



Scottish
**Independent
Advocacy**
Alliance

“Without advocacy - I don't want to think about that”

A summary of research exploring the value of Independent Advocacy and examining current advocacy provision in Scotland

November 2014

Promoting  Supporting  Defending

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1. Introduction

This report is a summary of the findings of three separate research documents produced by SIAA, together with data gathered from the 2013/14 Advocacy Map.

In summer 2014, SIAA commissioned a series of reports examining the value of independent advocacy in relation to three client groups; people with mental illness, people with learning disabilities and older people. The purpose of the three reports was to carry out in-depth analyses of the effectiveness of independent advocacy in relation to these three groups.

The three reports are available to download from SIAA in their entirety. The purpose of this report is to summarise the findings of the three reports, together with statistical evidence gathered in the 2013/14 Advocacy Map. All three reports focus on a unique client group, however there are striking similarities in the findings of the reports, which are backed up by statistical data from the 2013/14 Advocacy Map.

2. Scope and Limitations of this Report

Information gathered from the 2013/14 Advocacy Map is requested from advocacy organisations across 14 geographical NHS Boards and 32 Local Authority areas. The request for information generated a 95% response rate from advocacy organisations.

Evidence from the three impact research reports is based on individual experiences, taken from one-to-one interviews. The interviewees all reported a positive experience of independent advocacy.

This report cannot provide a definitive conclusion as to how independent advocacy affects everyone across Scotland, however it does provide a valuable insight into the current advocacy provision in Scotland and demonstrates how independent advocacy has been effective in supporting people to speak up for themselves, uphold their rights and have more control over their lives.

3. What is Independent Advocacy?

Many of us find it difficult, at times, to get our voice heard about decisions or actions that affect our lives. Some people have family, friends or other carers to help them to speak up. Others do not have people in their lives to do that, and sometimes, if they do, family members may have their own ideas about 'what is best' for the person involved. Paid carers may have a duty to defend the actions of the organisation that they work for. This means that they have a 'conflict of interest'.

Independent advocacy is as free as possible from conflicts of interest like these, is completely separate from service providers and funders and does not provide services other than advocacy.

Independent advocacy aims to help people by supporting them to express their own needs and make their own informed decisions. Independent advocates support people to gain access to information and explore and understand their options. They speak on behalf of people who are unable to speak for themselves, or choose not to do so. They safeguard people who are vulnerable or discriminated against or whom services find difficult to support.

Advocacy is about broadening horizons and widening the options that people have. It is about speaking up if you notice that something is wrong. An effective advocate will observe the whole person and all aspects of their life. They will notice what is wrong in the person's life, things that the person tolerates perhaps because they do not know any different, and tries to address them¹.

1 The Principles and Standards for Independent Advocacy, SIAA, P4

4. Why is Independent Advocacy Important?

The results of the reports examining the value of independent advocacy bear some marked similarities. Although the three reports each focused on separate groups of individuals, people with mental illness, people with learning disabilities and older people, the findings show that they face many of the same challenges. The evidence from the three reports shows how advocacy has been effective in addressing these challenges, as well helping people to feel more confident and empowered to speak up for themselves. The evidence also demonstrates how the soft outcomes of advocacy have a lasting, positive effect on people's lives.

(i) The Challenges faced by the people who used advocacy

Although each report focussed on a different group there were common themes to the challenges faced by individuals from all groups. These included:

1. Not being listened to or taken seriously
2. A lack of awareness of rights
3. Loss of confidence
4. Difficulties dealing with official matters

1. Not being listened to or taken seriously

All of the reports highlighted the struggle that people had in putting their views and wishes across and being taken seriously. Interviewees reported that because of the discrimination which may be experienced by those with mental illness or a learning disability and by older people, they were sometimes considered to be unable to understand or make choices, were not listened to or were not given access to information to allow them to make informed choices.

*"They didn't give me any choices. They took a lot of control over me and wouldn't just listen to my point of view. Just put me up in a care home. I didn't like it. Just didn't deal with me right at all."*²

Without a clear understanding of existing options it is impossible to make an informed decision especially as people with learning disabilities are often not allowed to make decisions on their own and rarely get options to choose from³.

² *'Without advocacy I'd probably be dead.'* – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P23

³ *'Without advocacy I'd probably be dead.'* – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P23

Some interviewees highlighted a power imbalance between themselves and professionals who have the authority to administer treatments and make decisions which affect their lives. Many reported feeling apprehensive when dealing with professionals because of their perception, and sometimes experience, of such a power imbalance. Many also reported a reluctance to raise concerns or issues as they believed they would then be seen as 'trouble makers' which may have resulted in them losing services. This fear when dealing with professionals affected many people's self-confidence and often made them even less able to speak up for themselves.

"..when I was younger I would've been more sort of a supporter for myself and I'd say no, I won't take this, here's the door just go and don't come back. I've lost a bit of confidence and I used to be a very confident lady, but people can reduce you.."⁴

Interviewees reported that having an advocate to support them at meetings helped to address the power imbalance and the anxiety they felt when dealing with professionals. For some people who experienced high levels of anxiety and did not feel confident speaking up for themselves, the advocate was able to be their voice and ensure that their point was put across.

"I went to a couple of sessions by myself to the solicitor, and I just went, mm, ah, aha, and didn't answer him, I couldn't tell him what I wanted to tell him. I knew what I wanted to tell him but I didn't have the confidence to tell him, to say it, and I spoke to the advocate, I told her what I wanted, she spoke up on my behalf, and she made it alright."⁵

For others, just having someone with them helped to make them more confident and they were able to speak up for themselves, when previously they would not have felt able.

"I can speak up more and my advocate is helping me learn how to stand up for myself and do things myself."⁶

Some interviewees reported that having an advocate beside them meant that they were taken more seriously in certain situations, like meetings, when previously they had not been listened to and their views had not been taken into account.

⁴ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P22

⁵ 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P25

⁶ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P27

*"And I know they have sat up a bit more....and listened since somebody else is right there. They're aware that somebody else is aware of the situation and helping me through this and you know, representing me. And I know it's made a big difference in meetings."*⁷

*"It's good to have the advocacy team. I think people listen better if you have someone speaking on behalf of you. Like from the advocacy team."*⁸

2. A lack of awareness of rights

Another common theme across all three groups was lack of information about their rights. For some, the lack of awareness of rights was due to difficulties accessing or understanding information. Interviewees from all three groups described how having an illness, disability or a cognitive impairment can make it difficult to know where to access information and how to make sense of it.

*"It would have been impossible for me to face the bureaucratic minefield and hurdles on my own to get the things that I'm meant to be entitled to"*⁹

Some interviewees described a struggle navigating their way through the Welfare and other Government systems, and keeping up to date with the latest developments. For others, a loss of confidence in their own abilities made accessing and understanding information about their rights a daunting task.

*"And you know, I sat and I listened what they'd had to say and they had lots of forms for me to fill out, and I couldnae fill out half the forms and there's that much information getting pumped into me at the time, that I didnae take in half of it"*¹⁰

Interviewees reported that often they were not provided with clear explanations about things which affected them. This echoes the point made about not being listened to or taken seriously; interviewees reported that being older or the stigma experienced by those with a mental illness or disability often meant that they were considered unable to understand what was going on or make choices. In these cases, interviewees reported that they felt that decisions were made for them and that they had no control.

7 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P27

8 'Without advocacy I'd probably be dead.'- Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P34

9 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P28

10 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P23

Many of the participants were experiencing difficulties in dealing with some services and addressing certain issues. Many reported feeling disempowered by the processes. This was often because they were not given full, clear explanations of the procedure or they felt like they had no control over the process.¹¹

*"I had the point of view that you went into hospital, you did as you were told, you got better, if you did, and got out, until the next time you went in to hospital again. ... For quite a few years I never realised I had any rights whatsoever."*¹²

Interviewees across all three groups consistently reported that with the support of their advocate, they were able to access information about their rights and make informed choices.

*"We didn't really know much about our rights, did we? Because they weren't answering the questions that we were asking them. We needed an advocacy worker or someone who could help us get the questions across, and the advocate managed that. He got the answers that we wanted."*¹³

Interviewees reported how their advocates made sure that they had access to information that they needed to make decisions. This helped them to put their point across in different situations and have more control.

*"The advocate would ask me 'do you agree with this?' and then highlight things I didn't agree with. Because before the advocate was involved I would just agree with what was said. I didn't understand what it was saying. They didn't use to explain it."*¹⁴

Having an advocate to help people access information about their rights, have their voice heard and make decisions was an empowering experience for many of the interviewees, and in many cases, it resulted in a better outcome for the person.

Ann, who, before coming into contact with advocacy *"never knew I had rights."*, claims that she now knows what her rights are and feels confident that she can access them, with some assistance from advocacy.¹⁵

11 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P19

12 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P32

13 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P19

14 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P23

15 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P32

*"Let me put it this way, without it [advocacy] we would've never been anywhere where we were. Never in a million years...you know. Oh they've been marvellous."*¹⁶

3. Loss of confidence

One of the most significant themes which came from all three reports was a loss of confidence.

Interviewees described the experience of discrimination associated with mental illness, learning disability or being older, which, in some cases, meant that they were considered unable to make decisions about their own lives. A perceived or an actual inability to make decisions can lead to a loss of confidence and in some cases, self-stigma, which can result in people having a lack of faith in their own abilities.

*The participants also talked about experiencing a loss in confidence as a result of old age; a general loss of confidence in their capabilities (physical and cognitive) and especially in their ability to stand up for themselves and make decisions.*¹⁷

As previously discussed, many interviewees reported not being listened to or taken seriously. This feeling of powerlessness and lack of control can eat away at people's self-confidence.

*..a sense of no control over your environment or the choices you can make often eroded the participants' self-confidence and their ability to stand up for themselves or even participate in discussions or decisions that were being made about their own lives and circumstances.*¹⁸

Interviewees across all three groups reported that their experience of advocacy had led to a renewed sense of self-confidence. Having an advocate on board who listened to them and helped them to access information about their rights gave them the confidence to speak up for themselves.

*"Advocacy changed my life dramatically ... I gained in confidence throughout the whole year, lots of issues in my life that I could have on a day to day basis got a lot better. I got more confident with it, it gave me the drive, the determination.."*¹⁹

¹⁶ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P20

¹⁷ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P18

¹⁸ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P22

¹⁹ 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P38

*Knowing what your rights are, and finding that your opinions are of value, enabled people to speak up in situations where they previously would have been silent.*²⁰

For many, having someone to talk to about their problems, made them feel that they were not alone and that someone was listening to what they wanted. This boosted their confidence. For others, having someone to support them at meetings and when dealing with professionals, made them feel supported and gave them more confidence.

*For Callum advocacy has had a deep impact on his life; as he went from being depressed and passive about his life to being active again and looking to reintegrate in the community. It made a huge difference for him to feel that someone was supporting and involving him and asking him questions about what he wants to do.*²¹

4. Difficulties dealing with official matters

The reports demonstrate that all three groups of people encountered similar problems when dealing with official matters which could include dealing with correspondence from Social Work department, letters concerning health, Council letters and legal documents or similar, dealing with services or making complaints.

Loss of confidence can lead to an inability to deal with official matters. Some people reported that their illness or disability made them less able to understand official correspondence, which also undermined their self-confidence and made them less likely to deal with any such correspondence.

*“Advocacy well they help me write letters and things like ... I mean I can read, write and spell and everything but some of the words you know, were ... a wee bit above my head...”*²²

For others, a lack of faith in their own capacity to understand information and make informed choices, led them to become fearful of dealing with matters.

*“Before I bring my letters into my advocate that I didn’t understand, like a job centre letter or a gas letter, I used to just fling them out.”*²³

²⁰ ‘Advocacy Changed My Life’, *Research into the impact of Independent Advocacy on the lives of people experiencing mental illness*, P31

²¹ ‘Advocacy is for the people’ – *Research into the impact of independent advocacy on the lives of older people*, SIAA, P29

²² ‘Advocacy is for the people’ – *Research into the impact of independent advocacy on the lives of older people*, SIAA, P19

²³ ‘Without advocacy I’d probably be dead.’ – *Research into the impact of independent advocacy on the lives of people with learning disabilities*, SIAA, P21

All three groups reported high levels of stress and anxiety when dealing with official matters.

"because of the situation I got myself in financially, I was in debt with all my bills and everything, cause I was just ignoring them, I mean I was just not opening envelopes and stuff, I was very unwell, ... I wanted to just run away and hide under my duvet.." ²⁴

People from all three groups described how having an advocate to support them with official matters helped them to understand the information they were presented with and make informed choices. This helped reduce some of the anxiety they felt about dealing with correspondence and made the process less daunting.

The advocate ensures that all information is understood by the partner and that nothing is missed as only then it is possible for the partner to make an informed decision. ²⁵

Jane said that knowing that her advocate would help her with all the paperwork that had accumulated gave her immediate stress relief. ²⁶

²⁴ 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P24

²⁵ 'Without advocacy I'd probably be dead.'- Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P22

²⁶ 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P24

5. The Soft Outcomes and the long-term value of Independent Advocacy

The reports show how independent advocacy has been effective in achieving measurable hard outcomes such as helping people to access information, including information about their rights, empowering people to speak up for themselves and supporting people to deal with official matters. However, in addition to these 'hard' outcomes, the common theme across all the reports was that the 'soft' outcomes attributed to independent advocacy were similar across all three groups and were extremely important to people.

We have already looked at how people's experiences of independent advocacy led to renewed self-confidence. However, interviewees also reported a number of other 'soft' outcomes which had a lasting positive effect on their lives:

1. Alleviating Stress and Anxiety

Stress was another common theme which was reported by interviewees across all three groups. Interviewees consistently talked about high levels of stress and anxiety they experience, when faced with difficult situations and how having the support of independent advocacy helped to take some of the pressure off them.

A lot of the participants experienced relief at having someone to share their problems with, having someone to talk to. Mary, for example, talked about how she felt that advocacy took a weight off her shoulders.²⁷

People across all three groups spoke about how having someone to listen to them and reassure them made feel that they were not alone. This helped to relieve the stress and anxiety they were feeling.

David was facing a conflict with the DWP which caused a lot of stress which in turn caused his mental health to deteriorate. However, when his advocate who had extensive experience of similar cases reassured him that he had "a really good case" David said that it "took the pressure off and relaxed him."²⁸

²⁷ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P27

²⁸ 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P35

*"Let's put it this way, I would know what to do to but being able to do it on your own is a different matter... it's a weight off your shoulders. ... oh no it's marvellous, it really is. I mean I couldn't be more positive on that"*²⁹

2. Having Someone on your Side

A common theme across all three groups was that their experience of independent advocacy made them feel like there was someone on their side, acting on their behalf, who was not accountable to anyone else.

*The advocate is seen as someone who, in contrast to other services, is there for them and not for anyone else.*³⁰

Interviewees reported that having someone on their side gave them the confidence to speak up in situations where they were not previously being listened to. People reported that in situations where there were perhaps conflicting priorities, the advocate would be there to represent what they wanted and not what someone else thought was best for them. This gave people a confidence boost and made them feel that their opinions did count.

Advocacy partners feel that they have someone on their side who they can trust. Victoria says that *"it's just having somebody on my side. I wouldn't have known what to do if I hadn't had Douglas"*³¹

3. Feeling empowered

Interviewees from all three groups talked about how independent advocacy gave them the confidence to speak up for themselves; and that having their voices heard and knowing that they were finally being listened to was a very empowering experience.

*Amanda explained that she was terrified of speaking in court and was not sure that she would be able to do it. But with the support of the advocate she managed to speak up in court all by herself*³²

²⁹ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P28

³⁰ 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P33

³¹ 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P33

³² 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P28

Interviewees also said that their experience of independent advocacy made them feel that they were involved in making decisions and consulted on what was going on, rather than having decisions made for them. This made them feel that they were in control of their own lives.

*All of the interviewees gave positive accounts of their advocacy processes. All had felt consulted and felt that they were ultimately in control over the process. This also resulted in people feeling that they were listened to and valued and that their views did matter.*³³

4. Improved self-esteem

Another common theme across all three groups of people was an increase in self-esteem. Interviewees described how positive impacts such as speaking up for yourself, having more control over your life and being listened to and taken seriously can contribute to an increase in self-confidence which eventually leads to renewed sense of self-esteem.

To Jane, being both encouraged and supported to make her own decisions gave her belief in her own ability: Having to make the choices has *“Actually given me a bit of confidence. Because at the end of the day I think it’s not just [the advocacy organisation] that has done all that work, it’s what I want to say and do...”*³⁴

The improvement in self-esteem contributed to many people feeling the confidence to try new things, which in turn, boosted self-esteem even further.

*Paul had never before been on public transport and felt that no one was supporting him to try, but is now confident enough to travel by himself without any help, something which gives him a great deal of freedom in his everyday life.*³⁵

5. Ability to Self-Advocate

The improved self-esteem and increased self-confidence in many cases led people to speak up for themselves in situations where they would previously have been unable to do so. This was a common theme across all three groups.

³³ ‘Advocacy is for the people’ – Research into the impact of independent advocacy on the lives of older people, SIAA, P32

³⁴ ‘Advocacy Changed My Life’, Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P43

³⁵ ‘Without advocacy I’d probably be dead.’ – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P27

*For Jane, learning more about the obligations that her housing association had towards her, meant that she eventually felt able to question them when they, for example, had broken an agreement. This was something she did not feel confident to do before working with her advocate.*³⁶

Interviewees also described that, in addition to new found confidence and self esteem, they also felt safe and supported, even after they had finished working with their advocate. Because they knew that they could call on independent advocacy again in the future if they needed to they were more likely to speak up for themselves in other situations.

*Victoria has received advocacy support about five or six times over the course of over a decade. It is apparent that the security of knowing that advocacy is there for her enables her to self-advocate at times, however when she is faced with issues that she cannot deal with on her own she identifies that and asks for support.*³⁷

The reports highlighted that the ability to self-advocate fosters a sense of independence, rather than dependency on advocacy. Advocacy partners know that they can contact independent advocacy if they need to. This promotes a feeling of security which in turn, boosts self-confidence, allowing the person to speak up for themselves.

*“..It’s good to know if I’ve got anything I can come back and talk to Douglas or anyone else. Preferably Douglas because he knows us, but I can speak to anybody else. But I’m hoping I don’t need to come back here.”*³⁸

6. Reducing social isolation

Another key theme across all the reports was the impact independent advocacy has had on reducing social isolation. All three reports demonstrate how independent advocacy has been effective in helping people to become more actively involved in the community. For some people, the advocacy organisation inspired people to join collective advocacy groups where they could access peer support and more opportunities to speak out on matters which were important to them.

*Finally, several of the interviewees tell about how they have joined collective advocacy groups to be able to share their struggle with peers. This enables them to speak up as a group and as it increases their individual confidence, many times it supports them in their daily lives as well.*³⁹

³⁶ ‘Advocacy Changed My Life’, Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P33

³⁷ ‘Without advocacy I’d probably be dead.’– Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P35

³⁸ ‘Without advocacy I’d probably be dead.’– Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P36

³⁹ ‘Without advocacy I’d probably be dead.’– Research into the impact of independent advocacy on the lives of SIAA: Without Advocacy - I don’t want to think about that, 2014

For others, the boost in self-confidence and new found self-esteem and sense of empowerment they felt from their advocacy experience, gave them the confidence to take up new activities, pursue a career or get out and about in the community.

Duncan confirms that without advocacy he would just “sit in the house doing nothing” whereas now he goes to discos and attends social events. ⁴⁰

7. Overall Improved Health and Wellbeing

The reports highlight how independent advocacy has been effective in boosting self-confidence and self-esteem, alleviating stress and anxiety and taking some of the pressure off people in stressful situations.

“Mary: ...you know that you’ve got support... Once you’re involved you’ve got that support until you don’t need it anymore and it takes the pressure off you, a lot of pressure, mentally and physically.” ⁴¹

Interviewees have reported feeling a sense of empowerment which has led some to self-advocate and given others the confidence to try new things and become more actively involved in the community and less socially isolated. This, in turn, gave many a more positive outlook and helped them to feel more optimistic about the future.

Laura: “I can speak up more and my advocate is helping me learn how to stand up for myself and do things myself.” ⁴²

“I feel like I’ve got the strength now, and the network of people to help me. Before I was on my own, I would just collapse under the pressure. But now I feel a lot more at ease if something goes to set me back.” ⁴³

people with learning disabilities, SIAA, P29

40 ‘Without advocacy I’d probably be dead.’ – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P29

41 ‘Advocacy is for the people’ – Research into the impact of independent advocacy on the lives of older people, SIAA, P30

42 ‘Advocacy is for the people’ – Research into the impact of independent advocacy on the lives of older people, SIAA, P27

43 ‘Advocacy Changed My Life’, Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P37

It is well documented that stress, anxiety and low self-esteem can have negative effect on a person's health, while having a positive outlook is beneficial to health and wellbeing. The evidence demonstrates how advocacy has been effective in alleviating stress and anxiety and bolstering self-confidence and self-esteem, resulting in a feeling of empowerment. It is clear, then, that the lasting, positive effects of independent advocacy can have a beneficial effect on overall health and wellbeing.

"Callum: "Life's changed, it's changed for me, I can smile again ... I don't think I'd be alive without it [advocacy]." ⁴⁴

⁴⁴ 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P29

6. The Principles and Standards of Independent Advocacy

One of the most significant common themes across all three reports was the relationship between the advocate and the advocacy partner. Interviewees across all three groups reported that the relationship with their advocate was of the utmost importance and had contributed to their positive and empowering experience of advocacy. Interviewees reported that advocates had been highly skilled at developing and maintaining positive relationships with them.

*The words which advocacy partners use to describe their advocates do indicate that their advocates do indeed have exceptional interpersonal skills and a strong ability to create trusting relationships.*⁴⁵

The key to delivering positive relationships between advocates and their advocacy partners is to ensure that advocates observe best practice. The *Principles and Standards* and the associated *Codes of Practice* in Independent advocacy published by SIAA provides guidance for advocates and advocacy organisations to help them to ensure they are delivering effective, high quality advocacy.

The findings of the three reports demonstrate that advocates have been delivering good quality advocacy which is in line with the *Principles and Standards* and associated *Code of Practice*, and that this has resulted in overall positive experiences for advocacy partners. Interviewees reported a high level of trust with their advocates. They reported that they feel that they were valued and listened to and that their opinions mattered. This is in line with independent advocacy Standard 1.1 *Independent advocacy is directed by the needs, interests, views and wishes of the people who use it.*⁴⁶

Interviewees from across all three groups described feeling actively involved in making decisions which affect their lives, and that the advocate ensured that they were in control.

*All of the interviewees gave positive accounts of their advocacy processes. All had felt consulted and felt that that they were ultimately in control over the process.*⁴⁷

This is consistent with Standard 1.2 *Independent Advocacy helps people to have control over their lives and to be fully involved in decisions which affect them.*

⁴⁵ 'Advocacy Changed My Life', *Research into the impact of Independent Advocacy on the lives of people experiencing mental illness*, P45

⁴⁶ *The Principles and Standards for Independent Advocacy*, SIAA, P14

⁴⁷ 'Advocacy is for the people' – *Research into the impact of independent advocacy on the lives of older people*, SIAA, P32

Another common theme across all three reports was how independent advocacy helped people to access information about their rights and make informed decisions. Interviewees consistently reported having difficulty accessing information about their rights and not knowing that they had any rights, before they came into contact with independent advocacy.

*Throughout the interviews it becomes apparent that before the advocacy partners receive the support of an advocate they know nothing or very little about their rights and what they are entitled to. It is also clear that the support of independent advocacy ensures that the advocacy partners increasingly learn about what they are entitled to.*⁴⁸

It is clear that the advocates have been effective in helping people access information about their rights, and have been instrumental in helping to ensure that people's rights are upheld. This follows Standard 1.3 *Independent advocacy tries to make sure that people's rights are protected.*

Another important theme across all three reports was how independent advocacy is accountable to the people who use it. Interviewees across all three groups reported on the importance of having someone on your side. Some people felt that they had been let down by other services and as such, it was important to have someone who was separate from other services. Others described the importance of having someone on their side representing what they want, rather than what other people think is best for them.

*There is no conflict of interests and Maddie and other advocacy partners are the single focus of the advocate's attention. This contributes greatly to the partners' feeling that the advocate is on their side and not answering to anyone else.*⁴⁹

It is clear that advocacy which is independent and not accountable to any other service contributes greatly to the advocacy partner's feeling that they have someone on their side who represents their wishes and not the wishes of anyone else. This is in line with Principle 3 *"Independent advocacy is as free as it can be from conflicts of interest."*⁵⁰

The reports show that advocates have been effective in developing strong and positive relationships with advocacy partners, based on a high level of trust and respect.

48 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P19

49 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P33

50 The Principles and Standards for Independent Advocacy, SIAA, P28

Interviewees consistently reported that advocates were able to provide a personal touch, while balancing this with professionalism.

Advocates are displaying excellent interpersonal skills. They are managing to be personal yet professional, whilst building relationships of trust in which advocacy partners feel able to share sensitive issues. ⁵¹

All three reports demonstrate how advocates and advocacy organisations have been delivering good quality advocacy in line with the *Principles and Standards* for Independent Advocacy. It is evident that having a clearly defined set of Principles and Standards and Code of Practice, has helped to ensure that advocacy organisations across Scotland are delivering good quality advocacy. This in turn, has ensured that advocacy partners have had positive and empowering advocacy experiences.

⁵¹ *'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P48*

7. Advocacy in Scotland

Interviewees across all three groups described positive experiences of independent advocacy. However, what was consistently reported was the difficulty in accessing advocacy. Almost all of the interviewees expressed that they would have liked to have been able to access advocacy at an earlier stage. Many reported that they did not know anything about independent advocacy until a member of health care staff or other professional made them aware about it.

When participants were asked how they had found out about advocacy almost all of them stated that they had been surprised at the fact there was such a service and especially at the fact they had never heard of it before. ⁵²

Our investigations show that despite the apparent benefits of advocacy support, it is not as accessible as it should be. All interviewees were initially referred by a third party, indicating that there is a lack of information. ⁵³

Interviewees expressed concern at the lack of public awareness about independent advocacy and the fact that there could potentially be significant numbers of people in similar situations who would not be able to access advocacy because they would not know about it.

"I feel sorry for the hundreds and probably thousands of people that haven't heard about advocacy you know...a lot of people you know, with mental health conditions, they wouldn't answer letters, they wouldn't even read them, and you know probably end up with police at the door or sheriff officers at the door...so it's imperative that ..people with mental health issues get the advocacy." ⁵⁴

Interviews were carried out with members of staff and Managers from advocacy organisations across Scotland, to ask them if they carry out awareness-raising activities. Interviewees consistently reported that they were aware that there is limited access to advocacy; however, they were unable to carry out any awareness raising activities, due to lack of time and resources.

52 'Advocacy is for the people' – Research into the impact of independent advocacy on the lives of older people, SIAA, P31

53 'Without advocacy I'd probably be dead.' – Research into the impact of independent advocacy on the lives of people with learning disabilities, SIAA, P39

54 'Advocacy Changed My Life', Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P46

Worryingly, a significant number of respondents reported concern that, due to limited resources, they might not be able to meet the increased demand for advocacy that awareness-raising would bring about.

*The organisations we spoke to are experiencing high workloads and struggle to respond to all those referred to them, even in current circumstances where awareness among the general public is limited. As one of our experts expressed it: “We are really stretched –if we reach more people, would we be able to help them?”*⁵⁵

Interviewees from all three groups of people have described a lack of awareness about independent advocacy and many reported that they felt that it had been down to luck that they had found out about it.

The Advocacy Map

The 2013/14 edition of the Map of Advocacy across Scotland shows that there are still significant gaps in the provision of advocacy. Furthermore the Map shows that despite the gaps in provision and lack of awareness raising, demand for advocacy has risen by 8% since 2011/2012.⁵⁶

Despite this marked increase in demand for advocacy, the map shows that increased demand has not been matched by an increase in funding. Figures from the 2013/14 Map show the average annual spend per person on advocacy across all NHS Health Boards at £2.07 which is a decrease of £0.01 per head from 2011/12.⁵⁷

In the 2013/14 Map, advocacy organisations were asked about their levels of funding. 65% of organisations stated that their funding had either decreased or remained the same.⁵⁸ It would appear, then, that the increase in demand has put extra pressure on advocacy organisations, which has not been met with an increase in funding. This added workload has resulted in organisations being over-stretched and unable to carry out awareness raising activities, or, indeed, meet any increase in demand that would come about as a result of awareness raising.

The Map indicates that that the rise in demand for advocacy and the lack of adequate financial resources to meet the demand has resulted in many organisations having to prioritise certain cases. 50% of organisations reported changes to Service Level Agreements to prioritise people who are facing compulsory measures under the Mental Health (Care & Treatment) (Scotland) Act 2003.⁵⁹

55 ‘Advocacy Changed My Life’, Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, P46

56 A Map of Advocacy across Scotland 2013/14 Edition, SIAA, P2

57 A Map of Advocacy across Scotland 2013/14 Edition, SIAA, P11

58 A Map of Advocacy across Scotland 2013/14 Edition, SIAA, P17

59 A Map of Advocacy across Scotland 2013/14 Edition, SIAA, P5

Prioritising specific cases for some organisations means more limited access to advocacy for other vulnerable people not subject to compulsory measures under the Act, but who do have a legal right to advocacy. Provision in some area has become even more limited for others who do not have a statutory right of access but would benefit from advocacy support.

Half of those organisations reported that they now have waiting lists and people sometimes have to wait some time before organisations can respond to a request for advocacy.⁶⁰

This makes worrying reading, as people often seek advocacy in a time of crisis and as such, they may not always be able to wait weeks to see an advocate. The continuing gaps in provision and the current limitations of the existing advocacy provision means that advocacy is now even less available than it has been in recent years as advocacy organisations struggle to meet the increase in demand with fewer financial resources.

60 A Map of Advocacy across Scotland 2013/14 Edition, SIAA, P5

8. Conclusion

It is clear from the evidence provided in the three reports on the impact of advocacy that independent advocacy is much needed. Independent advocacy is effective in supporting marginalised people to have their voices heard and in upholding their rights. Such support also has a lasting, positive effect on people's overall health and wellbeing.

What is also evident is that although every person's situation is unique, vulnerable people face often similar challenges; such as accessing and making sense of information, being listened to and taken seriously, having the confidence to speak up for themselves. The reports demonstrate how independent advocacy is effective in helping people to address these issues and have empowering and positive experiences. It is clear, then, that the value of independent advocacy is broad and that any vulnerable person could benefit from having someone on their side who can support them to understand their rights and have their voice heard. The reports demonstrate how independent advocacy is effective in delivering soft outcomes which have a long term positive effect on people's lives. The increased confidence which can arise from effective advocacy resulted, in many cases, in people feeling able to advocate on their own behalf, which is the ultimate goal of independent advocacy.

Despite of the obvious value of independent advocacy, the evidence shows that access to advocacy has become more limited. The three reports highlight a worrying lack of public awareness about advocacy. Advocacy organisations report that increasingly they have been unable to carry out awareness raising activities, due to limited resources. The 2013/14 Advocacy Map shows that gaps in advocacy still exist and there are still groups of people with a statutory right to advocacy but are not able to access it.

The evidence also shows that demand for advocacy continues to increase. The 2013/14 Map shows that while the demand for advocacy has increased, this has not been matched with an increase in funding. Organisations have reported that they have been required to prioritise certain cases, in particular those people who are facing compulsory measures under the Mental Health (Care & Treatment) (Scotland) Act 2003. This has meant that, in some areas, access to advocacy for people who are not subject to compulsory measures, but who do have a legal right to independent advocacy is more limited. With the increased demand for advocacy, organisations report that they are stretched and struggling to cope with the increase in demand with the limited resources that they have.

Given the current economic climate, together with recent welfare reforms, it is likely that the demand for independent advocacy will continue to increase.

Bibliography

- The Principles and Standards for Independent Advocacy, SIAA, Edinburgh, 2008
- 'Advocacy Changed My Life'- Research into the impact of Independent Advocacy on the lives of people experiencing mental illness, SIAA, Edinburgh, 2014
- "Advocacy is for the people"- Research into the impact of independent advocacy on the lives of older people, SIAA, Edinburgh, 2014
- 'Without advocacy I'd probably be dead.'- An investigation into the impact of Independent Advocacy on the lives of Advocacy Partners with learning disabilities, SIAA, Edinburgh, 2014
- A Map of Advocacy across Scotland 2013/14 Edition, SIAA, Edinburgh, 2014