Contents
1. EXECUTIVE SUMMARY ........................................................................................................ 4
2. INTRODUCTION .................................................................................................................. 10
  2.1 Purpose and Scope of the needs assessment ................................................................. 10
  2.2 Methodology ................................................................................................................... 12
  2.2.1 Steering Group .......................................................................................................... 12
  2.2.2 Definition of advocacy ............................................................................................ 13
  2.2.3 Data Collection and Analysis .................................................................................. 13
  2.3 Production of final report, including recommendations ................................................ 14
  2.4 Strengths and Limitations ............................................................................................ 14
  2.5 Outline of the Report .................................................................................................... 16
  2.6 Summary of Section ...................................................................................................... 16
3. WHAT DOES ADVOCACY MEAN? ...................................................................................... 17
  3.1 Definition of Advocacy .................................................................................................. 17
  3.2 Delivering advocacy ...................................................................................................... 18
  3.3 The evolution of advocacy services in England ............................................................ 18
  3.4 Statutory requirements for advocacy in England ........................................................... 19
  3.5 Current provision of advocacy services in Brighton & Hove ........................................ 22
  3.6 Summary of Section 3 .................................................................................................. 24
4. EVIDENCE OF GOOD PRACTICE ...................................................................................... 25
  4.1 Summary of findings regarding advocacy provision ...................................................... 25
  4.2 Evidence of innovation in commissioning and service delivery .................................... 27
5. USING DATA TO DESCRIBE ADVOCACY NEEDS IN BRIGHTON & HOVE ........... 30
  5.1 Need for advocacy for those with mental health needs .................................................. 30
  5.2 Need for advocacy for older people .............................................................................. 33
  5.3 Need for advocacy for adults with learning disabilities and/or autism ......................... 34
  5.4 Need for advocacy for people with physical and sensory impairment .......................... 35
  5.5 Need for advocacy for people with additional language needs ..................................... 37
  5.6 Need for advocacy for trans people .............................................................................. 39
  5.8 Need for advocacy under the Care Act 2014 ............................................................... 39
  5.9 Specific areas of support provided by advocates ......................................................... 41
  5.10 Summary of current advocacy demand in Brighton and Hove .................................... 42
  5.11 Summary of section 5 .................................................................................................. 42
6. COMMUNITY RESEARCH .................................................................................................. 44
  6.1 Methods used in community research project ............................................................... 44
  6.2 Results from community research project .................................................................... 46
  6.3 User feedback collated by advocacy providers ............................................................. 57
6.4 Summary of section 6 ........................................................................................................58
7. STAKEHOLDER ENGAGEMENT .........................................................................................60
  7.1 Methods .........................................................................................................................60
  7.2 Results .........................................................................................................................60
  7.2a Results: those who refer into advocacy services .....................................................60
  7.2b Results: those who deliver advocacy services .........................................................69
  7.3 Summary of section 7 ..................................................................................................78
8. Synthesis of findings and recommendations ..................................................................80
  8.1 Understanding of the term ‘advocacy’ .........................................................................80
  8.2 Awareness of advocacy services in Brighton & Hove ..............................................80
  8.3 Considerations for future provision of advocacy services in Brighton & Hove ........81
  8.4 Meeting current and future demand ...........................................................................82
Appendix 1: Commissioning Prospectus and Advocacy Mapping Exercise January 2012 ... 84
Appendix 2 – Terms of Reference for the Steering Group ..................................................96
Appendix 3 – Literature Search criteria ............................................................................99
Appendix 4: Innovation in Commissioning and Service Delivery ....................................100
Appendix 5 Specific areas of support provided by advocates ...........................................105
Appendix 6 – Community Research ..................................................................................108
Appendix 7 – Stakeholder questionnaires .........................................................................110
1. EXECUTIVE SUMMARY

Introduction

This needs assessment uses a combined epidemiological and corporate approach to identify the need for advocacy in Brighton & Hove. It has utilised a literature review; a review of data and both community and stakeholder engagement to inform the report.

The definition of Advocacy that we have used in this needs assessment is that used in the Advocacy Code of Practice\(^2\). Advocacy services in Brighton & Hove are provided by a wide variety of organisations across the city and are funded by multiple agencies. The scope of this needs assessment are the communities currently being provided for under the aegis of the existing contracts with Brighton and Hove City Council (BHCC) and Brighton & Hove NHS CCG based on the 2014 Commissioning Prospectus.

Strengths of the report include a comprehensive period of independent community engagement and a thorough and wide-reaching stakeholder engagement, with a good uptake of involvement from those referring into and providing advocacy services. It was therefore possible to produce a comprehensive view of the need for advocacy services within scope. However there is ambiguity around the meaning of the term advocacy.

What does advocacy mean?

Advocacy is a broad concept and covers a range of different expertise. Individuals are able to advocate for themselves, family and friends can advocate on behalf of another person, health and social care professionals can sometimes advocate formally on behalf of their client and professional advocates are able to provide expert support when needed. Access to advocacy can be affected both by how health and social care professionals assess the advocacy needs of their clients and also referral processes into service, hence these have both been included within the scope of this needs assessment.

Certain forms of advocacy operate within a statutory framework guided by legislation drawn from the Mental Capacity Act, the Mental Health Act and the Care Act.

Within the city advocacy is currently delivered by specialist providers; by statutory provision as detailed above and also as a community service. Specialist community services commissioned at the time of writing include provision of advocacy for those with: mental ill-health (including specialist LGBTQ mental health service); sensory and/or physical disabilities; learning disabilities; language needs; those who are older people; vulnerable adults with autism; and people who are trans.
Evidence of best practice

Evidence from the research literature around advocacy identifies that support can come in many forms and that delivery is shaped by the type of advocacy needed. The sector is diverse and there is no ‘best’ form of delivery. All forms of advocacy should encourage self-advocacy. Evidence exists that access to advocacy by particular groups can be problematic and the use of referral systems that automatically enrol a client with advocacy services (sometimes referred to as an ‘opt-out’ rather than ‘opt-in’ access) was suggested as a way of addressing this. Key themes that emerge from the review of innovative services include the integration and co-ordination of services and aligned to this the use of partnership working and the flexibility of provision.

Using data to describe advocacy needs in Brighton & Hove

The data evidences the need for advocacy support for the existing communities of need for whom specialist provision is currently provided, however it is accepted that there may be other communities who may also have a need for advocacy support. Brighton & Hove is particularly characterised by the high number of individuals with mental health problems in the city. Though there are proportionately fewer older people living in the city when compared with England and the South East there are a higher proportion living alone.

These data do not identify the intersection of multiple factors that can affect an individual’s requirement for advocacy support. The provision of advocacy is also in part determined by social factors such as family and friends acting in an advocacy capacity.

Data from the Projecting Older People Population Information (POPPI) system and the Projecting Adult Needs and Service Information (PANSI) system predicts that the sizes of all populations they measure that are currently supported by advocacy services are likely to rise between 2014 and 2025.

It can be seen that the largest rises in numbers are expected in older people, adults with moderate or serious physical disability and those with hearing impairment. It can be seen that the largest percentage rise is expected in those adults with hearing loss (19.9%) and it is unclear how their needs are being met with regard to BSL interpreters. It is also unclear whether people with additional language needs are able to access some advocacy services.

Community research

Advocacy services in the city are not well-known about amongst people in need and the lack of a high profile seems to be the result of a combination of lack of understanding of the word (advocacy), a lack of awareness and proactive referring to advocacy services by core NHS and social care services (including GPs and Adult Social Care staff) and a lack of specific resources devoted to local promotion of these services.
The current use of advocacy services is amongst people with complex combinations of needs, including multiple conditions and disabilities, who are trying to live independently within the city, but are likely to be socially isolated. Service users report that much current use relates to navigating increasingly complex access routes into health and social care systems, increasingly complex processes for receiving disability and other benefits and diminishing housing choices that are affordable, safe and secure.

The potential need for advocacy is likely to be significantly greater than current usage suggests, given the low profile of these services locally within the health and social care system.

Most advocacy users consider advocacy to have had a significant impact on the quality of their life and to have prevented them from having crises or deepening need and are grateful for being able to access services within the city. Users are particularly positive about the way that advocates work with them holistically, working alongside them to tackle their multiple issues and challenges over time, providing continuity of support in a welfare system that is increasingly fragmented and specialised. This is even though only some advocacy services support people struggling in the benefits system and there is little advocacy available to deal with housing problems. This research suggests that the impact of any reduction in advocacy for people like those interviewed in this research is likely to result in more crisis management and deepening need and therefore be felt in other parts of the local health and social care system.

**Stakeholder engagement**

The findings of the questionnaire consultation with those who refer into advocacy services indicates that participants felt that they assessed the advocacy needs of their clients and were able to refer clients into advocacy support without any difficulties, in a timely manner with refers commenting that they always referred clients who they thought would benefit (8). Issues identified included the complexity of service provision with each service having its own referral processes. Overall satisfaction with the provision was high.

Findings from the focus groups were affected by the role of the different teams. Teams with more specialist roles such as the Deprivation of Liberty Safeguards (DoLS) and Specialist Older Adults Mental Health Service (SOAMHS) teams had positive experiences of referral. However the more generic needs of clients supported by Adult Social Work teams in particular experienced greater difficulty in accessing advocacy support. Participants from the Adult Social Care Service and to some extent the Learning Disability Service identified the multiple needs of their clients as presenting a gap between client need and current service provision, as it was difficult to know which service to refer into with the effect that it deterred referrals. Other issues that negatively affected the uptake of services were the lack of a common access point and waiting times. Comments were also made about the need for advocates to be multi-skilled, probably reflecting the issue identified earlier in respect of the complexity of many clients’ needs. There was also some concern about the professionalism of some advocacy support, with respondents indicating incidents when they either felt there had been insufficient challenge to decisions, or
inappropriate challenges that touched on lobbying rather than representation. The need to raise awareness of local advocacy services was also mentioned, as was the need for greater integration of service provision.

Providers who took part in the questionnaire indicated that they felt that a gap existed between those who would benefit from accessing support and those who actually made contact with the service. Lack of awareness of existing services was considered the key factor affecting this and this was again referenced when respondents were asked what they would like to see changed. Ambiguity as to understanding what advocacy meant was also cited as a factor. Increased capacity and funding were also cited as elements that the participants would like to see changed.

Findings from the focus groups supported the findings identified in the questionnaire for the need to raise awareness, improve promotion of services and the need to aid understanding of what advocacy was. Participants also felt that the more socially isolated a potential service user was, the less likely they were to be in contact with advocacy support. When asked what they would like to see changed providers who took part in the focus groups indicated that they would like to see more partnership working between services. It was also suggested that greater in-reach exist into referring services with for example social care teams having a member of staff with specialist expertise around advocacy: an Advocacy Champion. The value of having advocacy services delivered by services with local knowledge was also identified through the focus groups.

Lack of clarity around the meaning of the word advocacy was identified by service users as an obstacle to access for some clients, as was a perceived lack of awareness amongst staff who may refer to advocacy services. The most common responses from those who deliver services were made in respect of the need to raise awareness of advocacy services. This theme was also the most frequently mentioned at the Focus Groups with 14 participants suggesting the need to raise awareness and increase promotion of services. Examples of ways of doing this that were provided included the use of a directory, and greater outreach into the community. The stakeholder engagement expressed the need for professional high calibre staff with wide ranging knowledge who had the ability to actively listen to a client’s wishes. Participants also mentioned the lack of integration between services and that this made access difficult to navigate. It was also recognised that many who access advocacy support have complex and specialist needs.

**Recommendations**

Findings from the preceding sections of the report have been synthesised and the following recommendations reached:

1. Commissioners and providers to work to the definition of Advocacy used in the Advocacy Charter (and in this needs assessment)
This definition is already used by the existing advocacy providers and by adopting the meaning already in operation this could aid consensus building and collaboration. It is important for commissioners and providers to identify what isn’t advocacy and support this need in other ways e.g. social prescribing, community navigator, mental health support.

2. Commissioners and providers to work to raise the awareness of advocacy and advocacy services through better promotion:

a. Promote awareness of the advocacy services in Brighton & Hove with a clear description of the offer available to: service users; those referring into services; service providers and other Council services (for example by updating the BHCC advocacy webpage, inclusion in the MyLife website)

b. Develop and maintain an accessible directory of advocacy services available in Brighton & Hove

c. Consider the development of ‘Advocacy Champions’ within teams who refer people for advocacy

3. Ensure that an effective and integrated advocacy service is offered in Brighton & Hove that is tailored to the specific needs of the city

a. Commission an integrated service across the city with a single point of referral reflecting the potentially multiple needs of the user. Ensure that all providers work in partnership, for example by sharing training, information and experiences

b. Commission a responsive service, features of which would include: a common point of access with referrals being responded to within an agreed period; a duty system able to pick up calls/e-mails and respond within an agreed time threshold; referrals allocated across services to aid workflows and reduce waiting times

c. Agree a care pathway with commissioners, providers and referrers that specifies levels of service and expected timescales

d. Consider co-location of advocates with referrers where appropriate

e. Commissioners and providers to ensure that people with interpreting needs (including British Sign Language) are able to access all advocacy services, and that demand in this group is monitored

f. Commission advocacy services with reference to the Social Care Institute for Health (SCIE) Care Act 2014: commissioning independent advocacy self – assessment tool. Consider co-commissioning and/or co-production of services with providers and community members where appropriate
4. Ensure that advocacy services in Brighton & Hove can meet current and future demand

a. Consider commissioning different types of advocacy e.g. could consider commissioning group advocacy or self-advocacy training courses, which anyone irrespective of their defined need could access

b. Provide feedback from advocacy services to relevant departments, for example workload requirements to assist with housing and benefits issues that could potentially be avoided if these services were more accessible

c. Further engagement work to be undertaken with older people and BME communities to better understand their needs for advocacy

d. Consider the development of an Advocacy Commissioners Network to aid integration and sharing of best practice between those who commission advocacy services across the city.
2. INTRODUCTION

Advocacy is a term that is open to interpretation. In this needs assessment, the term advocacy is used to describe the support given to individuals to allow their voice to be heard and their wishes to be expressed in situations where they may be unable to do this fully by themselves. The definition of advocacy that we are using in this needs assessment is that used in the Advocacy Code of Practice\(^1\). The Code recognises that people are entitled to be in control of their own lives but sometimes, whether through disability, financial circumstances or social attitudes, they may find themselves in a position where their ability to exercise choice or represent their own interests is limited. In these circumstances, independent advocates can help ensure that an individual’s rights are upheld and that views, wishes and needs are heard, respected and acted upon.

Within the Brighton & Hove the majority of the provision of advocacy was commissioned using a Commissioning Prospectus in 2014 (see appendix 1) and the Independent Mental Capacity Advocacy (IMCA) service was commissioned by tender with East and West Sussex. Other services have developed in response to changes within the legislative framework or identified need, for example within the Trans Needs Assessment\(^2\). The Commissioning Prospectus was also informed by an Advocacy Mapping exercise undertaken by Brighton & Hove City Council in 2012 (see appendix 1), which identified gaps in advocacy services reported by stakeholders.

As such local advocacy provision supports statutory requirements as well as providing support to meet the needs of adults requiring advocacy within particular identified communities: those who are trans; older people; those with learning disability; physical disability and those who have language needs. It is acknowledged that advocacy needs often presents in a cross-cutting manner across communities and needs, for example older people with mental health problems, who may also require support for their physical health.

2.1 Purpose and Scope of the needs assessment

The needs assessment will attempt to define populations who need advocacy and the type of advocacy support they need. Current and potential future demand for statutory and non-statutory advocacy will be explored and the results will aid commissioners in meeting their statutory duties. A needs assessment is part of the commissioning cycle, providing evidence against which to review current service provision, identify current gaps and estimate future need for services. The needs assessment will make recommendations for commissioners, service providers and


decision makers to use to inform service design and commissioning decisions for advocate services in Brighton and Hove.

The Social Care Institute for Excellence\(^3\) recommends that those commissioning for independent advocacy undertake the following tasks:

- Collect and analyse information to understand current and future demand for advocacy under the Care Act.
- Work closely with colleagues (researchers, public health, project leads, etc.) to gather information about the likely demand for independent advocacy under the new duties. (This could include data on population projections such as your local joint strategic needs assessment or national databases such as POPPI and PANSI).
- Review current advocacy provision and uptake, considering:
  - who currently uses advocacy services
  - what local people understand about advocacy services and the potential benefits
  - the barriers people currently experience in accessing care, which may best be addressed through improved access to advocacy
  - the types of advocacy services people want and need
  - how people currently access services
  - how they might choose to access services in the future
  - what people consider to be a good local advocacy service which meets their needs

In view of these recommendations, the aims of this needs assessment, as agreed by the steering group, are therefore to:

- Review the existing model of advocacy support through comparison with research and examples of good practice identified through the use of a literature search and as advised by members of the project steering group.
- Compare uptake of existing services against the profile of these communities within the city’s population to establish any gaps between service delivery and current and prospective needs.
- Evaluate the current service provision through consultation with: current providers of services; users of current services; communities who may be in need of advocacy support and those who refer into existing provision.

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Advocacy services in Brighton & Hove are provided by a wide variety of organisations across the city and are funded by multiple agencies. The scope of this needs assessment are the communities currently being provided for under the aegis of the existing contracts with Brighton and Hove City Council (BHCC) and Brighton and Hove NHS CCG based on the 2014 Commissioning Prospectus (appendix 1). As such it is recognised that the scope of the needs assessment is limited. It is recognised that the need for advocacy will exist in communities not included within the scope of this needs assessment.

It is recognised that young people are an important group in terms of need and use of advocacy services, however they are not included within the scope of this needs assessment.

2.2 Methodology

The needs assessment was conducted as part of the programme of Joint Strategic Needs Assessments overseen by the City Needs Assessment Steering Group who are accountable to the Brighton & Hove Health and Wellbeing Board.

2.2.1 Steering Group

A steering group was established to oversee the planning and production of the needs assessment. Group members were drawn from the following:

- Brighton & Hove City Council, including representatives from: Adult Social Care (including commissioners and a member of the Carer’s Team with

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experience of working as an Independent Advocate); Public Health; Communities, Equality and Third Sector Team
- Brighton and Hove Clinical Commissioning Group
- Community Works (representing the voluntary sector and providers)

Terms of reference for the Steering Group are provided in appendix 2.

2.2.2 Definition of advocacy

The definition of Advocacy that we have used in this needs assessment is that used in the Advocacy Code of Practice:

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

2.2.3 Data Collection and Analysis

The methodology was based on the standard methods agreed for the local Joint Strategic Needs Assessment process, gathering and synthesising evidence from National literature, quantitative data (demography and services), and public and stakeholder voice (see figure 1). The research questions (interviews and surveys) were agreed by the steering group. The key methods of data collection were:

<table>
<thead>
<tr>
<th>Literature review</th>
<th>Conducted by Public Health supported by Brighton &amp; Sussex University Hospitals (BSUH) Library, 2017.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community research</td>
<td>Conducted by Dr Andrea Jones, of Good Health Projects Ltd. 2017. The specific methods used were: a) semi-structured interviews with individuals, b) focus groups with individuals brought together by specialist providers, and c) a one-step deliberative engagement event with users and provider’s representatives. A total of 29 individuals who had used advocacy, or may need advocacy, participated.</td>
</tr>
<tr>
<td>Stakeholder focus groups and surveys</td>
<td>Conducted by Liz Tucker, Public Health 2017. Stakeholders included both those referring into advocacy services and those providing the service. 34 referrers into advocacy services took part in a focus group and 29 completed the survey. 44 providers of advocacy services took part in a focus group and 17 completed the survey.</td>
</tr>
</tbody>
</table>
2.3 Production of final report, including recommendations

The final report was produced by Liz Tucker and Rachael Hornigold in 2017. Data from the different sources were compiled and triangulated where possible. Steering group members were engaged with this process and commented on draft versions. Steering group meetings were held in June and July 2017 to produce draft recommendations. The final report was agreed in August 2017. The report recommendations were developed and agreed by the steering group on the basis of the evidence within the needs assessment.

2.4 Strengths and Limitations

Conducting a needs assessment of advocacy in Brighton & Hove was a challenging process, due not least to the ambiguity around the term itself. It is impossible to accurately predict who may require advocacy services, as it is possible that any resident of Brighton & Hove may require advocacy given a certain situation.

In view of these difficulties, an attempt was made to ascertain need for advocacy within those groups who have currently commissioned services. This means that a limitation of this report is that there may be an unmet need for advocacy that is not identified. However it should be noted the current services have been commissioned in response to need (from the stakeholder advocacy service mapping exercise of
2012 or other needs assessments) or statutory requirements, and therefore it is less likely that there are significant areas of unmet need in the city.

The approach used within this needs assessment is a combination of a corporate and epidemiological approach. A corporate approach to needs assessment uses mainly qualitative information to understand the views of stakeholders about current needs and priorities for future provision. An epidemiological approach studies and analyses the patterns, causes and effects of health needs within defined populations. In this needs assessment we attempt to define populations who may require advocacy services but as there is no consensus as to who may or may not require advocacy, these may not truly reflect the actual levels of need.

Unlike other areas of service provision commissioned in the City there are no national guidelines, standards or models of care for how advocacy should be commissioned and provided. Service providers are expected to have met or be working towards delivery of services in accordance with the standards detailed in the Advocacy Quality Performance Mark.

A comparative needs assessment identifies need by comparing the services received by one group of individuals with those received by another comparable group. However there is a sparsity of data available from other areas with regard to their advocacy provision, service and strategy so it was not possible to conduct a comparative needs assessment. It is likely the Brighton & Hove population has a higher need for advocacy than in other areas due to the higher than average prevalence of mental ill-health, but this may be balanced by the younger than average population.

The stakeholder engagement within this needs assessment was thorough and wide-reaching, with a good uptake of involvement from those referring into and providing advocacy services. It was therefore possible to produce a comprehensive view of the need for advocacy services within scope. However as already mentioned there is ambiguity around the meaning of the term advocacy. Many of those working in a paid or voluntary capacity will consider the provision of advocacy as an adjunct to their other professional responsibilities. Professional advocates may disagree with the application of the term advocacy in this context. Similarly, some examples of advocacy that have been identified as part of this needs assessment include roles that may be considered as going beyond expectations of what we may consider to be advocacy. It is recognised that advocacy is provided to the local community outside of the scope of this needs assessment, for example on an informal basis or for a particular need, such as the Independent Sexual Violence Advocate. Where it is considered relevant this type of support will be referenced, but it is not within the scope of this review.

The community research was also conducted thoroughly and systematically. There were two limitations to the sample in relation to the community research specification: no participants over 65 years were recruited and there underrepresentation from those in Black and Minority Ethnic groups. No participants were engaged via the local Age UK advocacy service. Once the low response rate by individuals within these categories was apparent, alternative routes to securing participation were sought, but no older recruits were secured through any of the
providers listed and all BME participants were recruited through Sussex Interpreting Service (SIS) Bilingual Advocacy service and Impetus advocacy services. Therefore, it remains unclear whether advocacy, as a concept and as a set of services within the city, is well-known enough amongst, or actively referred to by, local community organisations representing older people (aged 65+) or people from BME groups.

2.5 Outline of the Report

In view of the complex nature of advocacy, Section 3 describes definitions of the term, models of advocacy, the evolution of advocacy services in England and locally and the statutory requirements. Section 4 summarises the evidence for best practice in advocacy services. Section 5 provides a data snapshot of current demand for advocacy provision in the city and estimates of future need. Section 6 details the results of the Community Research and Section 7 the stakeholder findings. Section 8 synthesises and summarises the findings, leading on to the recommendations from this needs assessment.

2.6 Summary of Section

This needs assessment uses an epidemiological and corporate approach to identify the need for advocacy in Brighton & Hove. It has utilised a literature review; a review of data and both community and stakeholder engagement to inform the report.

The definition of Advocacy that we have used in this needs assessment is that used in the Advocacy Code of Practice²:

Advocacy services in Brighton & Hove are provided by a wide variety of organisations across the city and are funded by multiple agencies. The scope of this needs assessment are the communities currently being provided for under the aegis of the existing contract with Brighton and Hove City Council (BHCC) based on the 2014 Commissioning Prospectus.

Strengths of the report include a comprehensive period of independent community engagement and a thorough and wide-reaching stakeholder engagement, with a good uptake of involvement from those referring into and providing advocacy services. It was therefore possible to produce a comprehensive view of the need for advocacy services within scope. However there is ambiguity around the meaning of the term advocacy.
3. WHAT DOES ADVOCACY MEAN?

3.1 Definition of Advocacy

The definition of advocacy that we have used in this needs assessment is that used in the Advocacy Code of Practice:

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

It is also important to acknowledge what advocacy is not:

It is not:
- making decisions for someone.
- mediation.
- counselling.
- befriending.
- care and support work.
- consultation.
- telling or advising someone what you think they should do.
- solving all someone’s problems for them.
- speaking for people when they are able to express a view.
- filling all the gaps in someone’s life.
- acting in a way which benefits other people more than the person you are advocating for.
- agreeing with everything a person says and doing anything a person asks you to do.

It is also important to distinguish the advocacy defined in this needs assessment from lobbying. Lobbying is action that speaks in favour of, recommends, argues for a cause, supports or defends, or pleads on behalf of others or community groups. This form of advocacy is not in scope of this needs assessment, but it must be noted that providers of advocacy services may also undertake lobbying for the groups and communities they support.

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3.2 Delivering advocacy

Advocacy is a broad concept and covers a range of different expertise. Individuals are able to advocate for themselves, family and friends can advocate on behalf of another person, health and social care professionals can sometimes advocate informally on behalf of their client and professional advocates are able to provide expert support when needed. Advocacy can also take the form of both individual support and in the form of a group. Access to advocacy can be affected by how health and social care professionals assess the advocacy needs of their clients and referral processes into services and these have been included within the scope of this needs assessment.

Advocacy as described in this needs assessment can be delivered in many forms. Broadly advocacy can be delivered as:

- **Self-advocacy** - when someone speaks up or takes action by themselves or are helped to do this.
- **Informal advocacy** - when someone else such as a family member, friend or carer is a person’s advocate.
- **Peer advocacy** - when someone who has a similar disability, illness or experience is the person’s advocate.
- **Professional advocacy** - when someone’s advocate is a paid, independent person. This is often when an important change is happening, a decision is needed, or to help with a specific issue.
- **Independent advocacy** - when someone’s advocate is a person who is not connected with the organisations providing their care, support or treatment.
- **Group advocacy** - when someone asks a group of people or an organisation to speak up or take action for them. A similar model may also operate when aiding a family unit.

Key features of effective advocacy include: independence from services; empowerment; providing people who access support with a voice; supporting people who access support to achieve active citizenship, challenging inequality, promoting social justice, and supporting people who access support to challenge inequity and unfairness.\(^6\)

3.3 The evolution of advocacy services in England

Advocacy has a well-established history within mental health services and is referenced in both the Mental Capacity Act of 2005 which introduced the statutory

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role of the Independent Mental Capacity Advocate (IMCA) and the Mental Health Act of 2007 which introduced the role of the Independent Mental Health Advocate (IMHA). New vigour was added to the need for advocacy provision within social care environments after the findings of the Winterbourne View Enquiry that helped instigate the 2014 Care Act.

Following the Winterbourne View enquiry there was recognition that appropriate advocacy support for the patients could have inhibited the development of the abusive culture that existed at Winterbourne View. The Department of Health report ‘Transforming Care: A national response to Winterbourne View Hospital’ states that: “families and other visitors were not allowed access to the wards or individual patients’ bedrooms. This meant there was very little opportunity for outsiders to observe daily living in the hospital and enabled a closed and punitive culture to develop on the top floor of the hospital. Patients had limited access to advocacy and complaints were not dealt with”.

3.4 Statutory requirements for advocacy in England

Certain forms of advocacy operate within a statutory framework guided by legislation drawn from the Mental Capacity Act, the Mental Health Act and the Care Act.

**Mental Health – Independent Mental Health Advocate (IMHA)**

From April 2009, statutory access to an Independent Mental Health Advocate (IMHA) has been available to patients subject to certain aspects of the Mental Health Act 1983. This right applies to people subject to compulsory treatment or supervisory community treatment; informal or voluntary patients; and people considering life-saving treatment. Placing independent advocacy on a statutory footing was intended to empower and protect individuals and to support patients to understand and exercise their legal rights.

People who are eligible to use IMHA services in England are:

- people detained under the Mental Health Act 1983 amended in 2007 (even if on leave of absence from the hospital), but excluding people who are detained under certain short term sections (4, 5, 135, and 136)
- conditionally discharged restricted patients
- people subject to guardianship
- people subject to supervised community treatment orders (CTOs).

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7 Winterbourne View – A Time for Change, Transforming the commissioning of services for people with learning disabilities and/or autism, A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014
8 Winterbourne View Hospital: Department of Health review and response Department of Health Part of: Compassionate Published: 10 December 2012
9 Social Care Institute for Excellence. [http://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/](http://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/)
Other patients, who are informal (voluntary) attenders, are eligible for IMHA services if they are being considered for section 57 or section 58A treatment (i.e. treatments requiring consent and a second opinion). This includes people under the age of 18 who are being considered for electroconvulsive therapy (ECT).

**Mental Health – Independent Mental Capacity Advocate (IMCA)**

The Mental Capacity Act allows, among other provisions, the restriction of freedom of individuals who do not have capacity to agree to decisions regarding their freedom, finances, and choices about health assessments, treatment and visitors. The 2007 Mental Health Act made changes to The Mental Capacity Act, 2005 including the introduction of Deprivation of Liberty Safeguards (DoLS) from 2009. DoLS are used to restrict liberty of individuals who are not detained in hospital under the Mental Health Act (those people either not subject to the Mental Health Act, or those on a Community Treatment Order (CTO) or Guardianship order), such as people who need to be deprived of their liberty in a care home. IMCA provision is a separate statutory duty placed on local authorities to provide non-instructed advocacy for people who lack capacity to make certain decisions and who have no one able to support and represent them. An independent mental capacity advocate (IMCA) ensures that people who lack capacity have their views represented when potential life changing health and social care decisions are made. The best interests of the person are paramount when an IMCA is acting and making decisions, along with professionals involved in the care and treatment of the person.¹⁰

A Supreme Court ruling in March 2014 (P v Cheshire West) created a sharp rise in Deprivation of Liberty cases across the country. The Court ruled all people who lack the capacity to make decisions about their care and residence; are under the responsibility of the state; are subject to continuous supervision and control and lack the option to leave their care setting are deprived of their liberty and as a consequence need scrutiny and authorisation by the local authority and in some cases the courts. It threw out previous judgements that had defined deprivation of liberty more restrictively. The person’s compliance or lack of objection to their placement, the purpose of it or the extent to which it enables them to live a relatively normal life for someone with their level of disability were all irrelevant to whether they were deprived of their liberty, ruled the court. This has seen a significant sudden and sustained increase in DoLS case numbers regarding care home/hospital placements.

In Brighton & Hove the annual number of DoLS cases increased from 37 in 2013/14 to 2,085 in 2016/17. The Law Commission has been approached by the Department of Health to suggest a workable alternative: liberty protect guards. But the new model would give greater weight to the wishes and feelings of the person who lacks capacity, and as such would be unlikely to affect the continued demand

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¹⁰ Royal College of Psychiatrists, Independent Advocacy for People with a Mental Health Disorder, 2012.
for advocacy services for this client group. Draft legislation covering deprivation of liberty was proposed in March 2017 by the Law Commission. However there is no proposed timetable for this.

Independent advocacy under the Care Act 2014

The role of advocacy was further developed under the aegis of the 2014 Care Act. Under this provision advocacy duty applies from the point of first contact with the local authority and at any subsequent stage of the assessment, planning, care review, safeguarding enquiry or safeguarding adult review. If it appears to the authority that a person has care and support needs, then a judgement must be made as to whether that person has substantial difficulty in being involved and if there is not an appropriate individual to support them. An independent advocate must be appointed to support and represent the person for the purpose of assisting their involvement if these two conditions are met and if the individual is required to take part in one or more of the following processes described in the Care Act:

- a needs assessment
- a carer’s assessment
- the preparation of a care and support or support plan
- a review of a care and support or support plan
- a child’s needs assessment
- a child’s carer assessment
- a young carer assessment
- a safeguarding enquiry
- a safeguarding adult review
- an appeal against a local authority decision under Part 1 of the Care Act (subject to further consultation)\(^{11}\).

The need for advocacy has also been affected by other changes in the health and social care system including Care and Treatment Reviews Care (CTR). These reviews were developed as part of NHS England’s commitment to transforming the services for people with learning disabilities and/or autism who display behaviour that challenges, including those with a mental health condition\(^{12}\).

\(^{11}\) Social Care Institute for Excellence, Independent advocacy under the Care Act 2014, Published: October 2014, Updated: March 2015, accessed online 4\(^{th}\) July 2017

\(^{12}\) NHS England, Care and Treatment Reviews (CTRs): Policy and Guidance, Including policy and guidance on Care, Education and Treatment Reviews (CETRs) for children and young people, March 201
3.5 Current provision of advocacy services in Brighton & Hove

In Brighton & Hove advocacy services have emerged in response to legislative changes and identified need within the local community. Within the City the IMCA service was commissioned jointly with East and West Sussex in 2006. The IMHA, Community Mental Health and Specialist Advocacy were commissioned using a Commissioning Prospectus in 2014. Other services developed in response to changes within the legislative framework or identified need. For example the Trans Needs Assessment recommended that CCG and social care commissioners consider how advocacy to support trans people to access health and social care services can be provided. 

The scope of this needs assessment has been set by the current legislative framework within which Advocacy Services are delivered and the communities currently supported under the aegis of existing commissioning. Advocacy is currently delivered by the statutory provisions (IMHA, IMCA and Care Act) and also as a community service, delivered by specialist providers, as detailed in table 1 below:

Table 1 Current advocacy provision in Brighton & Hove in scope of this needs assessment

<table>
<thead>
<tr>
<th>Group provided for</th>
<th>Type of advocacy</th>
<th>Provider</th>
<th>Stakeholder and Community Engagement in Needs Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>People identified under the Care Act 2014</td>
<td>Statutory</td>
<td>Multiple</td>
<td>Yes</td>
</tr>
<tr>
<td>Mental Health needs</td>
<td>Statutory</td>
<td>Mind in Brighton and Hove (MiBH)</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>(Independent Mental Health Advocacy)</td>
<td>POhWER</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Statutory</td>
<td>Mind in Brighton and Hove (MiBH)</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>(Independent Mental Capacity Advocate)</td>
<td>Mindout</td>
<td>Yes</td>
</tr>
<tr>
<td>Community</td>
<td>Community</td>
<td>Age UK</td>
<td>Yes (stakeholder)</td>
</tr>
<tr>
<td>Learning Disability and</td>
<td>Community</td>
<td>B&amp;H Impetus</td>
<td>Yes</td>
</tr>
<tr>
<td>Category</td>
<td>Community</td>
<td>Organization</td>
<td>Yes/No</td>
</tr>
<tr>
<td>--------------------------------------------------------------</td>
<td>------------</td>
<td>---------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Learning Disability and/or Autism</td>
<td>Community</td>
<td>B&amp;H Speak Out</td>
<td>Yes</td>
</tr>
<tr>
<td>Physical and Sensory Impairment</td>
<td>Community</td>
<td>Possability People</td>
<td>Yes</td>
</tr>
<tr>
<td>Language needs (Bilingual advocacy)</td>
<td>Community</td>
<td>Sussex Interpreting Services</td>
<td>Yes</td>
</tr>
<tr>
<td>Trans advocacy</td>
<td>Community</td>
<td>MindOut</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Other advocacy services that operate within the city but are not included within the scope of the needs assessment include:

- Independent Health Complaints Advocacy (IHCA) – provided by Sussex Community Voice
- Youth Advocacy Project (YAP) – run by Sussex Central YMCA
- Independent Sexual Violence Advocates (ISVA) – provided by Survivors Network.
- The Advocacy Support provided by the Substance Misuse Service User representative, Mind in Brighton & Hove (MiBH).
- Macmillan Cancer Care Advocacy services: one-to-one advocacy for people living with cancer
- Oasis: key workers provided one-to-one advocacy, facilitated peer support groups & provided training courses
- Brighton Housing Trust: housing officers and key workers were mentioned as providing advocacy at times; BHT’s Fulfilling Lives project supports self-advocacy
- Pavilions drug and alcohol rehabilitation: support workers were mentioned as providing advocacy in relation to a range of needs, including benefits systems and housing
- Alcoholics and cocaine anonymous: users of these considered them to provide forms of advocacy at times of need, but the terms used are ‘mentoring’ or ‘sponsoring’
- Assert, for people with autism: provide some forms of advocacy
- Recovery College for people dealing with mental health issues: run a one day workshop called ‘Navigating Local Health Services’ and longer courses supporting ‘self-advocacy’

This is not a comprehensive list. Other advocacy provision also exists within the city.
3.6 Summary of Section 3

Advocacy is a broad concept and covers a range of different expertise. Individuals are able to advocate for themselves, family and friends can advocate on behalf of another person, health and social care professionals can sometimes advocate informally on behalf of their client and professional advocates are able to provide expert support when needed. Access to advocacy can be affected by how health and social care professionals assess the advocacy needs of their clients and referral processes into services and these have been included within the scope of this needs assessment.

Certain forms of advocacy operate within a statutory framework guided by legislation drawn from the Mental Capacity Act, the Mental Health Act and the Care Act.

Within the city advocacy is currently delivered by statutory provisions (IMHA, IMCA and Care Act) and also as a community service, delivered by specialist providers. Specialist community services commissioned at the time of writing include provision of advocacy for those with: mental ill-health (including specialist LGBTQ mental health service); sensory and/or physical disabilities; learning disabilities; language needs; those who are older people; vulnerable adults with autism and people who are trans.
4. EVIDENCE OF GOOD PRACTICE

A literature search was conducted by the Public Health Librarian using the following research title: Evidence for models of delivery of independent advocacy and evaluations of service. Details of the search criteria and databases are included in appendix 3.

There is a limited evidence base as to the effectiveness of specific models of advocacy and little guidance as to how implement an advocacy service. This is likely due to the lack of consensus as to what advocacy is – it means different things to different people. However, we have summarised the available evidence below.

4.1 Summary of findings regarding advocacy provision

Evidence from the research literature on advocacy identifies that support can come in many forms and that delivery is shaped by the type of advocacy needed. The sector is diverse and there is no ‘best’ form of delivery. All forms of advocacy should encourage self-advocacy. Evidence exists that access to advocacy by particular groups can be problematic and the use of opt-out rather than opt-in access was suggested as a way of addressing this.

The Institute for Research and Innovation in Social Services undertook an evidence review on advocacy: models and effectiveness in 2013. They concluded that:

- There is a range of models of advocacy, each with distinctive characteristics relating to type of work undertaken, length of involvement and appropriate person who should undertake the role.
- There is a limited evidence base about the effectiveness of advocacy. This is primarily due to differing definitions and a lack of understanding about the role of advocacy.
- There is some evidence to suggest that the advocacy process promotes increased self-confidence and ensures the voices of people who access services are heard.
- Advocates require a significant set of skills to undertake the role effectively; there is a need for ongoing training and regular supervision to maximise effectiveness.

The Royal College of Psychiatrists published guidance on Independent Advocacy for people with a mental health disorder in 2012. The Royal College acknowledges that:

- The advocacy sector is diverse and a variety of approaches to delivering advocacy exist but they all have a guiding set of common principles.

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14 Royal College of Psychiatrists (RCPsych), Independent advocacy for people with mental disorder. (2012)
• There is no ‘best’ form of advocacy: some advocacy organisations combine different approaches, and some approaches may be more common or suited to specific local need or groups of people.
• All forms of advocacy encourage and promote self-advocacy 6.

A review of the progress of IMHA in England, since its introduction in 200715, concluded that good quality IMHA services:
• Are easy to find and contact, and have the confidence and trust of the service user
• Enable the person to express their views and be active participants in their care and treatment under the Mental Health Act.
• Are commissioned in an informed way: investment needs to match local need and potential demand, and should be grounded in an understanding of the particular barriers that different groups face.
• Need to involve people with lived experience in their design and take account of the diverse populations that they serve. They should reach out to communities and factor their specific needs into the way in which the service is provided.
• Mental health services play a crucial role in providing an enabling context within which IMHA services are delivered. The attitudes of mental health professionals and their understanding of advocacy can make a difference to whether qualifying patients access the service.

In another study of IMHA services in England published in 201016, it was found that access to IMHA was highly variable and more problematic for people with specific needs relating to ethnicity, age and disability. Uptake of IMHA was influenced by available resources, attitude and understanding of mental health professionals, as well as the organisation of IMHA provision. It was suggested that access could be improved through a system of opt-out as opposed to opt-in. Service user satisfaction was most frequently reported in terms of positive experiences of the process of advocacy rather than tangible impacts on care and treatment under the Mental Health Act. They concluded that IMHA services have the potential to significantly shift the dynamic so that service users have more of a voice in their care and treatment. However, a shift is needed from a narrow conception of statutory advocacy as safeguarding rights to one emphasising self-determination and participation in decisions about care and treatment.

A number of interviews with advocacy providers in Scotland found that the key distinguishing feature of their role was thought to be their independence, and participants have noted lower than expected rates of referral (compared to national modelling) and variable experiences of communication with statutory services.

Awareness, understanding and acceptance of advocacy amongst the statutory services was felt to vary at both practice and strategic levels.\textsuperscript{17}

In addition to providing information regarding advocacy provision, the literature search also identified a range of resources that can support the commissioning of good quality service for particular communities, and these include:

- **Care Act advocacy**: Commissioning independent advocacy guide: a guide for local authority staff responsible for commissioning advocacy services under the Care Act (2014, updated 2016).\textsuperscript{18}
- **For older people**: Someone to stand up for me: A toolkit to promote advocacy for older people in the independent care home sector (2012).\textsuperscript{19}

There are additionally resources available to support evaluation of advocacy services. These include:

- The Advocacy Charter and Code of Practice and the Advocacy Quality Performance Mark – a quality standard for providers of independent across the UK, which involves independent external assessment of the quality of service.\textsuperscript{20}
- The Scottish Independent Advocates Alliance has produced an evaluation framework for self-assessment and independent external review of advocacy services.\textsuperscript{21}

### 4.2 Evidence of innovation in commissioning and service delivery

Key themes that emerge from the review of innovative services include the integration and co-ordination of services and aligned to this, the use of partnership working and the flexibility of provision.

Examples of innovation in the commissioning and delivery of models of advocacy services were reviewed. The principal source of this information was the Social Care Institute of Excellence. A summary of the key findings from this source are summarised below with a more comprehensive summary of individual service included in appendix 4. Some of common characteristics that feature in the examples of innovative delivery have been grouped under thematic sub-headings in table 2 below.

\textsuperscript{19} Someone to stand up or me. A toolkit to promote advocacy for older people in the independent care home sector. Patient and Client Council. HSCNI. http://www.patientclientcouncil.hscni.net/uploads/research/Patient_and_Client_Council_-_AdvocacyToolkit.pdf
\textsuperscript{20} Advocacy Quality Performance Mark. (http://www.qualityadvocacy.org.uk/)
The Institute outlines six key steps to strengthen the commissioning of advocacy (specifically under the Care Act). These include:

- Understanding what advocacy is and the need for independence
- Embedding co-production in commissioning
- Responding to local needs and diversity
- Supporting access to advocacy
- Strategic and quality approach to commissioning
- Meaningful and proportionate monitoring to measure outcomes

**Table 2. Thematic grouping of innovative practices in service delivery, from the Social Care Institute of Evidence**

<table>
<thead>
<tr>
<th>Integration and co-ordination</th>
<th>Sub-contracting of services but with a single point of contact, which triages and prioritises. Developing a prioritisation matrix in collaboration with stakeholders, with 'eligibility' to aid waiting list management. The value of a single point of contact to reduce transaction costs, reduce delays and provide a consistent service is referenced across many providers. Improving integration between health and social care provision. Effective network of providers, working collaboratively, not in competition and sharing good practice and making decisions collectively. Acknowledging that the local authority is not the expert. Having a lead partner with who is able to direct referrals to the right provider. The use of a single provider to provide seamless and cost-effective advocacy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partnership Working</td>
<td>Role of co-commissioning with service users. Consider how smaller organisations can contribute to the model. Collaboration with other local authorities can be difficult but could be considered.</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Expanding the definition of what Advocacy is to acknowledge the role of citizen, volunteer and peer advocacy and recognising the value of this model especially in expanding capacity. Having a commissioning model that enables services to move funds, in consultation with the commissioner, between services depending on demand. The importance of having a pool of people willing to train as advocates. Use of web-technology to accept referrals and a single database to manage referrals.</td>
</tr>
<tr>
<td>Local Service Delivery</td>
<td>Innovative and flexible provision of advocacy services also exist locally and include: drop-in groups, provision of online advocacy services, embedded provision within other services</td>
</tr>
</tbody>
</table>
4.3 Summary of Section 4

Evidence from the research literature about advocacy identifies that support can come in many forms and that delivery is shaped by the type of advocacy needed. The sector is diverse and there is no ‘best’ form of delivery. All forms of advocacy should encourage self-advocacy. Evidence exists that access to advocacy by particular groups can be problematic and the use of opt-out rather than opt-in access was suggested as a way of addressing this. Key themes that emerge from the review of innovative services include the integration and co-ordination of services and aligned to this the use of partnership working and the flexibility of provision.
5. USING DATA TO DESCRIBE ADVOCACY NEEDS IN BRIGHTON & HOVE

A variety of data sources have been used in order to estimate the current and future need for advocacy services. These include: data from the Joint Strategic Needs Assessment (JSNA) for Brighton & Hove (which in turn uses some of the following national data sources); Health and Social Care Information Centre (HSCIC, now NHS Digital) Community Care Statistics, Social Services Activity; Projecting Older People Population Information (POPPI) and Projecting Adult Needs and Service Information (PANSI) data. POPPI and PANSI data projections are produced by Oxford Brookes University and are specific to the local area. As with the data presented from the JSNA, only a proportion of those presenting within the communities detailed here will need receipt of advocacy support.

A nationally developed model of need for local Care Act advocacy has been utilised and the size of current populations supported through advocacy provision (demand) have also been included, whilst acknowledging that this is a proxy for need.

We have attempted to estimate the current and future need for advocacy services in the following groups:

Those requiring advocacy:
- with mental health needs
- who are elderly
- who are vulnerable adults (autism)
- with learning disability
- with physical and/or sensory impairment
- with language needs (Bilingual advocacy)
- who are trans
- particular needs under the Care Act

5.1 Need for advocacy for those with mental health needs

JSNA: an estimated 39,798 people aged 18-74 years in Brighton and Hove have common mental health disorders (17%). Local prevalence continues to be generally higher than England.22

Rates of hospital admissions across a range of mental health diagnoses are higher and in some cases significantly higher in Brighton & Hove than those for England, indicating the higher volume of need in our local community around mental health.

22 Brighton & Hove JSNA. http://www.bhconnected.org.uk/content/needs-assessments
Detentions under the Mental Health Act in Brighton & Hove CCG area (2012/13) were 82.4 per 100,000 population aged over 18 years. This is higher than the England rate of 58.7 per 100,000.\textsuperscript{23}

**PANSI**: predicts that the number of people with mental health problems in Brighton & Hove will rise by 3.7% between 2017 and 2025. It is likely that the need for statutory mental health advocacy (IMHA and IMCA) and also specialist community advocacy will also rise at this rate.

Advocacy requirements in those with mental ill-health may be categorised as statutory or non-statutory. As discussed in Section 3, Independent Mental Health Advocates (IMHAs) support people who are being assessed or receiving treatment under the Mental Health Act 1983. Independent Mental Capacity Advocates (IMCAs) support people who lack capacity to make certain decisions and are provided under the Mental Capacity Act 2005.

**Statutory Mental Health Advocacy needs and demand**

The Mental Capacity Act Deprivation of Liberty Safeguards (DoLS) provide protection for vulnerable people who are accommodated in hospitals or care homes in circumstances that amount to a deprivation of their liberty and who lack the capacity to consent to the care or treatment they need. Since the Supreme Court judgement (see Section 3) pressure on Deprivation of Liberty Safeguards (DoLS) work has increased dramatically and there has been an unprecedented volume of DoLS applications in Brighton & Hove:

### Table 3. Number of DoLS applications in Brighton & Hove, 2013-2017. From Adult Social Care, BHCC

<table>
<thead>
<tr>
<th>Year</th>
<th>DoLS applications</th>
<th>Change (year on year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013-14</td>
<td>37</td>
<td>-</td>
</tr>
<tr>
<td>2014-15</td>
<td>693</td>
<td>+1773%</td>
</tr>
<tr>
<td>2015-16</td>
<td>1504</td>
<td>+117%</td>
</tr>
<tr>
<td>2016-17</td>
<td>2085</td>
<td>+39%</td>
</tr>
</tbody>
</table>

Using current demand for statutory mental health advocacy (IMHA and IMCA) as a proxy for need:

<table>
<thead>
<tr>
<th>Type of advocacy</th>
<th>Number of cases 2015/16</th>
<th>Number of cases 2016/17</th>
<th>Year on year change</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMHA</td>
<td>320</td>
<td>411</td>
<td>+28%</td>
</tr>
<tr>
<td>IMCA</td>
<td>529</td>
<td>555</td>
<td>+4%</td>
</tr>
</tbody>
</table>

\textsuperscript{23} Brighton and Hove CCG Severe Mental Illness Profile 2017. [http://fingertipsreports.phe.org.uk/severe-mental-illness/e38000021.pdf](http://fingertipsreports.phe.org.uk/severe-mental-illness/e38000021.pdf)
It can be seen that the demand for both IMHA and IMCA has increased between 2015/16 and 2016/17. This is likely to be due to increased utilisation of services to meet the pre-existing need, rather than reflecting changes in need alone and may reflect a reduction in barriers to accessing these advocacy services and greater awareness in referring staff. The rise in IMCA reflects the increase in DoLS applications, following the Cheshire West court ruling (see section 3 for further details).

**Demand for non-statutory mental health advocacy**

Specialist community mental health advocacy is provided by Mind in Brighton & Hove (MiBH), with an LGBTQ mental health service offered by MindOut. MiBH also provide a community mental health advocacy service.

Non-statutory mental health advocacy can be accessed via professional or self-referral and is available to:

- Adults with mental health issues
- Adults with an undiagnosed mental health condition having difficulties accessing mental health services
- Adults living in the communities of Brighton or Hove
- Adults in a mental health unit but not detained under the mental health act (informal patients)

A total of 89 people received specialist community advocacy support from MiBH in 2016/17 (new cases): 73 under the specialist community mental health service, and 16 via the Care Act. This compares to a total of 111 in 2015/16, 88 via the specialist community service and 23 via the Care Act. A total of 397 people received community mental health advocacy from MiBH in 2016/17.

**Need for advocacy for LGB people with mental health needs**

**JSNA:** There is no definitive research into the number of lesbian, gay, bisexual (LGB) people who live in the city and the recent 2011 Census did not include a question on sexual orientation. The best estimate of the number of lesbian, gay and bisexual residents is 11% to 15% of the population aged 16 years or more. This estimate draws on information collected via large scale surveys and audits conducted over the last ten years (including Count Me In Too). This is similar to two recent representative surveys conducted across Brighton & Hove (Health Counts
and City Tracker\textsuperscript{24}, where 11\% of respondents identified themselves as lesbian, gay, bisexual, unsure or other sexual orientation.

Lesbian, gay and bisexual (LGB) people are at higher risk than heterosexual people of bullying, abuse, discrimination and exclusion. LGB people are also at greater risk of mental disorder, substance misuse and dependence, self-harm and suicidal behaviour/ideation than heterosexual people. Socially isolated LGB people and those on a low income are more susceptible than others.

In view of the above factors, the need for mental health advocacy may well be higher in LGB people than the general population and is provided as a service distinct from the specialist community service provided by MiBH. However, people who are LGB may of course access any of the other specialist community services, for example 5 people (13\% of those who completed equality monitoring form) who are LGB used the MiBH specialist community mental health advocacy service in 2016/17.

**Demand for Mental Health advocacy for LGB people**

Specialist services are provided by MindOut. In 2016/17 they provided advocacy for 192 individuals in Brighton & Hove. MindOut do not provide Care Act advocacy so LGB people may have received Care Act advocacy under the Brighton & Hove Advocacy Partnership arrangements. Monitoring from the Partnership shows that of those services making a return, during 2016/17 an average of 11\% of those supported by Speakout were LGBT and 34\% of those supported by Possability People.

**5.2 Need for advocacy for older people**

Older people may require advocacy services if they are unable to have their voice or wishes heard. This is likely to be due to an additional factor, for example mental ill-health or a physical disability. They could therefore access any of the other statutory or non-statutory advocacy services in the City.

**JSNA:** Older people (over the age of 65 years) comprised over 13\% of all residents of Brighton & Hove in 2015. In the 2011 census there were 35,800 people aged 65 or over in the city; 20,100 females and 15,800 males, with the ratio of women to men increasing with age. In 2011 the city had a lower proportion of older people than the South East and England as a whole.

Brighton & Hove has a relatively large proportion of older people living alone and potentially isolated who are more dependent upon public services. Single pensioner households are higher than average (14,500 households comprise single people aged 65 or over) and the majority of people aged 75 or over live alone; of those living

\textsuperscript{24} Health Counts and City Tracker [http://www.bhconnected.org.uk/content/surveys](http://www.bhconnected.org.uk/content/surveys)
alone, 34% are male, 61% female. Approximately 14,500 (41%) people aged 65 years and over live alone in Brighton & Hove compared to 31% nationally.

**POPPI:** It is predicted that there will be a significant rise in the total population aged 65 years and over in Brighton & Hove between 2014 (this is the baseline date that POPPI uses) and 2025, with an increase of 17.2%. There is expected to be an even greater proportion of those elderly with additional health needs, as detailed in the table below:

<table>
<thead>
<tr>
<th>Table 4 POPPI data: Population predictions for Brighton &amp; Hove</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change</strong></td>
</tr>
<tr>
<td><strong>Total Population Aged 65 and over</strong></td>
</tr>
<tr>
<td>Total Population Aged 65 and over</td>
</tr>
<tr>
<td>Serious visual impairment</td>
</tr>
<tr>
<td>With dementia</td>
</tr>
<tr>
<td>With severe depression</td>
</tr>
<tr>
<td>Living in Care Home (with or without nursing )</td>
</tr>
<tr>
<td>Moderate or severe visual impairment</td>
</tr>
</tbody>
</table>

**Demand for advocacy for older people**

Age UK provide the specialist community advocacy service for older people. In 2016/17 they provided advocacy for 61 people. Care Act advocacy for older people is provided by Mind, the majority of older people referred for Care Act Independent Advocacy need support due to a mental health issue such as dementia. The referrals for advocacy for older people have not reached the targets anticipated with the exception of 2016/17 where there was a significant increase and 61 older people received advocacy with a target of 36. 17% of referrals (10 people) came from Care Coaches, however, and this service is no longer funded so the referrals may reduce again.

**5.3 Need for advocacy for adults with learning disabilities and/or autism**

**HSCIC:** In 2014/15 there were 725 people with a learning disability receiving long term support from Brighton & Hove City Council. Applying the estimated rates of adults with a learning disability who also have an Autistic Spectrum Condition to this figure gives an estimate of between 145 and 242 adults with a learning disability receiving long term support from the council who also have an Autistic Spectrum Condition. In 2014/15 825 people with learning disabilities were receiving long term support from Brighton & Hove City Council, of these, 725 were aged 18-64 (88%).
**PANSI**: Estimated that in 2014 there were 1941 adults with an Autistic Spectrum Disorder in Brighton & Hove, and it is estimated that this will rise by 7.8% to 2,093 in 2025. Based on national prevalence rates, there were an estimated 4,746 adults aged 18-64 years with a learning disability living in Brighton & Hove in 2015, with around 6% of those with a severe learning disability. Projection of numbers of people in the city with a learning disability predict that the numbers will increase from 4716 in 2015 to 4,991 in 2025, a rise of 5.8%.

**Demand for advocacy for people with learning disabilities and/or autism**

Adults with learning disabilities and/or autism receive advocacy support in the city from Brighton & Hove Impetus and Brighton & Hove Speak Out. In 2016/17 Impetus provided advocacy support to 26 people: 20 via the specialist community service, and 6 via Care Act referrals. In 2016/17 Speak Out provided advocacy services for 127 people, 105 via the specialist community service and 22 via the Care Act. This means that specialist and Care Act advocacy services were provided for approximately 2% of the population of adults with learning disabilities and/or autism in the city.

**5.4 Need for advocacy for people with physical and sensory impairment**

People with physical and/or sensory impairments may require the support of an advocate to allow their voice to be heard. Sensory impairments include people who have sight or hearing impairments or both.

**JSNA**: It is estimated that in Brighton & Hove in 2015 there were: 13,590 people aged 18-64 with a moderate physical disability and 3,777 people aged 18-64 with a serious physical disability.

It is estimated that in Brighton and Hove in 2015 there were: 125 people aged 18-64 with serious visual impairment and 3,383 aged 65 and over with a moderate or serious visual impairment; 6,086 people aged 18-64 with a moderate or severe hearing impairment and 50 people aged 18-64 with a profound hearing impairment (deaf); 16,069 people aged 65 or over with a moderate to severe hearing impairment and 462 aged 65 or over with a profound hearing impairment (deaf).

In 2014 there were 920 residents registered as blind (535 were aged 75 or over). Of these 365 had an additional disability, 200 with a physical disability, 110 deaf or hard of hearing, 25 with a learning disability and 25 with mental health problems.

**HSCIC**: Brighton & Hove City Council Adult Social Care provided long term support to 4,663 people in 2015/16 with a physical disability. 58% was physical support, which includes access and mobility support (4%) and personal care support (54%).
PANSI: the table below contains the modelling for the change in numbers of people in Brighton & Hove with physical or sensory disabilities. It demonstrates a large projected increase in those with physical disabilities and hearing impairment:

Table 5. PANSI estimates for Brighton & Hove 2014 – 2025

<table>
<thead>
<tr>
<th>People aged 18-64 years with a disability</th>
<th>2014</th>
<th>2025</th>
<th>Change (n)</th>
<th>Change %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate or Serious Physical Disability</td>
<td>3,737</td>
<td>4,303</td>
<td>566</td>
<td>15.1%</td>
</tr>
<tr>
<td>Moderate, severe or profound Hearing Impairment</td>
<td>22,346</td>
<td>26,789</td>
<td>4,443</td>
<td>19.9%</td>
</tr>
<tr>
<td>Serious visual impairment</td>
<td>124</td>
<td>131</td>
<td>7</td>
<td>5.6%</td>
</tr>
</tbody>
</table>

Demand for advocacy for people with physical and/or sensory disabilities

Specialist community services for people with physical and/or sensory disabilities are provided by Possability People. In 2016/17 they provided advocacy services for 214 people, 203 via the specialist community service and 11 via the Care Act.

As advocacy services are provided for deaf people, we would expect that there is the requirement for British Sign Language interpreters. However we do not have access to information pertaining to the number of deaf people who received advocacy support and how many were also supported by a BSL interpreter.
5.6 Need for advocacy for people with additional language needs

People may have a need for advocacy services which are made more complex by an additional need for language support. An example may be a person who requires advocacy due to their learning disability, but who also does not speak English. Clearly, not all of those individuals who have language needs will require advocacy services.

JSNA: At the time of the 2011 Census\textsuperscript{25} in Brighton & Hove:

- 11\% of households had at least one person for whom English was not their first language.
- There were almost 6,000 households in the city where no-one has English as a main language, and this percentage (4.9\%) is higher than both the South East and England (3.1\% and 4.4\%).
- The three most commonly spoken languages after English were Arabic, Polish and Spanish.

Demand for advocacy for people with language needs

Since December 2014 Brighton & Hove Clinical Commissioning Group and the Council have funded a Bilingual Advocacy Project for those with both advocacy and language needs. Bilingual advocates support vulnerable and isolated service users who also have a language need. The Bilingual Advocacy Project does not provide statutory advocacy services.

Statutory and specialist community advocacy for those with language needs

It could be expected that statutory (and in some cases non-statutory specialist community) advocacy for those with additional language needs would be provided by the statutory and community specialist advocacy providers, with the support of an interpreter. In the case of IMHA, interpreters are provided by the Mental Health Provider and are booked to attend advocacy appointments. Taking into account the fact that people may have multiple reasons for requiring advocacy, we reviewed activity under the Bilingual Advocacy Project that may have alternatively been provided for by community specialist advocacy providers. In 2016/17 13\% (10/77) of those receiving support were over the age of 65; 32\% (46/77) had a disability; 1\% were trans; 1\% were LGB.

It appears that only 2 interpreting sessions have been utilised by those providers within the Advocacy Partnership for specialist advocacy since the contract commenced in 2014\textsuperscript{26}: one for a user of the community older people service; and one for a user of the physical and sensory needs advocacy service. However this data has not been routinely collected to date and may therefore not be an accurate


\textsuperscript{26} Information provided by Advocacy Partnership 2017.
representation of the true picture of interpreting use. We do not have information on the numbers of interpreters used for IMHA and IMCA.

This may indicate a gap in service provision of more specialist community advocacy support (outside of the Bilingual Advocacy project), to users with an additional language need, including those who are hearing impaired and in need of interpreting support.
5.7 Need for advocacy for trans people

The Brighton & Hove Trans Needs Assessment 201527 reported that trans people are less likely to report that they are in good health and more likely to report that they have a limiting long-term illness or disability. The Trans Needs Assessment recommended better provision of support for trans people, especially in relation to mental health (eg. counselling, advocacy, peer mentoring, etc.) In view of the above recommendations, a specific trans advocacy service was commissioned.

JSNA: estimates are that there are at least 2,760 trans adults living Brighton & Hove. The true figure is probably greater than this because a significant proportion of trans people do not disclose their gender identity in surveys. It is likely that the number of trans people living in Brighton & Hove will rise as the city is seen as a trans-friendly and inclusive city which attracts people who have had negative experiences elsewhere.

Demand for advocacy for trans people

Trans advocacy services are provided by MindOut. In 2016/17 they provided advocacy for 177 people. MindOut do not provide Care Act advocacy so trans people may have received Care Act advocacy under the Brighton & Hove Advocacy Partnership arrangements.

Trans people will also access the other statutory and non-statutory specialist community advocacy services. Data from 2016/17 shows that trans people used the Older People’s service (1%); Community mental health advocacy (5%); Physical or sensory needs service (2%) and Bilingual Advocacy Project (1%).

5.8 Need for advocacy under the Care Act 2014

Under this provision advocacy duty applies from the point of first contact with the local authority and at any subsequent stage of the assessment, planning, care review, safeguarding enquiry or safeguarding adult review. If it appears to the authority that a person has care and support needs, then a judgement must be made as to whether that person has substantial difficulty in being involved and if there is not an appropriate individual to support them. An independent advocate must be appointed to support and represent the person for the purpose of assisting their involvement if these two conditions are met and if the individual is required to take part in one or more of the processes described in the Care Act (see section 3 for more details).

Care Act advocacy in Brighton & Hove is provided by a number of the specialist community services, based on the referrer’s perception of the main need of the

person involved (Mind, Impetus, Speak Out and Possability People provided Care Act advocacy in 2016/17). In 2016/17 a total of 59 people received advocacy via the Care Act in Brighton & Hove.

**Modelling requirements for Care Act Advocacy**

The use of advocacy services was expected to grow following the introduction of the 2014 Care Act. The need to estimate the potential increase in demand for services was recognised and a model was developed by the Department of Health for this purpose. The model was developed to look at the impact of the 2014 act in isolation from provision provided as part mental health or community requirements.

The model reviews demand for independent advocacy for: older people, physical disability, mental health, learning disability and other vulnerable groups for example asylum seekers. Different types of engagement are also included in the model: assessment, review at mid-point and safeguarding. The model incorporates incremental increases in demand to 2019-20 with an annual step-change increase in activity of 25% across all client groups between 2015-16 and 2019-20.

**Table 6 Modelled Estimate for Advocacy Services by Client Group and type of Support for Financial Years 2016-17 and 2019-20**

<table>
<thead>
<tr>
<th>Incremental increase in take up by client group Assessments/reviews/safeguarding</th>
<th>2015/16 (25%)</th>
<th>2016/17 (50%)</th>
<th>2017/18 (75%)</th>
<th>2019/20 (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of Older People</td>
<td>73</td>
<td>147</td>
<td>220</td>
<td>293</td>
</tr>
<tr>
<td>Total number of Physical disability</td>
<td>31</td>
<td>63</td>
<td>94</td>
<td>126</td>
</tr>
<tr>
<td>Total number of Mental Health Assessments (including Dementia)</td>
<td>62</td>
<td>124</td>
<td>186</td>
<td>248</td>
</tr>
<tr>
<td>Total number of Learning Disability</td>
<td>16</td>
<td>32</td>
<td>48</td>
<td>64</td>
</tr>
<tr>
<td>Other vulnerable people</td>
<td>10</td>
<td>20</td>
<td>30</td>
<td>40</td>
</tr>
<tr>
<td>Total number of Carers</td>
<td>44</td>
<td>87</td>
<td>131</td>
<td>174</td>
</tr>
<tr>
<td>Total number of Self Funders Assessment/Reviews</td>
<td>48</td>
<td>97</td>
<td>145</td>
<td>194</td>
</tr>
<tr>
<td>Total</td>
<td>285</td>
<td>570</td>
<td>855</td>
<td>1140</td>
</tr>
</tbody>
</table>

The largest group of users identified in this model are older people and individuals with mental ill-health (including dementia). Those groups detailed in the model are amongst those for whom specialist community advocacy is already provided in Brighton & Hove, with the exception of a specific service for carers.

The actual number of individuals supported via the Care Act in 2016/17 was 59, almost a tenth of the modelled number of 570. This finding is commensurate with
findings elsewhere in England. It may be due to: inaccuracies in the model; advocacy provision being provided through other routes rather than the Care Act (for example through specialist community advocacy or IMHA/IMCA); or barriers to people accessing Care Act advocacy.

**Using CareFirst to identify demand for Care Act advocacy**

CareFirst is the case management system for Brighton and Hove City Council’s Social Work teams (children and adults) including the hospital social work teams. Mental Health teams (for example Sussex Partnership Foundation Trust staff) make partial use of this case-note/monitoring system.

This resource only has use when considering support required under the 2014 Care Act. It is acknowledged by the CareFirst Data Administrators that there is a degree of under-reporting in respect of needs related to advocacy.

CareFirst provides information about the proportion of clients with difficulties in understanding and/or expressing their needs. Of all those accessing Adult Social Care during 2016-17 (3,955) 46% had support needs ranging from mild to being unable to express basic needs/understanding. Of the clients accessing support during 2016-17 a total of 8% required support from an independent advocate (301), whilst a further 373 clients had their advocacy needs supported by family or friends.

Comparing the data generated from CareFirst this found that during the 2016-17 period there were 301 clients in need of independent advocacy (including IMCA) as above. This is 85 fewer cases (22%) than estimated using the department of health model. Possible reasons for a lower than expected uptake of services are discussed in section 7 (referrer’s focus group).

**5.9 Specific areas of support provided by advocates**

Information with regard to the area or issue that the advocate was providing support was also provided by the providers for each of the specialist community services. This can be found in appendix 5. In summary, the areas of need for advocacy support were relatively consistent across the specialist services and were not limited to health and social care. In fact requirements around wider determinants: housing; benefits and finance and employment advice appeared in the top five areas of need for all services, often ahead of issues with health services and social care. Child protection/family court issues were the number one area for advocacy support in vulnerable adults with autism.

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28 Community Care, Care Act advocacy referrals ‘way below’ expected level Advocacy experts fear people are being left without support to challenge council decisions about their care By Andy McNicoll on November 18, 2015, accessed online 13th July 2017
5.10 Summary of current advocacy demand in Brighton and Hove

Existing performance activity provides a valuable insight into potential service demand going forward. The majority of beneficiaries had accessed support as part of IMCA support. It is likely that this activity is linked to the increase in advocacy support provided linked with DoLS assessments, which have experienced a jump in activity.

Figure 3 Advocacy Activity IMHA, IMCA, Care Act and Specialist Advocacy Activity 2016-17* does not include Bilingual Advocacy Servic

5.11 Summary of section 5

The data evidences the need for advocacy support for the existing communities of need for whom specialist provision is currently provided, however it is accepted that there may be other communities who may also have a need for advocacy support. Brighton & Hove is particularly characterised by the high number of individuals with complex mental health problems in the city. Though there are proportionately fewer older people living in the city when compared with England and the South East there are a higher proportion living alone.

These data do not identify the intersection of multiple factors that can affect an individual’s requirement for advocacy support. The provision of advocacy is also in part determined by social factors such as family and friends acting in an advocacy capacity.
Data from POPPI and PANSI predicts that the sizes of all populations they measure that currently supported by advocacy services are likely to rise between 2014 and 2025:

Table 7 POPPI and PANSI population predictions for Brighton & Hove 2014-2025

<table>
<thead>
<tr>
<th>Community currently offered advocacy</th>
<th>Predicted change in population size 2014 to 2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental ill-health</td>
<td>+6%</td>
</tr>
<tr>
<td>Older people (&gt;65 years)</td>
<td>+17.2%</td>
</tr>
<tr>
<td>Adult with autism</td>
<td>+7.8%</td>
</tr>
<tr>
<td>Adults with learning disabilities</td>
<td>+5.8%</td>
</tr>
<tr>
<td>Adults with moderate or serious physical disability</td>
<td>+15.1%</td>
</tr>
<tr>
<td>Adults with moderate, severe or profound hearing loss</td>
<td>+19.9%</td>
</tr>
<tr>
<td>Adults with serious visual impairment</td>
<td>+5.6%</td>
</tr>
</tbody>
</table>

It can be seen that the largest rises in numbers are expected in older people, adults with moderate or serious physical disability and those with hearing impairment. It can be seen that the largest percentage rise is expected in those adults with hearing loss (19.9%) some of these their needs may be met with regard to BSL interpreters, but for others were the is an association with age, this may not be suitable. It is also unclear whether people with additional language needs are able to access statutory advocacy services.
6. COMMUNITY RESEARCH

This section describes the results of community engagement research to find out the needs and opinions of Brighton and Hove residents who may benefit from Advocacy Services. The research was completed by Dr Andrea Jones of Good Health Projects in 2017. Qualitative research methods were used (interviews and focus groups), providing insight into individual’s experiences and understanding of the diversity of such experiences, rather than seeking to quantify and generalise to wider populations. Ethical considerations included sensitivity to people’s needs and challenges and ensuring anonymity of participants.

In addition to the community research project, we were also provided with user feedback that had been collected by some of the advocacy service provided and this has been included at the end of this section.

The community research was user led and as a consequence included reference to some providers that sit outside of the current advocacy contracts. In order to be consistent with the scope of the needs assessment reference to these services has not been included here.

6.1 Methods used in community research project

The methodological approach to the community research project was qualitative. The key premise of qualitative methods is that such methods provide insight into experiences of life, rather than quantifying aspects of life. The interviews and focus groups undertaken in this project offer a systematic exploration of the stories and narratives generated by these individuals, but it is not appropriate to make generalisations to wider populations based on these insights. The term ‘sampling’ is used in qualitative research sense of conceptual sampling, rather than statistically representative sampling from which it might be possible to generalise about a total population.

Ethical considerations were:

- provision of full information to each potential participant about the context and requirements of the research
- allowing people time and choices in how they wished to engage
- sensitivity to people’s difficulties and challenges in describing their experiences
- gaining informed consent from each participant for each aspect of the research process
- assuring interviewees that their participation was voluntary and they could choose to leave at any point
- not using any individual names and maintaining confidentiality of respondents by anonymising aspects of their accounts and narratives.

The sample

People who had used, or who might need advocacy services were recruited through an invitation to participate, sent out via existing local providers and community
organisations (see distribution and provider engagement list in appendix 6). Interest was also generated through a short-term Facebook space created specifically for this community engagement.

There is no consensus on how many participants make a good qualitative study. In this instance, specific attention was paid to contacting representatives from within the groups identified in the Tender Specification document, having protected characteristics under the Equality Act 2010. A total of 29 individuals who had used advocacy, or may need advocacy, participated. Details of all the interviewees’ classificatory identities are provided in appendix 6.

There were two limitations of the sample in relation to the research specification: no participants over 65 years were recruited. No participants were engaged via the local Age UK advocacy service. There was also little participation via the local Black and minority ethnic community groups that are most well-known in the city. This issue has been previously discussed in section 2.

Interviews and other forms of engagement

The specific methods used were: a) semi-structured interviews with individuals, b) focus groups with individuals brought together by specialist providers, and c) a one-step deliberative engagement event with users and provider’s representatives. Deliberative engagement was part of the research because:

‘Deliberative public engagement provides decision-makers with much richer data on attitudes and values with communities of users and potential users than conventional consultations or engagement techniques. A deliberative approach offers opportunities to more fully explore why people feel the way they do and allows the time to develop ideas, options and priorities with the communities being engaged.’ (INVOLVE, 2017)

Deliberative engagement is particularly appropriate for users of advocacy services because it helps users to develop and consider their views with the support of other users. It enables there to be a dialogue between diverse user groups over what can often be competing demands for services, designed to achieve mutual understanding within communities and enabling greater buy-in of those user groups to the reports results (O’Mara-Eves et al., 2011). Five service users and four representatives of advocacy service providers participated in the Deliberative engagement event undertaken on the 4th May 2017.

A Facebook page was set up to engage with advocacy users or potential users and it was used by some participants to find out information and discuss practicalities, but no online dialogue about advocacy experiences took place through this medium. It is likely that the short timescales from inception to report limited this form of engagement which requires longer time to build up an online identity, connections and trust.
Analysis

All interviews and events were recorded and all recordings were partially transcribed. The resulting data was analysed thematically, using NVivo (qualitative research analysis software). Analysis coding reports are available on request. Profiles of each interviewee were generated, to retain a picture of each individual’s needs and experiences and to enable the reader to place any quotes used in this report into the context of the individual’s profile (appendix 6).

The structure of the analysis was based on the questions set out in the research specification and these questions form the basis of the structure of this report.

6.2 Results from community research project

Interviewees mentioned a wide range of services they had used in the course of dealing with their problems and issues, not as providers of advocacy, but as services they had used alongside advocacy. Some were services that interviewees had needed advocacy to help navigate (e.g. NHS mental health services, such as Mill View Hospital). A full list of the services that interviewees had used is provided in appendix 6.

There are also individuals within local communities who act as advocates on an informal and voluntary basis. Two independent advocates, who provide their support free and are often referred to by others within their local community, were interviewed. These independent advocates often help people to navigate BHCC services, especially housing, and the benefits system.

Understanding of advocacy

All interviewees acknowledged that ‘advocacy’ is not an easy word to understand and that what advocates do is not widely understood. Some interviewees asked if the services they had received might be considered advocacy, because some were unsure of the boundaries between other forms of support, advice and information giving and advocacy. Some roles, like key or support workers, were understood to include some elements of advocacy and some interviewees felt that their key worker had been their advocate at times of need or when supporting them through a specific process (e.g. child protection proceedings).

The lack of clarity about the word and the definitions creates a problem with raising the profile of advocacy services, which, in turn, limits access by potential users. This is a more of a problem for new, first-time users of advocacy and especially those in need who are also new to the city.

Individuals using an advocacy service come to understand what it means through experiencing a service. Some interviewees had a good understanding of what advocacy involves. Interviewees in a focus group described advocacy as:

*Participant 1 - ‘Support, one-to-one relationship that gives guidance and help and brings in expertise and experience to, in my case, do form filling and deal*
with housing.

Participant 2 – ‘To reach a goal or solve a problem that you don’t feel able to do on your own.’

Participant 3 – ‘It feels like you have somebody official on your side, because in this world it can feel very much like those with power and those without, and when you feel like a powerless vulnerable person its very frightening. It’s when you have somebody who has more power and more knowledge with you...’

In the Dialogue event on 4th May 2017 (designed as deliberative engagement event) several suggestions for alternative names for advocacy were put forward by users, but the consensus was that each suggestion had elements of what an advocate might do, but none of the ideas for new names adequately encompassed exactly what an advocate does (see appendix 6). There was acknowledgement by some users that advocacy has a precise meaning, but only if you understand the subtleties of what is being offered. One user talked about it being an ancient word, and a word of ‘the establishment’, of the law, which could make it feel problematic sometimes.

There were some common themes about needs. Many participants were dealing with mental health problems alongside other conditions. The need for an advocate to successfully receive support from local mental health services was commonly expressed. Some interviewees talked about the lack of explanations given about eligibility criteria for receiving mental health support and some spoke about the how health care professionals didn’t help them to retain any sense of control over the services offered to them:

‘They (NHS staff) say I need to ‘meet criteria’ but I don’t know what that is. No one tells you what it is… I feel entangled in the NHS (mental health) services but I don’t know if I feel any sense of self-advocacy is being encouraged and it kind of leaves you suspended in mid-air in a way.’ (Interviewee 24)

‘Also difficulties I have had with Millview - their staff situation is so critical. The very morning of the appointment they ring up and cancel because one member of staff is off. They ignore patients on their own, but if you have an advocate they don’t.’ (Interviewee 27)

Coping with physical disabilities (cerebral palsy) and physical impairment (blindness) were also common needs, including long-term conditions such as epilepsy or diabetes. Once again, it is important to note that individuals were often living with combinations of complex conditions and needs.

Social isolation was another factor interwoven into interviewee’s accounts. Many lived alone and many did not have anyone other than the advocate they could go to for help (see profiles in appendix 6). Several individuals had moved to the city within the last year or two and had found it difficult to navigate local services and had little informal social support to draw on in times of need.

Many interviewees were, or had been, involved in disability benefits re-assessment (including Disability Living Allowance, now called Personal Independence Payments) and had needed an advocate to support them to get through this assessment.
process. Most found the benefits system incomprehensible and described their experiences of being challenged about the legitimacy of their claims for benefits as ‘frightening’, ‘threatening’:

‘The PIP letter was quite threatening... I rang them up and I said 'Don't stop my money!' I know this form's got to be done, but if I'm living on my own how can I fill it out without someone to help me?’ (Interviewee 18, living with cerebral palsy and learning disabilities)

Housing was a dominant need that sat behind several of the other problems and difficulties individuals were experiencing and was something that advocates said they found most frustrating because there is so little help they can provide in relation to this. Three participants considered this to be their highest and most immediate need.

‘I don't know whether it was because they (MIND) compartmentalise the help they can offer, but really the only thing that the person at MIND could practically do was accompany me to a Dr's appointment, to discuss my mental health and I honestly felt I didn't need that... I have been avoiding the Dr and all that, but at the moment my needs are around getting rehoused and getting some benefits coming in and I am not succeeding very well at all and I can't find an advocate for me, somebody who might perhaps help me to look for and deal with rental flats. I need some quite major hand-holding to be absolutely honest and I literally can't find the right advocacy service for that, if there is one.’ (Interviewee 2)

There appears to be no formal advocacy service for people in housing need in Brighton & Hove, though some independent and voluntary advocates – people who seem to have become advocates through either community activism, or becoming a kind of champion of people in need in their immediate neighbourhood or estate - did provide advocacy type support to people struggling with either Private Rented Sector landlords or BHCC housing services and systems. Both independent advocates spoken to raised housing as one of the most significant problems they dealt with.

For some interviewees recovering from addiction, they talked about the long-term nature of the challenges they face - ‘You are never recovered. You are always in recovery until the day you die.’ (Interviewee 4) and how each step of this journey involves big changes when coming out of an addictive way of life, and how much support they need to sustain the courage to keep from lapsing back into old habits:

‘It takes a lot of courage to be locked away and to disassociate from your past life, no mobile phones, no contact with family. It is a big move.’ (Interviewee 7)

For individuals trying to turn their lives around like this, the support of an independent advocate, who is not associated with their past but who understands their issues and challenges, can be critical to the success of their recovery.

**Important qualities for an advocate**

Interviewees most often mentioned that an important quality for an advocate is that they listen to them, or hear their concerns and problems.
‘I go to Speak Out. I’ve been going a long time. If I can’t talk to my house staff then I can talk to an advocate. She’s not full-time (issue-based advocate) that’s the sort of advocate I want, that I can talk to about anything. Sometimes my house staff don’t want to listen to me, so that’s why I want to full-time advocate, that I can talk to them about it and see what they can do.’ (Interviewee 12)

It was also important that advocates allowed clients enough time to do things at a pace individuals could cope with – ‘They need to go through things with you in your own time...put you at ease... I don't feel like I am wasting anyone’s time....’ (Interviewee 14). Individuals valued being allowed to explain their problems in their own time, without being rushed. This was closely related to the care taken by the advocate; words like ‘kind’ and ‘caring’ were used.

Interviewees also talked about the importance of response times when they made the call for help; that advocates were available when they most needed them and there was not a lag between making the call and someone getting back to them. Some interviewees had made use of an online out-of-regular-hours service provided by MindOut, where they could engage via an online forum with an advocate.

Continuity of an individual advocate was also important to interviewees, so that they did not have to keep explaining their complex situations to new people. Continuity was highly valued amongst many respondents and when asked where they would most like to be able to access advocacy in the future, most interviewees that had used local services wanted to return the advocacy service they had already used and trusted.

Many interviewees mentioned that it was important that advocates let them speak for themselves, not simply do things for them and allow them to keep as much control as possible (empowerment).

‘What I liked about (advocate name) she just sat in the room and I done all the talking. Because in the end of the day it’s not them that’s going to get the benefit, you are, so you’re in control of what you are doing. And I went in there and she sat there... and when we came out she said ‘You’ve done really well.’ And I realised how much more difficult it had got (his physical ability and his motivation) in the last 6 months.’ (Interviewee 19)

Equally important were advocates being skilled and knowledgeable, having knowledge of law changes and understanding systems. Phrases like ‘good knowledge’ or ‘specialist knowledge’ or ‘know more than me about how to...’. Many interviewees valued advocates’ having a range of skills and abilities:

‘Someone who is up to date with how the changes are occurring in the law and benefits changes or legislation and who can access that, not just because they’re paid but because mentally they can. Whereas I have a disability that makes it too confusing. It's knowing the NHS, the systems awareness they have. Sit alongside me and support me while I am making phone calls’ (Interviewee 20)
Another theme that emerged from the question about what qualities are important for an advocate to have, was impartiality or independence from statutory services/the council:

‘I need to trust the people. Because you have to believe your advocate is not working with the big multi-agencies like Social Services, who are trying to push things through and doesn’t listen to you basically.’ (Interviewee 9)

‘I most often need advocacy accessing government services, so things like health, social care, housing, benefits. So a place independent of all those locations is best. I wouldn’t want to go into a Brighton Council building, for an advocate. Somewhere that is community based, like Community Base, if there was one organisation that specialised in advocacy and they maybe had specialist advocates in that one place…’ (Interviewee 1)

Another important theme, especially for LGBT people using specialist LGBT or Trans advocacy services, was the lack of judgement they experienced from advocates. Several users of these advocacy services expressed how important it was that they could access services without having to worry about the service provider being judgemental about their LGBT identity:

‘They understand you without judgement and that is particularly important for people with mental health issues. It’s hard enough being unwell. Then to be judged because you are trans or bi or gay. It’s too much. Here you can feel comfortable’ (Interviewee 26)

Peer advocacy was also valued for this feeling of being able to communicate about concerns and problems whilst knowing the space was ‘safe’.

**Positive experiences of advocacy**

Most interviewees were very positive about their experience of advocacy and of the advocates that had supported them. Words like ‘invaluable’, ‘really helpful’, ‘absolutely wonderful’, and ‘a tremendous help’ were used. One interviewee talked about how grateful they were for the help – ’what they are doing for me is really brilliant, they are like angels to me’ (Interviewee 15).

There was appreciation of the fact that such specialist services are available in the city and this wasn’t common in other places they had lived in: ‘There’s nothing like this in other places and to be able to get access to a service like MindOut is amazing.’ (Interviewee 3)

  I am really pleased with the help I have received. I used to be really, really worried, but since I used the service I have some of the information that I need and it has helped me to relax.’ (Interviewee 25)

Some interviewees found their advocate to have made a significant difference to the quality of their life:
It's invaluable, to be able to share something with someone else, to take the power out of it, and make it more manageable... when you're in it it can be the worse thing in the world, in your world anyway.’ (Interviewee 5)

These positive evaluations of advocacy were closely tied in with what interviewees described as the outcomes of advocacy for them – what advocacy has achieved for them.

Outcomes from advocacy

There was a lot of specific feedback from interviewees about what advocacy had achieved for them. The way that interviewees talked about it varied and the table below provides illustrations of the terms that individuals used.

<table>
<thead>
<tr>
<th>Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘able to talk about my problems’</td>
</tr>
<tr>
<td>‘increase in my confidence’</td>
</tr>
<tr>
<td>‘helped me to feel good’</td>
</tr>
<tr>
<td>‘able to sleep at night’</td>
</tr>
<tr>
<td>‘new knowledge and connections’</td>
</tr>
<tr>
<td>‘be more independent’</td>
</tr>
<tr>
<td>‘I was awarded benefits I wouldn’t have got otherwise’</td>
</tr>
<tr>
<td>‘gives me peace of mind’</td>
</tr>
<tr>
<td>‘I have learnt to defend myself’</td>
</tr>
<tr>
<td>‘someone official on my side’</td>
</tr>
</tbody>
</table>

The full range of outcomes that interviewees mentioned was categorised and this formed the basis of the 5 dominant themes outlined.

- access to health & social services
- awarded benefits
- prevention of crises
- saving money in the system by preventing crises
- reduce social isolation
- reduce anxiety, fears
- increases independence
- sharing of concerns
- increase in confidence
- able to talk about problems
- reflection on situation
- new knowledge and connections
- reduce suffering
- better relationship with health and social care professionals
- volunteering opportunities
- continued recovery, abstinence

A particularly strong theme was how advocates had supported people to navigate recent changes in the benefits system and particularly assessments, tribunal and appeals relating to disability benefits. It was evident that all interviewees felt that the
specialist knowledge, confidence and official status of their advocates were essential requirements for achieving a fair outcome from the benefits assessments:

Participant 1 - ‘I just needed to see the look of the ATOS assessor when (trans advocate) introduced themself to them. Mmn. At least they were more prepared to listen to me with advocate there. Empowerment was the word I would use.’

Participant 2 – I agree. It is really stressful still, having to fill out the DLA forms and all that, but knowing I had an advocate that had experience doing that and I didn't feel they (the advocate) were judging me for who I am. I think that's quite important. To feel safe and supported and they were very much led by what I said, they didn't try and do it for me, even though they had the experience. They listened to what I said... It's really important to feel that there's someone there that's on your side. (Focus group participants 26 & 28)

I am in the support group... and I attend at the Rough Sleepers day centre doing volunteering and I am very proactive and you wouldn't know I have health complications unless I shared it with you. I need advocacy because some of the terminology I don't know how to articulate. If you ask me what's wrong with me and I'll say the very basic response or something in layman's terms whereas someone who advocates might have some knowledge and understanding around it, without that emotional attachment, can talk on my behalf, in a sense that other people might understand. (Interviewee 5)

Another theme that emerged was how an outcome of advocacy was sometimes involvement in volunteering within the host organisation, or moving into some new community involvement. Interviewee 22 talked about how advocacy from Possability People to support claiming disability benefits had led to them subsequently volunteering for two years as a trainer in other aspects of disability awareness raising.

Two interviewees talked about how advocacy had enabled them to not only get their lives more stable, but had resulted in them starting training courses (within and outside of the advocacy organisation) which was leading to employment opportunities.

In summary, the main themes that emerged from the diverse ways that interviewees described what advocacy had achieved for them can be summarised as:

1. reduces suffering, including social isolation, anxiety and fear
2. enables access to health & social services and to improved experiences of these
3. prevention of crises in their lives
4. prevention of a deepening of their needs
5. improved relationships between individuals and health & social care workers (especially Social Services)
6. access to benefits, especially disability benefits, that might otherwise not be awarded.

It seems evident from these accounts that advocacy plays a role in saving health and social resources that would be incurred if individuals were to slide deeper into need.
or significant crises were to occur.

**Negative experiences of advocacy**

There were very few criticisms of advocates specifically. Only two examples of poor advocacy were given. The first involved an advocate who the interviewee did not feel had been proactive enough in their benefits assessment interview:

*(In PIP assessment interview) I started to crumble. This woman next to me, this advocate, she didn't come in and take over where I was flagging or say 'Wait a minute, (name) needs a minute to answer the previous question before you ask another question.'*, I got none of that and I said 'Can we stop and I come back?' and they said 'If you stop then we have to go through the whole thing again and it will not only affect the mobility component but the care component'. *(Interviewee 16)*

The second was to do with frustration at the high threshold that advocacy services put in place for a person to receive the support of an advocate:

*‘My experience of getting people (an advocate) to help me now is endless conversations about whether they are appropriate to help me, if I am bad enough for them to help and ‘Would I like to wait until I get a bit worse?’, and really not being heard, I don't think.’* *(Interviewee 2)*

This interviewee felt that the threshold was set too high and that people who found it difficult to communicate their needs were particularly at risk of not receiving services (those with autism, for example). This negative experience links to the kinds of barriers that interviewees mentioned to using advocacy services.

**Barriers to accessing Advocacy Services**

The lack of capacity in advocacy services – available advocate time – was the most often mentioned barrier to accessing an advocate. Some interviewees talked about this in terms of there being a high threshold to be accepted as needing an advocate, as in the example provided above. Others talked more about waiting times.

Others talked about there being a lack of awareness of advocacy as a service amongst those in need. Some talked about the scale of need they were aware of within their communities. Most interviewees acknowledged that not knowing about advocacy as a specific form of support was a significant barrier (see suggestions in the final section of this report).

Some interviewees acknowledged that an individual had to be ready or at the right stage in their life to seek help and to make the best use of an advocate. When asked about obstacles to getting advocacy, one interviewee described personal factors also playing a role, alongside not knowing about services:

*'Denial. Not believing they need it. Not believing they are worth it. Still stuck in the madness as it were. Not wanting the help. Not knowing about the help.'* *(Interviewee 6)*

53
A lack of knowledge amongst health and social care workers about advocacy was also mentioned as a barrier. Advocates in some services felt that Social Services were not sufficiently aware and knowledgeable about individuals in need being entitled to advocacy under the 2014 Care Act, resulting in individuals being bounced around between statutory and voluntary services unnecessarily, often at times when individuals were least able to cope.

One interviewee said that (local service) offered her no sign-posting to local advocacy services in the city when she first encountered them. She had ended up using Google to find a service to support her specifically with being involved in child protection proceedings, which had resulted in her contacting a London-based organisation, who then pointed her to a service in Brighton & Hove:

‘No one explained to me where can I get advocacy, they just said to me ‘go and find it’ basically. There is no specific place to go.’ (Interviewee 9)

Some interviewees raised the problem of the way local advocacy services are broken down into defined categories of need, saying that it could be confusing for new potential users, trying to work out which service to go to first if the individual had a range of issues and needs. Others made the point that organising services in this way made them feel alienated from the services from the outset because it suggested that their condition defined who they were:

‘Ones issues are not what one is. One is who one is and within that, one has issues… If one is LGBT that is not what you are, its only part of what you are. I have dyslexia but I am not dyslexic - my condition is not me.’ (Interviewee 23)

Whilst some individuals felt compartmentalised by this approach, as many also valued the specialist nature of some services – especially LGBT services – as evidenced in the section about qualities above.

Gaps in Advocacy Provision
The most obvious gap identified by interviewees was in advocacy for housing-related problems for people with high and complex needs. Several interviewees considered housing to be their most significant advocacy need:

‘I have been avoiding the Dr and all that, but at the moment my needs are around getting rehoused and getting some benefits coming in and I am not succeeding very well at all and I can’t find an advocate for me, somebody who might perhaps help me to look for and deal with rental flats. I need some quite major hand-holding to be absolutely honest and I literally can’t find the right advocacy service for that, if there is one.’ (Interviewee 2)

For people in recovery the difficulty of making the shift from supported accommodation into mainstream housing was evident. Some interviewees were part of the Brighton Housing Trust (BHT) Fulfilling Lives project, which is about peer support ‘helping each other as a group and trying to find gaps and barriers in services’ (https://www.bht.org.uk/services/fulfilling-lives/). Interviewee 4 talked about The Move On project (part of BHT, helps clients complete the project and resettle.
back into flat renting and landlords), but were finding it difficult since Private Rented Solutions (who provided match funding for house renting deposits) were no longer operating. Highlighting housing needs in Brighton and Hove is not new (see Brighton and Hove Fairness Commission, 2016), but some interviewees experiences reinforce how important a determinant of well-being housing has become in the city.

There was also concern that advocacy for people with autism was insufficient. Autism was described as a form of invisible disability, alongside mental health issues, with challenges for accessing services and being perceived as not being in need (Interviewees 20 and 27).

At the dialogue event, concern was also expressed about how people with multiple, long-term health conditions that did not have a mental health component, could fall between the criteria for the different advocacy services. Possability People provide advocacy for people with physical disabilities, but advocates working for the Macmillan Cancer advocacy service suggested that this focus did not always resonate for people with long-term health conditions.

Advocacy for older people is an example of an area of need that the qualitative research was unable to explore due to lack of participation in the project, but increasing numbers of older people living independently and in their own homes into much later life suggests that that advocacy needs of this age group are either being met through other service providers, or only being partially met. New services are developing all the time and the Elder Abuse Recovery Service (EARS) is an example of a new service (set up in March 2017; funded by the Lottery) concerned about older peoples’ welfare and the need for advocacy within this population group.

Suggested improvements that could be made to existing and future services
Interviewees were asked if there were aspects of their advocacy experiences, or the way that they found advocacy support, that could be improved. Interviews and focus groups were also aimed at drawing out any alternative or innovative methods or models that individuals had come across or experienced (for example group support; peer support; family/self-advocacy). In addition to the positive feedback most interviewees provided about their experiences of, and outcomes from, advocacy, described above, there were a few suggestions about what could work better.

One interviewee suggested that it was complicated for new users to navigate the different advocacy services offered within the city as they were currently organised and proposed a ‘one-stop-shop’ for advocacy:

What I'd like to see in the city is a one-stop shop for advocacy in the city. Where you could go and have one case worker who has the expertise and skills to work with you on your issues whatever that is. I don't really want to have to go to organisation a, b, c and d for different issues and have to re-tell my stuff each time. (Interviewee 1)

This interviewee also thought that advocates needed to have specialist knowledge to be effective and felt that they would have never got through the NHS system to get a diagnosis of autism without the support of specialist advocates.
One other interviewee (2) also expressed frustration at finding out that their advocate did not deal with disability benefit applications during their first appointment, after which they were signposted to another advocate in another location to seek help for this element of their needs.

In the Dialogue event on 4th May this was discussed between service users and local providers. No one contested the usefulness of maintaining separate specialisms in advocacy mainly because of the complexity of the different systems that individuals are trying to navigate. The advocate needs to understand those complex systems well to be effective. There was acknowledgement that, for new users a triage system or single helpline for people to call could be useful, if it could be made cost-effective. Only one user mentioned the BHCC Access Point as a central source of information about advocacy; most had found services by word-of-mouth and from contacting an organisation and being referred internally to advocacy. Providers acknowledge that signposting and referring to other services could sometimes be difficult for some users, but it would be a challenge to balance retaining specialist knowledge with having single points of contact.

The current Brighton and Hove Advocacy Partnership held a joint workshop during this research (27th of April 2017). This was a demonstration of the good links that exist between the partner organisations and of collaborative efforts such as joint training initiatives. But providers at the Dialogue event accepted that there could be closer working relationships and more sharing of knowledge and ideas across the current partners. Conversations with providers suggest that there is a limit to how much resource small voluntary organisations can devote to collaborative working when commissioner’s priorities are limited to contact time with clients and when there are such high new and existing demands on their services.

Interviewees who participated in the Dialogue event expressed strongly how they felt all the advocacy services they had experienced were needed, based on the benefits and outcomes they had felt from receiving advocacy. Other aspects of the current service provision were also highly valued:

- Specialist advocates knowledge (e.g. knowing NHS services, or the benefits system, or rehab services)
- Continuity of an advocate for the client – not having to get to know different people and re-explain their problems again
- Seeing an individual’s issues or process through to a solution (where possible), not having a fixed number of hours and then abandon the person to seek further help elsewhere (even though this did happen for some clients)
- LGBT-specific advocacy
- Learning Disability-specific advocacy.

At the Dialogue event, further ideas were discussed that could benefit advocacy provision in the city:

- How to make advocacy services better known about? For example, integrating advocacy into current websites to raise the profile and link advocacy in to other forms of local community activity and volunteering opportunities.
- How access to advocacy through Adult Social Care services need to be strengthened, with improved recognition of the need for advocacy amongst those working in adult social care, including social workers
- how general practice remains most people’s first port of call when they need help and how little is known within general practice about the value of advocacy and how few referrals come from primary care; a campaign to raise GP’s and primary care staff awareness of advocacy
- provision of an advocacy directory, not only available online but in hardcopy for people who do not regularly access online services (a number of interviewees found accessing information and services online to be a problem)
- more outreach by advocacy services to a cross-section of community groups to spread the word about what advocacy can achieve for people in need; the partnership could attract publicity by organising a ‘First Dates’ concept event where they illustrate what a good match of client and advocate can achieve
- all advocates having laptops with them when working with clients, to improve efficiency and enable answers to be found more quickly.

6.3 User feedback collated by advocacy providers

Current advocacy providers routinely conduct evaluation and try to access feedback from those engaged with their service. These findings are included in the performance reports submitted to commissioners as part of the performance management process.

The use of case studies is frequently cited in these returns. Feedback included in these returns may not reflect of the volume of clients supported by the services. The content of these submissions were reviewed and a summary detailed in table 8 below.

Table 8 Summary of user evaluation provided by advocacy providers.

<table>
<thead>
<tr>
<th>Service</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>MindOut – Trans Advocacy Service</td>
<td>2 case studies detailing the positive impact of the service in resolving clients presenting issues.</td>
</tr>
<tr>
<td>Possability People</td>
<td>1 case study detailing the positive resolution of issues related to welfare benefits</td>
</tr>
<tr>
<td>Age UK</td>
<td>1 case study detailing positive support provided to an older trans women</td>
</tr>
<tr>
<td>Speak Out</td>
<td>Feedback in respect of support provided under the Care Act advocacy found 9 respondents reporting that their advocate supported them to express their views and wishes to others. For issue advocacy 55 respondents said that this was the case.</td>
</tr>
<tr>
<td></td>
<td>100% of Citizen Advocacy clients were supported by their Advocate to understand life choices and options.</td>
</tr>
<tr>
<td>MiBH</td>
<td>2 case studies detailing the positive resolution of issues in relation to safeguarding/ financial exploitation and access to appropriate</td>
</tr>
<tr>
<td>Service</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Impetus</td>
<td>1 case study detailing positive support provided to a client experiencing care proceeding in respect of their child</td>
</tr>
<tr>
<td>MindOut – LGBT Service</td>
<td>2 case studies detailing support provided to two clients in respect of asylum support and mental health provision. 5 feedback statement evidencing positive support</td>
</tr>
<tr>
<td>MiBH – community advocacy</td>
<td>3 feedback statements evidencing positive support 2 case studies detailing positive resolution of a problem associated with noise disturbance and related to mental health diagnosis</td>
</tr>
<tr>
<td>MiBH – independent mental health advocacy</td>
<td>Feedback questionnaire, but historically participation has been low. Mechanisms are in place to improve completion. 2 case studies in respect inpatient stays, diagnosis and support.</td>
</tr>
<tr>
<td>POWhER - IMCA</td>
<td>5 case studies showing positive support in respect of 4 cases related to accommodation and one in respect of engaging with family support. Numerous examples of positive feedback from services users and other health and social care professionals.</td>
</tr>
<tr>
<td>Sussex Interpreting Service</td>
<td>85% average improvement across all 8 objectives for 41 out of 45 completed cases as defined by Service Users.</td>
</tr>
</tbody>
</table>

6.4 Summary of section 6

Advocacy services in the city are not wellknown amongst people in need and the lack of a high profile seems to be the result of a combination of lack of understanding of the word (advocacy), a lack of awareness and proactive referring to advocacy services by core NHS and social care services (including GPs and Adult Social Care staff) and a lack of specific resources devoted to local promotion of these services.

The current use of advocacy services is amongst people with complex combinations of needs, including multiple conditions and disabilities, who are trying to live independently within the city, but are likely to be socially isolated. Much current use is to cope with navigating increasingly complex access routes into health and social care systems, increasingly complex processes for receiving disability and other benefits and diminishing housing choices that are affordable, safe for people who are perceived as different and secure.

The potential need for advocacy is likely to be significantly greater than current usage suggests, given the low profile of these services locally within the health and social care system.
Most advocacy users consider advocacy to have had a significant impact on the quality of their life and to have prevented them from having crises or deepening need and are grateful for being able to access specialist services within the city. Users are particularly positive about the way that advocates work with them as a whole person, working alongside them to tackle their multiple issues and challenges over time, providing continuity of support in a welfare system that is increasingly fragmented and specialised. This is even though only some advocacy services support people struggling in the benefits system and there is little advocacy available to deal with housing problems. This research suggests that the impact of any reduction in advocacy for people like those interviewed in this research is likely to result in more crisis management and deepening need and therefore be felt in other parts of the local health and social care system.
7. STAKEHOLDER ENGAGEMENT

For this needs assessment, stakeholder engagement included both professionals referring into advocacy services and those providing advocacy services. The stakeholder engagement was led by Liz Tucker and supported by the Public Health Intelligence team, including questionnaire design, focus groups and analysis.

7.1 Methods

Stakeholder engagement was undertaken by using an online questionnaire and by undertaking a number of focus groups. Separate questionnaires for both professional groups as described above (See appendix 7) and were tested for acceptability and appropriateness prior to use. The questionnaires were completed either online via the BHCC Consultation Portal or on paper and were analysed. The focus groups involved group discussions around a number of key areas, and were analysed thematically: comments were subject to contextual analysis and coding in order to identify common themes.

The stakeholder engagement was promoted via the Advocacy Partnership, Community Works and the City Council’s intranet site. In addition, links to the questionnaire were forwarded to team leaders and cascaded to their teams. There was some potential for duplication between participation in focus groups and completion of questionnaires, with respondents choosing to take part in both research methods. The use of both focus groups and questionnaires enabled as many respondents as possible to take part, and additionally the two different methodologies have the potential to generate slightly different findings.

7.2 Results

The following number of professionals participated in the stakeholder engagement work.

<table>
<thead>
<tr>
<th>Type of professional</th>
<th>Questionnaires responses</th>
<th>Participants in focus groups (number of groups)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those who refer into advocacy services</td>
<td>29</td>
<td>34 (5)</td>
</tr>
<tr>
<td>Those who deliver advocacy services</td>
<td>17</td>
<td>44 (5)</td>
</tr>
</tbody>
</table>

7.2a Results: those who refer into advocacy services

Questionnaires

In total 29 questionnaires were completed from six different organisations, figure 2 below provides the number of respondents from each organisation. Of note, some
advocacy referrers work within organisations that provide advocacy services, however they completed the questionnaire with reference to referring into services only.

The first two questions referred to the professions and workplaces of people who refer into advocacy services:

Table 9 Q1 Professions of responders to advocacy referrers’ questionnaire

<table>
<thead>
<tr>
<th>Profession/job title of responder</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manager/deputy manager</td>
<td>6</td>
</tr>
<tr>
<td>Nursing staff</td>
<td>5</td>
</tr>
<tr>
<td>Advice and Information Worker</td>
<td>3</td>
</tr>
<tr>
<td>Senior House Officer (doctor)</td>
<td>2</td>
</tr>
<tr>
<td>Community and/or Volunteer Link Specialist</td>
<td>2</td>
</tr>
<tr>
<td>Assistant Psychologist</td>
<td>1</td>
</tr>
<tr>
<td>Community Employment Worker</td>
<td>1</td>
</tr>
<tr>
<td>Community Health Trainer</td>
<td>1</td>
</tr>
<tr>
<td>Customer Feedback Officer</td>
<td>1</td>
</tr>
<tr>
<td>Direct Payments Advisor</td>
<td>1</td>
</tr>
<tr>
<td>Occupational Therapist Assistant</td>
<td>1</td>
</tr>
<tr>
<td>Social worker</td>
<td>1</td>
</tr>
<tr>
<td>Specialist Speech and Language Therapist</td>
<td>1</td>
</tr>
<tr>
<td>Brighton and Hove Area Co-ordinator</td>
<td>1</td>
</tr>
<tr>
<td>No Response</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>29</strong></td>
</tr>
</tbody>
</table>
It can be seen that responses came from a wide range of referrers and organisations, reflecting both the variety of potential referrers and the range of individuals who need to be kept abreast of methods of referring into services, particular if staff turnover is high.

The following questions referred to how the clients the responders worked with may benefit from advocacy and if a referral had been made, this then led to a supplementary question on specific needs from advocacy:
### Table 10. Questions 3-5 advocacy referrers questionnaire

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>No response</th>
<th>Free text</th>
</tr>
</thead>
<tbody>
<tr>
<td>When assessing clients do you consider whether they might benefit from access to an Advocate?</td>
<td>27</td>
<td>0</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Do you feel that the clients you work with have needs that could be met through the use of an advocate?</td>
<td>29</td>
<td>0</td>
<td>0</td>
<td>Complexity of needs, need for written material, role of advocacy in social isolation, needs of deaf community</td>
</tr>
<tr>
<td>Have you referred into an advocacy service?</td>
<td>24</td>
<td>5</td>
<td>0</td>
<td>Those who answered no: Did not know about local service (3) Other staff make these assessments/referrals (1) They give contact details of the service to the client and asked them to self-refer (1)</td>
</tr>
</tbody>
</table>

### Table 11. Q4a, 4b

<table>
<thead>
<tr>
<th>If your clients do have advocacy needs, which type of advocacy could they benefit from?</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone to speak up for them, or act on their behalf.</td>
<td>28</td>
</tr>
<tr>
<td>Help to understand information</td>
<td>26</td>
</tr>
<tr>
<td>Help getting the support they need</td>
<td>25</td>
</tr>
<tr>
<td>Represent their interests</td>
<td>24</td>
</tr>
<tr>
<td>Secure their rights</td>
<td>22</td>
</tr>
<tr>
<td>Take action to help people say what they want</td>
<td>20</td>
</tr>
<tr>
<td>Advocacy IMCA as part of the Care Act</td>
<td>17</td>
</tr>
<tr>
<td>Advocacy IMHA as part of the Care Act</td>
<td>17</td>
</tr>
<tr>
<td>Can contribute to their local community</td>
<td>15</td>
</tr>
<tr>
<td>Make sure people feel part of the community</td>
<td>15</td>
</tr>
<tr>
<td>Other (free text)</td>
<td>4</td>
</tr>
</tbody>
</table>

Supporting family to advocate for client; many clients feel stigmatised and don't feel they have the same rights; although they are referred, referrer acts as an advocate for them themselves; attendance at tribunals; need for interpreter plus advocate (deaf client)
When asked if the respondent felt that their clients had needs that could be met through the use of an advocate, all those who responded to this question indicated that they did. Five free text comments were also made in response to this question: identifying the complexity of the needs that many clients presented with; suggesting having written material to give to clients and detailing the value of advocacy in breaking down social isolation. Another comment was made in respect of the specialist interpreting needs of members of the deaf community and the effect on the dynamic in having an interpreter, rather than an advocate able to provide this support in conjunction with advocacy.

The next questions referred to barriers to referring clients to advocacy services and situations when potential users were not referred. Responders were specifically asked to describe their experiences of referring into advocacy services in Brighton & Hove:

**Table 12. Q5a**

<table>
<thead>
<tr>
<th>Has there ever been an occasion when you haven’t referred someone to an advocacy service who might have benefited and if so why not?</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I always refer if I think the client would benefit</td>
<td>8</td>
</tr>
<tr>
<td>I haven’t referred as family/carer are able to support the client</td>
<td>4</td>
</tr>
<tr>
<td>It was unclear which service would best meet my client’s needs</td>
<td>2</td>
</tr>
<tr>
<td>The waiting times are too long</td>
<td>0</td>
</tr>
<tr>
<td>I’ve had a previous negative experience</td>
<td>0</td>
</tr>
<tr>
<td>I find the referral process difficult</td>
<td>0</td>
</tr>
<tr>
<td>Other, please give details:</td>
<td></td>
</tr>
<tr>
<td>Client declined (2)</td>
<td></td>
</tr>
<tr>
<td>Lack of knowledge re: service (1)</td>
<td></td>
</tr>
<tr>
<td>Other service more suitable (1)</td>
<td>4</td>
</tr>
</tbody>
</table>

**Table 13. Q6, including free text responses**

<table>
<thead>
<tr>
<th>How did you find the referral process into the advocacy service?</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy – no problems</td>
<td>18</td>
</tr>
<tr>
<td>Neither easy nor difficult</td>
<td>6</td>
</tr>
<tr>
<td>Difficult – lots of problems</td>
<td>0</td>
</tr>
<tr>
<td>Free text responses (grouped thematically):</td>
<td></td>
</tr>
<tr>
<td>Good - straight forward</td>
<td>5</td>
</tr>
<tr>
<td>Good - local service co-location</td>
<td>3</td>
</tr>
<tr>
<td>Encourage self-referral promotes independence</td>
<td>2</td>
</tr>
<tr>
<td>OK once I knew what to do</td>
<td>3</td>
</tr>
<tr>
<td>Good straight forward – in-house referral</td>
<td>2</td>
</tr>
<tr>
<td>Good but a waiting list</td>
<td>1</td>
</tr>
</tbody>
</table>

It can be seen that there were occasions where referrers hadn’t referred their clients for advocacy, even when they thought they may benefit (10/18 responders). This
was due to the referrer feeling that there were others able to advocate for that person in 4 cases and due to client refusing in 2, however 3/18 hadn’t referred a client as they did not have enough knowledge about referring into the advocacy service.

All responders to the direct query about referring into advocacy found the process either easy or neither easy nor difficult, although waiting list issues were mentioned. Some responders found that referral was straightforward after they had been through the process and learnt what to do. Those taking part in the survey were also asked if they had referred to more than one service how the referral process had differed. Four participants referenced the variance in the way that referrals are made between services and the lack of clarity around how referrals should be made to different services, another comment was made in respect of difficulties in accessing the right type of advocacy support for their client as the service was unclear as to the difference in different types of support. One comment felt that the advocacy support they had accessed on behalf of their client had been excellent.

Participants were next asked how they felt about the timescales from referral to the client accessing the service.

Table 14. Q7 including free text responses

<table>
<thead>
<tr>
<th>How satisfied were you with the time scales from initial referral to your client accessing the service?</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>12</td>
</tr>
<tr>
<td>Fairly satisfied</td>
<td>4</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>5</td>
</tr>
<tr>
<td>Fairly dissatisfied</td>
<td>1</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>0</td>
</tr>
<tr>
<td>No response</td>
<td>5</td>
</tr>
<tr>
<td>Free text responses: (Grouped thematically)</td>
<td>Good accessibility and time scales (7)</td>
</tr>
<tr>
<td></td>
<td>Long waiting lists, inconsistency with waiting times, managing client’s expectations (5)</td>
</tr>
</tbody>
</table>

Of the 23 respondents 17 were satisfied with the timescales and only one response indicated dissatisfaction. Twelve additional free text comments were made in respect of this question. Six respondents reiterated the quality of support provided and five comments were made about some experience of delays in accessing advocacy support.

The next question asked those completing the questionnaire to think about the definition of advocacy that was being used here and assess how satisfied they were that the advocacy needs of their clients were being met by the services currently being provided.
Table 15. Question 8, 9 & 10

<table>
<thead>
<tr>
<th>How satisfied are you that the advocacy needs of your clients are currently met by the services provided in B&amp;H?</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>11</td>
</tr>
<tr>
<td>Fairly satisfied</td>
<td>5</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>5</td>
</tr>
<tr>
<td>Fairly dissatisfied</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>7</td>
</tr>
</tbody>
</table>

Is there anything else you’d like to tell us?

Free text responses (grouped thematically):
- Benefits of advocacy (7)
- Long waits for clients to access (2)
- Need to provide info to clients re: welfare rights (2)
- Limitations of volunteers providing advocacy
- Need more information about services
- Need to increase provision
- Need to ensure everyone can access
- Fair access for deaf community

It can be seen that 16 of the 22 respondents were very or fairly satisfied that their clients’ advocacy needs were being met by the services in B&H. A relatively large number of respondents did not answer this question however and it cannot be presumed that they were satisfied or dissatisfied. Possible reasons for not completing this question may include the fact that it was at the end of the questionnaire (responder fatigue), but it may also due the responder not knowing the answer to the question or even due to concerns about impact of answering the question on advocacy services.

Focus groups

Five focus groups took place: two with the Adult Social Care (ASC) Area teams, one with the Deprivation of Liberty Safeguarding (DoLS) team and one with the Specialist Older Adults Mental Health Service (SOAMHS) and one with the Community Learning Disability Team.

Each of the focus groups used the same structure with participants being asked about their experiences of:
- referral into support
- the process of engagement with the service and ongoing communication
- changes that they would like to see to the existing provision
- any other issues relating to advocacy.

The referring teams included in this consultation had differing roles with for example the DOLS team tending to make referrals to the services delivered by POhWER, whereas the ASC team refer into a range of different Advocacy Services.
During the focus group comments were collated using a flip chart. This information was then transcribed into a Microsoft Word document and sent back to participants for their review and amendment. Comments were then subject to contextual analysis and coding in order to identify common themes. Three themes were identified: referral into advocacy support; engagement with service and ongoing support; and changes those referring into services would like to see. Comments for each of these areas have been tabulated and reported below, including how many participants raised these themes:

Table 16 – Advocacy referrers focus groups – theme 1

<table>
<thead>
<tr>
<th>Referral into advocacy support: themes identified</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clients have multiple needs – unsure which service should support them and this leads to delay</td>
<td>7</td>
</tr>
<tr>
<td>Problems accessing service deters referrals</td>
<td>4</td>
</tr>
<tr>
<td>Consider enabling more self-referrals by supporting service users</td>
<td>3</td>
</tr>
<tr>
<td>One point of contact for all services would help</td>
<td>3</td>
</tr>
<tr>
<td>Long waiting times</td>
<td>3</td>
</tr>
<tr>
<td>Vulnerable clients are less likely to access</td>
<td>2</td>
</tr>
</tbody>
</table>

*Individual comments:*
- Assessment of Advocacy needs of client is good
- Case load is increasing - Mental Health a key factor
- Clients value drop-in access
- Different criteria for different services
- Escalation post Supreme Court ruling March 2014
- Lack of capacity within services
- Ongoing referrals - waiting list – DOLS
- Service has a central e-mail – DOLS
- Speedy response – generally (Mill View)
- Speedy response – DOLS
- Speedy response when related to safeguarding

It is interesting to note that of those being consulted, the more specialised services such as the DOLS and SOAMH teams had positive experiences of referral, whereas the more generic needs of clients supported by Adult Social Work team’s experienced greater difficulty in accessing Advocacy Support.
Table 17. Advocacy referrers focus groups – theme 2

<table>
<thead>
<tr>
<th>Engagement with the service and ongoing support: themes identified</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of support is good</td>
<td>6</td>
</tr>
<tr>
<td>Good working with the IMCA service: communication etc.</td>
<td>4</td>
</tr>
<tr>
<td>Lower referrals because of delays in being able to access the service</td>
<td>3</td>
</tr>
<tr>
<td>Conflict of interest: neutrality of advocacy v. activism</td>
<td>2</td>
</tr>
<tr>
<td>Need a ‘care pathway’ between referrer and service: agreed expectations</td>
<td>2</td>
</tr>
<tr>
<td>Specialist needs of individuals with Learning Difficulties</td>
<td>2</td>
</tr>
</tbody>
</table>

**Individual Comments:**

- Access to an Advocate can be difficult
- Agreed referral criteria would help
- Because of delays using family and friends instead
- Do we need more written information to give the client?
- Once service engaged the quality of support is good
- The importance of working holistically to support the client

The most common comment made in respect of this theme related to the quality of the current provision. This included issues around the need for advocates to be client centred and multi-skilled in order to meet the needs of clients. Two comments were made about the need for Advocates to challenge decision makers more. Other comments included under this theme were the need for greater professionalisation with a suggestion that Advocates use a clear statement around their role as part of their introduction. Improved consistency and knowledge was also mentioned as was the need for knowledge about safeguarding. Four comments were made about the need to raise awareness of Advocacy services locally.
Table 18 Advocacy referrers focus groups – theme 3

<table>
<thead>
<tr>
<th>Changes those referring into services would like to see: themes identified</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop quality of provision – need for Advocates to be client-centred and multi-skilled, more challenging to decision-makers, greater professionalism (clear statement of their role included in introduction). Improved consistency and knowledge, including around safeguarding.</td>
<td>7</td>
</tr>
<tr>
<td>Increase awareness of advocacy services locally</td>
<td>4</td>
</tr>
<tr>
<td>Speed of response</td>
<td>3</td>
</tr>
<tr>
<td>Conflict of interest advocacy v. lobbying</td>
<td>3</td>
</tr>
<tr>
<td>Continue with current low levels of administration</td>
<td>2</td>
</tr>
<tr>
<td>Having a 'care pathway' with shared understanding of expectations</td>
<td>2</td>
</tr>
</tbody>
</table>

*Individual Comments:*

- Value of co-location
- The value of continuity of service provision
- Prioritisation of some referrals
- Need for support for older individuals with a LD
- Increase integration
- Increase capacity of the Advocacy services to take referrals
- Have built a good working relationship with the provider need to recognise the value of continuity when recommissioning
- Considering the use of a client’s personal assistant as an advocate - with suitable training
- Conflict of interest when an organisation is already supporting another family member
- Could there be a central point of contact

Issues in respect of the need for greater integration were highlighted here, with reference to having a care pathway (2), the value of co-location (1), integration (1) and having a central point of contact (1).

Other comments made with regard to advocacy included:

- reference to improved service provision leading to increased activity
- concerns that waiting times for current service provision may lead to referrers not making a referral when they should be doing
- recognition of the value of change and the need to recognise different models of advocacy and for future provision to incorporate this

**7.2b Results: those who deliver advocacy services**

**Questionnaires**

Seventeen questionnaires were completed by representatives from 10 different organisations providing advocacy services in Brighton & Hove.
Advocates from the following services completed the questionnaire:

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age UK B&amp;H</td>
<td>2</td>
</tr>
<tr>
<td>Impetus B&amp;H</td>
<td>1</td>
</tr>
<tr>
<td>Mind in B&amp;H</td>
<td>2</td>
</tr>
<tr>
<td>MindOut</td>
<td>2</td>
</tr>
<tr>
<td>POhWER</td>
<td>1</td>
</tr>
<tr>
<td>Possability People B&amp;H</td>
<td>2</td>
</tr>
<tr>
<td>Speak Out B&amp;H</td>
<td>1</td>
</tr>
<tr>
<td>Sussex Interpreting Service Bilingual Advocacy</td>
<td>3</td>
</tr>
<tr>
<td>Project</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>I would rather not say</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

Respondents were asked if they felt that all those who could benefit from the advocacy service that they provided are able to do so, reflecting the question from the referrer’s questionnaire. The responses are as follows:

**Table 19 Q2 Advocacy providers questionnaire**

<table>
<thead>
<tr>
<th>Do you feel that all those who could benefit from the advocacy service you provide are able to do so?</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total responses</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

If answer was no, why not?

- Poor awareness of local advocacy services: 11
- Waiting times are too long: 5
- Clients prefer their family/carer to provide this support: 2
- Referrers find the referral process difficult: 1

Free text responses (grouped thematically):

- Ambiguity and lack of understanding of the term advocacy: 2
- Target client group have had negative experiences of other health and social care services that they have become cynical and do not want to engage in advocacy support: 1
- Difficulty of maintaining service provision when funding was often short term: 1
- Social work staff withheld access to those who might have benefitted: 1

The majority, 13 respondents said ‘no’ that this was not the case. When asked to choose from a selection of answers (participants were promoted to choose all
responses that they felt applied i.e. more than one response per person) as to why this was the case, 11 of the 19 replies indicated that this was due to a lack of awareness of local advocacy services.

Respondent were next asked what they felt were the three things about advocacy services that worked well. All 17 respondents completed this part of the questionnaire, making a total of 44 different suggestions.
Table 20 Q3&4 Advocacy providers questionnaire

<table>
<thead>
<tr>
<th>Looking at how advocacy services are delivered across the city, what three things work well locally? (Responses grouped thematically)</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of the Advocacy Staff</td>
<td>8</td>
</tr>
<tr>
<td>Respected by Health and Social Care Professionals</td>
<td>5</td>
</tr>
<tr>
<td>Speedy response times</td>
<td>4</td>
</tr>
<tr>
<td>Clients are very satisfied with the services</td>
<td>3</td>
</tr>
<tr>
<td>Good promotion</td>
<td>3</td>
</tr>
<tr>
<td>Value of hospital based advocacy</td>
<td>3</td>
</tr>
<tr>
<td>Advocacy solves problems</td>
<td>2</td>
</tr>
<tr>
<td>Use of volunteers</td>
<td>2</td>
</tr>
<tr>
<td>Independence of the Advocate</td>
<td>2</td>
</tr>
</tbody>
</table>

**Individual comments:**
- Advocacy is embedded within the voluntary sector
- Being part of a larger organisation
- Bi-lingual advocacy
- Committed to the principles of the Advocacy Charter
- Cross referrals within the partnership
- Drop-in support
- Focus on empowerment of service users
- Future planning
- Locally based services with local knowledge
- Peer support
- Range of local provision
- Simple referral process

The three most common themes that emerged in response to this question were that the respondents felt that they provided high quality services (8), the services were respected by the professionals they worked with (5) and responded speedily to referrals (4).

Respondents were next asked what three things they would change about the current services. Fourteen respondents replied to this question making 37 comments.
Table 21 Q5 Advocacy providers questionnaire

Looking at how advocacy services are delivered across the city, if you could make three changes what would they be? (Responses grouped thematically)

<table>
<thead>
<tr>
<th>Change in Advocacy Services</th>
<th>Number of Responses (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase promotion/awareness of the services</td>
<td>8</td>
</tr>
<tr>
<td>Increase capacity of the advocacy service</td>
<td>5</td>
</tr>
<tr>
<td>Increase funding</td>
<td>5</td>
</tr>
<tr>
<td>Improve support for these communities - not related to advocacy</td>
<td>4</td>
</tr>
<tr>
<td>Better partnership working</td>
<td>3</td>
</tr>
<tr>
<td>Commitment to ongoing professional development of advocates</td>
<td>2</td>
</tr>
<tr>
<td>Increase referrals</td>
<td>2</td>
</tr>
<tr>
<td>Increase use of volunteers</td>
<td>2</td>
</tr>
</tbody>
</table>

**Individual Comments:**
- Advocacy for those with multiple needs
- Guarantee Independence
- Improve communication with referrers - e.g. DOLS
- Improve evaluation of the effectiveness of advocacy
- Increase use of interpreters
- More services for people with autism related conditions

The three most common themes that emerged in response to this question was that the respondents felt that there should be increased promotion/awareness of advocacy services (8), increase capacity of the advocacy services (5) and increased funding (5).

Respondents were asked if they had any other comments they wanted to make about the current provision of advocacy services and these are summarised in the table below:

Table 22 Q6 Advocacy providers questionnaire

Please tell us anything else about how advocacy services are provided across the city. (Responses grouped thematically)

<table>
<thead>
<tr>
<th>Comment</th>
<th>Number of Responses (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to increase promotion and awareness of the service</td>
<td>4</td>
</tr>
<tr>
<td>Do we have capacity to use volunteers as advocates?</td>
<td>1</td>
</tr>
<tr>
<td>All services should be grouped under one organisation</td>
<td>1</td>
</tr>
<tr>
<td>Advocacy should be part of another larger service</td>
<td>1</td>
</tr>
<tr>
<td>An increase in medical assessments by benefit claimants has increased advocacy work-load, reducing these requirements would have positive impact on work-load</td>
<td>1</td>
</tr>
</tbody>
</table>
Focus Groups

Focus Groups were conducted with advocates from POWhER, Sussex Interpreting Service and MindOut. A focus group was also held at the multi-agency event held as part of the Annual Advocacy Partnership Event which included representation from range of services29(April 2017).

Table 23. Attendees at focus groups for advocates

<table>
<thead>
<tr>
<th>Organisations of attendees at focus groups for advocates</th>
<th>Participating in event (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>POWhER</td>
<td>22</td>
</tr>
<tr>
<td>Sussex Interpreting Service</td>
<td>7</td>
</tr>
<tr>
<td>Mind Out</td>
<td>6</td>
</tr>
<tr>
<td>Advocacy Partnership Event</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
</tr>
</tbody>
</table>

Each of the focus groups used the same structure with participants being asked about their experiences of:

- people who could benefit from advocacy having access to the service
- things that work well locally
- things that could be improved locally
- any other issues relating to advocacy.

In total 44 individuals who deliver advocacy services as paid or volunteer advocates took part in the focus groups. Individual comments made by participants in the focus groups were initially recorded on the flip chart and were then transcribed into Microsoft Word Document and shared with the participants for their review and amendment. Responses to each question were then subject to thematic analysis in order to identify common topics. Three broad themes were identified: If people who could benefit from your service are not able to do so, then why could this be?; What would you like to see changed or improved within local advocacy services?; What would you like to be delivered going forward? Comments and quotes are included below:

29 Impetus Cancer Advocacy, IMHA Mind, Mind Brighton and Hove, Mind Social Worker, Independent Health Complaint Advocacy Service Brighton and Hove, Community Researcher, Age UK Brighton and Hove, Speak Out
Table 24 Advocates focus groups – theme 1

<table>
<thead>
<tr>
<th>If people who could benefit from your service are not able to do so, then why could this be? Themes identified:</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to raise awareness/promotion</td>
<td>14</td>
</tr>
<tr>
<td>Understanding of Advocacy the different types, roles and services</td>
<td>9</td>
</tr>
<tr>
<td>Socially isolated most likely to be excluded from Advocacy</td>
<td>7</td>
</tr>
<tr>
<td>Access for those with a learning disability</td>
<td>4</td>
</tr>
<tr>
<td>Effective once a referrals has been made</td>
<td>4</td>
</tr>
<tr>
<td>Lack of resources/capacity</td>
<td>4</td>
</tr>
<tr>
<td>Unmet need: Asylum seekers, LGBT, Older Trans Individuals and Older LGBT</td>
<td>4</td>
</tr>
<tr>
<td>Poor/variable communication</td>
<td>4</td>
</tr>
<tr>
<td>Access aided by being part of a bigger (sometimes national) organisation – aids cross referrals</td>
<td>3</td>
</tr>
<tr>
<td>Clients often have more than one problem</td>
<td>3</td>
</tr>
<tr>
<td>Communication with the Decision Maker can be difficult</td>
<td>3</td>
</tr>
<tr>
<td>Delays in referrals</td>
<td>2</td>
</tr>
<tr>
<td>Difficult to get feedback from those who refer</td>
<td>2</td>
</tr>
<tr>
<td>Digital exclusion - need for accessible information</td>
<td>2</td>
</tr>
<tr>
<td>Some teams better at referring than others</td>
<td>2</td>
</tr>
<tr>
<td>Value of internal referrals</td>
<td>2</td>
</tr>
<tr>
<td>Value of self-referrals</td>
<td>2</td>
</tr>
</tbody>
</table>

**Individual comments:**
- Turnover and continuity of staff
- Importance of advocate remaining independent
- Problematic to use family/friends
- Need for better partnership working
- Value of shared email
- Value of access via drop-ins

We noted earlier when reviewing the findings derived from the questionnaires completed by those who deliver services that the most common responses (11), were made in respect of the need to raise awareness of advocacy services. This theme was also the most frequently mentioned at the focus groups with 14 participants suggesting the need to raise awareness and increase promotion of services. Individual comments were made about issues relating to the variability of communication with services, issues around the turn-over and continuity of staff, the importance of the advocate being independent, use of a family or friend can be problematic, the need for better partnership working, the value of having a shared e-mail the value of having access via drop-ins.

**Examples of quotes from focus groups for advocates, theme 1:**

‘Different organisations have different cultures and approaches and this affects their use of Advocacy services.’

Findings from the focus groups also generated discussion about the need to increase understanding by those who use services both (clients and referrers) as to
the different types of advocacy that exist, the different services and their roles that run in the city (9).

‘Some health professionals don’t understand IMCA and IMHA so don’t know who to refer to. To some health professionals this is an option rather than a legal right.’

‘Need to re-frame advocacy from the perspective of the professional, what it can do for them.’

These findings in part dovetail with those relating to the need to increase understanding of the role of advocacy and its purpose.

Issues relating to health inequality were also identified with concerns about the ability of certain communities to access advocacy services, including people who were socially isolated (7), had Learning Disabilities (4), and Asylum seekers, LGBT, and Older LGBT (4).

Those taking part in the focus groups were next asked to consider what they would like to see changed or improved within local advocacy services. Fifty-six comments were made in response to this question.

Table 25 Advocates focus groups – theme 2

<table>
<thead>
<tr>
<th>What would you like to see changed or improved within local advocacy services? Themes identified:</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve awareness and training around Advocacy Services</td>
<td>18</td>
</tr>
<tr>
<td>Improve partnership working between services</td>
<td>10</td>
</tr>
<tr>
<td>Embed Advocacy in Referring Teams/Develop an Advocacy Champion role within services</td>
<td>7</td>
</tr>
<tr>
<td>Improve communication flows with referrers single points of contact</td>
<td>3</td>
</tr>
<tr>
<td>Increase capacity</td>
<td>3</td>
</tr>
<tr>
<td>Consider different models for delivering advocacy</td>
<td>2</td>
</tr>
<tr>
<td>Increase awareness of LGBTQ issues</td>
<td>2</td>
</tr>
<tr>
<td>Increase speed of access</td>
<td>2</td>
</tr>
<tr>
<td>Increase training for advocates</td>
<td>2</td>
</tr>
</tbody>
</table>

**Individual Comments:**
- Continuity of funding
- Cross reference with the findings of the Migrants Needs Assessment
- Increase referrals
- Socially isolated most likely to be excluded from Advocacy
- Use drop-in services
- Value the importance of the independence of Advocacy

Responses from the focus groups identified the need to improve awareness of what advocacy was and the services that were available locally (18). An example of how awareness could be raised was also suggested by participants with the training of a
member of staff with additional knowledge and expertise about advocacy practice and local services (7).

Examples of quotes from focus groups for advocates, theme 2:

“Should embed the role of Advocacy in staff inductions”

“Hospitals/units (should) have a trained Advocacy Champion who knows about different types of advocacy. Need single person they can go to, who has extra training/knowledge on advocacy. Help with case law knowledge.”

Improved partnership working was also identified (10). One participant commented:

“Would be good to know what the other advocacy services in the city are doing, a monthly update, better co-ordination if one service is meeting with a health or social care team it would be good to co-ordinate.”

The last question participants in the focus group were asked was whether there were any things that they would like to continue going forward. Twenty-seven comments were made in response to this question.

Table 26 Advocates focus groups – theme 3

<table>
<thead>
<tr>
<th>What would you like to be delivered going forward? Themes identified</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having locally based services with local expertise</td>
<td>6</td>
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<tr>
<td>Good working practice with local ASC/other services</td>
<td>5</td>
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<tr>
<td>Flexible/holistic working</td>
<td>5</td>
</tr>
<tr>
<td>The preventative role of advocacy</td>
<td>2</td>
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<tr>
<td>Partnerships working/good working relationship</td>
<td>2</td>
</tr>
<tr>
<td>Would like to expand service</td>
<td>1</td>
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<tr>
<td>Value different models of advocacy</td>
<td>1</td>
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<tr>
<td>The role of volunteers</td>
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<tr>
<td>The independence of Advocates</td>
<td>1</td>
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<tr>
<td>Quality of the Advocates</td>
<td>1</td>
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<tr>
<td>Continue to provide workshops for self-advocacy.</td>
<td>1</td>
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<tr>
<td>Client choice over who provides their advocacy</td>
<td>1</td>
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</tbody>
</table>

Six comments were made about the value of having locally based services. Five comments being made about the current positive relationships that exist between advocacy services and Adult Social Care (ASC) and other refers into the service (5). The use of flexible/holistic models of working was also referenced by 5 respondents.

Responses to the question asking what providers would like to continue to be delivered elicited responses that asserted the need to recognise the value of local expertise in the delivery of effective advocacy support (6), the existing good working
practice (5) and the flexible/wrap-around [holistic] support that was currently provided (5).

7.3 Summary of section 7

The findings of the questionnaire consultation with those who refer into advocacy services indicates that participants felt that they assessed the advocacy needs of their clients and were able to refer clients into advocacy support without any difficulties in a timely manner. Issues identified included the complexity of service provision with each service having its own referral processes. Overall satisfaction with the provision was high (16 of 22).

Findings from the focus groups were affected by the role of the different teams. Teams with more specialist roles as the DOLS and SOAMH teams had positive experiences of referral. However the more generic needs of clients supported by Adult Social Work teams in particular experienced greater difficulty in accessing advocacy support. Participants from the Adult Social Care service and to some extent the Learning Disability Service identified the multiple needs of their clients as presenting a gap between client need and current service provision as it was difficult to know which service to refer into with the effect that it deterred referrals. Other issues that negatively affected the uptake of services were the lack of a common access point and waiting times. Comments were also made about the need to advocates to be multi-skilled, probably reflecting the issue identified earlier in respect of the complexity of many client’s needs. The was also some concern about the professionalism of some advocacy support with respondents indicating incidents when they either felt there had been insufficient challenge to decisions or inappropriate challenges that touched on lobbying rather than representation. The need to raise awareness of local advocacy services was also mentioned as was the need for greater integration of service provision.

Some of issues identified by service providers in respect to an apparent lack of awareness of advocacy may in part mirror the experiences of those who refer into these services who felt referrals were being deterred because of the difficulties in making a referral.

Providers who took part in the questionnaire indicated that they felt that a gap existed between those who would benefit from accessing support and those who actually made contact with the service. Lack of awareness of existing services was considered the key factor affecting this and this was again referenced when respondents were asked what they would like to see changed. Ambiguity as to understanding what advocacy meant was also cited as a factor. Increased capacity and funding were also cited as elements that the participants would like to see changed.

Findings from the focus groups supported the findings identified in the questionnaire for the need to raise awareness, improve promotion of services and the need to aid understanding of what advocacy was. Participants also felt that the more socially
isolated a potential service user was, the less likely they were to be in contact with advocacy support. When asked what they would like to see changed providers who took part in the focus groups indicated that they would like to see more partnership working between services. It was also suggested that greater in-reach exist into referring services with for example social care teams having a member of staff with specialist expertise around advocacy: and Advocacy Champion. The value of having advocacy services delivered by services with local knowledge was also identified through the focus groups.

Lack of clarity around the meaning of the word advocacy was identified by staff who referred into services as an obstacle to access for some clients, as was a perceived lack of awareness amongst staff who may refer to advocacy services. The most common responses from those who deliver services were made in respect of the need to raise awareness of advocacy services (n=11). This theme was also the most frequently mentioned at the focus groups with 14 participants suggesting the need to raise awareness and increase promotion of services. Examples of ways of doing this that were provided included the use of a directory, and greater outreach into the community. The stakeholder engagement expressed the need for professional high calibre staff with wide ranging knowledge who had the ability to actively listen to a client's wishes. Participants also mentioned the lack of integration between services and that this made access difficult to navigate. It was also recognised that many who access advocacy support have complex and specialist needs.
8. Synthesis of findings and recommendations

The following key findings arose from the needs assessment and have led to the development of the subsequent recommendations. The source of the finding is identified in brackets after the finding.

8.1 Understanding of the term ‘advocacy’

This area arose from the literature review, community research and the stakeholder engagement and key points that led to the development of the recommendation are included below:

- Need to clearly define what advocacy is and isn't (literature review)
- A lack of understanding of the word ‘Advocacy’ (community research)
- Needs of the clients need to match our definition of what advocacy is (referrers)
- Need a common understanding about what advocacy actually is (providers)

**Recommendation:**

1. **Commissioners and providers to work to the definition of Advocacy used in the Advocacy Charter (and in this needs assessment)**

   *This definition is already used by the existing advocacy providers and by adopting the meaning already in operation this could aid consensus building and collaboration. It is important for commissioners and providers to identify what isn’t advocacy and support this need in other ways e.g. social prescribing, community navigator, mental health support.*

8.2 Awareness of advocacy services in Brighton & Hove

This area arose from the community research and the stakeholder engagement and key points that led to the development of the recommendation are included below:

- Advocacy services are not well known amongst people in need (community research)
- Lack of awareness of advocacy by health and social care staff (community research)
- Lack of promotion of advocacy services (community research)
- Some confusion around which service it was best to refer into (referrer)
- Need to raise awareness of advocacy and advocacy services through better promotion (provider)
  Embed advocacy services into the referring teams or have a role akin to an Advocacy Champion (providers)
Recommendation:

2. Commissioners and providers to work to raise the awareness of advocacy and advocacy services through better promotion:

a. Promote awareness of the advocacy services in Brighton & Hove with a clear description of the offer available to: service users; those referring into services; service providers and other Council services (for example by updating the BHCC advocacy webpage, inclusion in the MyLife website)

b. Develop and maintain an accessible directory of advocacy services available in Brighton & Hove

c. Consider the development of ‘Advocacy Champions’ within teams who refer people for advocacy

8.3 Considerations for future provision of advocacy services in Brighton & Hove

This area arose from the literature review, data snapshot, community research and the stakeholder engagement and key points that led to the development of the recommendation are included below:

- Social Care Institute for Health (SCIE) Care Act 2014: provide a commissioning independent advocacy self – assessment tool (literature review)
- Role of co-commissioning with service users and providers (literature review)
- Single point of contact, which triages and prioritises: to reduce transaction costs, reduce delays and provide a consistent service/workload (literature review)
- Use of technology to accept referrals and a single database to manage referrals (literature review)
- Effective network of providers, working collaboratively, not in competition and share good practice and make decisions collectively. Acknowledging that the local authority is not the expert (literature review)
- Consider how smaller organisations can contribute to the model (literature review)
- Have a commissioning model that enables services to move funds, in consultation with the commissioner, between services depending on demand (literature review)
- Provide continuity and long term support for services (literature review)
- Multi-faceted nature of need: multiple factors = which service to refer into (data snapshot)
- Potential gap in provision to those with interpreting needs (including British Sign Language) (data snapshot)
- Some examples of complexity and confusion about referrals (referrers)
• Referrals may be helped by co-location/intra-organisational referrals (referrers)
• Need a mutually agreed care pathway with agreed level of service/timescales (referrers)
• Waiting times can be a problem – the effect is to deter referrals (referrers)
• Current good practice: a central point of contact: e-mail, speed of response is valued (referrers)
• Advocacy as a role within organisations that are also lobbyists—a conflict of interest, which does not benefit the client (referrers)
• Waiting times can be too long – need to increase service capacity (providers)
• Need better partnership working (providers)

Recommendation:

3. Ensure that an effective and integrated advocacy service is offered in Brighton & Hove that is tailored the specific needs of the city

a. Commission an integrated service across the city with a single point of referral reflecting the potentially multiple needs of the user. Ensure that all providers work in partnership, for example by sharing training, information and experiences

b. Commission a responsive service, features of which may include: a common point of access with referrals being responded to within an agreed period; a duty service able to pick up calls/e-mails and respond within an agreed time threshold; referrals allocated across services to aid workflows and reduce waiting times

c. Agree a care pathway with commissioners, providers and referrers that specifies levels of service and expected timescales.

d. Consider co-location of advocates with referrers where appropriate

e. Commissioners and providers to ensure that people with interpreting needs (including British Sign Language) are able to access all advocacy services, and that demand in this group is monitored

f. Commission advocacy services with reference to the Social Care Institute for Health (SCIE) Care Act 2014: commissioning independent advocacy self – assessment tool. Consider co-commissioning and/or co-production of services with providers and community members where appropriate

8.4 Meeting current and future demand

This area arose from the literature review, data snapshot, community research and the stakeholder engagement and key points that led to the development of the recommendation are include below:
• Acknowledge the role of citizen, volunteer and peer advocacy. Recognise the value of this model especially in expanding capacity (literature review)
• Population of all groups for which advocacy is currently provided is expected to rise, largest rises predicted locally in older people, those with physical disability and hearing loss (data snapshot)
• Areas that most often require advocacy support include housing, benefits and employment, as well as health and social care related needs (data snapshot), Sharing the information about why clients have accessed advocacy support included in the routine reporting submitted by Providers, with partner agencies including housing, benefits and employment as evidence which can aid these services learn from this feedback and potentially prevent demand for advocacy support
• Potential demand is likely to be significantly greater than current usage suggests (community research)
• Under-representation of older people and those from BME groups in community research (community research)
• Increasing demand for all areas of advocacy – requires a need for flexible service providers to face changing demands e.g. commissioning for group, self-advocacy (referrers)
• Waiting times are too long, the effect is to deter referrals (referrers)

Recommendation:

4. Ensure that advocacy services in Brighton & Hove can meet current and future demand

a. Consider commissioning different types of advocacy e.g. could consider commissioning group advocacy or self-advocacy training courses, which anyone irrespective of their defined need could access

b. Provide feedback from monitoring of advocacy services to relevant departments, for example workload requirements to assist with housing and benefits issues that could potentially be avoided.

c. Further engagement work to be undertaken with older people and BME communities to better understand their needs for advocacy

d. Consider the development of an Advocacy Commissioners Network to aid integration and sharing of best practice between those who commission advocacy services across the Cit
Appendix 1: Commissioning Prospectus and Advocacy Mapping Exercise
January 2012
Brighton & Hove Commissioning Prospectus

Outcome Area 1 Specialist Advocacy

1.1 Community Advocacy,

We are proposing an overarching outcome for Advocacy provision –

1.2 Independent, free, local Advocacy Services to support adults using or seeking to use Adult Social Care and Health services.

Definitions of this statement are:

Independent –
providers need to evidence that they are able to operate independently from statutory organisations and service provider agencies, and minimise potential conflicts of interest. Action for Advocacy identifies four main aspects of independence – structural, financial, operational and psychological – these are further expanded within their Quality Performance Mark which clearly outlines 18 elements to ensure independence.

Free –
no direct cost to the service user

Local –
providers will need to evidence a good understanding of local knowledge, service provision and opportunities

Advocacy –as defined
a.6.1 Specialist Advocacy

Brighton & Hove Adult Social Care and the local NHS currently jointly commission a range of local advocacy services that have evolved through specific policies and funding attached to identified service user groups – predominately mental health, learning disabilities, and older people. Through this Prospectus we are aiming to initiate a new strategic positioning for advocacy within the city.

Shared agreement regarding a local definition of Advocacy.

**Advocacy is:**
- Speaking up for, or acting on behalf of yourself or another person
- Taking action to help people say what they want, secure their rights, represent their interests
- Making sure people feel part of the community and contribute to it.

**Advocacy is not:**
- Information – this is a collection of facts which helps to improve one’s understanding of a problem
- Advice – this is when someone gives their views or opinions about what could be done about a problem
- Mediation – this is when someone sorts out a problem between two or more people. A mediator is a person who gives their own views or opinions to help everyone involved to reach agreement.
- Making decisions for someone
- Telling them what to do
- Counselling
- Befriending/social support

**a.6 Overview of the commissioning plans**

We are proposing one overarching outcome for Advocacy provision –

To support adults using or seeking to use Adult Social Care and Health services – including adults who:
- have learning disabilities
- have mental health problems, including those affecting older people
- have physical disabilities or sensory impairment
- are carers for people included in any of the above groups

**Providers** –
will need to utilise local resources/building on social capital, volunteers, partnerships, connections.
1.2 Independent Mental Health Advocacy and Community Mental Health Outcomes

Advocacy has been available to support patients in many mental health services for some years, from 1 April 2009 under provisions introduced by the Mental Health Act 2007, qualifying patients in England have had access to help from an Independent Mental Health Advocate (IMHA).

IMHA’s are an important safeguard that have helped support patients to understand and exercise their legal rights.

In Brighton & Hove, our commissioning intentions are that we would like an IMHA service for qualifying patients to work along side a community mental health advocacy service, (i.e. all people in inpatient and community setting, not detained under the mental health act) to deliver a good quality service to all patients within inpatient and wider community settings. We therefore welcome either one bid for both elements of the service or joint bids for the IMHA and community component of this bid to ensure good partnership working.
### Objective

1.1

### 1.1.1

#### Independent, free, local Advocacy Services, to support adults using or seeking to use Adult Social Care and Health services

<table>
<thead>
<tr>
<th>Objective</th>
<th>1.1.1</th>
<th>The 10 key principles of the Advocacy Charter to be embedded within local Advocacy provision:</th>
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<tbody>
<tr>
<td></td>
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<td>- Clarity of purpose</td>
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<td>- Putting People First</td>
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<td>- Equal Opportunities</td>
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<td>- Supporting Advocates</td>
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<td>- Complaints</td>
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Locally we are echoing the nationally recognised Advocacy Charter and Code of Conduct, developed by a leading national advocacy organisation, Action for Advocacy, which identifies 10 key principles which should be embedded within advocacy provision:

- **Clarity of purpose:** Schemes should have clearly stated aims and objectives and be clear on their scope, and limitations of their roles.

- **Independence:** Schemes should be operating independently from statutory organisations and service provider agencies.

- **Putting People First:** Advocates should be non-judgemental, be respectful of people's needs, views and experiences.

- **Empowerment:** Schemes should support self advocacy and empower people to say what type and level of support they need.

- **Equal Opportunities:** Schemes should have an equal opportunities policy and be proactive in tackling all forms of inequality, discrimination and social exclusion.

- **Accessibility:** Schemes should be free of charge to eligible people. Offices, policies, procedures and publicity should promote access for the whole community as well.

- **Accountability:** Schemes should monitor and evaluate their work.

- **Supporting Advocates:** Advocates should be trained and supported in their role and helped to develop skills and experience.

- **Confidentiality:** Schemes should have policies on confidentiality and how information might be shared.

- **Complaints:** Schemes should make clear how complaints or feedback can be made and provide support to people to make complaints.
| Objective Guidance | 1.1.2 | Address social inequality and exclusion of key groups – Inclusion  
Ensure that advocacy provision enables those in society who potentially face discrimination to be supported to access services – provide evidence that your service or partnership will support the diversity of needs across the city, and challenge discrimination. |
|--------------------|-------|---------------------------------------------------------------------|
| Objective Guidance | 1.1.3 | Safeguard against abuse, discrimination and unfair treatment – Protection  
Ensure that advocacy provision identifies and appropriately responds to issues relating to safeguarding, discrimination and unfair treatment – provide evidence that your service or partnership will have appropriate policies to respond effectively to these issues. |
| Objective Guidance | 1.1.4 | Improve access to local services and increasing social capital, access to information – Promotion  
Ensure that the advocacy provision effectively enables individuals to express their views and have access to quality information – provide evidence that your service or partnership will be able to show how it will support people to express their views and how you ensure access to information and involvement of service users in the organisation. |
| Objective Guidance | 1.1.5 | Work towards solving specific individual problems (individual outcomes) and increasing control – Choices  
Ensure that the advocacy provision supports individuals through effective 1:1 or groups to make decisions, choices and take informed risks – provide evidence that your service or partnership will enable individuals to solve specific issues or outcomes. Enabling individuals to feel in control, through a range of proportionate responses, including utilising peer support models and volunteering. |
What we are NOT looking for

- Information – this is a collection of facts which helps improve understanding of a problem
- Advice – this is when someone gives their views or opinion about what could be done about a problem
- Mediation – this is when someone sorts out a problem between two or more people.

A mediator is a person who gives their own views or opinions to help everyone involved to agree.

- Making decisions for someone
- Telling them what to do
- Counselling
- Befriending/social support
- NHS Independent Complaints Advocacy Service

Target Group

To support adults using or seeking to use Adult Social Care and Health services – including adults who:
- have learning disabilities have mental health needs, including those affecting older people
- have physical disabilities or sensory impairment
- are carers for people included in any of the above groups

Funding Allocation (maximum)

£190,000 (including a ring fenced amount for Learning Disabilities £85,311)

Duration of funding agreement

Funding for 3 years from 1 April 2014 to 31 May 2017

You may be invited to attend a clarification or negotiation meeting relating to your bid

Expected dates for these meetings – to be arranged between 13 and 29 August 2013

1.1 Independent Mental Health Advocacy and Community Mental Health Outcomes

The aims of the service:
Ensure high quality Independent Mental Health Advocacy is made available to help qualifying patients understand the legal provisions that they are subject to under the Mental Health Act 1983 and the rights and safeguards to which they are entitled.
Ensure high quality Community Mental Health Advocacy to mental health service users (who are not detained under the Mental Health act) with advice, information and representation as required to facilitate their recovery.
| Objective | Guidance | 1.2.1 | Patients are provided with clear and timely information about their rights, about referral to service and what the IMHA service offers for qualifying patients detained under the Mental Health Act (see ‘target group’ section below for further definition)  
- Are given written and verbal information about their rights.  
- Are clear about the process of referral into the service whether in hospital or in the community  
- Have access to clear and appropriate information about the IMHA service and how it operates including in accessible formats e.g. in large print or their first language.  
Community Mental Health Advocacy Service for people not detained under the mental health act (see ‘target group’ section)  
- Mental Health Service users are provided with clear and timely information about the advocacy service and what the service offers. |
|---|---|---|---|
| Objective | Guidance | 1.2.2 | All IMHA patients detained under the mental health act show understanding of their rights under the mental health act.  
All patients should feel supported in meetings and their issues should be dealt with effectively.  
IMHA service (see ‘target group’ section for further definition)  
The service supports patients to understand the legislation under which they qualify and any restrictions imposed; the treatment being given or proposed under the Act and their rights under the Act and how to exercise those rights. Both IMHA and Community Mental Health Advocacy service  
- The service supports patients to access information and better understand what is happening to them;  
- The service supports patients to explore options, making better-informed decisions and actively engaging with decisions that are being made  
- The service supports patients to articulate their own views  
- The service can speak on the patient’s behalf and represent them. |
<table>
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<tr>
<th>Objective</th>
<th>Guidance</th>
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| **1.2.4** | Timely response of the IMHA and Community Mental Health Advocacy Service to all patients within the hospital and community settings. Both IMHA and Community Mental Health Advocacy service:  
- Service that is available from 9 – 5, five days per week and will operate flexibly to offer evening services as required to achieve greater coverage and accessibility for service users and carers.  
- All referrals will receive an initial response within two days with work beginning within five days. |
| **1.2.5** | Patients have the right to a private meeting and to meet in a fashion that is culturally appropriate and accessible. Both IMHA and Community Mental Health Advocacy service:  
- Patients are able to meet in private and can request a friend/carer to be present at the meeting  
- The service is available and accessible to meet the particular needs of the patient, eg a culturally appropriate service;  
- The service support patients during a range of meetings (eg clinic appointments, CPA reviews, mental health tribunals, S117 meetings)  
- The service supports people in meetings or over the telephone and other relevant means as required.  
- Any issues of accessibility are appropriately addressed – eg translation;  
- Patients have issues dealt with effectively  
- Patients feel they are appropriately supported at meetings. |
| **1.2.6** | Both IMHA and Community Mental Health Advocacy service will take referrals for all patients including self referrals, |
| **1.2.7** | Both IMHA and Community Mental Health Advocacy service will be responsive to comments, complaints and service user feedback. Both IMHA and Community Mental Health Advocacy service:  
- responds to comments complaints and user feedback  
- involves service users to continue to improve its performance |
<table>
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<th>Objective</th>
<th>Guidance</th>
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| 1.2.8     | Both IMHA and Community Mental Health Advocacy service will work in partnership. Both services will also work with other mental health providers including community mental health services, primary care and third sector organisations across the city to raise awareness of the service and ensure good links across agencies. Both IMHA and Community Mental Health Advocacy service:  
• Has a model of joint working for IMHA and Community Mental Health Advocacy service  
• Has a model of engagement with other mental health providers, primary care and third sector organisations as required. |
Target Group

**Independent mental health advocacy service:**

Is made available for the following groups of qualifying patients:

- Patients registered with GPs within Brighton & Hove.
- Patients of Sussex Partnership NHS Teaching Foundation Trust – ‘SPFT’
- For out of area patients. (The patient's responsible CCG/Council will need to make suitable arrangements for an IMHA to be made available).

Qualifying patients are defined as people who are:

- Detained under the MHA (even if they are currently on leave of absence from hospital) apart from those patients detained under sections 4, 5(2), 5(4), 135 or 136;
- Conditionally discharged restricted patients;
- Subject to Guardianship under the Act; or
- On Supervised Community Treatment (SCT). as well as patients not covered by any of the above but who are:
  - Being considered for a treatment to which section 57 applies (“a section 57 treatment”);
  - Under 18 and being considered for electro-convulsive therapy or any other treatment to which section 58A applies (“a section 58A treatment”). (See MHA, 130C (3))

**Community mental health advocacy:**

Is made available to mental health service users who are not detained under the act including:

- Patients registered with GPs within Brighton & Hove
- Patients of Sussex Partnership NHS Teaching Foundation Trust – ‘SPFT' not detained under the mental health act
- Specific focus to working with our vulnerable groups
  - LGBT  
  - Older people  
  - BME groups  
  - Groups with additional difficulties to accessing services such as people with disabilities, carers.
### Funding Allocation (maximum)

- £110,000 for IMHA
- £100,000 for community mental health advocacy

### Duration of funding agreement

Funding for 3 years from 1 April 2014 to 31 May 2017

### You may be invited to attend a clarification or negotiation meeting relating to your bid

Expected dates for these meetings – to be arranged between 13 and 29 August 2013

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### Advocacy Mapping Exercise January 2012 Summary of responses

47 responses received, of which 22 were from current providers of advocacy services in the city.

Of the 22 responses received by current providers:

Most providers defined the type of advocacy they deliver as:
- Assistance & support to people to articulate, exercise & defend their rights; (73%)
And/or
- Issue based advocacy focused on resolving specific issues (86%)

Advocacy is delivered by:
- Specialist staff (59%),
- Volunteers 45%
- Part of a wider job role (36%)

77% of providers determined priority for the service within the organisation

Average waiting time up to two weeks for 73% of providers

Main referrers were:
- Self referral (100%)
- Voluntary Organisations (68%)
- GP’s (68%)
- Adult Social Care (50%)
- Sussex Partnership Foundation Trust (45%)
- Brighton & Sussex University Hospital (41%)

Wide range in number of sessions provided from up to three (36%) and 13+ (36%)
Identified gaps by providers included specific services for:
• People with Physical Disabilities;
• LGBT;
• Women,
• BME,
• Young Adults,
• Dementia;
• Older People;
• Autism;
• dual diagnosis (both mental health/ learning disability and mental health/substance misuse);
• children as sibling carers;
• parents with learning disabilities going through child protection proceedings;
• provision to people with learning disabilities who do not meet the criteria for support from adult social care and people with complex needs needing long term input.

Gaps identified from the other 25 respondents:
• Women who are not engaged with statutory services in the city;
• The Roma community;
• Young people aged 19-25 with multiple needs;
• Advocacy for people using or wishing to use the transgender care pathway. Advocacy for older LGB&T people who use or wish to use social care or mental health services
• advocacy and advice in relation to money issues
• Bilingual Advocacy
• quality independent advocacy for people with learning disabilities
• Advocacy for parent carers on social care and health issues.
• Advocacy for disabled children and young people.
• Alleged perpetrators of crime who have a learning disability;
• Very limited advocacy services in Brighton for disabled and deaf people;
• No specific provision for people with Autistic Spectrum disorder;
• Acquired Brain Injury;
• Older people with mental health problems.
Appendix 2 – Terms of Reference for the Steering Group

Brighton & Hove Advocacy Needs Assessment Steering Group
Terms of Reference November 16

<table>
<thead>
<tr>
<th>Aims</th>
<th>The aim of the steering group will be to oversee the production of a needs assessment of advocacy in Brighton &amp; Hove. This will capture information about the need for advocacy services in Brighton and Hove, both present and future, current service provision and options for service delivery. The needs assessment will make recommendations for commissioners, service providers and decision makers to use to inform service design and commissioning decisions for advocacy services in Brighton and Hove.</th>
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</thead>
</table>
| Definition | An advocate’s role is to support and represent a person, always with regard to their wellbeing and interests, including helping a person to:  
• Understand processes;  
• Communicate their wishes, views and feelings;  
• Make decisions;  
• Challenge decisions;  
• Understand their rights;  
• When appropriate, support and represent them in the safeguarding process.  
(From http://brightonadults.proceduresonline.com/chapters/p_ind_advocacy.html#availability)  
The Care Act 2014 places a duty on local authorities to provide access to independent advocacy to those who would have substantial difficulty in being involved in care and support ‘processes’ and have no appropriate individual(s) – carer, family or friend – who can support their involvement. Under the Care Act, independent advocacy means a service that is independent of the local authority. Advocates under the Care Act will be managed by, and primarily accountable to, the advocacy organisation that recruits and employs them, thereby maintaining their independence from the local authority. A local authority or Clinical Commissioning Group may also choose to provide advocacy services for those individuals who are thought likely to benefit. |
| Objectives of the Steering Group | • To agree priority areas to focus on within the needs assessment  
• To agree a project plan, monitor progress and agree any revisions necessary as the project progresses  
• To provide specialist advice regarding  
  o community engagement/involvement  
  o provider engagement  
  o sources of evidence  
  o methodological issues  
  o service areas (provision and commissioning) |
To consider and resolve issues brought to the group
To comment on draft documents
To participate in developing recommendations
To approve the needs assessment report
To advise on the effective dissemination of the findings of the project including to service users and commissioners, decision makers and service providers

Reporting and governance
The final report and recommendations will be reported to:
Adult Social Services
Brighton and Hove Clinical Commissioning Group

Membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation/representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Rachael Hornigold (chair)</td>
<td>BHCC Public Health</td>
</tr>
<tr>
<td>Liz Tucker (project lead)</td>
<td>BHCC Public Health</td>
</tr>
<tr>
<td>Anne Richardson-Locke (sponsor)</td>
<td>BHCC Adult Social Care</td>
</tr>
<tr>
<td>Elaine Ramsay</td>
<td>BHCC Adult Social Care</td>
</tr>
<tr>
<td>Kerry Heyes</td>
<td>BHCC Carers Team/previous advocate</td>
</tr>
<tr>
<td>Michelle Pooley</td>
<td>BHCC Community Engagement Co-ordinator</td>
</tr>
<tr>
<td>Jane Lodge</td>
<td>BH CCG Head of Engagement</td>
</tr>
<tr>
<td>Linda Harrington</td>
<td>BH CCG Mental Health Commissioner</td>
</tr>
<tr>
<td>Alistair Hill</td>
<td>BHCC Public Health</td>
</tr>
<tr>
<td>Sarah Tighe-Ford</td>
<td>BHCC Equalities Co-ordinator</td>
</tr>
</tbody>
</table>

Meetings
The group will meet regularly starting in November 2016
The group will be administered by Public Health, BHCC

Working principles
All members will have equal voice in the meeting.
Members should use accessible language and be willing to explain technical terms. Meetings will be conducted in English.
As in conducting any needs assessment, no individuals should be identified by the needs assessment unless it is a) related to their professional capacity or b) with their explicit consent
All documents/drafts should be treated as confidential to the group members.
The group will aim to carry out as much business as possible in the meeting to minimize the number of group emails sent to members.

Media and communications
Brighton and Hove City Council is leading the delivery of the needs assessment, including leading on communications.
Wherever possible all Steering Group members will be actively involved in
agreeing communications; in return this will require group members to actively participate and respond promptly in this aspect of the project.

Any approaches by the media related to this project should be referred urgently to the Chair (Rachael Hornigold) and Project Lead (Liz Tucker)

| Reviews of Terms of Reference | The terms of reference will be reviewed in April 2017 |
Appendix 3 – Literature Search criteria

- **Sources searched**
  MEDLINE (1)
  BNI (0)
  CINAHL (0)
  PsycInfo (0)
  HMIC (0)
  Google (4)
  Google Scholar (3)
  Cochrane Library (0)
  Gov.uk (1)
  NICE Evidence Search (20)

- **Date range used** (5 years, 10 years): 2008-2016
- **Limits used** (gender, article/study type, etc.): None
- **Search terms and notes** (full search strategy for database searches below):
  The majority of helpful publications and resources were found via NICE Evidence Search which includes most of the guidance and examples of models of good practice. HDAS found mostly duplicate articles that were already retrieved from NICE.
Appendix 4: Innovation in Commissioning and Service Delivery

**Co-commissioning in Kent**

Co-production was used to support commissioning of advocacy services by Kent County Council in 2015. An commissioning event run by two independent consultants used a ‘World Café’[see appendix 2 glossary] approach to generate discussion about understanding what advocacy is and the important things about advocacy.

A steering group of people with support needs and carers was formed at the event to work with the commissioner to write the specification for advocacy services and define the outcomes.

The Council awarded the contract on 1 April 2016 to an advocacy provider who sub-contracted with eight other providers to make up Kent Advocacy (hub model).

Kent Advocacy provides a single point of access and assessment for all advocacy requests in Kent, and undertakes triage and prioritisation of referrals according to urgency, need and geography.

The service receives referrals from people who historically were excluded from commissioned advocacy services, such as people with sensory impairments.

A simple referral process, via a dedicated website, alongside other contact routes, makes referral accessible and easy.

Decisions regarding Kent Advocacy are made collectively by all providers in the network, enabling a supportive environment for problem-solving, and sharing good practice.

Commissioning continues to be guided by people who use the advocacy services.

**Learning**

The model is based on people and their advocacy needs but co-production is hard. Enable people to reach you from wherever they are in the stage of their journey.

Acknowledge the local authority is not the expert: ‘let go’ and trust the expertise of people who use advocacy services.

Give time to talk, avoid jargon, keep language simple.

Ask the market, the providers, who have the expertise and work together, not competitively.

Develop a sustainable model. There is a risk in a hub model of ‘putting all the eggs in one basket’ but this is a managed risk, with regular service review and close working relationship between partners and commissioner.

Consider how smaller organisations can contribute to the model – the solutions are often out there.

Working with other local authorities can be challenging, particularly in relation to out-of-area referrals, where commissioning approaches differ. Local authorities naturally prioritise resources to local demand.

**Outcome based Commissioning in Essex**

The current provision in Essex values provision of all kinds of advocacy, not limiting it to ‘statutory advocacy’ only. For example the value of citizen, volunteer, peer advocacy to support people who have a long-term need for advocacy was recognised in order to support continuity of support with the client seeing the same
advocate every time. Essex County Council aims to commission advocacy that is outcomes-focused, requiring services to show what difference advocacy is making to users.

The lead provider acts as a hub, directing access to the right advocacy service through the different partners.

The National Development Team for Inclusion produced an ‘Advocacy Outcomes Toolkit’ in 2016\(^\text{30}\). This is designed for use by services that provide advocacy support, and includes a variety of tools with which to measure performance, and sets these within the wider context of organisational development. Advocacy Services that applied this model would be able to assess the effectiveness of their provision against defined strategic goals and outcomes.

Another element of the work completed in Essex was the use of a ‘prioritisation matrix’ to help determine how waiting lists should be prioritised. It was proposed that a process for determining ‘eligibility’ for formal advocacy support was developed. It was agreed that this approach would ensure that those that were the most vulnerable had access to support but also reduce the duplication in the system. Formal public consultation was carried out and these areas agreed as key in determining if someone requires a formal advocate.

- Complexity of the advocacy issue
- Impact of the issue
- Support network(s) and ability to access community-based resources
- Individuals capacity to make decisions and ensure their voice is heard.

Essex have also developed a model of Citizen advocacy. Essex County Council has had a citizen advocacy service in Essex for a number of years but it had had patchy coverage. The review highlighted the importance of this approach to advocacy, building long-term partnerships to support people to make choices and have their voices heard. When the Care Act guidance was issued, Essex agreed that it needed to formalise the arrangements for citizen advocacy in Essex to provide long-term advocacy partnerships for people that were likely to have a repeat need for an advocate.

Essex is now tendering for a county-wide citizen advocacy service which will support 150 citizen advocates across Essex. This new service is due to be in place from 1 June 2015 and it is planned that if a person receives a service from the formal 1:1 advocacy route, if there is an ongoing level of need for that individual, they will then be referred to the Citizen Advocacy Service for that ongoing support. Both these models mean that Essex is in a good position to provide advocacy to the appropriate people when the Care Act regulations begin in April 2015.

The Manchester Advocacy Hub

The aim of the recommissioning in Manchester was to improve integration. The reason for doing this was to improve service provision but also reduce transaction

costs involved in having numerous providers. The objective was also for clients to experience fewer delays. A single gateway also meant people were given a consistent service. Service user consultation along side soft market testing resulted in retendering for the provision of a single gateway to a range of advocacy (hub model).

**Assessing need and preferences for Care Act advocacy service in Slough: Practice example**

This model looks at evidence drawn from wide variety of sources the local joint strategic needs assessment, who currently uses advocacy services, what local people understand about advocacy and its potential benefits, the barriers people currently experience in accessing care, which may best be addressed through improved access to advocacy, the types of advocacy services people want and need, how people currently access advocacy services and how they might choose to access services in the future and what people consider to be a good local advocacy service, which meets their needs.

Research was commissioned by the local authority and delivered by Health Watch. Their recommendations were: there should be a written strategy for advocacy, awareness of advocacy services should be increased, user views should be accessed, improve access and the recommendations should be reviewed.

**A single provider model in Cumbria: Practice example**

Commissioning Care Act advocacy as part of a block contract from a single provider was ‘paying dividends’ in Cumbria, where this was seen as a ‘cost-effective’ and appropriate way to deliver ‘seamless advocacy provision’ across diverse localities. A separate contract is held by another organisation to provide IMHA services. Critical to success in providing advocacy under the Care Act was the successful organisation having a good understanding of local issues.

A local advocacy organisation already commissioned to provide a generic service won a four-year contract through competitive tendering to provide a package including Care Act advocacy, NHS Complaints advocacy, IMCA, and Healthwatch advocacy. The contract has some inbuilt flexibility allowing the provider to move funds between different types of advocacy depending on actual demand and subject to agreement with the commissioner. Past experience of delivering generic advocacy meant the contract with this provider ‘naturally transformed into providing Care Act advocacy.

There is now no formal commissioning of non-statutory advocacy, apart from individual arrangements for some individuals, for example, when the courts have requested it. Bespoke advocacy was also recently commissioned for a group of people adversely affected by the flooding in Cumbria, in recognition of the impact on their services.

Success factors of its ‘thriving local offer’ from two providers (including the IMHA service) were the availability of a pool of people in the area willing to train as advocates, and the understanding and track record of the successful providers.

**Monitoring Care Act advocacy provision in Calderdale**

The outcomes used for monitoring were developed from a review of other local authorities’ service specifications for advocacy under the Care Act; a review of good
practice service specifications on the SCIE website and discussions with other commissioners.

The outcomes were then tested as part of market engagement. The provider is required to provide client feedback against the following five outcomes on a quarterly basis:

- percentage of individuals (service users and carers) who feel they have received information readily in respect of advocacy services and the service available in their particular circumstances
- percentage of individuals enabled to better understand and be involved in their care and support and health-planning processes and decision-making
- percentage of individuals who report an increased ability to negotiate arrangements and services to meet their need
- percentage of individuals who feel that advocacy services have contributed to achieving their personal outcomes
- percentage of individuals who feel empowered to challenge decisions.

**Lancashire County Council**

The advocacy landscape has been simplified for both staff and the public by creating a single point of access across all areas. The service has changed from a multitude of disparate user-group-specific services, which duplicated functions across the NHS and social care in Lancashire and Blackburn with Darwen, to a joined-up, clear and simple, single point of access. The demonstrable outcomes are:

- a whole-systems approach to advocacy agreed with six clinical commissioning groups and Blackburn with Darwen
- a single point of access with no postcode lottery in the Lancashire and Blackburn with Darwen areas, serving over 1.3 million people
- no gaps in advocacy provision for adults receiving health and social care services
- an increase in the number of people who are seldom heard getting help in health and social care processes and systems
- an increase in the number of children and young people who are supported with their health complaints
- joined-up children's and adult health and social care advocacy support
- a doubling of the number of people who are eligible under the Mental Health Act benefiting from their statutory right to independent mental health advocates.

**Total Voice Suffolk: a countywide advocacy partnership**

VoiceAbility, working closely with a range of local providers, developed a partnership model to respond to this ambitious vision and operated it initially for a one-year pilot during which the approach could be tested carefully. The model then moved to formal contract status following a tender exercise.

This model of integrated advocacy is:

- delivered by Total Voice Suffolk (TVS), a partnership of five Suffolk providers led by VoiceAbility
- accessed through a single point of contact
• provided as a fully integrated model, responding to evidenced need, and with flexibility to respond to variations in demand
• recorded on a single database, achieving consistency of data
• reaching a more diverse range of people
• significantly improving response times, with no waiting list
### Appendix 5 Specific areas of support provided by advocates

Table 27: Top 5 presenting issues for those in receipt of advocacy support for the specialist community service for mental health 2016/17.

<table>
<thead>
<tr>
<th>Top 5 presenting issues</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Access to Mental Health and Wellbeing services (inc treatment/diagnosis and physical health)</td>
<td>Housing/ Accommodation</td>
<td>Housing/ Accommodation</td>
<td>Access to Services (inc complaints, quality of services and communication with staff)</td>
</tr>
<tr>
<td>2</td>
<td>Legal Issues (family and relationships, including child protection)</td>
<td>Access to Mental Health and Wellbeing services (inc treatment/diagnosis and physical health)</td>
<td>Employment issues (inc disciplinary and tribunals)</td>
<td>Access to Mental Health and Wellbeing services (inc treatment/diagnosis and physical health)</td>
</tr>
<tr>
<td>3</td>
<td>Housing/ Accommodation</td>
<td>Legal Issues (family and relationships)</td>
<td>Access to Services (inc complaints, quality of services and communication with staff)</td>
<td>Housing/ Accommodation</td>
</tr>
<tr>
<td>4</td>
<td>Information on Benefits and Finance</td>
<td>Access to Services (inc complaints, quality of services and communication with staff)</td>
<td>Access to Mental Health and Wellbeing services (inc treatment/diagnosis and physical health)</td>
<td>Information on Benefits and Finance</td>
</tr>
<tr>
<td>5</td>
<td>Access to Services (inc complaints, quality of services and communication with staff)</td>
<td>Employment issues (inc disciplinary and tribunals)</td>
<td>Information on Benefits and Finance</td>
<td>Legal Issues (family and relationships)</td>
</tr>
</tbody>
</table>

---

31 The Brighton & Hove Advocacy Partnership. Referrals and Presenting Issues Annual Summary 2015-16
Table 28 Top 5 presenting issues for those in receipt of advocacy support for the specialist community service for older people 2016/17.

<table>
<thead>
<tr>
<th>Top 5 presenting issues</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Housing</td>
<td>Housing</td>
<td>Housing</td>
<td>Housing</td>
</tr>
<tr>
<td>2</td>
<td>Landlord &amp; tenant dispute</td>
<td>Legal</td>
<td>Social Care</td>
<td>Welfare Benefits</td>
</tr>
<tr>
<td>3</td>
<td>Social Care</td>
<td>Health</td>
<td>Legal</td>
<td>Social Care</td>
</tr>
<tr>
<td>4</td>
<td>Consumer</td>
<td>Finance</td>
<td>Health</td>
<td>Consumer</td>
</tr>
<tr>
<td>5</td>
<td>Noise complaint</td>
<td>Consumer</td>
<td>Landlord &amp; tenant dispute</td>
<td>Health</td>
</tr>
</tbody>
</table>

Table 29. Top 5 presenting issues for those in receipt of advocacy support for the specialist community service for vulnerable adults (autism) 2016/17. 32

<table>
<thead>
<tr>
<th>Top 5 presenting issues</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Child Protection/Family Court</td>
<td>Child Protection/Family Court</td>
<td>Child Protection/Family Court</td>
<td>Child Protection/Family Court</td>
</tr>
<tr>
<td>2</td>
<td>Housing</td>
<td>Health</td>
<td>Health</td>
<td>Housing</td>
</tr>
<tr>
<td>3</td>
<td>Health</td>
<td>Welfare Benefits</td>
<td>Other</td>
<td>Health</td>
</tr>
<tr>
<td>4</td>
<td>Welfare Benefits</td>
<td>Housing</td>
<td>-</td>
<td>Welfare Benefits</td>
</tr>
<tr>
<td>5</td>
<td>-</td>
<td>Other</td>
<td>-</td>
<td>Other</td>
</tr>
</tbody>
</table>

Table 30 Top 5 presenting issues for those in receipt of advocacy support for the specialist community service for adults with learning disabilities 2016/17.

<table>
<thead>
<tr>
<th>Top 5 presenting issues</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Housing and Accommodation (4)</td>
<td>Mental Health and wellbeing (4)</td>
<td>Housing and Accommodation (9)</td>
<td>Safeguarding (5)</td>
</tr>
<tr>
<td>2</td>
<td>Financial/benefits (3)</td>
<td>Family/relationships/Social Networks (3)</td>
<td>Family/relationships/Social networks (7)</td>
<td>Housing and Accommodation (4)</td>
</tr>
<tr>
<td>3</td>
<td>Employment/Education (3)</td>
<td>Legal (3)</td>
<td>Finance/benefits (2)</td>
<td>Family/relationships/Social Networks (3)</td>
</tr>
<tr>
<td>4</td>
<td>Family/relations/ Social Networks (2)</td>
<td>Housing and Accommodation (2)</td>
<td>Legal (2)</td>
<td>Mental health and wellbeing (3)</td>
</tr>
<tr>
<td>5</td>
<td>Legal (2)</td>
<td>Social Care and Health (2)</td>
<td>Safeguarding (2)</td>
<td>Finance and benefits (2)</td>
</tr>
</tbody>
</table>

32 The Brighton & Hove Advocacy Partnership. Referrals and Presenting Issues Annual Summary 2015-16
Table 31 Top 5 presenting issues for those in receipt of advocacy support for the specialist community service for adults with physical and/or sensory disabilities 2016/17.

<table>
<thead>
<tr>
<th>Top 5 presenting issues</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Benefits &amp; Finance</td>
<td>Benefits &amp; Finance</td>
<td>Benefits &amp; Finance</td>
<td>Benefits &amp; Finance</td>
<td>Benefits &amp; Finance</td>
</tr>
<tr>
<td>2 Housing &amp; Accommodation</td>
<td>Housing &amp; Accommodation</td>
<td>Housing &amp; Accommodation</td>
<td>Housing &amp; Accommodation</td>
<td>Housing &amp; Accommodation</td>
</tr>
<tr>
<td>3 Other</td>
<td>Other</td>
<td>Social Care</td>
<td>Social Care</td>
<td></td>
</tr>
<tr>
<td>4 Safeguarding</td>
<td>Social Care</td>
<td>Care Act</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>5 Health</td>
<td>Care Act</td>
<td>Other</td>
<td>Care Act</td>
<td></td>
</tr>
</tbody>
</table>

Figure 5 Areas around which advocacy services required in the Bilingual Advocacy Project 2015-16

### Appendix 6 – Community Research

#### Summary of advocacy services users, or potential users, engaged.

Numbers of people by type of engagement and by category of need/identity.

<table>
<thead>
<tr>
<th>Type of engagement</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview 1 to 1 (including face-to-face, phone, &amp; Skype)</td>
<td>19</td>
</tr>
<tr>
<td>Participants in focus groups</td>
<td>10</td>
</tr>
<tr>
<td>Online interaction e.g. via Facebook</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category of identity and need</th>
<th>Total number = 29</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex: Female</td>
<td>8</td>
</tr>
<tr>
<td>Sex: Male</td>
<td>16</td>
</tr>
<tr>
<td>Sex: Other</td>
<td>5</td>
</tr>
<tr>
<td>Age: under 25</td>
<td>5</td>
</tr>
<tr>
<td>Age: 26-49</td>
<td>12</td>
</tr>
<tr>
<td>Age: 50-64</td>
<td>11</td>
</tr>
<tr>
<td>Age: 65-74</td>
<td>0</td>
</tr>
<tr>
<td>Age: 75 or over</td>
<td>0</td>
</tr>
<tr>
<td>Ethnicity: White British, Welsh, Scottish</td>
<td>18</td>
</tr>
<tr>
<td>Ethnicity: any other White</td>
<td>4</td>
</tr>
<tr>
<td>Ethnicity: other</td>
<td>2</td>
</tr>
<tr>
<td>Ethnicity: Asian or Asian British</td>
<td>1</td>
</tr>
<tr>
<td>Sexual Orientation: Heterosexual / Straight</td>
<td>10</td>
</tr>
<tr>
<td>Sexual Orientation: Bisexual</td>
<td>4</td>
</tr>
<tr>
<td>Sexual Orientation: Gay man</td>
<td>4</td>
</tr>
<tr>
<td>Sexual Orientation: Gay woman/Lesbian</td>
<td>0</td>
</tr>
<tr>
<td>Sexual Orientation: other</td>
<td>5</td>
</tr>
<tr>
<td>Sexual Orientation: prefer not to say</td>
<td>2</td>
</tr>
<tr>
<td>Gender identity: same as at birth</td>
<td>21</td>
</tr>
<tr>
<td>Gender identity: different to at birth</td>
<td>4</td>
</tr>
</tbody>
</table>

| Disability: yes a little                               | 8                 |
| Disability: yes a lot                                  | 18                |
| Disability: none                                       | 3                 |
| Disability: Physical impairment                        | 10                |
| Disability: Sensory Impairment                         | 3                 |
| Disability: Learning Impairment                        | 7                 |
| Disability: Long-standing Illness                      | 8                 |
| Disability: Mental Health Condition                    | 13                |
| Disability: Developmental Condition                    | 3                 |
| Disability: other                                      | 3                 |
| Other health issues                                    | 6                 |

<table>
<thead>
<tr>
<th>Carer</th>
<th>none</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious or belief: atheist or ‘none’</td>
<td>11</td>
</tr>
<tr>
<td>Religious or belief: Christian</td>
<td>5</td>
</tr>
<tr>
<td>Religious or belief: other</td>
<td>6</td>
</tr>
<tr>
<td>Religious or belief: prefer not to say</td>
<td>2</td>
</tr>
<tr>
<td>Religious or belief: Agnostic</td>
<td>1</td>
</tr>
</tbody>
</table>
Community Research - Needs and issues leading to advocacy

Most interviewees were referred to an advocate by someone else, even though many of them had sought help from the organisation independently. There were only two examples of individuals being referred to advocates via NHS health care professionals (a Specialist Nurse) or Social Service staff (a Social Worker). Only one interviewee mentioned a health care practitioner (a specialist nurse) providing advocacy, in the form of writing letters to explain their hidden disability during disability benefit claims process.

The needs individuals described were varied and complex, with many individuals experiencing multiple challenges, diagnoses and disabilities (see interviewees’ profiles in appendix 5). The range of needs described are summarised in the table below. It is important to recognise the scale of issues some individual are dealing with and the multiple problems that one individual may be experiencing; the profiles in appendix 5 provide evidence of this.

Table 32. Summary of the range of needs and issues of the community research participants

<table>
<thead>
<tr>
<th>The range of needs and issues of the participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having their children taken away</td>
</tr>
<tr>
<td>Not knowing how to access state benefits at times of need</td>
</tr>
<tr>
<td>Having their disability benefits stopped without understanding why</td>
</tr>
<tr>
<td>Trying to get social care support, but finding the application forms impossible to understand</td>
</tr>
<tr>
<td>Being assessed because of the change over from Disability Living Allowance (DLA) to Personal Independence Payments (PIP)</td>
</tr>
<tr>
<td>Trying to get some support, but still feel they can be ‘independent’</td>
</tr>
<tr>
<td>Being harassed by neighbours because of their difference</td>
</tr>
<tr>
<td>Struggling to manage their physical and/or mental health conditions</td>
</tr>
<tr>
<td>Navigating NHS services, especially Mental Health services</td>
</tr>
<tr>
<td>Navigating getting a referral to NHS gender identity services &amp; the services themselves</td>
</tr>
<tr>
<td>Fighting alcohol or drug addiction</td>
</tr>
<tr>
<td>Not coping on a daily basis, due to mental health problems</td>
</tr>
<tr>
<td>Being put through tribunals and appeal processes to try and get state benefits</td>
</tr>
<tr>
<td>Living in temporary accommodation and unable to regain control of life</td>
</tr>
<tr>
<td>Not being able to explain their needs because of their learning disabilities</td>
</tr>
<tr>
<td>Being treated badly by people in society because of their learning disabilities</td>
</tr>
<tr>
<td>Worrying that their young son has autism, but unable to explain this to healthcare workers because of their lack of English language and their immigration status</td>
</tr>
<tr>
<td>Being in constant pain due to their physical ill-health</td>
</tr>
<tr>
<td>Losing their job and running out of money due to severe depression</td>
</tr>
<tr>
<td>Fearing being treated unfairly by professionals because of their identity as a Trans person</td>
</tr>
</tbody>
</table>
Appendix 7 – Stakeholder questionnaires

Do you use Advocacy Services?

This is a questionnaire about your experiences of accessing and using the support provided by our locally commissioned Advocacy Services.

In this questionnaire when we refer to Advocacy we mean a designated worker or service that:

• Helps someone to understand information
• speaks up for, or acts on behalf of, themselves or another person
• takes action to help people say what they want, secures their rights, represent their interests and helps people get the support they need
• makes sure people feel part of the community and can contribute to it
• provides Advocacy as part of Independent Mental Health Advocacy (IMHA) and Independent Mental Capacity Advocate (IMCA) and Care Act Independent Advocacy

When answering these questions think about the clients that you are currently working with.

Q.1 What is your job title or profession please write in the space below:

Q.2 Which organisation do you work for?

<table>
<thead>
<tr>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sussex Partnership Foundation Trust (SPFT)</td>
</tr>
<tr>
<td>Sussex Community Foundation Trust (SCFT)</td>
</tr>
<tr>
<td>Brighton and Sussex University Hospital (BSUH)</td>
</tr>
<tr>
<td>Brighton and Hove City Council (BSCC)</td>
</tr>
<tr>
<td>Other please write in the space below:</td>
</tr>
</tbody>
</table>
Q.3 When assessing clients do you consider whether they might benefit from access to an Advocate?

Yes ☐  No ☐

Please use the space below to tell us more about your answer.

Q.4 Thinking about the definition of Advocacy overleaf, do you feel that the clients you work with have needs that could be met through the use of an advocate? Please tick the box that applies to you:

Yes – go to Q. 4a ☐  No – go to Q.5 ☐

Q. 4a Yes - if yes which type of advocacy could they benefit from: Please tick all that apply

- Help to understand information
- Someone to speak up for them, or acting on their behalf
- Take action to help people say what they want
- Secure their rights
- Represent their interests
- Help getting the support they need
- Make sure people feel part of the community
- Can contribute to their local community
- Advocacy IMHA
- Advocacy IMCA

Q.4b Please use the space below to tell us more about your answer.


Q.5 Have you ever made a referral to an advocacy service?

Yes – go Q.6

No – if no go to question 5a

Q.5a Why haven’t you referred into an advocacy service?
Please tick all that apply.

- None of my clients have any need for Advocacy support
- I am not aware of local Advocacy Services, I do not know how to refer into local advocacy services
- I’ve had a previous negative experience
- The waiting times are too long
- I haven’t referred as family/carer are able to support the client
- Other – please use the space below to tell us more about your answer

Please go to Q.9

Q.6 How did you find the referral process into the Advocacy Service?

Easy – no problems

Neither easy or difficult

Difficult – lots of problems

Please use the space below to tell us more about your experience of referring into the service.

Q.7 How satisfied were you with the time scales from initial referral to your client accessing the service?
Q.8 Again, thinking about the definitions of advocacy that we are using here: how satisfied are you that the Advocacy Needs of your clients are met by the services currently provided in Brighton and Hove?

Very satisfied

Neither satisfied or dissatisfied

Very dissatisfied

Please use the space below to explain your answer, including any ways that you feel advocacy support could be improved.

Q.9 Please use the space below to explain your answer, including any ways that you feel advocacy support could be improved.

Q.10 Is there anything else that you would like to tell us about your experience of the advocacy needs of your clients?

Thank you for taking the time to complete this questionnaire. Please place in our post box.
Questionnaire for those who work as Advocates.

Please complete this survey if you work as an Advocate (either on a paid or voluntary basis). We are defining an Advocate as someone who:

• Helps someone to understand information
• speaking up for, or acting on behalf of another person
• takes action to help people say what they want, secure their rights, represent their interests and help them get the support they need
• makes sure people feel part of the community and can contribute to it

This survey is about your experiences delivering Community and/or Independent Advocacy.

All information provided as part of this survey will be treated in confidence.

Q.1 Which service do you work for? If you work for more than one organisation then please complete this questionnaire by thinking about the service with which you work the most.

- Mind in Brighton and Hove (MiBH)
- MindOut Lesbian, Gay, Bisexual, Trans & Queer Mental Health Service
- Age UK - Brighton and Hove
- Impetus - Brighton and Hove
- Speak Out – Brighton and Hove
- Possibility People – Brighton and Hove
- Sussex Interpreting Service – Advocacy Service
- POhWER
- I would rather not say
- Other

Q.2 Do you feel that all those who could benefit from access to your service are able to do so?

Yes – use the space below to tell us more about your answer

No – if no go to question 2b

Q.2b If no, please look at the options below and tick all the options that you feel may be affecting access:

• Awareness of local Advocacy Services
• People find the referral process difficult
• The waiting times are too long
• People prefer their family/carer to provide this support
• Other – please use the space below to tell us more about your answer
Q. 3 Looking at how Advocacy Services are delivered across the city are the anything that could be improved? Please use the space below:

Q.4 What are the three things that work well?
1.
2.
3.

Q.5 If you could make three changes what would they be?
1.
2.
3.

Q.6 Please use the space below to tell us anything else about how advocacy services are provided across the city.