they don't know they can be changed. Independent advocacy can help them address this.

Addressing the implementation gap – the oft cited 'implementation gap' that exists between Scottish policy and the reality of people's experience of services can be highlighted through collective advocacy.

Accountability

Which of the 5 options set out above do you think would best protect, respect and champion the rights of neurodivergent people and people with learning disabilities? You can select multiple options if you wish.

SIAA support options 4 and 5.

Please give the reason for your choice(s).

SIAA recommend that the Scottish Government include collective advocacy within option 4. Ensuring that collective advocacy groups can exist at a local grassroots level allows for more options for groups with a shared interest to emerge and impact change within their community or setting. Some groups may wish to remain as collective groups, be supported by a collective advocacy worker and not become incorporated charity organisations i.e. a Disabled People's Organisation (DPO). In some cases, this might mean a collective advocacy group is more resource efficient and

can be more flexible in its approach as there are fewer core costs that need to be accounted for. This is not to undermine the significant value of DPOs, whom SIAA firmly believe should have increased resource, but we would encourage the offering of choice that values independence and believe widening support to DPOs and collective advocacy groups would be beneficial in the challenging financial circumstances we are all operating in.

Why is grassroots, locality based independent advocacy effective?

The independent advocacy movement has grown and developed over the last 35 years. Many of the grassroots, community focused independent advocacy groups continue to develop based on the specific needs of their community. The Principles, Standards and Codes of Best Practice highlights the importance of independent advocacy being embedded in a local community or community of interest. Independent advocacy groups are often led and influenced by people with lived expertise and the needs of the specific community of interest and locality.

SIAA strongly supports grassroots, community based independent advocacy groups who have developed their expertise, knowledge, and practice of independent advocacy over many years. All these groups continue to hold the SIAA Principles, Standards and Codes of Best Practice central to their work to ensure local people and groups can have their voices heard and taken into account.

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

Collective advocacy and access to justice

SIAA would encourage the Scottish Government to enable collective advocacy provision as well as looking at individual advocacy provision. To ensure collective advocacy begins to have parity of esteem with individual independent advocacy.

The Scott Review²¹ noted that collective advocacy is considered an important element within a human rights-based approach to accountability frameworks. Collective advocacy has an ability to address systemic issues, identify trends and geographical areas where rights are being violated, and identify solutions and good practice. People valued its role in campaigning for human rights. It increases citizen participation and empowers people.

²¹ <https://webarchive.nrscotland.gov.uk/20230327160310/https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/09/SMHLR-FINAL-Report-.pdf>

SIAA recommend that Scottish Government look in detail at the Scott Review recommendations around collective advocacy and consider how explicit reference to collective advocacy can be made in the LDAN Bill to support participation and accountability. SIAA also urge the Scottish Government to consider how supports for collective advocacy can be increased to address rights issues for communities of locality or interest. This should be done at a grassroots level with expertise of existing collective advocacy groups utilized to ensure the principles of independent advocacy are maintained and human rights are central to their approach.

Scottish Human Rights Commission (SHRC) in their paper, written by Professor Katie Boyle, note that there are three distinct approaches to facilitating a collective or structural response to systemic problems and currently there is an over reliance on the approach that involves an individual taking a test case. 'The research suggests this can exacerbate access to justice issues for those impacted and that public interest litigation and collective cases are required to help alleviate the individual burden of a test case and the potential adverse impact on those cases that are suspended.' A key question to enable access to justice asked in the paper is; What other mechanisms might help support collective complaints or collective advocacy movements? SIAA suggest that the Scottish Government should use the LDAN Bill as an opportunity to create the resources to support collective advocacy groups to raise collective human rights issues via judicial and non-judicial routes. Particularly as collective advocacy and disabled people's organisations have been heavily involved in providing views from people with learning disabilities and neurodivergent people to the Scottish Government for this consultation and preparatory work for the LDAN Bill. Ensuring those organisations relied upon to share views are well resourced and their value understood is critical to continuing this work. SIAA strongly support the recommendations related to this in the Scott Review around collective complaints, namely:

- collective advocacy groups should have an explicit right to raise a court action for human right breaches. This right must be supported by access to legal advice, guidance and support for groups who wish to take this step.
- there should be an alternative way for collective advocacy groups to be able to escalate human rights issues that remain unresolved and unaddressed by services to another scrutiny body/Commissioner to investigate. This would need to be supported by a participatory process of referral and consideration within the identified scrutiny body.

Ensuring that there judicial and non-judicial pathways for collective groups to raise issues means that each group can decide for themselves which option is best for their collective. SHRC further noted in their report that independent advocacy is vital in creating an access to justice system that works for rights holders: 'In order for access to justice to function people should be able to participate in the system and in the decisions that impact them. The role of advocacy services can play an indispensable role in supporting and ensuring genuine participation and informed decision making.'²² Furthermore, UNCRPD Committee has said that governments need to strengthen the capacity of collective advocacy groups and emphasizes their importance in General Comment No. 7²³.

The Law Society of Scotland, in their response to the Scott Review, noted that independent advocacy organisations were well placed to notice patterns in human rights breaches and therefore are well placed to take court action for alleged human rights breaches. However, they conclude that 'without a corresponding proposal to develop and promote legal services available to individuals we have real concerns regarding how individuals and groups will be able to access justice.'²⁴

SIAA members are keen to reiterate that agendas must be set by collective advocacy groups themselves. The work of collective advocacy cannot be dictated to by public bodies/commissioners looking to make improvements. Scott also identified a need for greater awareness within NHS Boards and public bodies about what collective advocacy is and to engage with it.²⁵

Appendix 1 - Examples of independent advocacy upholding human rights

Independent advocates across Scotland work in a range of situations to support people to understand and realise their economic, social, and cultural rights. For example:

²² <https://www.scottishhumanrights.com/media/2496/access-to-justice-for-everyone-a-discussion-paper.pdf>

²³ <https://www.ohchr.org/en/treaty-bodies/crpd/general-comments>

²⁴ <https://webarchive.nrscotland.gov.uk/20230327160310/https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/09/SMHLR-FINAL-Report-.pdf>

²⁵ <https://webarchive.nrscotland.gov.uk/20230327160310/https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/09/SMHLR-FINAL-Report-.pdf>

The right to education

Brian and his mum contacted an independent advocacy organisation as Brian had been asked by his deputy head to collect and sign a leaver's form and told he could not attend the winter ball. Brian did not want to leave school and had planned to complete 5th year, so he refused the leaver's form. He was panicked as he thought he must have been excluded.

Brian's mum informed the independent advocate that she had been requesting additional support for Brian since his transition to high school, but that it had not been forthcoming.

The independent advocate shared information with Brian about his rights to attend and engage with education. The advocate established, from speaking to the deputy head, that Brian was not officially excluded but that the school thought it best for him to engage in college or work instead. With the support of the independent advocate, Brian was empowered to meet with the deputy head and ask why the decision to give him his leaver's form had been taken and ask that his rights be upheld. The legal information and guidance relating to exclusion and additional support was shared with the school. Shortly after this meeting, Brian was given a new timetable with support to complete his studies.

The right to housing

Many months before he sought this advocacy support, Malcolm had been having work carried out on his council house. Whilst carrying out the repairs, workmen discovered drug paraphernalia and left the premises immediately because of the related health and safety concerns. Malcolm was told by the local authority that, before the remainder of the work could be completed, his house would have to be 'made safe' by environmental health. In the meantime, he was left without a working toilet and had had to rely on the kindness of his neighbours letting him use their facilities.

This had been going on for over a year - environmental health inspectors visited the property on numerous occasions and found no drug paraphernalia and therefore no work that needed to be done to make it safe. However, despite Malcolm's repeated requests, the original repairs were not completed.

Malcolm met with an independent advocate, who spent some time with him outlining his various options and getting to know the situation. Malcolm expressed a desire to contact the local

authority again, this time with independent advocacy support, so he and the independent advocate called their offices. Malcolm observed that, on this occasion, he was treated much more respectfully by the local authority and the issue was handled in a totally different way. The person he was speaking to took time to explain the relevant processes, looked into what might be going wrong and took the necessary actions to set things right.

As a direct result of the phone call, local authority workmen were sent to Malcom's house within the week. They completed the repairs, thus restoring his dignity and materially improving his living conditions.

The right to health

Sometimes, collective advocacy groups already in existence can initiate specific pieces of work to address issues that have arisen for group members. One such example comes from a collective advocacy group led by people with lived experience of a mental health problem or diagnosis.

Group members had shared their experiences of A&E services at two hospitals and found that various aspects of the A&E environment had been challenging for them. In some cases, A&E staff had perceived them differently once their mental health history was known, which had sometimes overshadowed diagnosis and negatively impacted on their treatment.

These common experiences then became the catalyst for the development of a project. With funding secured, a group of peer researchers was recruited to gather views from people with lived experience of mental health problems who had experienced A&E in hospital. As the project developed, efforts were continually made to ensure that group members were comfortable with its direction and regularly offered the opportunity to be involved. The importance of understanding that a collective advocacy group is made up of individuals was always a consideration - members had the option to be involved flexibly, in different ways, taking part on their own terms. In this way, they felt safe and in control, rather than feeling overwhelmed by their involvement.

The release of the peer research results initiated an invitation from senior NHS staff to discuss the issues raised and steps that could be taken to improve people's experiences at A&E. This, in turn, led to specific positive actions, including group members taking part in training for NHS staff, and the development of an emergency card that people can choose to fill in and present at A&E. The

card sets out information they want staff to be aware of and enables them to communicate more easily their wishes at a time of potential stress.

Over the course of this piece of work, the collective advocacy group raised issues, identified common themes, initiated a project, collected and represented experiences, broke down barriers and, ultimately, made positive changes in order to address the problems they had experienced.

For more examples of how independent advocacy works in practice to uphold rights please see Independent advocacy in action: Case studies illustrating SIAA's 'Principles and Standards'²⁶

Appendix 2 - Independent advocacy in Scots law and policy

Independent advocacy is framed as part of Scots law and policy in a number of different ways:

- A right to (independent) advocacy for particular groups, e.g. for those with a mental disorder as set out in the Mental Health (Care & Treatment) (Scotland) Act 2003; for a disabled person accessing social security entitlements as set out in section 10 of the Social Security (Scotland) Act 2018
- A duty to provide advocacy services e.g. duty on health boards and local authorities to secure availability of advocacy services for those with a mental disorder as set out in Mental Health (Care & Treatment) (Scotland) Act 2003
- A duty on councils to consider the importance of independent advocacy services e.g. for adults at risk from harm as set out in the Adult Support and Protection (Scotland) Act 2007
- A duty to provide information about available advocacy services e.g. as set out in Social Care (Self-directed Support) (Scotland) Act 2013 where it specifically notes independent advocacy services; to children referred to a Children's Hearings as set out in the Children's Hearings (Scotland) Act 2011
- A duty to ensure that people can access the advocacy service e.g. in Mental Health (Care & Treatment) (Scotland) Act 2003
- The right for views expressed by advocates to be taken account of in decision-making e.g. Adults with Incapacity Act 2000

²⁶ <https://www.siaa.org.uk/wp-content/uploads/2021/05/Independent-advocacy-in-action-SIAAs-%E2%80%98Principles-and-Standards-in-action.pdf>

- A duty on Scottish Ministers to develop and publish service standards around provision of advocacy e.g. in the Social Security (Scotland) Act 2018
- A duty to allow advocates to take part in discussions or make representations on an individual's request e.g. Education (Additional Support for Learning) (Scotland) Act 2004
- A duty to ensure that advocacy support is available and free of charge when someone is going to a Tribunal or Hearing e.g. in the Education (Additional Support for Learning) (Scotland) Act 2009 or Children's Hearings (Scotland) Act 2011

Appendix 3 – Principles and standards of independent advocacy

Principle 1: Independent advocacy is loyal to the people it supports and stands by their views and wishes.

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests, and agendas of others.
- Standard 1b: Independent advocacy must be able to evidence and demonstrate its structural, financial, and psychological independence from others.
- Standard 1c: Independent advocacy provides no other services, has no other interests, ties, or links other than the delivery, promotion, support, and defense of independent advocacy.

Principle 2: Independent advocacy ensures people's voices are listened to and their views are taken into account.

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic, and personal interests of others.

Principle 3: Independent advocacy stands up to injustice, discrimination, and disempowerment.

- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control, and influence.

- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights. Find out more about independent advocacy and how it works in Scotland from the Independent Advocacy Principles, Standards and Code of Best Practice.

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