



Scottish
**Independent
Advocacy**
Alliance

“Advocacy changed my life”

Research into the impact of independent advocacy on the lives of people experiencing mental illness

September 2014

Promoting  Supporting  Defending

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Contents

Acknowledgements

Executive Summary. i

Advocacy is much needed support. i

Advocacy and quality of life i

Advocacy- best practice ii

Conclusion ii

Key Findings iii

- Access to advocacy is too restricted iii
- Advocacy organisations need more funding. iii
- Advocacy ensures that people experiencing mental ill health access their rights. iii

1. Introduction. 1

2. Background 2

- 2.1 What is Independent Advocacy?. 2

 - 2.1.1 One to one or individual advocacy 2
 - 2.1.2 Group or Collective advocacy 3
 - 2.1.3 Advocacypartner 3

- 2.2 Evaluating Impact and Outcomes: What has already been done? 3
- 2.3 Lack of Evidence: Addressing the Gap in the Literature 4

3. Key Findings. 6

4. Characteristics of Mental Ill-health: Advocacy a much needed service. . .	7
4.1 Difficulties with correspondence	7
4.2 Difficulties with meetings	8
4.3 Lost in a Complex System: Advocacy upholding rights, informing and ‘connecting the dots’	10
4.4 Understanding: Key to delivering the right support	12
4.5 Independent Advocacy: An important service	12
5. Positive Effects: Advocacy’s soft outcomes	14
5.1 Feeling empowered.	14
5.1.1 Knowledge about one’s rights	14
5.1.2 Engaging in Collective Advocacy	16
5.2 Emotional support	16
5.3 Breaking social isolation	17
5.4 Alleviating stress.	18
5.5 A Positive Turning Point	19
5.5.1 Matt: winning his case and finding fresh determination.	19
5.5.2 Nancy: from accepting patient to “a very demanding person”	20
5.5.3 Without advocacy –I don’t want to think about that....	20
6. Working for Human Rights	21
7. Advocacy and SIAA guidelines	22
7.1 People making their own decisions and being heard	22
7.2 Describe your Advocate: Good reviews	23
7.3 Access “why didn’t i hear about this earlier?”	24

8. Conclusions	26
9. Methodology	28
9.1 Choice of research methods	28
9.2 How the research was conducted	29
9.3 Ethics	29
9.4 Sampling: Limitations and Possibilities.	30
9.5 Characteristics of the sample	31
Works Cited	32
Appendix 1 - Semi Structured Interview	34
Appendix 2 - Participant Information Sheet	36
Appendix 3 - Glossary	37

Executive Summary

The aim of the research was to investigate the impact of independent advocacy on the lives of advocacy partners experiencing mental ill-health. By using qualitative methods we sought to determine not only if there were positive impacts, but what these impacts were and why they were positive. Several independent advocacy organisations across Scotland were contacted and 5 of these assisted us in making contact with interviewees. We conducted expert interviews with the organisations' managers and 12 interviews with advocacy partners experiencing mental illness, who had used one to one advocacy. Furthermore, interview data on the impact of advocacy collected previously by two other advocacy organisations was also included in our analysis. The findings can be divided into three sections as detailed below.

Advocacy is a much needed support

When considering the common characteristics of the interview sample it was found that persons experiencing mental ill-health often share similar struggles even though they may have different diagnoses. For some people mental illness can affect their ability to understand their situation, make sense of what in this report has been termed 'official communication'¹ or speak up. Another shared issue was accessing and understanding information about rights and benefits one was entitled to. In both cases advocacy support leads to better outcomes for the advocacy partner. Respondents repeatedly reported that the support they received from their advocate was so much more than the support provided by other organisations.

Advocacy and quality of life

Apart from delivering better outcomes for advocacy partners by offering practical help, our second finding is that advocacy also delivered many "soft outcomes". The soft outcomes could sometimes be tied to the practical support, the most prominent being that the practical support helped alleviate stress, which in turn helped to improved mental wellbeing. Other soft outcomes ranged from feeling emotionally supported and lessening feelings of social isolation, to advocacy support leading to 'a turning point in life'. In several cases receiving advocacy support led to advocacy partners being able to advocate for themselves, which is the ultimate aim of all advocacy.

1 Official correspondence and meetings" does in this report refer to letters and meetings, such as (though not confined to) bank letters, government communication, dealings with housing associations, legal matters and mental health tribunals.

Advocacy - best practice

In terms of reviewing the work of independent advocates in relation to the SIAA's Principles and Standards, the study presents two key findings. Interviewees' accounts of working with advocates show that advocates successfully supported advocacy partners to have more choices, power and control in their lives. The interviewees' descriptions of their advocates and what they have helped them achieve also presents a very positive picture. The majority of interviewees stated that they would have benefited from accessing advocacy earlier. The only criticism participants made of the advocacy organisations was that their services were not well or poorly advertised which meant that many people did not know about advocacy and were not able to access it during a time of need. Participants reported that they would have benefitted if they had known about advocacy earlier and knew there would be other people with similar problems who could benefit from advocacy but might never know about it.

Conclusion

Advocacy provides support for people experiencing mental illness which other services do not provide. The services offered by advocacy address difficulties that those experiencing mental illness may have with making their voice heard, knowing about their rights, influencing decisions, navigating and understanding legal matters and access to welfare and benefits. Therefore, independent advocacy is key to ensuring people's rights, that they have access to services and benefits it also fights inequality and discrimination.

The issue of promotion of advocacy was raised with advocacy managers who took part in this research. This issue presents an ongoing moral dilemma for advocacy organisations who feel unable to properly raise awareness about what they do. Sometimes this is due to resources; however respondents also stated that they would be unable to meet demand if more people tried to access the service.

Key Findings

- **Advocacy ensures that people experiencing mental illness access their rights.** Interviewees felt that advocacy “was supposed to be there” and provided a vital service that no other service provider could offer. Advocates made sure that people were aware of and understood their rights and ensured that rights were upheld.
- **Advocacy organisations need more funding:** Current funding levels constrain advocacy organisations. There are not enough resources to conduct awareness raising activities or to provide support for all those who need it, even though access to independent advocacy is a statutory right.
- **Access to advocacy is too restricted:** There is limited awareness about independent advocacy which means that people may access advocacy late or not at all.
- **Advocates following SIAA’s guidelines achieve good results in terms of empowering their advocacy partner:** Advocates supported advocacy partners to gather relevant information, consider options and potential consequences and make fully informed choices; they did not advise or make decisions for people. As a result advocacy partners stated that they gained in confidence and were more able to speak up for themselves.

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1. Introduction

The name of this report; “Advocacy changed my life...” was a quote from one of the participants in this research who had accessed advocacy support after a long period of ill health and resultant unemployment. He told us about the major difference that advocacy had made for him, that he “... gained in confidence ..., it gave me the drive, the determination.” Another quote; “advocacy –they’re just meant to be there” is taken from another participant of this research. Maddie told us that she couldn’t imagine not having the support of her advocate during her Tribunal and the financial aftermath of her manic episode. Since independent advocacy is a statutory right for people experiencing mental illness in Scotland, Maddie shouldn’t need to imagine life without advocacy. Truth is however, that advocacy is not as widely accessible for those experiencing mental illness as the SIAA would wish. Insufficient funding and lack of resources to deal with an increase in referrals mean that many people will never access advocacy, in spite of it being their right to do so.

The main reason for conducting this research was that there is very little published evidence about the impact of independent advocacy and the difference it makes to the lives of individuals and society as a whole. This is the first research in a series of reports produced by the SIAA, with the help of member organisations that outlines the unique way in which advocates operate the difference they make and the long term impact they have. The research was conducted in spring 2014 and 12 interviews were carried out with people who had used independent advocacy and had experience of mental illness. To further contextualise the findings, expert interviews with advocacy managers were also undertaken. The focus of the report is however on the lived experience of the advocacy partners themselves. Advocacy organisations regularly see the positive impact of their work on the lives of those they work with. This is also evidenced in the case stories that most organisations produce for their reports and websites. This research project is an attempt to provide more rigorous evidence of the impacts of advocacy. Advocacy stories were not only collected but coded and systematically analysed in order to shed light on what the impacts of advocacy are and how they are created.

2. Background

2.1 What is Independent Advocacy?¹

“Many people in society are disempowered by systems which have a significant effect on almost every aspect of their lives. These are people who are disempowered to such an extent that they are unlikely to be able to fulfil their basic human needs or demand their basic human rights. A person’s initial hopes and dreams can be severely limited by this. Independent advocacy can help to widen a person’s horizons and enable them to become active members of society”.

Principles and standards in Independent Advocacy organisations and groups,
Advocacy2000 (2002)

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 try to address them.

2.1.1 One to one or individual advocacy²

This includes professional or issue based advocacy. It can be provided by both paid and unpaid advocacy workers. An advocacy worker supports an individual to represent his or her own interests or represents the views of an individual if the person is unable to do this themselves. They provide support on specific issues and provide information but not advice. This support can be short or long term. Individual, issue based advocacy is the type of advocacy primarily researched in this report.

¹ Taken from: SIAA Principles and Standards for Independent Advocacy (SIAA, Principles and Standards for Independent Advocacy, 2008)

² Taken from Guidelines for Advocates working in Prisons: A companion to the Code of Practice for Independent Advocacy (SIAA, 2014)

2.1.2 Group or Collective advocacy³

Collective Advocacy enables a peer group of people, as well as a wider community with shared interests, to represent their views, preferences and experiences. A collective voice 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. Being part of a collective advocacy group can help to reduce an individual's sense of isolation when raising a difficult issue. Groups can benefit with the support of resources and skilled help from an independent advocacy organisation. Though collective advocacy was not the focus of this research project it was found that some interviewees went on from issue based advocacy to be involved in collective advocacy. For those engaging in collective advocacy it was very beneficial.

2.1.3 Advocacy partner

Advocacy partner is the term used to describe a person receiving support from an independent advocate. As the term implies, the relationship between an advocate and an advocacy partner is a partnership where power lies with the advocacy partner. An advocate will provide information and support but it is the advocacy partner who makes the decisions and whose voice will be made heard.

2.2 Evaluating Impact and Outcomes: What has already been done?

The funding of independent advocacy services is increasingly becoming the subject of tendering processes by Local Authorities and NHS Boards. Thus many of our member organisations are finding that evaluating and assessing the impact of their work is becoming more important in order to secure funds (Rapaport, Hussein, Moriarty, & Collins, 2006) (Brown B. , 2013). All the different managers interviewed during our expert interviews reported on conducting various types of evaluation of their work. Most of this was in the form of feedback on their services; relatively little data was gathered on how they had impacted the lives of their service users. If this was done it was often in the form of case study stories: short stories about individual advocacy cases published on web sites and in annual reports (Coyle, 2009).

One expert interviewee commented on the difficulty capturing what is often termed 'soft outcomes': the emotional support often provided by advocacy, the sense of empowerment that comes through learning about your rights and being listened to, and the wellbeing stemming from knowing that you can access support again, if you need it. For example questions in a survey might ask a respondent if they feel more confident after receiving advocacy but gives no room for telling the story of how this confidence was won, missing a vital aspect of the impact of advocacy in the life of the respondent. Thus though measuring of impact has been done in various ways there are still outcomes that may not have been captured in existing evaluations.

³ Refer to previous footnote

Therefore this research project was designed to draw together the strengths of case stories with the rigour of qualitative analysis in order to capture a wider range of outcomes, including the “soft outcomes” that are difficult to capture in surveys and feedback forms.

Rapaport et.al. investigated a number of different evaluation tools used by advocacy organisations working with people experiencing learning disabilities (Rapaport, Manthorpe, Moriarty, Hussein, & Collins, 2005). They find that there are distinct advantages and limitations of each evaluation tool; however, the act of evaluating in itself is seen as positive and needed in the current funding climate. Some advocacy organisations in Scotland have attempted to undertake SROI⁴ evaluations in order to prove their social impact. Part of an SROI evaluation is to investigate the views of different stakeholders, including those of the advocacy partners. Not all organisations completed the SROI process; it was found a costly and complex process and the managers we spoke to doubted its usefulness. One SROI evaluation done by a Scottish independent advocacy organisation did find that their social return on investment was 1:5-7 GBP, every £1 invested in advocacy resulted in a social gain which could be valued at between £5 and £7, suggesting that advocacy organisations may indeed create added value for service providers and other stakeholders (Malzer, 2013). However the advocacy managers we interviewed often expressed a degree of scepticism towards the SROI evaluations partly because they were complicated and partly because they felt uncertain about measuring their work solely in monetary terms. The view that current evaluative tools remained efficient in some regards was also held by advocacy organisations as reported by Rapaport et.al. (2006).

2.3 Lack of Evidence: Addressing the Gap in the Literature

Relatively few studies of the impact of advocacy on people with mental illness have so far been done. In a broad review of the development of advocacy in Britain, Harrison and Davies⁵ state that advocacy enables people experiencing mental illness to be better informed about their options which they argue “can only improve mental health” (2009, p. 63). Lacey and Thomas⁶ have investigated the attitudes towards advocates held by health professionals working in psychiatric care. They found that though staff had mixed feelings towards the advocates they had encountered, most thought that advocacy was “helpful for the partner” (Lacey & Thomas, 2001, p. 471). A recent scoping study done on advocacy for children and young people in Scotland found that advocacy was “regarded as a core service in ensuring that children’s and young people’s rights are upheld” (Elsley, 2010, p. 5). However, Elsley also found that awareness was relatively low and that advocacy services were unevenly provisioned geographically. The evaluation of the Voice Advocacy service for children and young people in England presents similar findings; advocacy is an appreciated and beneficial service but access is limited (Chase, 2005). Thus their recommendations were mainly concerned with widening access.

4 *Social Return on Investment*

5 Harrison, T., & Davies, R. (2009). *Advocacy: Time to communicate. Advances in psychiatric treatment*, 57-64.

6 Lacey, Y., & Thomas, P. (2001). *A survey of psychiatrists’ and nurses’ views on mental health advocacy. The Psychiatric Bulletin*, 477-480.

None of the above studies consulted advocacy partners. Instead they mainly consulted different external stakeholders such as health professionals, advocacy managers and Local Authorities. Thus views on whether advocacy is beneficial or not are included, but the reasons why advocacy is beneficial are not investigated further. One study that did investigate how advocacy partners experienced advocacy was the review of Independent Mental Health Advocates (IMHA) across England conducted by Newbigging et al. (Newbigging, et al., 2012). It should be noted that IMHA is a service that is different from the independent advocacy services provided in Scotland since it only is provided for those qualifying under the England and Wales Mental Health Act 2007. There are however also certain similarities, which is why the findings from the report are still of interest. Similar to most other studies, access is identified as an issue. Newbigging et al. further state that access is “directly linked to the level of local investment” (2012, p. 237). The study uses a model by Townsley et.al. which differentiates between process⁷ and outcomes⁸ of advocacy (Townsley, Marriott, & Ward, 2009). It was found that even when outcomes are less tangible, advocacy partners still benefited from the process of advocacy. (Newbigging, et al., 2012). Being listened to and supported in meetings created feelings of empowerment and wellbeing. IMHA was overall found to have a positive impact on those using the service. Lastly, Newbigging et al highlighted that any measurement of the impact of advocacy “needs to take account of the complexity [of advocacy] and incorporate measures of both process and outcome” (2012, p.10).

There are few academic articles investigating the impact of independent advocacy on those with mental illness, particularly in a Scottish context. The studies currently available are often concerned with other advocacy partner groups and are often set in an English context. Furthermore many studies are of an evaluative nature and therefore focus on the outcomes from different stakeholders’ point of view. This means that the impact on the advocacy partner’s life is a rather understudied aspect. Many reports claim that advocacy has a positive impact on advocacy partners but they do not outline exactly how these impacts are achieved. Furthermore, how these impacts are created is rarely investigated. Advocacy organisations often produce case studies that are narratives of how such positive impacts come about. However, a weakness with case studies is that they are rarely analysed thematically. To conclude, though some investigations on advocacy have been made, there is still a gap in the literature concerning the impact of advocacy on people experiencing mental illness. Particularly, there is little systematic evidence outlining the experiences of advocacy partners themselves, a lack of evidence which this research project has sought to address.

7 In this report termed “soft outcomes”

8 In this report termed “hard outcomes”

3. Key Findings

When analysing the data from the interviews carried out for the report as well as the data obtained from interviews carried out by two of the advocacy organisations we visited, there were several findings which have been divided into three sections.

Firstly, when considering the common characteristics of our interview sample it was found that persons experiencing mental ill-health often shared similar struggles even though they have different diagnoses. For some people mental illness can affect their ability to understand their situation, make sense of what in this report has been termed 'official communication'⁹. Another shared issue was accessing and understanding information about rights and benefits one was entitled to. In both cases advocacy support led to better outcomes for the advocacy partner. This suggests that advocacy is a service that responded well to the particular needs of the group.

Apart from delivering better outcomes for advocacy partners by providing some practical help, our second finding is that advocacy also delivered many "soft outcomes". The soft outcomes could sometimes be tied to the practical support, the most prominent being that the practical support helped alleviate stress, which in turn led to improved mental health. Other soft outcomes ranged from feeling emotionally supported and listened to, to advocacy support leading to 'a turning point in life'. In several cases receiving advocacy support eventually lead to advocacy partners feeling more able to advocate for themselves.

In terms of reviewing the work of independent advocates in the light of SIAA's Principles and Standards, the study presents two findings. Interviewees' accounts of working with advocates show that advocates successfully supported advocacy partners to have more choices, power and control in their lives. The interviewees' descriptions of their advocates also present a very positive picture. However many interviewees point out that they would have benefited from accessing advocacy earlier. As a matter of fact the only criticism of the advocacy organisations was that their services were not well or poorly advertised which meant that some people did not know about advocacy and were not able to access it during a time of need.

9 Official correspondence and meetings" does in this report refer to letters and meeting of a non-personal nature, such as (though not confined to) bank letters, government communication, dealings with housing associations, legal matters and mental health tribunals.

4. Common characteristics of Mental Illness: Advocacy a much needed support

Though our respondents experienced different types of mental health conditions they often shared similar characteristics in common. Firstly, mental health conditions are not static in nature; they may change over time, appear early or late over a person's life course, and occur in bouts (Brown & Kandirikirira, 2007). Most importantly they tend to worsen with stress. Mental health conditions are not static but:

The interviewees also experienced certain impairments to their abilities as a consequence of either their mental health problem and/or the medication used to treat it.

Though different conditions can have very different symptoms, the impacts of mental ill-health seem to have similarities for many people. Firstly a person's self-confidence is often affected; as a symptom of depression, because of a perceived inability to take part in paid employment or due to the stigma often associated with mental illness. Furthermore the ability to speak, write and read can be impaired; issues with concentration, the impact of medication and anxiety or inertia caused by depression were common causes.

4.1 Difficulties with correspondence

As figure 2 points out this often leads to an impaired ability to deal with "official¹⁰ correspondence", a theme which came up numerous times during the interviews. Below are three accounts of difficulty dealing with official correspondence, from interviewees with different mental health issues. Here David describes a meeting with a government funded agency which he visited to obtain information about how his benefits would be affected by him taking up part-time employment.

"-And eh, 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"

David (Lived experience of paranoid psychosis)

¹⁰ "Official correspondence and meetings" does in this report refer to letters and meeting of a non-personal nature, such as (though not confined to) bank letters, government communication, dealings with housing associations, legal matters and mental health tribunals.

This is Jane's account of her struggle with the paperwork accumulating due to issues with her housing association regarding a violent and threatening neighbour.

"And one of the symptoms that has sort of come about through the stress and, what I've been dealing with the past 4 years is, I have a, not a phobia but it's almost a, it's not even a fear, it's just I can't deal with paperwork, and obviously the amount of housing letters, meetings and all the rest, paperwork's piled up."

Jane (lived experience of Depression and Anxiety)

Maddie described the aftermath of a manic episode which left her in financial problems which, due to depression, she struggled to deal with.

"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, sort of thing, but they [her advocacy organisation] were sort of helping me to go through it, and helping me find a social worker to get help 'cause I had to end up selling my house, to pay my bills."

Maddie (lived experience of Bipolar Disorder)

Apart from the obvious problems that may arise when letters from a bank or a housing association are not responded too, the official correspondence together with the impaired ability to deal with it was a significant source of stress for the interviewees in the study. David told me how the letters regarding his case with the DWP (Department of Work and Pensions) "was making my health worse 'cause I didn't know how to respond to them". Jane said that knowing that her advocate would help her with all the paperwork that had accumulated gave her immediate stress relief.

4.2 Difficulties with meetings

In addition to struggling with reading, writing and interpreting the information in official correspondence, many interviewees also struggled to get their point across in meetings of importance. Such meetings could be a Mental Health Tribunal, meeting with an HR department representative or meeting with a solicitor. Having the support of an advocate was therefore really valued by our respondents. The presence of an advocate served several purposes. Firstly interviewees found it reassuring to have somebody supporting them in the meeting; with 'somebody on their side' many interviewees who would otherwise struggle to speak in such settings managed to do so. Furthermore, in case an advocacy partner still found it difficult to speak for themselves the advocate was able to speak on their behalf about what had been agreed on with the advocacy partner earlier. In some cases the advocate acted to safeguard the individual's rights in cases where they had formerly been ignored. With an advocate present, some advocacy partners found their case taken more seriously. Lastly it was found that having an advocate present helped some individuals to remain calm in meetings rather than get too emotionally involved.

Ann, with lived experience of depression and anxiety, found it difficult to speak with her solicitor due to low self-confidence. She described him as “someone in authority and someone I couldn’t converse with”. However, when her advocate attended the meeting she made sure Ann’s points came across;

“I’d went to a couple of sessions by myself to the solicitor, and ehm I just went, mm, ah, aha, and didnae answer him, I couldn’t tell him what I wanted to tell hm. Ehm, 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 Julia, I told her what I wanted, she spoke up on my behalf, and she made it alright.”

Ann (lived experience of depression and anxiety)

Similarly Matt, with lived experience of depression and anxiety, also describes feeling more at ease when having someone by his side in different types of meetings:

[The advocate accompanied Matt to] “meetings, that could be to an advice shop, could be to lawyers and to court, and tribunal, things like that (...) they always accompanied me. They gave me the choice whether I wanted to or not, I always did want someone. I felt a lot more comfortable, a lot more confident if someone from the advocacy was with me.”

Matt (lived experience of depression and anxiety)

Lisa, who has lived experience of alcohol addiction as well as mental ill-health, was interviewed by one of the advocacy organisations we were in touch with. For Lisa, having an advocate with her in meetings regarding her children, meant that she could avoid getting too emotional:

“I wouldn’t be able to manage the meeting on my own. I’d just kick off and she keeps me calm.”

Lisa (lived experience of mental ill-health and alcohol abuse)

In another study conducted by the second advocacy organisation that shared their data with us, Ian stated that having an advocate accompanying him to meetings helped him stay calm and focused when putting his “point across”:

“Advocacy helps to support me at meetings – instead of feeling paranoid and anxious which can lead me to overreact and be angry and shout because I feel threatened in formal situations, I am able to concisely and fairly put my point across.”

Ian (lived experience of mental ill-health)

As Gordon, who suffers from an acquired brain injury which has also caused depression commented, an advocacy worker could also help him to perceive situations (in his situation, conflicts with social workers) correctly:

“First thing is they will help you to make sure you are perceiving the situation correctly. With kindness and patience, that’s a good thing. Then they’ll help you, AND VERY SKILFULLY, reflect something so that for instance if you’ve been having a lot of bad feelings whatever, to sort of objectively express that it might not be as bad as you think, so that’s always a good thing.”

Gordon (lived experience of depression)

Apart from being a support, advocacy does at times act as a safeguard. Jane found that having an advocate present in meetings changed the outcome of the meetings; she was taken more seriously when the housing association realised they were accountable to a third party.

“And I know, they have sat up a bit more, my housing, 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. Because in previous meetings that I’ve been to, and they’ve said we’re gonna do this and we’re gonna do that, and I haven’t had a witness. And I’ll remind them, you said you we’re gonna do...”

-No no they either denied they’ve said it or, we didn’t promise that, and I think; No, you did, I know you did. But I’ve not had anybody to back me up.”

Jane (lived experience of depression and anxiety)

Jane’s experience was shared by several other respondents that were interviewed by the two other independent advocacy organisations that shared data with us.

4.3 Lost in a Complex System: Advocacy upholding rights, informing and ‘connecting the dots’

Though the welfare system is relatively comprehensive, accessing the services and support that one is entitled to might prove a difficult task when you find yourself unwell. As pointed out earlier, mental health is not a static state; rather it fluctuates over time. Furthermore mental illness might affect a person late in life. The consequence of this is that a person is often unprepared and uninformed about their rights when becoming ill. Maddie’s response to what she knew about her rights before accessing advocacy support sums it up well:

“-Before advocacy did you feel like you knew much about your rights?”

“-Ehm, well because it was something that I never thought would ever happen to me, it’s not like you prepare yourself to end up in a mental ward, so I suppose I didn’t really but I hadn’t really thought of it, because I didn’t expect it to happen to me, nobody I suppose does.”

Maddie, became ill with Bipolar disorder in her mid-20’s

Furthermore, even for those who have been experiencing mental ill-health for a longer period of time, keeping up with the changes to the welfare system can be a difficult task. In fact understanding the changes in rules and how to best respond to such changes may seem complicated to any citizen. For those struggling with a mental health problem, which as discussed earlier will likely affect the ability to process information and communicate, accessing ones rights will be even more difficult. For those receiving advocacy support, the information that independent advocates provided was vital in terms of the interviewees accessing the support they needed. Below is a selection of responses to an advocacy organisation's SROI study and the question - *"what does advocacy mean to you?"*

"[Independent Advocacy] "opened my eyes to other possibilities such as the Mindful Employer Initiative about disability guidance, when other agencies were not getting involved."

[Advocacy helps me]"To access my rights (support and welfare benefits)"

"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"

[Advocacy was helping the respondent] "To find different information. Just looking at options that are available."

[Advocacy]"Brings light to information and support about some things that I certainly wasn't aware of."

Further consolidating our point that the welfare system may be inaccessible to those needing it most is the fact that interviewees that had experienced mental ill-health for a longer period of time often kept in touch with advocacy to stay informed about their rights. Though an initial case may be closed, the most common reason for re-referral was needing help with new reforms such as the current welfare reform or the 'bedroom tax'. Most respondents found information about rights and support difficult to access and interpret; why this was the case has several explanations. Firstly it may well be that the information was difficult to find and interpret regardless of whether one had a mental health issue or not; respondents that sought support from family members stated that this was the case. Secondly mental ill-health issues may impair one's ability to deal with such information as well as one's ability to act on it. In the case of both, having the support of an advocate, who has an overview of the whole system and knows how to access the right information as well as to apply it, meant that individuals experiencing mental ill-health had better outcomes. Rather than a person being referred on from one institution to the next, the advocates were able to pin point which institution should be responsible and how to best address them.

4.4 Understanding: Key to delivering the right support

It has been argued that independent advocacy delivers a service which responds well to the needs of those experiencing mental ill-health. What furthermore emerged from the interviews was that an important reason behind advocacy successfully helping people was that the advocacy organisations and the advocates had a great understanding of mental health issues. The advocates were reported to have an understanding and patient manner, which interviewees greatly appreciated. Some, like Jane who had problems with attending meetings due to her recurring panic attacks, made clear that, without her advocate's understanding of her issues, *"it would put me off coming back, because I can't deal with any pressure just now"*. Maddie, who experienced high levels of anxiety during the depression following a period of ill health, also described how the understanding and support of her advocate were key to getting through her bills and paperwork:

"Because of how unwell I was like I would panic and I would start shaking, and say, you know, -I'm going for a fag, I'm going for a fag... (...) They had to be very patient, basically, with me, in order for anything to get done or it wouldn't have got done..."

Maddie (lived experience of Bipolar disorder)

In the interviews done by one of the advocacy organisations for an SROI evaluation it was common to refer to the advocacy organisation's office as a safe place. Interviewees commented on feeling comfortable and "listened to and able to speak freely". Sometimes this would be contrasted to how advocacy partners had been treated by other service providers or government bodies, which were often considered less attuned to what someone with a mental illness may struggle with.

Without generalising about other service providers and agencies it may be concluded that advocacy organisations were regarded as understanding of mental illness. This was important since many advocacy partners stated that if they had been received differently they might have refrained from seeking more help. This could potentially have led to them finding themselves with greater problems than they had when they first sought advocacy assistance.

4.5 Independent Advocacy: An important service

Advocacy partners did in some cases feel able to advocate for themselves after support from an advocacy worker. However, many reported that this ability was tied to their mental health status: when being less well interviewees reported that they needed support even though they would self-advocate at other times:

"-Do you feel like you can advocate for yourself as well now?"

"-Depending on how I feel, I've just gone through a very bad period, (...) Yes I do feel I could, maybe perhaps not as well as in other moments, but that happens to everybody. (...) I feel I can advocate for myself. Again, probably with support" [from an advocate]

Nancy (lived experience of depression and anxiety)

Though one goal of independent advocacy is for advocacy partners to be empowered to self-advocate, for some people with mental ill-health this goal may only be partially obtainable. However, rather than conclude that independent advocacy does not achieve all its goals, it can be argued that this shows how advocacy addresses a need among people with mental ill-health.

This is of particular importance since independent advocacy began as a movement that came about because of “a growing sense of anger and frustration about the way people accessing mental health services were being treated” (Brown B. , 2013, p. 3). Though there were examples of mental health care failing arising in the interviews, most interviewees were happy with the care they had received. Furthermore, most were referred to independent advocacy by a psychiatrist or mental health worker. This suggests that advocacy has moved on from being a resistance movement to become a service in its own right, which succeeds in addressing the particular problems that those experiencing mental ill-health may have with meetings, correspondence and accessing information about their rights. This is not to say that the power imbalance between service users (in this case those experiencing mental ill-health) and service providers as well as other bodies has ceased to exist. However it seems that advocacy has found a way to address some of the issues creating this power imbalance through supporting people experiencing mental ill-health.

5. Positive Effects: Advocacy's soft outcomes

Independent advocacy delivers practical help resulting in 'hard outcomes'; successful appeals to the DWP, Compulsory Orders being challenged through Tribunals and support to achieve a satisfactory resolution to a divorce case. These outcomes are easy to report in a feedback form. However, as one of the managers commented when interviewed, "the middle part is important" too. "The middle part" refers to the advocacy process; that the advocacy partner is listened to, informed about his/her rights and supported to make independent choices about his/her life. Emotional support, assistance to relieve social isolation and the stress relief stemming from knowing that one can access support if needing it, also belong to what may be termed 'soft outcomes'. During the interviews it became evident that these soft outcomes were of great importance to people. In some cases interviewees had not had any final resolution to their case, and very sparse 'hard outcomes'. A major reason why they felt very positive about advocacy was often that they had benefited greatly from the soft outcomes delivered by their relationship with the advocate. In cases where there were successful hard outcomes, interviewees still spoke about different soft outcomes as something that was very important to them, both during and after their case was closed. The following section will therefore consider each of the soft outcomes evidenced in the interview material.

5.1 Feeling Empowered

One of the goals of independent advocacy is that if possible, advocacy partners will eventually feel empowered to self-advocate. As has been discussed, this may not be possible for everyone with a mental illness. However, many interviewees felt empowered by their advocacy experience. Many gained in confidence through their relationship with their advocate, as suggested by research (Nelson, Lord, & Ochocka, 2001, s. 138). Knowing what your rights are, and finding that your opinions are of value, often enabled people to speak up in situations where they previously would have been silent. Furthermore, advocacy opened up new avenues for speaking up, such as collective advocacy groups. Such groups could be consulted on issues concerning the treatment of people with mental illness. They were also a forum for learning about one's rights and how changes in legislation and regulations would affect the group members. Empowerment has been defined as "opportunities for and conditions that promote choice and control, [and] community integration" (Nelson, Lord, & Ochocka, 2001, s. 127). The following section outlines how independent advocacy achieves this.

5.1.1 Knowledge about one's rights

Before accessing advocacy the interviewees generally had poor knowledge about their rights. Sometimes this was due to finding themselves ill unexpectedly; in this case they wouldn't have given much thought to their rights in regards to mental health. At other times, finding oneself mentally unwell for a longer time period created a strong 'patient-identity'. Nancy explains how seeing herself as a patient meant that she did not even realise that someone would be interested in her opinion in terms of her treatment:

“-So you feel people didn’t listen as much before you received advocacy? Or you didn’t even know they could listen?”

“-I would say I didn’t even know that was a possibility. (...) I took for granted that I was the patient. I had this very nice, person sitting there, but I didn’t question the relationship and I didn’t question the power relationship at all. That’s why I use this word I was the patient, I was kind of passive. Very good treatment but very passive.”

Nancy (lived experience of depression and anxiety)

Ann, also with lived experience of depression and anxiety, had a similar experience: “I had the point of view that you went in to 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 realized I had any rights whatsoever.”

For both Ann and Nancy, coming into contact with advocacy made them realise that they did have rights and that their views were important. For Nancy, this “boosted her confidence and helped deal with [my] depression”. Ann, who before coming into contact with advocacy “never knew [she] had rights” claims that she now knows what her rights are and feels confident that she can access them, with some assistance from advocacy. An example of this is how she is now in housing appropriate to her needs as opposed to the flat she lived in previously, where she did not even have an adequate bed. In the case of both Ann and Nancy, getting advocacy support meant that they could re-evaluate their relationship to service providers and health professional. Gaining knowledge about their rights they were then able to obtain better life conditions which in turn impacted positively on their health.

Being more aware of one’s rights also helped advocacy partners to speak up for themselves in all sorts of settings. When asked if he is more informed about his rights after accessing advocacy Matt answers:

“-Yeah, I feel more protected now in regards to basic human rights, basic rights (...) If somebody like a civil servant says something to me this is fact, I’d not just stand there and take it and sign something. I’d go away and get advice first off.”

Matt (lived experience of depression and anxiety)

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.

5.1.2 Engaging in Collective Advocacy

Some of the advocacy organisations which our interviewees had support from also facilitate collective advocacy groups. These groups are consulted by psychiatrists and other mental health professionals through projects seeking to improve mental health care. This is a very tangible way for our interviewees to have their say about the mental health system; collective advocacy becomes the vehicle for such empowerment to happen. Maddie began to volunteer through her advocacy organisation, speaking to medical students and health professionals about the issues she faced during her Tribunal process and how she thought the process could be improved. As a result of Maddie's involvement the rules regarding timing of Tribunals changed and Maddie comments:

"I'm incredibly glad I've managed to do that, that I've made a significant difference to other people. (...) I feel it's very beneficial and I'm kind of proud, you know, that I'm doing it"

Maddie (lived experience of bipolar disorder)

Maddie's experience that volunteering has been beneficial for her mental health is similar to that of others as found in a report by the Scottish Recovery Network (Brown & Kandirikirira, 2007) Due to the limited scope of our interview sample it is impossible to tell how common it is that advocacy partners become engaged in collective advocacy or other types of volunteering work after receiving issue based advocacy. However, the conclusion may be drawn that in the cases where it does happen it can be a profoundly empowering experience. Furthermore, by facilitating the organisation of groups for those with an experience of mental ill-health, it opens up an opportunity for a more equal power balance between service users and service professionals.

5.2 Emotional Support

For Maddie, who was stuck in a closed ward due to two tribunals being cancelled for reasons such as doctors failing to turn up, the visits from her advocacy workers during her time at the ward were very valuable:

"-They were listeners [the advocacy workers], their support is really important and it's just, something that you feel that you need there, you know. And the fact that they come in and visit you in a ward, where you know, it breaks down that day, to be visited in a ward anyway, by anybody. And they were you know, always friendly, always there."

Maddie (lived experience of bipolar disorder)

Though Maddie's advocacy workers were working with her to assist her through the Tribunal, it is evident that the emotional support the advocates provided by visiting her in the ward is something that stuck out for her. Edward, who was supported through a case against the DWP, also told us about his advocacy worker Laura who phoned him up on a regular basis both to update him on the case but also to ask him how he was doing, during and after closing the case. His wife, who was also present during the interview which took place at their home, sometimes spoke to Laura as well and told us that:

“When she’s on that phone, she’s on it for ages, so we keep her going. We get it all off our thoughts, our, what we didn’t like about Atos, just things like that, we just have a right ramble about things.”

Sharon, wife to Edward (lived experience of depression)

Jane describes how coming to the advocacy office always makes her feel better due to the understanding and support she receives there:

Every time I feel better when I leave here as to when I come in. It’s not because I dread coming here .It’s the absolute opposite it’s because I’ve offloaded I feel somebody taken that weight off my shoulder and dealt with it for me.”

Jane (lived experience of depression and anxiety)

Apart from allowing the advocacy partners to share what troubled them, another type of emotional support offered was reassurance in regards to the case. 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”*. As mentioned earlier, the fact that advocacy workers did not only provide practical help but also delivered this support in a compassionate and understanding fashion, created a sense of emotional support that stood out as important to our interviewees.

5.3 Breaking Social Isolation

“I think if you’re surrounded by a lot of good people it gives you a good chance, you know.”

David (lived experience of paranoid psychosis)

Connected to the need for emotional support is the fact that some advocacy partners experienced social isolation, to a lesser or greater extent. Advocacy was successful in breaking this isolation in a variety of ways. For those who had tended to isolate themselves completely (often as a symptom of depression) something as simple as seeing an advocate on a regular basis meant that they felt less isolated. In our interview, Callum stated that:

“-I have no, kind of, I have no social life at all, this is the highlight of my day, you may be the highlight of my week, eh, (...)Being involved with Sandra in the advocacy it helps me to, kind of stay focused on things, well that’s what I feel anyway”

Callum (lived experience of depression)

Having a point of social contact proved beneficial in numerous ways. For Nancy it “boosted her confidence” which in turn led her to become more sociable again. This happened partly through the engagement in a collective advocacy group committed to advocating for the rights of people with mental ill-health on a community basis, a group which was supported by the advocacy organisation that Nancy first got in contact with for issue-based advocacy. Similarly, advocacy in some cases opened up volunteering

opportunities for the advocacy partner, suiting their particular talents and work experiences. Maddie came to be employed on an hourly basis to lecture for medical students about the experience of being sectioned and of advocacy. Apart from helping her “get out the door”, Maddie told us that volunteering gave her “a confidence boost” and a feeling of doing something of importance to others. To Matthew, volunteering to do graphic designing at the advocacy office helped him to gain the confidence and has, in his own words, helped “push me into the other environment”. For Matt this was doing other volunteering and meeting people not connected to the advocacy office, something he was unable to do prior to getting advocacy support.

For David, the support from advocacy to solve his case helped him to recover his mental health back to a point of stability. This did in turn allow him to be able to retain his part-time job, as well as take on some volunteering jobs with his local church. He told us that he finds that both his part time job and the volunteering help him to relax and have more social contact:

“-They [people at the local church] asked me, do you want to come and help with the gardens, and I do that for a couple of hours a day and it gets me out in the nice weather and I meet a lot of nice people at the churches and the chapel and it makes you feel even better (...) I think if you’re surrounded by a lot of good people it gives you a good chance, you know.”

David (lived experience of paranoid psychosis)

Social contacts are, as found by Putnam and Helliwell (2004), key to mental wellbeing. Thus the fact that advocacy often manages to break advocacy partner’s social isolation, in a variety of ways, must be considered an important soft outcome.

5.4 Alleviating stress

Similar to social contact, stress is highly linked to mental wellbeing. Furthermore, high levels of stress will often have a negative impact on mental health. This was evidenced by several interviewees who reported that due to the stress caused by the cases they sought advocacy support for, their health had deteriorated significantly. Some had to increase the dose of medication, which in turn had impacts on their health in terms of side effects. A recurring theme in our interview with David was how his case was incredibly stressful, but how once he began to receive advocacy support he felt that “it took the pressure off him” and “relaxed” him. Eventually his mental health stabilized and he could return to his normal medication.

Matt, who suffered from chronic depression, recalls how, due to a charge by the DWP of not declaring savings, he experienced suicidal thoughts for the first time in his life. Though he got better he describes how he was “constantly waiting for a letter through the post, for things coming through the door, and it was just terrible”. However, after having had advocacy support he eventually recovered his mental health to feel better than he did before the appeal against the DWP. Furthermore he reports feeling more at ease even in the face of potential setbacks that may happen in terms of his mental health:

“-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.”

For David and Matt, as well as other interviewees, even after a case was closed advocacy continued to have a positive impact on their health. This was simply because the advocacy partners knew that if they needed it, they could access help again. This was a major point of stress relief, especially for those caught up in what can only be described as traumatic conflicts with the DWP in regards to benefits. In all cases knowing that there was somewhere to turn during a time of need was a source of reassurance and had a positive effect on peoples' wellbeing.

5.5 A Positive Turning Point

For the advocacy partners who agreed to take part in our study, advocacy had in all cases had a positive impact on their life. For some advocacy support had had a particularly profound impact: it was the turning point which changed their lives for the better. Sometimes this was rather dramatic; the interviewees who had mental ill-health paired with alcohol abuse told stories of being supported when feeling suicidal. Sometimes the change was more subtle. Nancy described how she used to be "very much the patient". However, by becoming more aware of her rights she now describes herself as "demanding". This section will look at examples of how advocacy have been a turning point for interviewees and what factors were key to such positive changes.

5.5.1 Matt: winning his case and finding fresh determination

Matt's used to work within the IT sector, but with the worsening of his depression he found himself unable to work. Fearing the stigma attached to mental ill-health he didn't feel able to seek support from friends and family. He isolated himself and says that he was "effectively on [his] own". When he received a letter from the DWP stating that he had not declared savings he found his health deteriorating further. In fact, Matt told us that he considered suicide for the first time. Matt's psychiatrist recommended he contact advocacy, which he did. Advocacy supported Matt for a year through a rather complicated case which was only resolved after a local MP had gotten involved. However to Matt the positive resolution to his case was not the only outcome of advocacy that he benefited from. He told us that:

"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. Having that sort of help and having that sort of human aspect –I suppose feeling trust again (...) gave me a little hope for humanity"

With his newfound confidence Matt found himself able to take up volunteering work within his field in IT, both for the advocacy organisation and later for a local politician. Knowing that he knows where to turn again if he ever needs support means a lot to Matt, he knows he has *"the strength and the network of people to help him"* to face whatever may happen. Matt's story shows the importance of the interpersonal relationship that advocacy offers; with the support of his advocate he found himself more confident and increasingly able to make choices. Since the advocate got to know him, he was able to help Matt find volunteering work which further strengthened Matt's confidence in his own ability, realising he "wasn't rubbish".

The accepting and understanding environment of the advocacy organisation helped Matt to *"push into another environment which was completely alien"* to him, working with a

local politician. For someone who used to get too anxious to put himself into new social environments this is a huge achievement. Matt says that the year with advocacy had “*a massive effect*” and that he had never been able to have meetings with politicians and well known people before he got into contact with the advocacy organisation. Matt is now on a journey towards recovery, and because advocacy has broadened his horizons he now has many more opportunities.

5.5.2 Nancy: from accepting patient to “a very demanding person”

Nancy’s story is a good example of how people may turn to advocacy not because they are unhappy with other service providers but because advocacy provides a different type of service they found themselves in need of. Nancy first got in contact with advocacy due to changing regulations regarding bus passes which hindered her accessing a day centre she had been referred to. The issue was soon resolved but Nancy kept in touch with advocacy through a collective advocacy group since she felt “*very interested in advocacy*”. Advocacy became her “*first port of call*” if any issues arose or she needed information. She describes how she used to be “*a patient*” who received good care but never felt that her opinion mattered; rather she felt obliged to accept what was offered and be grateful for the help. For Nancy, advocacy opened her eyes to the fact that she could have an input in her own care. Finding that her opinions were of importance she describes that “*it boosted my confidence*” which “*helped with dealing with my depression*”. Interestingly, later on in the interview Nancy describes herself as “*quite a demanding person*”. Though demanding may not be a word with positive association, it marks an important shift in mentality that positively impacted Nancy’s confidence and mental health. From being unconfident and passive Nancy is now actively engaged in her own care as well as that of others through her engagement with collective advocacy. Furthermore the confidence she has gained through “*finding her voice*” as she puts it, is continuing to have a positive impact on her health.

5.5.3 Without advocacy –I don’t want to think about that...

One of the advocacy organisations had conducted interviews with advocacy partners who struggled with both mental ill health and alcohol addiction. For this group advocacy was what one interviewee termed “*a life line*”. There were several stories of how an advocate had supported advocacy partners when they had suicidal thoughts, directly by for example getting someone off a bridge. For someone with an alcohol addiction life can be chaotic and several different service providers are often involved. It seemed that having an advocate ‘connecting the dots’ made transition from a rehab centre to independent living went smoother. Furthermore the positive nature of the advocacy partnership had a positive impact on people’s confidence. The advocacy partner felt accepted and able to confide in their advocate which sometimes allowed them to receive more appropriate treatment. Six interviewees reported that they had been able to stay sober, an achievement they felt would have been impossible without advocacy support.

6. Working for Human Rights

This report has, by examining the positive experience of advocacy for people with mental illness, been able to conclude that advocacy services both respond to support needs of the group and achieve soft outcomes such as a 'sense of empowerment'. It may be argued that supporting individuals with their official communication and helping those individuals to 'speak up' have intimate ties to the upholding of human rights and equality in society. One of our interviewees expressing this was David. David had a strong sense that without advocacy he would have been unfairly treated. He says that the difference having an advocate made for him was that *"it gave me proper justice (...) and it let me know my rights"*. Due to his condition he told us that he wouldn't have been able to fight the DWP since his health had deteriorated significantly due to the stress of his case. As argued in section 6, people experiencing mental ill-health who are a generally vulnerable group, often become more vulnerable under significant stress. Having advocacy support in these cases were often the only reason the advocacy partner had managed to appeal an unjust decision or managed to access the benefits they were entitled too.

Another term for advocacy partner used in relation to care or service providing organisations may be 'service user'. Though service user may indicate that there is a customer relationship between users and service providers, it can be argued that this is far from the reality. Rather, in dealings with care or support service providers, service users can find themselves in an unequal relationship where decisions are made about and for them. Furthermore, due to mental illness, their capacity to access their rights and speak up may be limited. One interviewee tells us that:

"On a good day, I can express myself fairly well with a psychiatrist but nothing will ever take away from the fact that it's an imbalance. I personally think it's a structural imbalance, I will never be their equal (...) If there is a particular problem [advocacy] will help balance it up for me"

Nancy (lived experience of anxiety and depression)

As Nancy points out there is a structurally unequal situation since service providers generally have the power to section, prescribe medication, and grant benefits as well as diagnose illness. For Nancy, even when she has "a good day", her being able to express herself well does not take away from this imbalance. To have an independent third person involved could, however, helped to shift the power balance. What Nancy's and David's stories testify to is that whether a person experiencing mental illness is facing a crisis or not, they are at a structurally disadvantaged position in relation to service providers. An independent advocate acts as a third party which may shift this power imbalance in favor of the advocacy partner as well as be a safe guard ensuring that human rights are protected in situations where the advocacy partner will be less able to fend for themselves.

7. Advocacy and SIAA's guidelines

When assessing the impact of independent advocacy one of the issues of interest to the SIAA as a member organisation is whether advocacy organisations adhere to the Principles & Standards and Code of Practice. Speaking to the interviewees we found that the advocacy organisations are doing well. When asked if the advocacy partners felt involved in the process of resolving the issue they sought help with, people did not only answer positively. Interviewees gave plenty of examples of how advocates had made sure that they made decisions themselves and that their views and wishes were heard and fully considered. When asked to describe their advocate, our interviewees responded by speaking warmly of their advocate and the relationship they had. It was clear that the personal yet professional approach of the advocates was consistent across different organisations and highly valued by advocacy partners.

Underpinning SIAA's work is the belief that societal structures of power mean that some groups in society may be 'disempowered' and unable to access the rights and services they are entitled to. Our finding is that people with mental illness are such a group, and that advocacy is a great tool to make sure that this issue of power equality is addressed. This became even more evident when speaking with our interviewees. Many did, like Maddie, state how important access to advocacy is. However, some interviewees said that they had not known about it at an early stage when problems began to arise. They felt that advocacy was a support they were entitled to, and that they 'should have heard about it earlier'. However they were, from personal experience, aware that knowledge about advocacy was generally low and public information about it sparse. Most people were referred by a health professional and felt that they were "just lucky" that they eventually accessed advocacy support.

7.1 People making their own decisions and being heard

The idea of advocacy is to enable those that may be disempowered in different ways to regain control over their lives by having their voices heard and being supported to make their own decisions about their lives. When asking our interviewees if they felt involved during the process of advocacy it was clear that this was the case. In fact, even in cases where the advocacy partner had been in great distress and would have liked to be absolved of responsibility, advocates always made sure that they were clearly making decisions themselves. This was often something that the advocacy partner appreciated in hindsight. Jane told us that:

"-I'm aware that they won't, ... they're not allowed to tell me; -well you should do this you should do that', which is kind of what I would love. You know somebody that would just totally [make all the decisions for me]."

But it's just recently I've been aware of that when I say' - What do you think I should do?' They kind of bounced it back, '-Well it's your decision!"

Jane (lived experience of depression and anxiety)

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, but they have helped to put it all together for me."

Jane's story is one example of how advocates work to help their advocacy partners make their own, informed decisions. Maddie told us that in regards to resolving her financial problems she "had to be involved, and they made sure I was". Matt similarly described how his advocate helped him to access all the relevant information, but that he was always asked what support he wanted, for example if he wanted his advocate to support him at meetings to meetings. Whether they gave a more or less detailed answers, all interviewees did state that they felt involved in the process of advocacy. This finding strongly suggests that advocates are following SIAA's guidelines in terms of empowering their advocacy partner to make their own choices.

7.2 Describe your Advocate: Good Reviews!

Advocacy partners often describe how the way they are received by their advocate stands in contrast to the relationship (or lack of) that they have with staff from service providers and governmental bodies. A criticism of government bodies was that the interviewees feel like they were "just a number"; they felt that their personal situation and the suffering they went through were not taken into account. Advocates, on the other hand, were able to be more personal in their approach. Ann says that: *"she [her advocate] made me feel worthwhile, as if I was worthwhile, instead of just nobody really."*

Though some of our interviewees strongly critiqued certain service providers as well as the DWP, it must be noted that the fault may not always lie with concerned individuals. The restrictions of their professional roles may not allow them to be as 'personal' as they would like to be. The fact that many interviewees were referred through a health professional suggests that those referring did indeed see independent advocacy as a service complementing their own, with a different function that could prove helpful to the person they referred. Advocacy partnerships can be concerned with a person's whole life situation, as opposed to for example a psychiatrist whose role is to treat symptoms of mental ill-health. Advocates, as discussed in section 7, often provided emotional support as well as support with whatever issue the person needed advocacy support to address.

Key to independent advocacy is the relationship between the advocate and the advocacy partner. For the advocate to successfully make the advocacy partner's voice heard, the relationship needs to be characterized by a high level of trust. This requires the advocates to have strong interpersonal skills. The words which advocacy partners use to describe their advocates do indicate that their advocates do indeed have exceptional interpersonal skill and a strong ability to create trusting relationships.

When asked to describe their advocate people came up with a number of different descriptions. What stood out from these is that advocates are perceived as understanding and professional, a balance that, though difficult to achieve, is reached by the advocates. There is also a great deal of praise for advocates, with words such as “great”, “brilliant” and “excellent” used by several interviewees. Advocacy partners were particularly happy with the relationship they had with their advocate and their descriptions of their advocates may be summed up as “good reviews”.

7.3 Access: “Why didn’t I hear about this earlier?”

One of SIAA’s principles is that advocacy should be accessible to everyone. Unfortunately, this is not always the case. Many of our interviewees pointed out that they had never heard of advocacy before being referred by a health professional. Furthermore several interviewees wished that they had accessed advocacy earlier and also expressed a concern that others in a similar situation would not receive the advocacy support they needed:

“I feel sorry for the hundreds and probably thousands of people that haven’t heard about advocacy you know, ehm, cause, 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, and they’re still not answering so it’s imperative that you know people with mental health issues get the advocacy”

David (lived experience of paranoid psychosis)

The managers of advocacy organisations that we spoke to were aware of this issue. They told me that they worked on raising awareness but that they were restrained by limited resources. Advocacy organisations often find that limited resources create a ‘catch 22’: if they spend resources on raising awareness there will not be enough resources left to respond to a rise in referrals. 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?”

Beth, manager of a Scottish independent advocacy organisation

Apart from the fact that our interviewees highlighted low awareness as advocacy organisations’ major short coming, their comments in regards to advocacy awareness reveal much about how the advocacy partners view the service. Several interviewees repeatedly told me of how “they never knew advocacy existed”, indicating that they saw this as a problem. For Ann, who told us that she never knew she had rights before accessing advocacy, it was obvious that she felt that advocacy had been a vital support and the fact that she never came in contact with advocacy during several periods in hospital was something she viewed as an issue. She told us that “nobody ever told her” about advocacy and that it was just “leaflets on the table” which she didn’t read since she didn’t know enough about advocacy for the leaflets to interest her. Callum felt that it was “just pure luck that I had these other people that knew about [advocacy]”.

According to Callum, without independent advocacy and the support of a mental health support team, he *“would be in a box by now”* and he strongly felt an obligation to raise awareness about advocacy himself. Thus, since awareness about advocacy is generally limited access is not as wide as SIAA would wish it was. However, our interviewees’ strong views on access show that they regard advocacy as a vital service that all people experiencing mental health problems should have access to. Since limited resources seem to be the key issue, we can only argue for an increase in funding to our advocacy organisations, to make sure that help reaches those needing it at an earlier stage.

8. Conclusion

Our investigation of the positive impacts of independent advocacy has shown that advocacy is important to people experiencing mental illness for several reasons. Firstly, many people with mental ill health do have an impaired ability to deal with what we have termed “official communication”. This means that they may not access all the information they need and also that they may find themselves in trouble because they were unable to answer certain letters or deal with their finances. Having an advocate in these situations meant that advocacy partners were informed and assisted so that their voices were heard. Furthermore, they were informed about their rights, and they received adequate support to access the help that they were entitled to.

Apart from the practical help to resolve whatever issue that the advocacy partner referred for, advocates also created “soft outcomes” benefiting their advocacy partners. Such outcomes could be the stress relief associated with having support, a sense of being emotionally supported that created wellbeing, or a boost in confidence that meant that the advocacy partners found themselves able to speak up in situations in which they before would have remained quiet. Last but not least, for some advocacy partners getting the support of an advocate was life-saving. Independent advocacy was their last resort. Some interviewees went so far as to state that without advocacy they had seen no other solution to their problems than suicide or homelessness.

As a member organisation working to ensure the quality of advocacy delivered by our member organisations, we were reassured by the finding that advocates are working in accordance with the Principles and Standards for Independent Advocacy and associated Code of Practice. Advocates are careful not to make decisions for their advocacy partners but rather support them to make their own decisions, from a well-informed stand point. Furthermore, 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. A serious issue raised in our study is that access is still limited due to low awareness about independent advocacy, an issue that several other researchers have identified¹¹. Many interviewees were referred by health professionals, indicating that professionals have an awareness of their duties regarding telling people about advocacy. However, since advocacy is independent, one should not need to rely on professionals to access advocacy support. Our interviews with advocacy managers reveal that lack of resources is the primary reason why more awareness raising is not undertaken. There is not enough funding to raise awareness and even less resources to respond to the increase in referrals.

Since advocacy is a means to ensure that everyone can access their human rights, we will argue that there are good reasons why advocacy is a statutory right for those experiencing mental illness. However our investigation has also made us aware that advocacy is not as accessible as it should be. This is mainly due to a lack of funding, constraining our member organisations both in terms of how much resources they can set aside for awareness raising and what capacity they would have to accept more referrals. Our key findings are the following:

11 See sections 2.2 & 2.3

- **Advocacy ensures that people experiencing mental illness access their rights.** Interviewees felt that advocacy “was supposed to be there” and provided a vital service that no other service provider could offer. Advocates made sure that people were aware of and understood their rights and ensured that rights were upheld.
- **Advocacy organisations need more funding:** Current funding levels constrain advocacy organisations. There are not enough resources to conduct awareness raising activities or to provide support for all those who need it, even though access to independent advocacy is a statutory right.
- **Access to advocacy is too restricted:** There is limited awareness about independent advocacy which means that people may access advocacy late or not at all.
- **Advocates following SIAA’s guidelines achieve good results in terms of empowering their advocacy partner:** Advocates supported advocacy partners to gather relevant information, consider options and potential consequences and make fully informed choices; they did not advise or make decisions for people. As a result advocacy partners stated that they gained in confidence and were more able to speak up for themselves.

The research showed that the advocacy organisations supporting interviewees are doing well in terms of following the SIAA Principles and Standards for Independent Advocacy and the associated Code of Practice. This good practice contributed to the high quality of the advocacy provided.

The work of these advocates ensures that people experiencing mental illness have access to the support they are entitled to and have their rights upheld. Looking towards the future the challenge now is to make sure that all those who need it can access independent advocacy.

9. Methodology

9.1 Choice of research methods

The aim of this research project was to investigate the impact of independent advocacy from the perspective of the advocacy partner. As pointed out by experts interviewed in the preliminary stages of the project, as well as earlier reports and studies, the impacts of advocacy are manifold and not easily captured in quantitative formats such as surveys. Therefore it was decided that data would be collected qualitatively through semi structured interviews with advocacy partners. Central to all independent advocacy is to listen to the service user and make sure their voice is heard. This study strives to do the same by listening to the story of each interviewee and use these stories to draw conclusions about what advocacy means to those who use it. In total 12 interviews were conducted. This is not a statistically representative sample of all people experiencing mental illness that access independent advocacy in Scotland. What it does represent though, is careful analysis of the life stories of 12 individuals that have had support from different independent advocacy organisations. As Polkinghorne affirms;

“The storied descriptions people give about the meaning they attribute to life events is, I believe, the best evidence available to researchers about the realm of people’s experience.”
(Polkinghorne, 2007)

Through the collection and analysis of such stories one can furthermore reach what social scientists have termed “theoretical saturation” (Guest, Bunce, & Johnson, 2006) (Marshall, 1996). When conducting interviews with a group of people sharing certain characteristics on a particular topic, such as in our study, certain themes tend to resurface in each interview. When no new themes are occurring this would be the point of theoretical saturation; at this point it has been found that even if further interviews were to be conducted, no new information is likely to surface. Further narratives will rather be variations of already existing themes found during the research. Thus though the sample in this study is not statistically representative, the number of interviews conducted was based on when we believed that theoretical saturation would happen, as suggested in literature to be at 10-15 interviews (Marshall, 1996) (Guest, Bunce, & Johnson, 2006). We thus believe the results from our purposive sampling give a good representation of a range of experiences and values which those experiencing mental illness attach to independent advocacy in the Scottish context.

9.2 How the research was conducted

This research project was conducted in two stages. Initially several advocacy organisations were contacted and asked whether they were interested in being involved in the study. After initial contact was made, 5 different organisations were visited. The managers of the advocacy organisations were interviewed about the work of their particular organisation. These interviewees are referred to as the experts, or advocacy managers. Possibilities of accessing and interviewing service users were also discussed as well as what potential causes of concern might be and where interviews would best be conducted. These initial meetings became a way of getting in contact with 'gate keepers' to advocacy organisations. Interviewees were later drafted by these gate keepers, and the advocacy organisations also facilitated the interviews by allowing us to use their premises for conducting the interviews.

The interviews with advocacy partners followed a semi structured format and lasted for 30 - 45 minutes. The questions used can be found in Appendix 1. The design of the questions from the toolkit for measuring impact and outcomes of advocacy provided in Action for Advocacy's report *Lost in Translation* (Coyle, 2009) was used and adapted to best answer our research question. All interviews were tape recorded and transcribed in ad verbatim before they were coded using the coding software Qsr Nvivo10.

9.3 Ethics

Before interviews began each interviewee was given an information sheet about the study. The sheet included information about anonymity and confidentiality¹² and the options to not answer questions and to leave the interview at any time. Therefore names of all participants have been changed to protect their anonymity. Furthermore contact details to suitable help organisations was included in case interviewees experienced any discomfort or need to talk to someone about issues that may have surfaced during the interview. Before the interview began a consent form had to be signed which included consent for the interview to be tape recorded. During the expert interviews it was found that two of the advocacy organisations had already conducted interviews on the impact of advocacy for an internal SROI evaluation. Since these interviewees were informed that their responses would be shared with external organisations through the tendering process that the organisation was going through at the time, consent for information to be shared with external organisations was already given. The responses were received in anonymised format and coded like the other interviews.

12 See Appendix 2 for details

9.4 Sampling: Limitations and Possibilities

To go through gate keepers (our experts) in order to access interviewees has both benefits and disadvantages. A major disadvantage may be that results will be skewed as gate keepers may be inclined to only draft interviewees with a very positive experience of advocacy. Furthermore the interviewees accessed by a gatekeeper may also be those that have kept in touch with the advocacy organisation in some way or another, which narrows the sample further. However this skewing of respondents may have occurred anyway as it is likely that respondents with a positive experience of advocacy may be more willing to 'help out' and be interviewed. Furthermore in spite of these possible disadvantages asking gate keepers for contacts was seen as the preferable method for a variety of reasons.

Firstly, people experiencing mental illness who seek advocacy help are often in a very vulnerable position. Having the assistance of a gate keeper judging who might be 'ready' to be interviewed about their experience was valuable in order to ensure that no additional pressure was put on interviewees that might worsen their mental health conditions. It was also judged that interviewees may be more willing to be interviewed about such a sensitive topic as mental health and advocacy support at a time of need, if contacted by an organisation they knew of, trusted and hopefully had positive experiences of.

Secondly, as found in earlier studies¹³ the premises of the advocacy organisation represented a safe space where the interviewees felt comfortable, making it an ideal location for the interview. Lastly contacting interviewees through the advocacy organisation was the most cost and time-efficient alternative.

Drafting interviewees through for example postal surveys, or by advertisement in places where potential interviewees might visit such as mental health clinics, would have been both costly and time consuming. Since the study was conducted during a limited time period (January-June 2014) contacting advocacy organisations directly and using them to get access to interviewees was the most viable alternative. Being aware that the respondents are likely to have a positive experience we decided to change the research question slightly. Rather than investigating what the impact of advocacy is, we narrowed it down to investigating what the positive impact of advocacy is. Our research does not cover all experiences of advocacy; to do so would mean that we would have to use a different sampling strategy. Using interviewees who probably had a positive experience, was however an opportunity to investigate in detail why the experience was positive. In the experience of the managers of advocacy organisation that we interviewed, many advocacy partners re-refer themselves after their first case is closed: what makes them come back? It is a common practice of advocacy organisations to collect 'case stories' to give evidence of the potential of advocacy support; where there any patterns to these stories. What do people using advocacy support have in common, and how does advocacy respond to their needs? This project has been designed to unpack why advocacy had a positive impact and what those impacts were, from the perspective of the advocacy partner.

13 Findings from interviews from an SROI study done by Advocard, Edinburgh

9.5 Characteristics of the sample

In total 12 interviews were carried out at 5 different independent advocacy organisations from different parts of Scotland. Originally 15 interviews were scheduled but due to sudden dropout 3 interviews never took place. There were 7 men and 5 women taking part in the study and their ages ranged from 30-70 years old. There was also diversity in terms of which mental health conditions interviewees were experiencing. However, depression and anxiety was the most common condition. No interviewee was in full time employment; some were working part-time, others were volunteering and hoping to be able to re-enter employment. Some did not expect to be able to work neither now nor in the future due to their health condition. In some cases the respondent had experienced mental illness from their teens onwards. However, equally common was to become mentally unwell later in life, for some as late as in their 50's. Lastly some respondents had become unwell as a consequence of a general life crisis or due to an acquired brain injury.

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APPENDIX 1 - Semi Structured Interview

Demographic data:

Gender

Age

Mental Ill-health issue at time of contacting advocacy

Email

Case data:

When did you access advocacy?

For how long did you receive advocacy support?

Are you still in touch with the advocacy organization in any way?

How did you hear about advocacy?

Did you refer yourself or did someone else refer you? (health professional, family, friend, yourself)

What particular issue were you referred for?

How did you feel about your life situation at the time when you sought help from an independent advocate?

- How would you describe your life at the time?
- What was the biggest issue/issues?
- How did you feel at the time?
- Did you have any other support?
- Did people listen to you?
- How did service providers treat you?
- How was your self-esteem?
- Did you feel confident to express yourself?
- Did you feel confident to make decisions?
- What did you know about your rights?
- Did you feel like you had choices?
- How was your physical health?
- How was your emotional health?

What did the advocate do to help you resolve the issue you sought advocacy for?

Calls, tribunals, company to meetings?

Did you feel part of this process?

Do you think you could have done this on your own?

Do you think that you managed to resolve the issue together with the advocate?

How would you describe your advocate through the process?

Where you happy with the outcome? Where there anything you were not happy with?

What could have happened to make your experience better?

How would you have tried to resolve the issue without the advocate?

Do you think you could have come to a similar outcome on your own?

What difference did it make to you to have the support of your advocate?

How did you feel about your life situation after you got help from an independent advocate?

- How would you describe your life now?
- Do you have support?
- How is your self esteem?
- Do you feel like people listen to you?
- Are you better informed about your rights?
- Do you feel you have (more) choices?
- How is your physical health now?
- How is your emotional health?
- Do you feel confident to express yourself?
- Do you feel confident to make decisions?
- Do you feel like you know more about your rights?

Do you think advocacy is important?

Why is it important?

APPENDIX 2 - Participant Information Sheet

Project Title

The Impact of issue-based Independent Advocacy in Scotland

What is the study about?

We invite you to participate in a research project about the impact of independent advocacy in Scotland. We would like to find out what people who have received advocacy think about advocacy. Specifically we want to know what impact advocacy has on the life of those receiving it. Results from this project will be used by SIAA.

Do I have to take Part?

This information sheet has been written to help you decide if you would like to take part. It is up to you and you alone whether or not to take part. If you do decide to take part you will be free to withdraw at any time without providing a reason.

What would I be required to do?

You will take part in an interview lasting no longer than 1 hour. You will be asked questions about your experience of advocacy. Questions will relate to how your life was before you got advocacy, if advocacy had any impacts on your life, and what these impacts are.

Will my participation be Anonymous and Confidential?

Only the researcher(s) and supervisor(s) will have access to the data which will be kept strictly confidential. Your permission maybe sought in the Participant Consent form for the data you provide, which will be anonymised, to be used for future research purposes.

Storage and Destruction of Data Collected

The data we collect will be accessible by the researcher(s) and supervisor(s) involved in this study and may also be used for future research projects by the SIAA. Your data will be stored for a period of at least 3 years before being destroyed in an anonymised format on a computer system.

What will happen to the results of the research study?

The results will be finalised by July 2014 and written up and published as part of a Research Project by the SIAA.

Are there any potential risks to taking part?

No, there are no immediate risks. However, if any of the questions asked causes you to be upset or feel unwell after the interview

Questions

You will have the opportunity to ask any questions in relation to this project before completing a Consent Form.

APPENDIX 3 – Glossary

Advocate

An advocate helps people express their views and make informed decisions. An advocate helps people to find out information, explore options and decide for themselves what they want. Advocates can be a voice for the person and encourage them to speak out for themselves.

There are different kinds of advocacy, though they all share things in common. Advocates will never tell people what to do, or allow their own opinions to affect the support they provide. All advocacy tries to increase confidence and assertiveness so that people can start speaking out for themselves.

Independent advocates are as free from conflicts of interest as possible.

Advocacy

The process of standing alongside another, speaking on behalf of another and encouraging the person to speak up for themselves. Advocacy can help address the imbalance of power in society and stand up to injustice.

Advocacy partner

The person who uses advocacy. Some advocacy organisations use the term 'client' or 'service user'.

Capacity

Ability to reason, make decisions and consider choices, express views and receive and understand information. The law assumes that people have capacity unless a doctor's assessment shows that a person lacks capacity.

Commissioner

Usually representatives from the Local Authority or Health Board who fund advocacy.
Community of interest

The group of people that the advocacy organisation has been set up to support, for example, people with learning difficulties or mental health issues.

Conflict of interest

Anything that could get in the way of an advocate being completely loyal to their advocacy partner. For example, it would not be appropriate for an advocate volunteering for a mental health advocacy organisation to also work in the local psychiatric hospital, because this would affect their ability to be on the side of the advocacy partner. It would also affect their relationships with hospital staff. Other conflicts of interest could include relationships as well as financial investments.

Independent advocacy organisation

Advocacy organisation that is structurally, financially and psychologically separate from service providers and other services.

Structurally — an independent advocacy organisation is a separate organisation in its own right. For example, they are registered as a charity or company and have their own Management Committee or Board of Directors. Everyone involved in the organisation recognises that they are separate and different from other organisations and services.

Financially — an independent advocacy organisation has its own source of funding that does not cause any conflicts of interest and that does not compromise the work it does.

Psychologically — Everyone involved in the organisation knows that they are only limited in what they do by the principles of independent advocacy, resources and the law. It is important to recognise that although there may be conflicts of interest present, psychological independence is vital.

Non-instructed advocacy

Non-instructed advocacy happens when a person who needs an independent advocate cannot tell the advocate what they want. This may be because the person has complex communication needs or has a longterm illness or disability that prevents them from forming or clearly stating their wishes/desires. This usually takes place with people who have dementia or profound and/or severe learning difficulties.

Register of interests

A register lists any conflicts of interest that people who are involved in the organisation have. The level of information recorded in the register will be decided by the organisation. The organisation will decide who is able to access this information in accordance with relevant legislation, such as the Data Protection Act 1998.

Safeguard

Ensuring that people's rights are protected.

Service provider

A person or organisation involved in giving support or care services to an individual.

Service User

The person who uses advocacy. Some advocacy organisations use the term 'client' or 'advocacy partner'.

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