



University of Brighton

Advocacy Services in West Sussex

Final Report
September 2010

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"Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice."

Advocacy Charter 2002

(Action for Advocacy: A manifesto for independent advocacy services in England and Wales, 2010)

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Section 1

Background

Advocacy, provided today by a range of independent organisations within the UK, is widely recognised as emerging from the Citizen Advocacy movement in the United States and Canada in the mid 1960s. Throughout the 1980s and 1990s service user movements in the UK, in particular those involving mental health service users, disabled people and people with learning disabilities, sought to enable users to have a voice in service development and delivery using a variety of means, including advocacy (Barnes, 1997). People First started in the USA and spread to the UK following a visit by a group of people with learning difficulties to the UK in 1984. As well as supporting self advocacy, People First organised conferences, developed campaigns (eg to get rid of the 'Little Stephen' image once used by the charity Mencap), conducted research and developed groups focussing on specific issues such as sexuality and parenting. In mental health, the UK Advocacy Network (UKAN) grew from the development of user organisations and groups such as Survivors Speak Out (SSO) and the Nottingham Advocacy Group (NAG) in the second half of the 1980s. UKAN promoted and supported the development of self and citizen advocacy groups across the UK, including in the closed environments of high secure psychiatric hospitals (Ashworth, Broadmoor and Rampton.)

There are a number of key features of advocacy that were evident in these early developments and are still relevant today:

1. Advocacy is designed to enable service users to have their voice represented in service decision making, even in situations when they are unable to speak directly for themselves or need help to do so.
2. Advocacy is designed to ensure users' views are represented as *they* want to be represented, ie it is the service user who determines the issues that are the focus of the advocacy relationship and it is clearly distinguished from advice giving. The issues service users may seek support on may go beyond service delivery issues and include, for example, their rights to enter into sexual relationships.
3. One consequence of these two fundamental characteristics is that it may involve 'questioning the configuration of power in service settings and the irreproachably well intentioned philosophies of the same' (Flynn and Ward, 1991, p 31).
4. Thus citizen and self advocacy should be distinguished from legal advocacy that involves professional representation that builds on professional knowledge of legal rights.
5. It also follows that advocacy is independent of service delivery.
6. Individual advocacy can be most effective when it is linked into broader initiatives through which service users can be involved in service development or evaluation, co-production or other means of shaping services. Some groups (eg NAG) have described this as 'collective advocacy'.

Advocacy is a means through which service providers can give account to service users and through which intelligence can be developed that enables service users to offer feedback on service performance generally, but the prime beneficiary of the advocacy relationship is the service user and not the provider.

Within the developments outlined here we have distinguished citizen and self advocacy. Citizen advocacy involves someone who is not a service user speaking on their behalf when they find it hard

to do so. For example, Ivers (1994) describes an initiative developed by the Beth Johnson Foundation that involved 'younger older people' being trained to advocate for older people in residential care and receiving community based support services. User groups seek to support self advocacy where possible as this has the potential to build self-esteem and transferrable skills:

"It's given me a life and without it I wouldn't have dreamed of doing half the things I do now. It's given me confidence, assurance....I get up now and speak at a conference quite happily. A few years ago I would have no more done than than fly!" (Barnes, 2007, p 24)

It also can enable self advocates to become peer advocates for others. The Nottingham Advocacy Group is a good example of a user group that enabled mental health service users to move from receiving advocacy support from other service users, to becoming peer advocates and supporting others, and to taking part in a wide range of other activities through which service users could influence services and develop an enhanced understanding of what it is to live with mental illness. In this context the peer advocates themselves become beneficiaries, as illustrated in the following quote from a woman who started out on the receiving end of advocacy from NAG and subsequently became an advocate herself:

"It is supporting people so that they're heard, and to do that is just really fulfilling. That's stage one and if you see that something has changed because of that, that's great. So it's just nice for people to be heard and I love that. I love putting that across. And then when things actually change for that person, you get terrific satisfaction..... [It's been] huge for my own personal self-esteem. I've started very small and suddenly realised that I was capable of a bit more and a bit more and a bit more, and now that I'm working full-time it's just lovely, it really is."
(Barnes, 2007, p 28)

Similar benefits have been experienced and reported in self advocacy groups of people with learning disabilities (eg Williams and Schoultz, 1984). Beyond this individual benefit, advocacy that is undertaken in the context of user led groups often provides a context in which friendships and supportive relationships develop so that collective organisation amongst service users itself operates as mutual support 'service'.

Action for Advocacy and Pohwer have defined types of advocacy in the following way:

Citizen Advocacy: An unpaid advocate who works with someone on a long term basis, sometimes throughout their whole life.

Short term, issue based or crisis advocacy: When an advocate empowers someone to speak up about a particular issue, or speaks up for them to support them through a crisis.

Self Advocacy: When someone speaks and acts for their self to present their case. They often come together to form a collective voice on issues that impact on their lives.

Peer Advocacy: When the advocate has something in common with the person they are advocating for.

Bi-lingual Advocacy: Bi-lingual advocates speak the language of the people they work with as well as English..

Health Advocacy: Like bi-lingual advocates, health advocates normally support people whose first language is not English. There are health advocates available who speak a range of languages and support people to access a range of health services.

Non-instructed advocacy: Taking affirmative action with or on behalf of someone unable to give a clear indication of their views or wishes in a specific situation. For example, this could be someone with dementia, profound learning disabilities or brain damage.

Independent Mental Capacity Advocacy (IMCA): A statutory advocacy provision for people who do not have the capacity to make their own decisions. IMCAs support these people through issues around medical treatment or residential care.

Independent Mental Health Advocacy: a statutory advocacy provision which provides an additional safeguard for patients who are subject to the powers of the Mental Health Act. This includes people who are 'sectioned' in hospital, people subject to guardianship, and people subject to Community Treatment Orders.

Legal Advocacy: This is provided by lawyers and aims to assist people to exercise or defend their legal rights.

(<http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=716&articletype=20>
http://www.pohwer.net/our_services/role_of_advocacy.html)

As it has become official policy to involve service users in decision making, advocacy has been adopted as one mechanism to support this. This has led to more formal relationships between service providers, commissioners and organisations providing advocacy services. The history of NAG is illustrative of the benefits and disadvantages of these developments. The value of NAG's input was recognised by those developing services in Nottingham and advocacy moved from an informal status to a contracted service that provided both income and recognition for the group. One example was a new core and cluster unit that was designed with advocacy provided by NAG built in from the start under what was claimed to be a 'partnership' arrangement. However, re-organisations within the NHS led to a re-contracting of advocacy on a wider geographical and generic service user basis. NAG was unable to compete on this basis, lost the contract and this undermined its entire existence. The preservation of independence is thus an inherent tension which becomes more complex as the providers of services becomes more diverse.

Whilst there has been limited research into the practice of advocacy (Miles 2009, Townsley et al 2009), its importance is reinforced by recent policy developments, such as the Mental Capacity Act 2005; Putting People First and personalisation; the Independent Living Strategy. The Coalition Government's white paper on the reform of the NHS reinforces the importance of advocacy to ensure equitable access to services. Recent responses to the Law Commission's consultation on creating a simple, consistent, transparent and modern framework for adult social care law include a variety of references implying the need for advocacy to be recognised in statute. In addition, the Care Quality Commission have highlighted the importance of provision of independent advocacy, particularly in relation to assisting users of self directed support, based on national evidence. This is further reinforced within the 2010 Department of Work and Pensions research report on understanding the needs of people with mental health and / or learning disabilities (Butters et al).

At a local level, the profile of advocacy has varied in West Sussex. In 2002 the Social and Caring services select committee recommended that an action group be set up to take forward proposals outlined in a report on Advocacy for Adults in West Sussex prepared by the Director for Social and Caring Services. It has not been possible to track the progress of that suggestion. More recently, a 2010 CQC report on Adult Social Care in West Sussex highlighted the need for older people who use services to have access to advocacy. In fulfilling its remit to ensure users of health and social care services can have a voice in relation to how services are delivered and managed, the West Sussex Local Involvement Network (Help and Care) decided to commission this report. One of the key priorities for members of the LINK is to gain a better understanding of what advocacy services are

provided, how they operate, what those involved in delivering and receiving the service think about it and identifying any gaps in provision. The research for this report was carried out by the Social Science Policy and Research Centre at the University of Brighton in collaboration with LINK staff and volunteers.

Section 2

Approach for this research

West Sussex LINK established a reference group to oversee the development and delivery of this research. LINK and the reference group advised on which commissioners and which service providers were most appropriate for inclusion. Advocacy provision related to the following groups was included in the research:

- Older people
- Learning disability
- Mental Health service users
- Carers
- Physical and sensory Impairment / acquired brain injury (PSI/ABI)
- Dementia

It is recognised that the necessary selection results in some advocacy services not being covered within this research. These include those for children and young people, the Independent Complaints Advocacy Service and Independent Mental Capacity Advocates.

Below is an outline of the tasks undertaken and a summary of progress to date.

Literature review (restricted to UK literature over last 10 years) drafted but continually up-dated. Literature referred to throughout this report.

Mapping of advocacy services in West Sussex - used three main sources of data:

- Action for Advocacy database
- Advocacy Resource Exchange database
- ICIS, West Sussex Information Service

Training of LINK members to carry out interviews

- Three volunteers and one staff member trained in research interview skills.

Commissioners interviewed:

- Seven relevant Commissioners of advocacy services within the NHS and West Sussex County Council.
(note LINK staff and volunteers conducted the majority of these interviews following training)

Service providers interviewed

- Mental Health advocacy provider
- Advocacy provider for those with learning disability and those with a physical or sensory impairment / acquired brain injury
- Advocacy provider to those with dementia

- Major provider of services for older people in West Sussex*
- Provider of support services to carers in West Sussex (x2)**
- Ex advocacy service for PSI/ABI and older people

** As no organisation is funded to provide advocacy services specifically for older people, a major provider of services to this group was interviewed*

***Advocacy only forms a small element of the support provided by the carer organisation.*

Advocates interviewed:

- Supporting those with dementia
- Supporting those with mental health issues
- Supporting those with learning difficulties/disability and those with PSI/ABI

Service users:

- Learning difficulty/disability, self advocacy group interviewed.

Issues explored:

- Type of advocacy services provided
- Commissioning / funding arrangements
- Levels of take up of service
- Experience of using service
- Barriers to access
- Gaps in provision (levels of unmet need)

Section 3

Identification of advocacy services in West Sussex was done using three electronic sources:

Action for Advocacy database

<http://www.actionforadvocacy.org.uk/>

Advocacy Resource Exchange database

<http://www.advocacyresource.org.uk/>

ICIS: Information for Life

<http://www.icis-info4life.org.uk/>

The following organisations were identified from their databases:

Table 1
Organisations providing specific Advocacy Services for adults in West Sussex

Client Group/issue	Organisation	Area covered
Dementia	Alzheimer's Society Advocacy Service	West Sussex Coastal area
NHS Complaint support	SEAP Independent Complaints Advocacy Service (ICAS)	Hampshire and Surrey Berkshire, Oxfordshire and Buckinghamshire East Sussex, West Sussex and Kent
Learning difficulties	Impact Advocacy Service	West Sussex
Learning difficulties	Self advocacy groups:	<ul style="list-style-type: none"> • Bognor and Chichester VOICE • Worthing Speakout • Mid Sussex SpeakUp
Physical and sensory impairment / acquired brain injury	Impact Advocacy Service	West Sussex
Mental Health (working age)	Mind Advocacy Project	West Sussex
Mental Health (detained) Independent Mental Health Advocates	Mind Advocacy Project	West Sussex
Mental Incapacity Independent Mental Capacity Advocates	POhWER (based in Birmingham)	West Sussex plus other areas
Deaf	Sussex Deaf Association (advocacy support service)	<ul style="list-style-type: none"> • Worthing • Bognor Regis • Burgess Hill
Generic	Advocacy Service Action Project (Shoreham CAB)	East and West Sussex
Generic "An independent advocacy service ... one to one citizen advocacy, casework advocacy"	Perry Nash Advocacy (based in Burgess Hill)	West Sussex

Table 2
Organisations that encompass advocacy within a mixed service

Client Group/issue	Organisation	Area covered
Visually impaired aged under 30	Blatchington Court Trust	Sussex
Blind / visually impaired	Worthing Society for the Blind	Worthing Borough
"Advocacy service for people with a vision loss, deaf, hearing loss and Older People. Provision of advocacy within personalisation budgets."	CCVision Associates Ltd (based in Seaford)	West Sussex and other areas
Black and Minority Ethnic	BME Community Services	West Sussex
Parkinson's Disease	Parkinson's Disease Society	South East
Carers	Carers Support Service	<ul style="list-style-type: none"> • Carers Support Service, Regis, Chichester and Rural • Carers Support Service, Worthing and District • Carers Support Service, North and Mid Sussex
Housing	Shelter West Sussex and Surrey Advice Centre	Outreach services in Bognor Regis, Chichester, Crawley and Haywards Heath.
Learning difficulties	Signposts Mid Sussex	Resource Centre in Burgess Hill
Learning difficulties "Wey Forward Initiatives has been providing residential services for and advocating on behalf of adults with a learning disability for over 15 years. We also provide care at home for, and advocate on behalf of, adults."	Wey Forward Initiatives Ltd (based in Farnham, Surrey)	West Sussex, Surrey, Berkshire and Hampshire
Diabetes	Diabetes UK Advocacy Service	National

Section 4

This section presents findings in relation to each of the client groups involved in this research. However, the scope of investigation in each was necessarily limited due to the remit of the project being broad, attempting to gain an understanding of advocacy services for a wide range of people, rather than an in-depth understanding of the complexities in each case. For each group we explain who we interviewed, issues arising and report where respondents felt there are gaps in advocacy provision in West Sussex. In addition, we provide vignettes, where appropriate, to illustrate issues raised.

4.1 Carers

*“In West Sussex there are estimated to be almost 74,000 unpaid carers, approximately 10% of the population ... this continually changing population of carers needs to have current and up to date information, advice and support relevant to their circumstances”
(report by Executive Director Adults and Children Director of Operations – Joint Commissioning)*

Background

Three organisations within West Sussex are commissioned as a partnership to provide opportunities for carers to receive advice, advocacy, information and emotional and social support. They are located in the North, West and South of the County. Services provided vary according to funding streams accessed. Two of the organisations contributed to this research.

Currently each organisation is commissioned by West Sussex County Council from the Carers Grant to provide their core service. In addition each receives funding for specific services targeted at carers of those with a mental health condition (Health budget) and those with a learning disability (WSCC). Beyond these, organisations may also contract for other services (for example one provides a service of Primary Care Workers, funded via local Councils and Health, to do outreach work with Carers within hospitals and GP surgeries).

Advocacy provision

As commented upon by the Commissioner, the service objectives for the information/advice core service are very broad but include “opportunities for carers to receive advice, advocacy, information and emotional and social support.”. The West Sussex Interagency Carers Strategy commissioning intentions and plans, 2010 – 2015 incorporates ‘access to advocacy’ within the ‘Carers having a voice’ section and describes the planned action around this as ‘to develop advocacy support for carers’. It remains to be seen how the extent of future advocacy provision will be identified and services resourced. Interviews with the relevant Commissioner and the carer organisations highlighted that there is a lack of clarity with regard to what ‘advocacy’ covers and the extent to which it is prioritised within the commissioned service as a whole. The staff from one organisation felt strongly that they would not wish to see an advocacy role separated off from the combined advice, advocacy, information and emotional and social support role. They noted that the diversity within their roles was welcomed but that they would like greater recognition and allowance for the time the advocacy element takes. It was recognised that this may not be the case for the other carers organisations.

Whilst they are commissioned as a partnership, the three provider organisations operate independently of each other, having varying organisation status, staffing levels and service provision

commitments. Therefore, the extent to which advocacy is provided within the total service package varies. It was reported that increasingly the advocacy provided is at the crisis intervention level. The point was also made that the client base of carers is a constantly changing one and therefore the service needs to be flexibly responsive:

"We're increasing about 25% a year, we've got 3,500 carers that are registered with us that at any time could phone up and need that advocacy support which we would have to provide more and more we're having to do crisis intervention"

The impact of the personalisation agenda within health and social care was also noted:

"The amount of advocacy that we provide is forever on the increase with direct payments, individual budgets, safeguarding issues, they're all on the increase ... Trying to get the services in, trying to get the right level of resources allocated is part of some of the advocacy that we would get involved in"

One organisation commented on the high numbers of carers requiring a home visit. The implication of this is that information and advice provided by phone is inadequate to meet their needs:

"So out of the figures that we had for last year we had in excess of four hundred and sixty-five requests for home visits and these are people where we have screened , we've signposted, we've given them to other organisations and the ones that still come through, where there's still a need and with no specialist worker we still managed to do two hundred and eighty five visits but that left just under two hundred people that still haven't had a service"

Whilst the need for advocacy work was recognised and valued by carer organisations, respondents commented on the time consuming nature of advocacy. One worker anticipated that her work with carers of those with learning difficulties would increase due to the loss of another support organisation in the area, and she feared it would be the advocacy element of her role that would need to be reduced, in order to maintain a responsive service to the greatest number of people.

"I'm going to have to prioritise which is just not ideal .. I might have to cut down on one to one, face to face meetings"

In a more general sense, the predicted impact of other service changes, such as the reduction in in-patient bed numbers, was noted:

"what we're trying to say is whenever there's a reduction in the service for the customer there's a greater impact for the carer"

The need for separate advocacy for carers and those they care for was emphasised. Future provision should ensure both voices can be heard.

Issues requiring services of an advocate

The following are some examples of issues on which the carers organisations would get involved in an advocacy role with clients.

- Negotiating with professionals on the sharing of information regarding the cared for person.
"often that's the point we will come in as an advocate and liaise with the mental health team on behalf of the carer to make sure the carer is included in the treatment and planning, to make sure they have enough information to enable them to care effectively"
- Ensuring the rights of the carer are taken into account when the cared for person is due to be discharged from hospital:

"I think when it comes to hospital discharges there's been quite a lot of need for advocacy. I've had psychiatrists doing an assessment to somebody in a hospital bed, not in the home and seeing the home situation, and the carer is saying "no, I can't cope, I can't look after them at home, I can't manage it". The psychiatrist will say "no no, they're fine, they can go home, they want to go home". So you have this issue where you've got to advocate on behalf of the carer to prevent this inappropriate discharge"

- Supporting carers of those moving to supported living:
"A lot of the advocacy work that I do has been around that, about parents not being satisfied or completely happy with the placements that are being offered"
 - Supporting carers of those who have a dual diagnosis (learning disability and mental health issues or substance misuse and mental health issues). Workers note that in such cases, clients interact with different agencies at different times:
"We end up doing joint working and I think dual diagnosis is a big area where advocacy might fill a gap"
- The point was made that the Sussex Partnership is developing work in this area.

Commissioning / monitoring

Both organisations and the Commissioner for Carers' services commented on a healthy relationship which allows some flexibility and room for discussion of issues affecting the terms of the contract. However, both organisations commented on the inappropriateness of some of the performance management targets on which they have to report included in their NHS contracts. It was recognised that this research was taking place at a time of change when joint commissioning was being developed within the County and that monitoring will be done differently in the future.

Use of volunteers as advocates

Currently volunteers are not used in the provision of advocacy for carers by the organisations involved in this research. Discussion of the potential for such raised the following points:

- Rigorous training, support and supervision would need to be in place
- Concerns around a high turnover of volunteers

"The person with learning difficulties, the cared-for person, was housed in sort of specialist accommodation, was evicted from there because they weren't complying and there were issues around their behaviour, again, perfectly understandable in the context of their disability. The carers that then stepped in were the brother and his wife who live in a one-bedroom flat. The cared-for person is sleeping on a floor, has been sleeping on that floor for months, there are issues about appropriateness of that situation. Both the carers work full-time, there has been issues about the safety of that cared-for person being left alone there, as in inviting people back, you know, sexually being very disinhibited, you know, subsequent pregnancies as a result of that and at every single point it has required having to sit with those carers and advocate for them in multi-disciplinary meetings to say they cannot sustain this. The only way that they can sustain this is if one of them gives up work, which is financially impossible for them. They felt that they were helping out as a short-term solution and nobody's getting their act together about getting decent alternative accommodation for that person. We have had to get psychologist reports, we've had to get people come in and do assessments on the person's IQ, i. their ability because of the nature of their condition sits between Mental Health and Learning Difficulties, we've had to bat and ball there and to support this family has taken months. It's required us to sit on lots of different meetings and appeals and all sorts of things and it's also required a hell of a lot of emotional support to that carer who just feels so frustrated, so angry, so ground down and, you know, this is just one case."

4.2 Mental Health

Background

A major provider of mental health services within the voluntary sector delivers a dedicated advocacy service across West Sussex for adults of working age. They employ ten community advocates covering four geographical areas, Mid-Sussex, Crawley & Horsham, Worthing, Chichester & Bognor. They also deliver the statutory Independent Mental Health Advocate (IMHA)¹ scheme with two advocates, one based in the North and one in the South of the County. The service is funded via the Mental Health Grant which is a joint budget from Health and Social Care though the service is commissioned by the NHS. Advocates are trained predominantly in-house, with external expertise being called upon as necessary. Supervision and support have two strands, one managerial, the other emotional. The emotional support for advocates was requested as it is seen as very necessary and is very highly praised and valued by the advocates.

Along with outreach work, referrals come from a range of organisations including Community Mental Health Teams, Crisis Resolution Teams, Outreach teams and hospitals. The majority of clients are either in the community or in hospital with a minority in residential care. The ethos of the team is that all referrals receive an immediate response at some level (maybe just a phone call). This is felt to be essential when running an advocacy service for those with mental health issues. The team describe continually working towards broadening access by working with community development teams along with organisations working with specific groups such as Black and Ethnic Minority service users, where appropriate.

In relation to accessing an IMHA (a right of any person detained under the Mental Health Act), staff have a duty to ensure patients are aware of their right to access an independent advocate.

Interviewed:

Advocacy Service Manager
Commissioners of MH services x 3

Focus Group:

Community advocates x 8
Independent Mental Health Advocates x 2

Advocacy

The community team provide issue based advocacy mostly in response to crisis. Contracts do not specify time parameters for individual issues and clients are not restricted to bringing just one issue. Caseloads are typically made up of a majority of short-term cases and a minority of longer term (ie six months or more) cases. Caseloads vary accordingly.

The team agreed that it was extremely important that the advocacy service was user-led and independent of the providers of health and social care services. The team felt that the fact that advocates may have been service users themselves at some point helped them to do their job well as it increased the chance that they would understand issues and processes within the system. With regards to their interpretation of 'advocacy', they stressed their belief in it providing a mechanism for a service user to have their voice heard:

"We don't take anything away from the individual in providing advocacy, it is very much a client led service and we respect the decision that the client would make, and they have the right to make, what we might consider to be a bad decision ... Once they're fully aware of what the likely consequences are of that choice, we respect the right for them to make their decision."

¹ IMHA services are a statutory advocacy provision which provide an additional safeguard for patients who are subject to the powers of the Mental Health Act. This includes people who are 'sectioned' in hospital, people subject to guardianship, and people subject to Community Treatment Orders. (http://www.pohwer.net/our_services/role_of_advocacy.html)

"It's about making sure that you're reaching out to individuals who might find it very difficult to be included in decisions about them and be involved in their care and treatment"

The importance of setting and observing boundaries within the advocate / client relationship was highlighted by both advocates and commissioners. As detailed below, advocates work with clients on a wide range of issues and as one advocate put it:

"If you're not careful you can be in a care co-ordinator role, support worker role, outreach role and you have to be very clear about boundaries"

The team were asked to identify qualities needed by an advocate. The following were mentioned:

- To be a good listener
- To have staying power (as issues are often complex and frustrating)
- To be a good communicator
- To be empathetic, non judgemental, flexible and imaginative (in terms of what might work for individual clients)
- Ability to gain trust quickly
- Ability to keep abreast of changes and new services.
- Ability to work alone
- To strike a balance between diplomacy and robustness:

"I think in terms of communicating with professionals on behalf of client's wishes .. it's a fine balance between using the right amount of diplomacy in order to get something heard and properly responded to but also having the courage to be challenging and fairly robust in your role"

One of the IMHAs described her role as being, at times, similar to an interpreter which other advocates agreed with:

"It's like I'm interpreting what the professionals are saying to the client and then I'm interpreting what the client's saying to the professional and getting them to listen to it. So although I am not a mediator because I am on the side of the client, sometimes it does feel like a kind of interpreting service"

In addition to this, an advocate highlighted the role that they play, not only as an interpreter, but also as a means of ensuring professionals treat their clients with respect:

"I think personally for me, a lot of clients with a lot of issues, whether it's housing or treatment, sometimes the professionals tend to forget they are actually dealing with the person and all they are seeing is the symptom or the illness and it's not till we sort of come on board that professionals start to act a little more appropriately towards the person"

Organisational and professional cultures were recognised as contributing to the need for advocacy. Advocates refer to a *'kind of expert culture that happens in meetings'*, citing the use of professional language etc which can exclude clients. She describes the role of the advocate as being there to ensure her client *'can feel included on their terms'*.

A mental health advocate described a case she had worked on with a family from a travelling community. The advocate was asked to accompany the family for an appointment with a psychiatrist. A key part of the role she played was ensuring effective communication between the two parties. She commented on the cultural differences between the medics and the family and noted that she was aware that in different ways, each could have felt intimidated by them. The role the advocate played was in offering appropriate support which enabled the family to fully participate in the meeting. She describes being able to work with the family when they left the meeting due to heightened emotions and enabling them to express and manage their reactions and return to the meeting. She commented: *"that might not have happened ... the professional moved on a bit, the family moved on quite a lot"*

Commissioning / monitoring

A mental health services commissioner commented on the need for a different relationship with an advocacy service and referred to the service as acting as their 'eyes and ears'. The need for the relationship to be that of partners was stressed. Findings from this research highlighted a positive relationship between commissioners and the advocacy service provider, one which allows for dialogue and flexibility.

In relation to monitoring, a Commissioner commented on the difficulty of measuring the impact of advocacy:

"One of the most difficult things is to always represent the value that a particular contract like advocacy is offering you I think we have a very light touch performance management process ... based on very, very close work with the advocacy service themselves, regular quarterly meetings, not rigid in the same way as other contracts might be"

On the issue of outcomes, the advocacy manager made the point that it is important to be clear about the way in which these are interpreted in relation to advocacy work. He goes on to explain that in relation to outcomes *"the decision is never ours, so the decision is beyond our gift, so that needs to be recognised in advocacy .."*. He offers examples of where an advocate may work with a client throughout a tribunal and the outcome may be positive in that the person is supported to have a voice and gets their Disability Living Allowance reinstated. However, in another example a client is supported through a court case, having clearly broken the law, where the 'outcome' could be seen as negative as the client went to prison but actually feedback detailed how the advocacy had enabled them to cope with the process and feel supported and the reasons for breaking the law related to their mental health condition being expressed.

"The value of the advocacy was really supporting someone with significant mental health problems through that process. That's where the value of advocacy was for that individual and that doesn't seem to be recognised enough"

Advocates discussed the desire for in-depth feedback from clients regarding working with an advocate and acknowledged group work as being the best method. An advocate explained that a school in which she had worked arranged for the young people to put together a display which explained what the advocacy had meant to them. It was observed that the staff who supported this activity benefited from deepening their understanding of the role of advocates. The potential benefits for other professions running such groups was commented on, for example nurses, in order to expand other professionals' knowledge and understanding of advocacy. However, it was noted that this would require resources currently unavailable.

A key issue emerging from the findings around monitoring and outcomes is the need for clarity around what benefits are sought from an advocacy service. It is clear that Commissioners view this point from a different standpoint than service providers and service users.

Monitoring of the IMHA service is somewhat different as it is a statutory service and response times must be met and evidenced. Quarterly meetings with Commissioners also take place. As the service becomes embedded and more widely known, referral numbers are increasing.

Gaps in advocacy services

Advocates, the advocacy manager and commissioners of mental health services all cited the need for advocacy services for those aged over 65. The work of IMHAs, who work with all age groups, has thrown the spotlight on some of the problems faced by this group *“we are seeing the difficulties close up of older people”*. Advocates commented on their efforts to ensure older people are not neglected if they attempt to access the service but that this inevitably creates tension for them as their main commitment, dictated by commissioning parameters, must be to those of working age. Mental Health Commissioners also highlight the gap but point out that they do not have responsibility for commissioning services for older people. With a view to the future, the Commissioner commented that it would be beneficial if they could have responsibility for commissioning advocacy for those aged 65 plus with a functional mental health problem as this would *“allow us to provide a seamless approach”*. The Advocacy Service Manager made the suggestion of a starting model of two advocates for this age group specifically, one each in the North and South of the County. The ‘better by design, under one roof’ initiative was mentioned as offering a potential framework for development in this area.

Respondents discussed whether advocacy could best be provided as a generic service to older people or whether there should be specialisms within that, for example for those with dementia. Foley and Platzer (2007) observed during their mapping of mental health services in London the lack of comprehensive services for older people noting that services were segmented with some not having any specialist advocates to work with those with dementia and others only being funded to work with those diagnosed with dementia and not other mental health conditions. In West Sussex it was recognised that there could be scope for working in partnership with other organisations such as the Alzheimers Society, Age UK and Carers organisations when considering what an advocacy service for older people might look like. The need for value for money was stressed by a commissioner:

“In West Sussex we’re clear that advocacy services are extremely important, but we are in an economic downturn and we do need to ensure that we’re getting absolute value for money everywhere”

The needs of the Lesbian, Gay, Bisexual and Transgender population were mentioned as another gap by one of the Commissioners.

An advocate highlighted the need for more advocacy in privately run residential accommodation. She describes visiting one such place following a referral from a family member and observing that other residents probably had similar needs and commented:

“but you don’t have the capacity to go round proactively advertising your service because you know you’ll be overwhelmed”

One IMHA expressed concern that those who lack capacity who are detained under the Mental Health Act could potentially find it harder to access an advocate as they are less likely to refer themselves.

Finally, one advocate highlighted the needs of those living within immigration detention centres where she is aware of a need for advocacy.

Issues requiring the services of an advocate

Housing and Benefits issues are the two most common that clients seek the assistance of advocates with. Housing can include access to accommodation or inadequate housing in place on discharge from hospital or rehabilitation, anti-social behaviour, arrears, harassment, homelessness, eviction,

transfers and unsuitable accommodation. Benefits include assistance when they are stopped, in particular around changes in eligibility for Incapacity Benefit, and attendance at tribunals. An advocate explains the support they give:

“co-ordinating the person to bring together the evidence they need to give to the housing so that they get the right banding or right placement or whatever, it’s more about making sure that that person is supported through the system rather than doing something for them”

In general terms, advocates report getting a good response from service providers on issues worked on with clients. However, the Advocacy Service Manager highlights the importance of the work they do around awareness raising of an advocate’s role with staff such as Modern Matrons in hospitals and the benefits that this can bring in oiling the wheels of relationships between advocates and other professionals and contributing to a greater understanding of each other’s roles and responsibilities.

The personalisation agenda is starting to impact on the work of advocates. Advocates are helping people choose aspects of their care and it was suggested that service users will be more effective in making choices with the help of an advocate.

Brokerage

The above point highlights the blurred distinction between advocacy and brokerage. Respondents were asked about the knowledge of brokerage and its relationship to advocacy. One Commissioner clearly made a distinction, though interestingly linked advocacy very much to health services:

“Advocacy is about someone represented in the process of clinical relationships, relationships between an individual and their practitioner. Brokerage is something that looks similar, and it is about representing people’s needs, but it’s about representing people’s needs largely speaking in terms of their social care needs and helping them commission, helping them get what they want. It’s a fine line between them, but I think we know it’s not necessarily about representing individuals in the context of performance”

Another Commissioner comments that in a tight financial climate, brokerage may be seen as competing with advocacy but that they see a clear distinction. They emphasise the necessity of clearly identifying the two models (advocacy and brokerage) and

“seeing the similarities but equally trying to defend the differences and I think that’s a tension at the moment and as commissioners it’s up to us to provide some leadership around ... well actually what are we still going to commission?”

Use of volunteers as advocates

The Advocacy Service Manager explained that the organisation had used volunteer advocates in the past but commented that the cost of training is high and that it didn’t really work within the crisis service that they provide. He notes it would be more workable if they were offering citizen advocacy (usually volunteers working with individuals over a long period of time).

4.3 Learning Difficulties

Background

A large voluntary organisation is commissioned to provide advocacy services for adults (no upper age limit) with learning difficulties in West Sussex. This organisation provides, or supports, three forms of advocacy: self, citizen and issue based. The organisation uses both paid and volunteer advocates and is also commissioned to work with adults with physical and sensory impairment and/or acquired brain injury (PSI/ABI). The service is funded by West Sussex County Council from a pooled budget and is currently located within the Workability Service². Of the four nationally determined 'domains' for access to care, the advocacy service is commissioned for those with moderate, substantial or critical learning difficulties, therefore those classified as having a mild disability are not eligible for the service unless they are parents being supported through childcare procedures. Referrals can be made by self, family, GPs, Social Workers, Community Teams etc. Clients are mainly living in the community, with a small number living in residential accommodation.

In addition, Commissioners mentioned an organisation which provides a service enabling people to build circles of support and another which provides advocacy for those affected by home closures.

Interviewed:

Relevant commissioner
Service Manager
Senior Team Leader
Self advocacy support worker
Advocates x 4
Self advocates x 3

Advocacy

The organisation provides both instructed and non-instructed issue based advocacy for adults with learning difficulties. They have 18 volunteer and 5 paid advocates working across both learning difficulties and PSI/ABI. They also employ a worker to support three self advocacy groups in West Sussex. Over the past year approximately 200 clients have been supported (this includes those with PSI/ABI). A part time advocate working 22-25 hours a week would have a caseload of approximately 15-18. A waiting list is operated.

Advocates tend to cover particular geographic areas. The benefits of this are that knowledge of local services is built up, along with relationships with personnel within local teams.

The advocacy commissioned is predominantly issue based, with a parameter of no more than four months to be allocated to an issue. Commissioners explained that whilst recognising the challenge of restricting work with a client to just one issue, the ability of the organisation to meet this criteria, was an important element of the selection process. Both commissioners and the volunteer co-ordinator recognised the need for robust support for volunteers to be enabled to disengage from a client once the referred issue has been dealt with.

However, representatives of the organisation, both management and advocates, flagged up the significant challenges that a time constraint can present when working with some clients. It was noted

² Provides help into work, education or training for people with physical or sensory impairments, an acquired brain injury or substance misuse issues.

that on occasion significant time needs to be given working with somebody to 'unpick' what the key issue might be. As an advocate comments, a referral could be as broad as:

"I need help making choices So then you have to talk to the person and think about what it is they really need help with"

"and what might appear like one issue at the start of a relationship ends up unravelling into a whole can of worms and that's been quite difficult and complex to deal with"

In addition to working with some clients to unravel what the key issue might be, advocates also highlight that the processes of building trust, providing materials in accessibly formats, and using appropriate communication aids also eat into the time allocation:

"and that isn't something that you can do in a very quick time, that's something that you might need to meet with them four or five times before you're anywhere near close to being able to help them with that issue"

Concern was also expressed that time constraints could potentially affect a client's ability to feel really involved in the decision making processes.

Another reason given that can affect the ability to work effectively within a given timeframe was that some issues require interacting with other agencies whose response times are beyond the control of the advocate. Housing and Social Services were given as examples and in the case of the latter, it was noted that:

" in relation to somebody saying, I need a social worker to help me deal with my issues, there is a lack of social workers and actually trying to even appoint a social worker during that period of time can be problematic"

There was recognition by the organisation that, whilst a number of problems are anticipated, at the time of the research taking place they had yet to complete a four month period.

Few referrals are received from the BME Community and from rural locations. Advocates mention work being done with relevant organisations to address this. In addition, work done with GPs and other health workers to raise awareness of the role an advocate can play for a person with learning difficulties was highlighted.

In relation to the growing area of work with adults with learning difficulties who are parents facing childcare procedures, it was noted that the late point at which clients get referred to the advocacy service causes some concern. Referral for advocacy needs to be at an early stage to ensure an advocate can work with the parents to access information in a suitable format and to work with other professionals to ensure that forms of communication are appropriate in order that client's can fully participate in the process.

Self Advocacy

Commissioners report that they fund three self advocacy groups across the County. A member of the longest established group explained that originally self advocacy developed in the mid 1990's and was linked to Community Care legislation. The original group supported the development of the other two groups and commented that training received was very good. In describing why they wanted to support other groups to become established, a self advocate commented that:

"because I thought it was really needed to have a voice, that self advocates could actually go and talk without being told by staff that they couldn't do things like going out with their friends and making rights that were quite difficult"

Self advocates describe the importance of independence and stress that staff can only accompany people to meetings to support and help with personal care but not contribute to the meeting. The Chair of a self advocacy group gave an example of why the work that goes into the group was worthwhile. She describes a married couple who attended and it was noted that the husband was doing the talking for the wife because her speech wasn't as good as his but in time and with encouragement:

"she actually spoke up and she has actually now stood up on her own feet and I felt that with all the hard work of actually setting up the group, it was the best thing I'd ever actually seen, somebody trying to speak up for themselves"

The main support offered to self advocacy groups by the advocacy provider organisation is around communication, co-ordination, fundraising and effective interpretation of up to date legislation in order that members understand fully their rights.

Advocates and self advocates described the campaigning element to self advocate groups' work on, for example, hate crime. On certain issues, West Sussex groups will work together with groups from elsewhere to take issues further.

Commissioning / monitoring

Until April 2010 advocacy for PSI/ABI was provided by a different organisation to that providing a service to adults with learning difficulties. Commissioners note that the move to jointly commissioning advocacy services from one organisation on one contract will require close monitoring of referrals to ensure neither client group is disadvantaged in terms of use of resources. In relation to projected need for advocacy services, Commissioners highlighted that impact on demand may alter in line with changes in policy, such as the personalisation agenda:

"we don't know and that was one of the reasons why we only did the contract for two years with the possibility of extending for a further two years so that we can see if there is any change in the level of advocacy demand, we don't know at this stage"

Respondents commented that the move to competitive tendering, whilst providing clarity around what is expected of a service from the Commissioners' point of view, can present challenges for providers in relation to fully costing the service (the example of incorporating the full costs of travel for advocates was given).

Both Commissioners and the provider organisation comment on a very healthy relationship between them. As the service provider commented:

"they're willing to spend time, listen and help you develop something, but to be honest, they can't make everything right and they can't change contracts but actually we have very personable relationships ... so we feel confident that we can resolve issues"

An example was given of a growing area of work for the service provider with parents going through childcare proceedings. The rising number of cases and inherent call on resources was highlighted to commissioners. The response was positive in that the contract developed reflected the issues raised by the provider. Another example was discussions held in relation to recording the number of issues versus the number of clients, the service provider commented:

"they are recognising that maybe it is too linear some of it"

In relation to monitoring, the service provider felt that the mix of qualitative and quantitative information supplied to commissioners works well and that the two types of data are given equal consideration. The organisation is adapting a 'soft outcomes' tool used with clients with learning difficulties for use with those with PSI/ABI. However, even with this tool it was acknowledged that the issue of capturing the full impact of advocacy work remains difficult. Commissioners commented on the general swing towards 'outcome focussed results' and commented on the challenge of this *"with advocacy when it's an individual issue"*.

Issues raised

Advocates identified the following as examples of issues on which they work with clients:

Accommodation

Support from either carers or social services

Finances

Safeguarding

Childcare procedures

Example of why advocacy was helpful given by self advocate who had worked with an advocate herself in the past:

The respondent described a very difficult situation she was dealing with regarding neighbours in her supported housing accommodation. She explains that an advocate helped her to participate in the process of taking a person to court and achieving a beneficial outcome. She commented that:

"It was helpful because she was sitting there beside me and explaining things. The advocate was always someone I could talk to and she was there if I wanted her at the end of the phone. It would have been quite difficult to actually involve my parents - it's because it was an independent person I could actually talk to and it really helped me because it gave me strength to actually be able to feel stronger in myself I think that (name of Advocacy Organisation) was actually marvellous because they really helped me get through it and now I'm living quite happily, I haven't had to move, because I didn't really want to move."

In reply to a question about response to issues from service providers it was noted that:

"Well I think you get generally a good response and a thorough response, but you don't always get the response you're hoping for, but generally I think we get a good hearing"

The Learning Difficulties Partnership Board was recognised as an effective mechanism for raising issues that affect clients collectively and also for raising awareness with service providers in relation to referrals.

Gaps in advocacy provision

People with Autism or Asperger's Syndrome were highlighted by the advocacy provider as they: *"fall between the gaps of all different sorts of services"*

They go on to mention that the Partnership Board are aware of the Autism Act 2009³ and the need for more provision of support to this group. However concern was expressed that it is not dealt with as a 'tag on' and is treated as a specific service.

People with mild learning difficulties were also highlighted as a group not in receipt of advocacy services as they do not meet current eligibility criteria. The advocacy provider expressed concern that the introduction of initiatives such as the personalisation agenda may increase the need for advocacy among this group and comment that:

"so for us not to be able to work with them as well, it's very difficult"

Staff of the organisation comment on the fact that their citizen advocacy service has reduced. This mainly served people in residential accommodation. The needs of this group of people were recognised as being somewhat different to those in receipt of the issue based advocacy *"because it doesn't have that crisis element to it"*

Self advocates also highlighted the needs of teenagers in transition, not just those with learning difficulties. There were a number of issues they felt this group needed support with including health, housing, work, friendship and sometimes relationships. Clearly self advocates make strong links between the provision of advocacy and the ability to achieve or maintain independence.

Volunteer advocates

As explained above, this advocacy provider does work with Volunteer advocates. Volunteer advocates hold much smaller caseloads and may work with one person at a time depending on how much time they want to give.

Advocates believe it works well to have both paid and volunteer advocates. Working with volunteers enables the service to be delivered to more clients but the benefit of some paid staff is that they can develop areas of expertise which volunteers can tap into as necessary. Examples of such expertise would be around childcare proceedings or the Mental Capacity Act.

In relation to volunteers coming to advocacy from a variety of different backgrounds and possibly bringing different ways of working, advocates mention an OCN training course the organisation used to run:

"that was quite useful in that it could ... pick out who understood advocacy and who didn't because they had to write about advocacy and that was quite interesting because you wouldn't necessarily know who hadn't really got what advocacy was until you got that written sort of assessment in"

4.4 Physical and Sensory Impairment and Acquired Brain Injury (PSI/ABI)

Background

The advocacy service for those of working age with PSI/ABI is jointly commissioned with those for adults with learning difficulties. Funding is from West Sussex County Council only. The current provider has delivered the service since April 2010 and inherited a waiting list of around 30 clients from the previous provider.

³ One of the Act's two provisions is "That the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31st December 2010."

Interviewed:
Relevant Commissioner
Service Manager
Senior Team Leader
Advocates x 4

Advocacy

The advocacy that is commissioned for this client group is issue based and time restricted to up to four months per issue. Commissioners express concern that providers find it difficult to restrict their work with clients to one issue only:

" part of the service is that being able to get through and support and advocate for as many people as possible. You need to have parameters and stop dealing with issues otherwise you end up with having customers on your caseload for months and months or longer in some cases and that is, in a way, preventing other people who may have an urgent need for advocacy getting through. As a consequence we've found in the past there's been long waiting lists that have arisen because of that lack of disengagement, so that's been a problem."

In relation to the detail of the service being commissioned, the Commissioner stresses the benefits of a tendering system stating that it brings clarity to what is required for a service. However, Advocates raised some concerns in relation to the restrictions of the contract in terms of time and number of issues, these are as discussed in the learning difficulties section (as advocates interviewed were serving both client groups). One suggestion made by the organisation who previously delivered advocacy services to those with PSI/ABI was that there might be opportunities to support self advocacy groups. The current provider has experience of working with self advocates for those with learning difficulties and this offers an alternative approach to the delivery of advocacy to the time/issue restricted one currently commissioned.

In response to a question about access to their advocacy service, an advocate observed that in their opinion it is probably the more articulate clients who know about, access and use the service rather than the most vulnerable and isolated.

Commissioning / monitoring

The Commissioner of advocacy for those with PSI/ABI comments that funds are from a small centrally held budget within WSCC. They went on to comment that there would be benefits from joint commissioning with the NHS (as in the case of those with learning difficulties) as this would then allow advocates to incorporate health issues within their work. The relationship between the Commissioner and provider was described favourably, with the past provider commenting that they felt the Commissioner had a clear understanding of what advocacy is/is not. In relation to a question regarding the connections/differences between advocacy and brokerage, the Commissioner stated:

"I think that advocacy is a very specific service ... to me it's totally different to service brokerage. Brokerage to me is about informing people of what different services there are and maybe guiding people to appropriate provision but it's providing them with a range of information. I think for advocacy an advocate may well, through the process of issue based advocacy, look at different provision with an individual but it is based on the issue that's arisen and it is particularly about empowering the individual to have their say in order to speak for that individual. I see it as totally different"

In terms of monitoring, the previous provider of the PSI/ABI contract felt, broadly speaking, that the monitoring and evaluation they did and that was required of them from Commissioners was fit for purpose. The current service provider is still in the early stages of delivery but felt the information required was appropriate and hope that future monitoring will retain an element of flexibility.

Issues raised

Advocates comment that the issues raised during the short period they have been delivering the service are wide ranging. They include housing, benefits (in particular Disability Living Allowance), appeals and employment tribunals.

In addition they comment that there are many issues arising around direct payments, how people have been assessed and levels of funding:

"I have a case where an individual was offered a personal budget or so much money which isn't enough money to provide the care that he needs, so I've helped him to write to tell Social Services why he needs more money"

Gaps

Commissioner identified older people as a gap.

4.5 Older People

West Sussex has 23.6% of total population over age 65 which is higher than both the regional, 19.6%, and national, 18.9% rates. (CQC, 2010, pg 9). No advocacy service exists for older people (other than those with greater than mild learning difficulties) in West Sussex, following the demise of Age Concern's advocacy service and the 'Advocacy for Independence' (AFI) service. The AFI service ceased due to lack of funding, despite demand for the service increasing.

A manager from a major provider of services to older people in West Sussex was interviewed, along with an advocate from a national dementia charity and the past provider of the 'Advocacy for Independence' service. The majority of respondents in this research highlighted older people as a significant gap in advocacy services in the County. This is supported by the findings of the Care Quality Commission inspection report which states that *"the Council should ensure that all older people who use services have access to advocacy"* (CQC 2010, p 6). In addition, the annual report of the Director of Public Health and Wellbeing 2009/10 reported findings from stakeholder events for professionals who work for and with older people held during early March 2010 which included:

"..... Advocacy services must be promoted and supported, to ensure older people have choice and voice. This is applicable throughout later life, and in all settings."

However, a report by the Executive Director Adults and Children and Head of Customer Services to the Adult Services Select Committee on Services for Older People: A Strategy for Information, Advice (and Advocacy), September 2010, states:

"This strategy does not cover the bespoke Advocacy services commissioned by the Council; references to 'advocacy' within this document are in the context of advising customers in a pro-active manner – advocacy is the style in which we deliver information and advice."

The absence of reference to a need for specific advocacy services for older people within this developing strategy could be cause for concern. In order to better understand where responsibility for addressing the need for advocacy for older people lies, the authors of this report would echo the sentiment of a statement made by the Head of Legal and Democratic Services in a report to the

Health Overview and Scrutiny Committee on Public Health and Well-being (May 2010) which states that Members asked for:

" information about the linkages between the various partnerships/boards involved in health and wellbeing (e.g. the West Sussex Health and Wellbeing Partnership Board, the 'Better Health for All' group and the Joint Commissioning Board)."

During the course of this research, a Commissioner stated that WSCC are in the process of working out what their 'universal offer to all residents' (NB not just those eligible for funded support from Social Care) is going to be and looking at how advocacy fits within that and describes wanting to engage with 'partners' in establishing this within a context of tighter budgetary constraints. In relation to the provision of advocacy to older people with mental health issues, a Commissioner made the point that a revision of funding and responsibility would enable providers of mental health services to develop a 'seamless approach', instead of service users being required to negotiate a total change in provision upon reaching age 65 due to funding arrangements.

Some work was developed and implemented in relation to services for older people through the Partnerships for Older People Project (POPP). However, funding for the POPP project ceased in September 2010 and the degree to which any advocacy element of the work which had been developed will continue is not clear at the time of writing. The evaluation of the POPP highlighted how some older people do not think in terms of expecting or looking for support. Similarly, the need to address the lack of understanding of the concept of independent advocacy by older people was highlighted by Townsley et al (2009).

Issues/need for advocacy

The provider of the (ex) AFI service also run a project to support people who are eligible for direct payments in respect of setting up and managing their own care. This brokerage service is no longer supported by advocacy since the end of the AFI service, resulting in those older people with more complex issues lacking adequate support.

The organisation that now delivers advocacy to those with PSI/ABI notes that since taking on the contract, they have had an increasing number of calls from older people (who they are not commissioned to work with), sometimes referred to them by Adult Services. Presumably this is because historically the AFI project was able to pick up these cases.

There was some discussion around the types of service older people might benefit from and that whilst some would need advocacy, others may be able to be supported via a befriending, or similar, scheme. Self advocates (learning difficulties) identified older people through their work with the NHS Foundation Trust on dementia:

"also because it is cheaper now for elderly to be living in their own homes so it might be because they need somebody to go and talk to them and also it's about their health as well and also it's about living independently. So it might be just that the advocate or whoever befriends them so that they actually see somebody and not be stuck in their four walls"

Age UK are commissioned only to provide information and advice and report a growing need for a specific advocacy service, especially now that the support offered by POPP has ceased. They cite ten cases that, in the absence of an advocacy service, were referred on to the Community Partnership Teams (supported via POPP) in the current calendar year but note that:

"We discussed this as a team and we have realised that we have not been recording these cases in the right place on our database and that is the reason why the figures do

not reflect the true situation. So as regards definite numbers we are talking about forty per year recorded but all five advisers agree that this is the tip of the iceberg."

One of the carers organisations involved in this research commented on the high numbers of carers they have on their books that are over the age of seventy. They highlight that in many instances an older person has managed to care for a spouse for many years but as their own health needs increase "*there's very little in terms of support for them*". For this organisation, the feeling is that the work being done with such clients is often advocacy and that there is not enough recognition of the time and resources this requires within their funding arrangement.

The potential for closer relationships between safeguarding teams and independent advocacy providers is highlighted in the OPAAL report 'Speaking up to Safeguard' (2009). It notes that advocacy can play a crucial role in prevention and protection from abuse by supporting the older person to secure or exercise their rights, choices and interests. Findings from this research echo this, with an advocate for those with dementia clearly stating that access to advocates can help identify or prevent abuse. Action for Advocacy and Action on Elder Abuse have recently begun a new project (July 2010) exploring what role independent advocacy can play in preventing financial abuse specifically. However, the extent to which any findings ultimately influence policy is questionable. Miles (2009) notes that OPAAL's efforts to enhance the statutory underpinning for older people's advocacy did not achieve desired results and that advocacy acquired little prominence under 'dignity' or 'safeguarding'. He highlights that instead, a role was proposed for advocacy in the piloting of individual budgets.

Hospital discharge

The issue of older people being discharged from hospital was raised as an area where the services of an advocate were much in need. The issue was raised from the point of view of both the patient and carers. The tension between the needs of the two parties was highlighted, with the point being made that the wishes and needs of each may be very different and each could benefit from the support of independent advocates to ensure their voices are heard and taken into consideration when arrangements for discharge are being made.

Mental Health Services

Again, the issue of older people's lack of awareness of, or feeling eligible for, support was raised by one of the Independent Mental Health Advocates: "*the idea of older people participating in their care and treatment is even more behind than in adult services*".

In relation to transition from working age mental health services on reaching age sixty five, a mental health advocate notes the inadequacy of a system that results in a person's care being transferred wholesale from one care system to another with few, if any linkages:

"you know for somebody who's been in residential accommodation for years, an adult up to 65 and then they've got to move out to a completely different service"

Residential Care

Representatives from three providers of advocacy services highlighted the need they believe exists for residents in care homes to have access to independent advocacy. Particular mention was made of those who self-fund their care.

4.6 Dementia

Background

Advocacy for those with dementia is provided by a branch of a large national charitable organisation which specialises in the provision of services to those with dementia in West Sussex. The advocacy service started in 2004, however, the service was reduced in April 2010 by a third and now employs one advocate for two days a week who serves only the coastal part of the County. The majority of the advocate's work is non-instructed. The majority of clients are not in residential settings, around 20% are. Referrals can be self, family or professionals. The advocacy is issue based and mainly short term.

Advocacy

Advocacy for those with dementia is mainly, though not exclusively, non-instructed. In order to conduct such advocacy, a mental capacity assessment is carried out in order to be sure the person is not capable of instructing and the advocate must work in the person's best interest, in line with the Mental Capacity Act. Whilst issue based, the advocate comments that the service is not restricted to one issue and that it could be multi issues at the same time or *"issues that come along at different times in their journey through dementia"*. Over the previous year, forty nine people had received an advocacy service (thirty eight new clients and eleven clients coming back). A waiting list is not operated as it is recognised that referred issues need dealing with quickly. However, in order to maintain the level of responsiveness the advocate feels is adequate, unpaid hours are regularly put in.

It was stressed that due to the restricted advocacy service on offer, referrals tend to be more urgent cases as professionals who refer are:

"acutely aware of the fact that the service is under pressure, that I've only so many hours in a week and so therefore I do get the really urgent cases it's really a case of priority management, being able to look at priorities as they come along"

The specialist nature of working with people with dementia was highlighted and emphasis was laid upon the need for quality training and support/supervision for advocates: *"it's a bit daunting for other services to be looking at it because it is a very, very specialised piece of work"*.

Similar to those working in the mental health field, the importance of the provision of emotional support for advocates was stressed though currently the desired access to a psychologist is not available.

Along with individual, issue based work, the advocate described providing collective advocacy as well. An example was given of many clients raising issues about a particular residential setting which he would then raise with Social Services.

Commissioning/monitoring

West Sussex County Council commission the advocacy service for those with dementia. The service provider explains that due to the fact that they receive some funding from a statutory body, they are unable to access other funders such as Comic Relief or the Big Lottery.

It was noted that the charity that employs the advocate are considering altering their model of advocacy provision in order to ensure consistency throughout the organisation. The advocate in

West Sussex commented on the effect this might have on WSCC funding. Despite the relationship with Commissioners being described as 'very very good', there were concerns about the effect such changes might have if they are not compatible with commissioners' requirements.

Detailed monitoring goes to WSCC on a monthly basis, outlining issues, number of hours on administration, contact time and information on referrals. In addition an end of year report is produced.

Issue Raised

One example given of an issue worked on by the advocate was maintaining the client's place within residential accommodation by researching his background and uncovering information that explained behaviour that staff misinterpreted as inappropriate. The advocate highlights that if better notes had accompanied the gentleman in first place, much of the anxiety of staff could have been avoided.

The advocate offers examples of where his intervention has been sought by carers on issues that were not within his remit. One example was around a carer asking for support in commissioning care on behalf of the cared-for person but the advocate felt this was a brokerage role and clearly not his. The carer was signposted to Social Services.

"I went to (x) Hospital one day to see a lady that had broken her leg, and her bed was turned to face the wall, and I just... I was absolutely disgusted. I walked round to the nurse's station and I said 'why is her bed facing the wall?' and they said 'well she keeps calling the nurses, every time a nurse walks passed she calls out'. I said 'well she has dementia', she said 'well the nurses are busy', and I said 'another thing as well is that she is a human being and that she has the same rights as the person in the next bed to her"

Gaps in advocacy provision

In relation to gaps in advocacy services, the advocate highlighted the areas of West Sussex that his part-time service does not cover, ie west of Littlehampton and north of Henfield.

Volunteer Advocates

Volunteer advocates were involved in delivering the advocacy service at one time. However, it was explained that for a number of reasons including volunteers leaving or volunteers not observing the boundaries of the advocate relationship, it was decided that volunteers should not be part of the service.

Age UK's report on a three year project exploring volunteer advocacy for those who lack capacity, highlights the resources needed to manage volunteer advocates: *"We would dedicate more time to the crucial role of project managerin order to fully recruit, train and support an extensive team of volunteers. We have learnt that in practice this is a full-time role, particularly where the advocacy being provided is non-instructed advocacy"* (Age UK 2009, pg 24)

Section 5

Discussion

This section identifies key themes emerging from the findings of this research, within the context of relevant literature. Within this section we also incorporate findings from our interview with a member of staff from an organisation that previously provided advocacy services to people with PSI/ABI and older people but no longer does so.

5.1. Understanding of advocacy

To a large extent respondents agreed that the key qualities associated with advocacy include: engaging in a relationship that has clear boundaries and is confidential, enabling people to have a voice, supporting people to assess their options, and enabling a person to exercise control and independence. The majority of respondents highlighted the importance of advocates being clear that their role was to enable those with whom they work to make informed decisions and that it was *not* their role to advise or attempt to achieve what *they* might consider to be in the person's best interest. As a mental health advocate put it "*once they're fully aware of what the likely consequences are of that choice ... we respect the right for them to make their decision*".

As noted within the background section of this report, a consequence of the fundamental characteristics of advocacy is that power in service settings can be questioned. Whilst providers of advocacy are clear about their role, findings suggest that a range of professionals including some social workers and some clinicians, either do not understand the role or don't value it. As an advocate put it:

"I think some professionals found advocacy really useful to their work and helping that person achieve their goal, others found advocacy a pain, and you're always going to get that .. you're always going to get people that don't understand the role of an advocate because they feel that it's in their role anyway"

Suggestions for training of other health and social care professionals around the nature of advocacy were made.

5.1.1 What does advocacy do?

Findings highlight that advocacy, as described by respondents within West Sussex, encompasses two important roles. The first is concerned with facilitating service users to make informed choices which may include challenging issues related to their care. Barnes (2007) notes that issues around clinicians understanding and accepting the role of an advocate date back at least 20 years. She goes on to comment that "*at a time when user involvement in planning and service delivery has become official policy it is important to understand how far we have come in terms of challenging professional dominance and control*" (pg 41). Some professions, such as medicine, may find changes in relation to service users' voices harder to adapt to. Sang (2009) suggests this is due to the culture being dominated by institutional thinking and aligned to 'very powerful interest groups'. However our findings suggest that significant headway is being made by some advocacy organisations within the medical field as evidenced by the work of IMHA's with Modern Matrons within the psychiatric field and of carers organisations working closely with GP surgeries.

The second role identified involves enabling service users to understand and negotiate the often complex systems, cultures and processes operated by various service providers. However, this raises a question regarding the relationship between the role of a broker and that of an advocate. It could be argued the role identified by advocates as part of their remit could be described as more of a broker's role. The necessity for clarity and agreement around the remit and responsibilities

associated with each is obvious if commissioners and providers of such services are to work effectively to meet the needs of service users. As the predominant advocacy service model in West Sussex relies to a large extent on other professionals recognising a need and making a referral, the level of understanding of what an advocate's role is by such people is crucial. One of the long term providers of advocacy commented that there is often a lack of this understanding among a range of professionals.

An additional key point that has been raised throughout this research is the need for separate advocacy for carers and those they care for. As recognised in earlier discussions, there may well be conflicts of interest which is why each party needs access to advocacy to ensure their voice is heard.

5.1.2 Types of advocacy

All the organisations that were involved in this research provide issue based advocacy, ie content specific and, in some cases, time restricted. In the case of learning difficulties, carers and mental health, providers comment that the reality is that they provide mainly crisis advocacy. Foley and Platzer (2007) suggest that issue based advocacy can be preferred by commissioners as it lends itself to 'clear and measureable outcomes' (2007, p 5). This highlights the tension between commissioning processes and ways of working that are intended to be driven by individuals' needs and interests. This tension will need to be acknowledged when considering the future 'advocacy offer' in West Sussex. Service users, commissioners and advocacy providers will need to assess various options in relation to what type of advocacy might best suit particular service user groups and best achieve the desired outcome for individuals or groups. If more self advocacy groups were considered favourable, what support might different service user groups need to develop and help maintain them? Which service user groups might benefit from developing peer advocacy schemes? These and other questions will help stakeholders identify when advocacy is necessary, what type/s of advocacy might be relevant to different service user groups and the resource implications of various options.

In addition, thought should be given to how advocacy relates to other opportunities for user influence on services. It was notable during this research that two commissioners mentioned such opportunities, for example user panels, in relation to advocacy provision. A mapping of relationships between advocacy and other opportunities would benefit the development of a variety of strategies.

5.1.3 Distinguishing support roles

Analysis of responses clearly demonstrates that further consideration must be given, at a local commissioning level, to clarifying the distinctions between a variety of support roles. It is important to remember that from a service user's point of view, distinctions between care managers, advocates, support workers etc may not always be clear, or indeed feel important. What is important is that there is a clear framework of support, within which advocacy sits. So, whilst there is a need for distinctions to be drawn and possibly even definitions to be agreed, these must be developed with a view to their viability from the perspective of the recipient of support. It will not be enough to merely identify clear definitions and fixed boundaries of roles without ensuring they are located within a framework of support. This framework must be adequately articulated to a wide range of service users in order that both those delivering and those receiving services are clear about not only where one person's support ends, but where continuing support can be accessed if necessary. In relation to the personalisation agenda, the findings particularly highlight the need for deeper consideration of distinctions between support, advocacy and brokerage. As noted by a Commissioner, this is of particular importance when considering what the 'universal offer to citizens' is to be in West Sussex.

5.1.4 Independence

With few exceptions, interviewees felt that advocacy services should be provided by organisations that are not delivering services. The issue of whether organisations felt tension with regard to the funding of their advocacy services being primarily from health and social care, when often the issues on which they work with clients relate to these services, was explored. On the whole, organisations did not state that this is problematic. What was considered more problematic for some, such as PSI/ABI and Carers, was the fact that the services they provide were not jointly commissioned /funded by both the NHS and Social Care.

Various respondents commented that certain professions, such as social workers, include advocacy as part of their role whilst other respondents felt strongly that such professionals cannot advocate for clients when they have strong affiliations with a particular service. Dunning's findings from research with older people identifies similar concerns (2005). A commissioner within this research commented on the need for a future advocacy strategy to be clear with regard to who can advocate for whom and in what circumstances. This relates to our earlier point about the need for distinguishing independent advocacy from other forms of support and ensuring that there is a clear framework of support within which advocacy sits which service providers and users can understand and negotiate.

5. 1.5 Prevention

The role that good advocacy can play in terms of prevention is raised in the literature both in relation to costs for service providers and outcomes for service users. In the case of the former the Department of Health Commissioning Framework for health and well-being (2007) encourages more flexible use of NHS resources in relation to preventative services or supports, with a view to reducing NHS spend further down the line. In relation to outcomes for service users, as highlighted in section 3.5, OPAAL (2009) highlight the 'crucial role' advocacy can play in relation to prevention of abuse of older people and the potential role that independent advocacy can play in preventing financial abuse is being explored. Here again, as noted in the background section, it is important to remember that the focus of an advocacy relationship may go beyond service delivery issues.

Our findings suggest service providers, such as those advocating for people with dementia, agree that advocacy can play an important role in preventing abuse. The role that GP surgeries can play in signposting to advocacy services is also highlighted by two organisations, with a view to ensuring service users access appropriate support to deal with issues and potentially prevent problems developing or escalating.

A key factor mentioned by respondents in relation to the ability of advocacy to contribute to prevention is that under current commissioning terms, many providers are limited to dealing with cases that have already reached crisis point. Little resource is available for working with clients at an earlier stage.

5.2 Personalisation

Whilst advocacy services work with service users on a wide range of issues, there are indications that for some, workload is increasing due to clients' need for support in understanding and negotiating the personalisation agenda. The Transforming Adult Social Care Programme Board commissioned work to scope activity and thinking in relation to information, advice and advocacy and the delivery of Putting People First. The 2009 report includes the following recommendation: "*Articulate and re-iterate the principle that transformation and personalisation are dependent upon good information, advice and advocacy, support planning and brokerage being available*" (I&DeA, 2009, pg 9). In

addition the Care Quality Commission highlight the 'crucial role' independent advocacy plays in assisting users of self directed support to express views and support them in decision making (2010). All of the organisations we worked with on this research fall into the category of 'third sector'. A report by the Cabinet Advisor on Third Sector Innovation recognises the 'crucial role' that third sector organisations providing advocacy will play in *'driving forward personalisation and enabling service users to exercise real choice, by ensuring they can access and maintain engagement with their clients'* (2010, pg 28). At a local level, Commissioners talked of having to 'advocate for advocacy' within a structure with many calls on funds. One argued that advocacy should be funded as it fits alongside the personalisation agenda:

"For me, I don't see how you can have a personalisation agenda without having an advocacy service"

For those able to access advocacy services, the complexity of the system is raised as a key issue by providers of advocacy. Dunleavy acknowledges this complexity and the need to simplify access to public services in the findings from the Commission on 2020 Public Services (2010). However, concerns around eligibility for advocacy services, for example those aged above sixty five or those with mild learning difficulties, were also expressed as there is evidence that such groups could also benefit from the services of an advocate.

Brokerage is often referred to, along with information, advice and advocacy, as a necessary service related to the effective implementation of personalisation. Attitudes to, and understanding of, brokerage differ. The Care Services Improvement Partnership (2007) comment that *'some advocacy agencies are confident that they can work effectively as brokers, others do not feel this is part of their role'* (pg 7). Analysis suggests some respondents in our research see brokerage as something clients can access following receipt of advocacy (where necessary). The distinction they draw is that whilst advocacy enables the person to assess their choices and express preferences, the broker's role is to assist with identifying resources to meet requirements. Dowson and Greig comment on the technical nature of the broker's role *"The broker avoids the presumptuous ambition of leading people into the light of self-determination, aiming instead only to provide a technical service"* (2009, pg 30). It was beyond the remit of this research to identify brokerage services in West Sussex and explore current relationships with advocacy providers. However, it is clear that such services link very closely with those of advocacy providers and the nature of their relationship to each other, particularly in terms of being commissioned, is one that requires prompt attention.

5.3 Commissioning / monitoring of advocacy services

Issues emerging around the commissioning of advocacy services differ according to service user groups and are highlighted in relevant sections above. Across the board, providers and commissioners of advocacy services reported generally healthy relationships which allow dialogue and some flexibility. However, we note that this is a period of change and development within commissioning in West Sussex, for example the Carers Strategy signals a move to joint commissioning and we are aware that commissioning of services for older people is under review. In addition respondents mentioned various initiatives such as the 'better by design' process (mental health) and the 'whole disability cradle to grave' approach being considered within WSCC. Analysis highlights that both commissioners and providers of advocacy services (or potential providers) would welcome a process that ensures need and access to advocacy, is assessed in a robust, inclusive way to allow commissioning decisions to be well informed. Such assessments could include the disparities in access to advocacy throughout the County, for example for those with dementia.

One key difference between organisations is whether they only deliver advocacy or whether advocacy is wrapped up within a package of support. The literature indicates difficulty in clearly identifying the percentage of resources that go specifically to the advocacy element of an

organisation's work (Foley & Platzer 2007). Certainly in the case of the carers organisations involved in this research, the issue of the extent to which they can offer advocacy has arisen as it is only one element (but a resource intensive one) of a package of support they are commissioned to provide.

Funding, apart from statutory advocacy such as IMHA and IMCA, is generally short-term. Rapaport et al (2006) report findings from advocacy organisations that this hampered their ability for long-term planning and therefore their effectiveness. However, two organisations involved in this research commented on the difficulties of accessing additional/alternative funding to that from care and health as funders, for example Comic Relief, do not support organisations that are in receipt of such funds.

5.3.1 Measuring / monitoring

The Department of Health Commissioning framework for health and well-being (2007) states that commissioning will be focused on outcomes in order that provision can be tailored to personal needs. The Office for National Statistics has recently (June 2010) produced a report on measuring outcomes for public service users which includes a section on information, advice and advocacy. The project aim was to develop and pilot an 'outcome tool'. At this stage, the tool needs further development addressing identified barriers to such measurement. However, the literature highlights the need to recognise benefits resulting from the process of advocacy as well as the final outcomes which relate to both the instrumental and the expressive elements of an advocate's role (Dunning 2005, Townsley et al 2009): "*In their instrumental role advocates may point to a truth that others don't want to acknowledge, or think they can't respond to. In their expressive role advocates must work painstakingly to help an oppressed individual find their voice*" (OPAAL, 2009, pg 2). In their study of service user involvement in commissioning local services with both commissioners and those they commission, Schehrer and Sexton note that "*many cultural norms are output/activity rather than outcome/process driven*" (2010, pg 35) and they note that a greater emphasis needs to be placed on the personal dimension in commissioning processes. A number of commissioners interviewed for this research commented on the challenge of identifying adequate measurement/monitoring processes to fully reflect the impact advocacy can have.

Findings from this research indicate that on the whole, Commissioners of advocacy services seek both quantitative and qualitative monitoring. What is not clear is the extent to which qualitative material, case studies etc, is weighted in comparison to the statistical information. Barnes (2007) highlights that the issue of judging the value of advocacy work has been problematic for some time. The issue of how need for different types of advocacy and outcomes for service users are measured should inform a developing advocacy strategy.

4. Use of volunteer advocates

The use of volunteer advocates varies across the organisations included in this research. Associated issues are resources for recruitment, training, supervision and support. Whilst some organisations use or have used volunteers very successfully (for example those working with learning difficulties and PSI/ABI), others have experienced difficulties (mental health, dementia). The advocacy service for mental health service users proactively encourages the paid advocates they employ to have had experience of mental health services themselves. In relation to developing advocacy services for various service user groups within West Sussex, consideration should be given to the benefits that peer advocacy can offer.

Section 6

Recommendation:

A working group should be convened to develop a comprehensive advocacy strategy for West Sussex. The group should be made up of a wide range of stakeholders, which would include service users, advocacy provider organisations, relevant user led organisations and commissioners.

Based on the findings of this research, the group should work towards the following:

- Defining and agreeing an advocate's role and its boundaries, in particular distinguishing advocacy from brokerage in the context of self-directed support.
- Recognising the range of types of advocacy, determining which should be the priority for development in different contexts (eg it may be more appropriate to prioritise early development of citizen advocacy for older people).
- Identify the range of groups and organisations that may deliver advocacy services (in addition to those currently doing so) and what support might be offered to them to develop this role. In particular, consider which organisations can develop and support self and peer advocacy and how this can contribute to collective input from service users in relation to service design, delivery and evaluation.
- Agree eligibility for advocacy services, for example should those not in receipt of Social Services support still be able to access advocacy?
- Reach agreement on boundaries of other support roles*, map a framework of support offered to residents of West Sussex and locate advocacy clearly within that framework.
- Determine how awareness and understanding of advocacy can be raised amongst service providers who may be on the receiving end of input from advocates.
- Prioritising the development of advocacy services to meet the needs of older people in West Sussex and what resources would be necessary to deliver these.
- Gain a clear understanding of strategic developments within Health and Social Care in West Sussex and ensure advocacy is incorporated appropriately. In particular, contribute to Services for older people: a strategy for information, advice (and advocacy).

* In addition to the outline of various forms of advocacy given earlier in this report, we offer below *an attempt* at clarifying key terms associated with the provision of support to service users. We believe that development of a shared understanding of these functions is essential to allow advocacy services to be clearly understood and located within a framework of support. We offer these as a starting point and basis for discussion/development:

Information:	The sourcing and disseminating of current, relevant information or signposting to sources of information
Advice:	Actively offering opinions / guidance on courses of action.
Advocacy:	Taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice
Brokerage:	Identifying existing services and negotiating with providers on behalf of service users.

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