



A Stronger Voice?

**A scoping study of independent
advocacy for people with
learning disabilities**

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1. Foreword

The Scottish Government wants to improve the lives of people with learning disabilities. Scotland's learning disability strategy, 'The keys to life', seeks to improve the quality of life for people with learning disabilities so that they live longer healthier lives, participate fully in all aspects of society and prosper as individuals. This report by the Scottish Commission for Learning Disability, undertaken at the request of the Scottish Government, aims to contribute to how we can achieve that change.



Independent advocacy can help people to express their views and wishes, to access information, to make informed choices and to have more control over different aspects of their lives. Our research tells us that advocacy can promote choice, access, justice, and empowerment for people with learning disabilities by helping them:

- To be listened to and have their views heard
- To understand what is happening and why decisions are made
- To be involved in decision making processes
- To become more confident and feel more able to self-advocate in the future.

However, while people with learning disabilities have a right to independent advocacy, they may struggle to access this right and may not always be aware of it.

This report was undertaken to explore current provision, delivery and experience of independent advocacy support for people with learning disabilities in Scotland. It draws on the experiences and perspectives of people with learning disabilities as well as commissioners of independent advocacy, and managers and frontline workers within advocacy organisations.

We hope it will provide a platform for dialogue and action for all those who share a commitment to improving the lives of people with learning disabilities in Scotland.

A handwritten signature in black ink that reads "Chris Creegan". The signature is written in a cursive, slightly slanted style.

Chris Creegan

Chief Executive, SCLD

2. Background and aims

Introduction

People with learning disabilities often find it difficult to make their voice heard and may experience barriers to accessing their human rights in areas such as health and wellbeing, housing, personal assistance, employment, finance and decision-making. Independent advocacy can promote choice, access, justice, and empowerment by helping people to have a stronger voice and address power imbalances¹. Although people with learning disabilities have a right to access independent advocacy under the Mental Health (Care and Treatment) (Scotland) Act 2003, the Scottish Independent Advocacy Alliance (SIAA) Map of Advocacy report 2015-16² identifies people with learning disabilities as a group for whom there are gaps in provision and who may be unaware of their right to access advocacy. The implementation framework for Scotland's learning disability strategy 'The keys to life' has four strategic outcomes which relate to the United Nations Convention on the Rights of People with Disabilities: A Healthy Life, Choice and Control, Independence and Active Citizenship. It affirms the Scottish Government's aim to work in partnership with advocacy partners to ensure the voice of people with learning disabilities is heard.

What is independent advocacy³?

Independent advocacy has two main roles: 1) speaking up for and with people who are not being heard, helping them to express their views and make their own decisions and contributions; and 2) safeguarding vulnerable individuals⁴. Advocacy helps people to express their views and wishes, to access information, to make informed choices and to have control over as many aspects of their lives as possible⁵. It is concerned with supporting people to achieve active citizenship and challenging inequality, inequity and unfairness but does not involve mediation, counselling, befriending, taking complaints or giving advice⁶. The aim of all methods of independent advocacy is to help individuals gain increased confidence and assertiveness so that, where possible, they will feel able to self-advocate when the need arises. There are two main types of advocacy: individual and collective⁷. These are described below.

Individual or one-to-one advocacy includes professional or issue based advocacy, citizen advocacy and peer advocacy. A professional advocate provides support on specific issues and provides information but not advice. This can be on a short or long term basis. Citizen advocacy is when an ordinary citizen provides advocacy support to someone in the community on a voluntary basis. A peer advocate uses their own life experiences to understand and have empathy with their advocacy partners. Non instructed advocacy is also a form of one-to-one advocacy where due to a lack of capacity someone is unable to personally instruct their advocate⁸.

¹ Independent Advocacy: A guide for commissioners, SIAA (2010)

² A Map of Advocacy across Scotland 2015-2016 edition, SIAA (2017)

³ For the remainder of the report 'advocacy' will be used interchangeably with 'independent advocacy'.

⁴ Independent Advocacy Guide for Commissioners, Scottish Government (2013)

⁵ Independent Advocacy: A guide for commissioners, SIAA (2010)

⁶ IRISS INSIGHTS Advocacy: models and effectiveness, Stewart and McIntyre (2013)

⁷ Independent Advocacy Guide for Commissioners, Scottish Government (2013)

⁸ In non-instructed advocacy the advocate will observe the individual, look for alternative means of communication, gather information from significant others and any 'past wishes' or any Advanced Statements. The advocate's focus is on upholding the person's rights, ensuring fair and equal treatment and access to services and making certain that decisions are taken with consideration for the individual's unique preferences and perspectives and that the partner is enabled to make choices as far as possible.

Group or collective advocacy enables a peer group of people, as well as a wider community with shared interests, to represent their views, preferences and experiences. It can help reduce an individual's sense of isolation when raising a difficult issue. A collective voice can be stronger than that of individuals when campaigning and can help policy makers, strategic planners and service providers know what is working well, where gaps are and how best to target resources.

The SIAA promotes, supports and defends the principles, standards and practice of independent advocacy across Scotland. A list of their publications including Principles and Standards for Independent Advocacy and the Code of Practice for Independent Advocacy is available in Appendix A.

Purpose of the scoping study

This scoping study, undertaken at the request of the Scottish Government, seeks to examine the current landscape of independent advocacy support for people with learning disabilities in Scotland⁹. It is based on both primary research and secondary analysis of existing sources. (The methods are described in more detail below.) The objectives of the scoping study are to:

- **provide a brief overview** of the historical, legislative and policy context for independent advocacy in Scotland, focusing particularly on how this has been applied to people with learning disabilities
- **examine issues** in relation to the provision of advocacy including current commissioning arrangements and aspects relating to access and awareness, particularly in relation to people with learning disabilities
- **describe the experience and impacts** of both one-to-one and group advocacy for people with learning disabilities
- **consider issues** relating to the monitoring and evaluation of advocacy services
- **discuss the future requirements** for advocacy for people with learning disabilities
- **make recommendations** about future provision of advocacy for people with learning disabilities.

3. Methodology

This scoping study involves both primary and secondary research. The secondary research uses published resources to set the context and to identify the areas for further development. The primary research uses a mixed-methods approach (i) quantitative surveys of commissioners, service managers and frontline (ii) qualitative interviews and focus groups with people with learning disabilities and (iii) follow-up telephone interviews with commissioners and service managers.

Survey of commissioners, managers and frontline workers

A data collection tool for commissioners of advocacy services was developed using Survey Monkey. The survey covered topics relating to: the type and coverage of advocacy support commissioned, the funding available, the priorities for support, monitoring and evaluation, future challenges, and the strategic planning of advocacy support services. The survey was sent to 71 commissioners in all, based on a list supplied by SIAA. A total of 16 responses from commissioners were received. It is not straightforward to calculate a response rate for the survey, as there are multiple overlapping organisations involved in the commissioning of advocacy services. However, the responses received covered all NHS Board areas in Scotland, with the exception of NHS Tayside, Fife and Orkney.

A data collection tool for advocacy service managers was developed using Survey Monkey. The survey covered topics relating to: the type and coverage of advocacy support offered, the finance available, the priorities for support and the management of priority cases, capacity of the service, arrangements for monitoring and evaluation, and future challenges. The survey was sent to 52 service managers in all, based on a list supplied by SIAA. Responses were received from 35 service managers. This equates to a response rate of 67%.

A data collection tool for advocacy frontline workers was developed using Survey Monkey. The survey covered topics relating to: the experience of the frontline workers in relation to advocacy in general and advocacy for people with learning disabilities in particular, the type and coverage of advocacy support offered, resources available, how success is described, and future challenges. The survey was sent to 49 organisations in all, based on a list supplied by SIAA. Responses were received from 55 frontline workers.

Follow up interviews

Three follow up interviews with commissioners and 3 with service managers were conducted by telephone. These were selected on the basis of comments they had made in their survey response. These follow up interviews covered issues relating to: competitive tendering, the availability of advocacy, (the assessment of) outcomes, group advocacy, promoting awareness, supported decision making, non-instructed advocacy and unmet need.

Qualitative interviews and focus groups

It was agreed from the outset that we would not undertake a 'purposive' or 'structured' approach to sampling for the qualitative interviews. Rather, we would advertise the research project widely across our various networks, and ask people to contact us if they would like to participate in a 1-1 interview. Our aim was to conduct around 20 interviews with individuals. In addition, we arranged to conduct four focus groups in Edinburgh, Dalkeith, Motherwell and Inverness using established groups who met on a regular basis. Signed forms indicating a willingness to participate and providing contact details, were returned to the SCLD office in Glasgow. The Project Manager contacted the potential participants to arrange a date for interview. The consent process was undertaken before the interview commenced.

The main areas covered in the interviews and focus groups were: awareness, availability and experience of advocacy, impact of advocacy and future requirements for advocacy. Talking Mats were used, if appropriate, to elicit participants' views about advocacy. Before the interview started, respondents were reassured that there were no 'right' answers and no 'wrong' answers. Individual interviews lasted between 15 minutes and 45 minutes. Focus groups lasted between 45 minutes and 1 hour. We transcribed the individual interviews in full.

The focus groups were facilitated by one member of staff whilst the other took notes. No full transcription of the focus groups was undertaken. We conducted 18 individual interviews and 4 focus groups. Seventeen of the 18 individual interviews were with people with learning disabilities whilst the final one was with a parent of someone with a learning disability. One of the interviewees was almost completely non-verbal and so the carer was present throughout and responded to the questions. In addition, a support worker or relative was present at three interviews. The quotes used in this report includes a reference which identifies the interview or focus group.

Limitations of the primary research

For the quantitative surveys, it was not possible within the time available to do any follow up of non-response. Thus, the analysis is based on those who were willing – and had the capacity – to engage. The self-selecting nature of the respondents means that we cannot necessarily view these findings as representative of commissioners, service managers, frontline workers as a whole. Those who participated in the qualitative research interviews were not selected according to any purposive sampling design; rather they were volunteers. No inferences can therefore be drawn to the effect that these findings represent the broader population of people with learning disabilities.

4. Legislative and Policy Context

Legislative context

The Scottish Government is committed to the implementation of domestic human rights legislation and international instruments including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and European Convention on Human Rights (ECHR), designed to ensure that people with disabilities are not discriminated against and have support to exercise the same legal and civil rights as other citizens. Article 12 of the UNCRPD states that people with a disability have the right to support that enables them to exercise the same legal and civil rights as other people and for this right to be protected from abuse. This includes a range of formal and informal support arrangements including independent advocacy and self-advocacy.

The Mental Health (Care and Treatment) (Scotland) Act 2003 provides a right of access to independent advocacy for anyone with a mental disorder in law – a definition which includes people with a learning disability. It gives people with a learning disability right of access to both collective and individual advocacy¹⁰. The Act also confers a duty on NHS Boards and partner local authorities to ensure adequate provision of independent advocacy (individual and collective) and to ‘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.

The Mental Health (Care and Treatment) (Scotland) Act 2003 has been followed by several pieces of legislation that either give people a right to access independent advocacy or mention advocacy as a way to involve people including the Adults Support and Protection (Scotland) Act 2007, the Patient Rights (Scotland) Act 2011 and the Social Care (Self-Directed Support) (Scotland) Act 2013¹¹. (See Appendix B)

Policy context

Over the past 10 years or so the Scottish Government has published a range of strategy and policy documents which relate to or explicitly set out its ambitions for the development of independent advocacy in Scotland. These include:

- In 2006, recommendations were made by the then Scottish Executive’s Advocacy Subgroup¹² in respect of the importance of the availability of choice in relation to the provision of independent advocacy for people with learning disabilities; their involvement in the planning of advocacy services and the development of local advocacy plans.
- In 2010 the Scottish Government published the **National Strategy on Self-directed Support** which states that in agreeing to opt for a direct payment or an individual budget, it is important that...adequate support and advocacy is in place to support people to manage, drawing on the experience of those who direct their own support. The strategy also states that progress towards greater choice, control and empowerment for social care users should be recognised via a number of routes and these include a sustainable network of advocacy

¹⁰ Working with Independent Advocates, Mental Welfare Commission for Scotland (2015)

¹¹ Independent Advocacy Guide for Commissioners, Scottish Government (2013)

¹² Having your Say? The Same as you? The National Implementation Group report of the Advocacy Sub Group (Scottish Executive, 2006)

and peer support organisations that support individuals to exercise choice and control.

- The **Charter of Patient Rights and Responsibilities** published in 2012 set out a summary of the rights and responsibilities of patients using the NHS in Scotland. The Charter states that: You have the right to request support when making decisions about your health care. You may ask (and if you have a mental health disorder you have a right) to have an independent advocate to help you give your views. NHS staff can help you arrange this.
- In 2013 the Scottish Government’s learning disability strategy **The keys to life**¹³ made a recommendation that the Government should work with SIAA, PAMIS and SCLD to scope the need for advocacy and to develop an Action Plan to improve delivery and uptake of independent advocacy at local level.
- The **Social Care (SDS) (Scotland) Act 2013** says that: A person must be provided with any assistance that is reasonably required to enable that person – (a) to express any views the person may have about the options for self-directed support, and (b) to make an informed choice when choosing an option for self-directed support.
- In 2016 the Scottish Government’s **A Fairer Scotland for Disabled People – Our Delivery Plan to 2021 for the UNCRPD** stated “We will empower people to know and claim their rights following the changes to the Mental Health (Scotland) Act 2015 by promoting independent advocacy and advance statements, alongside a rights-based approach in the statutory guidance on the use of mental health legislation”.
- The **Health and Social Care Standards** published by the Scottish Government in 2017 make specific reference to individuals being supported to use advocacy if they desire or require it. Standard 2.4 reads: I am supported to use independent advocacy if I want or need this.
- The **National Mental Health Strategy 2017-2027** states “Adults with Incapacity legislation should fully reflect the requirements of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), with particular emphasis on provision of supported decision making, addressing issues around deprivation of liberty and the interaction of Adults with Incapacity Legislation (AWI) legislation with the legislation on mental health and adult support and protection”.
- Finally, the role and remit of advocacy is relevant to a wide range of on-going public policy discussions including the Social Security Bill, Support for decision-making strategy, Review of Adults with Incapacity Act, the review of learning disability and autism in the Mental Health (Care and Treatment) (Scotland) Act 2003 and compliance with the UNCRPD.

¹³ The keys to life. Improving quality of life for people with learning disabilities (Scottish Government, 2013)

5. Advocacy Provision

Background

According to data published by SIAA in 2017¹⁴ the total number of people in Scotland accessing any type of independent advocacy in Scotland increased by 11.5% (from 27,000 to 30,500) in the period 2013/14 to 2015/16. During the same period, statutory funding decreased by 4.0% (from £11.5m to £11.0m). This funding decrease was partially – though not wholly – offset by increased funding from Scottish Government for specific advocacy projects as well as by increased funding from charitable trusts and other grant awarding bodies. However, this funding is usually time limited and not sustainable in the longer term. The overall picture for advocacy provision across the board is of declining resources, both in financial terms and also in relation to staffing (including volunteers). In this context SIAA reports that advocacy organisations are increasingly having to restrict and / or prioritise requests for referral and also to reduce or stop awareness raising work.

Advocacy provision for people with learning disabilities

The landscape in terms of advocacy provision for people with learning disabilities across Scotland is complex. There is considerable variation in the type of provision, advocacy models used and exact access criteria varies between local areas and from service to service. However, in line with their statutory obligations every area in Scotland makes some advocacy provision for people with learning disabilities. In some areas advocacy services are learning disability specific but more typically provision is generic¹⁵. There has been a shift in focus from collective and citizen advocacy to commissioning of individual, issue-based professional advocacy since the introduction of the Mental Health (Care and Treatment) (Scotland) Act 2003¹⁶. While citizen advocacy is still the predominant model in Fife and is available in one or two other local authority areas, many advocacy services now focus solely on professional one-to-one advocacy.

In our survey results only a very small number of service managers (8%) said the organisation they managed worked exclusively with people with learning disabilities. The vast majority (92%) reported providing advocacy to multiple different client groups and working with adults across a broad range of age groups. The exception to this is group advocacy for which services are often funded specifically for people with learning disabilities. Around two-thirds (63%) of commissioners and over one half (55%) of survey managers reported commissioning / providing both one-to-one advocacy and collective/group advocacy, the remainder did not. Reasons for commissioning both types of advocacy included:

¹⁴ A Map of Advocacy across Scotland 2015-2016 edition, SIAA (2017)

¹⁵ A Map of Advocacy across Scotland 2015-2016 edition, SIAA (2017)

¹⁶ "Without advocacy I'd probably be dead" Research into the impact of independent advocacy on the lives of people experiencing learning disabilities, SIAA (2014).

- there is a requirement to meet statutory obligations
- services were designed to meet demand / needs of the population
- services were designed to meet Scottish Government strategic outcomes.

For those who did not commission group advocacy the reasons given included:

- services were designed to meet demand / needs of the population (often these were strongly weighted towards requirements for individual advocacy)
- services were designed to make best use of available resources.

The legislation does not explicitly state which form of independent advocacy support should be made available. The Mental Health Act Code of Practice¹⁷ says ‘any or all of the various types might be appropriate depending on the circumstances and personal preferences of the patient concerned’ but there are few areas where all the types of advocacy referred to in the Scottish Government guidance for commissioners are available. SIAA have frequently expressed concern about gaps in provision for collective/group advocacy in some areas of Scotland ¹⁸.

Service managers were also asked to provide details of what models of advocacy they used. Professional or single issue advocacy and collective advocacy/group advocacy were the most common models. Seven (7) respondents said they only delivered professional or single issue advocacy. Two (2) respondents said that their organisations only delivered collective/group and/or self advocacy.

Professional/Single Issue Advocacy	86%	25
Peer Advocacy	7%	2
Citizens Advocacy	14%	4
Collective/Group Advocacy	62%	18
Self Advocacy	28%	8
Total Respondents: 29		

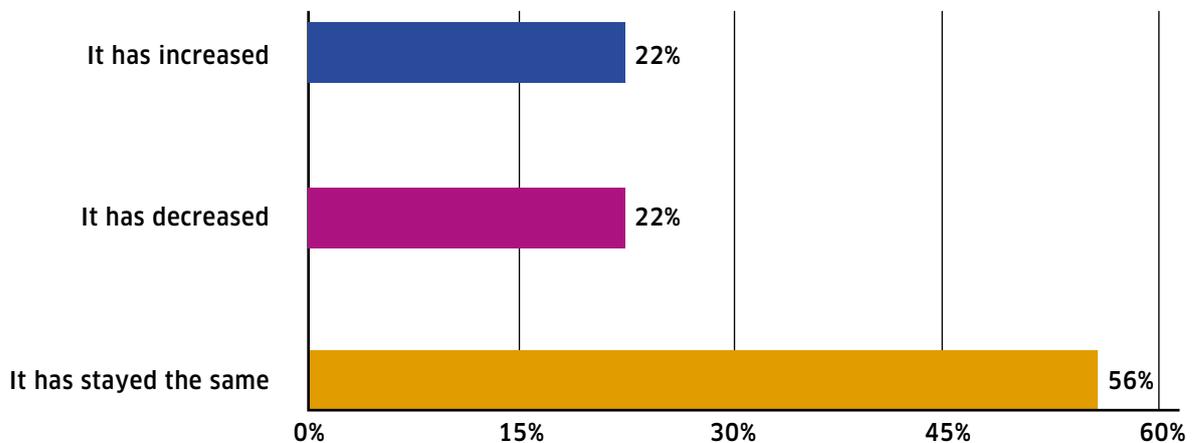
¹⁷ Mental Health (Care and Treatment) (Scotland) Act 2003 Code of Practice Volume 1 (2005)

¹⁸ SIAA Response Mental Health (Scotland) Bill - Call for written evidence

Advocacy funding

Over half of commissioners (56%) reported that they had a specific budget for advocacy support for people with learning disabilities. The remaining 44% said they did not. The table below shows how these budgets had changed since the previous funding cycle.

How has the commissioning budget for independent learning disability advocacy organisations changed since the previous funding cycle?



Around three quarters of commissioners reported their budget had either stayed the same or had decreased. In cases where it had decreased commissioners focused on the need to: prioritise statutory cases, introduce waiting lists and restructure the service.

Nearly three-quarters (74%) of commissioners responded that their funding arrangements did not stipulate the amount of support people are eligible for. The remaining 26% said that funding arrangements placed certain restrictions on advocacy support (either by amount of time, number of issues or number of meetings). Commissioners were generally of the view that availability of advocacy should not be restricted to a single issue. In particular, where a commissioner commissioned 'single issue' advocacy they emphasised that the number of referrals for the same individual was not restricted, and that referral could be open for a long (perhaps indefinite) period. Additionally, the vast majority of commissioners (88%) reported that organisations are funded to provide learning disability advocacy services to anyone who lives in their area, regardless of which local authority pays their support.

Service managers mostly reported multiple sources of funding from a variety of statutory bodies (health and social care partnerships, local authorities and health boards). Only 11 out of 29 managers (38%) cited a single source of funding. Around a quarter of organisations received some funding from either the Scottish Government and/or trust and grant awarding bodies. This funding was often earmarked for highly specific purposes (e.g. for victims of domestic abuse, for individuals seeking SDS support etc.). Around one in six service managers reported that their funder required them to provide advocacy to a minimum number of people per year. Some service managers explained that the contract or model was tailored to the individual requirements of the service user.

Key Points

- **The advocacy landscape is complex and provision varies between areas and from service to service**
- **Some advocacy services are learning disability specific but more typically provision is generic**
- **One-to-one professional advocacy was most common form of provision**
- **A third of commissioners reported they do not commission collective/group advocacy. Reasons for this included: services are designed to meet demand/needs of the population and services were designed to make best use of available resources**
- **Around a quarter of commissioners said that funding arrangements place certain restrictions on advocacy support either by amount of time, number of issues or number of meetings people are eligible for**
- **Around three quarters of commissioners reported their budget had remained static or decreased. Where budgets had decreased commissioners focused on the need to: prioritise statutory cases, introduce waiting lists and restructure the service.**

6. Awareness of Advocacy

Background

The Map of Advocacy 2015-16¹⁹ highlights that due to financial constraints organisations are increasingly unable to undertake any activities in addition to the direct delivery of advocacy. As a result many advocacy organisations report they have had to reduce or stop awareness raising work.

Promotion/Awareness of services

A wide range of ways of raising awareness of the availability of advocacy support in their area were reported by commissioners including:

- posters / leaflets in public areas
- information posted on local authority (and other) websites
- sharing of information to raise awareness via a wide range of local groups and networks; awareness raising by professionals including social workers, the police, local authority operational teams etc
- having a presence at events including roadshows; advertising and awareness raising by service providers and frontline staff; awareness raising sessions and training events.

Commissioners sometimes reported that these types of activities formed part of the contract monitoring framework. However, there appeared to be limited planning in a strategic sense to ensure that people with a learning disability are aware of advocacy, understand what it is and are able to access it.

Sources of referrals

Service managers reported mixed sources of referrals with nearly all receiving referrals from social work, NHS and self-referrals and most receiving referrals from advice or rights professionals as well. Respondents identified family, friends, other professionals (lawyers, teachers etc.), and other third sector agencies as the main additional sources of referrals. Other sources mentioned occasionally included the general public, carers, and other advocacy service users.

People with learning disabilities' awareness of advocacy

In both the one-to-one interviews and focus groups people with learning disabilities were asked about how they became aware of advocacy and what they thought it was. When people were able to tell us clearly how they heard of advocacy this tended to be through professionals they already had a relationship with, e.g. support workers, social workers or they heard about it through a group they are a member of.

I first heard about advocacy in 2006 when I was invited to the Stand Up For Yourself self-advocacy group. #15

People reported receiving presentations at various groups they attended where advocacy workers had explained what advocacy is for and who it can help. However, others reported little awareness or knowledge of advocacy. Those who are less linked in to other services or not involved in support and community groups may have less access to such information.

No I didn't know what it was, nobody had signposted me to it. I'd heard the name Ceartas but no one had signposted me to them. #14

But I don't think a lot of people know that it's available because I didn't know...I remember saying for months, so this is it, I'm just left to get on with this. #17

Even when people had heard about advocacy, they were often unfamiliar with the different models of advocacy which exist. Mostly people described it as a way to help them and in particular to help them speak up and get their point across.

I thought it was to help you get your point across. I can't remember if it was staff or other students that told me about it. #7

Well, advocates, I think I need because they can talk up for you. Like, I'm not good at explaining things, like to tell a company or a social worker. #11

Views were expressed around a desire for a greater choice of options. There were also comments which indicated people thought they would benefit from a long term citizen or peer advocacy partnership but these models were not always available.

I've been looking at other types of advocacy, I want to get someone closer to my age range to talk to. There is no one in my age range. #7

That would be good feedback for this that there is a lack of choice and that's bad. I think longer term citizen advocacy would be good for (son) but it's not available where we live.#17

There were also a range of misperceptions about what advocacy is, and what advocates do.

I don't know, what I first heard about it they just said it was people that would come in and help you, take the boys out. #10

Yes, well I always thought the advocate would be someone who had a bit of clout.... I thought they could say 'You should be doing this', 'You should be doing that'. I didn't honestly find that. #5

My general feeling is ... a few good advices given over the years...but a bit of disappointment.... Especially recently a few things happening... and like I say because the advocates are paid for by social work ... they are still the bosses... they are cutting it back... they should be separate from social work... the advocates should be separate... Social work can cut their budget to do things ...#5

In the focus groups word of mouth was discussed as playing an important role in encouraging people to join advocacy groups. People reported that they had heard about the group from a friend, family member or support worker.

The staff helped me apply to the group, the staff heard about it and asked if I wanted to join it. FG1

I got to know through word of mouth, the parents' group first then I learned about what they do outside the parents' group. FG2

A friend of mine told me about People First so I came along and became a member. FG2

Key Points

- **A wide range of awareness raising activities were reported including: communicating information by posters/leaflets/websites, attending local groups and networks, and holding promotional sessions and training events**
- **Nearly all service managers reported receiving referrals from social work, NHS and by self-referral and most received referrals from advice or rights professionals as well**
- **People heard about advocacy mainly through their contacts with voluntary and/or advocacy organisations or informally by word of mouth through others they meet. However, in general people didn't recall how or when they were made aware of advocacy**
- **People with learning disabilities were generally not aware of the different types of advocacy (1-1, group, citizen advocacy etc.) which exist**
- **People with learning disabilities described advocacy as a way to help you – and in particular to help you to speak up for yourself and to get your point across**
- **There were a range of misperceptions about what advocacy is, and what advocates do.**

7. Access to advocacy

Background

In the most recent publication based on the Learning Disabilities Statistics Scotland Dataset (LDSS)²⁰ local authorities reported that 2,329 adults (10.0% of all adults with learning disabilities known to local authorities) had attempted to access advocacy support. Of these, 17% had been unable to access support. The diagram below shows the types of advocacy support accessed.



Prioritising access to services

In our survey, the vast majority of commissioners (86%) reported that the advocacy services they commissioned were expected to prioritise people affected by compulsory measures. This accords with previous observations by SIAA²¹. The vast majority of service managers (89%) reported having a system for prioritising access to their services. In terms of who was prioritised, service managers referred repeatedly to those under statutory orders who were detained under the Mental Health (Care and Treatment) (Scotland) Act 2003. They also talked more generally about prioritising both on the basis of (other) specific priority categories (e.g. older age adults, those with learning disabilities) and on the basis of an assessment of urgency (in terms of identified deadlines relating for example to an education tribunal or appeal) and / or

need. The factors affecting who was seen as being in greatest need were wide ranging and included those who had no other form of support, those who were non-verbal, those in transition and those who were seen to be 'in crisis'.

Over a third (38%) of service managers reported having a target for how long someone should spend on a waiting list. For those who provided more details, the (target) waiting times varied from 24 hours to 3 months. In many cases these targets were tailored to the urgency/priority assigned to the particular case. Urgent/priority cases were generally seen within 5 working days and often sooner. In general, respondents provided an upbeat assessment of their success rates in meeting their targets and reported that in the vast majority of cases targets were met. A few respondents provided more ambivalent answers which indicated either that the data were not available to answer this question, or that there were fairly strict limitations placed on who would fall within the group to whom any targets would apply.

Respondents were asked to provide details of what happens when an individual requests further advocacy support once an advocacy partnership ends. In general responses emphasised that in almost all cases further support is forthcoming. Where it was mentioned, there is a tendency to allocate – if possible – the same advocacy worker. However, in one case the organisation said they made a deliberate choice to allocate a different worker as a way of managing/reducing dependency.

Commissioners were also asked how they ensure that services are available to those with complex needs in their area. On the whole, commissioners either emphasised that the service was available to all comers, or that the planning process (following guidelines and procedures) would mean this was achieved. Others talked in more general terms about: good liaison, taking a casework approach, the expertise of advocacy workers in relation to relevant communication tools, and promoting this service and approach through PAMIS.

People with learning disabilities' experience of accessing advocacy

In the interviews people were asked about the process of accessing advocacy and whether this had been straightforward. Experiences ranged from people perceiving that access to advocacy had been very quick and easy to arrange to those who felt it had been a long, drawn out and difficult process.

[Interviewer: Did you have to wait a long time to see her?]

No really no....a few days. #14

Before I ever got one, I waited a wee bit. I can't remember but I think I waited a wee while but not that long....#11

I had to wait for about six weeks I think. At the time, I don't know what it's like now ... it was [a really long time to wait].

When you really needed one you know? ... [and things] got worse [while I was waiting], it just got worse over the time...#6

Once people had an advocate they generally commented that they were able to see them when required.

We met twice a month. I could arrange to meet her at any time #4

I seen her about 3 or 4 times in the time that I needed to see her... That was about right what I saw her. #8

Well it used to be every week [I saw her] when I first got her and then it changed. I had her for quite a while then she changed it to once a month. And then to continue working with her I kept it at once a month. It was a choice for me if I gave up with (advocate) or kept her to once a month, I took once a month. #11

However, there were times when it was difficult to access advocacy.

[Interviewer: OK. And do you find it quite easy to see her if you need to?] No. I've got to phone. I just didn't like filling in a lot of forms. I have to phone. Well I've got to try and do the number. And I dinnae like it. Too many numbers. ... [Interviewer: How easy was it then to make an appointment?] Well she would find out if she could get a day off and if she couldnae she would leave it for another day. Because it's difficult to get someone because it's really busy. #18

Reasons given for needing an advocate included support to resolve highly specific single issues as well as more general requirement for ongoing access. For both these groups there was some dissatisfaction about the level and frequency of contact they had with their advocate. In general, this was not aimed at the advocate themselves, but at the 'system'.

No it's my worker. I've never met her. I had [named worker] but she left, she left so I've got this lassie now but she doesn't come out much, I don't hardly see her. #10

.... recently she's been hard to get hold of. She's been busy and it takes weeks to get back to me sometimes after I leave a message. She's overworked, there's long waits between things. She's always been busy but it's got worse lately. #17

People were keen that an advocacy service was available to others as well.

But I just liked to know if that would happen to somebody else it would ... [Interviewer: Be also be able to get that support and help?]...Yeah. That feeling as well... safe feeling. #2

There was a reasonable degree of confidence across the sample as a whole that they would know how to go about accessing an advocate in the future if they needed to. People were asked about whether they thought they would continue to need advocacy in the future.

I don't think I would, no. But that does not mean I would not call them up if I do. I know where they are. #6

If a situation came up I would probably go to my carers or someone I know better. I would only go to advocacy if they couldn't help. #7

In the focus groups people did not report any significant barriers to joining collective advocacy groups. Being a member of an advocacy group was described as being beneficial in terms of accessing one to one support when required. There were examples of people accessing other services through the help of the group facilitator including referral to one-to-one advocacy services.

(Group facilitator) can put us in touch with people in town who can help us. FG3

Key points

- Most commissioners reported that the advocacy services they commission are expected to prioritise people affected by compulsory measures
- The majority of service managers reported having a system for prioritising access. The nature of access criteria varies from service to service
- Access to advocacy was variable for people with learning disabilities. They reported mixed experiences of how long they had to wait to see an advocate. The reasons for this were not always clear
- Where people with learning disabilities had frustrations about lack of contact with an advocate, these were generally aimed at the 'system' rather than the advocate themselves
- Being a member of an advocacy group was described as being beneficial in terms of accessing one to one support when required.

8. Experience and Impact of Advocacy

Background

Below are three case study accounts of the experience of one-to-one advocacy as provided by respondents in their individual interviews. These accounts have been selected to illustrate the wide ranging nature of the kinds of situations in which advocacy has been applied, and the wide range of outcomes which can result from advocacy.

We did not attempt to collect broader, contextual information which might 'explain' some of the reasons why respondents felt their experience of advocacy had not been ideal; rather we were interested in hearing from respondents about their own perceptions of the experience.

Each account focuses on five key questions:

- What situation did the person need help with?
- How did they link up with an advocate?
- What kind of contact did the person have with the advocate?
- What kind of input did the advocate provide?
- What difference did it make to the person to have an advocate?

Example 1 - Interview #2

Respondent #2 was living in residential accommodation. She was not happy with it. She felt she wasn't being treated well by the staff, and that she wasn't able to do the things she wanted to do.

I didnae like it. It was like I wasnae getting treated right...I wasn't getting treated like the same... and I was getting stressed and angry and all that. it.....I wasnae getting my freedom like.... The way they would speak to you was really bad.

She told her social worker that she wasn't happy with her situation. The social worker put her name down on a waiting list for advocacy. After a relatively short wait, an advocate came to visit her, and to talk to her about her situation.

I had to wait a while anyway to get on the list... but I didnae know how long it would be...'cos there's far too many people on that list... waiting... but it wasn't that long a timeBut [waiting] was OK. Because everybody else had to wait as well.....Emm...she came to my house and met me there one-to-one.

Respondent #2 saw her advocate during the period when the move from her present accommodation to new residential accommodation was being discussed and organised. Her social worker was also present at many of these meetings. Respondent #2 knew she wanted to move somewhere else and that the advocate's role was to help her to think about how she could achieve this.

And I was speaking to my advocate to see what ... how I would do it... how to go round it...

The advocate spoke on behalf of Respondent #2 when a move was discussed at meetings. Speaking at meetings was something the respondent found difficult and stressful and this could prevent her from having effective conversations. Having an advocate meant she was able to discuss things with the advocate first and they could then speak to relevant staff to help find a resolution. The advocate also helped to explain (with the social worker) to Respondent #2 what was happening and what she should expect. The advocate went with her to visit the new accommodation.

She was really helpful and she would do anything for you... I really liked her... she was warm and helpful... she was really nice to you... She would speak to you... and how you could speak to her... like that... I just felt I needed someone to talk on my behalf... but [Name] was there when I needed her...

Respondent #2 was very grateful for the support and help provided by her advocate (and her social worker). She appreciated having someone she had built up a relationship with - and that she trusted - to help her with a major change in her life. She reported that the new accommodation arrangement is working very well.

Example 2 - Interview #6

Respondent #6 is a disability activist. His wife also has learning disabilities. He had an experience of advocacy when their son was taken into care. His hope was that the advocate would be able to bring about their son's return to the family home.

He referred himself to advocacy when it became clear to the couple that the social work department were considering placing their child into care. As an active disability activist he was aware of advocacy and referred himself. He reported that he had a wait of six weeks and felt that this was a long time to wait. He felt this wait meant that his situation got worse and even more input was required from the advocate. He met the advocate in preparation for social work meetings and in child protection meetings. The advocate wrote a letter on his and his wife's behalf setting out all the issues in relation to the care of their son. She also helped to set up a meeting with the social worker to discuss the situation. However, respondent #6 did not think that the advocate had helped him:

It was good in a way but obviously she was not able to do the job for what she was supposed to do to help someone with a disability.

The barriers he identified were the social worker's perceived discriminatory attitudes and the inaccessible language of the social work reports. He didn't feel the advocate was able to clearly explain the social worker's report:

My son was took off us ... the social worker looked at two people with disabilities so that was where it all came from... Even she had difficulty with the social work terms. It was how social work put it down.

Though he reported that the advocate listened to him he felt that the advocate wasn't able to speak on his behalf effectively enough. He thought the advocate 'tried her best' but that she was not able to influence events in any way:

[The advocate] wrote a letter and put in all the problems and that was easy enough. And getting the meeting with social work and trying to get all the family together and meet and do it. I found that was OK. But social work just ripped up the letter type of thing and said no.

He thought advocates might be good for people in care, and that they might be able to help with applications for benefits, but that they were not equipped to help someone with a learning disability. It was a frustrating experience for him because nothing good seemed to have come from the advocate's involvement:

[I: Was there anything that changed for you as a result of having advocacy?] Not really. They [advocates] are good for people who are in care, you know, to have a voice. They do help people to have confidence that way. But when you are like myself and my wife who are so able bodied to do something, you know, advocacy is not, it can't help you as much except when it comes to PIP or if you need an ESA. They can help give advice with that.

Example 3 Interview #8

Respondent #8 had experience of advocacy when she was the victim of an assault. She attended a group which had an advocacy office next door. The advocacy organisation had given a presentation to the group to promote their service. She was aware that advocacy was for 'people who had learning difficulties that need help to speak'. When she was assaulted, she contacted the advocacy organisation herself, simply asking for help. The organisation took some details from her and explained that it might take a few weeks to find someone suitable, who could help her speak to the police. She saw her advocate about three or four times before they went to see the police. She then saw them a couple of times afterwards 'just to make sure everything was OK'. She was able to speak for herself at the meeting to a large degree, but the advocate also spoke. The advocate helped to prepare her for the meeting, to give her as much control as she wanted or needed, and a way of communicating that she wanted some help in a

discrete and respectful way:

She was a really good help and we worked out a thing to help us when we went to speak to the guy and then if I didnae – couldnae – speak then she would speak for me.

The advocate was like a safety net for her in the meeting, which gave her confidence to speak up. They also acted as a bridge between the person and professionals facilitating good communication and better relationships:

So we had a really good conversation. I think at the end she spoke up but I had done most of it myself but having somebody there it was a lot easier than trying to speak for yourself.

[Without her] I wouldn't have got as far and the inspector wouldn't have gave me his phone number that I could get in touch with him. I could just phone him and make an appointment instead of going through a PC...

Ultimately Respondent #8 did not get the result she wanted as she decided not to take things further in terms of a prosecution:

But it ended up we couldn't get an agreement with the policewe had to give up on the case anyway because there was too much problems that I couldn't get sorted or I would have had to go through a medical which I didnae want to do.

However, it was still a positive experience and she was very appreciative of the support and help from the advocate. She felt the advocate was able to change the way she looked at the situation and to facilitate her access to the police. She now feels better able to speak up for herself.

But that was my choice... the woman had tried her best to help us... I can talk up better now than what I could before.

Relationship with the advocate

In general, the people with learning disabilities who were interviewed or took part in focus groups were very complimentary about the advocates they had been involved with. People's experience of working with an advocate ranged from short term interventions on highly specific issues; to longer term support to resolve deep-seated, complex and long standing situations. In both cases the relationship with the advocate was considered to be key to a successful intervention. In particular, people talked about the importance of continuity, and of developing a relationship based on trust and honesty.

She was very wise. She never put her personal views. I really like her. She was very helpful. She listened to me and helped me understand what was going on especially through the adoption. #4

They make me feel safe and keep things confidential. My advocacy workers are good people. They are nice people. They are helpful people. They are friendly people. My advocacy workers are good at listening to me. I trust my advocacy workers. #15

I would say she is really kind and helpful. Helps you with your problems as well. [Interviewer: And did you trust her?] Yeah. [Interviewer: And did that take a long time? Or did you trust her instantly?] Ehh.. well It was like a relationship ... I was really like close friends with her. #2

There were responses which raised questions about people's understanding of the professional boundaries integral to the advocate role. There were also responses which suggested that people possibly felt overly reliant on their advocate.

She'll say nearly time you go yourself. No chance! [Interviewer: so you would never go by yourself?] no, no no no. Even if she had to cancel an appointment and said I cannae make it this day, I says then can you phone up the school and make arrangements and appointment cause I ain't going myself and she'll come with me. ... She'll explain it to me cause I get confused. And she'll say do you understand what I'm saying? and she's got to split it up. Cause sometimes they can't split the words...And (advocate) will split it up for me. #9

There were also opinions expressed where participants were less positive about the personal qualities of the advocate and their relationship with them.

She is quite feisty and she'll say some things in meetings but then other times she'll say something to (son) and me and then not say it in the meetings with social work. She doesn't always pipe up when I'd like. Maybe because it's a small community and they all know each other... But if there's one thing I would say it's that (advocate) talks over the top of me sometimes as if she's arguing with me..... She's good overall, she can be bolshy when needed but sometimes she's not bolshy enough. #17

Impact of advocacy

People with learning disabilities' views of the overall efficacy of the advocacy support they received ranged from highly positive to quite mixed. Participants identified two main types of positive impact resulting from advocacy support: greater confidence in speaking up for themselves/ability to communicate their views, and resolution of problems they were experiencing. Overall, 'soft outcomes' relating to the former were more identifiable and numerous than tangible 'hard outcomes' which were less common. Many examples were given of the positive benefits of advocacy related to

'soft' outcomes such as feeling calmer in meetings, being listened to, having processes and rights explained and having help to articulate their view in meetings with other professionals. Feeling that someone was on their side was seen as a major advantage of advocacy.

She helped me resolve things in a calm way... She listened to me and helped me understand what was going on. #4

I would just end up exploding with folk (unclear) if (advocate) wasn't there I don't know what I would dae, to be honest with you. #9

I have a review with my support manager. Once a year. Big meeting. [Advocate] and any social workers. She comes to some of them to see how well they are doing.

[Interviewer: And how have those meetings been for you? Have they been successful?] R: Oh yes. ... I don't think I would manage without her. I wouldn't be able to manage. She is good. #3

In some ways it was good, it helped me get my points across, I was getting lost in what was going on. Without advocacy I'd be stuck in the same old pattern, stuck in meetings, not getting my say. #7

[Interviewer: So do you feel that's something that the advocate has been helpful to you in explaining things about what the entitlements and rights are?] Yeah. It's good to have someone who is doing the job every day.... it's betterThen they know what they are talking about. And if you go to an advocate they will give you advice. They do try their best. They'll say something ... you should see about getting Colin reassessed ...care packages... which I probably will do ... but they don't really follow that up ... they should say look this is what we should probably do ... #5

It was mentioned that the presence of an advocate can have a positive influence on other professionals and enable people to get the point across more effectively.

They don't talk down to me or treat me like dirt when she's there. #11

Before we couldn't get a word in. They were always doing the talking. The doctors. The staff. It was terrible.....#18

I talk up for myself and talk more now. #12

There were also examples of 'hard' outcomes where people were able to give examples of concrete changes that had resulted from an advocacy intervention.

[Interviewer: And did your advocate sort of explain to you what all the steps were in terms of the move?] Yeah. The social worker and her came

and spoke to me about it explained all about it and told me what was gonnae happen and all that ...so they moved me here and so ... I've been here a year now. Emm... and I love it so much. I've settled down so quick. All the staff are lovely and I wouldnae move again. This is gonnae be my house now for good. #2

[Sister]: she has a friend she has been dying to visit and there was trouble in her getting things organised. (advocacy worker) came in spoke to them and arranged meetings and R was able to go down and see here friend.

However, there were examples of frustration and disappointment when an advocacy intervention had failed to achieve the end result or hard outcome that they were hoping for.

[Interviewer: So what is your advocate doing for you?] Well, I don't know but em, we're tryna get more hours with social work but, I mean, they're (unclear) but I think she's writing things down that I'm not saying.... with care companies, clients are entitled to have their say. I'm not getting a say [Interviewer: And do you think she is doing a good job for you?] I'd like to get more say in my support which I don't getno matter how much I try it doesn't happen ... it's not her fault ... I couldn't fault (advocate) at all. I wouldn't let anyone fault her #11

It would have been, to my knowledge, about ten, fifteen, meetings. Give and take. And then, obviously, it went on to where she had to give it up. And then handed it on to a solicitor. And that was when they pulled out. And the solicitor carried on. #6

[Interviewer: So was it helpful just to have someone to listen?] eh, yeah it was, I mean (advocate) came out sort of a good few times and he always said to me, anytime if you ever need to talk about something or need help just phone me. You know the guy was really really helpful.... I mean he phoned social work and all that but his hands were kind of tied there wasnae really much he could do.... #14

In the focus groups the opportunity for social interaction was highlighted as an important reason for joining an advocacy group. Being part of a group was described as providing opportunities for people to meet each other and also to feel more involved and included in the wider community. People also enjoyed the opportunities which the advocacy group offered to hear presentations and have discussions on a wide range of different issues.

It has helped me make new friends. Good to have people to talk to...We find out about things. FG3

The relationship with the group facilitator was cited as an important part of group

advocacy especially when group members experienced difficulties in their lives. In such cases people had someone they trusted who knew them well and could help them navigate situations, obtain help and/or access additional support services. People also reported that being involved in a group had led to them feeling more confident and more able - and willing - to express their opinions and preferences:

I spoke up for the first time recently at a meeting, I felt nervous but it felt good. I talk for Scotland now and never shut up.FG1

The view was also expressed that cutbacks to support packages have impacted on the ability of some people to attend.

Key Points

- **People offered a wide range of situations and circumstances in which they had experienced advocacy covering both one-to one advocacy and group advocacy**
- **There was a wide range of issues relating to the type of issue, the duration and intensity of the advocacy, and the requirement for ongoing support**
- **Two main types of positive impact resulting from advocacy support were identified: greater confidence in speaking up/ability to communicate views, and resolution of particular problems experienced**
- **Soft outcomes were more identifiable and numerous than tangible hard outcomes which were less common**
- **People talked about the importance of continuity, and of developing a relationship based on trust and honesty. The interviews raised questions about people's understanding of the professional boundaries integral to the advocate role and/or the danger of overreliance on advocacy support**
- **Some disappointment was expressed with lack of progress in relation to specific identified problems and a desire for deeper and more intensive support in order to achieve the changes that were required**
- **A range of other issues were touched on during the interviews including that:**
 - **Advocates should be able to offer advice and information**
 - **There should be more funding for advocacy**
 - **There should be more choice about the type of advocacy available**
 - **There should be more general support – including social support and befriending for people with learning disabilities**
- **Participants described the main benefits of being part of an advocacy group as related to social interaction, a long term relationship with the group facilitator, and increased confidence.**

9. Monitoring, Evaluation & Outcomes

Background

SIAA have highlighted that there are few studies addressing the impact of advocacy on people with learning disabilities²². More generally, research by IRISS points to a limited evidence base about the effectiveness of advocacy stemming partly from an absence of effective monitoring and evaluation tools. Furthermore, it found that the effectiveness of the evaluations of advocacy is patchy and outcomes are not always scrutinised by funders. A literature review by National Development Team for Inclusion NDTi in 2013 found a lack of both quantitative and qualitative data that evidences the impact of advocacy. Additionally, their findings identified three main problems in the robustness and quality of existing published evidence. These were a reliance on individual stories and anecdotes without analysing common themes, a reliance on people's views rather than empirical evidence, and no consistent basis for assessing the evidence of advocacy's impact. It identified a lack of rigorous, routine and consistent collection of local data on outcomes by both providers and commissioners of advocacy.²³

Reporting and evidencing outcomes

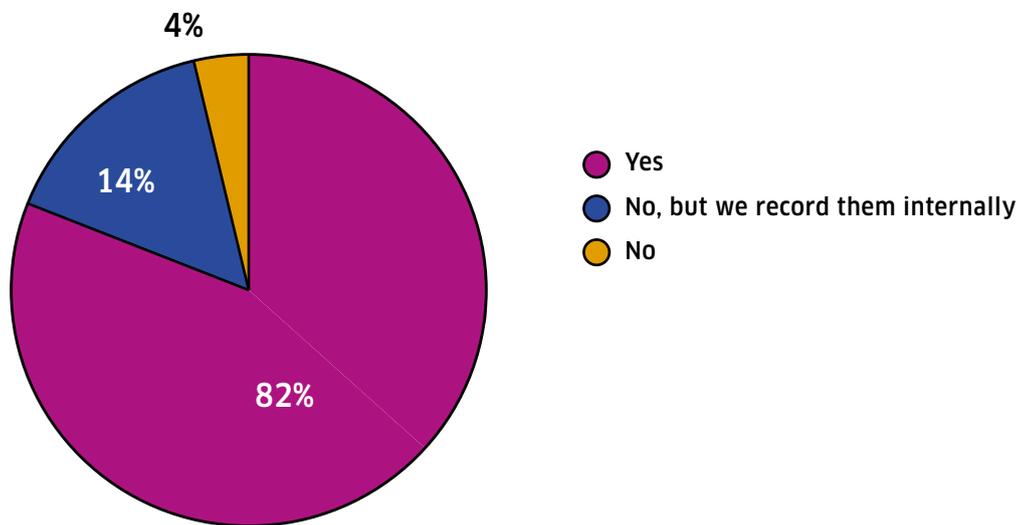
Commissioners on the whole said that outcomes were monitored through a contract monitoring framework (quarterly, six-monthly and / or annual). A large majority (82%) of service managers responded that they were required to report on outcomes to their funder. Some service managers included the frequency of reporting (usually quarterly) and the purposes to which information on outcomes was put (quality assurance and to make the case for funding). The remaining 18% stated they were not required to do so, although all but one of these said they recorded outcomes for internal reasons.

Service managers described a variety of approaches to evidencing outcomes based both on advocacy partner / service user views and advocate views of the outcome of the advocacy intervention. Both quantitative and qualitative measurements were collected. Quantitative measures included questionnaires and other data collection instruments containing scales to measure before and after assessments. Qualitative assessments were often collected in the form of case studies, or personal stories. Special mention was made of the ways in which attention was paid to collecting information from a wide range of players, as well as from individuals with communication difficulties. Some services discussed the question at a more generic level, discussing the use of information management systems, performance management software, and the adoption of a process of review and reflection applied on a case by case basis. There was no explicit reference to the Independent Advocacy: An Evaluation Framework in the survey responses.

²² "Without advocacy I'd probably be dead" Research into the impact of independent advocacy on the lives of people experiencing learning disabilities, SIAA (2014).

²³ Impact of Advocacy for people who use Social Care Services - NDTi

Are you required to report on your outcomes to your funder?



Recording outcomes

The outcomes mentioned by commissioners and service managers covered both personal outcomes (i.e. outcomes for those receiving advocacy) and project / organisational / statistical outcomes (i.e. outcomes which focus on e.g. organisational development, throughput, and resolution of issues). As far as the personal outcomes were concerned, those mentioned most often by commissioners related to those receiving advocacy support:

- being better informed and knowing their rights
- being empowered, confident and more independent
- feeling that they have been listened to and involved in decision making about their situation
- having improved health and wellbeing and reduced anxiety and stress
- being aware of the service.

The personal outcomes mentioned by service managers were very similar to the above but also included those receiving advocacy support:

- being less socially isolated
- better networked and connected to sources of support
- feeling that their risk of harm has been reduced.

As far as project outcomes were concerned, commissioners most often referred to:

- (statistical) assessments of the numbers of individuals helped (and the demographic characteristics of those individuals)
- the numbers of issues resolved/improved and the time taken to do this
- the sources of referrals
- the number not meeting the eligibility criteria
- the number and type of complaints.

In addition to these, responses from service managers included:

- the numbers of workers trained in advocacy
- the numbers of tribunals/case reviews supported
- the increased awareness in the community of the role and purpose of advocacy support.

One commissioner explicitly said that most of the data recorded (both the personal outcomes data and the statistical / project outcomes data) related to outputs rather than outcomes. Another three commissioners simply said that their systems for recording outcomes were currently 'under development'.

Other Monitoring

All commissioners stated that they required organisations to monitor and report on the number of people who accessed advocacy. Seventy-one (71%) of respondents said they required organisations to monitor and report on the number of people with complex learning disabilities who access advocacy. Commissioners were asked how they require organisations to monitor and evidence levels of unmet need. Most commonly the response was that unmet need was reported on at the monitoring meetings. One commissioner said that information on unmet need was not identified as a requirement for reporting.

All but one of the commissioners reported that they monitored complaints from people who have accessed or applied for advocacy. Most commonly, commissioners said that complaints were monitored through the regular contract monitoring meetings and / or part of the wider complaints process. Commissioners also described a variety of methods for collecting complaints including the completion of proformas by service users, telephone enquiries, random sampling, feedback from social workers or other professionals and direct correspondence with the provider.

Commissioners did not provide detailed information about how monitoring and information is used to inform future planning. Most simply emphasised in their responses that the monitoring information was used by the teams responsible for producing advocacy plans. Specific mention was made of the extent to which

information on referrals could be used to predict future demand and to help with decision making about how resources should be deployed in future.

Frontline workers most commonly defined success in terms of making sure that the person with learning disabilities:

- was listened to and had their views heard
- understood what was happening and why decisions were made – even if they did not agree with those decisions
- was involved in the decision making process and had their rights upheld
- became more confident and more able to self-advocate in the future.

Less often, frontline workers commented in terms of the improved health and wellbeing of the individual, and a decrease in their social isolation/increase in their friendships and networks of support. Occasionally frontline workers focused on the difficulties of evaluating success and/or the difficulties of ensuring success given the limitations of time and resource and/or the difficulties of explaining advocacy (including non-instructed advocacy) to people with learning disabilities and/or the difficulties of obtaining the outcome the individual wishes to achieve.

Measuring impact framework

In 2016 SIAA ran a Quality Assurance Pilot Project which involved six advocacy organisations undergoing an independent evaluation using the Evaluation Framework to measure the quality of the work of the organisation. Following a workshop at their 2016 conference SIAA set up a Measuring Impact of Advocacy Working Group which looked at the various methods organisations use to evidence the difference they make. Animate Consulting was then commissioned to develop a framework which captures evidence around the impact advocacy organisations have on the lives of individuals and communities in a consistent way. The working group is planning to ‘road test’ the new framework later in 2018 before wider roll out. The long term plan is that SIAA’s Advocacy Map will include information about impact alongside the current data around numbers of people accessing advocacy and funding levels.

Key Points

- **A large majority of service managers responded that they were required to report on outcomes to their funder and all commissioners said that they required organisations to monitor and report on access to advocacy**
- **All but one of the commissioners reported that they monitored complaints from people who have accessed or applied for advocacy and most said they required organisations to monitor and report on the number of people with complex learning disabilities who access advocacy**

- **Outcomes mentioned by commissioners and service managers covered both personal and project / organisational / statistical outcomes**
- **Frontline workers emphasised achieving soft outcomes for people with learning disabilities**
- **Service managers described a variety of approaches to evidencing outcomes using both quantitative and qualitative measurements**
- **The level of detail provided by organisations was extremely mixed and each organisation appeared to have its own internal processes**
- **There was no explicit mention of the Independent Advocacy: An Evaluation Framework by any service manager**
- **Commissioners provided little information on how the information they gathered is used to inform future planning and decision making.**

10. Commissioning and Strategic Planning

Background

The Mental Health (Care and Treatment) (Scotland) Act 2003 obliges NHS Health Boards and local authorities to work together to provide independent advocacy and to ensure individuals have the opportunity to use these services.²⁴ The Scottish Government advocacy commissioning guidance published in 2013 says development and investment in advocacy should be evidenced in a three year Strategic Advocacy Plan and be reviewed annually as part of the advocacy planning process. This plan should be signed off by senior management in both the NHS Boards and local authorities. All Strategic Advocacy Plans should be Equality and Diversity Impact Assessed using the Equality Impact Assessment Toolkit (EQIA). There should also be an Advocacy Planning Group in each commissioning area which has responsibility for developing, overseeing and implementing the plan.²⁵

Health and Social Care integration has resulted in different planning structures and arrangements in different local areas. In a number of areas responsibility for planning and commissioning is now undertaken within the Health and Social Care Partnership (HSCP). However, in Lanarkshire, Forth Valley, Highland and Grampian planning and commissioning remains on a health board wide basis. There are also six health board areas which are coterminous with the new HSCPs – NHS Borders, Dumfries and Galloway, Fife, Western Isles, Orkney and Shetland.

The Mental Health (Scotland) Act 2015 created new responsibilities for health boards and local authorities to demonstrate that they are discharging their legal responsibilities in relation to independent advocacy services. NHS Boards and local authorities must give the Mental Welfare Commission information about what they have done in the previous two years and what they intend to do in the next two years to ensure that independent advocacy services are available for people who have a statutory right of access and that people are able to access these services. The Mental Welfare Commission intends to monitor this activity and report on it. It is hoped that this more robust scrutiny of advocacy service provision should lead to better planning process with gaps in provision being identified and filled.

Strategic advocacy plans

The SIAA map of advocacy report 2015-16, reported there were only 5 up to date strategic plans: NHS Fife (2014-17), NHS Highland (2014-17), NHS Lanarkshire (2012-16), NHS Lothian (2012-16) and NHS Western Isles. There were no plans in four NHS Board areas, NHS Ayrshire and Arran, Forth Valley, Greater Glasgow & Clyde and Orkney. In five areas the most recent plans had ended and were under review in NHS Borders, Dumfries and Galloway, and Grampian while in Shetland and Tayside there was no information about plans being reviewed or updated.²⁶

²⁴ Working with independent advocates, Mental Welfare Commission (2017)

²⁵ Independent Advocacy: A guide for commissioners, SIAA (2010)

²⁶ A Map of Advocacy across Scotland 2015-2016 (SIAA)

Our survey found similar results. Only six commissioners (35%) reported that there was an up-to-date strategic plan in their area with the other eleven (65%) stating that there was no current plan in place. Of those who said they had no plan, five said they had no plans to develop one; four said they were in the process of developing one; one said the HSCP had no plan but there was a health board wide plan; and one provided no information. We received four current plans:

- Dumfries and Galloway (2015-2018)
- Grampian (2016-2018)
- Scottish Borders (2017-2019)
- Lanarkshire (2016-2020).

Advocacy planning process

The advocacy commissioning guidance is clear that strategic plans should be developed based on local needs assessment and information about unmet need and gaps in provision and used to inform future commissioning decisions. It states “a Strategic Advocacy Plan should be developed based on the information gathered from a needs assessment, scoping exercises and consultations”.

In our survey we asked commissioners about their consultation processes and how identified areas of unmet need were used in their planning processes. In areas where a strategic plan existed nearly all commissioners said they had consulted with advocacy organisations in the development of the plan and around two-thirds said they had consulted people with learning disabilities. However, the extent to which this constituted meaningful involvement of providers and people who use services was difficult to assess.

Forty percent (40%) of commissioners said that there was no local group which oversees the development and/or implementation of the strategic plan. Commissioners described the following ways that identified areas of unmet need were used in their strategic planning:

- information is passed to the planning team who adapt the strategic plan as appropriate
- discussions take place about what to do in relation to unmet needs in strategy groups, advocacy groups, and communication groups
- services and contracts for services are changed to adapt to changing priorities
- alternative sources of funding for specific priorities are sought
- information about unmet need informs resource allocation decisions

Little detail was provided by commissioners about what information they obtained from providers e.g. on waiting lists, internal monitoring and their mechanisms for doing so.

Key points

- Two-thirds of commissioning areas appear not to be meeting the Scottish Government's expectation to have a three year strategic plan
- For those who said they had no plan, five areas had no plans to develop one; four were in the process of developing one; one said the HSCP had no plan but there was a health board wide plan and one provided no information
- A sizeable minority of commissioners reported there was no local group responsible for development and/or implementation of a strategic plan
- Nearly all commissioners had consulted with advocacy organisations in the development of the plan and around two-thirds had consulted people with learning disabilities
- Little detail was provided by commissioners about the information they obtained from providers on assessment of unmet need and their mechanisms for doing so.

11. Challenges and Future Requirements for Advocacy

Background

Evidence from monitoring and research indicates that laws and strategies to empower and enable choice for adults with disabilities are not working as intended. A major issue is the lack of clarity about the meaning of Support for Decision-making and the rights of individuals to be supported to make their own decisions as far as possible. The Scottish Government has established an advisory group on supported decision making that has been tasked with producing a 'support for decision making strategy' focused on delivery and best practice in advance of proposed reforms to the Adults with Incapacity Act. The Government has also tabled an amendment on advocacy in the Social Security Bill and a review of learning disability and autism in the Mental Health (Scotland) Act is also forthcoming. In this context, while there is recognition of advocacy's role in ensuring that people with disabilities have support to exercise the same legal and civil rights as other citizens, demographic and financial challenges are exerting significant pressure on advocacy provision.

Challenges from a commissioner's perspective

The biggest challenge identified by both commissioners and service managers was around funding. Commissioners highlighted that demand was increasing and there was not always the capacity/resource to respond to it. Moreover, more complex cases are increasingly presenting to services placing an even greater demand on existing provision. Commissioners identified a number of groups who had unmet needs including those with complex needs and parents with learning disabilities. In addition, a few commissioners identified types of advocacy that needed to be expanded – in particular, citizens advocacy and long-term advocacy.

Other issues raised were that:

- there are insufficient advocacy providers which can make for difficulties in the competitive tendering process
- it was not always clear how best to use multiple providers within a single contract
- it was difficult to recruit advocates in remote areas
- a very dispersed population made for difficulties with service provision
- for some people a befriending service rather than advocacy would be a more appropriate form of provision.

Challenges from a service manager's perspective

For service managers the main issue raised was the challenge of continuing to provide a good and comprehensive service at a time when demand for services was rising, combined with stable or declining budgets. They felt there was simply not enough time or resource or capacity to meet the multiple needs identified. Moreover, there were difficulties associated with the short term nature of the funding contracts.

Other issues raised covered:

- the need to restrict requests for referral and also to reduce or stop awareness raising activity
- the lack of understanding and awareness of what advocacy is. This can lead to inappropriate gatekeeping and an inadequate referral process as well as to a poorly run tendering process
- lack of good information in an appropriate format available for potential service users
- the necessity of sometimes relying on information from other professionals or family members.

Challenges from a frontline worker's perspective

From a frontline worker's perspective there were a number of themes – often linked – related to challenges in providing advocacy support to people with a learning disability.

These were:

- the amount of time it takes to build up a relationship in which the individual's issues can be properly understood and responded to. Frontline workers emphasised that this was a complex task, especially where there were extensive communication difficulties and a high level of support was required
- the lack of understanding and awareness of the remit and purpose of independent advocacy by a range of people including professionals of all kinds as well as families and carers
- only becoming involved late in the day when a crisis had developed
- conflicts and a lack of trust/engagement between the various parties (advocacy partners, advocates, local authorities, other professionals, families, carers etc.) including a sense that the concept of 'reasonable adjustment' was not well understood or implemented
- guardians sometimes prevent people from accessing advocacy support.

Other issues were mentioned occasionally including the difficulty of operating in a rural area where travel distances and costs were prohibitive, identifying sufficient volunteer advocates, poor liaison with other professionals, specific difficulties with particular benefits (e.g. SDS), and poorly trained staff.

The broader context which was not always explicitly mentioned, was the difficult financial context. This was linked to rising demand, and issues around a lack of capacity in terms of worker time.

Overcoming challenges

On the whole commissioners did not expect that funding pressures would be alleviated. Therefore they focused more on improving the strategic planning process and ensuring that there was a good understanding of needs and demands, and good relationships amongst relevant players, so that services could be designed accordingly. It was thought that the integration of health and social care might prove to be helpful in the future. It was suggested that sharing ideas across local authorities would be beneficial. One commissioner said that work was being done to test out whether some services could be delivered through video links.

In terms of support required to overcome these challenges on the whole, service managers reiterated the requirement for more funding in order to provide and develop advocacy services in general and specialist advocacy training in particular. Some service managers discussed their efforts to apply for other sources of funding (in addition to the statutory funding). This was described as very challenging but was being actively pursued by a range of managers.

Others talked about:

- the importance of good planning
- regular liaison with referring agencies
- effective use of (free) internet resources
- awareness raising activities to improve understanding of the role of advocacy.

One service manager described some additional services (e.g. workshops on internet bullying, internet safety and self-advocacy) that their organisation had developed which could generate additional funding; another described getting a wider range of professionals (including Speech and Language Therapists, and art therapists) involved.

Frontline workers most commonly talked of the need to improve understanding and awareness of the remit and purpose of advocacy amongst the broadest possible constituency of both professional and lay people. This was described in various ways as 'networking', 'promoting', 'building understanding', 'raising awareness' etc. A range of more specific suggestions covered the need for greater training – both generally and in relation to specific communication tools; the benefits of fundraising and looking for alternative sources of funding; earlier referrals; and better time management and organisation skills. Frontline workers also stressed the need for increased funding and – more particularly – increased time made available for advocacy support for people with learning disabilities.

Key points

- Commissioners and service managers identified increasing demand alongside static/declining budgets as the main challenges for advocacy provision
- Commissioners identified a number of groups with unmet need including those with complex needs and parents with learning disabilities
- Some commissioners felt that certain types of advocacy required expansion e.g. citizens advocacy and/or some people would benefit from a befriending service rather than advocacy
- Service managers mentioned the negative impact of having to restrict requests for referral and reduce or stop awareness raising activity
- Frontline workers highlighted some of the particular challenges in providing advocacy support to people with a learning disability including the length of time it can take to build up a relationship; and difficulties relating to conflicts and a lack of trust/engagement between various parties
- Commissioners focused on the needs to improve the strategic planning process, have a good understanding of needs and demands, and good relationships amongst relevant players
- Service managers emphasised the requirement for more funding in order to provide and develop advocacy services in general and specialist advocacy training in particular
- Frontline workers most commonly talked of the need to improve understanding and awareness of the remit and purpose of advocacy.

12. Discussion/Conclusion

Advocacy provision, awareness and access

The landscape for advocacy provision for people with learning disabilities is complex and there is considerable variation in the type of advocacy support which is accessible in different areas. In our survey one-to-one professional advocacy provision was the most common form of provision with around a third of commissioners reporting they did not commission any collective/group advocacy.

Self-advocacy and group based advocacy play an important role in helping people with learning disabilities to assert their right to a stronger voice, increased choice and greater empowerment. However, since the introduction of the statutory provisions within the Mental Health Act there has been increased focus on one-to-one professional advocacy. In our focus groups people with learning disabilities described the benefits of being part of an advocacy group as related to social interaction, a long term relationship with the group facilitator, and increased confidence/ability to express themselves. The benefits of group advocacy for people with learning disabilities in particular is a reminder for planners and funders to recognise and value the broad range of advocacy models within the Scottish Government guidance for commissioners.

Advocacy services in Scotland are facing significant pressures in the context of static or reducing budgets and increasing demand. There are concerns within advocacy organisations about their ability to meet their statutory obligations and to conduct awareness raising activities. As a result there is a danger that people with learning disabilities may struggle to access their right to independent advocacy and moreover may not always be aware of this right. Most commissioners reported that the advocacy services they commission are expected to prioritise people affected by compulsory measures under the Mental Health Act and a majority of service managers reported having a system for prioritising access. People with learning disabilities reported mixed experiences of how long they had to wait to access advocacy. In terms of awareness of advocacy, both commissioners and managers listed a wide range of activities undertaken to promote services despite current funding constraints. However, while many people with learning disabilities had heard about advocacy, they were generally not aware of the different types of advocacy which exist and there were a range of misperceptions about what advocacy is, and what advocates do. The new responsibilities on the NHS and local authorities in the 2015 Act represent an opportunity to identify gaps in provision and work to improve overall access, awareness and quality of advocacy.

Impact of advocacy

In our research the two main types of positive impact resulting from one-to-one advocacy support were: greater confidence in speaking up for themselves/ability to communicate their views, and resolution of problems they were experiencing. In one-to-one advocacy the importance of continuity, and of developing a relationship based on trust and honesty were common themes. People also perceived that the

presence of an advocate could lead to more positive attitudes by professionals working with them. There were also some responses which raised questions about people's understanding of the professional boundaries integral to the advocate role or the danger of overreliance on an advocate's support. Some expressed disappointment with a lack of progress in relation to specific identified problems and a desire for deeper and more intensive support in order to achieve the changes that were required. Overall, 'soft outcomes' such as self-confidence were more identifiable and numerous than tangible 'hard outcomes' of problem resolution which were less common. Frontline workers highlighted some particular challenges in providing advocacy support to people with a learning disability. These included the length of time it can take to build up a relationship; and difficulties relating to conflicts and a lack of trust/engagement between various parties. They identified some hard outcomes such as people having their rights upheld but also emphasised soft outcomes as key markers of success in their role. These included making sure that the person:

- is listened to and has their views heard
- understands what is happening and why decisions are made
- is involved in the decision making process and
- becomes more confident and more able to self-advocate in the future.

However, soft outcomes present a challenge for organisations as they can be more difficult to measure than more tangible hard outcomes.

Monitoring and evaluation

The difficulties in capturing soft outcomes together with different understandings and interpretations about the role of advocacy present challenges to effective evaluation. In our survey commissioners and advocacy providers recognised the importance of monitoring and evaluation of outcomes. Service managers described a variety of approaches to evidencing outcomes using both quantitative and qualitative measurements. A large majority of service managers responded that they were required to report on outcomes to their funder. However, commissioners offered limited detail on the way they use this information and how it informs future planning and decision making. Additionally, the level of detail provided by organisations was extremely mixed and internal processes appear to vary markedly between organisations. There was no explicit mention of the Independent Advocacy: An Evaluation Framework by any service manager. The lack of an easily recognisable and universal approach to advocacy evaluation and outcomes measurement continues to leave funders and organisations open to criticisms that they are over-reliant on case studies, anecdotes and personal opinion rather purposefully measured outcomes or robust assessments or evaluations of services.

Commissioning and strategic planning

Our research and SIAA's Map of Advocacy highlights an absence of robust, up to date strategic advocacy plans in many areas. In our survey two-thirds of commissioners

reported not having an up to date plan. Additionally, a sizeable minority of commissioners reported there was no local group responsible for development and/or implementation of a strategic plan. Overall, there was little information from commissioners about whether they require information from providers on waiting lists, and how they assess impact on other groups when people subject to compulsory treatment are prioritised. Moreover, it was difficult to assess the extent to which consultations constituted meaningful involvement of providers and people who use services. The existence of thorough needs assessment and meaningful consultations are essential if decisions about the types of support commissioned are to be informed by information about local needs and types of support that would best meet these. This will help planners to take account of local needs and ensure that advocacy is available to those who need it, and in particular people with learning disabilities who have a statutory right of access to advocacy.

Future requirements for advocacy

Our findings highlight a number of challenges and future requirements for advocacy provision for people with learning disabilities. Commissioners identified a number of groups with unmet need including those with complex needs and parents with learning disabilities, and also felt that certain types of advocacy required expansion. They focused on the need to improve the strategic planning process, have a good understanding of needs and demands, and improve relationships amongst relevant players. Service managers stressed the negative impact of having to restrict requests for referral and reduce or stop awareness raising activity. They emphasised the requirement for more funding in order to provide and develop advocacy services in general and specialist advocacy training in particular.

Frontline workers also spoke of the need for increased funding and – more particularly – increased time made available for advocacy support for people with learning disabilities. They commonly emphasised the need to improve understanding and awareness of the remit and purpose of advocacy. In interviews with people with learning disabilities a variety of views were expressed including the desire for more long-term citizen advocacy and peer advocacy partnerships.

Discussions around the role and remit of advocacy are currently relevant to a wide range of public policy discussions including the Social Security Bill, Support for Decision-making Strategy, Review of Adults with Incapacity Act, the review of learning disability and autism in the Mental Health (Scotland) Act and compliance with the UNCRPD. In highlighting some of the current issues around advocacy provision, access and planning as well as the advocacy experience for people with learning disabilities, this report can help to inform and contribute to these discussions and future debate.

13. Recommendations

We undertook this research to create an evidence base which can be used to effect positive change for people with learning disabilities. We want people with a learning disability and others to be able to benefit from high quality advocacy (both individual and collective) which is accessible and effective in supporting them to have a stronger voice, increased choice and greater empowerment.

We envisage a range of key stakeholders working together to take these recommendations forward, including:

- Advocacy planners and commissioners
- Advocacy providers
- Scottish Government
- Scottish Independent Advocacy Alliance (SIAA)
- Scottish Commission for Learning Disability (SCLD).

We have made the following eight recommendations which span four key themes:

Increasing access to provision

1. Advocacy commissioners and providers should work together to ensure that people with learning disabilities are aware of their legal right to access advocacy, understand what advocacy is and know how to access it.
2. Advocacy commissioners and providers should review policies and service level agreements which prioritise access for those subject to compulsory measures taking account of the needs of other groups who also have a statutory right of access under Mental Health (Care and Treatment) (Scotland) Act 2003.

Improving strategic planning and commissioning

3. Health boards, local authorities and HSCPs with responsibility for advocacy planning must ensure robust, up to date strategic advocacy plans are in place. In line with Scottish Government guidance there should be a local group with responsibility for development and implementation of the plan.
4. Advocacy commissioners and planners should undertake local needs assessments and consultations with people with learning disabilities to inform decisions about what models of advocacy are commissioned.

Developing monitoring and evaluation practices

5. Advocacy providers should continue to develop and improve approaches to monitoring and evaluation, with particular focus on outcomes and impact measurement. Identifying barriers to advocacy for groups with unmet need

e.g. those with complex needs and parents with learning disabilities should also be a priority.

6. Advocacy providers and commissioners should be involved in road testing the new Measuring Impact of Advocacy Framework with a view to implementing a national evaluation tool which can better inform future delivery plans and strategic commissioning cycles.

Facilitating knowledge exchange and learning

7. All advocacy stakeholders should work to promote a better understanding and awareness of the remit and purpose of advocacy amongst their fellow professionals, commissioners, policy makers, and the wider population.
8. All those involved in the planning, commissioning, management and delivery of advocacy would benefit from the establishment of a learning network to support the sharing of good practice.

Appendix A

Scottish Independent Advocacy Alliance (SIAA) Standards and Guidelines

[SIAA Principles and Standards for Independent Advocacy \(2008\):](#)

This document sets out the advocacy movement principles and standards that underpin good advocacy practice. They can be applied to all advocacy practice.

[SIAA Code of Practice for Independent Advocacy \(2008\):](#)

This document details how independent advocates and independent advocacy organisations should work to meet the advocacy movement Principles and Standards for Independent Advocacy.

[Mental Health Tribunal Guidance for Advocates \(2012\):](#)

This companion guide to the Code of Practice provides guidance for advocates when supporting service users through a Mental Health Tribunal process.

[Elder Abuse Advocacy Guidelines \(2008\):](#)

This is also a companion guide to the Code of Practice. It details issues that an independent advocate might encounter when working with an older person experiencing abuse.

[Non-Instructed Advocacy Guidelines \(2009\):](#)

This is a companion guide to the Code of Practice. It details why and how advocates and organisations can advocate for someone who lacks the capacity to instruct the advocate.

[Independent Advocacy: An Evaluation Framework \(2010\)](#)

Appendix B

Independent advocacy in legislation

- [Adults with Incapacity \(Scotland\) Act 2000](#)

Amended by the Adult Support and Protection (Scotland) Act 2007 which states: In determining an application or any other proceedings under this Act the sheriff shall ... take account of the wishes and feelings of the adult who is the subject of the application or proceedings so far as they are expressed by a person providing independent advocacy services.

- [Mental health \(Care & Treatment\) \(Scotland\) Act 2003](#)

Section 259 states that:

Every person with a mental disorder shall have a right of access to independent advocacy; and accordingly it is the duty of

(a) each local authority, in collaboration with the (or each) relevant Health Board; and
(b) each Health Board, in collaboration with the (or each) relevant local authority, 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.

- [Education \(Additional Support for Learning\) \(Scotland\) Act 2004](#)

The Act states:

Where, in connection with the exercise of an education authority's functions under this Act in relation to any child or young person, the relevant person wishes ... another person (referred to as an advocate) to;

(i) conduct such discussions or any part of them, or
(ii) make representations to the authority, on the relevant person's behalf, the education authority must comply with the relevant person's wishes.

- [Adult Support and Protection \(Scotland\) Act 2007](#)

Amended The Adults with Incapacity (Scotland) Act 2000 and states:

In determining an application or any other proceedings under this Act the sheriff shall ... take account of the wishes and feelings of the adult who is the subject of the application or proceedings so far as they are expressed by a person providing independent advocacy services.

- [Education \(Additional Support for Learning\) \(Scotland\) Act 2009](#)

The Education (Additional Support for Learning) (Scotland) Act 2009 adds to the Education (Additional Support for Learning) (Scotland) Act 2004, and states:

14A Provision of advocacy service: Tribunal

(1) The Scottish Ministers must, in respect of Tribunal proceedings, secure the provision of an advocacy service to be available on request and free of charge to the persons mentioned in subsection **(2)**.

(2) The persons are:

- (a)** in the case of a child, the child's parent,
- (b)** in the case of a young person;

(i) the young person, or

(ii) where the young person lacks capacity to participate in discussions or make representations of the type referred to in subsection (3), the young person's parent.

(3) In subsection (1) advocacy service means a service whereby another person conducts discussions with or makes representations to the Tribunal or any other person involved in the proceedings on behalf of a person mentioned in subsection **(2)**.

[Guidance on Looked after Children \(Scotland\) Regulations 2009 and the Adoption and Children \(Scotland\) Act 2007](#)

Provides guidance on the requirement to consider the views of the child. The underpinning principle is summarised as follows: children and young people should not be passive in decision making processes. They have the right to input into decisions about their lives and the services provided to them.

[The Children's Hearing \(Scotland\) Act \(2011\)](#)

The Act introduces a requirement to ensure that children and young people going through the Children's Hearings system will, for the first time, be able to get advocacy support. The 2011 Act defines advocacy support as;

- services of support and representation for the purposes of assisting a child in relation to the child's involvement in a children's hearing.

- [Patient Rights \(Scotland\) Act 2011](#)

The Act placed a responsibility on Scottish Ministers to publish a [Charter of Patient Rights and Responsibilities](#). The Charter sets out a summary of the rights and responsibilities of patients using the NHS in Scotland, and of people who have a personal interest in such patients' welfare. The Charter states that:

- You have the right to request support when making decisions about your health care.
- You may ask (and if you have a mental health disorder you have a right) to have an independent advocate to help you give your views. NHS staff can help you arrange this.
- [Social Care \(Self-directed Support\) \(Scotland\) Act 2013](#)

The Self-directed Support Act 2013, which applies to children, adults and carers, states that:

The authority must give the person...

(d) in any case where the authority considers it appropriate to do so, information about persons who provide independent advocacy services (within the meaning of section 259**(1)** of the Mental Health (Care and Treatment) (Scotland) Act 2003 (asp 13)).



Published July 2018

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