



Sensible Sharing: Safeguarding Scottish Advocacy Independence Through Data Sharing Best Practices

SIAA Position Paper

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Scottish
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Executive Summary

Overview

This position paper by the Scottish Independent Advocacy Alliance (SIAA) addresses the critical relationship between data sharing practices and the independence of advocacy organisations. It emphasises that independent advocacy can only be high quality if it remains truly independent, highlighting growing concerns about how data sharing requirements from commissioners and funders may compromise this independence.

Key Points

Understanding Independent Advocacy

- Independent advocacy is about speaking up for and standing alongside individuals or groups, without being influenced by others' views
- It helps people navigate public services, acts as a catalyst for change, and can prevent situations from escalating
- Independence comprises three key components: structural, financial, and psychological independence

Current Challenges

- Increased demand for advocacy services with simultaneous funding reductions
- Rising complexity of referrals requiring more advocacy worker time
- Significant increases in mental health detentions, welfare guardianships, and reported mental health conditions
- Only 5% of people with legal rights to independent advocacy can actually access it

Impact of Data Sharing on Independence

- Growing requests for output-focused data (travel time, identifiable information, etc.) rather than outcome-focused metrics

- Detailed operational information disclosure can negatively affect psychological independence
- Data sharing that compromises independence undermines the very service being commissioned
- Health and Social Care Partnerships (HSCPs) must balance statutory duties with maintaining advocacy independence

Value of Independent Advocacy

- When properly funded, independent advocacy saves public resources
- Research shows £1 spent on advocacy services saves approximately £7 to the NHS and £5 to local authorities
- Independent advocacy enables human rights, enhances participation, and serves as an accountability mechanism

Legal Context

- Mental Health (Care & Treatment) Act 2003 provides broad rights to independent advocacy
- Seven Scottish laws mention independent advocacy, with two additional child-related laws awaiting implementation
- International human rights laws (UNCRC and UNCRPD) emphasise participation rights that advocacy helps fulfil

Recommendations for HSCPs

1. **Ensure up-to-date strategic advocacy plans** that fulfil duties under the 2003 Act to secure availability of independent advocacy services for those with a right of access.
2. **Utilise the SIAA Outcomes Framework** to build understanding and properly commission independent advocacy services.
3. **Work collaboratively with local advocacy organisations** to ensure monitoring activities do not impact independence while providing necessary information to understand and improve quality of services.

Introduction

The [Scottish Independent Advocacy Alliance \(SIAA\)](#) advocates for independent advocacy. SIAA has been dedicated to promoting and supporting independent advocacy in Scotland for over two decades. With a focus on its provision, quality, and accessibility, we provide support to independent advocacy organisations throughout the country and maintain a national perspective that enables us to identify and promote best practices.

SIAA has 32 member organisations that offer collective and individual independent advocacy in various settings, including communities, hospitals, and prisons. The majority of this is provided in-person to ensure it is accessible and person-centred. Our members work within the [Independent Advocacy Principles, Standards and Code of Best Practice](#), which emphasise the PANEL principles of Participation, Accountability, Non-discrimination, Empowerment, and Legality. This human rights-based approach is pivotal in helping individuals and groups understand how their rights apply to their situations, ensuring that independent advocacy is enabling rights to be realised and voices to be heard across Scotland.

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 is especially important when individuals or groups are not heard, are vulnerable or are discriminated against. This can happen where support networks are limited, someone has been affected by trauma or if there are barriers to communication. Independent advocacy also enables people to stay engaged with services that are struggling to meet their needs. 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.

Context

We know that public services are incredibly stretched across the country. Independent advocacy organisations have similarly struggled to sustain their provision in recent years. Organisations are seeing an increase in the need for independent advocacy at the same time as funding is reduced or remains static. SIAA are aware that local councils and health boards are in challenging financial positions, which at times results in making funding cuts to independent advocacy as well as requesting stricter eligibility criteria for those accessing independent advocacy. A lack of understanding about independent advocacy from commissioners and funders, can hinder an organisation's ability to maintain independence and directly impacts the quality of provision. **Independent advocacy can only be high quality if it is truly independent.**

What has changed? Increased need and reduced funding for independent advocacy

SIAA member organisations have experienced increases in referrals for independent advocacy dating back to before the 2020 pandemic. 71% of SIAA members that reported to us in 2023 identified groups with an unmet need for independent advocacy. Members also report an increase in complexity of referrals, which means that advocacy partners need more time with advocacy workers to navigate the barriers they are facing.

In 2024, the Mental Welfare Commission reported the [highest number of welfare guardianship recorded and noted that guardianships had doubled in the last 10 years](#). The Commission also found that [numbers of detentions of people in Scotland for compulsory mental health care and treatment rose in 2023-24, while safeguards fell](#). As a human rights-based practice that enables participation, independent advocacy can be a form of safeguarding for people that fall under the Mental Health (Care & Treatment) Act 2003, which governs how detentions are carried out nationally. Scotland's 2022 Census found an [increase in reporting of health conditions](#). The percentage of people reporting a mental health condition in the census increased from 4.4% in 2011 to 11.3% in 2022. This was the largest increase across condition types.

The increases in the number of guardianships and mental health-related detentions, as well as the significant increase in people reporting a mental health condition is significant for independent advocacy. These groups of people not only have a right to independent advocacy under the 2003 Act, but they are also the ones who often face the greatest barriers in having their rights fully realised.

More information about ‘what should happen?’ with independent advocacy, including rights of access, is contained in the later sections of this paper. The section explains the international and Scottish laws and policy that determine independent advocacy access and provision.

When independent advocacy is funded sustainably it saves public resources

SIAA are clear that in order for independent advocacy to be high-quality it needs to be truly independent, rooted in local communities or communities of interest, sustainably resourced and connected to other independent advocacy organisations across Scotland. For independent advocacy to be accessible for advocacy partners, there should be choice in how independent advocacy is provided. This means that if an advocacy partner requires or prefers in-person independent advocacy, this should be provided. This ensures it is person-centred and trauma-informed. Where grassroots, high-quality independent advocacy is available, it can lead to significant savings for public funds by aiding individuals in navigating systems, enhancing their self-advocacy skills and confidence, and improving access to communities while addressing barriers to realising their rights.

In the 2025 report ‘[Independent Advocacy for Independent Lives](#)’, which looked at Henry Smith funded independent advocacy across the UK, evaluation partner, Social Finance, undertook a financial analysis for independent advocacy services. This showed that for every £1 spent on advocacy services, there were savings of approximately £7 to the National Health Service and £5 to local authorities. The report also found that independent advocacy can potentially contribute to wider economic benefits by helping people improve their well-being, gain greater independence and participate more actively

in society (including employment). It is important to note that the Social Finance report looks at ‘non-statutory’ independent advocacy. In the Scottish context, ‘statutory’ and ‘non-statutory’ independent advocacy framing does not apply as it does in other parts of the UK. In Scotland, people with a learning disability and autistic people, the groups that the Henry Smith fund covered grantees to work with, already do have a right of access to independent advocacy under the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#). This right is not limited to statutory processes, this is made clear in The Mental Welfare Commission [guidance on working with independent advocates](#). In practice, only 5% of people that have the right in Scots law to independent advocacy can actually access it, this is noted in the [Scottish Mental Health Law Review published in 2022](#). The low uptake of the right to independent advocacy is due to local interpretation of the law being too narrow and limited resources being allocated for independent advocacy organisations.

Why is independence important?

SIAA are clear that the components of independent advocacy identified by SIAA members through their collaboration on [the Independent Advocacy Principles, Standards and Code of Best Practice](#), should be the basis upon which independence is understood by advocacy partners, policy makers, funders and commissioners. This definition comprises of ‘**structural, financial and psychological independence**’ being the key components of independent advocacy.

Structural and financial independence are fundamental to establishing and maintaining the independence of the organisation providing independent advocacy. Structural and financial independence enable independent advocacy workers to have psychological independence. Psychological independence is a part of the practice of independent advocacy, as well as speaking to the quality of independent advocacy provision.

Psychological independence enables:

- Trust to be built with advocacy partners.
- Awareness of and active minimisation of conflicts of interest.
- A person-centred practice that does **not** take a ‘best interests’ approach.

- A human-rights based approach.
- Independent advocacy to be an ‘everyday’ accountability tool.

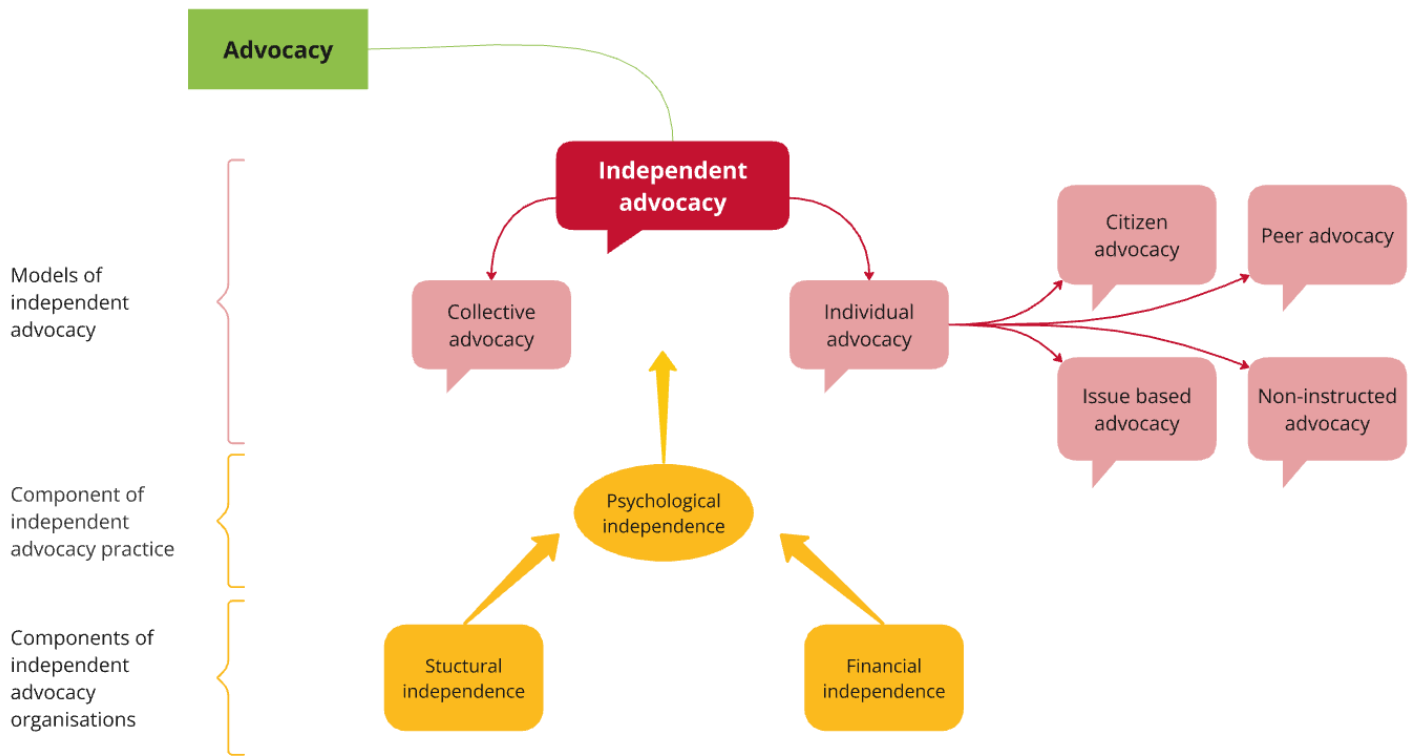


Figure 1: Models and components of independent advocacy

The Scottish Government’s [Independent Advocacy Guide for Commissioners from 2013](#) identifies key factors that underpin good independent advocacy, including:

- advocacy groups should be firmly rooted in, supported by and accountable to a geographical community or a community of interest.
- advocacy groups and those involved as advocates should be constitutionally and psychologically independent of local and national government.
- advocacy groups should not be involved in the delivery of care services or the provision of other services to the individual who requires advocacy.
- different approaches to independent advocacy are needed; there is no best model
- advocacy groups should maintain a clear and coherent focus of effort
- advocacy groups should undergo regular independent evaluation of their work, and commissioners should provide financial support for this.

These factors all represent different aspects of ensuring independence, which are crucial considerations for independent advocacy commissioners and funders. SIAA and its members emphasise the first factor as particularly vital to understanding how high-quality independent advocacy is delivered. Being grounded in and accountable to the local community or community of interest often necessitates in-person engagement as the default approach. This is especially important when individuals have had their rights limited by decisions made by public services and may lack a clear understanding of the reasons behind these decisions. In such cases, independent advocacy serves to balance rights by capturing authentic views, facilitating participation, and functioning as a routine accountability mechanism for decision-makers. For instance, a vulnerable person with uncertain capacity discharged from hospital under Section 13za of the Social Work Scotland Act will require in-person interaction initially to understand what independent advocacy is and how it can be beneficial.

Data sharing and independence

[Evaluation Support Scotland](#) identifies: “An increased emphasis on **evidence based** policymaking and **outcome-based** funding means that evaluation is more important than ever. If ‘what works’ or ‘why’ is not clear, then it is extremely difficult to deliver the **best services** for those who need them, and to meet Scotland’s priorities.”

Evaluation and data sharing are important considerations in funding and commissioning. Gaining a clear understanding of quality independent advocacy provision and collaborating effectively with funders and commissioners to report on the impact of independent advocacy has been a key focus for SIAA and its members in recent years. In 2024, SIAA partnered with members to develop and publish the [Outcomes Framework: Toolkit for Demonstrating Impact of Independent Advocacy](#), we continue to dedicate staff resources to further develop this work.

However, members have expressed concerns that they are increasingly being requested to provide output-focused data about their activities, such as travel time, time spent with advocacy partners, and identifiable information about those partners—including location, initials, and relevant legislation. Such data does not necessarily contribute to a meaningful understanding of the quality of advocacy services provided. Furthermore, the

collection of these monitoring requirements can inadvertently compromise an organisation's independence. When advocates are asked to disclose detailed operational information, it can negatively affect their psychological independence, potentially compromising their ability to represent advocacy partners or groups effectively. This challenges the fundamental purpose of independent advocacy and may hinder the commissioner's statutory obligation under the 2003 Act to ensure the availability of **independent** advocacy services.

The [Independent Advocacy Guide for Commissioners](#) has clear guidance on the level of information a commissioner should request from independent advocacy organisations:

“Commissioners can advise advocacy organisations on what information to collect and this information will be useful in discussions between the organisation and commissioners. However, advocacy organisations should see monitoring as primarily something which benefits them, not as a chore to please the commissioners. This means limiting the information collected to the useful minimum. In order to protect the confidentiality and anonymity of the advocacy partners, the information passed on to commissioners should not contain any identifying detail.” p. 31

SIAA maintains that when data sharing requests from a commissioner or funder jeopardise the independence of an independent advocacy organisation, these requests effectively undermine the commissioning of independent advocacy. This is of particular concern for Health and Social Care Partnerships (HSCPs) who have [legal duties under the 2003 Act](#), which are: “to secure the availability, to persons in its area who have a mental disorder, of independent advocacy services and to take appropriate steps to ensure that those persons have the opportunity of making use of those services.” It is important to note that ‘mental disorder’ in the context of the Act includes any mental illness, personality disorder or learning disability (as per s328). Additionally, the [Scottish Government has noted that](#); “Although not specifically listed, autism has historically been understood as being encompassed within the definition of mental disorder.”

To fulfil their obligations under the 2003 Act, HSCPs should carefully consider how data sharing may affect the independence of advocacy services. SIAA acknowledges that this

is a complex duty, as they have responsibilities to commission local services that remain fully independent. With this in mind, HSCPs must work with independent advocacy organisations to ensure they have a thorough understanding of how to measure the quality of the independent advocacy itself that does not impact independence.

Independent advocacy organisations alongside commissioners and funders must also consider how the UK Data Protection Act 2018 (DPA 2018) and the UK General Data Protection Regulation (UK GDPR) apply to the data collected about advocacy partners. Ensuring organisations are complying with data protection laws is part of upholding human rights, in this case [Article 8 of The Human Rights Act 1998: Respect for your private and family life](#).

What to consider around data collection and sharing for independent advocacy?

- SIAA advocate that funders and commissioners should agree with independent advocacy organisations on monitoring activities that can support measuring both outcomes and processes. These monitoring activities should be undertaken to understand the quality of independent advocacy provided. Monitoring activities that have an outcomes or quality focus enhance accountability to independent advocacy boards, staff, volunteers, commissioners, funders and most importantly, the people and groups being supported.
- SIAA have co-produced the [Outcomes Framework: Toolkit for Demonstrating Impact of Independent Advocacy](#) to support independent advocacy organisations, their funders and commissioners to understand how to monitor independent advocacy. The toolkit has practical recommendations and examples of what can be measured and what that data can tell you about the quality of independent advocacy.
- It is important that independent advocacy staff and volunteers are confident about why information is being collected about their work and from or about advocacy partners, and how the information will be used in monitoring independent advocacy.
- Advocacy partners must have a clear understanding of what happens to their information. It is crucial to underline that advocacy remains independent. If a

data-sharing agreement exists that could compromise this independence, it must be disclosed to the advocacy partner. Such disclosure is essential, as it may influence their trust in the organisation's commitment to genuine independence.

- Every dataset should be assessed for identifiability on an individual basis. If a dataset makes an individual identifiable, then Advocacy Partners (data subjects) must explicitly consent to sharing their information in line with UK Data Protection Act 2018 (DPA 2018) and the UK General Data Protection Regulation (UK GDPR). Organisations do not need to do this if aggregates are shared with commissioners rather than individual data.
- In remote and rural areas with smaller populations, individuals may be easily identifiable if case-by-case monitoring is required. For instance, noting Advocacy Partner's town of residence, age bracket, and the legislation under which they're eligible for independent advocacy could be enough to lead to their identification, especially if combined with contextual knowledge.

Independent advocacy: what should happen?

International human rights law

International human rights laws are clear that participation is an essential part of realising human rights. This is emphasised by way of particular treaty articles for children and disabled people. This is because they will often face barriers to having their views listened to and taken seriously. [The United Nations Convention on Rights of Persons with Disabilities \(UNCRPD\)](#) and [United Nations Convention on the Rights of the Child \(UNCRC\)](#) both have articles about voice and participation.

[UNCRC Article 12 gives children the right to express their views and be taken seriously.](#)

This right applies at all times, including during court proceedings, housing decisions and the child's day to day home life. Article 12 is a key principle of the UNCRC, meaning that it helps to interpret all the other articles and plays a fundamental role in realising all the rights in the Convention for all children.

The UNCRPD Article 12 recognizes that disabled people have legal capacity on an equal basis with others. To ensure that this is a reality for disabled people it requires that states

must provide them with access to support in order to exercise their legal capacity. This is called supported decision-making. The Mental Welfare Commission's [2024 Guidance](#) states that 'the purpose of supported decision-making is to ensure that the individual's will and preferences are central to and fully respected in decisions that concern them.'

Independent advocacy is one of the methods of supported decision-making recommended by the UNCRPD Committee. Although the UNCRPD is not part of Scots law yet, the UNCRC has been brought into Scottish domestic law. On 16 July 2024 the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024 came into force. This legislation gives babies, children and young people routes to redress in Scots law if a public authority has breached their rights under the convention.

These international human rights law should bring into focus how central to the human experience participation and voice are for people in Scotland and beyond.

Scottish law and policy related to independent advocacy

The right of access to independent advocacy within the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#) is critically important to the provision of independent advocacy in Scotland. Independent advocacy should be made available in connection with other Scottish laws and policy areas, however the right in the 2003 Act provides the strongest access and can interact with other policy areas. This is because it is a broad right that is not connected to specific statutory processes for example a Mental Health Tribunal, Guardianship or Children's Hearing. This is made clear in The Mental Welfare Commission's [2017 guidance on working with independent advocates](#):

“It is important to note that this right is for all people with a mental disorder; whether or not they are subject to compulsory measures under the Act; whatever their need for advocacy and whether or not they are incapacitated, or have communication difficulties. The Act gives people a right of access to both collective and individual advocacy, including citizen advocacy. The 2003 Act confers a duty on each local authority and each NHS Board to work collaboratively to ensure that independent advocacy services are available to people with a mental disorder. Ensuring that the services are available is not sufficient though; it is also incumbent upon these two bodies to ensure that staff 'take appropriate steps' to ensure that people are informed about the

availability and remit of independent advocacy and have the opportunity to access advocacy services.” (page 3)

In brief, there are seven Scottish laws that mention independent advocacy and where there is connected provision for individuals and groups;

- [Adults with Incapacity \(Scotland\) Act 2000](#)
- [Mental Health \(Care & Treatment\) \(Scotland\) Act 2003](#)
- [Adult Support and Protection \(Scotland\) Act 2007](#)
- [Education \(Additional Support for Learning\) \(Scotland\) Act 2009](#)
- [Children's Hearings \(Scotland\) Act 2011](#)
- [Social Care \(Self-directed Support\) \(Scotland\) Act 2013](#)
- [Social Security \(Scotland\) Act 2018](#)

A further two laws, both relating to children, have not yet been implemented:

- [Children \(Scotland\) Act 2020](#)¹
- [United Nations Convention on the Rights of the Child \(Incorporation\) \(Scotland\) Act 2024](#)

Independent advocacy is also a key part of ongoing policy work and strategy related to substance use, care arrangements and dementia:

- [Medication Assisted Treatment \(MAT\) Standards - Standard 8](#)
- [Scottish Government's 10-year Dementia strategy: Everyone's Story](#)
- [Staff and registered service summary guidance on the use of 13ZA, Social Work \(Scotland\) Act 1968](#)

Strategic advocacy planning

An update to the Mental Health Act in 2015 created new duties for local authorities and health boards to tell the Mental Welfare Commission (MWC) how they have ensured access to advocacy services up to now, and how they plan to do so in the future. The

¹ The Children and Young People's Commissioner Scotland provides information on the delay in implementation of the Children (Scotland) Act 2020 on the Commissioner's website: [Non-Implementation of Acts of the Scottish Parliament](#)

MWC's [most recent 2023 report](#) found that of 32 local authority areas only 18 respondents confirmed having a strategic plan in place; only 11 were said to be up to date. There remained 13 areas who do not have strategic plans, 10 of which are in the process of developing one and three areas report having no plans at this stage.

There is clear guidance outlining best practices for strategic planning within the Scottish context. Certain elements of this guidance are particularly pertinent when considering the strategic development of independent advocacy, especially in relation to human rights, prevention, and participation. The [Scottish Government's Health and social care - strategic plans: statutory guidance](#) emphasises prevention, as articulated in the Christie Commission's pillars, as a central component of local strategic planning, alongside the active participation of individuals and communities. The [National Health and Wellbeing Outcomes: Framework](#) highlights the importance of a human rights-based approach and underscores that Integration Authorities' strategic planning should embed a 'preventative and anticipatory approach to commissioning services – rethinking how best to meet the needs of communities.' Many of the nine Outcomes in the Framework are enabled by grassroots, high quality independent advocacy provision. [Healthcare improvement Scotland's \(HIS\) Strategic planning: good practice framework](#) also identifies two relevant principles: firstly, that effective strategic planning should 'maximize the use of existing local user, carer, and advocacy groups, as well as national representative bodies,' and secondly, that the vision and values underpinning strategic plans should prioritise prevention. Well-resourced independent advocacy fosters a culture rooted in human rights, promotes participation, and supports prevention by assisting services to engage with people and communities where they are.

SIAA believe strategic advocacy plans could be improved upon, and we are keen to work with HSPCs to develop an understanding of how SIAA can support work in this area.

Independent advocacy: what exists in Scotland?

“When we talk about rights, we have the benchmark for how everyone must be treated. This standard, which is set out in law, is not optional. If rights are breached this must be remedied and prevented from happening again. This shifts

the focus from ‘sticking plasters’ to long-term solutions.” – [British Institute of Human Rights](#)

Independent advocacy has been consistently identified in law and policy as an important tool for people to have their voices heard. Many independent reviews have also understood the value of independent advocacy and made detailed recommendations about increasing provision of and access to independent advocacy, including recommending opt-out provision for some groups. These reviews include the [Scottish Mental Health Law Review](#), the [Independent Review of Learning Disability and Autism in the Mental Health Act](#) and the [Independent Review of Adult Social Care in Scotland](#).

Despite the strong recommendations in independent reviews and good understanding from some policy makers, in practice, [only 5% of people that have the right in Scots law to independent advocacy can actually access it](#). This is due to local interpretation of law and policy, particularly the right under the 2003 Act, being too narrow and limited resources being allocated for independent advocacy organisations as a result. In other words, independent advocacy should be sustainably funded by HSCPs so it can be provided beyond statutory processes like a Mental Health Tribunal. This would both enable human rights to be realised for advocacy partners and produce cost savings for local authorities and the NHS.

While we will not go into detail in this paper about the complexities of the laws and policies that influence decision-making about independent advocacy, it is important to note that although the policy landscape is complex, SIAA members are clear about their independence, the quality and accessibility of their work and can support local authorities and health boards to identify areas of need. **Data collection requests from independent advocacy commissioners should focus on meaningful quality measures rather than operational details that could compromise the fundamental independence that makes independent advocacy effective.**

Recommendations

SIAA recommends that Health and Social Care Partnerships:

1. Ensure up-to-date strategic advocacy plans that fulfil duties under the 2003 Act to secure availability of independent advocacy services for those with a right of access.
2. Use the [SIAA Outcomes Framework](#) to build understanding and properly commission independent advocacy services.
3. Work collaboratively with local advocacy organisations to ensure monitoring activities do not impact independence while providing necessary information to understand and improve quality of services.

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