Home Sweet Home

How Advocacy can support the residents of care homes.

The Mental Capacity Bill

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Contributors

Mike Le Surf has worked over the past 8 years developing, training and supporting members of People First (Havering) to become respected citizens in their own community.

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Giles Frampton has worked as an advocate with people with learning difficulties for 8 years. He is currently the Advocate Senior at Advocacy Partners in Croydon and previously worked at Camberwell Advocacy in Southwark.

Jonathan Coe is the Chief Executive of POPAN (The Prevention of Professional Abuse Network). He has worked in mental health advocacy for many years and is currently the chair of the Mental Health Alliance advocacy special interest group and the newly formed Association of Mental Health Advocates.

Samantha Emerson has worked at Advocacy for Older People in Greenwich for 4 years. Previously she ran a group home for people with learning difficulties in New York for 7 years and has also worked with repeat offenders, here and in the US, doing drama therapy based work. She is currently studying for a diploma in counseling.

Joel Rasbash works for PoHwer Advocacy in Hertfordshire. Joel’s main areas of interest are in non – instructed advocacy and advocacy for people with learning difficulties who are detained under the Mental Health Act.

Lynne Laidlaw is A4A’s new Capacity Building Officer. Most recently she worked at The Disabled Living Foundation as Head of Communications and Fundraising. She has a wide range of skills in fundraising, communications, monitoring and evaluation, and strategic development within the not-for-profit sector. She has also been a lecturer in Politics in both the UK and the USA.

Cover picture story
For the residents of four care homes in Greenwich, Samantha Emerson became a regular visitor. In her article on page 5, we hear how she provided advocacy support to address some of the issues that arose when the homes were due to close.
In one of the first issues of Planet Advocacy, a couple of years ago, I wrote an article entitled, ‘Flavour of the Month.’ The aim was to highlight how advocacy had begun increasingly to feature in legislation and government policy, but I questioned the true commitment to resourcing and supporting advocacy as the advocacy sector knew it! These issues have not gone away and the relationship between the advocacy sector and government policy looks set to enter a new era.

See the news pages to read about the work of the advocacy alliance and their attempts to lobby ministers to ensure advocacy is planned and resourced at local level and plays a part in new social care initiatives to be announced in the autumn. See page 12 for an overview of the Mental Capacity Bill and the ‘independent consultee service’. These policies, along with the forthcoming Mental Health Bill, ‘Choosing Health’ white paper and the ‘Choose and Book’ programme are all likely to feature advocacy but do we recognise the advocacy they propose?

Richard Downes (page 8) and Mike Le Surf (page 10) are concerned about this new era and the impact it will have on the advocacy sector and our practice. After all, the sector has been providing advocacy for many years. We will have to use this experience and the examples of our work now more than ever to show how advocacy can make a difference. Samantha Emerson (page 5) provides us with just this in her article outlining her work with the residents of care homes and offers an insight in to the issues that arise when care homes are due to be closed and residents moved.

Planet Advocacy will continue to provide a mixture of policy news, and comment but more than ever would like to hear from advocacy workers and the lessons that can be learnt from providing advocacy on the ground.

Karen Mellanby
Planet Advocacy Editor
Representatives of the Advocacy Alliance met with Stephen Ladyman, the Minister for Community Care, in August to discuss the role advocacy can play in the government’s forthcoming new vision for adult social care. Wendy Lewington, Advocacy Advisor at Scope, and Karen Mellanby of Action for Advocacy presented the Minister with findings from the ‘Advocating for Equality’ research report previously undertaken by the Independent Advocacy Campaign.

The Alliance is lobbying the government to recognise the importance of advocacy for supporting people to have their voices heard, and for advocacy to be planned and resourced at local level to meet the need and fill in the current gaps in provision.

“We feel the report is timely and relevant in light of the government’s commitment to developing a new vision for adult social care that promotes inclusion and diversity and places an emphasis on supporting people to make choices,” says Mellanby.

It is likely that the new framework for adult social care will be published for consultation in the autumn and the Alliance is keen to ensure the dialogue with government over the importance of advocacy continues.

As Lewington states, “Independent advocacy services have an important part to play in any vision and can ensure that the groups of people who are most likely not to have their voices heard, for example people with physical, sensory communication and profound and multiple impairments, can also be supported in their choices and aspirations and this new approach to adult social care can become a reality for everyone.”

Earlier in the month Lewington and Mellanby also met with David Behan, Chief Inspector of the Commission for Social Care Inspection, the single, independent inspectorate for social care in England, as part of a programme to promote the work of the alliance.

The Government is set to publish the revised Mental Health Bill on 15 September. A Lords committee has been set up to scrutinise the draft bill and report by 31 March 2005.

This committee has been appointed by the two Houses of Parliament to examine and report on the Mental Health Bill to be published by the Department of Health.

The committee will meet for the first time on 15 September (in private). After this meeting, the Committee will issue a call for written evidence, and it will take oral evidence from late October up to the end of the year.

The inquiry will lead to a report, published together with the evidence on which it is based, setting out the committee’s recommendations to the Government on how to improve the Mental Health Bill before it is formally introduced into Parliament.

This process is known as a pre-legislative scrutiny. The Government publishes a number of Bills each parliamentary session in draft form before they are introduced in Parliament as formal Bills. The purpose of pre-legislative scrutiny is to take evidence on the policy underlying draft bills and to consider whether bills can be improved before they are introduced into Parliament.
Advocacy Alliance Campaigns for Advocacy Plans

An alliance between national charities, and the advocacy and user involvement sector is lobbying for the introduction of local Advocacy Plans to improve access to advocacy for people with significant communication difficulties.

The Alliance formed from the Independent Advocacy Campaign which researched the extent to which people with physical, sensory, communication, profound and multiple impairments lacked effective advocacy support. The name change is in recognition of the unique relationship between sectors and in recognition that while it will continue to campaign for improved access to advocacy, it also wishes to engender good practice in relation to advocacy for people with significant communication difficulties.

A number of key national charities were involved in the original Campaign, including Scope, National Autistic Society, SENSE, Royal National Institute of the Blind and Mencap as well as key advocacy networks such as CAIT, NAN, A4A and BILD. The Campaign report ‘Advocating for Equality’ had a reception launch at the House of Commons early this year with Tom Clarke MP as keynote speaker. An early day motion supported by 56 MPs supporting the report and its recommendations was also introduced.

A key recommendation of the report was the development of advocacy plans at local level to support the strategic development of effective advocacy services for people who could benefit from advocacy support. The alliance is now looking to expand its membership to include other national charities such as Mind, Age Concern and Action on Elder Abuse and user groups which have an interest in the development and resourcing of effective local advocacy services for the groups of people they provide services to.

Regional health authorities in Scotland are required to submit detailed advocacy plans to the Advocacy Safeguards Agency. These identify local need and address development issues. In addition Action for Advocacy is currently working with the local community in Enfield to pilot the idea of advocacy plans. The Alliance will be learning lessons from these models and urging for similar planning to take place in England.

The Alliance is also asking advocacy schemes around the country to renew their commitment to the Alliance and pledge their support for the campaign around Advocacy Plans.

For more information about the Advocacy Alliance, contact co-chairs Angie Lee Foster aleeefoster@nas.org.uk or Rick Henderson rick@actionforadvocacy.org.uk

Dyspraxia leaflet for Advocates

The Dyspraxia Foundation Adult Support Group has produced a leaflet as a guide for support and advocacy workers. The leaflet aims to provide information about developmental dyspraxia in adulthood and explains the main characteristics and difficulties associated with dyspraxia.

For more information or to request copies of the leaflet please contact Mary Colley 020 7435 7891

Insistent Voices

‘Insistent Voices’ – Stories on Claiming Identity by Tony Taylor (Kingston Advocacy Group)

‘Insistent Voices’ consists of the life stories of five individuals with learning difficulties and the struggles they face. Written by Tony Taylor of Kingston Advocacy Group, the book offers an insight into the lives of people who have experienced institutionalisation first hand and went on to live ‘ordinary’ lives in the community.

The book is available for sale priced £7.99, from Kingston Advocacy Group, Siddeley House, 50 Canbury Park Road, Kingston upon Thames, KT2 6LX. Telephone 020 8549 1028
News Update

Promoting Equality

Following consultation on the Draft Disability Discrimination Bill, advocacy has been recognised as important for promoting equality for disabled people.

Following comments by Action for Advocacy (A4A) the Joint Committee on the draft Disability Discrimination Bill have, in their first report, emphasised the importance of advocacy for disabled people. A4A, along with the Scottish Independent Advocacy Alliance (SIAA) and the National Centre for Independent Living highlighted the importance of advocacy for enabling disabled people to access services and secure their rights in the recent consultation.

SIAA and NCIL argued a duty should be placed on public authorities to provide advocacy services. A4A argued the strategic development and funding of advocacy should specifically be included in the new duty to promote equality of opportunity.

The Joint Committee agreed with A4A and recommended that, following consultation, the Disability Rights Commission code of practice to be made on the new clause 8 duty should emphasise the importance of independent advocacy services, and provide guidance on the circumstances in which public authorities will be expected to ensure that such services are available for disabled people.

The Department for Work and Pensions are now consulting on this extension of the Disability Discrimination Act and in particular the introduction of a duty to promote equality for disabled people.

Voluntary and Community Sector (VCS) organisations may be contracted to put information readily available from NHS sources into appropriate formats for their client groups and to provide appropriate advocacy or other support as part of the new choose and book programme.

By the end of 2005 all patients who require elective surgery will be offered a choice of hospital by their GP or other health professionals (e.g., an optometrist), at the time they are referred to see a hospital consultant. It is estimated that this will effect some 10 million patients a year.

Primary Care Trusts (PCTs) will be carrying out needs assessments and considering how best to serve their local populations. A significant minority of patients, who have experienced obstacles to equal access in the past, should be able to benefit from new regulations coming into effect.

New guidance coming out of the Department of Health recognises that VCS organisations are often well placed to support some disadvantaged groups in accessing and taking up choice.

Download the consultation document called ‘Delivering equality for disabled people’ from www.dwp.gov.uk/publications
The Joint Committee on the Draft Disability Discrimination Bill First Report is available from: http://www.parliament.the-stationery-office.co.uk/pa/jt200304/jtselect/jtdisab/82/8202.htm
Home Sweet Home

Over the past four years Advocacy for Older People in Greenwich has worked with 106 older people who have been forced to move due to the closure of their residential care homes. In this article Samantha Everson outlines the main aims and objectives of her advocacy involvement and some of the issues that have arisen in the course of the project.

In July 2000 I began work to support the residents of four residential care homes in Greenwich that were being closed down. Funding from government had been obtained to replace the remaining local authority homes with ‘Neighbourhood Resource Centres’ provided in partnership with the private sector. It was envisaged that these centres would provide residential, nursing and day services to meet the range of health and social care needs of older people across Greenwich.

The local authority contacted Advocacy for Older People in Greenwich and invited us to support the residents through these changes by providing group advocacy opportunities, and to a lesser extent individual advocacy, as needed. Originally the project was for a year and our main aims and objectives were to share information about the re-provisioning process through advocacy groups and accessible information points within the homes for relatives and residents who did not wish to participate in the group process. We aimed to elicit residents’ thoughts and feelings about the process, identify issues, concerns and questions and ensure residents were able to make as many choices as possible. We wanted to ensure these were raised in the relevant forums and to act as a resident representative in meetings or offer support to residents who were able to attend themselves.

We also aimed to work with individuals within the homes to identify, create and support advocacy partnerships and support individuals until suitable volunteers could be recruited, trained and matched. Within this we also hoped to identify those residents who wished to move out of the borough and ensure they were informed and included in this process. These are some of the approaches we adopted and what we learned.

Group Work

Very early on in the project it became apparent that the size and duration of each group needed to be flexible depending on the needs of the residents involved. Also, that to some extent, I would have to be flexible with regard to the content of the discussions, often allowing residents to focus on issues that were relevant to them at that time. Some of the issues raised needed individual follow-up and I have met with over half of these residents on many occasions.

One of the most important realisations to come out of running the groups is that residents wanted to ‘keep hold’ in someway to what they like about where they live now. Many have questioned, on more than one occasion, why the residences have to be closed down at all. Reassuring them that certain things will remain the same and that they can influence what those...
things are, has been an important part of the process. In order to ensure this happens, I have been helping residents creatively through making videos, taking photos of them, their friends and their rooms and recording their thoughts and feelings about their homes which will become part of their ‘Life History Books’.

**How We Live Now**

Generally residents feel very protective of where they live and talk a lot about feeling safe and supported by the staff around them. They like knowing the routine and where they stand within the group. They feel comforted by the fact that staff know them well and know their likes and dislikes. They have identified people they consider to be friends, whom they spend a large majority of their time with.

A lot of the sadness and anxiety expressed during the groups seems to stem from the fact that people want to be assured that they will be allowed to move with their friends. During several of the advocacy groups there have been residents who have become upset when talking about the assessment process. At that time they have received a lot of support from other members of the group. I have asked residents if they wish for me to bring their feelings to the managers of the homes or to their key workers, but so far people have preferred not to, choosing instead to talk about it amongst themselves during the groups or preferring to ‘wait and see’ what happens during the assessment period.

Residents have agreed for me to document some of these issues in their “Important Information about my transition process” sheets, which will be put into each person’s ‘Life History Book’. Some of the issues residents want documented are lists of who they would like to transfer with, (staff and peers) and how they feel about the process of having to move.

**Hopes for the Future**

During the advocacy groups we also talk about the fact that if people do end up moving to a different residence to their friends, efforts will be made to ensure they are able to stay in touch through visits and phone calls, etc. The difficulty here is that people have to live with uncertainty for a prolonged period of time. Residents are asking for answers to specific questions such as ‘can I move with my friend’ or ‘which staff will be coming with me’, questions which can not be answered yet.

Many residents have complained about the length of time the re-provisioning process has taken and have asked why they were consulted ‘so early’ when so little seems to have happened until recently. Although residents have said they enjoy coming to the advocacy groups, that seems to be as much for the social aspects of the group and the sense of support they get from one another, (the realisation that they are all ‘going through’ the same thing), as it is about being able to ask questions and influence the process.

The residents are able to identify positive outcomes that will happen as a result of the changes. For example, many have expressed excitement about having a bigger room, which would offer more chances for privacy and their own bathroom. Also they are looking forward to an increased level of staffing and have identified hopes that the staff team will be more consistent, with less reliance on agency staff. They hope this will lead to more chances for interaction and direct involvement with the staff and that they will have an opportunity for more meaningful engagement and activities in the future.

**Reminiscence**

A very common theme throughout all the groups I have run is the need for the residents to have time to reminisce about
themselves and their lives. There is a very clear sense of peer support gained during these groups, as residents begin to share common histories and experiences. Being able to talk about ways they have coped with changes and adversities during other times in their lives seems to bring with it a sense that, “we will get through this change too”. That their lives, their pasts, their likes and dislikes, their feelings and thoughts will be recorded somewhere and brought with them. I believe this is one of the reasons that residents have so far responded very positively to creating ‘Life History Books’.

Individual Advocacy Work
My work within the homes has led to the creation of 15 advocacy partnerships, eight of which I have provided the advocacy support for. Individual issues and needs seemed to come up a lot more in the final part of the process. Some of the issues include: writing a will; attempting to find family members; organising a funeral for a resident’s husband; working with care managers to help someone move home and regain their independence; helping residents to become more involved in their local community; dealing with financial issues.

Accessible Information Points
This was identified very early on in the project as being a very important piece of work, ensuring that those residents who did not wish to attend an advocacy group, had access to clear and accessible information about the re-provisioning process. What started out as small information points in each home, has grown into the co-ordinated and creative information rooms we have today in each residence.

As a member of the Information Room group I have been responsible for organising, copying and creating a lot of the information held in these rooms including:

- The information files
- The sites photos and photos of residents
- The signs, ‘top ten questions’, the ‘Statement of Expectations’, etc
- Maps and information on ‘How to get to the sites’
- List of important numbers and addresses

In conclusion
My experience in running the advocacy groups has shown that the wish list of the residents’ is very simple. Residents want to live with people they know and trust and consider friends. They want to be meaningfully engaged in activities they enjoy. This means being able to make individual choices of activities. They want a regular staff team who they know and can rely on. They want that staff team to be well trained, to be kind, to be people they can ‘have a laugh with’. They want to feel safe. They want to be asked their opinion and know that their opinion will be listened to and treated with respect. They want to be able to say no. The final home opened on August 9th this year and my involvement will continue until March 2005. This will allow me to support the residents to adapt, but just as important, I will be able to monitor if the local authority and the new provider, keep their promises to the residents.

Samantha Everson
Over Exposed

Advocacy is increasingly mentioned in government policy, leading to closer links with the NHS. Richard Downes is concerned about this and feels NHS exposure is threatening our advocacy culture.

Brent Advocacy Concerns participates in a Advocacy Standards for Black Minority Ethnic (BME) groups consultation. We are the only disabled peoples’ organisation participating and the only non-BME group. Not all groups involved are advocacy groups but many have an advocacy role. This proves anyone can be an advocate and that difference is good.

But something’s really bugging me. It’s renewed NHS exposure. There is a culture looking in on advocacy, pushing for standards, accreditation, qualification and it’s extremely aggressive. These people are confused by advocacy, they don’t understand it and they may not like it either. They prove this by undermining an advocacy culture, prevalent in the UK for over 30 years, which has developed and evolved, by under-funding us, by requiring that we (us) be like them. This ‘us’ and ‘them’ divide needs to be fought.

At the Kings Fund Summer Event a NHS Chief Executive started her speech by clumsily commenting on the West Indies cricket team (at a BME event), moved on to say her 20 year old experience of once meeting an advocate as being adversarial (for NHS professionals to agree) and then completely lost this audience member by repeating the Blairite position (repeated only recently in his infamous ‘the 60’s caused all our problems’ speech) if we want rights we must take responsibility.

This is one of the most despicable positions I have come across. It says everything about powerful people not being in touch with the disempowered people we represent. I first heard this when Tony commented on the Disability Discrimination Act. I’m a 48 year old disabled person. I’m fairly empowered. For the first 36 years of my life I wasn’t. It wasn’t rights that started the empowerment process. It was good friends. It was meeting and discovering the politics of the disability movement. Previously the NHS was my primary source of discrimination. Their professional opinion led to incarceration in abusive institutions, unmonitored by education departments. It continued when I was the only disabled person in a mainstream school and was reinforced in early employment when I was unprotected by law. Because of institutional abuse and societal exclusion, I acquired other impairments, I experienced mental distress and knew better than to go back to the NHS for
support. A new right does not improve this experience. There is no way I need to be responsible for it. It is reasonable to take the position (as I did) that if society does not include me I don’t have to be a part of it. It abused me I can abuse it back.

I survived. So did the woman who was overmedicated in an NHS ward, who was leapt on and forced to the floor in spite of her oesteoarthritis, who was injected with Haliperidol in spite of a allergy noted on the front page of her case notes, who was dragged along a corridor, who was left in a secure room and not monitored whilst her allergy kicked in, who was deprived of water when she could not swallow solids, who was bribed to conform through cigarette deprivation, who was left in a dormitory with a broken window in the depths of winter, who reports she was constantly intimidated and uncared for by NHS professionals and who only yesterday had to listen to a clinical assessor at an independent review say that if he was the doctor, he would have done the same thing. Advocacy adversarial? Sometimes we have to be.

The NHS aggression and abuse continues apace. At the Kings Fund Summer Event it was proposed advocacy had a use. We should promote the benefits of health. We should be responsible for telling partners it is good and proper to take medication, it is only right they eat good food and throw out the chips. Advocates like PALS and the Health Promotion Unit should become the friends of the NHS. We should do their job for them.

These aggressors come into our lives now to tell us what advocacy should be. They think they can do it because they don’t know what advocacy is. Why should they? Advocacy groups don’t know what advocacy is either. At the Kings Fund event when we were being attacked we agreed with this. We went along with this grand old advocacy claptrap. Advocacy.... Erm!!! We don’t know what it is. It’s different for all these groups, individuals and issues. Rubbish!!

We know what advocacy is. We do it every day. We have a definition of advocacy on the Advocacy Charter, which can be tested in every piece of advocacy we do. It works. Its time we started promoting it. It might even be time we looked at what we did in accordance with this definition and picked some standards out. Its time we started advocating for advocacy.

Richard Downes
Brent Advocacy Concerns
Are Advocates giving Advocacy a Bad Name?

Mike Le-Surf, co-ordinator of advocacy organisation, People First (Havering), implores all advocates, advocacy groups and advocacy providers to take a good look at their practice and ask “Are advocates giving advocacy a bad name?”

Anyone can advocate. Everyone should advocate, when asked, for the people they love or work with, people they support or just enjoy being friends with. Sometimes, however, people need an independent advocate to help them speak up when others may have a difficulty or a conflict in offering support.

Independent advocacy should be a right for all people with a learning difficulty. If someone needs some extra support to speak up for themselves, or needs someone to speak up on their behalf, they should have access to good, strong, independent advocacy support.

Lately, however, I have had the feeling that in some areas, advocates are giving advocacy a bad name! Advocates too, must be accountable for their actions and need to take more of a lead in promoting the voice, the rights, and support the steps that lead from good advocacy, to a better life for an individual.

Advocacy has to be more than words, or the people that do need an advocate to help them to get their message across face just another tokenistic round of meetings, gatherings, reviews, ideas, “person centred approaches and plans” that will lead to nothing except frustration and disappointment.

There must be nothing more frustrating for people with learning difficulties and their families, to plan and dream, to hear about a better time ahead, a “fight” that needs to be won to help someone get the things (services or otherwise) that they want and need, and then for that advocate to disappear into the sunset, never to be seen again. I am beginning to see why people resent the “half-baked philosopher”, who is paid to support people to speak up, but instead, spouts out their own version of how things should be, and has no intention of giving any hands on, practical support that may be needed.

Some may stand firm that an advocate should not be a provider of services outside of their advocacy remit. Possibly true. But there is also a role to support people to move their “voice” to where it can be heard properly and clearly. Where there is more chance of being listened to. Where people can attempt to do the things that they
want to do, in the arena where hopes and wishes have the most chance of being fulfilled. That arena is, of course, with local people, in the local community.

And what about that group of so called “independent advocates” that live firmly in the pocket of social services, or other funders, and have no interest, or personal strength, to challenge the decisions made for people, by those services. Token advocacy, tick box advocacy, is just as disgraceful as no advocacy at all.

Advocacy needs to be real, something that benefits people on a daily basis. Not just “called in” when there is a “closure” of a residential home, or a change in day service provision. Not just when things are bad, or BIG or at crisis. Speaking up about the little, day to day things that make life different, more enjoyable. Little things that we all take for granted. The little things that make us smile, or cry. That is advocacy. That is where advocates need to be. Working on the “ground floor” with the people that need support. In places where people are, and in places where people want to be.

As independent advocates, we have a job to listen to people. We have a job to support people to speak up. We also have a duty to be real, honest and practical about the support we are offering.

Let’s get on with it independently, honestly and inclusively!

Mike Le-Surf
Co-ordinator People First (Havering)
Access to advocacy, or the lack of it, has become a key issue in relation to government's proposals outlined in the new version of the Mental Capacity Bill. Karen Mellanby gives an overview of the legislation and highlights some of the key concerns.

The second version of the Mental Capacity Bill was published in June, almost a year after the first proposals and following many years of consultation, policy statements and papers. But despite the length of time in development, there are still many people who feel a major piece of the jigsaw has been left out.

Organisations of disabled people and national charities have both expressed concern about the restrictive advocacy role outlined in the legislation. As it stands many people who could benefit from advocacy will be unable to under the legislation. Advocacy under the guise of an independent consultee service is deemed to be necessary only for the most vulnerable, at times of serious or significant change and then only if they do not have friends or family to support them. There is a general feeling that without full recognition of the advocacy role in relation to all people with impaired capacity, key messages underpinning the legislation will be lost and the new proposals will be open to abuse by formal and informal carers.

The New Proposals

Overall the Mental Capacity Bill aims to clarify the law in relation to anyone over the age of 16 who is unable to make decisions, either temporarily or permanently, for themselves. It provides a framework which aims to balance empowerment and protection for adults with impaired mental capacity and a number of proposals are introduced.

Predominantly it seeks to offer statutory protection against liability for acts in connection with care and treatment. As long as the five guiding principles of the bill are met, it is in the person's best interest and they have formed a reasonable belief as to the person's lack of capacity.

Lasting Powers of Attorney (LPA) will replace Enduring Powers of Attorney (EPA). This means individuals will be able to plan for future incapacity by granting LPA’s to people of their choice. These LPA’s will incorporate health and personal welfare decisions in addition to financial decisions. A person will be able to leave clear instructions that they would like to refuse certain treatments should they lose capacity in the future. In addition the bill allows for intrusive research to be carried out on those who lack capacity under certain circumstances.

A new court of protection will be established that will have jurisdiction over all areas of decision making for adults who lack capacity and will have the final say when there is a dispute amongst decision makers if, for example, best interest decisions were to be challenged.

Key Messages

There are five guiding principles in the bill which are intended to underpin the key messages of the legislation. Namely, that everyone has a right to make choices and have their decisions respected, that individuals should be enabled and encouraged to make choices and decisions where possible, and that people have the right to take risks and make decisions that other people may think unwise. Where decisions have to be made on behalf of people, the key message is that it should be ‘in the best interests’ of the person concerned and all options should be considered before a decision is made.

The Bill sets out factors for consideration when assessing a person’s capacity which includes the extent to which they can understand and retain information, use the information to make a decision and communicate their decision. It also suggests checks to demonstrate best interest decisions including the extent to which a person’s views, wishes and values have been considered.

Detailed codes of practice have still to be developed and issued to provide additional guidance on how the principles and standards will work in practice.

So Where is Advocacy?

So where is advocacy and why are people unhappy with the proposals? The Making Decisions Alliance believe the key principles are a considerable improvement on the
current legal position but any positive or significant impact will depend on how the principles are ‘implemented, communicated and resourced’. A coalition of organisations of disabled people, that include the National Centre for Independent Living, British Council of Disabled People and National People First feel the bill will reinforce the power of relatives, carers and staff and prevent disabled people making day to day choices about how they live their life. They believe a ‘right to supported decision making’ should be written in to the bill to guard against this. Both coalitions believe Advocacy should be at the heart of the bill to support the clauses of the legislation that stress the importance of supporting individuals to communicate their decisions and, in best interest, cases for involving individuals to have their wishes and feelings central to any decision made.

Independent Consultee Service
Instead the government is proposing a new ‘Independent Consultee Service.’ This service is deemed a necessary safeguard only in connection with care or treatment and only in cases where serious medical treatment is being considered or significant changes in residence are being made by public bodies, and even then, only if the person affected lacks family, friends or contacts.

Any advocate will recognise the role advocacy can have in relation to the key principles outlined in the bill and the new proposals. The sector has built up considerable experience over the past 30 years supporting people who have impaired capacity. This support has been essential to enable people to have control and a say over day to day choices, like what to wear, what to eat, who to spend time with. Choices that many of us take for granted and that together have a significant impact on our quality of life. Advocacy has also provided much needed support to individuals at times when conflict arises about what they want versus the views of the people closest to them and at times when family or professionals think they know best.

It is disappointing that this experience and the full value of advocacy has been sidelined in the proposals. Without committing adequate resources and support for independent advocacy there is a danger that the chance to make a difference to millions of vulnerable people will be lost.

The five key principles of the bill

1. The presumption of capacity – ‘A person must be assumed to have capacity unless it is established that he lacks capacity.’

2. Maximising decision-making capacity – ‘A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.’

3. Freedom to make unwise decisions – ‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision.’

4. Best interests – ‘An act done, or decision made, under this Act for a person who lacks capacity must be done, or made, in his best interests.’

5. Least restrictive alternative – ‘Before the act is done, or decision made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedoms.’
Precious Metal

Volunteers are like gold and deserve to be valued and treated accordingly. Lynne Laidlaw suggests some volunteer policies and procedures which will help advocacy organisations do just that.

At a recent training course, the topic of volunteers came up in relation to a case study presented by a volunteer who felt un-supported, un-appreciated and ill-informed as to what was expected of her in her role within the organisation. One of the participants, new to the charitable world and working to establish a new charity, could not understand why she didn’t simply leave the organisation and go elsewhere. I am happy to report that the response from the other participants was ‘gentle’ but quick and professional -- volunteers are like gold and they deserve to be valued and treated accordingly. By the end of the discussion, the ‘novice’ had gained an appreciation of the important contribution volunteers make to the charitable world; a ‘value’ shared by a great many major trust donors who consider a vibrant volunteer role within an organisation to be important when considering grant applications.

We all know the value of volunteers: increasing our capacity and contributing to an inclusive, diverse and committed ‘workforce’; providing opportunities for people to gain skills and knowledge as well as an appreciation of the contribution the charitable sector makes in advancing social justice. We also know the organisational and management costs associated with running successful volunteering programmes; they take a lot of thought and effort. With some notable exceptions (advice and information sharing, befriending and caring), it can be argued that the delivery of advocacy places a special responsibility upon volunteer advocates. We ask volunteer advocates to work with some of society’s most vulnerable, and often troubled, people. True, quality advocacy provision requires a demanding level of human interaction -- listening, watching, learning and trusting -- and not only with the people we support but with the agencies involved in service provision.

Because of this ‘near unique’ position, it is important that advocacy schemes have in place policies and procedures which, while advancing the work of advocacy, also protect all the players -- the organisation, the funders, the advocate, and the users. Please excuse me if this sounds like instructions to grandmothers in respect of eggs. However, in my experience of working with advocacy schemes, best practice in respect of policies is patchy -- not for lack of commitment but most often for lack of time and resources.

So let us cut to the chase and address just a few of the issues. At the end of this article is a list of resources for all the materials and issues raised here.

First, you need a written, agreed Volunteer Policy. Developing one of these will help you focus your aims and objectives and how volunteers can be most effectively used, and areas where their involvement may not be appropriate. This policy should be written in consultation with your staff and volunteers. Paid staff are often apprehensive about volunteers and feel that their jobs may be under threat. Full involvement in volunteer policy development should ensure that
there is transparency and a clear understanding between volunteers and paid staff as to who is responsible for what and to whom, and to create a collegial atmosphere of sharing and learning.

Develop an interview process which insures that the potential volunteer gains a broad and deep understanding of your work and the organisation. This saves time later.

Review your induction pack and its contents. Is it professional, inviting ('plain English' with an EOPs commitment) and with adequate information about the work and the organisation; updated regularly with all the contact details necessary? Take soundings as to its quality and effectiveness; does it 'fit' and complement the induction process?

It is advisable that your volunteer policies are distinct from those of the staff, and clearly state that volunteers are not under any obligation to work specific hours nor perform specific tasks, and will not be 'sanctioned' for failure to work, but that you have 'reasonable expectations' of each other. A case, ultimately decided by EAT (Employment Appeal Tribunal), provides guidance for what constitutes a contractual arrangement - subject to employment law - versus a voluntary one. It is advisable that your voluntary policies reflect this guidance in order to protect you from possible litigation if a relationship with a volunteer sours (South East Sheffield Citizen's Advice Bureau v Grayson [2004] IRLR 353).

It is also advisable that volunteers not be subject nor have access to your standard discipline and grievance procedures (but entitled to use the organisation's complaint procedure and be subject to a separate review and disciplinary process such as for gross misconduct). Further, under no circumstances are volunteers to be compensated for anything other than out of pocket expenses (for the present, lunch money seems to be safe but concerns have been raised). Training necessary for the work was not, in the case before EAT, considered to be a type of compensation (a 'consideration') in exchange for a volunteer's commitment which could have created a contractual arrangement. Take care! This is one case decided on a specific set of circumstances, the law will probably develop further.

Last but not least, does your Employers' Liability Insurance policy explicitly mention coverage for volunteers? It should, as should your Public Liability Insurance policy which is designed to protect your organisation from a charge of negligence related to the provision of professional services such as advice, information and counselling.

It is less costly to keep volunteers, in whom you have invested, happy and committed, than to have a revolving door -- panning for more of that gold!

Show your appreciation with clearly stated aims and boundaries, a professional approach, which will guard against misunderstandings.

Lynne Laidlaw
A4A Capacity Building Officer

Items discussed are not a full or definitive statement of the law and are not intended as a substitute for professional legal advice. No responsibility for loss occasioned as a result of any person acting or refraining from acting can be taken by the author or Action for Advocacy

Resources

Volunteering England (www.volunteering.org.uk) good site which offers guidance on all aspects of volunteering ('Get it Right From the Start'). They also manage a grant scheme.

Islington Voluntary Action Council (www.ivac.org.uk) good site with free downloads related to organisational development, including a sample volunteer policy.

Sinclair Taylor & Martin, The Charity Team at Russell-Cooke Solicitors (www.rusell-cooke.co.uk) sign up for monthly legal update (Services for Charities; Charities Team; Events Updates). Great links to....

Sandy Adirondack (www.sandy-a.co.uk) great resource for lots of information, updates and links about the law and governance of the non-profit sector.

Reach (http://www.volwork.org.uk/about.htm) '...aims are to recruit and support people with managerial, professional, business and technical experience and match them with part-time voluntary roles throughout the UK, and to help voluntary organisations gain access to these potential volunteers and benefit fully from their expertise.'
Building on experience

Advocacy careers.

"I work for an advocacy project where we provide support to local residents on a variety of issues including housing, benefits, work, community care etc. Most of my clients are either homeless or refugees/asylum seekers. I have worked here as an advocate for nearly two years. Although I have quite a lot of experience, I have had very little advocacy training and would like to develop my skills in this field. I feel that I need to brush up on my theory. Can you suggest ways to help me move forward in my own career?

Clara via email

You’re not alone! The lack of high quality accessible training is the Achilles heel of the advocacy sector, many advocates are trained on the job, many are not trained at all, few have a good training budget and fewer still have access to relevant courses.

There is no advocacy training course in the country which has been approved and accredited by a national advocacy agency and indeed no national advocacy agency ready to approve and accredit them.

There are several examples around the country of local advocacy schemes and advocates working with universities to establish certificate courses. My understanding is that many of these courses have done well in terms of developing a knowledge base, but much less well in terms of supporting and assessing the development of skills. Core competencies in advocacy are in need of development and national agreement.

So, until national agreements are reached, how can you develop your practice, stay in touch with advocacy theory and move forward in your career?

Start with basics: do you have a personal development plan (PDP)? If not, talk to your line manager about developing one. PDPs at their best are holistic, that is they begin with your own view of all your training aspirations, including day to day advocacy work, professional and career development and more individual issues (creative courses, learning for your own pleasure and so on). Agree with your line managers a feedback mechanism so that these aims can then be converted to a timelined plan, based on available resources and agreed priorities. You could also explore setting up an action learning set (a focused and secure space to reflect on practice) with colleagues from other organisations.

With regard to theory the best thing you can do is get hold of the few published books on the topic (contact A4A for suggested reading).

In terms of career development, advocacy is in its infancy. Most people are either full-time advocates or have moved on to management roles which often don’t include direct advocacy work. However some organisations have instituted new posts such as ‘senior advocate’ which are filled by advocates with more experience and often include some management responsibilities. The status of these roles is very much determined by the individual employer and you should always check out the detail of the job description when applying for these posts.

As an employer, I have come to believe that what is most important when recruiting new staff is not the candidate’s length of experience but his or her level of skills and abilities. Whilst if you have been an advocate for several years, it should follow that you know what you are doing. However in practice this is not always the case. So, working on gathering evidence of your skills and thinking about how best to demonstrate them in your application and interview will count for much more than emphasising the length of your experience or the depth of your theoretical knowledge.

Jonathan Coe is Chief Executive of POPAN and chairs the Steering Committee for AMHA, the Association of Mental Health Advocates

email: info@amha-online.org.uk
Website: http://www.amha-online.org.uk
IT’S THAT CONFERENCE TIME OF YEAR AGAIN!

It’s that time of year again. Advocacy conference season! A time to renew old advocacy friendships and forge new ones at a range of advocacy events and conferences.

27th September,
The Cait Annual Conference at the Kings Fund London will build on the learning from CAIT’s advocacy outcomes training programme. Download an event flyer and booking form from www.citizenadvocacy.org.uk/web/flyer.pdf

20th October
The Citizen Advocacy Coalition will be holding their National Assembly in London. For full details please contact Joe Monaghan on 0151 733 6705 or joe@cacoalition.org.uk The CA coalition also holds regular regional meetings up and down the country. Contact Joe for more details.

9th -10th November
The National Advocacy Network will be holding their annual bash in Coventry this year on the 9th-10th November. This year the focus is on practice and the challenges of advocacy. All enquiries to Fast Forward 01903 767 070

ADVOCACY
14 Sep 04
Asylum Seekers, Accommodation and Community Care. Action for Advocacy
020 7820 7868

21 Sep 04
Advocacy for Carers: introduction
Carers UK
020 7566 7632

23 Nov 04
Advocacy: effective skills
Carers UK
020 7566 7632

29th/30th November, 1st/2nd December
Accredited Training in Advocacy
AILA /University of Essex
01245 381658

COMMUNITY CARE
8 October 04
Housing and Community Care Advanced.
Carers UK
020 7566 7632

20 Oct 04
Asylum Seekers, Accommodation and Community Care.
Carers UK
020 7566 7632

26 Oct 04
The Human Rights Act
Carers UK
020 7566 7632

3 Nov 04
Community Care Law Advanced
Carers UK
020 7566 7632

22nd/23rd/24th/25th November 2004
Community Care Practice and the Law
AILA/ University of Essex
01245 381658

Carers
16 Nov 04
Carers and Their Rights
Carers UK
020 7566 7632

8 Dec 04
Carers Awareness
Carers UK
020 7566 7632

Mental Health
13 October 04
Carers and Mental Health Law
Carers UK 020 7566 7632

Organisational
4 Oct, 28 Oct, 24 Nov and 16 December
Promoting Advocacy Effectively
Action for Advocacy
020 7820 7868

5-6 October or 27-28 Oct
Implementing PQASSO
Charities Evaluation Service
020 7713 5722

This is just a small selection of courses taken from a list on www.actionforadvocacy.org.uk

If you have any ideas for training that you would like us to consider please email or call Katja 020 7820 7868 katja@actionforadvocacy.org.uk

Developing Teams
Level Headed
020 7538 9387

22 Nov 04
Involving Service Users in Evaluation
Charities Evaluation Service
020 7713 5722

1 Nov 04
Presenting evaluation findings effectively
Charities Evaluation Service
020 7713 5722

2 Dec 04
Service
020 7713 5722

This is just a small selection of courses taken from a list on www.actionforadvocacy.org.uk
What Would You Do?

In the last issue Richard Downes of Brent Advocacy Concerns invited readers to send in their comments on the following case study. Joel Rasbash of PoHwer Advocacy in Hertfordshire responds.

A social worker refers a woman with learning disabilities who has little or no verbal communication. Her parents want her to be sterilised. The social worker is worried about this as is the health authority which is reviewing the situation through their legal team. You accept the referral. You reach a point where you are able to meet with the partner. In the intervening period the social worker leaves and no one else has taken up the story. Your only point of contact is the parents. So what do you do?

This case has many dimensions. The most important starting point is to separate the client’s wishes from that of all other parties. With most forms of advocacy this can be done by asking the client, and offering options and consequences. In the case of someone with profound learning disabilities, we have to start by independently verifying the extent to which a client can grasp the issues. For this to happen the advocate will need to spend time with the client finding out about how they relate to others. A part of this may be to seek access to speech therapy, and ask questions from family and professionals involved.

Running parallel with this is the work with social services and the health authority. In the case of someone with a profound learning disability, the Learning Disability social work team should have allocated someone to the client. The advocate should contact them requesting a meeting with the manager to discuss a locum arrangement (at the least). The advocate can also find out if the client uses a day service, and pursue the issue there. If there is no willingness to provide statutory support for the client, then the advocate could go down one of two routes. They could make a formal complaint on behalf of the client or they could request that the advocacy service formally raises the issue with health and social services commissioners. The latter route works particularly well when a professional advocacy service operates for people who have communication difficulties and when there are service protocols in place for handling these kind of situations.

As for working with the parents, it is important to have information aimed at informal carers and friends, giving details about the advocacy provided for people with profound learning disabilities and similar conditions. The advocate may also try to find out if there are carers’ advocacy projects or generic advocacy services in the area, so that the family can receive their own independent support. The advocacy service needs to be clear about the differences in working in these situations from those where clients can direct the advocate. The work is on behalf of the client. This requires a degree of judgement, and to safeguard this, careful documentation of actions is essential. If through this work it becomes clear that the client can use particular communication aids, then the nature of the work will change into client led advocacy.

In terms of answering the question of whether a client should be sterilised, that is not for the advocate to do. They should try to ensure that no decisions are made without the right support services in place, and that the right services are doing their best to involve the client and understand how they would deal with the situation.

With or without the Capacity Bill, this matter can only be resolved by the decision makers using a client centred approach rather than a ‘best interests’ approach.
Relative Values

The first responsibility of an advocate is to represent the needs and wishes of their client. However, the relationship between advocates and the families of their clients is one that has not received very much attention. A workshop at last year's London advocacy forum gave advocates the opportunity to reflect upon some of the issues.

Workshop leader Giles Frampton reports back from the discussion.

As a starting point, we explored our current approaches and found the degree to which advocacy organisations consider, in detail, the approach to adopt when becoming involved with someone's family, is variable. Not all advocates felt confident when working with families and it was generally felt that there is a particular set of skills needed when liaising with the families of clients. Some advocacy organisations may prioritise work with individuals with limited family involvement because of the advocacy role undertaken by peoples' families.

Advocacy involving work with a client's family often also gives rise to questions about consent. Whilst our work with a service user will involve entering their personal space, this is done so with their agreement, where capacity allows. When, as advocates, we engage with the issues that cross over into the personal space of their family, it may be far less clear cut whose agreement is needed. There may be confusion, either on behalf of the advocate or the client's family, as to who the advocate represents, or the issues that are relevant to them to act upon. There can be significant cultural issues which advocates may be unequipped for.

It is important, however, to remember that working alongside someone's family can be extremely rewarding and the input of families can add greatly to the outcome and process for the client. To achieve this advocates must recognise the importance of good communication and developing trust. The advocate needs to consider discussing with the referrer the best way of establishing a positive relationship with the family and consider in what situations it is right to share information with their client's family if the person themselves is not able to decide this. Be prepared to explain the additional assistance that having an independent advocate can bring, and make sure that this is based on the constructive relationship you have built up with the person. Develop good initial contact with families; write letters; explain your involvement and provide literature appropriate for different audiences. Charters and leaflets may help. Make follow up phone calls. Advocates should also keep an open mind about the perspective of the family and consider whether parents may need some additional support themselves and where appropriate suggest useful contacts.

It is important that advocacy organisations consider their approach to working with families. Advocacy organisations can develop a statement about its approach to working with families and provide information that is specifically written for families about the role of an advocate. They can also establish systems by which families can feed back to the organisation their experience of advocacy as well as providing clear support systems, training and supervision that are attentive to issues in working with families.

In 2003 Advocacy Partners held a full team training day to explore issues in working with family members. We are really keen to share information and gain advice from other organisations. We would be delighted to hear from advocates who are interested in discussing and developing ideas. Please contact us.

Giles Frampton, Advocate Senior, Advocacy Partners
gilesframpton@advocacypartners.org.uk
Dear Editor

UKAN under threat

The future existence of the UK Advocacy Network is under threat as sources of national funding they can apply for seem to be drying up. This has already led to the redundancy of one of the 3 workers, and will probably lead to a further redundancy soon, leaving only one member of staff, able to provide only a minimal service to its 260 member groups.

This should not be allowed to happen at a time when the right to have an advocate is coming onto the national agenda in a way that UKAN have consistently campaigned for in the past twelve years or more.... We need more than ever a national network of service user-led advocacy to continue to uphold the principles of independence and the central role of service users in defining good practice in advocacy.

If there was no survivor/service user led advocacy organisation, we would have to invent one, and why do that when we already have an organisation which has provided standards, guidance, training, networking and support for many years, despite receiving only minimal funding? Yes, we do need a body of professionally trained and paid advocates available once a person has been assessed under the Mental Health Act, but advocacy needs a wider basis in the community, so that people can access an advocate at any stage - not only when immediately under threat of section.

If UKAN goes, who will be there to defend community-based local advocacy projects set up and run by service users for service users?

Its time for the survivor/user movement to begin acting together, with or without funding, to ensure we have a place in our own right in the future of mental health.

Dr. Jan Wallcraft,
NIMHE Fellow for Experts by Experience
Sainsbury Centre for Mental Health.
Senior Researcher

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Dear Planet Advocacy

The Advocacy Federation

I write to introduce you to The Advocacy Federation (TAF). TAF is a coming together of all national and regional networks of advocacy providers, and the key national and regional advocacy support agencies, with the primary aim of representing a unified, coherent and influential voice for the ‘advocacy movement’.

It is important to say that TAF is not an attempt to undermine or override any existing advocacy representative group. We envisage and earnestly hope that TAF will be strong enough through its membership, to raise the profile of advocacy considerably, and in doing so to make it easier for advocacy at grass roots level to claim its ground and do its work without the need to explain what advocacy is, and why it is so vital in the fulfilment of the aspirations and needs of so many people.

Within the next few months we shall be writing to each of the major networks’ contacts, and inviting their network (not always referred to by that term) to register with TAF. That will be the final act in bringing TAF into being. The federal framework provides us with the opportunity to look for realistic ways in which we may work together for the common good of all who are involved in advocacy.

Yours,
Nick Pizey
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LETTERS

Voluntary and Community Sector (VCS) organisations may be contracted to put information readily available from NHS sources into appropriate formats for their client groups and to provide appropriate advocacy or other support as part of the new Choose and Book programme. (See news article page 4).

A significant minority of patients, who have experienced obstacles to equal access in the past, should be able to benefit from new regulations coming into effect. New Guidance coming out of the Department of Health recognises that VCS organisations are often well placed to support some disadvantaged groups in accessing and taking up choice.

Some PCTs may already have adequate support in place. Others will need to put it in place to ensure that all patients, including those who are currently disadvantaged, can benefit from Choose and Book and that may include decision making support and/or advocacy services.

Disadvantaged, in this context, means those who have not been easily reached in the past. For example:
• Patients for whom English is not a preferred language or who do not speak English at all.
• Patients who require non-standard formats of communication such as SIGN for the deaf and hard of hearing, Braille and large print for the blind and partially sighted.

It also means that:
• Advocates supporting self-advocacy of patients should be brought into the decision making process for those with learning disabilities and those with mental illnesses which do not preclude them from making decisions concerning their own healthcare.
• Support should be available to all who need it.

A set of guidelines aimed at VCS organisations and PCTs has been drafted in consultation with stakeholders and will be piloted later this year and these will be available from www.Chooseandbook.nhs.uk www.ethnicminorityfund.org.uk

The consultations were carried out for the Department of Health and in association with members of the Patient Forum and the BME Health Network. Interested VCS organisations should:
• Download the draft guidelines, and make any views about them known to CEMVO at the email address shown on the websites.
• Contact their local PCT to express their interest and find out what the PCT strategy is.
• Respond to PCTs which put services out to tender.
• Respond to requests to help with local needs assessments.

Finally, if you are a reader who is part of a VCS organization and you have a newsletter that you think that this article could be reproduced in, please contact us.

Susan Barber and Vanessa Gordon-Dseagu
Choice and Social Exclusion Unit, Council of Ethnic Minority Organisations (CEMVO) – College of Health Ltd 020 8 432 0307
The monthly email bulletin from action for advocacy provides the latest news for the advocacy sector.

events* funding* policy* resources* meetings* training* links

To register for your monthly bulletin call 020 7820 7868 or email info@actionforadvocacy.org.uk