



Scottish
**Independent
Advocacy**
Alliance

“Advocacy is for the people”

Research into the impact of independent advocacy on the
lives of older people

November 2014

Promoting  Supporting  Defending

Acknowledgements

The Scottish Independent Advocacy Alliance wish to thank all the individuals who graciously shared their stories and therefore made this research possible.

We also thank member organisations for volunteering to take part in the research, for taking time to help arrange interviews, support advocacy partners and recognise the value of the research.

Finally, we are grateful to Andreea Boccioaga for all her time, enthusiasm and commitment to this project

This research project was only possible due to funding for the internship from TSIS and SIAA.

For more information about the TSIS internship programme see <http://www.3rdsectorintern.com/>



Published by
Scottish Independent Advocacy Alliance
www.siaa.org.uk

Scottish Charitable Incorporated Organisation
Scottish Charity No. SC033576

Any part of this publication may be reproduced in any material form. The SIAA would like this document to be distributed as widely as possible. If you would like to photocopy it, feel free to do so. An electronic copy can be found at www.siaa.org.uk.

The Scottish Independent Advocacy Alliance is funded by a grant from the Scottish Government.

Copyright © Scottish Independent Advocacy Alliance 2014

About the author

Andreea Bocioaga graduated with an MA (SocSci) in Business Management and Sociology from the University of Glasgow in June 2014. She joined the SIAA as Research Intern in June 2014. Andreea is now back in Glasgow working for the Self Directed Support Forum East Renfrewshire.

Contents

Acknowledgements

- Executive Summary. i
- Challenges that may be faced by older people i
- Soft outcomes i
- The advocacy process i
- Conclusion ii
- Key Findings ii
- 1. Introduction. 1**
 - 1.2 Research Question 2
 - 1.3 Background 2
- 2. Advocacy - What is it?. 3**
 - 2.1 Types of Advocacy 3
 - 2.2 Legislation and Policy. 4
- 3. Literature 7**
 - 3.1 Why is there a need for advocacy?. 7
 - 3.2 Measuring Outcomes. 8
- 4. Key Findings. 9**
 - 4.1 Challenges for Participants 9
 - 4.2 Soft Outcomes 17
- 5. The processes of Advocacy 21**
 - 5.1 Meaning of advocacy. 21
 - 5.2 Advocacy an unknown service 22
 - 5.3 Advocacy practice - on the right track 23

6. A voice for older people	25
7. Describe your Advocate	26
8. Challenges of Advocacy	28
8.1 Limits of advocacy.	28
9. Conclusion.	29
9.1What are the existing evaluative measures for advocacy?	29
9.2What impact has advocacy had on those receiving it?	29
Appendix 1 - Methodology.	30
Appendix 2 - Bibliography	32
Appendix 3 - Semi Structured Interview	34

Executive Summary

This report aims to investigate the impact of independent advocacy on the lives of older advocacy partners. The study is based on qualitative data and it explores people's perspectives of advocacy. 13 interviews were conducted at 7 different advocacy organisations across Scotland. The findings draw on interviews with the advocacy partners and previous literature and are detailed below.

Challenges that may be faced by older people

Some older people may face a variety of radical changes in their lives. Some may experience changes in their capabilities physical and/or mental, some changes in their personal lives, losses and the breaking of family ties. These changes can influence the ability to deal effectively with the services around them. Research participants credit advocacy with helping them maintain their independence or regain control over their circumstances. Advocacy support was also beneficial when navigating their way through officialdom, through forms, complaints and meetings empowering them through improved confidence to speak up and addressing imbalance of power and any information imbalance. Advocacy also ensured that participants' rights were safeguarded.

Soft outcomes

Independent advocacy support leads to measurable outcomes like finding a house, resolving a complaint or helping access better care or support. It also has deeper impacts that are less measurable but have just as much relevance for the advocacy partners' sense of wellbeing. They are called 'soft' outcomes and refer to the effects advocacy has on levels of confidence and self-esteem. Participants reported feelings of relief that someone was on their side, helping them to deal with issues, ensuring that their voice is heard and their views and wishes taken fully into account. This had a huge impact on the quality of their lives and their general health.

The advocacy process

The research participants had a broad range of different issues for which they sought advocacy support. These different issues required a range of approaches and responses depending on the particular issue and needs of each individual. The variety of responses and outcomes illustrates the focus on the advocacy partner and the fact that it is the views and wishes of the partner that shapes the process. All participants felt fully involved and in control when working with their advocate. This in turn contributed to increased confidence and an increased ability to express views and wishes on future occasions. Participants reported that, when they did access advocacy, it was of considerable benefit however many participants did not find out about advocacy until they had reached some kind of crisis point.

From the interviews it was clear that advocates were acting in line with the SIAA Principles & Standards for Independent Advocacy and the associated Code of Practice. All the participants felt they were directing the process, that they were making the decisions and were kept fully informed of actions and progress. In some instances advocacy provided a safeguarding role.

Conclusion

Independent advocacy is a unique service. It provides for older people a type of support they cannot find anywhere else. Advocacy has significant impacts on people's lives through measurable outcomes (helping them access services, challenge agencies, leave a care home, etc.) and also through more subtle changes in increased confidence and in regaining and maintaining control over their own lives and situations. It appears however that advocacy can remain an unknown concept for many of those who need it most.

Key Findings

- Advocacy can help older people maintain their independence. The support participants had accessed helped them to regain control over their own lives and situations, either by finding new accommodation, making complaints or dealing with the services around them.
- Advocacy can help older people access relevant information and address any power imbalance. Participants credited advocacy with helping them access the information they needed in order to make informed choices, challenge the status quo and achieve their goals.
- Advocacy helps safeguard the rights of older people.
- For those older people suffering from a (perceived or actual) physical or cognitive impairment advocacy can offer vital support when dealing with official matters. Some of the participants reported on how their advocate helped them make sense of official documents and ensured that their views were heard when raising an issue with statutory or non-statutory agencies or when making a complaint.
- Advocacy makes the advocacy partners feel valued and listened to, improved their confidence and contributed to reduced stress when dealing with difficult issues.

Independent advocacy for older people regardless of condition or circumstances should be made available across Scotland.

1. Introduction

'Advocacy is for the people, is to help people like myself, that's maybe lost a bit of confidence and it really does'

Victoria

Advocacy is for the people – is a phrase one of our participants used to describe her understanding of advocacy. Her experience of working with advocacy revolves around finding someone to trust.

As someone who suffers from Korsakoff 's syndrome, Victoria was finding it really hard not only to understand what was going on around her, but also to trust those who were helping her. For Victoria, "people" are adults who may be vulnerable or insecure and who may feel that they have no power or control over their circumstances, situation or lives. She echoes the definition of advocacy which focuses on empowerment.

Some older people in particular may be at risk of losing control or of being vulnerable for several reasons. Firstly, older adults may face challenges associated with the aging process (Hyduk & Moxley, 1997). These challenges may occur as multiple losses and changes in physical appearance, physical ability and biological systems; emotional reactions and social changes such as an inability to live independently, or environmental changes. Some older people may also experience radical social changes or changes to personal relationships (loss, loneliness, isolation). How they deal with these changes and what kind of support is available to them has a huge impact on their ability to remain in the community (Hyduk & Moxley, 1997).

In this context, advocacy can make a crucial difference for an older person trying to navigate the services available to them while maintaining power and control over their own lives and situations. Advocacy ensures that the person's rights are being respected and upheld, that they are making informed choices, that their views and wishes are heard and especially that they are being protected against abuse (Manthorpe & Martineau, 2009). This report draws on previous research concerned with advocacy and its impacts from various fields including social work, government reports and reports from advocacy organisations. There are as many situations for advocacy as there are human experiences and a wide range of effects and impacts of advocacy. This makes it difficult to generalise advocacy impacts.

Additionally, very little research is dedicated to exploring users' experience of advocacy directly. This suggests that constantly updating the research is necessary and that there is more to be explored and understood about the impacts of independent advocacy. This report includes an overview the literature on advocacy and outlines the research directions and the limitations of existing research. A qualitative empirical study will use Coyle's (2009) recommendations for measuring advocacy outcomes. This model is tested in the context of older people's lived experiences of advocacy.

1.2 Research Questions

What are the existing evaluative measures for advocacy?
What impact has advocacy had on those receiving it?

1.3 Background

“Independent advocacy helps individuals to make their voices stronger and to have as much control as possible over their own lives, supporting them to express their own needs and make their own informed decisions. It supports people to gain access to information and explore and understand their options. They speak on behalf of people who are unable to do so for themselves or choose not to. They safeguard people who are vulnerable or discriminated against or whom services find difficult to support.¹”

¹ Taken from *The Scottish Independent Advocacy Alliance, Code of Practice for Independent Advocacy, 2008*

2. Advocacy - What it is?

2.1 Types of Advocacy²

2.1.1 One to one or individual advocacy

One to one or individual advocacy; this includes professional or issue based advocacy. It can be provided by both paid and unpaid advocacy worker. 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.

Another model of one to one advocacy is citizen advocacy. Citizen advocacy happens when ordinary citizens are encouraged to become involved with a person who might need support in their communities. The citizen advocate is not paid and not motivated by personal gain. The relationship between the citizen advocate and the advocacy partner is on a one-to-one, long term basis. It is based on trust between the partner and the citizen advocate and is supported but not influenced by the advocacy organisation. The citizen advocate supports the partner using their natural skills and talents rather than being trained in the role.

Peer advocacy is also individual advocacy. Peer advocates share significant life experiences with the advocacy partner. The peer advocate and the advocacy partner may share age, gender, ethnicity, diagnosis or issues. Peer advocates use their own experiences to understand and have empathy with the advocacy partner. Peer advocacy works to increase self-awareness, confidence and assertiveness so that the individual can speak out for themselves, lessening the imbalance of power between the peer advocate and the advocacy partner.

2.1.2 Collective advocacy

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.

The aim of all models of advocacy is to help individuals gain increased confidence and assertiveness so that, where possible, they will feel able to self-advocate when the need arises.

² SIAA, *Guidelines for Advocates Working in Prisons 2013*

2.1.3 Advocacy Partner

The person receiving support from an independent advocate is often described as the advocacy partner and this is the term which will be used in this report. The term implies that it is a collaborative process, that the power lies with the advocacy partner and that the advocacy partner and the advocate are working together as a team.

2.2 Legislation and Policy

Due to her condition, Victoria is entitled to access independent advocacy under the Mental Health (Care & Treatment) (Scotland) Act 2003. This act mandates that “Every person with a mental disorder shall have a right of access to independent advocacy”³. This applies to people of all ages and circumstances. This has been a huge step forward in helping to protect the rights of people with a mental disorder. However many older people who would benefit from access to independent advocacy do not have any form of mental disorder and therefore do not have a statutory right of access to independent advocacy. The Mental Health Act is the only piece of legislation actively enforcing advocacy but it is included in other pieces of legislation and Government policy such as⁴:

- **Adults with Incapacity (Scotland) Act 2000 as amended by the Adult Support and Protection (Scotland) Act 2007.** The Adults With Incapacity (Scotland) Act 2000, as amended by the Adult Support and Protection (Scotland) Act 2007, states “In determining an application or any other proceedings under this Act the sheriff shall... take account of the wishes and feelings of the adult who is the subject of the application or proceedings so far as they are expressed by a person providing independent advocacy services.”⁵
- **Adult Support and Protection (Scotland) Act 2007.** The Adult Support & Protection (Scotland) Act 2007 places a duty on Local Authorities “...to consider importance of providing advocacy and other services”⁶
- **Patient Rights (Scotland) Act 2011 in Patient advice and support service** The Patient Rights (Scotland) Act 2011 places a duty on Patient Rights Officers to signpost individuals to “(ii) persons providing representation and advocacy services.”⁷

3 From *The Mental Health (Care & Treatment) (Scotland) Act (2003)* found at <http://www.legislation.gov.uk/asp/2003/13/part/17/chapter/2>

4 From SIAA's website found at <http://www.siaa.org.uk/resources/legislation/>

5 From <http://www.mwscot.org.uk/the-law/adults-with-incapacity-act/principles-of-the-act/>

6 From http://www.legislation.gov.uk/asp/2007/10/pdfs/asp_20070010_en.pdf

7 http://www.legislation.gov.uk/asp/2011/5/pdfs/asp_20110005_en.pdf

- **Social Care (Self-directed Support) (Scotland) Act 2013** The Self-directed Support Act places a duty on Local Authorities to provide "...in any case where the authority considers it appropriate to do so, information about persons who provide independent advocacy services (within the meaning of section 259(1) of the Mental Health (Care and Treatment) (Scotland) Act 2003 (asp 13)).⁸
- **National Care Standards: Standard 19.** "You have access to other agencies and services, such as advocacy, that can support you in making your needs and preferences known. They can, with your permission, represent you and give your views. Information on these services is provided in a way you can understand."⁹
- **The keys to life. Improving quality of life for people with learning disabilities (2013)** This policy recognises that advocacy [provision is patchy across Scotland. It states that "Not everyone will need or want an advocate but, as the Joint Committee on Human Rights report on the human rights of adults with learning disabilities highlighted, it is of particular value to people with profound and multiple disabilities."¹⁰
- **Road to Recovery. The Scottish Government Drug Strategy (2008)** The Government will set in train a number of actions to achieve a shared understanding of how to promote and support recovery, including the following: build the capacity of advocacy services, to help service users choose the treatment that is right for them.
- **Caring Together: The Carers' Strategy for Scotland (2010-2015).** This strategy confirms the importance and value of advocacy for carers in their own right and encourages support for the development of carer advocacy.
- **Standards of Care for Dementia in Scotland (2011)** - Promotes the importance of access to independent advocacy.

While these emphasise the importance of advocacy and recognise that providing access to advocacy is good practice **they do not form a sufficiently strong basis to ensure that all those who need it are receiving it.**

Apart from the **Standards of Care for Dementia in Scotland (2011)** all the other regulations refer to everyone, in any age group. Older people are doubly disadvantaged as there is no comprehensive national strategy that refers specifically to them and no standalone national strategy for advocacy for older people (in contrast with children and young people and other groups like mental health service users) (Dunning, 2010). As a result many older people (for example older people with a disability or impairment) fall between the cracks of these regulations and may be discriminated against.

⁸ From <http://www.legislation.gov.uk/asp/2013/1/contents/enacted>

⁹ From <http://www.nationalcarestandards.org/203.html>

¹⁰ From <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrightts/257/25708.htm>

It has been recognised in previous research and acknowledged by Government that advocacy is beneficial in helping to safeguard the rights of individuals, ensuring that they are empowered to make fully informed choices and that they are as fully involved as possible in decisions made about their lives and circumstances. Also, there is a general view that advocacy for older people is under researched and that funding for non-statutory advocacy in particular is insufficient (Dunning, 2010). There is still a substantial gap in provision of independent advocacy for older people.

3. Literature Review

3.1 Why is there a need for advocacy?

Some older people may have their independence threatened and their control over their lives and circumstances reduced as they become more dependent on services around them. It is important to support them in preserving their independence while treating them with dignity and respect at all times and protecting their safety (Qureshi & Henwood, 2000).

Harding (2000) argues that the importance of retaining independence and autonomy, being in control of one's life, having choices about how one lives and having one's privacy respected are important at all stages of life and especially in older age. Henwood and Waddington (1998) found reinforcement of such themes as groups of both older and middle aged people associated maintaining their independence with having financial security, appropriate and timely information and keeping a healthy body and mind. These are just as important for those who are less able as they are to very active older people.

However, some older people may feel unable to speak for themselves as a result of vulnerability or loss of confidence at a time of significant change, such as when entering a residential or nursing care home. Some feel that other age groups are more deserving, some are fearful that they will be seen as a burden. Dunning (2010) suggests there are several other reasons why older people may not always speak up for themselves including:

- preconceptions and attitudes held by society and services which can lead to age discrimination in the provision of services and/or medical treatments
- a reluctance to complain that arises from cultural attitudes held by some older people that those in authority know best

and/ or

- fear that complaints will lead to losing those services they are currently receiving.

Advocacy helps in addressing these issues by challenging attitudes and discrimination, supporting older people to consider their situations and make informed choices, ensuring their voices are heard and that their views and opinions are taken fully into account. Advocacy can have an even greater importance for people who may have lost friends and family and are living in isolation with very little access to information or other forms of support. In such a situation a vital aspect of the advocacy role is to address social isolation and support individuals to be included in their community.

3.2 Measuring Outcomes

In order to understand how we measure the impact of advocacy, it is important to consider an advocate's role. Previous literature distinguishes between an instrumental role of the advocate, which is more formal and focused on the doing or representing, and an expressive role of the advocate, concerned with "being" and emotional support (Dunning, 2010). Although both aspects are often needed by the same person to advocate effectively, the focus in research is on the instrumental role. This relates to the distinction between outcomes and processes of advocacy. The processes are seen as the actions taken in pursuit of a specific goal and can produce positive changes like more choice and control for the advocacy partner, improved empowerment, and improved quality of life. The outcomes are those positive results like policy changes, self-advocacy and changes in how services operate. Considering these distinctions, measuring the impact of advocacy is not always straight-forward.

At the same time, there are a variety of advocacy organisations and types of advocacy which makes it a lot more difficult to determine what should be measured in which type of organisation, and the comparative value of different types of advocacy and organisation (Rappaport et al 2005). There are no widely agreed benchmarks to test performance (Henderson & Pochin 2001) and only a few such models currently exist. This has led to a tendency for purchasers of advocacy (usually statutory organisations) to impose their own monitoring regimes on advocacy schemes (Henderson and Pochin 2001). Furthermore, the literature suggests that an understanding of the effectiveness of existing evaluation models for advocacy is patchy as commissioners do not systematically collect or scrutinise the outcomes of the advocacy services that they fund (Hussein et al, 2006). It is possible to measure whether or not the partners achieved what they set out to do, but as others suggest there are different kinds of outcomes: hard outcomes and measurable ones but also soft outcomes that have to do with a deeper impact on individuals' lives and experiences like trust, breaking social isolation, feeling valued. Advocacy per se is an under-researched topic and the available literature rarely attempts to address its effectiveness (Atkinson & Forbat, 2003).

The involvement of advocacy users in the evaluation and development of the support that they use has been argued by several authors (Whittaker, Gardner and Kershaw 1990). For example, acknowledgement of ways in which people with learning disabilities can and do participate in evaluation is not widespread and good practice does not appear to be widely disseminated (Manthorpe, et al 2005). Service user involvement in the evaluation process is therefore an important component of any credible evaluation tool. Coyle (2009) as well argues that in order for an outcome based evaluation to be effective we need to understand what advocacy achieves for individuals and their communities.

Based on Manthorpe et al's (2005) suggestions, and using Coyle's (2009) tools for measuring the outcomes of advocacy, this study uses the information gathered from 13 interviews conducted with older people to offer an insight into how older people value advocacy and their own perception of the impact it has had on their lives.

4. Key Findings

4.1 Challenges for participants

All of the participants interviewed had accessed advocacy for different reasons, they were all experiencing a range of issues some arising from changes in their environments and/or circumstances or situations. These included for example losing capacity, changing house and dealing with loss. A lot of the participants were experiencing the loss of certain capacities such as sight, hearing and sometime cognitive impairment. Some talked as well about having reduced mobility and dealing with illness.

All the participants, while coping with changes, had experienced a range of difficulties including for many a loss of control over their own lives or circumstances. This had led them to seek advocacy. These changes and difficulties had long-lasting effects, eroding some people's confidence and increasing their anxiety levels which then impacted their ability to access and process information.

Some participants talked about experiencing a loss in confidence as a result of old age; a general loss of confidence in their capabilities (physical and cognitive) and especially in their ability to stand up for themselves and make decisions. Additionally, a decrease in mobility for some created physical barriers to accessing the information they needed to make informed decisions. For those without internet access who were unable to visit their local library or Citizens Advice Bureau this meant they were reliant on people around them, family, friends, support staff, for information.

For many these issues increased the difficulties created by having to deal with a potentially stressful situation such as going through a transition period (changing house, going into hospital or going into care) or going through a complaint procedure. Such stresses can take a toll on people's general wellbeing and may lower their confidence even more or adversely affect their mental health.

4.1.1 Lack of external support

Some participants reported that a major factor they felt contributed to a loss in confidence was a lack of external support, especially family support. They reported feeling isolated and lonely of not having anyone on their side or who might help to safeguard their rights. Especially for those participants who had been abused by their family or had lost contact with them, the feeling of isolation was even stronger and it left them feeling vulnerable. Callum is still upset about breaking the ties with his family. He talked extensively about his niece and was very proud of his children. At the same time he spoke about his daughter physically abusing him which had caused him a lot of distress. He had also discovered that a great deal of his money had been stolen. He was referred to the advocacy organisation when he moved into a care home.

"I had nobody, even my own family was against me and that was really bad"

Callum

Victoria had been alone for a long time since her husband died and after breaking ties with her children. She suffers from Korsakoff's Syndrome and until recently she had been living on her own. She told us that she had felt increasingly scared and vulnerable to people taking advantage of her. She had become increasingly unwell and was referred by a Social Worker to her local advocacy organisation when work was underway to move her into residential care. Victoria reported that the support she received at that time and since then from her advocate has given her confidence that there is someone she can trust to make sure her views and wishes are always considered.

"I thought, I'm not gonna have anybody to help me, my family were away...

I'm grateful to have good intelligent people here to help."

Victoria

Roger who is visually impaired is the main carer for his wife, Denise who suffers from dementia. They had severed their ties with family members as they felt the family were taking control over their lives and were going against their wishes. Roger said that his family had wanted them to move out of their home and into a care home which they did not wish to do, he felt that the Social Worker involved at the time was listening only to his family and not to his or Denise's views, at one point he reported that he became very depressed and had attempted suicide. Following that he was referred to his local advocacy organisation. He told us that he felt that the advocate listened to him and made sure that their views were heard; they felt that they had someone on their side.

"Our family didn't help us but she's [the advocate] been there for us"

Roger

These examples demonstrate difficulties which some of the participants have had and the challenges they faced. All felt that they had limited or no external support from family or friends before the involvement of the advocate and that advocacy support made significant differences to how their own views and wishes were taken into account when decisions were made about their lives and situations.

4.1.2 Knowing your rights and making informed decisions

Apart from feeling isolated and unsupported some participants also felt that there was at times a lack of clear communication from professionals which made it very difficult when it came to making informed decisions. Additionally, some participants reported that they had not routinely had access to information about all options. Some participants found it difficult to make sense of all the services they were dealing with and many remained confused as to the differing roles and responsibilities of the varying professionals they dealt with. Some participants felt frustrated at their lack of options but also by their dependence on the staff and services around them for information and guidance. This became especially stressful in times of illness or in times of transition. In these cases participants told us that they felt advocacy addressed the information imbalance and gave people the opportunity to make their own choices, which at times differed from the ones recommended to them by services.

Roger and Denise were going through a transition period as their health worsened and were forced to move from their house as they not did feel safe anymore. Roger told us that he did not know what their options were and that he felt disempowered by the official language and lack of information provided.

***“We looked after ourselves all our life and suddenly these things coming up... things you haven’t got a clue what they were speaking about.”
Roger and Denise***

The advocate supported Roger to gather information about different options and, in particular different sheltered housing complexes. Donald had been put in touch with his local advocacy organisation by social services. He is elderly and is the main carer for his wife who has support workers coming in twice each day to provide help with washing, dressing and going to bed. With the support of his advocate Donald found out about adaptations that he could have installed in his home that would help him and his wife. When he and Denise had decided on the complex they wanted to move to the advocate supported Roger through the process.

***“Anything I have, like something I’m not understanding... I give [advocate] a ring and he keeps me right. [the advocate] tells me that there are things I can get help with; you know, maybe what I need.
Donald***

Chris found out about advocacy from his local Citizens’ Advice Bureau when he asked about making a complaint to the hospital where his wife died about the care and treatment she had received leading up to her death. He had tried to deal with this himself but felt that he was not being listened to and felt upset and angry. Chris told us that the advocate ‘knew the procedures’.

***“oh yes. ... without her we would’ve had to find out ourselves from well... wherever you go, I don’t know. Probably had to go to a solicitor...”
Chris***

Callum also spoke about how his advocate supported him when he was sorting out his finances. He reported that most of his money had been stolen by family members, his advocate supported him to go through papers and in a trip to the bank where he discovered he had funds he had forgotten about. This was a huge relief for Callum as he had become increasingly depressed about his financial situation.

Several of the participants reported that, in times of great stress, they had experienced significant difficulties when it came to accessing relevant information. They went on to explain how their advocate had helped them to gather information and identify possible options. Callum found out, with support from his advocate, that he could live in sheltered housing rather than in a care home. He was quite surprised to find out there was such a place as previously he had believed the care home was his only option. Callum told us that the move has had a huge positive influence on his life as he had been very unhappy in the care home previously.

Laura used advocacy to find more support in the community following the closure of the day centre she had attended. That was really important to her as she had relied on the day centre to get ongoing support for her mental health condition. Laura found herself in a stressful situation and it was very important to her to find additional support in order to be able to stay in the community and maintain her independence.

“The advocate got it all sorted out [...] working with me, phoning things up, going and asking me what I wanted out in the community”

Laura

All these cases demonstrate the additional pressure of dealing with this information imbalance. Very often participants were very clear about what they wanted but they were told that they could not get it or that it was not in their best interest. Advocacy helped to ensure that people had access to the information they needed to make informed choices and ensured that they were able to take control over their lives.

4.1.3 “I wanna do my own thing” - independence and empowerment

It became very clear that, contrary to how older people may be portrayed as vulnerable and subdued victims by the media or other literature, the participants valued their independence above everything and they were fighting to secure that and to make sure that they were being listened to. Although some of the participants had been financially and psychologically abused they retained a strong desire to be independent and have control of their own lives and circumstances.

Sam told us that, following a stroke, his family wanted him to move to a care home. He did not want to do this but he felt that the social worker assigned to him was agreeing with his family and not listening to him, he felt that all control over his own life and situation had been taken from him.

“She [the care manager] tried to run my life. I don’t like anybody running my life. I want to be independent; I wanna do my own thing.”

Sam

He first became aware of advocacy when an advocate from the local advocacy organisation visited the care home he was living in. He then got his own advocate who supported him to move out of the care home. He is now in sheltered housing and feels he has regained control over his own life, decisions, timetable and the life style that he prefers. That was really important to Sam as he has been independent for most of his life. Sam believes that without the support of his advocate *“I would be still in the care home.”*

Diane had similar issues about living in a care home. She is visually impaired and has severe mobility issues as a result of MS. It is very important to her to have some control over her environment so she fought to secure the technology that would help her preserve her independence. She lives in a sheltered housing complex and has support workers who come in several times a day to help her with personal care. She feels that, without the technology and adaptations in her flat she would be even more dependent on the visiting care staff.

“This place would have you sitting in a chair and doing everything you’re told and I won’t have that. I won’t allow it. As I keep saying, I’m not stupid.”

Diane

When a problem arose with the technology in Diane’s house she told us “I fought, but no one listened.” Diane heard about the advocacy organisation through the sensory impairment support organisation she was in touch with. She told us that *“people think because I’m disabled, I’m stupid. I’m not. I’m far away from stupid, I’ve got my head screwed on the right way and they won’t listen to me but they’ll listen to [advocate].”*

Callum also was really unhappy about living in a care home and accessed advocacy support to move to sheltered housing. Before that, he thought his wishes were being bypassed by his family and carers and had no control over his life. He felt that he was alone.

“I had nobody, even my own family was against me and that was really bad.”

Callum

The same story was told by Roger who felt powerless and caught between his family and the services.

“We weren’t being allowed to make decisions, cause the social worker was making decisions about us through our family. And when we rebelled and got [advocate], she got a hell of a life from my family for a while, they didn’t want her interfering, they didn’t want her cause she was looking after our own interests. And she did, she sorted it”

Roger

A lot of the participants were dealing with a range of changes around them either in their health or ability or their environment. These accounts are evidence of their active struggle to maintain their independence and that advocacy is actively helping them achieve that goal.

“I can speak up more and [advocate] is helping me learn how to stand up for myself and do things myself.”

Laura

4.1.4 Difficulties in dealing with official matters

Many participants reported experiencing lower confidence and changes in their capacities. They spoke about having difficulties in dealing with bills, official documents, letters and forms. Below are several accounts of difficulties in dealing with official documents, from older people. The participants talk about the pressure of dealing with these procedures and how advocacy has helped alleviate this pressure.

Sam has a visual impairment and told us that he had experienced psychological and financial abuse by his relatives. He feels anxious and stressed when having to deal with bills or forms. He relies on his advocate, Jackie, to help him to deal with them. He told us that he had real difficulty at times dealing with official correspondence.

"No I couldn't dae it, I panic. [Advocacy] helps me a lot."

Sam

Chris has found the support of his advocate invaluable when raising the complaint with the hospital about his late wife's care and treatment.

"Because, ah, when you're old you can't stand the pressure the same you know, I don't have the confidence I had say 20 years ago"

Chris

Louise has recently lost her husband who previously had dealt with all the formal documents. She also has learning difficulties and mobility issues which have reduced her confidence in dealing with formal issues. Since her husband's death, Louise has been accessing advocacy to help her deal with 'red tape'. Amanda, her advocate, also supported her when visiting her bank to set up direct debits after moving house and organising suppliers.

"Well I cannae deal with letters if there's a letter coming [Advocate] helps me "

Louise

Victoria spoke about not having confidence in dealing with forms and paperwork, particularly as she is not familiar with all the words and official phrasings.

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

Victoria

4.1.5 Upholding rights and dealing with complaints

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

For these reasons many of the participants started using advocacy and they have really valued the support received. Not only did the participants believe that the advocate had helped them communicate better with those agencies services and institutions but they also felt that having an advocate was like having a back-up. They felt that the advocate would safeguard their rights. Advocacy made a huge difference for the participants when it came to taking control of situations and their own lives.

Chris had been trying to complain about the circumstances of his wife's death for over 2 years. He was very upset by the feedback he was receiving and sought advocacy support to help him forward his complaint. They are now at the stage where the British Medical Association is considering his complaint and Chris is quite happy with the outcome so far.

"...without it [advocacy] we would've never been anywhere where we were. Never in a million years. ... Oh they've been marvellous."

Chris

Getting this far in the process was really important for Chris. He believed it had a positive impact on his health having the advocate on his side helping him to take this forward. Mary was in a similar situation. She was trying to flag up some issues around the care and subsequent death of her mother. She was seeking acknowledgement that certain things had happened, to be listened to and not to be simply dismissed as a 'troublemaker' which she felt had been happening.

"so the advocacy came on board and just having somebody there to discuss it with and realise that the incidents had happened, you know. Actually taking on board what you were saying... [the advocate] contacted the registration service and the [Care Inspectorate] so it took the bulk of it off me ... [the advocate] did the contacting arranging the meetings, reminding me of what I wanted to say"

Mary

The advocate helped to secure a meeting with a manager and Mary was given assurance that the manager did believe her. That has taken a lot of pressure off Mary and made her feel confident that she's doing everything she can to address this issue.

Diane has had advocacy support in dealing with her local council when she was having difficulties with the technical adaptations, for example to doors and telephone, installed in her home to support her to lead a more comfortable life. She could control these adaptations from the remote on her wheelchair. There had been an incident with Diane's devices and she was struggling to redress the situation.

"...and advocacy took it up with the city council... I did eventually get compensation but we didn't ask for it. The council was feeling guilty cause they'd taken so long to sort it out but [advocate] has helped me with a few things"

Diane

The same concerns are echoed by Roger who had sought advocacy support for help with the issues he had care services for him as well as for his wife.

"... we were being cared for, in our own home by care companies, now they made mistakes, with the tablets, mistakes with the needles, everything, [care staff] didn't turn up, turned up, didn't turn up so we had a row of companies ... the council took us over after that and the council carers, they were worse. We got in touch with advocacy and they helped us to get it sorted out to such an extent that the lady in charge of the council workers came to our house in front of witnesses and apologized for the care workers"

Roger

All of these participants talked about the importance, along with having requested changes made, of receiving some acknowledgement from those agencies, services and institutions of their complaint and their rights. Many reported they felt that was a validation of their struggle and proof that they had been listened to. In all these cases advocacy support was instrumental in putting people's views across, making sure that the views, wishes or complaints got to the right people and getting the acknowledgement participants felt they wanted.

Most participants agreed that the services they were dealing with were doing their job; however participants struggled to cope with the fact that felt they were often not consulted on all the decisions being made about them.

This confirms the findings of previous research (Jenkins, 2012) which argued that sometimes older people are bypassed by carers or social workers. Participants credit advocacy for helping them redress that power imbalance and for making sure that their view is clearly got across. Some participants acknowledged difficulties for them in getting their point across clearly but others were very clear about what they wanted and told us they had no problem speaking up but without advocacy support they felt that they were just being ignored.

Diane told us that she had experienced discrimination which she felt was due to her disability. She felt it was that which prevented her from getting her point across to certain services.

"I would try [to get her point across] but no one listened, much though you try no one listens. They think you're stupid cause you're disabled"

Diane

Roger also believed that while he had tried to communicate with services, he felt that both he and his wife were ignored and so were not in control of their lives.

"Well we didn't have any backing before. We were on our own. We just spoke. There was nobody to back us. [Advocate] listens ... it definitely gives a lot of confidence."

Roger

4.1.6 Loss of confidence

These changes in their lives and a sense of no control over their environments or the choices they were offered often eroded the participants' self-confidence and their ability to stand up for themselves or even participate in discussions or decisions that were being made about their own lives and circumstances. This decrease in confidence was at times worsened by the stress of dealing with difficult and emotional issues with, often, high stakes for the participants.

Callum felt he was in a desperate situation as his wife had died, he had no money, he was in a care home and his health was deteriorating. These combined had a strong impact on Callum's confidence and made him think there was nothing left to do.

"[advocacy] saved my life because I was very down, I was very depressed,"

Callum

Chris felt that his confidence was lower due to the aging process, as his eyesight and hearing were deteriorating. Several of the participants associated older age and physical deterioration with mental deterioration. People stated that they felt that they were "not the person they used to be".

"...when you're old you can't stand pressure the same you know... myself, I don't have the confidence I had say 20 years. 20 years ago I was a different person. No, no you don't have the same confidence."

Chris

The same views are echoed by Victoria who used advocacy to get some support in dealing with legal matters but also because she needed someone to trust.

“I’m not as young as I was, I’m not looking for sympathy but when I was younger I would’ve been more sort of a supporter for myself and I’d say no, I won’t take this, here’s the door just go and don’t come back. I’ve lost a bit of confidence and I used to be a very confident lady, but people can reduce you ... if they keep attacking you know.”

Victoria

Some participants experienced a loss in confidence after feeling disempowered by the services they were dealing with. Donald had accessed advocacy to help him find out about services he could access and to find out how he can be more in control when dealing with the services around him. He found dealing with a service was an intimidating experience if you are not familiar with their workings.

“Well I never dealt with social services in my life before, I didn’t know which way to go and I was just in the hands of people telling me here, there and there.”

Donald

Some participants stated that they did not want to cause trouble because they feared they would stop receiving the service.

For Martin, this lack of confidence manifested through him actually losing the volume of his voice. He felt out of control as he was being moved from one hospital to another and also unable to stand up for himself so he would refuse to go to meetings about his assessment.

“What happens is that I usually lose the volume of my voice, especially if there are a lot of people around I’ve got to speak to. I don’t know why but I just lose it... the capacity to speak. ...my retrieval of data from the brain the recall, doesn’t work. So she [the advocate] would be able to step in at that time and say something for me when I had meetings.”

Martin

In this case the advocate acted as a spokesperson for Martin, making sure his views were heard during the meetings and that he was contributing to decisions about his care. Martin is now in a care home of his choice.

4.2 Soft outcomes

4.2.1 “A problem shared is a problem halved” - invaluable emotional support

Most of the participants were happy with the processes of advocacy and how they had been supported to achieve their goal such as moving out of a care home, changing house or having their complaint acknowledged. However, as mentioned earlier, advocacy also had a deeper impact on the participants relating to being able to trust someone, feeling valued and reducing social isolation.

Some of the participants reported experiencing relief at having someone to share their problems with, having someone to talk to. Mary for example talked about how she felt that advocacy took a weight off her shoulders as she had previously felt responsible for the way her mother had been treated. Having someone to discuss things and check things out gave her confidence and a belief that she was doing the right thing and she no longer blamed herself.

Martin appreciated the fact that through advocacy you could talk about issues and “bounce ideas off someone”. This made him feel like he had someone he could trust, that he was not completely alone and that he had the support he needed to make choices that were right for him.

For some participants knowing they have this support and someone they can contact when they needed help was even more important than having a positive outcome.

“I feel now that I can discuss it with someone who knows a bit more than me rather than me wondering what I can do here, ... they [the advocate] knows the situations and the help you can get from various quarters.”

Donald

This also echoes how important it is for people to know about their rights, to have easy, full access to information and to know that advocacy can help with that.

Diane feels that she has someone to support her point of view and even though she is aware advocacy has limited powers, knowing that she is not alone in her struggle has made a huge difference to her comfort and wellbeing.

For Chris advocacy has helped him look objectively at his problem and get some peace of mind. It has reassured him that someone is there to help him and that he feels confident.

“I would know what to do to but being able to do it on your own is a different matter... it’s a weight off your shoulders.”

Chris

For Roger advocacy was there to support him when he and his wife were looking for new accommodation. He felt that he and Denise were abandoned and let down by all those around them. Advocacy supported him so that he and Denise could have a lifestyle where they feel safe and in control.

“We could’ve done none of this without [advocate]”

Roger

Louise told us she believed that advocacy had helped her find solutions to her problems, like finding a house and moving, finding carers and getting help with her mobility issue.

“If I didn’t have [advocate] I would have nobody.”

Louise

4.2.2 Improved well beings

It is inevitable that stressful and difficult situations can have serious consequences on an individual's health as stress is related to a number of health conditions. It becomes obvious that relieving some of the pressure and making individuals feel supported can make a positive impact on people's health and their general wellbeing (Helliwel & Putnam, 2004).

Donald illustrates this very well as his advocate has helped him with information about his right to access support while also providing reassurance of a willingness to help.

"it makes me feel better day by day rather than worrying about something and I can discuss it with them and get a solution"
Donald

Donald's words illustrate the fact that feeling in control is very important for general wellbeing. Advocacy plays an important role in supporting people to regain or maintain control over their lives and their situations.

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

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

Victoria also believes she feels better since she first accessed advocacy and less worried and frightened since she's moved home. Advocacy helped her regain trust in her own abilities and trust in those around her, before then she felt that she had lost control over her life and her illness.

Mary believes that after getting some acknowledgement for her complaint she *"felt 20 times better"*. Advocacy had helped her not only relieve some of the pressure she felt in dealing with the process by herself but also by supporting her to achieve some redress.

Similar views are echoed by Chris for whom advocacy has made a huge difference in relieving the tension of dealing with his complaint against the hospital.

"It's a big load off my shoulders."
Chris

4.2.3 Reducing social isolation

For some of the participants their advocate was the only constant presence in their lives apart from their carers. However, the nature of their relationship with their advocate meant that they felt valued which they believed improved their general wellbeing. They felt it was important having someone to talk to on a regular basis when they faced difficulties. For people who lead really isolated lives that made a huge difference. For Victoria having an advocate visit her regularly in hospital and in her care home helped her regain confidence in those around her.

“Even coming up to the hospital and seeing me, ... I felt it was good to know there was somebody that believes in you and you know that you can trust them”

Victoria

This also demonstrates just how important the soft outcomes of advocacy were for people's lives and how much of a difference it made to their wellbeing.

5.The processes of advocacy

5.1 Meaning of advocacy

Participants were asked to think about what advocacy meant to them. From their responses it was clear that their perception of advocacy is hugely influenced by their personal experience of it. Some people emphasise the support role of advocacy while others mention the instrumental role of “getting things done”.

Roger drew most value from the feeling that someone was watching out for him and his wife and he sees advocacy as a safeguarding service. He captures the aim of advocacy to improve people’s wellbeing.

“There’s somebody looking over our shoulder for us and that’s the only way I can describe it.”
Roger

The same views were echoed by Mary who saw advocacy as something that is continuous and instrumental in relieving her of the pressure of dealing with official matters.

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

For Diane advocacy was about getting help to deal with official matters and also about representing her and getting her views across. She valued the effort her advocate put into helping her.

“Just helping you with things ... [advocate] is very good and she will help me call and do things like that and try and sort the paper work “
Diane

These views are also echoed by Laura who also believed advocacy was a way to give feedback to the service she came in contact with.

“Helping people, helping you with your problems and telling the government what’s not right and what is right with organisations”
Laura

Donald told us the term advocacy was not very clear to him at first and he was surprised to come across such a service.

“The first time I heard about advocacy... I didn’t know what it was about until they come in and started working with Flora [his late wife] and I didn’t know there was such a thing.”

Donald

The accounts indicate that, depending on their own experience, people have different views on the role of advocacy. Most importantly these accounts are indicative as to the contextual nature of advocacy and the focus it has on the advocacy partner, fitting around their needs and putting them at the centre of the process. However, all the participants agreed that, before they were referred to their local advocacy organisation, it was a service they knew nothing about.

5.2 Advocacy an unknown service

When participants were asked how they had found out about advocacy almost all of them stated that they had been surprised at the fact there was such a service and especially at the fact they had never heard of it before. This reflected the findings included in Wright’s (2013) report for the Older People’s Advocacy Alliance.

Most of our research participants had been referred to advocacy by care homes, social workers or Citizen Advice Bureaux. The fact that other services are willing to make referrals or ensure that people find out about advocacy is testament to a widespread belief of the value of advocacy. All the previous accounts illustrate the different and intricate ways that advocacy can bring positive change to people’s lives. Moreover, advocacy provides a service that is unique because of its mix of instrumental or measurable outcomes and expressive ones, helping improve people’s confidence and quality of life. These are some of the accounts on how people came across advocacy. When asked how they had heard about advocacy responses included:

“With a lot of difficulty, there was a lot of difficulty finding it to start with, once we found it it was perfect after that”

Roger

“I didn’t know what advocacy was until I got a notification in to say they were coming in to see me and after they came in and explained things it opened my eyes with what they could do”

Donald

“I just couldn’t believe there was such a service for people.”

Mary

“My son went down to the citizen advice and the lady there she couldn’t help with this but she told us about advocacy and that’s how we found out but I never heard of it before [advocacy], never ever.”

chris

Laura spoke about her discharge from a long stay hospital and the support from her advocate during the move. She was clear about how important advocacy is in relation to transition services for people who have been institutionalised. For Donald discovering advocacy gave him a new perspective over his passive relationship with the services around him and made him think about things he could have access to.

All participants found the support from advocacy invaluable but many had been unaware of the existence of advocacy before being referred to their local organisation. These examples illustrate a lack of awareness of independent advocacy. Advocacy organisations increasingly are unable to undertake much awareness raising work due to limited resources which can result in advocacy not being as accessible as it should be.

5.3 Advocacy practice - on the right track

Apart from the impacts on people's lives it was important to understand if the advocacy organisations were adhering to best practice as defined in the SIAA Principles and Standards for Independent Advocacy and the associated Code of Practice. It is important that advocacy organisations follow this best practice guidance for the benefit of the advocacy partners.

For this study we wanted to identify if advocacy was indeed putting the people who use it first. Participants were asked questions about the advocacy process in order to understand if they had felt actively involved in the process and in taking control over their circumstances and environments. All of the participants gave positive accounts of their experiences of advocacy processes. All had felt consulted and felt that they were ultimately in control over the process. Participants clearly felt that they were listened to and valued and that their views did matter. The fact that people gave really detailed accounts of how they had felt involved in the process is an indication that it had been significant to them.

For example Victoria had some cognitive impairment and she could not always remember the precise details of either her advocate's name or the circumstances under which she met them. She did not feel comfortable with her bank anymore and wanted to change to another bank. Her advocate supported her through the process and Victoria explained that she felt fully involved and in control, this had a significant impact on her.

"[the advocate] said, where would you like to go? I said I'd never been in this bank but hopefully it will be ok ... I was all shaky inside, and she explained for me [to the bank clerk], "Victoria is not feeling good today ... any questions she's not too sure about we'll talk through with her" and [the clerk] said "oh no, that's alright, that's fine"

Victoria

Diane also felt in control of the process and that she was making the decisions.

"she always told me what she was doing and included me in the choices, always asking do you want to do this and she was excellent. I always felt supported with her."

Diane

Mary details the process of working with her advocate, and how they jointly decide what will be the responsibilities of the advocate while making sure she was kept informed of the development of her complaint.

"... I was kept informed, everything that was going on, she [advocate] knew exactly how I felt she knew exactly what I wanted out of it so she really did perfectly."

Mary

Roger's account of how his family were opposed to his wishes and to him having an advocate illustrates very well how family and services had sometimes different interests to those of the participants and the importance of there being no conflict of interests for the advocate. Advocacy is crucial in making sure that person's views are fully taken into account and that they are not being bypassed by those around them who although they may believe they are acting in the person's best interest, might ignore the person's desires or opinions. Donald cared for his wife who had an advocate. His views might sometimes differ from those of his wife and, in order to avoid any possible conflict of interest, he was referred separately for an advocate who would represent his views as his wife's carer. This example shows how in this case advocacy avoided a conflict of interests.

Another example of good practice in advocacy is given by Laura's case. Laura had been working with her advocate for several years; her advocate found out that Laura's friend was stealing her money. Laura did not want anything done about this however her advocate, following the organisation's policies and procedures and the Principles & Standards for Independent Advocacy, reported the situation to her manager who made a referral to the Adult Protection Committee.

6. A voice for older people

The idea of advocacy as a way to give older people a voice was articulated by a participant, Roger, who felt that no one was taking notice of his views in regards to matters about his and his wife's lives. Advocacy helped them "get a bit of backbone" and was a way for their views and wishes to reach those that could do something about it.

Laura is convinced that advocacy is a way for people to make their views heard by service providers, a way to address injustice and mistreatment. Some participants talked about not knowing where to take issues with services and the fact that their advocate helped them to raise these to the right people to help increase their chances for a positive outcome. As Mary told us, advocates know how to get to "the right people" as they are familiar with the workings of public services. For Martin, advocacy has helped give him a voice in the most literal sense as he loses his voice when under pressure. Having an advocate has meant that Martin feels that he is getting his point across.

These accounts have shown that participants believed that they were discriminated against and their voices ignored when they were on their own and that advocacy helped them get their views across. It is important that advocacy can support people to make their own informed choices and to be fully involved in matters and decisions about their lives. However, this becomes increasingly problematic when considering all the people in Scotland who are not using advocacy or do not know that advocacy exists.

7. Describe your advocate - instrumental and expressive roles

The participants were also asked to describe their advocate and all of them spoke warmly and with great enthusiasm about how much they appreciated their advocate and how much help they had received. Surprisingly there was a balance between the formal role of an advocate and the informal role and people valued both equally. Most of the participants talked about the availability of their advocate, how they could always call them or leave them a message if they had a problem. They trusted that the advocate would get back to them. This feeling of trust and of continual support made a significant contribution to some of the participants' lives as they felt less worried and anxious about dealing with services and unpredictable situations.

The respondents were also very appreciative of how they were the focus of their advocates' whole attention and how reliable the advocate had been throughout their relationship. This is particularly important when considering that some of the participants were disillusioned with the services around them and the lack of purposeful communication with those services. The participants' accounts point to very strong personal relationships developed with their advocates based on the trust the advocate inspires. There was also a lot of praise for the advocates' interpersonal skills and their capacity to listen without judging and be open and approachable. Although all those interviewed were aware that it was a professional relationship they all felt very close to their advocate. These are some of the accounts:

"She's a lovely person, easy to talk to, very very professional and very punctual. You know what I mean. If she says she'll be here at a particular time she's here."
Chris

"They're very compassionate people, and they listen to people's needs"
Laura

"Very very open to what you're saying, very comfortable, she makes you feel totally relaxed and she gives you her whole attention when you go for an appointment with her."
Mary

"She says 'sit where you are', makes a note and she comes and sits there and phones and sorts it out. She really is a good woman."
"...she's done a lot of good for us and she's never too busy. She says she'll phone me up or if I leave a message she phones up"
Roger

"She's [Advocate] always great, she's always smiling and everything,she always kind of calmed me down, never said shut up or anything like that, she would say we'll get this in hand and everything and that gave that wee bit of spur to keep going cause I was ready for taking a breakdown."
Victoria

"...they really done wonders, I don't need to worry anymore because [Advocate] keeps coming in to see me and he's telling me about different things, about what's happening outside. I never had anybody like that."

Callum

Along with the practical outcomes, for those interviewed, the fact that they were listened to, that they felt continually supported and felt they were treated with respect and taken seriously was what mattered most for them.

8. Challenges of advocacy

Our research showed that, for older people, advocacy can be a vital component in the prevention of or protection from abuse. Advocacy support can be crucial in making a decision about entering a care home, whilst living in a care home or in the event of leaving a care home due to its closure or change of circumstances. However, some older people can have little understanding or awareness of the term advocacy (Northway et al 2004) or how to access it (Scourfield, 2007). This suggests that there is a need for active promotion of advocacy to older people.

This becomes problematic when considering funders' focus on statistics and quantifiable results which inevitably leads to the needs of older people being overlooked in favour of statutory targets and priorities (Rappaport, 2006). The SIAA Map of Advocacy across Scotland 2013-2014 edition shows static or reducing funding and increased demand across all advocacy provision along with requirements by commissioners in many areas to prioritise those with a statutory right of access and even further reducing that to those facing compulsory measures under the terms of the Mental Health (Care & Treatment) (Scotland) Act 2003. As a result advocacy provision for older people is by no means universal.

8.1 Limits of advocacy

Although most participants felt very strongly about the positive effects advocacy had on their lives, some participants were very aware that advocacy has limited powers. For those who are terminally ill or in very complex situations, advocacy cannot "turn things around" as it did for some. The same goes for those who feel that the problems in their lives will not change. For example being resident in a care home and feeling as if one's life and choices are restricted or controlled by others. Advocacy is not a miracle solution to everyone's problems and it is important to remain aware of that. Nonetheless, given that advocacy had an instrumental role in improving the wellbeing of the majority of those interviewed is a strong testament to the importance of advocacy.

9. Conclusion

9.1 What are the existing evaluative measures for advocacy?

Following a literature review, it is clear that currently there is only limited research about the impact of advocacy and much of that research has focussed on professionals and service views, there is very little that has sought the views of those people who use or have used advocacy. Previous authors look at the different roles of advocacy and distinguish between outcomes and processes of advocacy. Most of the literature focuses on measuring the outcomes with a focus on providing evidence for commissioners. Because of this, the views and experiences of advocacy users are often not taken into consideration. Measuring the impact of advocacy can be problematic when we consider that while some impacts will be clearly defined and measurable others may be hard to measure, so called 'soft' outcomes.

9.2 What impact has advocacy had on those receiving it?

Overall all of the participants felt advocacy made a positive impact on their lives, improving people's wellbeing and their ability to regain control over their lives. Advocacy is especially needed in times of transition, when moving home, going into care or dealing with the loss of someone close. Advocacy is crucial in maintaining independence. As older people deal with changes in their lives concerning loss of ability or loss of control over environments, they are still trying to maintain their independence. Very often their views are bypassed by services or families for the sake "of what's best for them" and advocacy has helped them make their views heard.

- Advocacy can help older people maintain their independence. The support participants had accessed helped them to regain control over their own lives and situations, either by finding new accommodation, making complaints or dealing with the services around them.
- Advocacy can help older people access relevant information and address any power imbalance. Participants credited advocacy with helping them access the information they needed in order to make informed choices, challenge the status quo and achieve their goals.
- Advocacy helps safeguard the rights of older people.
- For those older people suffering from a (perceived or actual) physical or cognitive impairment advocacy can offer vital support when dealing with official matters. Some of the participants reported on how their advocate helped them make sense of official documents and ensured that their views were heard when raising an issue with statutory or non-statutory agencies or when making a complaint.
- Advocacy makes the advocacy partners feel valued and listened to, improved their confidence and contributed to reduced stress when dealing with difficult issues.

Appendix 1- Methodology

In addressing the aim of this research, namely to explore the impact of independent advocacy on older advocacy partners, selecting a suitable methodological approach was made with the help of existing literature and existing models. As suggested by others, capturing the full impact and implications of advocacy is very difficult and a quantitative approach would fail to detect the nature of people's experiences with advocacy. That is why, for this study, a qualitative approach was deemed more suitable.

The study has an exploratory nature, as it tries to uncover individual experiences of advocacy and understand the impact advocacy has had on the participants' lives. Given the exploratory nature of the research it was decided that an approach which examined individuals' own perceptions of the impact of advocacy on their lives would allow for more particular and detailed analysis of the underlying structures, focusing on the depth of research (Saunders, 2009). In the study data collection is used to explore a phenomenon, identify themes and patterns and create a conceptual framework.

In order to understand the variety and multiple dimensions of the advocacy partners' experiences it was decided that semi-structured interviews would provide a more robust set of findings. The focus was on listening to people's life stories without intervening, very much echoing how they would talk to their advocate as well. It is through analysing these accounts that we could understand how advocacy has influenced those using it.

RESEARCH METHODS

Semi-structured interviews are preferred by most researchers as they provide a convenient way of ensuring both consistency and flexibility in the study. Moreover, it allows for the basic topics to be covered with all participants while allowing participants to discuss their own concerns (Bryman, 2001). This has proven invaluable in identifying issues that were not considered by the researcher.

The questions were created based on Coyle's (2009) research on measuring advocacy outcomes and they focus on the difference before and after using advocacy services. The order of the questions was not always respected as it was more important to maintain a flowing conversation. As the participants had very different life experiences, not all the topics were always relevant.

In total, 14 interviews with older people using advocacy and one interview with an older board director for an advocacy organisation were conducted. However, we are aware that this sample is not statistically representative of older peoples' experiences of advocacy, given the variety in backgrounds and circumstances. Nonetheless, the interviews provide an invaluable account of how advocacy supported these individuals.

SAMPLE

To accomplish the set objectives it was necessary to obtain access to older people using advocacy across Scotland. A simple random sampling procedure was intended however, due to the small size of the research project and the time limitations a convenience sample was more suitable. This involved using the cases that were the easiest to obtain and access (Saunders, 2011).

RESEARCH PROCESS

The sample was secured by contacting local advocacy organisations from the SIAA members list. The advocacy organisation then identified potential participants and secured their consent. In some of the instances, the researcher was given the participants' details and some background information about their case. First contact was established via telephone to arrange a meeting time. In some cases, the advocate accompanied the researcher to the homes of participants who had agreed to this.

All of the 14 interviews were conducted in the participants' homes including care homes. They lasted between 21 minutes and an hour and 2 minutes. The questions guide used during the interviews can be found in Appendix 3. Seven of the interviews were conducted with the advocate present; the remaining 7 were between only the advocacy partner and the interviewer.

The purpose was to understand older people's experience of advocacy. All interviews were tape recorded and transcribed. Semi-structured interviews were used to gather data which were analysed qualitatively.

ETHICS

Before interviews began each interviewee was given an information sheet about the study. The sheet included information about anonymity and confidentiality and the options to not answer questions and to leave the interview at any time. Before the interview a consent form had to be signed which included consent for the interview to be tape-recorded. The interviews were conducted in the participants' homes with the agreement of the participants.

SAMPLE CHARACTERISTICS

The report is based on a total of 14 interviews with advocacy partners from different parts of Scotland. Out of the 14 interviews, 13 were validated as one participant had recently suffered a stroke and could not remember much about advocacy. The interviews were conducted at 7 different independent advocacy organisations across Scotland. 7 of the participants are women and 6 are men. Their ages range from 63 to 91 years old, with 5 of the participants being in their 70s, 5 in their 60s and 2 in their 80s. 7 of the participants lived in their own home while 5 lived in a sheltered housing and 2 in a care home. There was no unifying health condition or family situation, as the participants had very different backgrounds and experiences. They were all retired and most of them had worked during their lives.

Appendix 2 - Bibliography

- Atkinson, D., & Forbat, L. (2003). A review of independent advocacy services in Nottinghamshire. Milton Keynes, Open University.
- Bryman, A. (2001). The nature of qualitative research. *Social research methods*, 365-399.
- Coyle, M., 2009. *Lost in Translation*, London: Action for Advocacy.
- Dunning A., (2010), *A Scoping Study of Advocacy with Older People in Wales*, for the Older People's Commissioner for Wales
- Get Heard, 2007, *Commissioning Advocacy for Older People: A Common Lack of Approach?*, Older People's Advocacy Alliance (OPAAL UK)
- Guest, G., Bunce, A., and Johnson, L., 2006. "How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability", *Field Methods*, pp. 59-82.
- Helliwell, J.F. and Puttnam, R.D. 2004, *The social context of wellbeing*
- Henderson, R., & Pochin, M. (2001). *A right result?: Advocacy, justice and empowerment*. MIT Press.
- Henwood, M. and Waddington, P. (1998) *Expecting the worst – views on the future of long term care*, Help the Aged and Nuffield Institute for Health: London
- Hussein, S., Rapaport, J., Manthorpe, J., Moriarty, J., & Collins, J. (2006). Paying the piper and calling the tune? Commissioners' evaluation of advocacy services for people with learning disabilities. *Journal of Intellectual Disabilities*, 10(1), 75-91.
- Hyduk, C., & Moxley D., (1997) *A Personal Advocacy Model for Serving Older Adults*, *Journal of Gerontological Social Work*, 28:4,
- Jenkins, R. (2012). Using advocacy to safeguard older people with learning disabilities: Robert Jenkins discusses how nurses can promote the use of independent advocates to help protect this increasing group of patients from abuse. *Nursing older people*, 24(6), 31-36.
- Living in Residential Care: An exploratory study of advocacy*, Report to Manthorpe J., & Martineau S., (2009) *Scoping review of the research and evidence base relating to advocacy services and older people's entry into care homes in England*
- Northway R. et al (2004) *Information, Advice and Support for Older People*
- Polkinghorne, D. E. (2007). *Validity Issues in Narrative Research*. *Qualitative Inquiry* , 479.
- Qureshi, H., & Henwood, M. (2000). *Older people's definitions of quality services*. York: Joseph Rowntree Foundation.

Rapaport, J., Manthorpe, J., Hussein, S., Moriarty, J., & Collins, J. (2006). Old issues and new directions Perceptions of advocacy, its extent and effectiveness from a qualitative study of stakeholder views. *Journal of Intellectual Disabilities*, 10(2), 191-210.

Rapaport, J., Manthorpe, J., Moriarty, J., Hussein, S., & Collins, J. (2005). Advocacy and people with learning disabilities in the UK How can local funders find value for money?. *Journal of Intellectual Disabilities*, 9(4), 299-319.

Saunders, M. N., Saunders, M., Lewis, P., & Thornhill, A. (2011). *Research methods for business students*, 5/e. Pearson Education India.

Scourfield, P. (2007). A commentary on the emerging literature on advocacy for older people. *Quality in Ageing and Older Adults*, 8(4), 18-27.

Harding T., (2000) *Services for the 21 st Century: meeting the needs of older people*, Welsh Office of Health and Social Care: UDID University of Glamorgan

Whittaker, A., Gardner, S., & Kershaw, J. (1991). *Service Evaluation by People with Learning Difficulties: Based on 'The People First Report: an Evaluation of Services in London Borough of Hillingdon'* March, 1990. King's Fund Centre.

Wright, M., (2013), *A voice that wasn't speaking: older people using advocacy and shaping its development*, Older People's Advocacy Alliance

Appendix 3 - Semi Structured Interview Questions

- Why did you access advocacy?
- For how long did you receive advocacy support?
- Are you still in touch with the advocacy organisation in any way?
- How did you hear about advocacy?
- Did you refer yourself or did someone else refer you?
- How did you feel about your life situation at the time when you sought help from an independent advocate?
- 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 control over your life?
- How was your physical health?
- How was your emotional health?
- How involved were you in planning your care?
- Would you say you achieved your goal with the advocate's help?
- How satisfied are you with the outcome?
- What did the advocate do to help you resolve the issue you sought advocacy for?
- 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 do you think you handle a similar situation to the one you used advocacy for?
- Do you think advocacy is important?



Scottish
**Independent
Advocacy**
Alliance

Published by
Scottish Independent Advocacy Alliance
www.siaa.org.uk
London House, 20-22 East London Street, Edinburgh,
EH7 4BQ
Scottish Charitable Incorporated Organisation
Scottish Charity No. SC033576