Scottish
Independent
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“Without advocacy I’d probably be dead”

Research into the impact of independent advocacy on the lives of people experiencing Learning Disabilities

November 2014

Promoting Supporting Defending

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About the author

Karin Vajta Engström joined the SIAA as Research Intern in the summer of 2014. She is now in her final year of studying an MA (Honours) in Politics at the University of Edinburgh. After her graduation in June 2015 she wishes to further explore the world of social research both through theory and practice.

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Executive Summary

The aim of this report is to investigate the impact of independent advocacy from the view of people with learning disabilities. The study is based on qualitative data from 12 interviews conducted at 5 different advocacy organisations across Scotland. In addition, interviews with a family member as well as two advocacy workers and two advocacy coordinators took place in order to contextualise the findings further. The findings are drawn from the interviews with people with learning disabilities and are detailed below.

Independent advocacy provides a unique and irreplaceable support

It is apparent that independent advocacy provides a form of support for individuals which otherwise would not be addressed. Before receiving advocacy support, many interviewees knew nothing or very little about their rights and entitlements but with the support of advocacy, this changed. There is for example a strikingly low awareness of the statutory right to access advocacy and all interviewees were initially referred to advocacy organisations by a third party. Following that referral interviewees reported that their advocates ensured they had all relevant information on their rights and on what was available and supported them to consider options and make fully informed choices. As a result they were able to make informed decisions based on real choices which in turn encouraged a sense of independence and empowerment, a feeling of taking control of their lives and situations.

Soft outcomes: Important 'side effects'

Independent advocacy support contributes to 'hard' outcomes such as finding a job, winning a court case or receiving the correct benefits. But it also delivers outcomes which are just as important despite the fact that they are more difficult to pin down, so called 'soft' outcomes. Interviewees reported that they felt listened to and consequently become increasingly confident to try new things and speak up for themselves. They felt that this had a huge impact on their well-being and self-esteem. It was also clear from their reports that some interviewees believed that independent advocacy reduced or removed their sense of social isolation and helped them to engage with their communities.

The relationship with the advocate creates a network of support

A picture emerged from the interviews of the relationship between interviewees and their advocates as being built on a high level of trust. Importantly, this trust often encompasses the whole advocacy organisation and other advocates from there and was thus not confined to a single person. Interviewees told us about the importance of having someone who is 'on their side' that they know they can call on if they need help. This special relationship consistently has the service users' wishes at its core.

Conclusion

Independent advocacy clearly fills a need for people with learning disabilities which other services do not address. Apart from contributing to successful hard outcomes, advocacy can deliver soft outcomes which have a great impact on the individuals' wellbeing and sense of empowerment. It is striking that despite this, access is still an issue.

Despite these benefits, our investigations show that independent advocacy support is not always as available as it should be. All interviewees were initially referred by a third party, indicating that there is a lack of information. This is the case in spite of the fact that accessing independent advocacy is a statutory right for people with learning disabilities as outlined in the Mental Health (Care and Treatment) Act Scotland 2003.

1. Introduction

One of the interviewees, Paul, explained that having an advocate on your side made a great difference to his life since "they help you with what you want". When Paul initially accessed advocacy, he was living in a place he did not like and he was self-harming. He had no control over his money or any knowledge about his rights and choices. Working with his advocate he feels has increased his self-confidence and today he feels as if people now listen to him. He has moved to a new flat and is very proud of how well he is taking care of himself. Paul found not only the confidence to speak up for himself but also to try new things. He had never before been on public transport and found the very thought of it intimidating. As his confidence increased Paul decided to spread his wings and go by himself and he now travels by public transport regularly. Paul's story demonstrates how independent advocacy supports the advocacy partners to make both small and big decisions which will ultimately have a huge impact on their quality of life.

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 heard.

This report investigates the impact independent advocacy has on the lives of advocacy partners with learning disabilities. There is surprisingly little research on the impact of independent advocacy from the perspective of the advocacy partners. Often more powerful stakeholders are prioritised and the voice of the advocacy partners is lost. This report sets out to address this gap in the literature.

Moreover, the support from advocacy is hugely appreciated by the advocacy partners and many of them told us that they now could not imagine how their lives would have been without it. Still, independent advocacy is not as available as it could be. Despite the fact that people with learning disabilities have a statutory right to independent advocacy access can be limited. Ever tightening budgets, increasing demand and requirements to prioritise people who are in crisis or facing compulsory measures under the Mental Health Act mean that advocacy organisations have introduced waiting lists which can lead to lengthy waits, are less able to reach out to those harder to reach people and less able to conduct awareness raising activities. Interviewees reported that information on advocacy services was not wide-spread. None of them knew about independent advocacy before being referred by a third party. Advocacy organisations also told us that they do not have enough time or resources to carry out awareness raising work to the extent that they would wish.

By interviewing 12 advocacy partners from 5 different organisations across Scotland, data was collected and a picture of how and why independent advocacy is important to advocacy partners with learning disabilities emerged. It is striking that independent advocacy provides an invaluable service, it broadens people's horizons and, as Paul states, "you can't do without them".

2. Background

2.1 What is Independent Advocacy?

> *"Advocacy is about broadening horizons*
> *and widening the options that people have."* [1]

People with learning disabilities often find it difficult to make their voice heard and can struggle to gain control over their lives (Harrison and Davis 2009: 57). This has a significant impact resulting in inequality in relation to choice and opportunity and can also result in a lack of human rights. The underpinning ethos of independent advocacy is the belief in the rights of all individuals. Independent advocacy, listening to people who struggle to make their voice heard and helping these people to have a stronger voice is key to redressing this power imbalance. Independent advocates do not provide advice or make decisions on behalf of the person or the group they are supporting. Instead, they support the advocacy partner to make their own informed choices about their own life and to gain as much control over their life and circumstances as possible. Independent advocacy helps the advocacy partner to make real choices and to access the information needed to do so. In addition, an independent advocate may speak on behalf of people who are not able to do so for themselves, or who choose not to.

The independent advocate and the advocacy partner work together to find ways to enable the advocacy partner to have control over their life and to find out about their rights as well as what makes them feel good and valued. Independent advocacy is about safeguarding vulnerable and socially marginalised people who are discriminated against or whom services struggle to serve. An effective advocate will observe the whole person and notice what is perhaps tolerated by habit and help the advocacy partner address or question it even without being asked to do so directly.

Independent advocacy is structurally, financially and psychologically separate from any other service provider and does not provide any other services than independent advocacy. Therefore there is no conflict of interest and the advocacy partner's views and wishes are always given first priority. Independent advocacy is accountable under the law but also to the people who use its services. Advocates are committed to act on issues agreed by their advocacy partner and at an appropriate pace, while ensuring effective communication methods. As Brandon puts it: "It is not the professional deciding what is best, but the genuine attempt to get into the mind of the patient/client, which is the basis of genuine advocacy" (1995: 35).

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[1] *The Scottish Independent Advocacy Alliance, Independent Advocacy: An Evaluation Framework, 2010: 2*

2.1.1 One-to-one Advocacy[2]

This includes professional or issue based advocacy. It can be provided by both paid and unpaid advocates. An advocate supports an individual to represent their 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 their advocacy partner is on a one-to-one, long term basis. It is based on trust between the partner and the advocate and is supported but not influenced by the advocacy organisation. The advocate supports their partner using their 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 their advocacy partner may share age, gender, ethnicity, diagnosis or issues. Peer advocates use their own experiences to understand and have empathy with their advocacy partner.

2.1.2 Collective or Group 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.

2.1.3 Non-Instructed Advocacy[3]

If the advocacy partner is not able to give a clear indication of what they want, non-instructed advocacy takes place. The non-instructed advocate speaks up on the behalf of the person, seeking to uphold their rights and ensure that they receive a fair and equal treatment (Henderson, 2006).

2.1.4 The 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 the power does not lie with the advocate but rather with the partner and that they are working together as a team instead of the advocate making decisions for the partner.

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[2] *The Scottish Independent Advocacy Alliance, Independent Advocacy: An Evaluation Framework, 2010*

[3] *The Scottish Independent Advocacy Alliance, Non-Instructed Advocacy Guidelines, 2009*

2.2 Addressing the Lack of Evidence in the Literature

It is becoming increasingly important for independent advocacy organisations to evidence their work in order to secure funding, yet this is something that many organisations struggle with (Rapaport et. Al 2006). In contrast to outcomes that are easy to measure, such as success in finding employment or housing, 'soft' outcomes, such as feeling listened to, are less tangible and more difficult to monitor. Still, several studies come to the conclusion that not only evaluation of advocacy is patchy, but so is access and awareness (Elsley 2010, Chase 2005).

Moreover, it is striking that there are few studies addressing the impact of advocacy on advocacy partners with learning disabilities. Manthorpe et.al. state that "Advocacy per se is an under-researched topic", adding that the literature rarely addresses the effectiveness of advocacy (2005: 12). Furthermore the literature suggests that the effectiveness of the evaluations of advocacy is patchy and outcomes are rarely scrutinised by funders (Rapaport et.al 2006).

The reason why advocacy is often considered under-evaluated is largely because the existing monitoring tools struggle to capture the benefits of advocacy on people's lives (Rapaport et.al 2006: 193). Often research on the impact of advocacy relates to the view of stakeholders, such as when Manthorpe et.al investigated key indicators to measure outcomes of advocacy (2005). Thus the perspective of the advocacy partner is not visible in the debate and the soft outcomes are often overlooked. Manthorpe et.al further note that the habit of conducting research that includes people with learning disabilities as agents – and not mere subjects – is not very wide-spread (2005: 12).

Research on the lives of people with learning disabilities often concerns marginalisation, discrimination and social exclusion. Advocacy may be mentioned as a possible tool to address these issues. Surprisingly, no further investigation into why and how it would help has been initiated. By asking the question 'What is advocacy for?' Henderson and Pochin identify seven areas, namely choice; access; justice; societal development; support; empowerment and prevention – all of which relate well to the principles to advocacy (2001: 57). Unfortunately, this has not been investigated further. As previously noted, Manthorpe et.al (2005) provide an extensive research report concerned with the outcomes of advocacy for key stakeholders concerned with commissioning and providing advocacy services. They identify key indicators of advocacy as well as different evaluation models to suit different types of advocacy for organisations working with people with learning disabilities. Along with the fact that there are both benefits and limitations of each evaluation tool, they find that it is apparent that the process of evaluation is important in itself (Manthorpe et.al 2005). Furthermore Coyle describes how advocacy groups struggle to evidence "voice, choice and empowerment" (2009: 16).

Indeed, it is common that advocacy organisations compile stories from advocacy users and share them on their website or in annual reports and this is an effective way to highlight specific experiences. However this does not allow for links between the isolated stories, so overarching themes and a wider analysis are potentially bypassed. Accordingly, this report aims to address the gap in the literature by marrying the rigour of qualitative analysis with the strength of case stories and produce a report which highlights the impact of independent advocacy for the advocacy partners, specifically those with learning disabilities.

3. Key Findings Summary

Three key findings emerged from the data collected at the interviews with the advocacy partners as well as the interviews with the advocacy workers. Each theme will be discussed briefly in this section before being analysed and explored further in the following sections of the report.

Firstly, it is evident that independent advocacy is an important, unique support which meets needs for advocacy partners both when issues are resolved and when they are still underway. Before receiving the support of advocacy, advocacy partners knew nothing or very little about their rights and rarely made any choices on their own. With the support of advocacy this changed and partners were supported to make informed decisions based on a thorough knowledge of their rights as well as an understanding of existing options. The advocate contextualised the partner's options and helps them consider their choices and potential outcomes of those choices as well as assisting them with communication and official correspondence. This process of informed decision-making does encourage a sense of independence and many advocacy partners went on to make plans and set up goals for the future. The support of independent advocacy played a key role throughout this process. Strikingly, interviewees reported little knowledge about the right of access to independent advocacy before they were referred, suggesting a lack of information and limited access to independent advocacy.

Moreover, our second finding concerns the so called 'soft' outcomes which are delivered by independent advocacy. 'Hard' outcomes, such as winning a court case, moving to new accommodation or finding a job, are more tangible than the impacts that may be viewed as soft outcomes. It is clear that the support of advocacy benefits the advocacy partner in ways that are more difficult to pin down but nonetheless incredibly important and have a huge impact on their well-being. Interviewees demonstrated how their confidence was increased by the advocacy support. The partners explained that they felt listened to, that this increased their confidence and how this improved confidence encouraged them to try new things. Increasingly – and significantly – they told us that they now also feel that they can speak up for themselves. Another significant soft outcome is how advocacy support contributes to a reduction in social isolation and also contributes to supporting the inclusion of the interviewees into their communities and society generally.

Finally, it can be concluded that the relationship between the advocate and the advocacy partner was highly valued and that there was a high level of trust involved. However it is also striking that several of the advocacy partners declared that their trust was not confined to 'their' advocate but encompassed other advocates working in the same advocacy organisation. The advocacy partners felt that the advocate was on their side no matter what and that the advocacy organisation is independent of other services. Furthermore they expressed how important it was for them to know that advocacy can be there for them if they feel they need it; it gave a great sense of security knowing that they can come back if they need to. They reported that this led to an increase in self-confidence and ability to advocate on their own behalf. Overall, the unique advocacy relationship creates a network of support in which the advocacy partner is always in focus.

4. Independent Advocacy: A Unique and Irreplaceable Support[4]

The interviewees were in agreement with each other: they could not imagine what their life would have been like without advocacy. A number of advocacy partners explained that they could not think of anyone else who would have filled the role of their advocate. Advocacy support contributed greatly to positive outcomes for many of the issues they first sought advocacy for, irrespective of their situation and circumstances or the advocacy issues dealt with. Hannah and Joanna, interviewees for this research, both believed that without the help from the advocacy organisation their sons would still be in care. They told us that this would have continued to have a substantial impact on the quality of family life and relationships. Maddie told her story about her dependence on alcohol and drug use and how she was kicked out of her home at the age of 16 shortly after her daughter Evelyn was born. She explained that it made an incredible difference that her advocate Douglas was there for her and that no one else could help her in the same way as he could.

"Without advocacy I'd probably be dead."
Maddie, 21

Maddie told us that she "[doesn't] understand how lawyers talk" so if it was not for her advocate she "would not have a clue". She described how Douglas helped her to learn about her rights as a mother when working to get custody of her daughter.

It is evident that advocacy plays a key role for advocacy partners with learning disabilities, both when issues are resolved but also when the desired outcomes are not yet achieved. The advocacy support is crucial in order for the advocacy partners to gain knowledge of their rights and understand available options. This support takes different forms ranging from help with practical tasks, such as responding to official letters and attending meetings, to support with finding out about court procedures and legal rights. Consequently, advocacy partners not only gained knowledge of what their rights and options were but were also supported to make informed decisions based on this knowledge. Finally this gaining of knowledge and control appeared to encourage advocacy partners to become more independent, make independent plans and set up goals for the future. This process of making informed decisions is closely tied to one of the main principles of independent advocacy which states that independent advocacy should ***"help people to have control over their lives and to be fully involved in decisions which affect them"*** .[5]

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[4] All names have been changed throughout this report to protect identities.

[5] Scottish Independent Advocacy Alliance, Principles and Standards for Independent Advocacy 2008

4.1 Increased knowledge of rights

The *Principles and Standards for Independent Advocacy*[6] make it clear that independent advocacy has a responsibility to make sure that people's rights are protected. Throughout the interviews it became apparent that before the advocacy partners received the support of an advocate they knew nothing or very little about their rights. Interviewees reported that, with the support of independent advocacy, they increasingly learned about their rights and entitlements. Independent advocacy safeguards the partners' rights and ensures that the advocacy partners are in control of their lives and decisions, as is charted by the Universal Declaration of Human Rights, Article 3: "Everyone has the right to life, liberty and security of person" .[7]

This is Joanna's account of what she knew about her rights before she met her advocate Douglas and how he helped her in her struggle for guardianship of her two-year old son Roddy:

"We didn't really know much about our rights, did we. Because they weren't answering the questions that we were asking them. We needed an advocacy worker or someone who could help us get the questions across, and Douglas managed that."
Joanna, 34

Victoria, another interviewee, initially accessed advocacy when she was in the process of trying to get the custody of her son. The following conversation with Victoria demonstrates how she was not aware of her legal rights at all before her advocate investigated them further.

"Did you know about your rights and what you were entitled to before you and your advocate started talking about it?"
Interviewer

"I don't think I had any rights to start with, did I."
Victoria

"Well you did, but the question is whether you knew if you did or not."
Advocate

"No. Because they didn't explain before you started going to meetings [with me]."
Victoria

In addition to having their legal rights upheld advocacy partners also experienced issues with benefit entitlements, housing and financial independence.

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6 Scottish Independent Advocacy Alliance, Principles and Standards for Independent Advocacy 2008

7 United Nations, Universal Declaration of Human Rights 1948

Paul, who accessed advocacy to help with getting employment and new accommodation, told us that he was not in charge of his own money, even though he wanted to be, until advocacy helped him to strengthen his voice and supported him to explore his options and rights.

A number of other interviewees shared this experience of having no financial control. Jennifer's brother-in-law, Tom, 61, has a learning disability and has been in care since the age of 5. Tom had been in a care home where he was very unhappy and had no control over his finances. With support from his advocate as well as pressure from his family he was moved to a new care home where he was much happier. He also regained control over his finances. Jennifer said that the first thing her brother-in-law Tom did after gaining control over his savings with the help of advocacy workers was to book a holiday. She believed before this his money had been put in a collective pool of money by the care home.

Both Dan and Anna explained that now they knew about their rights and reported that they now tell other people about advocacy in order to ensure that as many people as possible get what they are entitled to. Victoria told us that she is taking part in this research project as she is keen on helping others to learn more about advocacy.

People with learning disabilities have a statutory right to access independent advocacy support under the Mental Health (Care and Treatment) Act Scotland 2003. Yet very few of the interviewees had heard about independent advocacy before they were referred by a third party, often a family member, social worker, care worker or a friend.

Duncan, 57, told us that he wished that he had known about advocacy earlier. He believed that he would have benefitted from such support at an earlier stage. The fact that the research interviewees did not know about their right of access to advocacy before they were referred by someone else indicates limited access to advocacy support, something which many advocacy organisations across Scotland are fully aware of. Whilst many organisations have undertaken awareness raising work, there are scarce resources to support such activities in addition to their other roles. Almost half of the advocacy organisations in Scotland have Service Level Agreements which require them to prioritise people who may be subject to compulsory measures. This requirement results in substantially decreased accessibility, organisations report the need to establish waiting lists and sometimes lengthy waits for people who are not facing compulsory measures. A significant number of organisations also announce that they have been forced to reduce or completely discontinue carrying out awareness raising work.[8]

Moreover, in comparison to recent years, 22% of the advocacy organisations state that statutory funding in 2013/14 has gone down, and 38% of the organisations declare that levels of statutory funding have remained the same. This is despite the fact that demand for advocacy has increased significantly following the economic recession.

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[8] *SIAA, Advocacy Map 2013/14*

4.2 Communication crucial for informed decision-making

One important aspect of independent advocacy for all of the interviewees in the study, irrespective of the nature of the initial issue of referral, was the support at meetings and also help with official correspondence such as letters. The support from the advocate resulted in immediate stress relief as several advocacy partners explained. Here Victoria describes how she used to deal with the letters she received:

> ***"Before I [was able to consult with my advocate on] my letters that I didn't understand, like a job centre letter or a gas letter, I used to just fling them out."***
> Victoria, 47

Moreover, the interviewees often related back to their learning disabilities and stated that support with both communication in meetings and written correspondence is very important to them. The advocate ensured that all information was understood by the partner and that nothing was missed. It was only with all relevant information that it was possible for the advocacy partner to make an informed decision. Victoria explained that she needed the support of her advocate in meetings when:

> ***"…other people bring out these big words and everything. But the advocate helped me talk,…before they wouldn't have understood me."***
> Victoria, 47

Clearly, a substantial part of the advocate's role is to ensure that information is easily accessible and understandable in order to support the advocacy partner in making and expressing informed views and decisions. When the advocate and the advocacy partner spend time together they learn how to understand each other and how to communicate with each other and with others.

As Paul's advocate Helen pointed out this is also a main focus for non-instructed advocacy. Another advocate, Leslie, agreed and said that she believed that advocacy partners are supported to get a better understanding with the help of advocacy.

Both Helen and Leslie touched upon the fact that repetition can be key in supporting people to consider facts, understand options and make informed decisions, some people with learning disabilities need to go over information or an issue a number of times. This is reinforced by the experiences shared by the interviewed advocacy partners. Dan, who initially accessed advocacy during transition to adult services, says that his advocate "explains things in a different way which helps me to express what I want" and that before advocacy he was not a 'good decision-maker'. He found it intimidating to make decisions at the job centre as they were not aware of his capabilities and limitations in regards to his learning disabilities. But when discussing his different employment options with his advocate he understands what they entail and can make an informed decision.

Finally, an example given by Victoria, who has been accessing advocacy on several occasions in relation to benefit claims, housing issues and a guardianship case, highlights the difference between a decision and an informed decision. It demonstrated how the advocate can assist the partner to make an informed decision based on facts and wishes instead of the advocacy partner agreeing out of habit or fear that they would be perceived as being difficult.

"We used to get reports and Douglas went over it with me a week or so before the meeting.
And he would ask me 'do you agree with this'
and then highlight things I didn't agree with.
Because before Douglas was involved I would just agree with what was said.
I didn't understand what it was saying. They didn't used to explain it."
Victoria, 47

4.3 Exploring options and choices

Independent advocacy evidently supports advocacy partners to learn more about their rights, something which is an important part of making an informed decision. Additionally, independent advocacy also supports the partner to find out what their choices are. Without a clear understanding of existing options it is impossible to make an informed decision especially as people with learning disabilities are often not allowed to make decisions on their own and rarely get options to choose from. Paul explained that he did not want to live where he was and that, before he accessed advocacy:

"They didn't give me any choices.
They took a lot of control over me and wouldn't just listen to my point of view.
Just put me up in a care home. Didn't like it. Just didn't deal with me right at all.
I was lucky to meet you Helen."
Paul, 25

Making decisions can therefore be an intimidating task and things that many people take for granted may be extremely difficult for people with learning disabilities without support. Amanda was referred to her local advocacy organisation while she was living in her family home. Amanda was unhappy about the level of control held by her family and also by her support staff over all aspects of her life. One example of that level of control was that each morning her support worker laid out clothes for Amanda to wear without checking what she would like to wear. Amanda told her advocate that she would like to choose herself what to wear each morning, who helped her to explain that wish. Since then, she started dressing in her favourite colour pink and says that she is very happy that she can choose what to wear. For Amanda this started a process of taking back control over other aspects of her life.

Furthermore the advocate's role is crucial when supporting the advocacy partner in their understanding of potential outcomes of different options. One of the interviewees, Sylvia, has been accessing advocacy for many years, and her advocate Heather explained that she helps Sylvia to think about her options and choices and consider possible outcomes from different choices in a way that other services fail to do. She has helped Sylvia to understand not only her choices but possible consequences arising from these choices. When Sylvia was going on a caravan holiday with her family, her care and support workers had decided that Sylvia needed to go home each night. They felt that staying in the caravan with her family would be too much of a strain for Sylvia. Heather realised that Sylvia said she was fine with this without fully understanding what she said yes to. Heather spent time with Sylvia explaining that she could either go on a holiday and sleep away from home in the caravan with her family, or have a week full of day trips and come home each night to sleep in her own bed. Sylvia decided that she wanted to stay in the caravan with her family. Similarly, Greg, who has a citizen advocate called Peter, described how Peter supported him when preparing for his Mental Health Tribunal Hearing. Peter explained to Greg that it was his choice deciding whether to attend or not.

Together they considered what would happen at the Tribunal and what might happen if Greg chose to go and what might happen if he chose not to go. Greg was clear that he understood what would happen and decided not to attend.

As with the case of Sylvia and her family holiday, advocacy workers often challenge the status quo and question things that may be taken for granted by service providers and accepted without question by advocacy partners. This is an important part of the advocacy role ensuring as it does that the advocacy partner is supported to be fully involved in decisions that are made about them and their lives.

4.4 Agency, control and independence

It is striking that the interviewees in this report felt that they did not only receive support and help from their advocacy workers, but that they were working on the issues *together* with the advocate. The interviewee Dan explained that when he was first referred to independent advocacy, he spent a lot of time with his advocate telling him his story and giving him details on who to contact to learn more. He was clear that his advocate would never do anything without his permission and that the advocate would always ask what Dan's views and wishes were in order to ensure that they were working as a team.

A number of interviewees agreed with Dan and said that they felt included in the work. One of them, Victoria, contrasts it to one of her lawyers and says that "he came one time. But one visit, that's not working with somebody." This sense of involvement is a key aim for independent advocacy and is of particular importance in relation to people with learning disabilities whose views can often be overlooked when decisions about their lives are made. It is clear that this sense of working together generates a sense of agency and control which in turn encourages independence.

When Paul spoke about his life before accessing advocacy he said that "I do kind of get depressed if I'm not able to look after myself" and that previously he felt unwell and used to self-harm. He explained that he did this when he was living in a place he did not like and felt he had no control over that. When his advocate, Helen, got involved she supported him to get a new place to live. He felt after the move that he had gained more independence and he now takes better care of himself.

It was clear from these interviews that independent advocacy, and the increased confidence that resulted from this support, led to advocacy partners setting new aims and goals for the future. A number of interviewees told us that they wished to find a job and one interviewee, Anna, has now started working in an administrative role giving her experience and confidence to look for more jobs in the future.

Another interviewee, Amanda, who had advocacy support during a court case against her power of attorney, brought her 'wish-list' to the interview. The list included many things from "go shopping" and "choose what to wear myself" to "move out of the care home". When she achieves one of the things on her list she ticks them off. Amanda was supported by her advocate in drawing up this wish list and told us how proud and confident she felt as she ticked things off her list and added others to them.

Finally, Greg told us that he wants to "be like Jamie M". Jamie M had previously been supported by Greg's advocate, Peter. He now lives on his own, has a job and no longer accesses support services. This long-term goal to support advocacy partners to be able to self-advocate completely is an important aim of independent advocacy. While it may not always be possible for Greg or for some other people with learning disabilities to become completely independent of services the confidence Greg has gained through advocacy support has led to him feeling able to self-advocate in some situations.

5. Soft Outcomes: Important 'side effects'

Advocacy delivers outcomes which are possible to measure and keep track of, such as successfully closing a court case, finding a new place to stay, leaving an abusive situation or getting custody of a child. These hard outcomes are appreciated by the advocacy partners in this research; however they all told us that the support of advocacy gave them even more than that. In contrast to the hard outcomes, soft outcomes are less tangible, and therefore difficult to note down on a feedback form. Still, the soft outcomes had a huge impact on the advocacy partner's life and well-being as has been noted in regards to increased knowledge of rights and agency in the previous section of this report.

The interviewees reported that receiving support from independent advocates increased their confidence to speak up and gave them emotional support; they felt listened to. Moreover it is clear that advocacy support contributes to reducing social isolation for some interviewees. The advocacy partners described how these positive changes stay with them even after the advocacy case is closed. In some cases, where there were few or no hard outcomes, the soft outcomes were of even greater importance.

5.1 Increased confidence

The first time Anna came into the advocacy office to receive support during the transition to adult services, she would not even make eye contact with anyone. She describes it as "nerve-wrecking at first, I was quiet as a mouse". Over time Anna developed much more confidence and at the time of the interview was working in the advocacy office doing administrative work. She used the confidence she gained through advocacy support to develop in the role and to face her fears of answering the phone – which she did not dare to do at all when she first started but became very comfortable with.

Paul also described how his confidence grew when supported by his advocate Helen and how he now actively tries new things such as getting to places by himself on public transport. Paul had never before been on public transport and felt that no one was supporting him to try, but is now confident enough to travel by himself without any help, something which gives him a great deal of freedom in his everyday life.

Helen added that even the fact that he feels comfortable being interviewed by a stranger is a significant indication of increased confidence.

"Yeah I think I stand up for myself. But I don't know [if I could] without the advocacy team."
Paul, 24

Having gained new confidence and more knowledge about their rights, many interviewees told us they felt increasingly confident to not only try new things but to speak up for themselves. Dan, who is now receiving support to find employment, expressed very clearly that advocacy helped him to stand up for what he wants; he now feels able to speak up. Another example was provided by Hannah who told us about her friend who always made her buy coffee for her, even though Hannah could not afford it. After having discussed the situation with her advocate, Hannah felt more confident and was able to tell her friend she has to buy her own coffee from now on.

Victoria described how she was able to stand up for herself when attending a meeting in relation to the guardianship of her son Mikey.

> ***"It feels like, in meetings they bring up words that you don't understand. I met my son and his social worker and they took us to a café but I didn't like to discuss my private things in a café so I said I just don't agree with that."***
> Victoria, 47

Victoria was certain that she would not have been able to speak up in the same way before she had advocacy support.

One of the interviewees, Amanda, told us about when she went to court to challenge her Power of Attorney who was her mother's friend and Amanda had felt forced to sign the papers which she felt meant that she was giving away control of major parts of her life against her will. When preparing for the case to go to court she was supported by her advocate. Amanda explained that she was terrified of speaking in court and was not sure that she would be able to do it. But with the support of her advocate she managed to speak up in court all by herself. Today, Amanda lives away from her family and has managed to end the relationship with her previous Power of Attorney.

As has been noted, often the advocacy partners were not listened to. Instead decisions were made against their will and their views were ignored. For Paul this was one of the main reasons why he sought the support of advocacy.

> ***"Just to get my point of view across, in my meetings and stuff like that. … I want my point of view heard. Life before wasn't very good. Like I just couldn't get my point of view across. … [Before] I just felt a bit down, nobody [was] listening to my point of view."***
> Paul, 24

He told us he felt that he is lucky to have met his advocate Helen, and that she listens to what he has to say.
Finally, several of the interviewed partners told us about how they subsequently joined collective advocacy groups to be able to share their struggle with peers. This enabled them to speak up as a group and as it increased their individual confidence, many times it supported them in their daily lives as well.

5.2 Social inclusion

The citizen advocacy movement in the US initially sprung from a wish for people with learning disabilities to break social isolation. Citizen advocates have a strong connection to the community which is beneficial for the advocacy partner. This is also a prominent theme in this research, however the aspect of social inclusion expands beyond citizen advocacy and encompasses all types of advocacy researched. A number of interviewees reported that they now feel more part of the community, have made friends and spend more time on social activities than they used to do before they had the support of their advocate. This evidently increases the advocacy partners' wellbeing and was highlighted as important by the interviewees.

One interviewee, Greg, told us about his weekly coffee mornings with Peter, he wants to get out more and this is a good way to see people without it being overwhelming. Greg goes to college and takes courses in cooking, while being involved in the photography society. He says meeting people and taking part in these groups make him feel happy and content. Sylvia's advocate Heather described how they have been a partnership now for eight years and meet up for lunch, shopping or just to chat. Both Sylvia and Greg are in citizen advocacy partnerships however other interviewees, who receive one-to-one issue-based advocacy support, also testify to feeling much more socially included. Duncan confirmed that without advocacy support he would just "sit in the house doing nothing" whereas he now goes to discos and attends social events.

It is striking that the advocacy partners' sense of social inclusion is not dependent on the type of advocacy. Also in issue-based advocacy relationships, breaking social isolation is a prominent theme and is often encouraged throughout the process. For advocacy for people with learning disabilities there may, in some cases, be a long-term aspect to the relationship, regardless of the type of advocacy delivered, which can lead to increased confidence and a greater level of social inclusion.

Dan, who had been referred for issue-based advocacy support, now takes part in a collective advocacy group once a month and explained that he has found lots of friends through advocacy. He says they are a "good circle of people", that they stick together and that it's a "two-way thing" as they help each other. The social element is interconnected with an element of support. Many times collective advocacy groups serve as safe spaces which are perceived as less judgmental and more supportive for people with learning disabilities, people have a sense of belonging to something important.

Anna's advocate supported her through the transition from children's into adult services and Anna went from not knowing anything about advocacy and not feeling included in her own life or in social situations, to advocating for advocacy and making many new friends. She described how getting involved in the advocacy movement as a representative for Learning Disability Alliance Scotland, a board member and a member of the young person's group, helped her to feel part of the community. She explained that it made her feel "more experienced and confident as well".

In contrast to the majority of interviewees who feel they are more active and included in society, Paul told us that he would rather not meet with new people at the moment even though he has the opportunity to as part of his issue-based support to find employment and address issues around housing.

> ***"I tried to go to groups but I feel like I don't want to interact with people right now. Just feel like that. But I just don't want to right now."***
> Paul, 24

However he was clear that that this is his own choice, because he does not want to interact with new people and after going to a group he chose to leave as he did not like it. This relates back to what has been discussed earlier in the report about agency and decision-making. In Paul's case, he is aware that he can join a group or go to social activities, however he prefers not to, thus he is making an informed decision based on what he wants – not on what is expected of him.

6. The Advocate-Partner Relationship: Creating a Network of Support

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The relationship and trust between the advocate and the advocacy partner is key to the concept of independent advocacy. Independent advocacy reaches out to people who are socially marginalised or may feel let down by other services. Accordingly there must be a high level of trust involved in the advocacy relationship in order for the advocate to be able to offer effective support for the advocacy partner and ensure that their voice is heard. Interviewees were asked to describe their advocates. The advocacy workers are described as helpful, marvellous, amazing and also good listeners and assertive. Several of the interviewees said that their advocate is great and that without their advocate they would not be alive today. It is evident that the advocacy partner and the advocate have a unique relationship. Moreover it is striking that a number of the interviewees emphasised that they feel comfortable not only with 'their' advocate, but with the other advocates in the same organisation as well. Dan, for example, explained that he feels that he can always come and talk to anyone in the office, and that he trusts them to keep the information confidential; it is important for him that he knows that the information stays with them. This indicates that even though the relationship between the advocate and the advocacy partner is remarkable, the partner is not relying on a single person and consequently an active network of support is initiated.

The following section outlines the impact of the relationship between the advocacy partner and the advocate has on the partner's well-being. Notably, advocacy partners feel that they have someone who is on their side that they can trust. The partners placed great emphasis on the fact that advocacy is always there and that they felt that they could go back if they needed to. This enabled them to speak up and self-advocate. Finally, through this advocacy relationship, a network of support was created which benefitted the partner in several ways.

6.1 To have someone on your side

One of the interviewees, Victoria, highlighted a recurring theme; the advocacy partners felt that they had someone on their side that they could trust. She said that "it's just having somebody on my side. I wouldn't have known what to do if I hadn't had Douglas". Often the advocacy partners told us that they felt that they had no other support. Again, Victoria explained that before contacting the advocacy organisation she "had to just read the letter and try to understand it myself I didn't even have a lawyer or anything". In contrast, Paul told us that he has support from other services today but said that was not always the case. While he had previously had social care he said that he was not happy with it and that he did not trust the support staff or his social worker. He now feels that, with the help of Helen his advocate, he has "alright bonds" with his social worker and social care support staff today and that they now listen to him. He puts that down to the fact that Helen supported him to go through the process of looking over the support he received.

The advocate is seen as someone who, in contrast to other services, is there for them and not for anyone else. Maddie described how she felt during the process of retaining guardianship of her daughter Evelyn.

"But I felt like I had everyone taking the mickey out of me and I felt like they weren't on my side. They were more on my mum's side."
Maddie, 21

Maddie's testimony demonstrates the importance of one of independent advocacy's core principles; namely that it is independent of other services. Hence there is no conflict of interests and Maddie, and other advocacy partners', views, wishes and choices are the single focus for the advocate. This contributes greatly to the partners' feelings that the advocate is on their side and not answering to anyone else. It also illustrates the requirement that an independent advocate must prioritise the advocacy partner's wishes over what might be considered to be in their 'best interests', ***Independent advocacy puts the people who use it first*** - Principle 1 in *Principles and Standards for Independent Advocacy*.[9]

Several of the advocacy partners said that, at times they needed their advocate to speak up on their behalf which they felt helped to alleviate their levels of stress. An example of this was given by Hannah who told us that Lynne, her advocate, stands up for her at times for example if she is in a large group when she does not feel comfortable or able to speak up. At these times Lynne speaks on her behalf.

Dan found it very stressful going to the Job Centre but felt that this improved when his advocate went to the Job Centre with him and spoke up for Dan when he felt unable to speak up himself. Paul's experience is very similar and he acknowledged that independent advocacy provided a unique support.

"It's good to have the advocacy team. I think people listen better if you have someone speaking on behalf of you."
Paul, 24

Victoria, another interviewee, described how her advocate Douglas helped her to stand up for herself and challenge arrangements that she was not satisfied with:

"He stood by me and he's been in meetings and everything. When the boss at the place I stayed at said things that I didn't agree with Douglas would challenge that for me."
Victoria, 47

She believed that it was a good thing that Douglas was assertive and stood up for her when she felt that she would not have been able to do it on her own.

6.2 A Sense of Security

A recurring theme amongst the interviewees is that the support from the advocate and the advocacy organisation made them feel safe. Knowing that advocacy may be available to provide support with an issue in the future provides a sense of security and emotional stress relief. For example, Maddie feels that she can get in touch with her advocate at a future time if she needs to. She explained that she did not have that option with anyone else before, but now "if I have anything to ask … I know that I can just phone the office". Likewise, Dan repeated several times during the interview that "advocacy is always there".

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[9] Scottish Independent Advocacy Alliance, Principles and Standards for Independent Advocacy 2008

Dan initially accessed independent advocacy when he turned 21 and was moving from his foster family and children's services. On that occasion he worked with his advocate for a few months to get issues around accommodation and services resolved and felt that his confidence improved to the point that he was able to self-advocate fully. However, two years later he struggled with employment issues and self-referred to the same advocacy organisation as he needed their support again. He says that knowing that he could seek advocacy support again was a great relief and even though he had developed confidence and had been able to speak up for himself on this occasion he found that the employment process was intimidating as well as emotionally difficult.

Victoria told a similar story of self-referral. She had received advocacy support about five or six times over the course of over a decade. She made it clear that the security of knowing that advocacy is there for her in case of need enables her to self-advocate at times, however when she is faced with issues that she cannot deal with on her own she identifies that and asks for support.

The fact that advocacy organisations know them and something about their situation and that they therefore do not need to explain their story to another person was highlighted by several interviewees as a major advantage and source of stress relief. It is important to note however that several of the interviewed advocacy partners were very clear that they hope not to have to re-refer and come back to the advocacy organisation. As Joanna puts it:

> ***It's good to know if I've got anything I can come back and talk to***
> ***Douglas or anyone else.***
> ***Preferably Douglas because he knows us but I can speak to anybody else.***
> ***But I'm hoping I don't need to come back here."***
> Joanna, 34

Advocacy partners told us that they hope that they will not have any reason to seek advocacy support in the future. The knowledge that advocacy can be accessed after a case is closed or at any point during the process, provides a source of increased confidence and strength rather than creating a bond of dependency.

6.3 Independent Advocacy: Building a Network of Support

Throughout the interviews a picture of a growing support network emerged as a kind of soft outcome. Though many of the interviewees declared that they had no other support than advocacy that they fully trusted, there are also examples of how independent advocacy generated the growth of a network of people around the advocacy partner. This happened in several ways and may relate to the expansion of the network, for example the advocate may involve more people to support the partner. At other times it is a matter of working to change services which are not meeting the advocacy partner's needs or wishes, as in the case of Paul who changed his social worker and social care staff and now feels safer and more comfortable. Similarly, when going through the process of retaining guardianship of her daughter, Maddie decided to change from a criminal lawyer, who she felt was not helping her, to a family lawyer. As a result she felt that she received more relevant support and her wellbeing increased. Noticibly strengthening the network of support around the partner is not necessarily the main aim of the advocacy partnership or a deliberate strategy but it still benefits the partner in the long run.

The fact that the advocate may at times spend a lot of time with their partner can be of real importance to the partner. Not only does this ensure that the advocacy partner feels valued but it also gives a clear message to everybody that the advocacy partner is an individual with their own views, wishes, dreams, aspirations and that they should be taken account of and listened to.

The amount of time that the advocate spends with the partner helps in ensuring effective communication between the advocacy partner and the advocate. This in turn helps to ensure when speaking up on behalf of the partner, the advocate is clear that they are accurately reflecting the partner's wishes. Most of the interviewees had varying communication support needs.

This is especially true in the case of more complex communication styles, it is crucial that the advocate and the partner know each other well, as illustrated by the case of Tom. Tom has a special gesture for when he is happy, and when he moved from one care home to another he stopped doing this gesture. His family believed that he was the victim of abuse. Sheila, Tom's advocate, worked with Tom's family to have him moved to a different care home. Once he had moved Sheila and Tom's family saw a swift improvement and he soon returned to gesturing to indicate that he was happy. In this case it was crucial that the advocate, Sheila, spent a lot of time with Tom and observed how he communicated with her and with others.

This research also demonstrated that, for some of the advocacy partners, those with the most complex needs, the people closest to them may also feel supported by the advocacy worker as they know that their loved one has someone who is there just for them. Helen explained how she felt that her work as an advocate had also helped Paul's family.

> ***"And often you feel like you are repeating yourself quite often but it's like 'until you're going to listen I'm going to keep saying it'. So I think that there is that kind of determination and I think that when the family sees that, I think that they feel stronger sometimes and feel more able to cope with it. Just knowing that they can say stuff and ask questions."***

Similarly Anna described how, when she first accessed advocacy and was stressed and not feeling well, it affected her family; "mum was going through the roof, they were pleased when I got support at last". This in turn made Anna feel relieved; that her mum was not worrying about her as much because she knew that Anna had an advocate, Olivia, to support her. Jennifer, Tom's sister-in-law confirmed that when she and her husband were fighting for the rights of her brother-in-law Tom, they found the fact that Tom had an advocate was also a great support for them. She told us "it was a hellish and terrible time. We were down on our knees and advocacy acted as a back-up; we felt Tom always had support and we could call at any time and that the advocacy team had time and cared". Jennifer and her husband felt that the fact that Tom's advocate Sheila was also arguing on his behalf strengthened their position. Jennifer told us that she believed; "if it wasn't for advocacy, Tom would be dead".

However, as all the interviewed advocates point out, there are also cases when the family wants different things than the partner and as the advocate is on the side of the partner and not the family, clashes might occur. This was the case in Amanda's situation when she decided she wanted to move out of her family home and live by herself. Her family now refuses to talk to her despite the fact that she would still prefer to stay in touch with them. Her advocate is continuing to support her throughout this process.

In conclusion, it is clear that the independent advocate's support can help to build and strengthen a full support network which benefits the advocacy partner. This suggests that independent advocacy creates a chain effect of benefits for the advocacy partner which will stay with them for a significant amount of time.

7. Conclusion

It can be concluded that independent advocacy has a great impact on the lives of those receiving the support and, in this specific study, people with learning disabilities. Firstly, advocacy encourages informed decision-making. It makes sure that the advocacy partner is aware of their rights. The advocate supports the advocacy partner to gather information, explore their different options and choices and helps them at meetings as well as with letters and written correspondence. Thus interviewees felt that they made informed decisions based on a thorough understanding of their rights, available options and potential consequences of their choices. This in turn is shown to empower the advocacy partners to become more independent and make plans for the future. It was also clear that, for those advocacy partners who had more limited communication or capacity they were safeguarded and their rights were upheld.

Along with the more tangible hard outcomes such as supporting a partner through a successful court case or a move to different accommodation, independent advocacy delivers soft outcomes. These include increased confidence and feeling listened to, which results in the advocacy partner feeling empowered to speak up and often also self advocate. Additionally, the advocacy support contributes to breaking social isolation for the advocacy partners, irrespective of the type of advocacy delivered.

It is evident that the relationship between the advocate and the advocacy partner is very special and that it relies on mutual trust. The interviewees consistently told us about or demonstrated that they felt that the advocate is on their side and always there for them. Consequently, they feel secure and many felt more able to self-advocate as they know that advocacy would be there if they did need that support. This builds the foundation for a network of support which benefits the partner in several ways.

Finally, our investigations show that despite the apparent benefits of advocacy support, it is not as accessible at it should be. All interviewees were initially referred by a third party, indicating that there is a lack of information. This is the case in spite of the fact that accessing independent advocacy is a statutory right for people with learning disabilities as outlined in the Mental Health (Care and Treatment) Act Scotland 2003.

8. Methodology

8.1 Aim of the research

The overall aim of this project is to investigate the impact of independent advocacy from the perspective of service users with learning disabilities. It seeks to explore individual stories and experiences while qualitatively mapping the impact that independent advocacy support has on their lives.

8.2 Sample Characteristics

The report is based on a total of 12 interviews with advocacy partners from different parts of Scotland. The interviews were conducted at 5 different independent advocacy organisations across Scotland. 8 of the interviewees are women and 4 are men. Their ages range from 21 to 75 years old, with 8 of the interviewees aged between 21 and 38. The interviewees' learning disabilities ranged from mild to more complex.

8.3 Choice of research methods

In order to detect the many and diverse layers of the advocacy partners' experiences it was decided to collect the research data through semi-structured interviews with individuals. Thus the researcher is able to gather a more in-depth and authentic analysis than would have been possible through, for example, questionnaires (Seale and Silverman 1997: 379). Furthermore, it was concluded that conducting interviews would be the best method in regards to the interviewees' learning disabilities and potential difficulties with understanding questionnaires. In addition, interviews provide an environment where the advocacy partner can ask questions and it is possible to explain the interview questions in further depth. The close focus on the advocacy partner's story also relates well to the purpose of independent advocacy as one of the central ends of advocacy is to strengthen the advocacy partner's voice and make it heard.

It is important to note that since the sample is relatively small it is not representative of the experiences of all independent advocacy partners with learning disabilities across Scotland. Nevertheless this sample is representative of the individual interviewee's experiences which are carefully investigated in this report. Moreover, the number of interviews conducted was selected with reference to literature on 'theoretical saturation' which suggests that this point is reached at 10-15 interviews (Guest, Bunce and Johnson 2006) (Marshall 1996). Theoretical saturation is the point at which certain themes reappear when conducting interviews on the same topic with a group of individuals sharing specific characteristics such as learning disabilities in this specific case. If one would conduct further interviews there would be no new information gain but a confirmation of the already emerged themes. Thus this report gives an indication of the impact of independent advocacy to the client group of learning disabilities as a whole and in the context of all of Scotland.

The data has been organised with the help of the computer software QSR NVivo 10. Whilst computer-assisted qualitative data analysis (CAQDAS) does not replace the researcher, it serves as a useful tool to help organise, structure and keep rich data easily accessible for potential future research projects.

8.4 Research process

This research project was conducted through interviews with advocacy partners at five different organisations around Scotland over the course of three weeks during June-July 2014. The interviewees were identified by advocacy organisations after initial contact was made over the phone. The different organisations thus acted as gatekeepers to the interviewees, which is discussed in more detail later on in this report. The interviews were facilitated by the organisations by offering us the use of their space for the interviews which thus created a familiar and safe space for the interviewees.

The interviews lasted for up to an hour and followed a semi-structured format. This allowed for the interviewees to talk freely about their experiences, while at the same time ensuring that the data would be possible to code consistently. All interviews were transcribed from either recorded audio or, in the case of the interviewees who preferred not to be recorded, from written notes before they were coded with the help of QSR NVivo 10.

All but one of the advocacy partners chose to attend the interview with their advocate because they felt more secure and comfortable. The advocate sometimes also facilitated the communication thus ensuring that the advocacy partner's views came across to the interviewer as accurately as possible. When the interviewee was asked to describe their advocate, the advocate often chose to leave the room or asked if the partner wanted to be alone. The presence of the advocate during the interviews may cause issues in terms of potential bias in the responses. Still, this was a criterion for the advocacy partners to attend the interview and it also encourages the authenticity of the findings. That the advocacy partner feels comfortable and capable of communicating their views is crucial for effective independent advocacy.

The design of the questions was partly borrowed from the toolkit for measuring impact and outcomes of advocacy introduced in Action for Advocacy's report *Lost in Translation* (Coyle 2009). Coyle suggests that the most efficient way to investigate the impact of advocacy is by exploring the advocacy partners' perceptions of their lives before, during and after receiving the support of advocacy. Furthermore the design draws on the question format used in the SIAA's report on the impact of independent advocacy for advocacy partners experiencing mental health issues (2014). The underlying intention is to strengthen the body of research of the impact of independent advocacy produced by the SIAA as a whole.

The present research is underpinned by the 'social model of disability' rather than by the medical model of disability. Thus the interview questions focus on the experience of the advocacy partner and social barriers in their lives rather than arguing that having a learning disability brings limitations. The social model of disability also underpins the Scottish Government's report *The Keys to Life* (2013).

Additionally, the main interviews are complemented by a number of interviews with non-service users who are either family members of the advocacy partner, advocates or advocacy co-ordinators. All in all three such interviews were conducted, and out of these interviews one was conducted as a group interview with three advocates and advocacy co-ordinators present.

Finally, this project aims to make the research as inclusive as possible. Nind and Vinha (2012) describe how inclusive research generates rich data that will have great impact on the lives of people with learning disabilities. While inclusive research can be conducted in several ways it is key that the project is accessible as well as "genuine and meaningful" and that it "makes use of insider knowledge of what it is like to live with learning disabilities" (Nind and Vinha 2012: 4). The design of the questions is as straight forward and easy to understand as possible and complex sentence structures or grammar are avoided (Finlay and Lyons 2001). Furthermore the participant forms are designed to be easy to read with straight forward language and font size 14. Most importantly people with learning disabilities are included in this research 'as more than just subjects of research. They are actors; people whose views are directly represented in the published findings in their own words' (Walmsley and Johnson, 2003: 61).

8.5 Ethics

Issues of ethics are pertinent in all research and should be carefully addressed when exploring the lives of people with learning disabilities. Therefore the method of contacting organisations before the interviews and using them as gatekeepers is important as it ensures that only advocacy partners who are capable and comfortable with participating took part. All interviewees were given a project description sheet and a consent form in advance of the interview. They were asked to go over the forms with their advocate in order for the forms to be familiar at the time of signing the consent form. The forms addressed issues of confidentiality and anonymity and made it clear that this is a voluntary project with the possibility to withdraw at any point during the interview. The consent form was signed at the beginning of the interview and potential questions were replied to and clarified.

8.6 Sampling method

The interviewees were selected on a purposive basis and accessed by the advocacy organisations. To identify interviewees through gatekeepers does present both benefits and limitations in regards to the sample. It is possible that the interviewees identified by the advocacy organisations are likely to have a positive experience of independent advocacy which may skew the findings. Yet this would also be a concern if advocacy partners had been contacted directly or asking them to contact the SIAA themselves as it is likely that advocacy partners with a positive experience of advocacy are the ones most willing to take part in the research. Still, being aware of the fact that the majority of the interviewees probably have a positive experience of independent advocacy, we decided to acknowledge this at an early stage of the research. Thus this research is exploring the positive impact of independent advocacy and aims to investigate why advocacy has a positive impact as well as what these impacts are. Hence, despite the fact that this sampling method entails drawbacks, it was used for several reasons.

Firstly, it ensured that the interviewees felt safe when being interviewed, thus the data and the findings are more likely to be authentic and genuine. The gatekeepers also ensured that the interviewees were capable of and comfortable with being interviewed, something which we considered very important especially in relation to learning disabilities. Secondly, the option to use gatekeepers is very time and cost efficient. Though organisations were selected based on the type of client group, because of time factors they were also selected based on the expected willingness to help out and the geographical distance to the office. Finally it is important to note that using gatekeepers might be the condition of access to conduct interviews in the first place thus making the contribution of the advocacy organisations invaluable.

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