Lothian Independent Advocacy Plan

2012 - 2016 Inclusive

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Language used throughout this document

Advocacy Partner
We have used this term throughout to refer to the person/ member of the public in receipt of independent advocacy

Independent Advocacy
When we use this term we mean providers of advocacy services where Independent advocacy and promoting independent advocacy are the only things the organisations do.

Independent Advocates
We use this term to refer to the person, either employee or volunteer who is the person that meets and provides independent advocacy support to the member of the public.

Advocacy Provider

We use this term to mean the organisation that delivers the actual advocacy to members of the public.

The Partners

We have used this term to refer to the five statutory commissioning agencies in Lothian, i.e.
NHS Lothian
City of Edinburgh Council
East Lothian Council
Midlothian Council
West Lothian Council

People with Protected Characteristics

We use this term to refer to people who have the following characteristics which have an enhanced level of protection in statute from the Equalities Act 2010.

The protected characteristics are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

Introduction

What is advocacy?

Independent advocacy aims to help people by supporting them to express their needs and make informed decisions. Advocacy reaches out to people in the community, who may be isolated, lack confidence to speak up, have lost faith in services, or be unaware that services and support exists.

Independent advocates are people who help individuals gain access to information and to explore and understand their options. Although many organisations like councils and health boards offer advocacy services, *independent* advocacy is unique in being as free as possible from conflicts of interest because it is the only service that the independent advocacy service provides**.**

Advocacy is not about securing the best interests of the person, but about protecting and supporting that individual's right to express his or her own view. The advocate has a responsibility to engage with the person in a manner, pace and place that is most appropriate to the individual. The overall aim is to support the person to express an informed view about an agreed issue.

Different types of advocacy

There are three main kinds of advocacy services. These are:

- *Professional, individual or issue-based.*

  This kind of advocacy is provided by both paid and volunteer advocates. The advocate supports a person to represent their own interests or represents the views of an individual if the person is unable to do so themselves. They provide support on specific issues and provide information, but not advice. This support can be short or long term.

- *Collective advocacy*.
  This is where a group of people who are all facing a common problem get together on a formal basis to support each other over specific issues. Individual members of the group may also support each other. The group as a whole may campaign on an issue that affects them all.

> "Where I think collective advocacy is so powerful is that an individual patient has very little voice, but when you get people acting together in support of each other, there's nothing more powerful."
> **Jim Kiddie, Extract from *Oor Mad History***

- *Citizen advocacy.*
  When an unpaid member of the community is matched with a person who needs someone to be on their side. A citizen advocate would not expect to receive any financial or material benefit from being an advocate. They support their partner in an open-ended, usually long-term basis.

Non-instructed advocacy

In some cases, the advocacy partner may be unable to express themselves and tell the advocate what they want. Examples of this may include people who have lost their speech through stroke, either temporarily or permanently, people with severe learning disabilities or people with advanced dementia. This list is not exhaustive.

In cases like this, the Scottish Independent Advocacy Alliance has guidance on ‘non-instructed’ advocacy.

Non-instructed advocacy is about:

- where possible, spending time getting to know the advocacy partner, observing how they interact with others and their environment and building a picture of the person’s life, likes and dislikes

- trying different methods of communicating

- gathering information about the person in a variety of different ways. This may include identifying past wishes or any advanced statement made, for example, living wills

- speaking to the significant others in the person’s life

- ensuring that the advocacy partner’s rights are respected

- taking account of the advocacy partner's likes and dislikes when decisions are being made and helping them make choices as far as is possible

- making sure all options are considered and that no particular agenda is followed

Background to the plan

This 2012-2016 Independent Advocacy Plan for Lothian is the fourth plan developed by the Lothian partners.

It is the work of five organisations, who are each responsible for ensuring the provision of independent advocacy services to people in the Lothians. These are:

- NHS Lothian
- City of Edinburgh Council
- East Lothian Council
- Mid Lothian Council
- West Lothian Council

Throughout the plan, these organisations are referred to as ‘the partners’.

The development of this plan has been dependent upon substantial contributions through consultation with advocacy partners, carers, organisations that provide independent advocacy services, and the wider public.

While previous plans covered three years, this new plan covers five, 2012 - 2016 inclusive. It is hoped that the longer time frame will be supportive in helping the partner organisations to work together with stakeholders and continue to improve the provision of advocacy services to the people who need it most.

Services currently available
The availability of independent advocacy services varies across the local authority areas in Lothian, which reflects the diversity of local populations and need. Services are currently provided to the following groups:

- children and adults with learning disabilities
- mentally disordered offenders
- children and adults with mental health support needs
- physically disabled adults
- older people
- people who have dementia
- carers of people with learning disabilities or mental health support needs
- adults at risk

A detailed list, by agency and location, can be found in Appendix 3.

Legal and policy developments

Since the last plan, published in 2008, there have been many important legal and policy developments which have influenced how we provide our services and our plans for the future.

- Adult Support and Protection (Scotland) Act 2007.
- Equalities Act 2010.
- Criminal Justice and Licensing (Scotland) Act 2010.
- Aggravated Hate Crime 2009
- Children's Hearing (Scotland) Act 2011
- Patient Rights (Scotland) Act 2011.
- Self Directed Support - a National Strategy for Scotland 2010.
- *Getting it Right for Young Carers*: The Young Carers Strategy for Scotland 2010 – 2015.
- The National Dementia Strategy and associated Dementia Standards of Care, 2011
- The Scottish Independent Advocacy Alliance (SIAA), various good practice documents.

For more details on these and other relevant legislation, see Appendix 2.

New legislation and policies have helped improve our understanding of gaps in the current provision of advocacy services.

For example:
The Patient Rights (Scotland) Act 2011 now protects the rights of all patients of NHS Scotland.

The Act gives all patients the right that the health care they receive should:

- consider their needs;
- consider what would be of optimum benefit to them;
- encourage them to take part in decisions about their health and wellbeing, and provide information and support for them to do so

Where patients need additional support to uphold their rights - in the first instance this will be provided by a new Patients Advice and Support Service which will:

- Provide information about the NHS and what it does;
- Help people to know and understand their rights and responsibilities when using the NHS;
- Help people who wish to give feedback or comments, or raise concerns or complaints about the care they have received; and
- Tell patients about other support services, ***like advocacy***, (our italics) or interpretation or translation services, which might be helpful to them.

This highlights the importance of considering, over the life of the plan, how to support independent advocacy organisations in extending the provision of independent advocacy to those who may now be sign posted to them from sources such as the above service.

The Equalities Act 2010 protects people from discrimination on the basis of protected characteristics (see page 3). Developing equalities-sensitive advocacy provision is an important part of this plan.

Criminal Justice and Licensing (Scotland) Act 2010. As part of the transfer of healthcare from the Scottish Prison Service (SPS) to NHS Scotland, we aim to look at the provision of independent advocacy for those prisoners who have a statutory entitlement to independent advocacy under the Mental Health(Care and Treatment)(Scotland) Act 2003 .

The value of advocacy has also been recognised for people with particular needs, who may not have previously had easy access to it. One example is "The Road to Recovery" 2008 which recognises the importance of advocacy in supporting families, and in particular children who are part of a family affected by alcohol or substance misuse to, for example, engage with and access support services

Local Issues

During the term of the last 2008 - 2011 Lothian Independent Advocacy Plan there has been a full review of the commissioning of independent advocacy services undertaken by City of Edinburgh Council in partnership with NHS Lothian. This is discussed in more detail on page 16.

Working in partnership

NHS Lothian and the four Lothian local authorities mentioned above, "the partners" are committed to hearing the views of everyone involved with advocacy in the development and subsequent implementation of this plan

We recognise the expertise and knowledge of independent advocacy providers across Lothian, while remaining sensitive to the potential for conflicts of interest around business opportunities. With this in mind, the Lothian partners are committed to ensuring that all providers of independent advocacy have the opportunity to engage with the development, monitoring and review of this plan

This plan has been developed taking into account the Scottish Health Council Participation Standards (2010) an abbreviated version of the standard is included here at Appendix 7.

Relationships and networks have been more formally recognised reflecting the importance of supportive partnerships across and with all stakeholders throughout the life of this plan in order to achieve our stated commitments.

These are currently referred to as:

1. Lothian Independent Advocacy Steering Group
2. Lothian Independent Advocacy Providers Reference Group**
3. Lothian Independent Advocacy - Network of Engagement with Advocacy Partners Groups **

**These groups will, as an early action - determine their own titles.

The membership of the Lothian Independent Advocacy Steering Group reflects the 5 partner agencies, and representatives from the Providers Reference Group.

We are currently negotiating with Advocacy Partners to establish how they want to engage with the over arching steering group.
Essentially we want to ensure that the voice of stakeholders is a fundamental part of every meeting.

The remit of the Steering Group is:

- to support the sharing of good practice to build on the consistency of delivery of quality services across Lothian
- to support and build on the engagement of stakeholders to ensure as wide and robust engagement as possible
- to support the continued work to reduce barriers and maximise the availability and accessibility of independent advocacy to people with protected characteristics who may be harder to reach
- to support the development of peer review.

The remit and membership is enclosed in full at Appendix 4.

The Steering group is also responsible for the delivery, monitoring and equality impact analysis of the annual advocacy action plan. The Action Plan for 2012 is enclosed at Appendix 1 of this document.

Lothian Independent Advocacy Providers Reference Group

This group has been established to provide a forum of all providers of independent advocacy across Lothian to support the sharing of good practice and innovation, assist the Steering Group in delivering the Lothian Independent Advocacy Action Plan and to work towards the reduction of duplication of effort, for example, in the development and delivery of training for advocates.

Lothian Independent Advocacy - Advocacy Partner Engagement Plan

It is recognised that there are a number of well established groups of Advocacy Partners across Lothian. Rather than create another group, it was agreed that a period of negotiation with those already in existence would be undertaken to establish how they wish to engage with the work of the Steering Group, if indeed this is something they do want to do.

It is noted that not all groupings of advocacy partners have established fora and we need to ensure we create appropriate accessible opportunities for people from all areas of Lothian and from each "grouping" of advocacy partner. For example: there is not an established collective group for disabled people who are users of advocacy services.

Part of the remit of all of the above groups and engagement networks will be to develop effective and ongoing engagement with advocacy partners across Lothian, for example collective advocacy groups, to ensure that we provide opportunities for engagement in its widest sense - and do not restrict this to those individuals who are members of the currently established groups.

Review of the Lothian Independent Advocacy 2008-2011 Action Plan

A consultation event was held on 15 June 2011 at The Quay in Musselburgh to review the 2008-2011 Lothian Independent Advocacy Plan.

Over 50 participants attended the event. They included advocacy partners, organisations who provide advocacy services, as well as representatives from the five partner organisations.

Key messages

These are the main issues from the consultation:

1. There has been some success in increasing the level of investment of advocacy across Lothian.

2. The partners have been successful in addressing some of the gaps in independent advocacy (for example, providing independent advocacy to people with physical disability in some parts of Lothian).

3. The move towards joint Service Level Agreements (SLAs), which have now been delivered in the majority of areas, was viewed as a step in the right direction. SLAs are contracts drawn up with service provider organisations to provide services.

4. Equality Impact Assessment came too late in the process last time and the opportunity to address many of the issues was felt to have been lost.

5. The partners accepted that they did not deliver on the ambition to have ongoing engagement/ annual events throughout the life of the plan.

6. It was noted that there was a related review of independent advocacy provision in Edinburgh, carried out by NHS Lothian and City of Edinburgh Council. More detail about this is included at page 16.
   This required a significant investment in time of monitoring officers from both CEC and NHS Lothian, It was accepted that there is now a requirement to invest time and focus in the other areas to ensure equity of access to advocacy services across Lothian.

Going forward

It was agreed the following themes should be part of the 2012-2016 plan:

1. A need to bring providers of independent advocacy across Lothian together in a Providers Reference Group to support multi agency working and collaboration

2. An annual consultation event should be established and delivered

3. The monitoring of advocacy services across all organisations needs to be more consistent across the different localities

4. Users of services should be involved in this monitoring and reporting

5. Collaborative work needs to be done to address the needs of people with protected characteristics more successfully

6. An awareness programme needs to be developed across Lothian to promote independent advocacy amongst staff groups. It was agreed any such programme would have greater success if users of advocacy services were part of the training

7. The need to work to deliver information in “easy read” formats

8. The need to ensure that advocacy is not a substitute for getting the basics right when providing services

Discussion groups

The afternoon session of the event focussed on discussion to help us identify initial thoughts about the increased entitlement to advocacy and our legal responsibilities to ensure availability and access. The partners were keen to discuss creative ideas with advocacy partners and organisations about ways in which the partners might respond to these increased duties.

Ideas from these discussions included:

- recognising that we have to respond to groups which have an existing entitlement to advocacy services before we can expand further

- a suggestion that perhaps organisations need to consider offering advocacy services that are less specific to certain groups. It was also suggested that we need to recognise that people have multiple needs and different aspects to their identity

- concerns were raised from advocacy partners that increasing entitlement to "new groups" would put their existing services under pressure or at risk

- concern that we could not / should not prioritise areas for service development as this would immediately exclude some groups or suggest that their needs are not as important

Some specific suggestions that need to be looked at during the life of the 2012-2016 plan included:

- explore how we address early intervention and prevention

- finding a balance between prevention, recovery and legal duties

- exploring how we fully include the experiences of advocacy partners in future service development?

- how we will develop and enhance existing services to meet the needs of people with protected characteristics as flexibly as possible

- understanding the benefits and added value of both independent and non-independent advocacy services

- finding ways to respond to the needs of other groups not mentioned to date (for example, people with autism/ Aspergers Syndrome and people with addictions)

- how we will consider the differences between how advocacy works in rural and urban areas and influence the development of services with this in mind

- how we will "test" different models in different areas. For example, advocacy engagement with young carers or people with protected characteristics in rural areas, or advocacy in prisons in Lothian. Lessons learned can then be expanded to other areas and/or providers in Lothian as appropriate.

Consultation and Development of the Action Plan for 2012 - 2016

A number of further consultation events were held to specifically explore the above issues and more directly inform the development of the priority actions for year one of this 5 year plan.

Recognising the different environments, experiences and populations across Lothian, three events were held in September hosted by East and West Lothian Councils, with the final event hosted by City of Edinburgh Council:

- 13 September- morning: East Lothian. The Stables Pavilion, Musselburgh - this event was for interested people from both Mid Lothian and East Lothian Council areas.
- 13 September - afternoon: West Lothian Ability Centre, Livingston
- 30 September: City of Edinburgh. Waverley Gate, Edinburgh.

There was also a final feedback event which included stakeholders from across all the local authority areas. This event was hosted by NHS Lothian on 16 December 2011 and reported back on the information gathered from the

discussions at the September consultations and presented a final draft of the action plan for 2012.
The events in September focussed on particular areas; examples of the outputs from each area are given below:

The Development and Delivery of Training to Raise Awareness of Independent Advocacy

We wanted to know how we can make sure the training about advocacy is as good as possible.

Some of the ideas that were consistently suggested to us included:

- supporting advocacy partners to become fellow trainers, involving people in the design and the delivery of advocacy training.
- making sure the training includes information about the Scottish Independent Advocacy Alliance (SIAA) Principles and Code of Practice
- being flexible about the times of availability of the training to try and ensure it is accessible to the people we most want to target.
- evaluating the training to monitor its effectiveness

Outcomes and the Impact provided by Advocacy

We wanted to explore how we could work with providers and advocacy partners to identify and gather information that demonstrates the positive impact that independent advocacy can have.

Stakeholders discussed a huge variety of options including the suggestions that we:

- give consideration to developing an on line review function
- provide a third party for people to feed back to, as a means of providing the feedback anonymously if that is the individual's preference
- seek to develop universal protocols with all Lothian providers to deliver a consistent approach to the gathering of user feedback

A consistent message from all consultation events was the concept of developing peer review amongst Lothian providers as a method of evaluation from subject experts, building on local best practice and continuous development of services which understand the local need.

Provision of information about independent advocacy

We wanted to think about what we can change to make sure that we work well with different groups of people from across Lothian including:

- ways in which we can let then know about independent advocacy

- making it easier for people to find out about independent advocacy, and understand how it can support them

- make advocacy more accessible to them regardless of whether they live in the city or in rural communities

Suggestions for delivering against this included the use of local and social media, for example community newspapers, local radio stations, Facebook etc.

It came across strongly that all information should be culturally accessible in the widest sense, i.e. not just community languages but having a dialogue with different parts of the population from across Lothian to support accessibility, for example; on what a shared understanding is of the definition and impact of independent advocacy.

It was acknowledged that we need to listen to and learn from the lived experiences of the people we are designing / delivering services for and to, also that we must be prepared to act on the learning from these experiences and be prepared to change as a result of those in line with the Patient's Rights Act.

It was also recognised that we should work collaboratively to build on the relationships between collective advocacy groups and community planning structures to raise awareness and understanding of the availability of advocacy.

With regard to the issues of urban and rural environments it was broadly agreed that we should use existing community information options as creatively as possible to be more successful in advertising the availability and potential supports available through independent advocacy. The role of advocacy in helping to tackle social and cultural isolation would be considered as part of this.

We used all the information gathered from these events to develop the action plan for 2012 which is included here at Appendix 1, page 23.

NHS Lothian and City of Edinburgh Council Review 2009 - 2011

As already noted, City of Edinburgh Council, with NHS Lothian undertook a review of the delivery of independent advocacy within Edinburgh. This review concluded in February 2011.

The purpose of the review was to look at different ways of delivering services, which would ensure that all client groups have equal access to them. It also looked at ways of making potential financial savings, by reducing management and infrastructure costs.

The review focussed on the availability of advocacy services for:

- people with mental health support needs and their carers (individual and collective advocacy)
- people with learning disabilities (individual and collective advocacy)
- older people (individual and collective advocacy)
- people with a physical disability (individual advocacy)

Following the conclusion of the review the commissioning partners undertook a procurement exercise to recruit organisations to deliver these services. The procurement of independent advocacy services for Edinburgh concluded with the newly commissioned services becoming operational from 1st December 2011.

The outcome of the review reduced the number of providers and enables savings to be reinvested in advocacy provision, addressing the gaps in service which had been identified.

While it is recognised that this was a difficult process for all involved, and that advocacy services across Edinburgh will require a period of time to become established within the parameters of the new commissions, the aims of the Lothian Independent Advocacy Plan remain the same.

Next steps: developing this plan

Assessing wider need across Lothian

NHS Lothian, along with all other Health Boards in Scotland, received funding from the Scottish Government to review current gaps and identify potential inequalities in the way independent advocacy services are provided

The NHS Lothian needs assessment was undertaken in parallel with the other consultation events that informed this plan.

The NHS Lothian Health Needs Assessment of Advocacy defines relevant terms. It describes the groups included within the needs assessment, its aims and methods as well as its limitations. Finally it summarises overall findings on unmet need, and suggests developments in current advocacy provision (and how it is supported by the statutory sector) in order to address this need.

The definition of a "Health Needs Assessment" applied in this case is "a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities".

To begin with, the needs assessment focussed on the groups known to have poor health outcomes and health service experiences:

- black and minority ethnic groups (including Gypsy/Traveller and refugee and asylum-seeker communities)
- lesbian, gay, bisexual and transgender people
- homeless people
- people dependent on drugs and alcohol
- prisoners and ex-offenders
- people living in areas of multiple deprivation
- people with low levels of health literacy

There is obvious overlap between many of these groups: it is known that prisoners, for example, are more likely to come from deprived areas and also have low levels of health literacy.

We are also aware that there are other groups not mentioned above who may have needs for independent advocacy which we are not yet meeting. These groups may also be unaware of, or find it difficult to access existing advocacy services. For example: the needs of specific groups such as those experiencing the consequences of sexual abuse or gender-based violence have been highlighted since we embarked on this exercise. However, we hope that through an initial focus on the groups mentioned above, we will identify general pointers regarding other potential inequalities in service provision.

How can advocacy help people who currently experience difficulty in accessing services?

Focusing on the groups defined above, the review investigated:

- The potential for independent advocacy to improve their health service experiences
- How their needs for advocacy are currently met in Lothian
- Models for providing advocacy sensitive to their particular needs and protected characteristics

The needs assessment drew upon:

- local data on the health and health service experiences of these groups
- the views of staff who work with them
- UK projects which have tailored advocacy to the particular needs of certain groups.

We also sought the views of all of Lothian's existing independent advocacy providers to see whether they believe they are as accessible as they would like to be when it comes to reaching these groups, their perceptions of barriers of access, and views on potential ways in which these could be overcome.

The Needs Assessment in full is attached to this report at Appendix 5, however an executive summary is provided here.

- There is a disproportionately high level of mental distress or ill-health for many people in all of the defined groups, and some groups also have disproportionately high prevalence of learning disability. Examples include a high prevalence of mental ill-health amongst Gypsy Travellers, prisoners, LGBT people, and members of some black and minority ethnic groups (such as asylum seekers and African and Caribbean men). These patterns are linked, among other factors, to histories of stigma, discrimination and poverty.

- There is evidence in all groups of difficulties in articulating health needs, and a lack of awareness of their right to healthcare. There is evidence of difficulty in engaging with health service providers. The factors underpinning this are distinct for particular groups. They include lack of trust in service providers based on past experiences or fear, and the barriers experienced through not sharing language or cultural understandings of health and illness with service providers.

- Advocacy has a clear role in supporting people in different groups to engage with health services, alongside wider ongoing work to tackle inequalities in health service provision. This includes tackling and dismantling stereotyped ideas such as certain communities "look after their own" and therefore either will not access or do not require assistance from services such as the NHS.

- Providing advocacy for particular groups calls for a range of distinctive skills, knowledge of specialist networks and appropriate practical arrangements (for enabling advocacy to be provided in prisons, for example).

- There is considerable expertise in Lothian in addressing the issues arising from the need for inclusive advocacy services, however this is currently fragmented.
  Lothian is fortunate to have a range of voluntary sector organisations with skills and expertise in working with the defined groups. While many of these advocate for their service users, this advocacy is not independent. Meanwhile, independent advocacy organisations are increasingly striving to provide their services to diverse local communities. Despite pockets of good practice, many are constrained by resources.

- Various models have emerged for providing advocacy to those from the defined groups. This includes dedicated projects serving specific groups; ‘universal’ advocacy services which strive to be inclusive; and the forging of strong associations between independent advocacy organisations and those organisations with expertise in working with the defined groups.

- Partners have an important role to play to support inclusivity in advocacy services through, for example, disseminating and enabling existing good practice in inclusive advocacy; actively fostering productive associations between independent advocacy providers and other community organisations; and piloting inclusive forms of practice.

The Recommendations which emerged from the Health Needs Assessment are:

- Directly seek the views of members of the defined groups on independent advocacy during the first twelve months of the 2012 – 2016 plan in order to incorporate their views into the development of advocacy provision. This should be both in relation to general health (in response to the Patients’ Rights Act) and those who have a statutory right to advocacy.

- NHS Lothian and its Local Authority partners should support the sharing of existing local good practice in inclusive advocacy provision between independent and other advocacy providers; and create opportunities to learn from advocacy providers dedicated to particular communities of interest elsewhere in the UK.

- In response to the Patients' Rights Act, and use of any additional associated resources, NHS Lothian and its Local Authority partners should support a structured sharing of expertise between independent advocacy providers, voluntary sector organisations and statutory services well-established within communities who are marginalised, and where there are specific barriers to service uptake.

- NHS Lothian will work to directly support greater inclusivity in provision of independent advocacy services, including working to ensure that lack of communication and interpretation support does not constitute a barrier of access to advocacy, and that monitoring and equalities data in Lothian is made easily accessible to advocacy providers.

- Advocacy is an important part of wider activity to address health inequalities, but is not in itself a substitute for good service provision. Major issues identified by advocacy providers are valuable indicators of areas where focused inequalities work within the health services is needed. NHS Lothian should encourage and support dialogue with advocacy providers to make optimum use of this experience.

  The picture of need for advocacy in Lothian and Scotland as a whole is a dynamic one, and new waves of migration and deepening economic recession are likely to have an impact on advocacy need. The groups who potentially have unmet need for advocacy and what is necessary to meet this should be regularly reviewed, in partnership with existing advocacy providers and the voluntary sector.

- Resources should be made available to test and evaluate methods for providing advocacy in ways which are sensitive to the needs of specific groups and take account of protected characteristics.

Equality Impact Assessment

Stakeholders supported an equality impact assessment, which is referred to in NHS Lothian as a Rapid Impact Assessment (RIA), of both the needs assessment and the (then draft) action plan for 2012.

Two different sessions were held with advocacy partners and advocacy providers respectively.

The outputs from both RIAs have been combined and the recommendations incorporated into this plan are reflected below:

Advocacy Training

Equality and diversity and cultural sensitivity should be embedded in advocacy training and advocacy awareness events.

We need to expand the training to carers and to Care Home Staff groups and amend the language and focus of the awareness training accordingly to encompass and respond to cultural differences.

We will support advocacy partners to become deliverers of training.
This support needs to include time and investment in building the confidence of advocacy partners to undertake this role.

Information about Advocacy

Standards about core information will be agreed and applied across all providers within Lothian.

Partners and stakeholders will seek to develop relationships with other groups who are already working successfully with particular communities e.g. travellers, to raise awareness about advocacy and tackle barriers to access.

Partners will support the consistent availability of interpretation services for advocacy partners.

Making Advocacy Accessible to as Many People as Possible

It was recommended that we needed to further develop equality monitoring to help us identify uptake and use of advocacy from people with protected characteristics and those living in areas of multiple deprivation.

It was also reinforced that we, i.e. partners and providers need to go to where people are, rather than expect them to come to us. We were reminded that this may include a period of time to build up trust with various communities before they are prepared to share their stories, experiences and needs with us.

Performance monitoring - how we will measure our progress

The Lothian Independent Advocacy Steering Group (LIASG) consists of representation from all five partner organisations and is currently chaired by NHS Lothian. It will meet on a minimum of a quarterly basis for the life of this plan to ensure regular and consistent monitoring of progress.

The Steering Group will report annually to the Mutuality and Equality Governance Committee to demonstrate progress, and less formally, to the Improving Patient Experience Group.
The Chair of the Steering Group also reports to the NHS Lothian “Involving People Group" chaired by the Associate Nurse Director.

As agreed though consultation with advocacy partners and providers, the Steering Group will host an annual event to report back on progress, review what needs to be done, and build on our learning and successes.

The financial situation

As with all public services, opportunities for investing in the advocacy sector have been significantly reduced as a result of the national financial climate. Partners have continued to work to promote the unique place of advocacy within health and social care and have been successful in securing opportunities, however small, for growth in investment which is welcomed by all.

Across the Lothian local authorities, in response to the additional duties encompassed in the Adult Support and Protection (Scotland) Act 2007, all four local authorities have invested in advocacy services.

In addition, NHS Lothian has received a recurring allocation of £73,000 per annum from Scottish Government for investment in advocacy services.

The proposed allocation of this funding, plus reinvestment of NHS Lothian efficiency savings back into advocacy services are included in the 2012 action plan, Appendix 1.

Detail of the current level of financial investment, excluding the new resource indicated above is show in Appendix 3.

Appendix 1

Year One

Action Plan 2012

Commitment 1 - Continuing Engagement & Involvement

Outcome: Improved involvement of Advocacy Providers and Partners in the delivery of the Action Plan

	Action for the Steering Group	**Lead**	**Progress Reports Due**
1.1	The Lothian Independent Advocacy Steering Group (LIASG) will support the setting up of a Lothian wide Providers Reference Group to support the delivery of this action plan.	Chair	May 2012 Aug 2012 Nov 2012 Feb 2013
1.2	The LIASG and Lothian wide Providers Reference Group will support the development of a network of engagement with Advocacy Partners across Lothian to support the delivery of this action plan.	Chair Allocation £5,000	As above
1.3	We will ask the Providers and Advocacy Partners Reference Groups to agree the best ways for service users to tell us what they think about independent advocacy, particularly; • for people to tell us if they felt supported to be heard • to also ask people if they felt supported to understand the meetings and/or processes that they are involved in e.g. Adult Support and Protection investigations and case conferences	LIASG	May 2012 Aug 2012 Nov 2012 Feb 2013

1.4	We will review the mechanisms of LIASG to ensure representation from both the Providers and Advocacy Partners Network.	Chairs of providers and service users reference groups	May 2012

Commitment 2 - Training and Awareness Raising

Outcome: The capacity of Advocacy Providers, Partners and Carers to deliver awareness raising and training on advocacy is increased

	Action for the Steering Group	**Lead**	**By When**
2.1	We will ensure training is developed and delivered for NHS and Local Authority staff groups and carers in partnership with people with lived experience. We will ensure that advocacy partners are involved as trainers to join us in delivering training sessions. We will ensure this is in line with SIAA Principles and Guidelines We will offer this training to 3rd sector and private provider staff teams.	Chair Allocation £15,000	May 2012 Aug 2012 Nov 2012 Feb 2013

2.2	We will work with advocacy partners trainers to support them in developing their training skills, in conjunction with the Providers Reference Group	LIASG	May 2012 Aug 2012 Nov 2012 Feb 2013
2.3	We will work with Providers to support their delivery of awareness raising and training to staff groups, carers, advocates and volunteers.	LIASG	May 2012 Aug 2012 Nov 2012 Feb 2013
2.4	We will ensure delivery of on -going training for paid and unpaid volunteer advocates on universal issues, for example, new legislation or national policies that apply to all. We will assist in the provision of materials and offer places in established training opportunities if available and where relevant.	LIASG	May 2012 Aug 2012 Nov 2012 Feb 2013

Commitment 3 - Giving and Receiving Information

Outcome – Information on advocacy services will be fully accessible to all those who are eligible in the Lothians

	Action for the Steering Group	**Lead**	**By When**
3.1	We will make general and local information about independent advocacy for users, carers and support staff available on each of our websites, in the full range of formats and make this available to other partners We will ensure this information is updated annually	Lothian Local Authorities and NHSL leads Allocation £5,000	Completed April 2012 Feb 2013
3.2	We will agree an on-going communication strategy which will include an annual 'Lothian Advocacy Awareness Day'.	Linda Irvine Allocation £3,000	November 2012
3.3	We will encourage access and promote information about advocacy services, through ongoing work with groups who are already working with people with protected characteristics	Lesley Boyd Allie Cherry Judith Sim Allocation £3,000	May 2012 Aug 2012 Nov 2012 Feb 2013

Commitment 4 - Raising Awareness with people who may have experienced exclusion, disadvantage and/or social isolation to support them to access Independent Advocacy Outcome: Improved knowledge and understanding of advocacy and service accessibility for those who have previously experienced barriers to access services			
	Action for the Steering Group	**Lead**	**By When**
4.1	We will consult with communities to; • Learn from their experiences, to help shape the way that their particular needs can be met in the future in different ways, with a particular focussing on working with Gypsy Travellers and people experiencing Homeless • Explore what supports are useful for people who experience barriers in accessing independent advocacy services based on outcomes of equalities monitoring.	LIASG Allocation £15,000	Throughout 2012 To begin March 2013
4.2	We will develop and deliver a programme for small community grants to support creative approaches to developing awareness and access to advocacy services. The launch of the programme will be publicised at the same time as the launch of the Advocacy Strategy	Linda Irvine Allocation £15,000	
	The mechanism for application, award and evaluation of the impact of the grants will be agreed by LIASG.	Linda Irvine	July 2012

4.3	We will host a test period throughout 2012 to provide independent face to face or telephone interpreting services to advocacy partners who require this service, to support equity of access to independent advocacy and use this to understand better how often this might be required.	Chair Allie Cherry Allocation £15,000	May 2012
4.4	We will explore opportunities for training for interpreters to include consideration of the advocacy relationship and, if possible, consideration of the sensitivity required in the provision of advocacy in therapeutic settings. This work will also ensure links with other Lothian and national training developments, particularly across the field of mental health.	Judith Sim Lesley Boyd Linda Irvine	May 2012 Aug 2012 Nov 2012 Feb 2013

Commitment 5 - Working to address identified gaps

Outcome: Services to groups who have not previously been in receipt of advocacy will be improved

	Action for the Steering Group	**Lead**	**By When**
5.1	We will work with HMP Edinburgh and HMP Addiewell to provide advocacy services to prisoners	Chair Linda Irvine Allocation: TBC	May 2012 Nov 2012
5.2	We will work with the Alcohol and Drug Partnerships across Lothian to understand how advocacy can support people whose lives are affected by	Jamie Megaw	May 2012 Nov 2012

	substance misuse, including children and young people.	Allocation: TBC	
5.3	We will consider and learn from the outcomes and recommendations following the national consultation on improving advocacy for children and young people.	LIASG	April 2012
5.4	The LIASG will determine how efficiencies, new monies and investments will be allocated most effectively to meet the identified gaps, issues raised by the needs assessment and meet new requirements including the Patient Rights (Scotland) Act 2011	LIASG	February and August, annually
5.5	We will continue to make a concerted effort to attract new resources to support continued investment into advocacy services.	LIASG	February and August, annually

Commitment 6 - Implementation, Monitoring, Annual Review and Action Planning

Outcome: Increased effectiveness of monitoring, review and reporting procedures to enhance service provision and uptake of advocacy services for those with protected characteristics and at risk groups

	Action for the Steering Group	**Lead**	**By When**
6.1	The LIASG will meet at least four times a year to monitor progress of the implementation of the plan, and to develop the Action Plan for the following year The Steering Group will also discuss issues and learning from the monitoring of contracts	Chair	Jan 2012 Nov 2012
6.2	We will monitor the diversity of those accessing services to gauge who advocacy is reaching and identify where gaps remain. We will use this information to inform the action plans for future years to address any barriers to access.	Chair	December 2012
6.3	We will consider the SIAA training about Social Return on Investment, and how this can help improve the health and social care outcomes for advocacy partners, plus assist commissioners and providers in the identification and evaluation of advocacy outcomes.	In partnership with the Providers Reference	Aug 2012

		Group	
6.4	The LIASG will host a yearly event to review the action plan delivered in that year, consider how the plan is progressing and inform the development of the action plan for the next year. This event will happen every December	Chair Allocation £2,000	October 2012
Commitment 7 - Developing Co- Production and Building Social Capital **Outcome: Improvement in service provision through learning from practice**			
7.1	We will host learning sessions to facilitate the sharing of learning amongst advocacy providers and partners to develop our understanding and approaches to/ support of community engagement, community participation, building social capital and co-production	Chair	Summer and Autumn 2012
7.2	We will learn from organisations that have undertaken the Social Return on Investment Programme and, following review consider the wider application of this across advocacy provision throughout Lothian.	In partnership with Providers Reference Group	August 2012

Appendix 2: Legislation and Policies

There have been many pieces of legislation since the 1990s that have had an influence how advocacy services are delivered. These include:

Adult Support and Protection (Scotland) Act 2007. This Act imposes a duty on local authorities working with adults at risk "to have regard to the importance of provision of appropriate services (including, in particular, independent advocacy services) to the adult concerned."

Adults with Incapacity (Scotland) Act 2000. This act aims to help people (age 16 and over) who lack capacity to act or make some or all decisions for themselves. It introduced arrangements for making decisions about personal welfare and managing the finances and property of individuals whose capacity to make or carry out specific decisions is impaired. It allows carers and others to have authority to act and make decisions on their behalf.
Visit: www.scotland.gov.uk/Topics/Justice/law/awi

Aggravated Hate Crime 2009. An aggravated hate crime is an offence against a person motivated by religious or racial hatred or as a result of their actual or presumed disability, sexual orientation or transgender identity. In most cases, if it is proven that aggravated hate crime was the main motivation for the offence, sentencing will be more severe.
Visit www.equalityhumanrights.com

Children's Hearing (Scotland) Act 2011. This new Act is intended to come into force in April 2012, and will make major change to the processes and procedures around Children's Hearings/ children's panels etc. This Act also brings into law the right of the child or young person to be supported by independent advocacy.

Children's (Scotland) Act 1995. Provided for the entitlement to have a representative present at a Children's Hearing. This can be a person that children and young people choose to support them such as a member of their family, teacher or advocate.

Criminal Justice and Licensing (Scotland) Act 2010. This act includes a number of reforms to the criminal law and court procedures to protect the rights of victims and witnesses. Special measures will be available to child and adult vulnerable witnesses in all criminal proceedings in Sheriff and High Court as well as in trials.
This Act is also the legislative driver which is enabling the transfer of the responsibility for healthcare to prisoners to NHS Scotland from the Scottish Prison Service.
Visit www.scotland.gov.uk/Topics/Justice/criminal-justice-bill

Education (Additional Support for Learning) (Scotland) Act 2004 and 2009. The 2009 Act includes a duty for the Scottish Government to fund a national independent advocacy service (on request and free of charge) to support parents and young people in Additional Support Needs Tribunal proceedings.

Equalities Act 2010. This Act aims to tackle disadvantage and discrimination and promote equality of opportunity and good relations between people more effectively. It focuses on the needs of people with protected characteristics of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. It moves away from a focus on "Communities of Interest" and recognises the multi-factorial nature and complexity of individuals.
Visit www.equalityhumanrights.com

Human Rights Act 1998. Amongst many of the legal articles of this act is the importance of giving and protecting people's opportunities to realise their full potential, free from discrimination.

Mental Health (Care and Treatment) (Scotland) Act 2003. This act gives people with a mental disorder the entitlement to independent advocacy. The Act places a legal duty on local authorities and NHS Boards to collaborate to ensure that independent advocacy is available.

Patient Rights (Scotland) Act 2011. Aims to improve patients' experiences of using health services and to support people to become more involved in their health and health care. The Act details the rights and responsibilities of patients of the NHS in Scotland and also for the first time sets out the Healthcare Principles by which NHS Scotland will be held accountable.

Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010- 2015. As part of this strategy, the Scottish Government is currently developing work which aims to drive improvements to the quality, consistency and availability of advocacy support for children and young people. The Scottish Government will consider the needs of young carers within this work.

National Care Standards 2005. A series of standards for different types of service users all recommend access to advocacy services.

Self Directed Support - a National Strategy for Scotland 2010. This strategy aims to develop the personalisation of health and social care services, based on a cultural shift in the delivery of care and support that views people as equal citizens with rights and responsibilities.

The Self Directed Support Bill 2012 notes the importance of advice and advocacy services and the relationship between these services and supporting people to undertake informed engagement with self directed support options.

The Caring Together Strategy for Scotland 2010 - 2015. This strategy states that carers are equal partners in the planning and delivery of care and support and that without them, the health and social care system would not be sustained. Carer advocacy provides an important support to the most vulnerable carers to help them to communicate their views clearly and to support them on complex issues relating to caring.

The Standards for Care for Dementia in Scotland, 2011

These new standards for Scotland explicitly state:

- People with dementia should know how to make a complaint about services and receive support and assistance (e.g. from independent advocacy) to make a complaint
- Where the person with dementia is; at home, attending a day centre, in hospital or in a care home, they will know about the purpose and availability of local independent advocacy services and be given any necessary support to contact and use advocacy services
- Advocacy services will be publicised in a way that the person with dementia and/or their carer can understand and be given the necessary support to enable them to contact advocacy services.

The Scottish Independent Advocacy Alliance. Since 2008, the Scottish Independent Advocacy Alliance, in partnership with providers of independent advocacy from across Scotland, has developed a range of documents to advise on good practice.

- Code of Practice for Independent Advocacy 2008
- Principles and Standards for the Provision of Independent Advocacy 2008
- Guidelines for the Provision of Non-Instructed Advocacy; A Companion to the Code of Practice 2009
- Elder Abuse Advocacy Guidelines: A Companion to the Code of Practice 2008
- Independent Advocacy – An Evaluation Framework 2010
- Independent Advocacy - A Guide for Commissioners 2010

Generic

- *Changing Lives*: Report of the 21st Century Social Work Review 2006
- Better Health, Better Care: Action Plan, Scottish Government 2008
- NHS Lothian Communication Strategy 2008
- National Concordat and Edinburgh's Single Outcome Agreement 2009-12
- The National Care Standards
- East Lothian Council Draft Consultation and Engagement Strategy

Older People

- *Better Outcomes for Older People:* Framework for Joint Services 2005
- *All Our Future*: Planning for Scotland with an Ageing Population 2007
- *A City for All Ages* (City Plan for Older People) 2007

- *Live Well in Later Life* (Joint Capacity Plan and Commissioning Strategy for Older People's Services) 2008-2018

Dementia services
- *Remember I'm Still Me* – Care Commission and Mental Welfare Commission 2009
- Scottish Dementia Strategy, July 2010
- Standards of Care for Dementia in Scotland
- Dementia Action Plan 2008-11

Carers
- Towards 2012 – Carers' Strategic Action Plan for Edinburgh 2007-12
- NHS Lothian Carers Information Strategy 2008-11

Learning disability
- *Same as You?* 2000
- Lothian's Joint Learning Disability Strategy 2008-2013
- East Lothian - Adult Resource Centres Participation Strategy - Draft 2010

Children and young people
- *Delivering a Healthy Future*: An Action Framework for Children
- Young People's Health in Scotland, Scottish Executive 2007
- *Getting it Right for Every Child* 2009

Mental health
- Delivering for Mental Health, Scottish Executive 2006
- With Inclusion in Mind, 2007
- *Towards a Mentally Flourishing Scotland*: The Future of Mental Health Improvement in Scotland 2008-11, Scottish Government 2007
- *Choose Life* Action Plan 2002-2012
- *Sense of Belonging*: Lothian's Joint Strategy for Mental Health Services 2011 - 2016

Disabled people
- *Our Lives Our Way* – Lothian Joint Physical and Complex Disability Strategy 2008 - 2013

People who Misuse Substances
The Road to Recovery: A New Approach to Tackling Scotland's Drug Problem 2008.

The UK Equality Measurement Framework:
*has 10 dimensions including :the capability for participation, influence and voice**.***

Appendix 3

Lothian Independent Advocacy Provision and Funding 2011/12

East Lothian Local Authority/ CHP Area					
Provider/ Agency	**Service User Group**	**Funding Level**	**Source**	**Total**	**Additional Comments**
East Lothian Anti Bullying	Children and Young People	13,500	ELC	£13,500	EL Council - Education
Who Cares?	Children and Young People	£33,817 £13,527	ELC ELC - Education	£47,344	
Edinburgh Advocacy and Representation Service (EARS)	Older People	£18,829 £19,100	ELC East Lothian CHP (Includes £5,304 resource transfer)	£37,929	
Partners In Advocacy	Learning Disability	£35,000 £20,000 (SMART TALK)	ELC ELC	£55,000	
CAPS	Mental Health	£57,830 £16,000	ELC MH and WB Programme, NHS Lothian	£73,830	

West Lothian Local Authority/ CHCP Area					
Provider/ Agency	**Service User Group**	**Funding Level**	**Source**	**Total**	**Additional Comments**
Edinburgh Advocacy and Representation Service (EARS)	Physical Disability (16+) and Older People living in the community (ie. Additional funding from Adult Support and Protection monies)	£45,000	WLC	£45,000	Council only commissioned service
Edinburgh Advocacy and Representation Service (EARS)	Older People in residential care, hospital etc	£26,636 £25,500	WLC NHS Lothian	£51,636	
Enable Ace Advocacy	Learning Disability	£35,000 £30,250	WLC NHS Lothian	£65,2500	
MH Advocacy Project WL	Mental Health - Adults	£69,950.20 £57,184	WLC MH and WB Programme, NHS Lothian	£127,134	

Mid Lothian Local Authority/ CHP Area					
Provider/ Agency	**Service User Group**	**Funding Level**	**Source**	**Total**	**Additional Comments**
Who Cares?	Children and Young People	tbc	MLC		Children who are looked after away from home and care leavers
Edinburgh Advocacy and Representation Service (EARS)	Older People	22,525 13,796	MLC NHS Lothian	36,321	NHSL contribution includes 2011 - 12 one off funding of £9000.
Partners In Advocacy	Learning Disability	10,982 10,000	MLC NHS Lothian	20,982	
People 1st Midlothian	Learning Disability	13,982 10,000	MLC NHS Lothian	23,982	
CAPS	Mental Health	87,171 11,000	MLC NHS Lothian	£98,171	

City of Edinburgh Council and Edinburgh CHP					
Provider/ Agency	**Service User Group**	**Funding Level**	**Source**	**Total**	**Additional Comments**
Who Cares?	Children and Young People	25,000	CEC - Children and Families	25,000	Works alongside Children's Rights Officers
Partners In Advocacy	Older People	72,554.64 46,700.36	CEC NHS Lothian	119,255.00	
Partners In Advocacy	Learning Disability	89,878.34 57,850.91	CEC NHS Lothian	147,729.25	
Advocard	Mental Health- includes MDO's, children, Older People's mental health -	350,932.52 225,880.48	CEC NHS Lothian	576,813.00	
Advocard	*Edinburgh Carers Council*	*Included in the Advocard total above*	CEC NHS Lothian		

There are a number of projects supported by the Mental Health and Wellbeing Strategic programme budget that are pan-Lothian collective advocacy:

Oor Mad History	£50,000	CAPS	End Date:	31. 03. 14
Early Onset Psychosis	£17,000	CAPS	End Date:	31. 03. 14
Personality Disorder	£17,000	CAPS	End Date:	31. 03. 14

We are finalising the arrangement of ongoing pan-Lothian service user and carer collective advocacy into the delivering "A Sense of belonging" indicative levels:

Participation and Engagement	£8,500	CAPS	End Date:	31. 03. 15
Participation and Engagement	£8,500	Edinburgh Carers Council	End Date:	31. 03. 15

Non-Independent Advocacy

VOCAL : Voice of Carers Across Lothian

Vocal are commissioned by NHS Lothian to provided advocacy to Carers across Lothian, supported through a Service Level Agreement, specifically:

The provision of an advocacy service for carers in the NHS Lothian area through recruitment, training and support of volunteers.

Service Value: £33,853

Appendix 4: Remit and membership of Lothian Independent Advocacy Steering Group.

The Lothian Independent Advocacy Steering Group will, in partnership with all key stakeholders, lead on the development of and oversee implementation of Lothian's Independent Advocacy Action Plan:

It will:

- ensure that any advocacy provided meets national requirements, guidance and Lothian strategies to reflect the agreed stratified approach

- provide information and access to training that raises awareness of advocacy and improves the advocacy partner and carer experience

- Undertake an advisory and monitoring role which demonstrates strategic commitment to advocacy.

This will be achieved by:

- working in partnership with a range of stakeholders including statutory and voluntary sectors, advocacy partners and carers

- reviewing the current Lothian Independent Advocacy Action Plan on an annual basis

- working to facilitate the sharing of good practice and support of opportunities for the demonstration of positive outcomes from advocacy provision

- acting as an ambassador for advocacy, both individual and collective options, and promoting the role of advocacy through partnership and stakeholder networks

- ensuring service level agreements are developed and progress monitored of all providers of independent advocacy across Lothian

- coordinating responses to relevant consultation and information requests

- Ensuring all independent advocacy is compliant with equality and diversity legislation and is accessible

- advising on opportunities, standards, new developments and other strategic imperatives

- reviewing financial monitoring of the spend on independent advocacy across Lothian

Membership

- Representation from each of the Lothian Local Authorities
- Representation from Equality and Diversity colleagues
- Representation from each of the service user Programme areas.
- Representation from Advocacy Partners Networks
- Representation from the Providers Reference Group
- Representation from NHS Lothian

Frequency of Meetings

Flexible in order to facilitate delivery of the action plan commitments, but a minimum of quarterly

Expenses

Out of pocket expenses will be covered for advocacy partners.

Appendix 5: Full Report
NHS Lothian Health Needs Assessment - Independent Advocacy 2011

Assessing unmet need for health advocacy in Lothian

1. Introduction

The Patient Rights (Scotland) Act was passed in February 2011. It aims to improve patients' experiences of using health services, and to support people in becoming more involved in their health and health care. It does this by bringing together existing and some additional patient rights in a single piece of legislation, in order to make them easier to understand and enforce.

The Patient Rights Act does not directly extend rights to independent advocacy beyond those who, under the Mental Health Act, have a statutory right to it. However, a new Patient Advice and Support Service has been established under the Act, and this has a duty to signpost people to advocacy services, amongst other potential sources of support. In order that NHS Boards are prepared for this, the Scottish Government funded each Board to undertake an assessment of need for advocacy services. This is intended to inform the development of local advocacy plans, and make sure that unmet advocacy need is addressed in these.

This report summarises the initial phase of NHS Lothian's needs assessment. Firstly, it defines relevant terms. Secondly, it describes the groups included within the needs assessment, and its aims and methods as well as its limitations. Finally, it summarises overall findings on unmet need, and suggests developments in current advocacy provision (and how it is supported by the statutory sector) in order to address this need.

The needs assessment was carried out with little direct engagement with users or potential users of advocacy services because time did not allow this. This engagement is essential to Lothian's advocacy plan as it develops, particularly in the light of evidence suggesting that voluntary sector workers, those in the statutory sector and potential end users of advocacy can each have slightly different perspectives on its value and how it should be provided. (6)

There remains uncertainty about the extent of extra resources to address the needs identified in this assessment. In the light of this, no concrete proposals are made about ways of meeting identified need. Instead, local, and wider, evidence and expertise is drawn on to point to important considerations in developing inclusive advocacy services. These are intended to serve as the basis for further discussion.

2. What is advocacy?

Advocacy supports people in expressing their own needs and making their own decisions. It enables people to gain access to information, explore and understand their options, and to make their views and wishes known; and will speak on behalf of people who are unable to do for themselves.(10, 13) Advocacy works with and on behalf of individuals and communities who historically have been disempowered or discriminated against, generally and by public services. It aims to give people as much control as possible over their lives.

Independent Advocacy is provided by organisations which are separate from other services: their only function is to provide advocacy for their users. This means that advocacy is not affected by any other organisational aims. Advocacy provided by those who also have responsibility for delivering other services is not independent.

There are different forms of advocacy, including collective or group advocacy, peer advocacy and self-advocacy, as well as one-to-one advocacy provided by professional advocates. The Scottish Independent Advocacy Alliance has a glossary of the terms used in Advocacy[1]

3. What is health needs assessment?

There are many definitions of health needs assessment. Its description as ‘a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities’ is widely subscribed to(17).

Health needs assessments conventionally describe the incidence, prevalence and distribution in the population of a particular condition; and compare these with the provision of existing services, in order to help guide service development. (19) Some needs assessments also analyse the effectiveness and cost-effectiveness of services in meeting identified need, but that has not been attempted here.

4. Groups included within the needs assessment

In Lothian, the needs assessment has focused on those groups who experience the health consequences of social and economic inequalities, and who encounter specific barriers to accessing health services as well as poorer health outcomes. This is in line with the ‘proportionate universalism’ recommended in the Marmot Review.(2) While not suggesting that resources be targeted solely at the most disadvantaged, this recognises that they should be applied in a way that is ‘proportionate to the degree of disadvantage experienced’

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[1] This is available at http://www.siaa.org.uk/content/view/14/27/

The Lothian Independent Advocacy Strategy Group (LIASG) agreed that those included in the 'Keep Well' project in Lothian should serve as a marker for disadvantaged groups. These comprise:

- Those living in areas of multiple deprivation
- Gypsy/Traveller populations
- Other Black and Minority Ethnic populations
- Current and ex-offenders
- People who are homeless

After further discussion within LIASG the following groups were added to incorporate further dimensions of inequality:

- Lesbian, Bisexual, Gay and Transgendered (LGBT) people
- People dependent on drug or alcohol use

There is clearly significant overlap between these groups. To take two examples, current and ex-offenders are disproportionately likely to live in areas of multiple deprivation (23) and there is an association between homelessness and a history of problem drug or alcohol use. (24)

These groups are clearly not exhaustive list of all those who may have specific unmet needs for independent advocacy. However, focused work with these groups has the capacity to identify general pointers to inequalities-sensitive practice in the provision of advocacy, as well as specific areas for development for the defined groups.

Additional groups were highlighted in the course of the needs assessment, and the needs of further specific groups for advocacy have been established in recently-published policy. The latter are listed in Lothian's independent advocacy strategy, and are noted for further focus during the life of Lothian's advocacy strategy and action plan.

5. Aims of the needs assessment

The needs assessment aims to identify in relation to the defined groups:

- Indication of direct or indirect evidence of need for advocacy provision, both in relation to general health services and for those who have an existing statutory right to independent advocacy.
- The extent and nature of existing advocacy provision in meeting need.
- How advocacy might best be provided for defined groups.

6. Methods

The restricted time-scale for carrying out the needs assessment meant that it was not possible to carry out thorough-going research directly with the target groups. Instead, a pragmatic approach was taken which drew on relevant existing local knowledge about potential need, supplemented with relevant published Scottish and UK evidence relevant to the aims of the needs assessment.

In relation to each of the groups:

- The size and nature of local populations was established.
- Local and national publications and reports about the health outcomes, needs and health service experiences of the respective groups were identified. Findings relevant to advocacy need were collated.
- Meetings were held with a range of voluntary sector groups and those in the statutory sector working with the respective groups. This was in order to gather their perspectives on need for advocacy, whether this was met by existing provision, and particular issues in providing advocacy for the different groups.
- Meetings were held with a number of existing independent advocacy providers in order to learn about their experiences of providing advocacy to the defined groups within a model of 'universal' service delivery.
- A rapid review of the 'grey' and published literature was undertaken in order to identify examples of dedicated provision of advocacy elsewhere in the UK which meets the needs of the defined groups; and the factors facilitating or inhibiting take-up of advocacy.

A list of those consulted during the course of the needs assessment is included at Appendix one, and the invitation to independent advocacy providers to participate in the needs assessment at appendix two.

7. Challenges and limitations in assessing unmet need for advocacy

There are a number of challenges in identifying unmet need for advocacy.

Firstly, there is significantly more directly relevant evidence available for some groups than others, which should not be interpreted to mean that evidence of their need is stronger, but simply that a greater amount of research has already been done, and evidence gathered.

For example, advocacy services for Black and Minority Ethnic (BME) groups have been extensively used in the UK to support access to health services and articulation of need. A significant volume of publications include descriptions and evaluations of these initiatives (25-27), standards for provision (28, 29) and assessments of unmet need within BME communities (30-32) in relation to mental health, learning disability and other areas of health. Similarly, an independent advocacy needs assessment in relation to drug users has been carried out in Scotland, and the Scottish Government has published focused guidance. (33, 34) On the other hand, there is very little published material directly addressing the advocacy needs of other groups such as Gypsy Travellers or homeless people.

Secondly, this needs assessment draws primarily upon indirect evidence of advocacy need, such as health outcomes and experiences of health services. These cannot translate directly into identification of need, although they can suggest areas for further exploration about the role of advocacy and independent advocacy in addressing the issues raised.

Thirdly, many geographical communities and communities of interest have established their own ways of articulating their health concerns and garnering support, individually or collectively, for presenting these to health service providers. While much of this is not labelled as advocacy, it significantly overlaps with it and may meet some of the same needs. In order to identify specific unmet need for independent advocacy, further direct assessment of need with the defined communities should explore the extent to which existing community-based networks and initiatives are already perceived to be meeting need; clarify the difference between independent and non-independent advocacy (a distinction which is likely to be unfamiliar to many within the defined communities); and elicit views on the value placed on different forms of advocacy.

Box 1: Met or unmet need?

One advocacy provider serving the City of Edinburgh noted through monitoring that it had fewer than expected users from an area of multiple deprivation in the city. Plans are afoot to explore reasons for this. Are residents unaware of their advocacy service? Or does the existing well-established voluntary sector dedicated to community health and mental health support in the area meet needs which might otherwise have been

Fourthly, Lothian's population and its needs are likely to change over the life of the five year Advocacy Strategy which may generate new or greater need for advocacy than that captured here, and it is important that LIASG keep alert to potential new forms of need. The forecast growth in poverty and unemployment will have a potential effect on physical and mental health which in turn is likely to have consequences for advocacy need. (35) There are also indications of an increasing local population of 'new' groups of migrants such as Roma whose poor health status and experience of stigma has been well-documented in Europe. (36)

Finally, advocacy itself cannot be a solution to unequal or insensitive service delivery, as consultation on the Advocacy action plan highlighted. While equal access to advocacy is crucial, It is a scarce resource, and in extending it to more general health issues it is important that it is not perceived by service users or providers as a 'catch-all' to improve poor communication or dissatisfaction with services; or as a substitute or solution for insensitive service delivery.

Findings

8. Health outcomes: mental health and learning disabilities

All the defined groups are disproportionately represented amongst those who have a statutory right to independent advocacy in Scotland under the Mental Health Act. Box 2 provides examples from the published literature on mental health outcomes for each of the groups.

Box 2: Prevalence of mental health problems and distress amongst the defined groups

- Those living in areas of multiple deprivation are six times more likely to experience depression and anxiety than those living elsewhere. (2) Poor mental health is closely associated with socio-economic disadvantage in Scotland (4)
- Lesbian, gay and bisexual people are at higher risk of mental disorder, suicidal thoughts, substance misuse, and deliberate self-harm than heterosexual people. (7)
- 100% of those identifying themselves as Transgendered in a recent Lothian survey reported poor mental health. (9)
- Although there has been little published research**,** Gypsy Travellers have amongst the highest levels of mental distress in the UK, (8, 10, 11) findings echoed locally in Lothian's Equally Connected action-research project which found that settled Travellers have reported high levels of depression linked to loss of their traditional lifestyle. (14)
- The prevalence of mental health problems varies by ethnicity – with, for example, higher than expected rates of hospital admission and compulsory detention for people of Black, Black/White mixed and Irish groups (15), enhanced levels of attempted suicide and self-harm in young South Asian women and lower than average prevalence of mental health problems in some minority ethnic groups (18)
- it has been estimated that 70% of those sentenced have two or more mental health problems. (20, 21) Between 11-15% of Lothian prisoners have been estimated to have a history of psychiatric disorder. (3)
- People who are homeless or living in insecure accommodation have significantly higher rates of mental illness than the general population. (22)

These patterns are associated with particular forms of stigma or exclusion experienced by these groups which precipitate distress and mental ill-health. For example, Gypsy Travellers settled in houses reported to the Equally Connected project that feeling they had to hide their cultural identity contributed to mental and emotional health problems (37).

There is less evidence available in relation to the prevalence of learning disability in the respective groups, although there are indications that prisoners with learning difficulties and disabilities are over-represented in prison populations in Scotland and the UK. (38, 39) This has been related to a variety of factors, including that people with learning disabilities and difficulties may be more easily manipulated than others by criminals or the police. There is equivocal evidence on learning disability and ethnicity. Almost all research has focused on South Asian populations, with some estimates suggesting that prevalence is similar to that in White populations, and others suggesting that it is higher. (40) There is set to be a significant rise in the population of people with learning disabilities from South Asian communities in future decades. (41)

There is therefore a clear picture of ‘double discrimination’ emerging for many marginalized groups in relation to mental health and to some extent learning disability which highlights the importance for existing advocacy services of incorporating as central the needs of these populations.

9. Health outcomes: general health

In relation to other health conditions, there is a plethora of evidence on differential life expectancy and health outcomes across a number of other conditions. These patterns of health and illness vary between groups and sometimes within them. Some examples are summarised below, and are further detailed in the sections on the respective groups.

Box 3

- Areas of multiple deprivation in Scotland are characterised by shorter life expectancy and longer periods of time spent living with disability. (1)
- The health of prisoners in Lothian is significantly poorer than average across almost all indicators, reflecting the national picture. (3)
- Recent evidence from Lothian’s Keep Well project suggests that Gypsy Traveller health is significantly poorer than the wider population, again reflecting the wider UK picture. (5) (8)
- There is a mixed picture for ethnicity across different conditions and different groups. While health outcomes in some groups are better than the majority population for some conditions, they are worse in others. For example, 31% of maternal deaths in a recent UK audit occurred in women of non-White ethnicity (12); and while prevalence of Coronary Heart Disease is higher than average amongst UK South Asian

Multiple forms of disadvantage compound each other, and physical and mental health issues work together. For example, homelessness and problem drug and alcohol use are closely associated, and all minority ethnic groups in Scotland appear disadvantaged on one or more poverty indicators, with those of Pakistani and Bangladeshi backgrounds having higher rates of poverty than other ethnic groups. (42)

10. Health service experiences as indicators of advocacy need

While adverse life circumstances and societal inequalities underpin inequalities in health outcomes, there is evidence in a number of areas that these inequalities are compounded by poor access to treatment and care – for example in relation to coronary and maternity services listed in box 3. This and other evidence of poor access to and experiences of health services collated during the needs assessment indicate areas where advocacy may be needed. It also highlights the elements which need to be included in advocacy if it is to address the needs of the defined groups and not risk reflecting barriers of access to health services themselves.

- **Supporting basic access to health services**

  Some of the groups with greatest health need in Lothian encountered problems in getting over the threshold to gain basic access to health services. A number had problems registering with GPs because they were uncertain of their rights to healthcare, or being turned away when they attempted to register with a GP. Examples provided by the Lothian Keep Well project include those recently released from prison or homeless people who did not have the requisite proof of address, and Gypsy Travellers whose mobility meant that they were not necessarily registered with a GP when they found themselves in need of healthcare. Local qualitative research on access to maternity care found that three of seven Mandarin-speaking participants reported not booking for pregnancy care until they were seven months pregnant because of fear that they did not have the correct documents. (43) This highlights the importance of including in any more focused assessment of need those who are not already users of services.

- **Experience or fear of stigma or discrimination**

  Past experience or fear of stigma and discrimination can prevent people from accessing services, articulating concerns or disclosing important aspects of their identity. For example, there is published evidence that some LGBT people may not feel able to be ‘out’ about their sexual identity when using health services (44) , and from the Lothian Keep Well project that ex-offenders fear stigma if they disclose their history. There is also evidence that people may not use services because they lack confidence that they will provide them with the right support. For example, the Equally Connected project found that some Gypsy Travellers prefer to travel considerable distances, often across Health Board boundaries, to visit a GP in whom they have trust and confidence rather than using local services (14); and young Gypsy Travellers mentioned only being able to gain access to health, housing and education services if they denied or hid their ethnic identity. (45) Stereotyped ideas about particular communities also compromise full access to care – for example, a widespread myth that members of certain communities ‘look after their own’ and don’t need outside help.(46)

- **A lack of ‘fit’ in understandings of lives and health**

  In some cases, services are not provided in ways which ‘fit’ how people conceptualise their lives and health. There is local and national evidence suggesting that understandings of physical or mental health and wellbeing on the part of some groups can be at odds with those of service providers. In relation to minority ethnic people, for example, significant local evidence of this has emerged from the Equally Connected project and more widely in much UK research, suggesting important differences in cultural expressions and experiences of mental distress. (47, 48)

More widely, there may be mismatched understandings of models of support. As mentioned above, advocacy itself may well be an alien concept within certain groups, and dedicated work may be needed to explore this within the respective communities. Specific understanding is also needed where stigma about particular conditions exists within communities. ‘What’s Out There?’ a report of research on learning disability and ethnicity carried out by the Scottish Consortium for Learning Disability in close collaboration with the BEMAS group in Lothian highlighted the particular issues faced by some minority ethnic parents of children with learning disabilities: they have reported isolation as a result of the stigma attached to disability within some communities and their difficulties in garnering the right support. (49)

- **Language and communication**

  There is very well-established evidence UK evidence that lack of fluency in English is associated with poorer than average experiences of health services, which can compound the cultural mismatches described above (50). There is free access to interpreting services in Lothian, but we know from local evidence that communication problems persist because people are unaware of or are reluctant to use interpreting services, or that apparently fluent English can collapse at times of crisis or be inadequate to express feelings and health concepts.

- **Health and life in the round**

  Evidence from the Keep Well outreach project, community-based health projects and those working with prisoners and ex-offenders suggests that health and experiences of health services are often closely intertwined with other aspects of life, such as benefits, social welfare and council services in the worlds of users. The short-term advocacy service based at the Wester Hailes Health Agency found that advocacy support had to be flexible and take into account the fact that users did not compartmentalise their lives in alignment with the bureaucratic divisions between services. This echoes the experience of the Health All Round Community Health project which is used for informal advocacy support, and by Scottish research on advocacy need amongst drug users. (33)

11. How does advocacy provision in Lothian address these issues?

There is considerable expertise in Lothian for addressing the issues arising from the need for inclusive advocacy services. However, this is currently rather fragmented and dispersed across existing independent advocacy providers, voluntary sector organisations working with specific groups, and specialist expertise within the statutory sector provision.

- **Independent advocacy provision**

  There are currently 9 independent advocacy providers in Lothian. This needs assessment draws on the experience of a number of these, and of other providers whose remit has changed following a review of advocacy provision in the city of Edinburgh.

  All the independent advocacy organisations interviewed for this exercise are aware of some of the barriers encountered by the defined groups. In a number of cases they are actively working to monitor uptake of their services by the defined groups and to address these barriers within their specific remits by actively working to include those who are underrepresented as workers, volunteers or service users. They currently primarily serve those who have a statutory right to advocacy services, and cannot therefore be expected to address wider health advocacy.

  The organisations which are monitoring uptake are generally more aware than others of patterns of use of their services amongst the defined groups, although they – like other voluntary and statutory organisations - are more aware of ‘visible’ minority ethnic groups and those groups routinely included in equalities monitoring than others such as homeless people, prisoners or ex-offenders. Monitoring uptake of advocacy services can be particularly challenging, as described below, and more refined monitoring is unlikely to be taken up. Making links with other voluntary sector organisations working with a range of marginalised groups is a strategy being pursued by a number of independent advocacy providers.

- **Dedicated advocacy provision**

  There is limited current provision dedicated to some amongst the defined groups, and some previous initiatives, but in but in no case is this independent. All were or are short-term or pilot initiatives. The four examples identified were advocacy services at LGBT Health, focused on mental wellbeing within this population; at The Minority Ethnic Carers of Older People Project (MECOPP), and (in the past) a health advocacy service for those living in Wester Hailes hosted by the Wester Hailes Health Agency. VOCAL also hosts an advocacy service for carers. Such dedicated services aim to improve access to advocacy through tailoring services to users’ identities or particular roles. Although not independent, these projects work to the SIAA advocacy standards, and the advocacy service at VOCAL retains a steering group independent of the wider organisation.

Evaluation of the LGBT Health advocacy service suggests that the service is used by those who would not go elsewhere for advocacy, although may contemplate using other services for issues where their sexuality is not their prime concern. MECOPP have argued that there are barriers to the use of mainstream advocacy provision because advocates do not necessarily speak relevant languages or possess the requisite cultural understanding. (51) This perspective is endorsed in evaluations and guidance on advocacy provision for minority ethnic groups. (26-28, 52) This literature suggests that there are positive advantages to advocacy being an intrinsic part of other culturally-appropriate services, and that greater value was placed by users on this than independent provision. However, Bowes and Sim found in Glasgow that South Asian communities welcomed the prospect of independent advocacy not linked to existing BME community organisations. (53)

- **Voluntary sector expertise**

  There is significant expertise in Lothian's voluntary sector in relation to supporting people from the defined groups, individually or collectively, to articulate their health concerns and needs to service providers. While much of this activity does not have an advocacy label, numerous activities overlap with individual, peer or collective advocacy. Demand for such activity – which is impossible to quantify across a vast and diverse range of groups and organisations – indicates continuous need for such support. A number of voluntary organisations have also highlighted that need for such support is likely to grow as the consequences of financial recession start to be felt by people through falling incomes and cutbacks in public and voluntary sector services – and that this has potential consequences for mental as well as general health.

  Within this sector, specialist skills in working with particular communities have been built up over time, and trust has been engendered. For example, there is a highly active network of groups operating within the Black and Minority Ethnic voluntary sector, a forum for community health projects working primarily in areas of multiple deprivation in Lothian and coordinated through the Lothian Community Health Projects Forum, and a wide range of groups working with prisoners and ex-offenders, problem drug and alcohol users and homeless people.

- **Statutory sector expertise**

  There is dedicated statutory sector provision for some of the defined groups within the statutory sector. Some statutory sector employees have considerable expertise in working to identify and meet their needs. In some cases they undoubtedly advocate within the health services for their clients, for example by supporting them in articulating their needs and coordinating care. While this is clearly not independent advocacy in any sense, it represents a valuable source of knowledge about the skills and expertise required if advocacy needs are to be better addressed. Examples include Keep Well, MEHIS, health professionals working at the Access Practice and drug outreach workers.

12. Overcoming barriers of access to advocacy: identifying and sharing good practice

A significant amount of existing good practice, and ideas for how to overcome identified barriers to improving access to advocacy for the defined groups, emerged from the needs assessment. These came from independent advocacy organizations actively working to address these issues, from those voluntary and statutory agencies with experience in working with the different groups, and from the published literature on health need and advocacy. There is considerable scope for sharing and developing this good practice over the life of the five year strategy and action plan as part both of continuing to improve inclusive access to advocacy for those with a statutory right to it, and in considering extending advocacy to support access to general health services.

The following main areas emerged:

- **Monitoring of advocacy service users.**

  Monitoring which groups are using advocacy services – and which are not – is an important way of assessing whether an agency’s services are accessible to all groups within Lothian; Several agencies have developed robust ways of monitoring the characteristics of those who use their services, although this is generally experienced as easier in the community than in hospital where users may be acutely unwell. (54) There was concern amongst other agencies that an emphasis on monitoring when contacted by users might compromise the advocacy relationship, and they were more reluctant to monitor service use in this way.

  Clarifying the baseline against which use is measured is important. For example, given the disproportionate rates of ill-health in some communities, should advocacy uptake be measured against the proportion of the population represented by the respective groups, or adjusted to take into account higher prevalence of ill-health and therefore potential advocacy need?

  There is scope for sharing good practice in sensitively monitoring the characteristics of service users, and analysing and taking action on the results; and for dissemination of training packages such as NHS Health Scotland’s ‘Happy to Ask, Happy to Tell’ programme. (55)

- **Outreach and active identification of those who may benefit from advocacy to access basic health services**

  There is considerable expertise across in Lothian in identifying those who potentially need but are not accessing services through outreach work. Additionally there are a number of organisations and individuals working with some of the most marginalised groups who may have the greatest problems registering with and accessing basic health care. Among many others, these include The Welcoming, the Scottish Refugee Council, and key workers in hostels for homeless people. The Access Practice in Edinburgh has good links to many of these groups, and collaborative working will be essential to any future attempt to extend advocacy in order to support basic access to health services.

  The successful provision of health services for some of the defined groups has been characterised by a high degree of flexibility, where the service fits around the patterns of everyday life of its users and is sensitive to the ways in which they present their identities. (56) Such practice should be built on in extending advocacy for groups such as Gypsy Travellers, and may potentially entail working across Lothian boundaries and in close partnership with neighbouring Health Boards, local authorities, voluntary groups and Gypsy Traveller organisations

- **Communication with non-English speakers**

  The lack of fluency in English which can compromise access to health services is also a potential barrier of access to advocacy services. Being able to publicise and provide means of communicating with minority language speakers was recognized by all existing advocacy providers as crucial to providing advocacy services.

  A number of advocacy organisations were able to access free interpreting through the local Interpretation and Translation Service funded by the local authorities and NHS Lothian where clients were referred by one of the funding organisations. However, this was more problematic where minority language speakers referred themselves for advocacy. No existing advocacy organisations publicized their ability to provide interpreting support, in some cases because they were insufficiently confident that this could be guaranteed for all their clients.

  Overcoming this barrier is crucial for improving access to advocacy services for minority language speakers, and a key consideration in providing advocacy support for general health services. There are various models, locally and nationally for enabling this. Non-independent agencies such as MECOPP and the Minority Ethnic Health Inclusion Service (MEHIS) employ staff fluent in minority languages, and in their view this is crucial to their effectiveness: the ability to communicate in their mother tongue attracts clients who may otherwise not use services. MEHIS along with voluntary groups with minority language expertise is effectively picking up and meeting some of the need for advocacy. Elsewhere, there is convincing evidence that the employment of advocates fluent in minority languages broadens access to advocacy, although this is almost always part of dedicated minority ethnic provision, and language runs together with broader shared cultural understanding of health and models of support.(26, 28, 30) One Lothian independent advocacy provider had recruited two South Asian language speakers. While this had general benefits, it did not attract the increase the organization expected in clients from these groups, suggesting that the provision of mother tongue speakers alone is not necessarily a 'magic bullet'.

- **Culturally appropriate provision and specialist expertise**

This importance of people being able to assert their identities and articulate their particular cultural needs in accessing health services both marks a potential advocacy need and has key implications for how inclusive advocacy services are provided. Advocacy provision must recognise the historical barriers and current anxieties for some groups in accessing services, and ensure that it is not perceived to mirror the barriers which prevent access to services themselves.

There is considerable debate locally and nationally about optimum ways of providing culturally appropriate advocacy provision for minority groups, and specific ways of brokering the trust which is key to all advocacy provision. In brief, those agencies locally providing dedicated services to particular groups highlight the advantages of being able to build up specific expertise and tailor provision to the needs and cultural backgrounds of their clients. They are almost always part of wider projects which have built up trust with particular communities over time, and are located in what are perceived to be 'safe' environments. For services such the LGBT mental health advocacy service based at LGBT Health or the advocacy service at MECOPP, these factors are perceived to be crucial to their effectiveness. (51) These factors have also emerged as important in evaluations of dedicated advocacy services for Black and Minority Ethnic communities elsewhere in the UK (27, 31, 52) as well as in published analyses of the real challenges universal services face in being fully inclusive. (57)

One Lothian advocacy organisation working with carers is participating in the LGBT 'kitemark' scheme. This involves undertaking training in order to become LGBT 'friendly', and being assessed on this. The 'kitemark' can then be included on all the organisation's publicity

All existing independent 'universal' advocacy organisations aimed to be culturally sensitive, but some were taking more active steps towards this than others. Establishing links and joint working with voluntary organisations with specific experience in working with particular constituencies was the most common way of doing this, although some encountered barriers to doing this as comprehensively as they would have liked. This is described further below.

There is an increasing volume of guidance and standards for providing ‘culturally competent’ advocacy in relation both to minority ethnic groups and to other minority groups. (29, 31, 58)

- **The importance of choice in advocacy provision.**

  Emphasising the importance of culturally sensitive advocacy provision should not imply a ‘boxing’ of potential users into hard and fast identities. Different individuals can identify themselves differently at different times and in different contexts.

  For example, in some circumstances it may be paramount for people to access provision tailored to their own community, but on other occasions they may explicitly want to seek support outwith their own communities and it is important that this is recognised by providers. Independent advocacy providers also emphasised that an apparent lack of cultural ‘match’ does not necessarily impede highly effective advocacy, and in some cases can free people from the constraints they may perceive with shared cultural norms.

- **Collaborative working**

  Almost all existing advocacy organisations have forged links and wished to work collaboratively in order to match their advocacy expertise with those who have skills and experience relating to particular communities. A number of successful examples of this were identified locally, as well as barriers and suggestions for improving joint working between advocacy organisations and others.

  Brokering of trust between organisations can take time, and in some cases forging robust links was a slow process. This may be exacerbated by a difficult funding climate, where there is increasing competition for scarce resources; and where organisations which have built up expertise over time working with minority communities fear being ‘taken over’ by mainstream agencies. In some cases, advocacy organisations found ‘sideways’ collaboration over specific creative projects more successful than direct approaches.

  Suggestions for improving collaboration included funders writing into contracts of both voluntary organisations working with specific groups and advocacy organisations the imperative to work together, and supporting this.

- **Clarity about the role of advocacy.**
  Views amongst advocacy providers echoed those expressed during consultations over the plan about the importance of clarity about the role of advocacy.

13 Conclusions

Assessing unmet need for general independent health advocacy is challenging, and impossible to quantify. Distinctive barriers of equal access to health services can be identified through data on health outcomes, patterns of health service use and – particularly – health service experiences. These data can highlight particular areas where advocacy may have a potential role. Along with the experiences of potential users of advocacy services, voluntary sector organisations working with groups who have historically been marginalised, and those of existing independent advocacy providers they can also identify ways of ensuring that advocacy provision is accessible to those experiencing particular and multiple forms of marginalisation. However, evidence of poor and unequal access to health services does not in itself indicate advocacy need, and further exploration of this is needed locally.

Assessing the extent to which need for independent advocacy is already being met is similarly challenging. There is a range of ways in which people can harness support for articulating their individual or collective concerns to service providers, and independent advocacy is one. Needs which could be met by independent advocacy may be being met – wholly or in part – by Lothian’s existing network of voluntary sector organisations, or by parts of the statutory sector which have developed expertise in working with particular groups (for example, those working with Gypsy Travellers or Minority Ethnic groups). The fact that this is not independent may be less important to users than its locality, trust that has built up over time or sensitivity to cultural or linguistic needs. Intrinsic links with other services may, for some, be part of the appeal of informal advocacy provision embedded within wider services.

Again, further exploration of this with particular groups of users is needed in order to gain a fuller picture. While existing providers are highly committed to the principle of independence, some have pointed out in the course of the needs assessment that advocacy is a specific and limited resource, that it is not for everyone, and that it cannot be a ‘catch-all’ for support needs, particularly where alternative forms of provision exist.

However, it remains crucial that independent advocacy, to which particular groups have a statutory right and which has a specific and important role, is accessible to all who need it. This is particularly important because those in the groups which have formed the focus for this needs assessment are over-represented amongst those who have a statutory right to it. There are high levels of awareness of this amongst Lothian's independent advocacy providers, and developing areas of good and innovative practice. This has included forging links with wider and trusted community networks in order to pool independent advocacy expertise with expertise in meeting the needs of communities of interest. Supporting and developing this in order to promote inclusive service provision across the life of the plan; and will inform any extension of advocacy to include general health issues in order to respond to the requirements of the patients' Rights' Act.

12. Recommendations

1. Directly seek the views of members of the defined groups on independent advocacy during the first twelve months of the 2012 – 16 plan in order to incorporate their views into the development of advocacy provision. This should be both in relation to general health (in response to the Patients' Rights Act) and those who have a statutory right to advocacy.

2. NHS Lothian and its Local Authority partners should support the sharing of existing local good practice in inclusive advocacy provision between independent and other advocacy providers; and create opportunities to learn from advocacy providers dedicated to particular communities of interest elsewhere in the UK.

3. In response to the Patients' Rights Act, and use of any additional associated resources, NHS Lothian and its Local Authority partners should support a structured sharing of expertise between independent advocacy providers and voluntary sector organisations and statutory services well-established within communities who are marginalised, and where there are specific barriers to service uptake.

4. NHS Lothian will work to directly support greater inclusivity in provision of independent advocacy services, including working to ensure that lack of communication and interpretation support does not constitute a barrier of access to advocacy, and that monitoring and equalities data in Lothian is made easily accessible to advocacy providers.

5. Advocacy is an important part of wider activity to address health inequalities, but is not in itself a substitute for good service provision. Major issues identified by advocacy providers are valuable indicators of areas where focused inequalities work within the health services is needed. NHS Lothian should encourage and support dialogue with advocacy providers to make optimum use of this experience.

6. The picture of need for advocacy in Lothian and Scotland as a whole is a dynamic one, and new waves of migration and deepening economic recession are likely to have an impact on

advocacy need. The groups who potentially have unmet need for advocacy and what is necessary to meet this should be regularly reviewed, in partnership with existing advocacy providers and the voluntary sector.

7. Resources should be made available to test and evaluate methods for providing advocacy in ways which is sensitive to the needs of specific groups.

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Appendix 5 (a): Those consulted in the process of compiling the needs assessment

Kate Burton, Public Health Practitioner (in relation to health literacy)

Ellis Ciruello, Deputy Director (Mental Health Project) LGBT Health

Smita Grant, Project Manager, Minority Ethnic Health Inclusion Service.

The team at Health All Round Community Health project (serving Gorgie Dalry and surrounding areas)

Kathy Hamilton, Project Coordinator, Mental Health Advocacy Project

Mark Johnston, Advocacy Manager, VOCAL

James Lambie, Nurse Case Manager, Edinburgh Access Practice Keep Well Team Gypsy and Traveller Outreach Service

Keith Maloney, Co-ordinator, CAPS

Euan McCleay

Eileen McGuire, Team Leader, Keep Well Team, Lothian

Suzanne Munday, Director, Minority Ethnic Carers of Older People Project (MECOPP)

Penny Richardson, Manager, PROP Stress Centre, Pilton.

Royal Edinburgh Hospital Patients' Council

The Wester Hailes Health Agency

Chris Mackie, Director, Advocard

In addition, informal discussions were held with participants at the Lothian Community Health Projects Forum Annual general Meeting and at an event to disseminate findings from the Equally Connected project. Findings from the strategy consultation events and Equality Impact Assessments held in relation to the Strategy also informed the needs assessment.

Appendix 5 (b): letter sent to independent advocacy organisations

Dear

Independent advocacy needs assessment

I have been asked to undertake a needs assessment to inform (alongside public consultation and engagement) Lothian's independent advocacy plan for the next five years; and to contribute to NHS Lothian's response to the forthcoming Patients' Rights' Bill. As you may know, the Patients' Rights Bill has highlighted the potential the value for the wider population of health service users of the model of independent advocacy which has been established for those, for example, who have a statutory right to advocacy. Each Scottish NHS regional Board is required to assess need for this more general independent health advocacy.

The primary focus of NHS Lothian's needs assessment is the potential for independent advocacy to improve the health experiences of those bearing the brunt of health inequalities; and how such advocacy might best be provided for defined groups. These groups include Lothian's Black and minority ethnic and Gypsy/Traveller communities, Lesbian, Gay, Bisexual and Transgender people, homeless people, those dependent on drugs and alcohol, and prisoners and ex-offenders.

The experiences of Lothian's existing independent advocacy organisations in relation to meeting the needs of these groups is obviously a potentially valuable source of information, and one on which we are keen to draw. In particular, we would like to know:

- Your impressions – or any data you may have – on the extent to which your service is used by people from these groups. I appreciate that this may vary with need and distribution of population across the Lothians.
- Whether you feel there are any barriers to you being able to provide the service you would ideally like to these groups – for example, lack of specific expertise or access to relevant networks, or staff who speak minority languages.
- Whether you have met with particular success in providing services to any of these groups, and if so what has contributed to this success.
- What you feel might help you or others to provide services to these groups.
- Any other thoughts you may have on the specific shape independent advocacy could or should take for any of these groups.

I would appreciate the opportunity to meet you to discuss these questions or, if time doesn't allow, to book a phone call. I will obviously feed back to you the findings from the needs assessment. Wide consultation is also planned on the draft of Lothian’s most recent independent advocacy plan during September and October in order to ensure public and voluntary sector input into the final plan.

I will ‘phone you over the next few days. Meanwhile, I can be contacted on 0131 465 5490 or 07518947230

Appendix 6: Equality Impact Assessment

A Rapid Impact Assessment (RIA) was undertaken with representatives of advocacy organisations, users of services, and representatives from both local authorities and NHS Lothian.

An initial joint service users and professionals RIA meeting took place on 5th September 2011. However in retrospect, this meeting was too early in the process as the local consultation events had not been carried out and the Action Plan was not available to participants.
Therefore, separate follow up meetings were held on 24th November 2011 for professionals and 28th November 2011 for service users.

Participants in the RIA were asked to consider 3 main questions regarding advocacy;

- How can we make training as good as possible?
- How can we make information as good as possible?
- How can we make it easier for people to get advocacy?

The participants in the RIA agreed that the development of a Lothian wide Advocacy Provider's Reference group would be very welcome. It was agreed that this would provide opportunities for ongoing consultation between the Partnership and Providers to make sure each group is meeting their commitments, as agreed in this action plan once developed.

The participants discussed the need for more opportunities for users of services to be involved in the monitoring of the plan, over and above the agreed annual event.

It was noted that some service users are Board members of advocacy agencies, but it was agreed that we also need to reach people who used services but are not engaged in formal roles. Participants agreed this is a good idea, but we need to think more about how we can do this.

Barriers to Engagement and Access to Advocacy Services

Participants agreed that there are barriers preventing people who might benefit from advocacy from getting an advocacy service and engaging in this consultation and ongoing monitoring of the plan.

These barriers are:

- Language - engaging with people who do not have English as their first language
- Trust of individuals and/or groups.
- Cultural issues - some groups do not have experience of independent advocacy and may not necessarily know what this type of service may offer.

It was agreed that the Lothian Advocacy Steering Group would need to include measures to address these barriers in the developing action plan.

RIA Outcomes

Participants agreed that the Advocacy Plan would have the following impacts;

- Equality & diversity - positive impact
- Lifestyles – in certain circumstances neutral
- Social environment – positive impact
- Physical environment – neutral to positive depending on work / living conditions.
- Access & Quality of services – positive impact
- Communication - positive impact

Appendix 7

Scottish Health Participation Standard - Abbreviated Version

Standard Statement 1
Care and services are provided in partnership with patients, treating individuals with dignity and respect, and are responsive to age, disability, geographic location, gender, race, religion or belief, sexual orientation, socio-economic status.

Criteria
1.1 NHS staff provide information and advice to patients in response to individual needs and preferences throughout the journey of care enabling and supporting informed patient choice and shared decision making.

1.2 Processes are in place to capture comments and complaints and include arrangements for ensuring feedback has an impact on service improvement.

1.3 People are able to access independent advice to support them in making a comment or complaint or obtaining information about health services.

1.4 Independent advocacy services are provided and developed in partnership with other agencies and the people who need them.

1.5 Individual need for independent advocacy is assessed, recorded and provided where necessary.

1.6 Support is in place to meet the needs of carers.

1.7 The NHS Board provides information about services in a range of formats, and has clear systems for responding to the specific communications needs of individuals.

1.8 People are treated with dignity and respect, in ways which recognise and respond to diverse cultural and social values.

Standard Statement 2

There is supported and effective involvement of people in service planning and improvement.

Criteria

The six elements of the Informing, Engaging, and Consulting Guidance are covered by the criteria: planning; informing; engaging; consulting; feedback; evaluation.

2.1 The people who may be affected by the proposed service development or change are identified and their support needs assessed (planning).

2.2 The people who may be affected by the proposed service development or change are provided with relevant information and other appropriate communication aids that meet identified support needs (informing).

2.3 The people who may be affected by a proposed service development or change take part in developing, and appraising options, and are consulted appropriately (engaging and consulting).

2.4 Feedback is provided to the people involved on decisions made and how their views are taken into account (feedback).

2.5 Evaluation of the involvement is planned and carried out on an ongoing basis (evaluation).

Standard Statement 3

Robust corporate governance arrangements are in place for involving people, founded on mutuality, equality, diversity and human rights principles.

Criteria

3.1 The NHS Board is assured that systems and processes are in place to enable it to meet statutory requirements in relation to the participation agenda.

3.2 The public feed into governance and decision-making arrangements.

3.3 The NHS Board is assured that a culture is encouraged throughout the organisation where participation forms part of the day-to-day planning and delivery of services.

Appendix 8: Reporting timetable for the Final Plan

Agency	**Committee**	**Date**
NHS Lothian	Mutuality and Equality Governance Committee	
Mid Lothian Council	Cabinet	
East Lothian Council	Cabinet	
West Lothian Council	Council Executive	
West Lothian CHCHP	CHCP Board	
City of Edinburgh Council	Joint Board of Governance	