Medway Advocacy Project

Evaluation Report

9th July 2015

Background

This report details an independent evaluation of the Medway Advocacy Project, a pilot study designed to improve the lives of individuals with severe learning disabilities and complex needs. Independent advocacy is often quoted as having significant potential capacity for enabling the empowerment of people with complex needs. However the experience of the Challenging Behaviour Foundation is that access and availability of high quality independent advocacy for people with severe learning disabilities who display behaviour described as challenging is rarely available. The Medway Advocacy Project employed a person-centred approach and tested out a dual-model of non-instructed advocacy, designed to promote continuity of relationships for these individuals, during a period of transition in their lives. This specifically involved an individualised recruitment process and the appointing of two advocates for each client - an independent advocate and a family or friend advocate.

The aims of the work were to support and facilitate the development of the skills and competencies needed to improve confidence in those working with individuals with severe learning disabilities who display challenging behaviour. The research also had the wider objective of trialling a long-term, person-centred, intensive model of advocacy with an approach specific for working with this client group as an alternative to statutory or issue-based advocacy. Another intended outcome of the project was to disseminate the findings of this pilot and the potential development of a resource to provide guidance and applications for other advocacy organisations working with this client group, and complement the existing Challenging Behaviour Foundation resource - *A Guide for Advocates. Supporting people with learning disabilities who are described as having challenging behaviour.*

The Medway Advocacy Project was set up by the Challenging Behaviour Foundation, the Tizard Centre (University of Kent) and the Young Lives Foundation. It was funded by research monies from the British Institute of Learning Disabilities, Medway Council (Learning Disability Development Fund), the Colyer-Ferguson Charitable Trust and Inclusion North.

Evaluation Findings and Recommendations

This evaluation used qualitative data collection methods in the form of a document review, meetings with members of the Medway Advocacy Project steering group and semi-structured interviews with the independent advocates, members of the steering group and the staff from the clients' service provider. The interviews were transcribed and a thematic analysis performed on the information gathered.

The results from the thematic analysis and document review, in addition to comments and information gained from meetings with the steering group, demonstrated a number of clear successes to the project. These included:

- Clear evidence of the benefits of long term, consistent, person-centred advocacy for individuals with severe learning disabilities and complex needs;

- Records demonstrating that this adapted model of non-instructed advocacy can be provided with success;
- Evidence to support the enrichment of lives and increased social network of both clients and independent advocates;
- Supporting evidence of the need for consistent relationships in non-instructed advocacy for individuals with severe learning disabilities and complex needs;
- Highly valued and informative supervision meetings, demonstrating the importance of ongoing support and guidance for independent advocates;
- Acquisition of transferable skills and proficiencies by the independent advocates;
- Partial success of inclusion and value for some family advocates who took part in the project;
- Development of a comprehensive and well received training programme.

The evaluation also highlighted a number of difficulties experienced throughout the course of the research. Some of these were anticipated by the steering group, however others were not and raised a number of challenges for those taking part in the project. These included:

- Recruitment and retention of advocates;
- The time and investment required from members of the steering group throughout the project;
- Complex relationships with service providers (including a change of service provider after the work had begun) and local authority;
- Some sacrificing of experience and ability in advocates for commitment to core values;
- Project management - including aspects such as implementation of policies on recording of advocate contact and activities, feedback and progress reports for issues addressed by both staff and advocates, and management of individuals retained and independent advocates (either as volunteers or paid staff);
- Challenges in acquiring and maintaining relationships with family/friend advocates resulting in a lack of evidence to support dual-advocate aspect of the advocacy model.

From the work undertaken as part of this evaluation, a number of recommendations have been made. Furthermore, wider applications of the findings from this pilot have also been suggested regarding the model and provision of independent advocacy for individuals with severe learning disabilities who have complex needs.

Similar future projects should consider the following:

- Value of project manager who is involved with overall organisation of project and daily running of tasks;
- Building and expanding upon the strengths and successes of pilot project e.g. importance of core values, person-centred approach, matching of advocates with clients and individualised recruitment process;
- Important to invest in identifying and recruiting potential advocates, plus additional support or training for new/inexperienced advocates (perhaps shadowing option);

- Valuable to have policy or specification guidelines regarding recording of meetings with clients and documenting advocacy issues;
- Ways of increasing involvement of family advocates and promoting relationships and collaborative working with independent advocates;
- Development and investment in working relationship with service provider.

More generally, it is recommended that:

- Availability of independent high quality advocacy for this group of individuals is increased significantly;
- This model of advocacy for individuals with severe learning disabilities and complex needs be promoted widely;
- Findings are disseminated to other advocacy agencies to enable incorporation or adaptation of the model into their existing services;
- A resource be developed from the findings and lessons learnt in the project to supplement the existing Challenging Behaviour Foundation resource - *A Guide for Advocates. Supporting people with learning disabilities who are described as having challenging behaviour;*
- Funding be sought for development of larger scale projects that help to develop an evidence base supporting long-term, person-centred models of advocacy;
- Revenue identified for sustained delivery of independent advocacy services, including non-instructed advocacy for individuals with severe learning disabilities and complex needs on a day-to-day basis.
- Support be provided to independent advocates, especially those not associated with a larger organisation, when they encounter barriers or potential conflict with service providers or statutory agencies;
- Work be developed with service providers to promote awareness of how advocacy applies to the specific needs of individuals with severe learning disabilities and complex needs.

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Notes:
All data collected has been anonymised to protect the identity of those who took part in the advocacy project and its evaluation. Comments have been edited and minor amendments made to remove gender or location or other identifying information.

An easy read version of this report has been provided for clients involved in the Medway Advocacy Project.

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INTRODUCTION

Advocacy for Individuals with Severe Learning Disabilities and Behaviour that Challenges

Independent advocacy is recognised as imperative in ensuring a person's voice is heard. It is a crucial resource for vulnerable individuals in the health, care and social systems. Those with complex needs often have a severe learning disability and can experience difficulties in communication. They may also display challenging behaviour including aggression, self-harm, destructive or disruptive actions and stereotyped behaviours. The needs, wishes, desires and even rights of individuals within this population or assigned this label, are often overlooked or ignored due to a lack of independent ability to be heard, to have a voice. Advocacy exists to give that voice, with large and small advocacy organisations and charities and statutory advocacy such as Independent Mental Health Advocates (IMHAs) and Independent Mental Capacity Advocates (IMCAs) which aim to ensure that the wishes of vulnerable individuals are heard and their rights protected.

Non-instructed advocacy for individuals with complex needs is less common. In fact, it could be described as rare. There is a suggested absence in the skills and proficiencies needed for working with young people and adults with severe learning disabilities who have complex needs, and a general unawareness of the specific issues that affect them. Family members and close friends often take on the role of advocating for their loved one. However, differing priorities or conflicts of interest can result in the individual's wishes or needs remaining unmet.

Non-instructed advocacy is crucial for individuals who lack capacity to make decisions regarding their own lives. It is also important for those who are unable to express their needs due to difficulties in communication. There is a large body of evidence highlighting the communicative functions of behaviour described as challenging including unmet needs, avoidance/escape and social attention (e.g. Hastings *et al*., 2013; Iwata *et al*., 1994; Pitonyak, 2005). However, challenging behaviour places individuals at risk of being managed using restrictive practices, potentially lowering quality of life, and increasing vulnerability to abuse or neglect. Independent advocates can encourage care providers to identify the functions behind the behaviour and employ pro-active and preventative strategies to reduce challenging behaviour and increase health and wellbeing, a key aspect of the new Care Act (2014).

Independent advocates, therefore, not only provide a voice for an individual but also perform a protective role, adding an additional layer to ensure the safeguarding of vulnerable adults and young people. Many individuals who display challenging behaviour are placed, or at risk of being placed, in out of area residential units, sometimes many hundreds of miles away from their families (Mansell, 2007; McGill *et al.,* 2010). There is evidence to suggest that out-of-area placements have been associated with poor outcomes in relation to care standards, wellbeing and quality of life (Beadle-Brown *et al.* 2006). Recent

national scandals such as Winterbourne View illustrate the increased vulnerability of individuals placed in these settings to abuse and poor care.

Independent advocacy is, therefore, vital, not only for an additional perspective for those with families and friends, but also, and just as importantly, for those without a personal relationship or someone to advocate on their behalf. The importance of access to independent advocacy is further demonstrated by its inclusion in the recently published NICE Guidelines on Challenging behaviour and learning disabilities (2015). In the current financial climate of increasing cuts in health and social care services (including charity funding), and the subsequent impact on availability and quality of care, it is critical, now more than ever, that advocacy services remain available, particularly for those with complex needs.

Although recognised in social policy and national guidance, there is an absence of regular or sustained funding for independent advocacy. Local Authorities have a duty, under the Social Care Act (2015), to provide statutory advocacy, however this is typically in the guise of generic, issue-based advocacy and not longer-term, sustained, non-instructed independent advocacy that may better suit the needs of individuals with severe learning disabilities and complex needs. Non-statutory independent advocacy is provided by charities and organisation that compete for funding bids, and rely on revenues that are not permanent.

The **Challenging Behaviour Foundation (CBF)** is a charity for individuals with severe learning disabilities who display behaviour that challenges and their families. The CBF provides information about challenging behaviour and peer support to family carers and professionals. The charity also has a national helpline for families and provides training workshops on communication and positive behavioural support. The CBF is committed to improving understanding of challenging behaviour, empowering families with information and support, and helping others to provide better services so that children and adults with severe learning disabilities who display challenging behaviour have the same life opportunities as everyone else.

The **Tizard Centre** (University of Kent) is one of the leading UK academic groups working in learning disability and community care. The Centre has extensive practical experience in services and aims to advance knowledge about the relationship between the organisation of community care services and their outcomes. The Centre's work reflects a commitment to social justice and focuses on the relationship between policy, management and practice to help improve services. Tizard Centre staff and students are dedicated to helping service agencies (both purchasers and providers) develop their own competence to provide and sustain high quality, comprehensive community care services.

The **Young Lives Foundation** (YLF) is an independent children's charity established in 2007. It is committed to delivering quality services designed to ensure that effective outcomes are achieved in the lives of vulnerable and disadvantaged children and young people. The YLF

provides support in Kent and Medway and ensures that children's rights and advocacy services are provided for all young people entitled to receive support in these areas. YLF advocates attend alongside young people at important meetings, speaking on their behalf or encouraging and enabling them to speak up for themselves at looked-after child reviews, care proceedings and Family Group Conferences and on issues such as education, placements, leaving care and family contact. The YLF also delivers a positive activities programme designed to provide young people with opportunities to gain self-esteem, learn new skills, and develop new interests.

Background to the Medway Advocacy Project

The Medway Advocacy Project (MAP) was part of a programme aimed to improve the lives of four individuals, aged nineteen to twenty-four years. Like many young people with complex needs, these individuals had lived in out of area placements. They had recently returned to the Medway area at the time the project commenced. To support this transition, the Local Authority, the CBF and the Tizard Centre collaborated with service providers to develop a specialist service, designed to promote independence and inclusion, providing accommodation, care and further education for these young people in their local community.

In developing this specialist service it was recognised that there was no locally available advocacy service that possessed the level of skill required to support the needs of these four young people, or others with similar needs. The MAP was developed by the CBF, the Tizard Centre and the YLF as a pilot study, with the purpose of equipping advocates with the skills, confidence and competencies needed to support individuals with complex needs and behaviour described as challenging , and, ultimately, to give these four young people a voice during a time of transition[1]. A MAP Steering Group was created and included representatives from the CBF, the Tizard Centre, the YLF, the local authority and the service providers. During the development of the MAP the social care service provider was a local NHS Trust. Subsequently, social care provision was taken over by a charity which already had extensive social care provision in the South of England. The provision of advocacy took place over a period of approximately seven years, was extended beyond the original four individuals and was funded by a number of small grants from The British Institute of Learning Disabilities, Medway Council (Learning Disability Development Fund), The Colyer-Ferguson Charitable Trust and Inclusion North Community Interest Company.

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[1] The MAP was later expanded to include a further three clients with complex needs, in addition to the original four.

Principles and Approach

The Medway Advocacy Project incorporated the core principles of the three leading organisations - the CBF, the Tizard Centre and the YLF. These organisations saw their paramount mission as focussing on the needs of the individual. They, therefore, emphasised the importance of a person-centred approach and incorporated the four key principles of the Department of Health's (DoH) *Valuing People Now* (2009), those of rights, independence, choice and inclusion, in their work.

The MAP steering group recognised the lack of available advocates who are confident or proficient in the knowledge and skills needed to provide non-instructed advocacy to those with complex needs or a very limited capacity to communicate. This deficit in expertise and resources results in individuals within this group being disempowered and restricts their voice, limiting their options for choice, inclusion, equality and independence. Due to the level of learning disability and difficulties in communication of the young people involved in the project, the pilot utilised a model of non-instructed advocacy.

Valuing People Now (DoH, 2009) identifies the importance of family members and friends in person-centred planning, recognising that family members or close friends often take on an advocate role for their loved ones. This pre-existing relationship is vital in advocating for individuals with limited communication as it lays the foundations for the advocate's ability to understand and recognise the individual's preferences, wishes and needs, without the use of typical, verbal communication methods.

That being said, individuals with severe learning disabilities or severely restricted communication abilities exhibit higher levels of dependency and vulnerability which may produce conflicts of interest between the wishes of the family members and those of the individual. For example, the desire to keep a loved one safe may result in restriction of choice or independence. Independent advocacy is therefore important in ensuring that an individual has the ability to retain control over decisions in their lives, and have the power to protect their rights.

One of the key features of the Medway Advocacy Project, therefore, was to assign each individual two advocates – pairing an externally recruited, independent advocate with an existing family (or friend) advocate, thereby coupling the independence of the external advocate with the pre-existing knowledge and relationship of the family advocate.

Methodology of the Project:

The project followed a clear design placing the individual at the centre of all stages.

The recruitment process was client specific. This involved investing time and resources in identifying potential candidates. Applicants were required to express an interest in

advocating for a particular individual rather than respond to a generic 'advocate role'. The interview process matched the advocate to each individual and involved one or two sessions where each client (the young person) met the advocate before a decision was made.

The client-specific approach and person-centred ethos of the project meant that that an applicant's core values were viewed as more important than experience or existing skills or knowledge of advocacy during recruitment.

The interviews were run by members of the MAP steering group. A number of family members or friends also undertook an interview to ensure that both advocates were a good match and best able to meet the needs of each individual.

Continuity of relationship was also an important feature of the project design, therefore the independent advocates were asked to sign up for two years. Family advocates were presumed to have a continuing relationship.

The role required attendance of an initial training programme and follow up group meetings/supervision. The independent advocates were expected to have two hours of contact time with their client per fortnight and needed to document/record their visits and interactions.

In the early stages of the project, the independent advocates were recruited as volunteers then later offered payment when funding became available. Payment was not offered to the family advocates.

A one-day training package was provided to independent and family advocates. The programme was developed and delivered by the MAP steering group, who together possess extensive experience and a comprehensive background knowledge of the topics. The subjects included:

- Approaches to Advocacy (specific models, the role of an advocate and issues of capacity and consent)
- Learning Disability (including Autism Spectrum Conditions)
- Safeguarding Vulnerable Adults and Young People
- Person-centred planning
- Communication (skills, methods and practice)
- Working with individuals who display challenging behaviour (including positive behavioural support, and issues such as restraint and medication)

Monthly support meetings and supervision from the MAP steering group were offered to both sets of advocates in order to extend training, undergo case reviews and provide the opportunity to share best-practice. One-to-one supervision from a clinical psychologist was also available.

Support for the independent advocates in between these meetings was also offered by telephone or email with a member of the MAP steering group, should they require it.

The advocacy in the project was designed to focus upon areas that were particularly salient in the young people's lives as a result of their developmental status and circumstances at the time. For example:

- person-centred plans for the individuals' future lives and support arrangements during the transition;
- potential for development and growth (as older teenagers/young adults) is capitalised on by formal and informal educational arrangements;
- the extent their complex needs (especially, but not only their challenging behaviour) are being proactively managed to limit potential adverse impact on current and future lives;
- the extent to which current support arrangements fully recognise their status as young people with futures.

Independent Advocate Records/Documentation Review:

Eleven independent advocates were recruited for the MAP between 2009 and 2013. There is very little documentation on the first three advocates that were enrolled and little is recorded of the work they did. However, feedback from the Steering Group during evaluation meetings and data from the interviews has been able to provide some information regarding the advocacy issues and experiences of these early advocates (discussed later in the report).

From the records kept by the remaining eight independent advocates and the CBF, the tables below detail descriptive information regarding the number of independent advocates each client had, the frequency and duration of contact the independent advocate had with their client and the purpose of those visits.

Detailed records were only available for five of the MAP clients and some of these were incomplete. However, they have been included to supplement the information gathered from the interviews with the independent advocates.

Table 1: Contact from Independent Advocate listed by Client

	No. Independent Advocates throughout the Project	No of Visits	No. months in receipt of Independent Advocacy	Visits per month	Average duration of visit (hours)
Client 1	1	Missing*	Missing*	Missing*	Missing*
Client 2	1	16	28	1	1.9
Client 3	2	17	17.5	1	3.3
Client 4	2	9	5	2	1.3
Client 5	2	14	10.75	1	1.3
Client 6	1	8	4	2	Missing*

Table 2: Contact listed by Independent Advocate

Independent Advocate	Retention of Advocate (months)	No. of visits
Ad1	*Not available*	*Not available*
Ad2	*Not available*	*Not available*
Ad3	*Not available*	*Not available*
Ad4	15	14
Ad5	2.5	3
Ad6	2.25	4
Ad7	10.75	13
Ad8	0.25	1
Ad9	3	5
Ad10	28	16
Ad11	4	8

Table 3: Purpose of Visits/Contact

Purpose of Contact by Independent Advocate
First meeting/visit with client
Liaison with Avenues
Liaison with clinical/community team
Client Progress/Care Meeting
CBF Meeting

Table 4: Independent Advocacy Issues/Concerns

Issues Advocating on behalf of Client by Independent Advocate
Use of communication aids
Quality of life including restricted activities and home/living environment)
Personal care and hygiene needs (including medical concerns)
Access to services e.g. SALT
Relationships with staff

Evaluation Interviews

Independent Advocates

Of the eleven advocates that took part in the MAP, contact details were available for six. Of these six, four consented to interview. The interview was semi-structured and conducted over the phone by an independent researcher[2]. It lasted approximately half an hour and the questions focused upon the advocate's experiences during the MAP, including aspects of the training, the support, working with the client and the relationship with the family advocate.

MAP Steering Group

Three of the four members of the MAP steering group were available for interview. Again, these were conducted by the researcher over the telephone[2]. The interview focused on the members' views of the project, its rationale, the challenges and successes and the possible wider implications of the work.
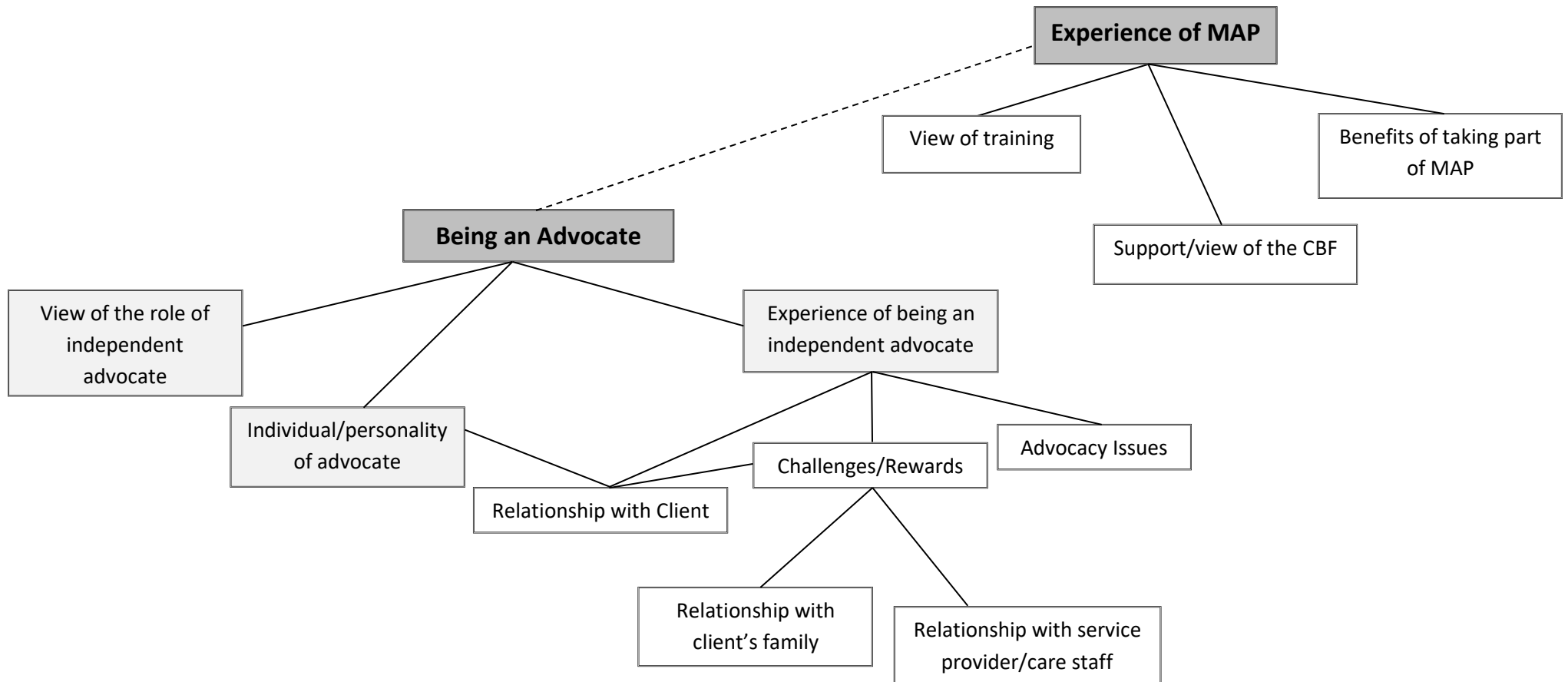
Service Provider Staff

Three members of the service provider staff were available for interview, two support workers and one manager. The interviews were held over the phone and conducted by the researcher[2]. The staff worked at a number of the service provider's sites and were able to discuss at least one client and advocate involved in the project.

What follows in this report is a thematic analysis of each set of interviews and then a review of the themes leading into the overall evaluation of the project and further recommendations and applications of the findings. The thematic analysis follows the guidelines set out by Braun and Clarke (2006) and copies of the raw data coding are included in the appendices.

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[2]A copy of the interview schedule is included in the appendices.

Independent Advocate Interviews Thematic Map:

Legend:

	Theme
	Subtheme
	Components

Boxes in the map:

- **Experience of MAP** (Theme)
  - View of training
  - Support/view of the CBF
  - Benefits of taking part of MAP
- **Being an Advocate** (Theme)
  - View of the role of independent advocate
  - Individual/personality of advocate
  - Experience of being an independent advocate
    - Relationship with Client
    - Challenges/Rewards
      - Relationship with client's family
      - Relationship with service provider/care staff
    - Advocacy Issues

Thematic Analysis of Independent Advocate Interviews

The following sections outline the main themes and subthemes that emerged from a thematic analysis of the interview transcripts.

From the four interviews conducted with the independent advocates, two main themes emerged, those of **being an advocate** and their **experience of the MAP.**

The two themes are highly related and extracts from the data will demonstrate that sub-themes from one contribute to the sub-themes of the other. However, analysis of the transcripts revealed that data fell within these two themes.

1. <u>Being an Advocate</u>

1.1. View of the role

The majority of those interviewed spoke of the role as one of being 'for the client', giving them a voice and communicating and acting on their behalf, for their needs.

 "you know that, that's their choice at the end of the day … I really liked giving them a voice. –Ad7

"…standing up for them really, you know giving them a voice", – Ad7

The interviewed advocates also implied a protective element to their role in safeguarding the rights and choices of their clients as vulnerable adults.

"and you know you feel you know the person a bit more than, than you realise but actually you start making decisions for them and I think an advocate is somebody who can kind of step in and go, step back for a second and you know, see what's really going on so I think it's important cos you know everything changes and people's opinions change" – Ad5

 "So you know, for me, if you think about it, I was only just that PECs© board[3] in a way, and figuratively speaking that's who you are, you're just facilitating their communication making sure what they want to be said is said, what they need is met, and that, that was the most satisfying element of the advocacy I think"– Ad10

"unless you have an independent person coming in that's highly skilled and well trained, it's very difficult for that young person to have the choice" – Ad10

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[3] Picture Exchange Communication System, a visual communication tool.

1.2. Experience of being an Independent Advocate

1.2.1. Advocacy Issues

The issues raised by the advocates on behalf on their clients varied in some respects but also ran along similar themes. Many of them focused on quality of life, including restricted activities, living environment and engagement in the community.

Nearly all of those interviews raised issues regarding communication and communication tools, and many of the points made were linked to occurrences of challenging behaviour. The advocates spoke of the difficulties in highlighting the importance of communication in the pathway to behaviour that challenges.

"I tried to bring up about that idea of maybe making a book of his favourite places and using a pictorial aid as well as just the Makaton" – Ad5

"and I completely understand why they would get frustrated when one of the agency workers would say there's a bit of a delay or we'd go in about 5-10 minutes" – Ad7 (regarding a Client with ASC)

A number of these issues highlighted the pro-active strategies and preventative measures advocates were attempting to encourage for possible triggers to behaviour that challenges.

"[If they had] used the sign language or even PECs or whatever worked with them and whatever the worker was comfortable with and to actually make a choice, that would've stopped some of the challenging behaviour" - Ad7

Advocates also spoke of the difficulty in conveying that knowledge of an individual does not mean you should restrict their choice and choose for them.

"a lot of the time the challenges were around 'well I've known them, so I know this is what they are saying', whereas each time… as an advocate although you used what you knew of them to give you a framework of where they might be, you never assumed that was what they were trying to say and you know that was, that was a real challenge"– Ad10

"[the] carers that were with them were absolutely amazing but sometimes they know them inside out they feel like they know and can make choices on their behalf because that's what they normally like" - Ad5

Choice, and restriction of choice were also linked in to service provision.

"they've got every right if they [the client] *don't want to see people there, the agency staff member, that's their* [the client's] *house". – Ad7 discussing a difficult relationship between a client and a staff member.*

"for example, if one of the other residents was due to go out to do whatever, then Client 2 was taken along because either there weren't enough staff indoors to manage them or

whatever, and that should not happen and for me, as Client 2's advocate, for me, my role was to look at well hold on, if you've identified these as Client 2's needs and goals …. then that's what we should be meeting, not fitting in with whatever someone else is doing because you don't have [inaudible], because you have [a] lack of staff." – Ad10

1.2.2. Challenges of the role

Very few of the advocates mentioned communication difficulties or challenging behaviour as a difficulty of the role. One expressed that as they did not know Makaton it was a challenge[4], however they found other ways to communicate with their client and that the client was actually teaching the advocate some Makaton symbols.

Challenging behaviour was only mentioned briefly but the advocate did not speak of this as a barrier to her work.

The advocates did speak of time demands and the difficulties of finding the time to see their client when working. This however did not appear to be the case so much when the individual advocate was at University.

The majority of challenges faced by the advocates within their role seemed to stem from conflicts of interest between staff and in service provision. This included issues to do with time and resources, but also attitudes of staff, and the barriers they sometimes created to the work being undertaken on behalf of the client.

"they just denied it by saying you know it's relationship building, there are good times" – Ad7 regarding the client's indication they were not comfortable with a particular staff member.

"I just felt it was so inappropriate and you're sort of powerless, so you're reporting these things and, but, you're absolutely powerless to do anything" – Ad6

"I think they felt they had so much other work to do which they do of course with Client 3, you know personal care, meals, you know the general day to day living with them I think they felt it was a bit of an effort to be honest" – Ad5 speaking of creating a picture book as an additional communication tool.

"because there was never time, as the washing had to be done, or the rest of it had to be done, the time with the [young] people needed to be valued as much as the chores that needed doing". – Ad10

1.2.3. Rewards

Three out of the four advocates would recommend becoming an advocate. The advocate that did not overtly recommend it did not specifically state that others should not do it, but spoke of the difficulties and gave some advice regarding

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[4] Makaton training was provided however advocate was reported not to have attended

expectations. All of those interviewed appeared to enjoy the experience on some level. The rewards of being an advocate mentioned by those interviewed primarily centred around their relationship with the client, whilst others spoke of the experience it gave them and the knowledge they learnt.

"I'd say go for it, you know it's an amazing opportunity" – Ad7

"I just got to know Client 3 which is a pleasure in itself because they're… just a really, really nice person." – Ad5

"I think it's kind of character building" – Ad7

The issue of payment did not appear to play a big part in the decision to become an advocate or continue being one. Whilst some recognised the money helped, it did not appear to be a big influence.

"No not really, for the amount of money that you get for it it's quite negligible" – Ad6

"I mean for me, you know,…the money made a difference, of course it did because I didn't do any paid work at all but for me it was a great learning curve in a very different role and, and for me that satisfied me enough so I would've carried on whether I was paid or not but it certainly helped" – Ad10

1.2.4. Client's family (inc. family advocate)

Unfortunately two of the interviewees were advocates for clients who had little contact with their family and had no family advocate to speak of, therefore there was little data to collect regarding this aspect of the project. Additionally, one of the other family advocates was a member of the MAP steering group with extensive experience of providing advocacy for her son which potentially altered the dynamic of this relationship also. However, a data extract from the advocates who did have a relationship with the Client's family advocate demonstrates the recognition of the importance of the pre-existing relationship and how that benefited their dual role:

"'cause what they [the client's relative] *would've known about Client 2 I could have never known" – Ad10,* speaking of client's relative .

"if we invest in that relationship building [independent and family advocate], I think, together, it's quite a good … relationship, … for Client 2, it worked well for them. So yeah it was really good to have that." – Ad10

"I often found sometimes that because they're such a good advocate [family advocate] and because they have such, they've worked with them and you know and they know them inside out…that sometimes they didn't really give other people a chance to get involved as much as they would probably like" – Ad5 discussing client 3's family advocate

"because they're their advocate but they're also their relative [the client] and in essence they're the boss if you know what I mean (laughs) so, it was, it was kind of interesting enough to kind of see that dynamic" – Ad5

1.3. The individual/personality

The person-centred approach and core values that were central to the recruitment process were displayed in many of the answers given by a number of the advocates, reflecting the success and importance of this aspect of the recruitment process. The recognition and respect for the client as an individual with equal rights, needs and choice was clear throughout the interviews.

"because they do take time to make a choice and they can change it like five or ten times in a minute (laughs) so they're quite outspoken and they know what they like, and they do change their mind quite a bit" – Ad5

"If they want to do something, you know, providing they're not in any kind of danger or anything like that, you have to work with their interests, … they're an adult" – Ad7

The motivation of the individuals to join the project and become an advocate stemmed from an existing interest, concordance with current studying/occupation or the desire to do something meaningful or fulfilling.

"I wanted to just, at least if I could help one person achieve what they wanted to achieve, yeah, that's why I did it really" – Ad5

"I was studying to be an occupational therapist" – Ad5

"I was studying speech and language therapy so kind of the whole communication side was something that really appealed". – Ad7

2. Experience of MAP

The overriding experiences of advocates taking part in the MAP were positive. Many expressed gratitude for the opportunity to work with the CBF and members of the steering group, but were also grateful for the opportunity to work with the clients.

"I don't know what it is, but there is something very, very special in that place, it is short of saying magical, it is magical and that it is a whole package and for me" – Ad10

2.1. View of Initial Training Programme

Generally, the consensus on the training was that it was very good or excellent. There were very few comments regarding the initial programme which suggested it was

lacking in any element. The comments by those interviewed reflected the obvious value of a specific and tailored programme for this particular client group. The only additional topics that advocates would have liked to have been included were teaching Makaton and more guidance on things to look for as an advocate.

"but that's one thing[Makaton] I suppose that would've been helpful from maybe the CBF cos when we first started they said that we, that they would do training on that and there wasn't anything so that was a bit difficult with the communication wise" – Ad5

"I think if I was more experienced in doing support work I'd know what I was looking for and what I was looking at … so something to make it a bit more specific" – Ad6

However, most found it comprehensive.

"and there were all these resources that I could use and websites that I could refer to and videos that I've borrowed on autism, so training was fantastic." – Ad4

"with the project I think [inaudible] supervision was just so useful, you know pertinent learning, at the right time, real good support, when you're dealing with some quite difficult issues in terms of challenging constructively, making sure people are heard and then managing those competing rights, that's just, it was just so spot on." – Ad7

"you know they gave us good background history and a good profile on people that we were working with and how to communicate with them" – Ad5

2.2. Continued Training, Support and Supervision

The majority of advocates interviewed said they felt supported by the CBF. However, one individual felt, towards the end of the project, that contact from the CBF and support was lacking.

"I think it kind of got to the point where we were... well, I felt a little bit lost, I was like 'what am I supposed to be doing now with Client 3' and I think if we'd have had more meetings it would've given us more direction." – Ad5

Others reported feeling supported and confident in the assistance and guidance provided by the CBF.

"I think the support network was definitely there" – Ad7

"if there was any problems I know the CBF was always there if I needed help with anything"- Ad6

All the advocates agreed on the usefulness of the monthly supervision meetings and the benefits of shared-practice.

"it was really useful to have the, the kind of meetings to catch up with the others and get their advice"– Ad7

"and we talked it though in one of the meetings, that support was required 'cause at that point, I felt really frustrated [okay] and think that was the one point where I felt 'are we making a change' or are we not and we talked it through in the group supervision and I came away feeling a lot more optimistic about the role". – Ad10

The importance of continued support was evident in a number of comments made on this topic, particularly when the independent advocate experienced difficulties they were unable to resolve with the service provider. Of those mentioned in the interviews, these included access to care plans and difficulties in staff and client relationships. In these cases having that additional layer of support enabled the advocates to feel supported and guided. Additionally, the extra level of hierarchy appeared vital for the advocates, and as a consequence, the clients, in taking issues forward.

"I was having some trouble accessing some documents. I know at that point there was some high level communication between [steering group member] and somebody in the provider to address that" – Ad10

2.3. Benefits of taking part in MAP

Many of the positives that were spoken of in taking part in the project (in addition to the benefits of the client relationship mentioned previously) highlighted the practical skills developed. These skills and related experiences were perhaps not only applicable to advocacy but also transferable to other areas.

"one of the things [the trainer] taught me … yes, you feel the emotion[s], feel that, then put them to one side, step back and the [keep/see the] objectivity, that I learnt hugely, hugely from [the trainer] you know and the supervision we used to have". – Ad10

"I think it has a little bit but I think it's not necessarily through the training I got through the CBF but more through the training Client 3 gave me in communicating with them" (laughs) – Ad5 responding to a question on transferable skills

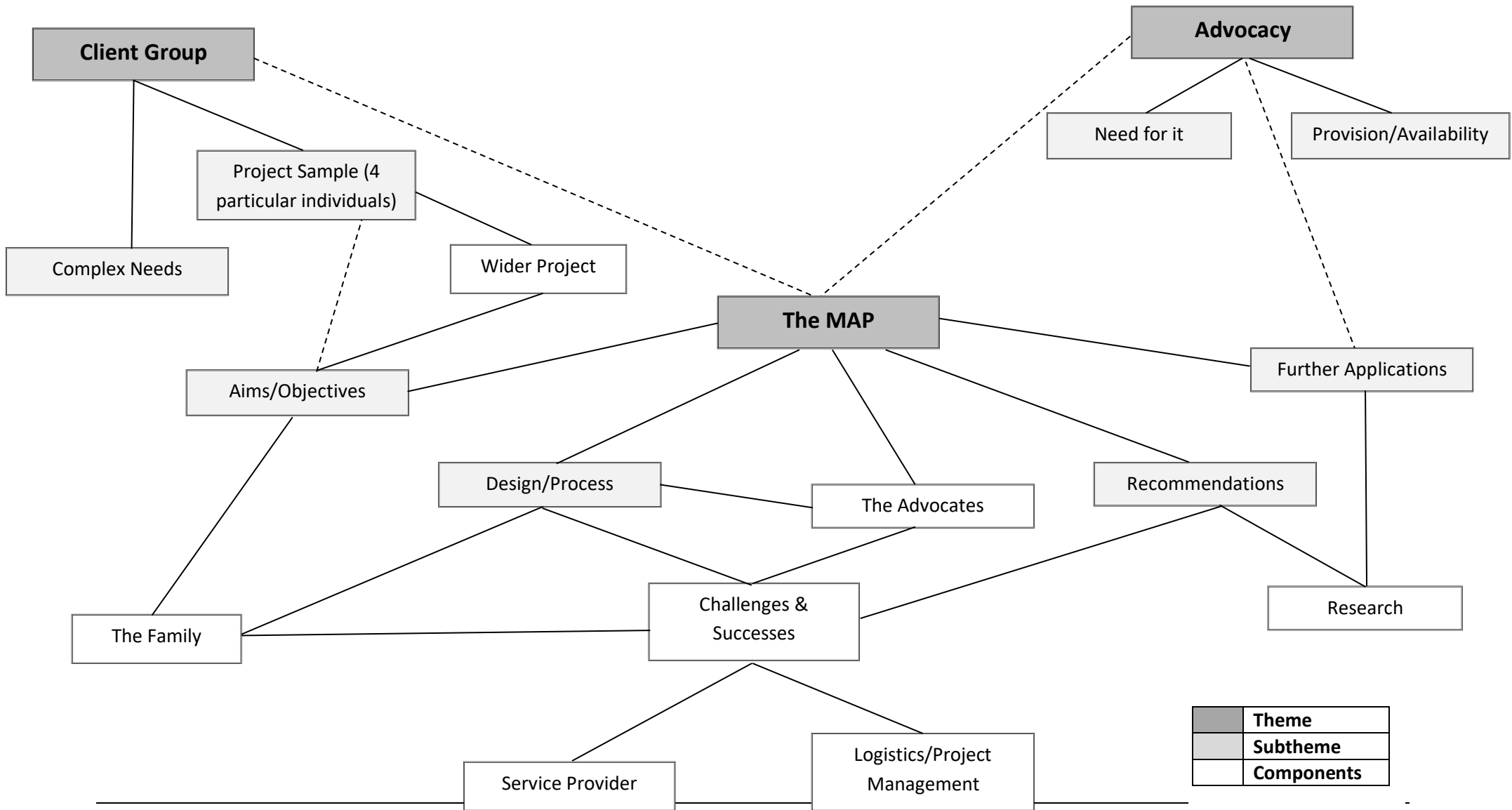*"Yeah it kind of helped me in the practical element of my course as well" – Ad7*

"it was such a positive experience, I mean I have grown so much from it." – Ad10

"Patience I think, patience and that things don't necessarily happen in the time period that you would want them to" – Ad7

"it made me really open my mind and open my eyes to people who can't communicate and actually the different ways of getting them to communicate" Ad5

I can't thank [members of the steering group] enough for giving me the opportunity but I also in a way can't thank Client 2 enough for facilitating my learning – Ad10

MAP Steering Group Interviews Thematic Map:

Diagram nodes:

- Client Group (Theme)
  - Complex Needs
  - Project Sample (4 particular individuals)
  - Wider Project
  - Aims/Objectives
- Advocacy (Theme)
  - Need for it
  - Provision/Availability
- The MAP (Theme)
  - Design/Process
  - The Advocates
  - Further Applications
  - Recommendations
  - Research
  - Challenges & Successes
  - The Family
  - Service Provider
  - Logistics/Project Management

Legend:
(dark grey)	Theme
(light grey)	Subtheme
(white)	Components

Thematic Analysis of MAP Steering Group Interviews

Three main themes were identified in the data collected from the MAP Steering Group interviews, each with a number of subthemes. The main themes that emerged were **the client group**, **advocacy** and **the MAP** itself.

As with the advocate interviews, these themes, and a number of their subthemes, are related.

1. <u>The Client Group</u>

   1.1. Complex Needs

   All members of the Steering Group interviewed discussed the complex needs of the particular client group targeted within the MAP and identified issues specific to those with severe learning disabilities, communication difficulties and challenging behaviour. These issues included a lack of advocacy, the need for continuity in relationships and the need for safeguarding vulnerable individuals within this population.

   "how are we going to check the quality is good and how are we going to check that this group of particularly vulnerable people have good quality advocacy, as it's difficult, it's time consuming but they are most in need of it so we need to prioritise them" - SG3

   1.2. Project Sample

   One of the interviews revealed how these broader problems and challenges (including a lack of independent advocacy) contributed to the development of the wider project mentioned in the background section of this report. This project had been designed to improve the lives of the four specific individuals initially involved with the MAP.

   "part of the point of the advocacy project was about, forcing attention on individuals, and on their, and what might be their aspirations for the future… there were a number of things we did to try and do that, and I think the advocacy project was probably one of them - SG1

2. <u>Advocacy</u>

Advocacy was a major theme discussed by all members of the steering group. Comments centred around the need for advocacy, not only in general but also specifically for individuals with complex needs and around current provision and availability of good quality advocacy for individuals with severe learning disabilities who may display behaviour that challenges.

2.1. Need for Advocacy

The need for advocates to provide a voice for vulnerable individuals was mentioned in all interviews, as with the advocate interviews. However, members of the steering group focused their answers on the specific requirements and the potential issues that may arise with individuals with complex needs, such as restraint, medication and understanding the function of behaviours that challenge.

"There are really, really big issues around advocacy …generally everyone is agreed advocacy is a good thing, and everyone's generally agreed advocacy for individuals with learning disabilities is a good thing and potentially, very, very powerful and, yet when you try and unpick that, and… who's ultimately responsible to ensure that there's the availability of advocates... and who's going to ensure and when you try to unpick that… it's really hard to find how that works" - SG3

"[it] seems to me to be really hard to be an advocate for someone whose behaviour is challenging if you don't really have any idea of challenging behaviour and how it should be supported" - SG1

"also lacking is the expertise, we feel … having the right skills to support someone who is non-verbal, in particular or have, might have autism and find it really hard to express their opinions" - SG2

Additionally, the steering group interviews highlighted the importance of the potential safeguarding role an independent advocate can provide for individuals with complex needs who display behaviour that challenges.

"the amount of knowledge and understanding that people need to have because, there's the downside to poor advocacy, which could potentially be quite damaging if people come in and, don't get to know the person and don't get to understand the behaviour, don't understand the functions behind it may think' well, that's ok', and then it legitimises some potentially poor practice - SG3.

"For instance, if people are being restrained, that may or may not be an issue … similarly with things like medication ... I think you have to have some understanding of these things to be able to detect what you need to explore, as an advocate, in those situations" - SG1

2.2. Provision/Availability

The lack of independent advocacy available to individuals with complex needs was evident in the number of times it was mentioned throughout the interviews by the steering group members. This gap in services was highlighted across a number of levels, for example, in one member's direct experience with her child, but also on a general

level in terms of the current economic climate and funding for charities and social care services to be able to provide advocacy.

"they weren't able to demonstrate that they had skills or knowledge to advocate for them properly" - SG3, in relation to accessing advocates for their child

"there was a gap … when the project started it was a problem and then as time went on, throughout the project, it became more of a problem with the recession, charities receiving less funding, there just seemed to be less and less advocacy around at all, and practically no independent, non-instructed advocacy" - SG2

"advocacy is funded by people providing the service and it's not independent" – SG3

"there's minimal funding available it's got to come from an existing pot, so you know it's then not funded adequately, to the level it needs to be" - SG3

As mentioned in the previous subtheme, the specific requirements of individuals with complex needs can necessitate the need for non-instructed advocacy. This style of advocacy requires a particular type of relationship i.e. ongoing and consistent, utilising a person-centre approach. Responses from the steering group interviews highlight that this approach or advocacy style is not readily available through existing advocacy organisations.

"there tends to be the statutory advocacy, like IMCA, IMHA and then sometimes you get some quite specific advocacy around a particular issue that someone's experiencing, and not really, that ongoing, kind of protective, more protective kind of advocacy, or the type where you can, kind of get to know someone enough to be able to speak out for them" - SG2

"if advocacy was available it was more sort of generic advocacy, where people didn't really understand the individual, didn't get to know them, sort of issue based advocacy rather than longer term advocacy" - SG3

"Continuity of relationships, because of nature of needs, takes a while to get to know them and get to understand their methods of communication" - SG1

"danger advocate of coming in, and either doing virtually nothing for a long time, take a while to get to know and understand the individual and their situation or they'd make assumptions about things they shouldn't make or jump to conclusions too quickly" -SG1

Nearly all members of the steering group identified that it was, partly, in response to this gap, that the project was developed; not only with the aim of meeting the immediate needs of the four individuals initially involved with the project, but also on a wider scale to perhaps influence other advocacy organisations.

"trying to think about why that wasn't available and could we do something to test out, a way of delivering it [longer-term advocacy] *so that we could help advocacy organisations to think about*

doing things differently when they did include this group of people [individuals with complex needs]" - *SG3*

3. The Medway Advocacy Project

Much of the data from the interviews focused upon the project itself, not only in the need for it, as discussed above, but the specific design and approach it took, the lessons learnt and the challenges it faced and successes it achieved.

3.1. Aims/Objectives

Many of the comments in the interviews centred on the trial nature of the pilot project and the need to 'test things out'. There was a lot of discussion regarding lessons learnt and one member referred to recording the outcomes so it's a "*more formal project*", designed to demonstrate the need for this type of advocacy for clients with complex behaviours and the potential benefits to person-centred, longer term, non-instructed advocacy (SG3). The same member also wanted the project to act as a "*catalyst*" for discussion around advocacy. All of the members interviewed felt that the project achieved its aims in piloting a specific model of non-instructed advocacy and demonstrating that it is possible to provide this type of advocacy with some success.

"*it was never aiming to do a lot of advocacy in numbers, it was always about what can we do, what will work and what can we learn from it so yeah, I think it's achieved that*" - *SG2*

"*Essence of the project was about providing person centred solutions not about treating them all the same, would've been contradictory to the wider project aims to do anything that wasn't exclusively person centred*" - *SG1*

"*I think yes. Was to try it out, let's see how it works. Demonstrate to others what works and what doesn't*" - *SG2, in response to question regarding the project achieving its outcomes.*

As mentioned previously, another aspect to the advocacy was the transitional nature of the client's situation and the advocacy was there to help these individuals in their return to the community and their plans for the future. However, most members of the steering group felt these aims were only partially met, with some individuals still in their transition service.

"*…partly achieved it, don't know where all the individuals* [from the wider project*] are… it* [was] *certainly successful for client 3, and partly to do with advocacy. For others, [it] drew attention to things that the providers weren't paying attention so in that sense it was helpful but the fact that the services still exists and people living in it suggests that the entire project didn't fully achieve its initial aims*" - *SG1*

3.2. Design/Process of the Project

3.2.1. The Advocates

The specific project design described in the introduction was felt to be justified and to some part, successful in the MAP.

"*Client 3 and 1 could not be more different and their way of relating to people be more different so people who are likely to be effective advocates for them are likely to be different too*" - *SG1 in response to question regarding individualised advert for each client rather than generic recruitment and assigning of advocate.*

The focus on core values and a person-centred approach over experience or knowledge of advocacy appeared successful in the quality of relationships developed with the clients and the commitment to the individual as a person.

"*the way the advocates were able to develop a rapport and relationship with the person and get their trust. So if they wanted to share something, in however they communicate they would be able to do that*" - *SG2 in response to question regarding what they thought the most important outcome of the project was.*

"*It's that ongoing connection, that was the real success*" - *SG2*

However, one of the difficulties in the project identified by those interviewed was the recruitment and retention of advocates, and that it took some time before enough potential candidates were identified to be able to start the project.

"*Recruitment was a challenge, asking for quite a big commitment, and wanting the right sort of people to make that commitment*" - *SG3*

"*getting advocates was a challenge, especially at first, should we select these, are these individuals ok, there wasn't much of a choice effectively*" – *SG1*

"*or by the time they'd become a more effective advocate they'd move on*" - *SG1*

Despite the difficulties experienced, the importance of dedicating time and resources into the recruitment and identification of advocates and their subsequent training and ongoing supervision was clearly important and valued. Investing in the advocates from the outset adds to the investment in the advocate-client relationships.

"*When I think about the advocates that client 3 had as part of this project, they've got a huge amount out of them and one of the advocates, certainly they are still in contact with, they still very much have a relationship and he goes and visits…still enjoy each other's company… it's increased [the client's] social network*" - *SG3 (and family advocate).*

3.2.2   The Family

A second key aspect to the design of the MAP was the inclusion of a family advocate. Families were recognised by all of those interviewed as a really important aspect of an individual's life, and that many often advocate on behalf of their relatives. The three members of the steering group interviewed, however, felt there was only partial success in this part of the project.

"*Wasn't very successful at all. Don't know if it was this project and this set of families but quite a difficult thing to do, some people didn't really have a family member who was engaged or even around*"- SG2

"*Didn't really work at all with one client, we actually had some incredible difficulties with their* [relative] *who didn't really want anyone involved*" - SG1

In addition to a number of the clients not having a second advocate (family or close friend), the inclusion of the family member in the project proved problematic in terms of keeping contact, attending meetings and having the resources to invest the relationship in a similar way/depth to the independent advocate.

"*it was quite difficult for them to come to meetings or for us to arrange the meetings at the CBF office, where we had group discussions so it never really got going having the family/friend advocate coming to meetings*" - SG2

"*… I think we shouldn't underestimate the layers of poor experience people's families have had and how we need to address that and get them to trust that this would be a good, helpful thing to do… Perhaps a learning point that we need to invest more if we're going to use this model going forward*" - SG3 in relationship to getting clients' families on board with the MAP.

"*So much to do with the advocates they kind of dropped down on the priority list*" – SG2 on engaging with the families, inviting them to the meetings (also see below).

However, the model was still felt to be useful and one client clearly benefited from the two advocates and another was thought to have partial success from it.

"*Clearly that worked with Client 3. Also worked to some extent with client 2's relative. It worked a little with Client 1, who had no family contact but there was a person who had previously been, I think their independent visitor*" – SG1

"*From my perspective it worked quite well, able to recruit good advocates for client 3 and were able to have a dialogue and work together*" – SG3

"*Did work with some situations, I think it could've worked better and we could've done more to try and encourage it. Certainly an interesting way of working*"- SG1

3.2.3 Challenges and Successes

In addition to the challenges related to the family and recruitment, two other themes emerged as challenges faced during the project – (i) those relating to logistics and practical management of the project and, (ii) those relating to the service provider.

All members of the group mentioned the need for a project manager and someone dedicated to organising the overall running of the work and the advocates. The steering group felt it underestimated time and organisation involved and spoke of the difficulties in trying to run this in addition to their day jobs and lives. A member of CBF staff was brought in later to manage the project and join the steering group. This did mean, however, that the person's not being involved from the beginning meant that some of the original information was lost.

"*When I took over… I only had the contact details of one of the family/friend advocates, and I didn't really know that they were supposed to be coming to the meetings*" - SG2

"*Quite a lengthy spell when we didn't have anyone managing the project… bit undermanaged and a bit under-resourced*" – SG1

"*we were all doing them* [support meetings] *really in our spare time so they were evening/weekends, done a bit in the margins, isn't an ideal way to do a project*" - SG1

Difficulties were also mentioned in managing the advocates, initially in terms of the types of demands made when they were volunteers i.e. feedback, paperwork, communication etc., but also later when funding became available for payment and how to manage paid staff or more formally operationalise the procedure.

"*At first go easy on people as they were volunteering and then when it became paid it was hard to make a change from how it had always been, also I hadn't supervised paid staff before*" - SG2

"*Although occasionally wouldn't hear from people then they would get back in touch and say I've done all these things and that's brilliant, but it would've been helpful if we'd known*" – SG2

It was identified in the interviews that there were some unexpected challenges in relation to the service provider, and in one instance, the local authority. All members of the steering group acknowledged the difficult dynamic between independent advocates and the service provider and the delicate balance needed in that relationship.

"*building awareness of what advocacy is … it's about giving the person a voice. I think staff felt they had inbuilt support mechanisms for the person but it's not independent enough*" - SG2

"*certainly were problems with the service … where they didn't really like some of the feedback they were getting, from the advocates or the project more generally, in some sense inevitable … perhaps an inevitable problem but maybe we could've managed it better*" - *SG1*

"*Need to work with the provider and support workers, all those involved with the person so they're really clear about the role, that it's a positive thing and not checking up to criticise but see how we can work together*" — *SG3*

"*there* was *also some difficulties with local authority who felt that people didn't really need advocates … and there were issues raised around consent*" - *SG1*

"*Telling about advocacy that the support provider didn't really seem to see the need for it or take it seriously*" - *SG2*

A major theme regarding the success of the project, and mentioned by all members of the steering group, was the fact that this pilot demonstrated that this kind of advocacy can be provided. Although there were differences of opinion over expense, the actual provision of long-term, non-instructed advocacy to clients with complex needs was considered achieved and a success.

"*Can offer advocacy for a number of people for quite a small amount* [of money]" - *SG2*

In addition to this, other benefits of the project were those where the clients themselves directly benefitted from having an advocate, for example, someone to pick up on issues that may have been missed otherwise.

"[I] *thought the actual advocacy work they did for the individuals was really beneficial. There … looking back doesn't seem like a lot of changes were made but think they did make a big difference, it can be the little things that make a big difference to people with a learning disability*" — SG2

There were also considered to be benefits to the advocates who took part and potential to apply learning from the pilot to other advocacy organisations.

"*Meetings with the advocate were always generally, usually quite positive, partly because the advocates were having experiences that were clearly significant for them, developing relationships with someone or were …*" SG1

"*Hope for the advocates, opened their eyes to the needs of people with complex needs and help them have a good grounding and understanding about how to support them*" — *SG3*

3.3. Recommendations

From the interviews, recommendations were made not only for future projects of this kind (these centred around the direct challenges faced, such as family involvement, managing staff relationships and planning/organisation) but also about further implications and applications of the findings.

"Brilliant if advocacy providers could use what we've learnt and improve what they do and widen what they offer" - SG2

"thinking about …could we do something to test out a way of delivering it so that we could help advocacy organisations to think about doing things differently when they include this group of people" – SG3

3.3.1 Future Projects and Research

All steering group members highlighted the need for a Project Manager and someone to organise the advocates and daily running of the project. Comments within this subtheme emphasised the need for investment in people and resources It was important to monitor the progress of advocacy issues and the work undertaken by the advocates. This person should have dedicated time from the outset and operate within a system that provides a solid structure for the advocates to work within and feel supported, thus enabling them to fulfil their role for the clients.

"It needs some dedicated time and resources, you know it doesn't just happen… that's perhaps an important lesson you know, you can recruit an advocate, link them up with a person and provide training but it's that ... they need that ongoing dedicated time to come together to get some feedback … to know that they've got support" - SG3

"more management and resources from the beginning, which we didn't really have but improved over time and ideally the person should've been there from the beginning" – SG1

Whilst the supervision/support meetings were considered positive, one member recommended more flexibility in running them and organising them so that not all advocates had to attend for a meeting to run, but perhaps that advocates could attend when they can. The importance of these meetings was clear and therefore would be a priority in future projects of this kind:

"so we'd have a range of times and dates and opportunities for people to get together as it's not realistic to expect people to attend all of those but we'd just need to get a core number to attend … be more flexible about that" - SG3

Targeted recruitment was also suggested by members of the steering group:

"would've been great to find a way of improving recruitment, maybe linking in with social work training or something like that" – SG1

Another recommendation for future research was for a specific funding budget for training. The training within this programme was provided on a volunteer basis (and by a number of those involved with the project). It was suggested that a specific training budget would potentially open more avenues for specialist training.

"there was some external training, however this was provided voluntarily, but projects can't always rely on that. There was no specific training budget so it would be good to build that into a project" – SG2

As mentioned in the family sub-theme, two of the three group members mentioned more attention and commitment to the family advocate in future research and investing more time in getting them on board and involved.

"I was already signed up to the idea [and] heavily invested in the project, [I] knew what I wanted from it, whereas other families didn't and they would rightly be suspicious or not see the value, with hindsight perhaps we should've done more to help people in [the client's] social networks to understand the project, what we were are trying to do … and get their input as we went along rather than thinking it would work automatically" – SG3

3.3.2 Wider Application

In addition to the applications mentioned in the successes all members of the steering group identified that the pilot demonstrated that this kind of work can be done, and all expressed hope that these findings will inform practice and can be applied to other advocacy organisations

"Demonstrated that you can provide good advocacy for people with very complex needs but that it takes time and effort and ongoing commitment, it's not a simple thing to do but you can deliver good outcomes for people" – SG3

"Most conservative hope people would notice what was done and think 'oh that's really important'… that would be nice if it just got people thinking" - SG2

"There is an opportunity with all the post-Winterbourne work to say actually advocacy is really important and that is said but then it doesn't translate into any practical implementation of it and so… would hope we can use the basis of this evaluation to start a discussion with some of the bigger advocacy organisations and with some of the potential funders" - SG3

There was a slight difference of opinion over whether this model of advocacy is applicable to other client groups, for example, where more instructed-advocacy might be present. However, there was general consensus, particularly from a safeguarding standpoint, that the more voices, the more perspectives and more people involved in a vulnerable individual's life, committed to them, the better.
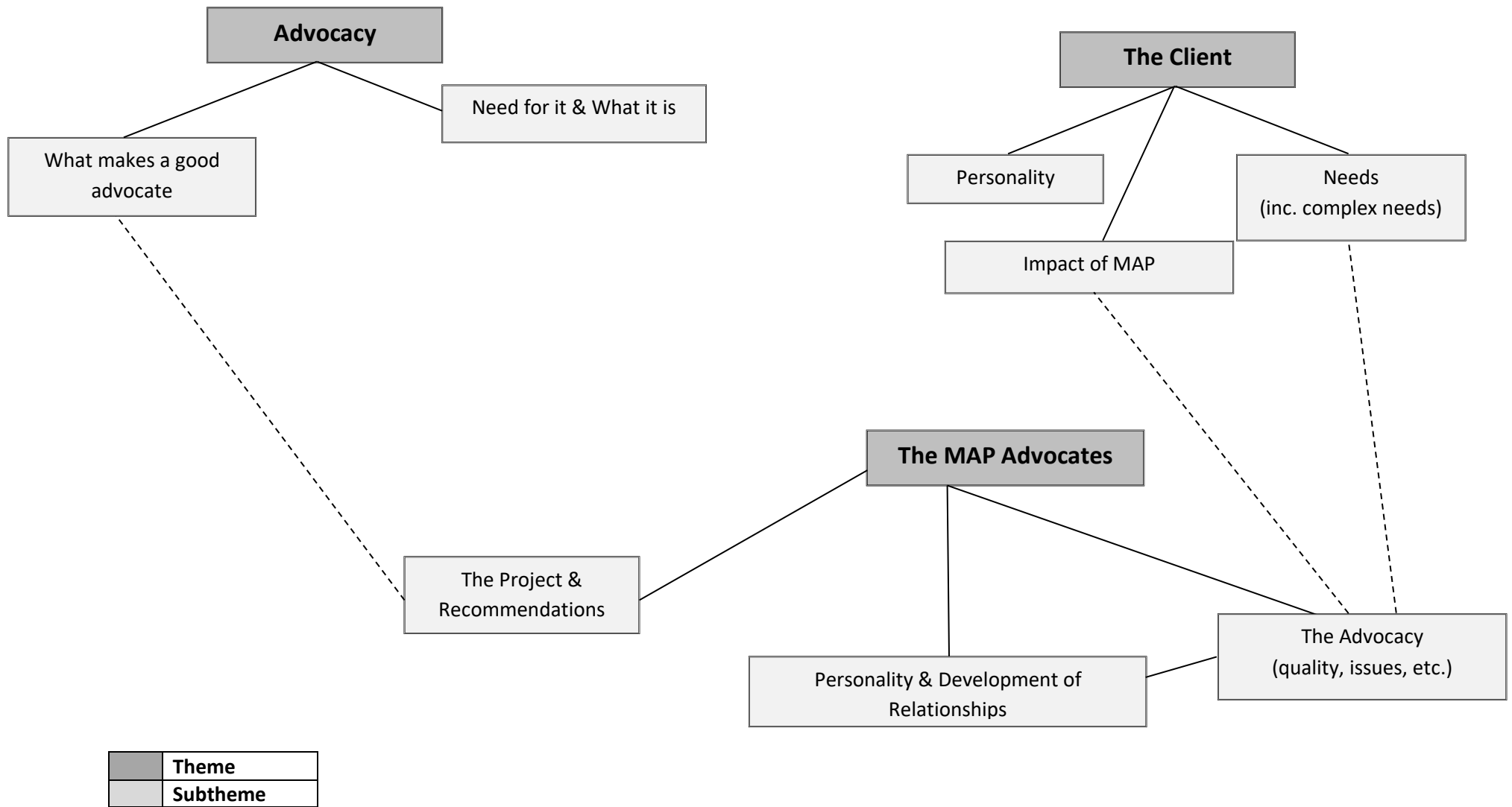
"possible analogies to circles of support, have a variety of people, no fixed number maybe offer elements of advocacy that could be used/developed in that kind of way… similar to a key worker, and you now get mini-teams… [who] can offer different expertise to support a particular individual so in a way I think there's potential usefulness for that kind of model for people with milder learning disabilities" - SG1 responding to a question regarding the application of independent and family advocate to individuals with mild or moderate LD as well as the severe learning disabilities seen in the MAP clients.

Also mentioned by a member of the steering group was the development of an advocacy guide, or resource, for advocates working with individuals with complex needs and behaviour that challenges. This resource is not part of this evaluation, however it was supplied to advocates that took part in the later stages of the project, and viewed as a positive outcome of the project.

One of the interviews highlighted how the lessons learnt and recorded from this project can be the start of an evidence base, and laying the foundations for arguments and proposals for funding in support of this type of advocacy.

 "perhaps we can roll out the things we've learnt in a bigger scale to very formally collect evidence to build the case for advocacy and what it delivers to people" – *SG3*

Staff Interviews Thematic Map:

Advocacy

Need for it & What it is

What makes a good advocate

The Client

Personality

Needs
(inc. complex needs)

Impact of MAP

The MAP Advocates

The Project &
Recommendations

Personality & Development of
Relationships

The Advocacy
(quality, issues, etc.)

	Theme
	Subtheme

Thematic Analysis of Service Provider Staff Interviews

Interviews with the service provider staff revealed three main themes with various subthemes. The clear themes that emerged were ***advocacy***, ***the client***, and ***the MAP advocates***.

1. Advocacy

   1.1. What Advocacy is and the Need for it

   In discussing advocacy, the staff were able to identify the role of an advocate and why it is important. There was a general consensus that an advocate is there to 'speak for' or 'be the eyes' of the vulnerable person. However, there were also some differences of opinion in when an advocate is used and for what types of situation. Some considered, for example, that an advocate is brought in primarily for life changing events.

   "a voice for the individual, and can speak for the individual when it comes to.. care reviews and person centred planning meetings" - Sf2

   "advocacy come in to support our clients when they've got a life changing decision that possibly needs to be made" - Sf3

   "putting themselves in the eyes of the vulnerable person's shoes…speak where they can't speak" - Sf1

   1.2. What makes a good advocate

   Staff were also able to use their experiences, not only of the advocates involved in the MAP, but their previous experience, to identify characteristics which they felt were important in an advocate for their clients.

   "what you don't want is an advocate to come in, wherever they're from, and them be reporting back what's going on in the service if they don't understand what the service is about and what the client's needs are"- Sf3

   One of the staff interviewed also recognised the importance of independent advocacy and the need to be separate from the service provider.

   "Most vulnerable people should have an advocate, definitely not employed by [the service provider]*… have to be an outside agency"* - Sf1

   Other aspects of a good advocate identified by staff included working with the staffing team but also being assertive. Two of the interviewees also mentioned the importance of matching the client to the advocate in terms of age or background.

"listening and working together… what you don't want is an advocate on one side and the team on the other… you want everyone working towards the same goals whether it's looking at a new placement or looking at opportunities that maybe the team have missed" - Sf3

"..shadowed first, with support workers.. the support workers can give info about client 3 and if [the relative] was involved with the advocate as well then they can explain how to approach client 3 and how to get to know them"- Sf2, in response to question regarding recommendations for future projects and training advocates

"look at the advocate and look at the person and try to match them" - Sf1

"the advocate was young advocate, client 3 is …, same age bracket which really helped" – Sf2

Staff also recognised the protective role of an advocate.

"Someone that wasn't easily intimidated who would say 'I don't like what's going on' and have the means and knowhow to take it further" - Sf1

2. <u>The Client</u>

2.1. Personality

Most of the staff members interviewed discussed their client's personality and how this related to their relationships. The discussions around their engagement with the advocate and others were not simply around their behaviours and needs but also their interpersonal skills and personality.

"Really important that when an advocate comes in, for whatever reason, they have an understanding of the client as well" - Sf3

2.2. Needs (including complex needs)

All staff did mention the complex needs of the clients and the impact this can have on their lives. The staff spoke of the client's needs in terms of the relationship between the advocate and the client, but also their wider needs. Particularly pertinent were the issues of friendship, social inclusion and consistency in relationships.

"but to have someone come in purely for client 3 and not for staff, I think that sort of helped client 3 cos they had like a friend, to themselves…client 3 doesn't really have friends, outside, like a social structure … they're always based with support workers" - Sf2

"If the advocate was still coming to client, take them out and do things… I think client 4 benefits more from building up a kind of trust with someone, on a friendship basis" - Sf1

2.3. Impact of the Advocacy

Two of the three staff members felt their client benefitted from the advocates provided by the MAP[5], however only one staff alluded to any benefits in relation to advocacy issues.

"*It worked for client 3 and it works in* [service location]*, gave a fresh pair of eyes to enhance community participation*" -Sf3

Most of the comments regarding the benefits of the advocate were focused on aspects of expanding the client's social network and the quality of relationship developed. There did appear to be a significant focus on the advocate being a friend and having an established, personal relationship with the client. However, one staff member questioned the relevancy of advocacy for their client due to his complex needs, and suggested that perhaps a friend would be more beneficial than an advocate unless there was a safeguarding need.

"[In response to question regarding the benefits of the project for the client]… *I think there would be benefits* (for others)*, but I think for client 4, the only benefit I could see for client 4 is if they were being mistreated and if the advocate came to the service and saw that… I can see the benefits of advocacy 100% but in client 4's case I think it would've been nicer if they'd had a friend, because Ad6 came for such a short time and then left… no I don't see any benefit at all*" - Sf1

"*[there] wasn't anything life-changing occurring in his life at the time…maybe brought in to look at new activities for client 3 to do and become friends, which Ad4 most certainly has*" - Sf3

"*That's really it, friendship side of things*" - Sf2, *in response to a question asking if there were any other benefits to client 3 having an advocate*

Staff did feel that one potentially negative impact of the project was when it finished or when the advocates left. They spoke of this having an impact on the clients and although one of the advocates remains in touch with the client, they struggle to understand the difference in frequency of visits.

"*I mean people come in and out of our lives all the time, we can understand that but client 3 … they will still talk about staff that have gone and they will still talk about them, but how can you explain that they've gone?*" - Sf3

3. The MAP Advocates

3.1. Personality and Developing Relationships

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[5] Must be noted that two of the staff are discussed the same client, however the client had two advocates during the course of the project.

All of the staff discussed the ways in which the advocate developed a relationship, not only with the client, but with the staff as well. From the data gathered, this appeared to be an important aspect of the role, and personality was as much a part of this as skills and competencies.

"*but the main thing was they didn't show that they were scared of client …but they just sort of adapted really well to client 3 and sort of, you know, just jumped straight in*" - *Sf2*

"*the relationship was nice and both[6] got on with all the staff and both got on with client*" - *Sf3*

3.2. The Advocacy itself

There was a general consensus amongst those interviewed that the advocates fulfilled their role for the client. Even those who felt the client did not have any issues to be advocated for, expressed the belief that they felt the advocate would have spoken out if need be.

"*I suppose if [the advocate] was there and they picked up on something… then I would've like to think they would've taken that further*" - *Sf1*

Learning from the staff and getting to know the individual emerged as being an important theme in developing relationships. Although this was not overtly expressed in all interviews, the integration of the advocate into the client's daily life and activities and with those around him, seemed to be viewed positively by staff and an integral part of the process.

"*sometimes they [the advocate] would take client out with that member of staff*" - *Sf1*

"*didn't treat them like an advocate, treated like staff member, do what staff would normally do*" - *Sf2*

The staff interviewed were able to give few specific examples of the advocacy provided for the clients. The main things referred to were activities and new opportunities. Larger issues were not mentioned, except in one case where it was mentioned because nothing was followed up or considered achieved.

"*mainly activities wise, new opportunities for client 3*" - *Sf2*

"*Looked at different activities, went out on a few activities…enhanced community participation*" - *Sf3*

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[6] Referring to client 's two advocates.

"The advocate came in one day and told client that they were going to be getting moved, they [the advocate] were going to advocate for them [the client] to get moved somewhere but nothing was ever done about it" - Sf1

3.3. The Project and Recommendations

Most of the staff interviewed seemed unaware of the MAP and its aims or wider objectives. However, once explained to them by the researcher, the staff made a number of recommendations regarding training of advocates, which echo those identified in the subtheme of 'what makes a good advocate'. One staff member felt that they could make no recommendations regarding the project beyond how it had worked for their client.

"Someone with life experience, someone who can see it from their eyes" - Sf1, on recommendation for training advocates

"What you don't want is an advocate going in and thinking they know everything" - Sf3

"I don't know about the MAP but … it opened new opportunities for client3… No recommendations as it worked for client 3 " - Sf3

Evaluation of the Medway Advocacy Project

From the document review, the interviews conducted and the meetings/discussions with members of the MAP steering group, it is evident there were some very positive outcomes from the MAP and its specific, piloted model of non-instructed advocacy.

The Design and Model for the Project

The data gathered from this evaluation clearly demonstrates that aspects of the model were beneficial for this client group and supports the need for long-term, person-centred non-instructed advocacy.

The core values in the advocates that were seen as crucial to the recruitment process were demonstrated in a number of the statements and comments made by the advocates, staff and members of the steering group. This emphasises the importance of careful consideration in the identification and recruitment of advocates. All the staff commented positively on the personalities of the advocates and praised their efforts in engaging individuals who may be challenging or not always easy to engage. Information gathered from the staff interviews referred to the need to 'know' the clients and the level of engagement required with the individual to develop a relationship, and in this, the prioritising of core values and a person centred approach over experience, seems to have been beneficial and a success.

This 'core value system' or personality was also identified by the advocates in their peers and colleagues with the majority appearing to be working from a common, person-centred framework, a perspective which can only have enhanced the depth of relationship developed between the advocate and their client.

However, this approach, in not prioritising experience, may have sacrificed some of the quality of the advocacy service provided. Their own inexperience was something a number of the advocates commented on (Ad6 and Ad7), with regards to knowing what to look for, or how to help. This was also commented on by a staff member who spoke of "the youth and inexperience", of the individual who "meant well" (Sf1). Additionally, the records and documentation of these more inexperienced advocates gave a general description or recollection of a visit and were more akin to Nursing or daily reports, rather than observations or identification of potential advocacy issues. Perhaps more balance was required in the recruitment process, between experience and values, or additional training or shadowing could have been provided for newer/less experienced advocates.

The training programme itself appeared highly beneficial and this was reflected in a number of comments by the advocates themselves. Specific comments illustrated that the training equipped them with the skills to be able to undertake the role and advocate for individuals

with complex needs who may display challenging behaviour e.g. "*we did, we got to a place where you know, I felt comfortable that I understood what they were asking for and then confident because of CBF's training to actually challenge if their needs were not met*" (Ad10).

There was one reference to Makaton not being part of the training, however consultation with training documents and the Steering Group determined that it was included, and it is possible that the individual referred to did not attend the specific training session. This could raise the question of whether attendance at all the training modules should be compulsory (particularly if the client you are advocating for needs a signed communication method). However this may have been in the early stages of the project where the advocates were volunteers and demands on their time were less formal or enforced.

Support for advocates was clearly highlighted as crucial, not only in the form of supervision meetings but also in having help and an additional level of hierarchy to address any challenges or issues which the advocate was unable to resolve. This was a real strength to the project and, whilst the issues may have taken time or not always been resolved to their liking, advocacy did not stop if the advocate experienced difficulties or barriers with an issue. They were able to take it to a higher level and receive support and guidance to try again, or in more serious cases, the members of the MAP Steering Group became involved. This was evidenced in a case where an advocate had contacted a client's care team due to the inappropriateness of a staff member being assigned to the client's team. The advocate met with resistance from the immediate care team and a member of the steering group was able to become involved and provide support (email documentation included in appendices). This was an additional resource available to the MAP advocates that perhaps is not available to independent advocates who are not associated with an organisation or charity. The role the CBF played within the MAP clearly demonstrates the importance of a support structure for independent advocates and how it can prove vital in ensuring that they are able to advocate on behalf of their client.

The value of support from the CBF was reflected in all the advocate interviews, through positive feedback in three and potentially negatively in one, where the advocate describes the lack of support towards the end of the project. This in itself, however, implies that support was there initially, and was needed, because it was only after it was withdrawn or "fizzled out" (Ad5), that its absence was recognised as a problem. A lack of support was also highlighted in an email by an advocate who was unavailable for interview (included in appendices). The email spoke of a lack of guidance or direction as a result of not being able to attend the support meetings due to scheduling conflicts and transportation.

Whilst both of these instances are faults in the project (which have been recognised by the Steering Group members also in terms of suggesting more flexibility for future supervision meetings and requiring the new steering group member/project manager to be available for support on the phone), it appears that for the majority, the support provided in terms of

phone contact and supervision meetings, when running and attended, were a clear strength of the project and an important part of the advocacy model

There was not much scope to assess the success or impact of the client having an independent advocate and a family/close friend advocate. It was not possible to evaluate this part of the design due to the lack of family advocates in general (further emphasising the need for good quality, independent advocates), but also due to very little contact with them in the evaluation[7].   There was some success for one client, as discussed by Ad10, who spoke of "*almost a lightbulb moment for the family in terms of what, you know, they [the client] needed and it was really interesting to see* [the family's] *perspectives as well*" (Ad10), and the positive experiences reported by the steering group member who was also a family advocate. Otherwise, there was very little data reflected in the MAP documentation and advocate and steering group interviews on this aspect of the project to evaluate.

Quality of Advocacy

The data from the interviews was not able to bring to light much information on the issues advocated for by the MAP advocates during the project. However, other discussions with the steering group[8] demonstrated substantive issues that were addressed successfully, including a client not accessing the community for an extended period of time and an inappropriately sized. Additionally, although a particular issue surrounding a member of staff was not resolved whilst an advocate was part of the MAP, it has since been resolved and potentially, may not have been addressed at all had the advocate not raised it in the first place. Whether dealing with larger or smaller issues, the presence of the advocates in some of the clients' lives clearly made an impact.

In addition to these overt advocacy issues, evidence from the interviews also demonstrated the proactive role the advocates played in supporting the implementation of measures to prevent possible triggers to challenging behaviour and improve choice, inclusion and quality of life. These typically focused on communication methods and approaches e.g. Ad5, Ad10.

One of the themes that emerged from the advocate and the staff interviews regarding the issues being advocated on behalf of the clients was the lack of feedback on issues. The advocates themselves reported issues centred on communication and some health or hygiene needs.

The transitional aspect of the project was not as successful as would have been hoped for in the beginning. This was mentioned in all three data sets, by an advocate, a steering group member and a staff member (Ad10; SG1; Sf1). Although this is disappointing, it is important to note that advocating for service change or transition may have been particularly challenging in the current state of national service provision and the lack of progress or

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[7] One member of MAP steering group was also a family advocate for a client.
[8] Steering group and evaluator meeting 01.04.15

change in this area may be the result of wider issues outside of the immediate control of the advocates, MAP Steering group and service provider. This is not to suggest that progress cannot be made but that change may be harder and take longer to effect.

Benefits to Clients and Advocates

All advocates spoke of the MAP as a positive experience, with the majority describing it as very worthwhile and recommending being an advocate to others. The advocates interviewed referred to the gains they had made, not only in terms of skills and abilities, but also in terms of what meeting the client and having a relationship with them added to their lives.

Due to the level of learning disability and communication complexities of the clients, it was not possible to discuss with them the benefits of being part of the MAP. Indeed, some of the advocates recognised this limited level of understanding and were unsure whether their client truly understood their role. However, feedback from the staff and one of the family advocates indicated that the additional relationship and expansion of social network was beneficial to the clients. This relationship was clearly an additional benefit to the advantages directly experienced (and previously discussed) as result of having an independent advocate. A feature of the advocacy model which was commented on by staff was that of matching the advocate (where possible) to the client. For example, one staff member (Sf2) noted the benefits of the closeness in ages between Ad4 and client 3 and another staff member (Sf1) spoke of how the relationship between client 4 and Ad6 perhaps was not as fruitful because of the age gap and other differences. Whilst it was not always possible, the practice of attempting to match a client in age, culture or background to an advocate and the person-centred recruitment style i.e. an advocate applying to work with a particular individual, did receive some support from the data collected and provides evidence for investing in the advocate recruitment process.

The benefits to the service provider are unclear from this evaluation. One member of staff noted that "*it is good for staff to have someone outside the company around*" (Sf3) though their meaning was not entirely clear. The relationship between MAP and the service provider may have been a consequence of the change in service provider at the beginning of the project and information being lost in the transfer. This difficulty or loss in communication was also evident in regards to the lack of information the staff had about the MAP overall. Although a number of them knew about the advocates themselves, they were unaware of the wider project.

The difficulties related to the service provider were echoed in the paperwork and documentation from Steering Group meetings. The challenges or barriers referred to by the advocates in their interviews were reflected in emails and contact with members of the CBF

and MAP steering group. In the early stages of the project a meeting was held with the Service Provider in an attempt to address some of these conflicts or difficulties. That was possible as a single service provider was involved in the project. The careful management of this dynamic and delicate relationship between advocates and service providers is paramount and communication, particularly positive communication, with a service provider is imperative (as identified by members of the Steering Group - SG1&3). The early change in service provider at the beginning of the MAP may have also resulted in a loss of communication pathways , as it was not the original service team that signed up to the project.

The fact that a best interests meeting had to be held to determine if a vulnerable individual, without a family advocate, needed an independent advocate, may reflect a wider problem between local authorities, advocacy providers and care services.

Achievement of Aims and Importance of Project

Overall, the MAP achieved a number of its aims and the findings can clearly contribute towards making a case for the need for this type of advocacy. The need, importance and value of long-term, invested, person-centred, non-instructed advocacy were echoed across the thematic analyses and reflect the applicability and benefits of this model for this group of clients. Both staff and advocates reflected in their answers the importance of getting to know the client, and how that can be challenging, potentially as a result of the individual's complex needs, and has to be done over an extended period of time. The pre-existing relationships, whether with staff or family, were also emphasised and the comments of the advocates and staff supported a number of the key objectives of the MAP and the hopes of the Steering Group members.

Clearly, there were a number of costs in the project not having a designated manager or organiser and it is likely that data and evidence have been lost as a result, particularly in the keeping of records and/or contact details of the advocates and family members.   The lack of formal operational style in the project was mentioned in the steering group interviews, highlighting the slightly relaxed demands made on the advocates when the position was voluntary, and how it was then difficult to change this when funding became available for payment. This also perhaps contributed to poor communication - one email indicates an advocate had left or did not show up for a long time and the CBF was unaware (see appendices). The detail and number of records kept (very sparse in some cases) and the contact with the CBF could suggest that some advocates rarely visited their clients. However, SG2 recalled how they might not hear from an advocate for a period of time but would then receive emails or a call updating on a large amount of work the advocate had done. From the reports of the staff, the advocates themselves and the recollections of the steering group, the majority of advocates were very involved with their clients and upheld

the requested 2 hours contact time every fortnight. Unfortunately, there is little recorded documentation to support this and hardly any at all from the early stages of the project. It is likely that this reflects the lack of a project manager at that stage to follow up and monitor those aspects of the project.

As a pilot project, the lessons learnt and outcomes produced from trialling this model of advocacy have had a number of clear benefits and successes. These should inform the practice of other advocacy organisations in order to expand the quality and availability of advocacy services for individuals with complex needs.

<u>Recommendations:</u>

From the data collected from this evaluation of the MAP the following recommendations are proposed:

Future advocacy activity:

- Project manager to be involved with overall organisation of project and daily running of tasks
- Building and expanding upon strength and successes of pilot project e.g. importance of core values, person-centred approach, matching of advocates with clients and individualised recruitment process
- Additional support or training for new/inexperienced advocates (perhaps shadowing option)
- Policy or specification guidelines regarding recording of meetings with clients and documenting advocacy issues:
    - Particularly feedback option for staff and advocates on ongoing issues or concerns
    - Guidelines for reporting to CBF or agency responsible for advocate
    - Perhaps have a 'work' contract drawn up (even for volunteers), specifying expectations and demands
- Development of role of family advocate
    - Further investment in developing relationship (perhaps involve in early stages of project)
    - Larger scale project with more family advocates
- Developing working relationship with service provider
    - Provide training package or programme for staff as part of the project, including a session on the aims and objectives of the project
    - Have an advocate/service provider liaison manager (perhaps project manager)

Wider Implications:

- Promotion of this model of advocacy for individuals with severe learning disabilities and complex needs.
- Dissemination of findings to other advocacy agencies to adapt/incorporate model into existing services.
- Development of a resource from the findings and lessons learnt in the project as a supplement to the existing Challenging Behaviour Foundation resource - *A Guide for Advocates. Supporting people with learning disabilities who are described as having challenging behaviour.*
- Identifying funding revenue for:

a) developing larger scale projects and gathering an evidence base to further support long-term, person-centred model of advocacy; and,

b) Sustained delivery of independent advocacy services, including non-instructed advocacy for individuals with severe learning disabilities and complex needs on a day-to-day basis.

- Consider support available (or lack of) to independent advocates, especially those not associated with a larger organisation when they encounter barriers/difficulties with services providers or commissioning authorities.
- Consider approaching/liaising with service providers to promote better awareness of how advocacy applies to the specific needs of individuals with severe learning disabilities and complex needs.

Evaluation Process

The evaluation was undertaken by a researcher independent of the MAP.

The incomplete or partial paperwork/documentation meant that the majority of data collected to complete the evaluation involved the subjective recollections of individuals involved with the project. The lengthy duration of the project (beginning in 2007), and the time between its completion and the undertaking of this evaluation meant that the memories of those interviewed may not be as vivid as they once were. However, the depth of detail recalled by those interviewed (the steering group, staff, and advocates) was impressive, and better than could have been anticipated considering the length of time since some of the advocates had been involved in the project (over 12 months).

The response rate for those invited to interview was high for all three groups involved in the evaluation.

Contact details were not available for all the advocates and many of those involved at the beginning of the project were unreachable. This evaluation has, therefore, not been able to capture the experiences of advocates involved in the early stages of the MAP. However, of those with correct contact details, six were contacted and four agreed to be interviewed - a response rate of 65%. Of the two that did not respond, one is known to be travelling and this advocate is actually the one who has retained their relationship with their client and has regular visits and contact.

75% of the MAP Steering Group were also able to take part in the evaluation and discuss the project with the researcher as well as take part in the interviews.

Again, duration since the project and the turnover of staff in care services, and additional time constraints and demands on the service provider meant that only a small number of staff were available for interview. This limited the data available on the staff experience of the advocates and the project and also only allowed the evaluator to collect information from a staff perspective relating to three advocates for two clients when there were eleven advocates and seven clients in the whole project. However, the evaluator and steering group had the aim of interviewing two managers and two support staff, and managed to fulfil 75% of this quota in the timeframe for the evaluation.

The interviews were conducted by telephone which does lose some of the depth and quality of face-to-face interviews. However, it was the most convenient for those involved, and most efficient in terms of funding and time available.

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APPENDICES

- **Copies of interview schedules**
- **Email Communication from Independent Advocate re: level of support**
- **Emails regarding communication with/monitoring of independent advocate-client contact**
- **Coding for thematic analysis**

Independent Advocate Interview Schedule

1. Can you tell me about why you took part in the MAP? What attracted you to apply? Were your expectations met?

2. You advocated for [Name]. Can you tell me about your relationship with them?
   a. How did you get to know [Name]?
   b. Were there any challenges in working with them or advocating on their behalf? *With follow up questions ask about staff, family, communication, set up, etc. where appropriate*).
   c. What did you enjoy about advocating for them/ getting to know them?

3. Advocacy is a skilled position and requires time, effort and commitment, perhaps more so when the clients have limited communication and such complex needs. Can you talk to me about the training you received? (*Can you give me some examples?*)
   a. Were there any specific aspects you found particularly helpful in developing skills for advocacy or working with an individual with complex needs?
   b. Were there any topics that you felt were irrelevant or missing from the training?

4. So going back to your work with [Name], one of the key features of this project was to appoint two advocates for each individual. [Name]'s family advocate was [Name], can you tell me about how you found that relationship? (*Whether it helped, hindered, etc.*)

5. The project was initially set up to help 4 individuals, including [Name] during a time of transition. Can you talk to me about the issues you advocated for on [Name]'s behalf?
   a. How do you feel your work was received by the client/service provider/family?
   b. How did the CBF support you in your role? (*follow up question re: supervision, monthly support groups/review meetings, etc.*) Was there anything different they could have helped with?

6. You've mentioned … Can you talk to me about any other difficulties or challenges you experienced during the project? (*Families, services, communication, time-demands [volunteering VS payment?], support, skills, differences from instructed advocacy, etc.*).

7. And the positives? (*confidence in working with client group, development of skills, awareness of issues, importance of advocacy, direct benefit to client*)
   a. For yourself?
   b. For your client?

8. What was the most important thing you learned through this project? Did you learn anything you weren't expecting in this project? If the project were to be done again, are there any recommendations you would make?
   a. If you were approached by someone considering becoming an advocate, what would you say to them?

9. Finally, is there anything else you'd like to say or add about your experience of the project?

MAP Steering Group Interview Schedule

1. Can you tell me about the MAP?
    a. The need for it? Why it was important? Its aims? Do you think it achieved this?

2. There was a specific design for the project and the model of advocacy provided, can you tell me about this and why you chose this approach? (*recruitment process, person centred - 'core values' rather than 'role of an advocate', training and support, etc.*).
    a. Why it was important to do it in this way? How differs from other advocacy models?

3. One of the key features of this project was to appoint two advocates for each individual. A family advocate and an independent advocate, can you tell me about the rationale behind this?
    a. How successful do you think this was? Do you think it is an adaptation/model that could be applied to other advocacy services?

4. Can you talk to me about any difficulties or challenges experienced during the project? (*Recruitment and retention of advocates, interaction with services, and quality of advocacy provided, etc.*).
    a. Were any of these anticipated? unexpected?
    b. How did you/would you overcome them (in future projects of this kind)?

5. What do you feel the positives of the project were?
    a. For the advocates? For the client?
    b. How can these be applied for the wider community?

6. What do you feel was the most important outcome from project? Do you think you achieved this?
    a. If the project were to be done again, what changes or recommendations would you make?

7. What do you hope will be the further implications or outcomes of this project?

8. Finally, is there anything else you'd like to say or add about your experience of the project?

Avenues Interview

1. Can you tell me about your understanding of an advocate and what they do?
   - Do you feel [Advocate Name] fulfilled this role for [Client Name]?
   - Can you give me some examples?

2. Can you tell me about the relationship between [Advocate Name] and [Client Name]?
   - How [Advocate Name] developed a rapport with [Client Name]?
   - How they overcame communication difficulties or managed challenges in behavior?
   - How they were able to learn about areas or issues important to [Client Name] and identify their advocacy needs?

3. How did you feel [Advocate Name] worked with other people in [Client Name]'s life?
   - Their family?
   - The services/staff?
   - Other members of their community/care team e.g. social worker, psychologist, etc.
   - (*Follow up on any potential conflict within this question*)

4. One of the aims of MAP was to help equip individuals with the skills and abilities to advocate for clients with severe learning disabilities who can display challenging behavior?
   - Do you feel the project achieved this?
   - Can you talk to me about what you thought were the benefits of the project/the work done - for the individual? The staff? The family?
   - Were there any challenges or difficulties?
   - If the project were to be undertaken again are there any recommendations you would make?

5. Finally, is there anything else you like to say or comment on with regards to the project or advocacy in general?

Email Contact from Independent Advocate re: Lack of Support/Supervision

-----Original Message-----
From: ██████████ [mailto:████████████████████]
Sent: 23 May 2011 20:04
To: ████████████
Subject: Re: Advocacy project

Hello [steering group member],

██

I see ██████ regularly and have built up a great rapport, unfortunatly I do feel greatly let down by the CBF, as I have only been invited to one meeting and belive the supervision has been awful.

I get on really well with everyone at ████████████, but I don't think I have been able to have that much of an impact in ██████'s life and lifstyle choices because I feel unguided and unsure on what I am spesfically doing.

Sorry to be saying all of this to you, as I do not blame you at all and some people must be very busy at the moment, I just feel that you may need to know this in order to understand the next steps and to work collaborativly.

I am very sorry I have been unable to speak to you at the moment, I am an ██████████████████ student on placement at the moment and work 9-5 monday-friday. Although I may be able to ring you on my lunch break.

As for the meeting in Chatham I am on placement in ████████ and do not drive therefore It would be needed to changed to half six if you could make it? I alo work on saturdays so sundays are the only days I am free if no-one can do half six?

Sorry for the inconvience and I don't mean to be rude or unprofessional I just feel that I could be doing a lot more for ██████ if I had the right support and supervision.

Thank you and looking forward to meeting you,

[Advocate]

Emails communication between CBF and Service Provider regarding independent advocate-client contact

From: ████████████████████████████████████
Sent: 31 August 2011 15:39
To: ██████████
Subject: Advocate

Hello ████

 I'd like to check whether [advocate] has been to see [client] recently. Do you know when the last time they visited was?

Unless they've improved their commitment since I last spoke to them, I'm going to have to ask them to leave the advocacy project as they have not been giving the minimum commitment of a visit every fortnight, and this is not fair to [the client].

If [advocate] leaves we will do our best to find a new advocate for [client] as soon as we can.

Kind regards,

████

████████████████████████

The Challenging Behaviour Foundation
Email ████████████████████████

www.challengingbehaviour.org.uk

From: ██████████████████████████████████████
Sent: 31 August 2011 17:41
To: ██████████
Subject: RE: Advocate

Hi ████

What a coincidence – I was speaking to [service manager] about the advocate project yesterday. Unfortunately [advocate] has not visited since before we last spoke. I can check the date they visited if need be, let me know

Regards, ████

████████████ I House Manager, ████████████

<div style="text-align: center">**Thematic Analysis – Coding of Raw Data**</div>

Table 1: Coding for Independent Advocate Interviews

Initial Coding from Raw Data	
background/previous experience of indp. advocate	challenges of project
view/attitude to client	advocacy issues
experience of MAP	family relationships
support by CBF/view of CBF	service structure/provision
view of role of independent advocate	carers/management
experience of being an independent advocate	relationship with staff
challenges of the role	Demands of the project
benefits/rewards	benefits/rewards
relationship/engagement with client	exp/view of family advocate relationship
view of training	motivation of independent advocate

Table 2: Coding of Raw Data for MAP Steering Group Interviews

Initial Coding from Raw Data	
Talking about needs of client group – communication, continuity of relationship, potential vulnerability	Economic climate/wider context – charities, funding, government, etc.
Provision of advocacy in general	Specific advocacy model for project
Advocacy servicers/availability for client group	Change in service provider
What the project did	Capacity, consent and best interest issues for clients
The aims of the project (for individual, research, possible wider applications)	What can do done regarding advocacy for client group
Training programme	Family relationships
Recruitment process, different stages, selection, problems.	Life situation/specific circumstances of project sample (transition, young adults, etc.)
Person-centred approach - matching advocates to clients	Families acting as advocates, established relationships, potential conflicts
Advocate/person specifications – importance of core values *cf* experience	Clients without family/relatives/close friends
Validation of family concerns, issues, role as advocate	Family advocate within MAP - relationship with independent advocate
Family advocate within MAP – purpose, rationale	Project management – need, loss/costs of not having one
Direct benefits of project for clients	Benefits of project for advocates
Recommendations for future projects	Lessons learnt/value of MAP
The advocates themselves	Relationship between advocates and CBF/Steering group
Quality of advocacy provided – issues, follow up, abilities	Implications/Outcomes of project
Role of advocate	Relationship development between client and advocate - consistency, quality, presence
Challenging behaviour	Challenges/difficulties of project
Application of model to other advocacy services	Successes of project

Table 2 (Cont.):

Initial Coding from Raw Data	
Importance of independent advocacy	Support/Supervision meetings
Complex needs	Advocate contact/interaction with project
Danger/concerns over poor/insufficient/inadequate or inappropriate advocacy	Relationship with service provider
The need for this model of advocacy	Services/organisations involved in the MAP
Background to the MAP/Rationale or justification for project	Structure of project – payment of advocates VS volunteers

Table 3: Coding of Raw Data for Service Provider Staff Interviews

Initial Coding from Raw Data	
Benefits of advocacy for client	Individual/personal characteristics of client
Relationship development	General needs of client
Problems of continuity/shame relationship ended	Complex needs of client
Friendship/a person 'outside' staff	Difficulties/challenges of relationship with client
What an advocate does/should do	How well advocate fulfilled their role
Advocate speaking up for clients	Engagement with other people in client's life
Specific aspects of advocacy or issues to be noticed activities/life changing decisions, etc.	What they thought/view of the advocate (and project once explained)
What makes a good advocate	Demographics of client and advocate
Staff relationships	What an advocate should do
The importance of advocacy	The need for independent advocacy
Personality of advocate	