



# Advocacy



## a voice for our future

a case study report by the  
Voluntary Organisations  
Disability Group (VODG)

October 2012



# The Voluntary Organisations Disability Group (VODG)



The VODG is the leading umbrella group of voluntary sector providers of social care services for adults with disabilities. Our members' shared aim is to ensure that people with disabilities are supported in ways that they themselves define. We are committed to personalisation and the principle of "no decisions about me, without me".

Our ambition is to shape the development of social care policy, to influence its implementation and to provide sector leading information and research.

VODG members believe that meaningful engagement and fair negotiation between commissioners and providers, focused on the needs of people who rely on social care services, helps build strategic relationships, enhances service design and is more likely to ensure that beneficial outcomes and efficiencies are achieved.

We have more than 65 members who work with about a million disabled people throughout the UK providing services that promote independence, choice and control. Our members employ more than 75,000 staff and have a combined annual turnover of more than £2.5bn.

Our overarching aim is to ensure that VODG members, working in partnership with commissioners can provide progressive, high quality and sustainable service that reflect the Think Local Act Personal partnership principles ([thinklocalactpersonal.org.uk](http://thinklocalactpersonal.org.uk)) and meet the needs of disabled people.

If you're passionate about delivering services that people with disabilities want and are keen to have an influence and say in the wider sector then why not join us?

Find out more on our website and blog, [vodg.org.uk](http://vodg.org.uk), or follow us on Twitter @VODGHQ and @VODG\_Editor

## About this report:

This report has been produced with the help and support of VoiceAbility, a VODG member and leading advocacy organisation. The organisation aims to ensure that people using its services are fully involved in the care they receive and feel informed and empowered to speak up for what they want in their lives.

This report has been commissioned by the VODG and written by social affairs journalist Saba Salman ([sabasalman.com](http://sabasalman.com)), a regular contributor to the Guardian who also manages the VODG blog ([vodg.org.uk](http://vodg.org.uk)).

All images in this report are from VoiceAbility; the pictures are not of the individuals featured in the case studies.



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## Foreword

### Liz Sayce OBE, chief executive, Disability Rights UK

It has never been more important for disabled people to know our rights and have access to advocacy to help realise them. At a time of major change - and often reductions - in services, people who already feel powerless can get overwhelmed by a sense of lack of control over their own lives. Advocacy can help meet the fundamental human need to make choices - through which we define our selves in the world. And that can restore a sense of control, which in turn reduces anxiety in times of uncertainty.

Since the 1980s groups led by disabled people have both campaigned for advocacy - and shown how it can be done, on issues ranging from compulsory detention under the Mental Health Act to securing support for independent living. With the current policy emphasis on personalised services, advocacy has become even more crucial, as it can enable people who have relatively less power to exert control. This can help redress inequalities between those who already have a voice - and those who with high quality advocacy support will have a voice.

*"I welcome the contribution this report makes to explaining and promoting the valuable role that advocacy can play in helping people access the care and support that they need in a way that suits them and their families. The case studies are especially helpful in showing how advocates can help people work with statutory services to take control and turn their lives round."*

*Sarah Pickup, president, Association of Directors of Adult Social Services*

The individual stories in this report show the difference advocacy can make to living the life you choose, with the support you need to follow your aspirations. It shows how advocacy can help services to apply principles of independent living: for instance, ensuring safeguarding is not based on a protective system that restricts opportunities, but rather builds safety by enabling individuals to have greater power and confidence.

Given advocacy's role in supporting people to have a voice as they navigate complex systems it is particularly important that individuals understand what advocacy itself can offer. This guide helpfully takes readers through the types of advocacy available.

It also lays out how the understanding of advocacy can be deepened, not only for citizens who use public services but importantly for service providers, inspectorates and government. As agencies consider how best to take forward the suggested actions on advocacy, the key message is co-production: the approach needs to be co-designed and co-led with disabled people and other citizens requiring advocacy support.

## Introduction

### Jonathan Senker, chief executive, VoiceAbility

## What is advocacy?

It was just over 30 years ago that a single community-based project gave rise to a new movement we now know as advocacy.

In the first scheme of its kind in the UK, the Advocacy Alliance - now known as VoiceAbility<sup>1</sup> - began developing partnerships between local volunteers and people with learning disabilities in long-stay hospitals in south London and Surrey. The volunteers gave independent support to help vulnerable people speak up for themselves, or ask that someone speak up on their behalf - advocacy.

What began in 1981 as a small voluntary group is now a diverse sector boasting hundreds of organisations of varying size, shape and form. According to 2009 figures from the Advocacy Consortium UK<sup>2</sup>, more than 1,000 independent advocacy organisations provide various forms of independent advocacy to disabled people and others who face disadvantage or discrimination, using both paid staff and volunteers. These services enable people to have real control over where and how to live, over decisions on social and health care and about how to engage with and contribute to the communities in which they live.

This sector has grown to include self-advocacy, group advocacy, user involvement, co-production and statutory and non-statutory advocacy (see p10, 'Advocacy FAQs'). Some people in especially great need, who are eligible for help under the Mental Capacity Act 2005<sup>3</sup>, have a statutory right to Independent Mental Capacity Advocacy or Independent Mental Health Advocacy under the Mental Health Act 1983<sup>4</sup> (see p10, 'Advocacy FAQs' for more information about statutory provision). The sector is now subject to nationally agreed, and in some cases mandatory, training.

From its early, informal beginnings the sector has developed its own performance framework and minimum standards. The Quality Performance Mark<sup>5</sup> (QPM), developed by umbrella body Action for Advocacy<sup>6</sup>, has helped to drive up the quality and consistency of advocacy and provide minimum standards for those who commission it. In addition, the Department of Health's (DH) National Minimum Standards<sup>7</sup> for independent healthcare providers states, amongst other issues, that 'patients must be informed about how to access independent advocacy'.

1 VoiceAbility: [voiceability.org](http://voiceability.org)

2 Advocacy Consortium UK: [acuk.org.uk](http://acuk.org.uk)

3 Mental Capacity Act 2005 on Directgov website: [direct.gov.uk/en/governmentcitizensandrights/mentalcapacityandthelaw/makingdecisionsforsomeoneelse/dg\\_186479](http://direct.gov.uk/en/governmentcitizensandrights/mentalcapacityandthelaw/makingdecisionsforsomeoneelse/dg_186479)

4 Mental Health Act 1983 (amended 2007): [dh.gov.uk/health/2011/07/mental-health-act/](http://dh.gov.uk/health/2011/07/mental-health-act/)

5 QPM on Action for Advocacy website: [actionforadvocacy.org.uk/articleServlet?action=list&articletype=60](http://actionforadvocacy.org.uk/articleServlet?action=list&articletype=60)

6 Action for Advocacy: [actionforadvocacy.org.uk](http://actionforadvocacy.org.uk)

7 National Minimum Standards on DH website: [dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4085259](http://dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4085259)

The Care Quality Commission's (CQC) regulation framework, Essential Standards of Quality and Safety<sup>8</sup>, adds that a good service “makes people who use services aware of independent advocacy services wherever they are available” and “co-operates with independent advocacy services wherever a person who uses services uses one”. *Delivering Dignity*<sup>9</sup>, the final report from the Commission on Improving Dignity in Care for Older People set up by the NHS Confederation, Age UK and the Local Government Association, reinforced the need for providers to “listen to patients and residents and their families, carers and advocates”.

“Advocacy promotes social inclusion, equality and social justice. It takes action to help people say what they want, secure their rights, represent their interests and obtain services they need” (Advocacy Charter 2002, Action for Advocacy). Ultimately, advocacy helps to address disadvantage, helping to ensure that those who need it have more equal access to support and greater chances of being in control of their lives.

### The aim of this report

Despite its 30-year history and perhaps because of its diverse nature, advocacy is often poorly understood. In 2007, a survey by Action for Advocacy of paid advocacy staff in England and Wales found that many had difficulty defining advocacy, or their role as an advocate.

By showcasing best practice in different kinds of adult advocacy, this report seeks to explain what independent advocacy looks like, how accessible it is, how it can be applied and how it contributes to the quality of life, rights and safeguarding of otherwise vulnerable people. We want to explain how advocacy can help achieve good quality care and support as well as helping to make the best use of increasingly limited public funding.

As the VODG's focus is adult social care, this report concentrates on the role of advocacy working alongside adults rather than children, although advocacy organisations carry out vital work in this area.

As well as presenting a cogent, modern understanding of the role and benefits of independent advocacy, we want to show how the practice fits with the current and emerging economic and policy context. We end this report by looking at the challenges that stand in the way of advocacy delivering greater benefit to people needing support and the key priorities for different stakeholders.

### Advocacy and the current policy agenda

The hallmarks of advocacy are precisely the aims of Caring for Our Future, the social care white paper<sup>10</sup> published in July 2012.

Advocacy enables people to access and use information to make good choices about care, supporting them to develop their own care and support plans, express their views and help improve services or be in control of their own budget for support. These outcomes are what the white paper's proposals strive to achieve.

Yet whilst the white paper and draft bill specifically highlight the need for advice and information, the term advocacy itself is largely absent from both publications. Advocacy is the foundation from which the policy ambitions in the white paper could be achieved. Information alone is useless without the support to understand and take action on it.

White paper aside, the phrase “nothing about us without us” was a rallying cry from the self-advocacy movement long before the present government realised its potential as a mantra for its NHS reforms<sup>11</sup>.

Before policy makers came up with the language of co-production<sup>12</sup>, personalisation<sup>13</sup> and person-centred planning<sup>14</sup>, advocates were insisting that we should all have real control over our lives. Advocacy involves empowering people to be the architects of their own lives with real choice and control, rather than consumers of pre-packaged services.

The personalisation agenda, for example, seeks to offer choice and control about how to spend a budget, where to live, who to live with, what support to receive, from whom and how. But to achieve this, individuals need to understand the options, their voices and choices must be heard. Independent advocacy enables this to happen.

Advocacy also underpins how people navigate the care system; the consultation on the social care white paper<sup>15</sup> highlighted how difficult people find it to understand their entitlement, access services and find other options. This suggests the benefits to be gained by increasing the availability of advocacy.

There are further possibilities as yet not fully developed. One of the critiques of personalisation is that, because of its focus on the individual, it inadvertently separates people. Critics say that resources should instead be combined so people can pay for the support they require and be better placed to help each other. Advocacy organisations could also enable people to pool finances and other resources.

10 Caring for Our Future, the social care white paper: <http://www.dh.gov.uk/health/2012/07/careandsupportwhitepaper/>

11 White paper, Equality and excellence: liberating the NHS: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_117794.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf)

12 Co-production on the Social Care Institute for Excellence (SCIE) website: [scie.org.uk/publications/briefings/briefing31/](http://scie.org.uk/publications/briefings/briefing31/)

13 Personalisation on the SCIE website: [scie.org.uk/publications/guides/guide47/index.asp](http://scie.org.uk/publications/guides/guide47/index.asp)

14 DH guidance on person-centred planning and personalisation: [dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_115175](http://dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115175)

15 VODG on the social care white paper: [guardian.co.uk/social-care-network/2012/apr/26/social-care-white-paper-integration](http://guardian.co.uk/social-care-network/2012/apr/26/social-care-white-paper-integration)

8 The Essential Standards, CQC: [cqc.org.uk/organisations-we-regulate/registered-services/guidance-meeting-standards](http://cqc.org.uk/organisations-we-regulate/registered-services/guidance-meeting-standards)

9 Delivering Dignity, final report from the Commission on Improving Dignity in Care for Older People: [nhsconfed.org/Publications/reports/Pages/Delivering-Dignity.aspx](http://nhsconfed.org/Publications/reports/Pages/Delivering-Dignity.aspx)

## Advocacy and safeguarding

Advocacy plays an essential role in preventing, detecting and responding to abuse by enabling people to learn about their rights and to be more confident in promoting them (every year, for example, VoiceAbility works with around 1,000 people in relation to allegations of abuse or concerns about adult safeguarding). As Winterbourne View<sup>16</sup> demonstrates, legal requirements are meaningless unless people have the power or support to ensure action when they are not met.

The Social Care Institute of Excellence<sup>17</sup> (SCIE) has concluded that advocacy makes a significant contribution to prevention of abuse through enabling adults at risk to become more aware of their rights and able to express their concerns (Prevention in Adult Safeguarding<sup>18</sup> SCIE May 2011). The former care services minister Paul Burstow stressed the importance of advocacy being made available to patients following the crimes committed against vulnerable people at the Winterbourne View private hospital.

The DH's interim review into Winterbourne View published earlier this year and the CQC inspections on which it was based<sup>19</sup> prove how far people were failed by the very system designed to protect them. Advocacy is mentioned in the interim report in relation to the government's desire to promote "open access for families and visitors including advocates" in all care settings.

## Advocacy and today's economic context

Public sector funding cuts have put unprecedented pressure on statutory services; advocacy enables otherwise vulnerable people, whose support might be under threat, to have a greater voice. Yet advocacy itself can be seen as a soft target, providing easy pickings for authorities looking for budget cuts. Earlier this year, an Improving Health and Lives report on advocacy stated that funding for people with learning disabilities has been cut by 15% over the last four years<sup>20</sup>.

Rather than introducing major new services, advocacy drives improvement in existing provision and enables people to develop community-based supports rather than relying exclusively on specialist services. Advocacy support often enables innovative solutions to be found, for example, in exploring ways to ensure as many people as possible can benefit from the resources available.

And, from a commissioning and provider perspective, at a time when value for money and efficiency are critical, advocacy provides a cost effective solution because it encourages both prevention and innovation. When advocates become involved in a person's life at an early stage, they can reduce the likelihood of difficult situations arising or escalating. Advocacy reduces expensive crisis responses, designing the right support in the first instance by listening to the person – moving from crisis intervention to prevention and well-being.

Advocacy is also cost-effective because it tailors services to individuals, reducing one size fits all solutions which fail to target resources – people who rely on social care move from being 'service users' to be informed decision-makers.

## What do the case studies in this report show?

The five examples included in this report do not attempt to cover the entire spectrum of advocacy nor do they focus exclusively on independent advocacy, but instead they also show the benefits of provider and family's role in supporting people's voices being embraced. They each describe how putting the person's views at the centre, can make a profound impact on someone's life.

Among the impacts, the case studies show how advocacy-based approaches:

- achieve personalisation and cost-efficiency (VoiceAbility p12)
- lead to creative partnerships between provider and advocate that support people to develop a stronger voice (Certitude p14)
- involve relatives in co-production (SeeAbility p16)
- improve safeguarding (KeyRing p18)
- boost support planning and enhances skills and independence (Wired p20).

## Advocacy for the modern age

Based on individual and community needs, rather than imposed from above, the advocacy sector has developed organically and without much fanfare, but has all the more potential for being truly rooted in the experience and demands of people who have benefitted from it. The solutions that people require in today's policy and economic landscape dictate that we recognise the potential of advocacy as an established, tried, tested and successful method of support for both our current times and so that we all have a voice in our future.

16 VODG on Winterbourne View [vodg.org.uk/cgblog/13/105/Commenting-on-shocking-Panorama-programme.html](http://vodg.org.uk/cgblog/13/105/Commenting-on-shocking-Panorama-programme.html)

17 SCIE: [scie.org.uk](http://scie.org.uk)

18 SCIE report on Prevention in Adult Safeguarding: [scie.org.uk/publications/reports/report41/index.asp](http://scie.org.uk/publications/reports/report41/index.asp)

19 DH interim report and link to CQC inspections: [dh.gov.uk/health/2012/06/interimwinterbourne/](http://dh.gov.uk/health/2012/06/interimwinterbourne/)

20 Improving Health and Lives, Advocacy by and for adults with learning disabilities: [improvinghealthandlives.org.uk/publications/1072/Advocacy\\_by\\_and\\_for\\_adults\\_with\\_learning\\_disabilities\\_in\\_England](http://improvinghealthandlives.org.uk/publications/1072/Advocacy_by_and_for_adults_with_learning_disabilities_in_England)



# Advocacy: frequently asked questions

## What is advocacy?

- advocacy involves independent support to help people to speak out for themselves, or have someone to take their side and speak out on their behalf
- action for Advocacy, the sector's umbrella body, defines the practice as "taking action to help people say what they want, secure their rights, represent their interests and obtain the services they need"
- advocates and advocacy schemes work in partnership with the people they support and take their side
- advocacy promotes social inclusion, equality and social justice.

## Who is advocacy for?

- different advocacy support has developed for different groups of people who feel they are being ignored, overlooked, or treated unfairly/poorly
- key services include those for people with learning disabilities, people with an autistic spectrum disorder, older people, people with mental health problems, people with physical disabilities and carers.

## What is an advocate?

- an advocate is someone who, with permission, acts independently on someone's behalf. He or she helps the person voice their own opinions or represents the person's views and interests to another party such as a care home, the NHS, the council, or a family member.

## What legal rights do people have to advocacy?

- if someone is dealing with a care home, NHS service or council, it is best practice to assist them to find an advocate if they feel they need one
- there is a duty on the NHS, local authorities and other responsible bodies to appoint an Independent Mental Capacity Advocate (IMCA, see below) under the Mental Capacity Act 2005<sup>21</sup> and a duty on mental health services to ensure access to an Independent Mental Health Advocate (IMHA, see below) under certain powers of the Mental Health Act 1983<sup>22</sup>
- an individual has a right to an advocate if they wish to make a complaint against the NHS. This is known as the Independent Complaints Advocacy Service and features in the Health and Social Care Act 2012<sup>23</sup>. The act heralds new arrangements and the service will be known as the NHS Complaints Advocacy service
- in certain circumstances, someone might have the right to advocacy under Article 8 of the European Convention on Human Rights, or as a result of a specific ruling.

## What different types of advocacy are there?

- statutory advocacy is where people have a legal right to an advocate
- statutory advocacy includes Independent Mental Capacity Advocacy (IMCA) which supports people who have been assessed to lack capacity to make specific decisions, and who have no family or friends to support them; decisions involve issues such as medical treatment or long term accommodation
- statutory advocacy also includes Independent Mental Health Advocacy (IMHA), which supports people detained under the Mental Health Act or people on Community Treatment Orders to understand and champion their rights and entitlements
- local authorities have a duty to provide advocacy services for looked after children and children in need if they wish to make a complaint; advocacy aims to protect looked after children and young people and safeguard them from abuse and poor practice.

Non-statutory advocacy includes:

- issue based, one to one professional advocacy, which recognises that some people require the support of an independent advocate during a major change in their life (such as the death of a carer) or with a particular issue (such as housing advice, arranging social care services or making a complaint)
- self advocacy - involving people speaking up for themselves
- peer advocacy, which is when an advocate has a shared or common experience (for example, someone with a mental health condition supporting someone with similar experiences)
- citizen advocacy - when a member of the public volunteers their time to get to know someone and supports them to speak up for themselves, helping them to get their views across
- group advocacy, which is when people who face a similar situation come together to make their cause known and get their collective voice heard.

## How is advocacy different to staff support?

Unlike support staff or services, advocates:

- are independent and on the side of each person they work with
- tailor the support they provide to each individual person and their situation
- are independent from the delivery of direct services
- act on behalf of the individual rather than needing to safeguard service budgets; they will want to understand the financial context as important information, but must help the person express their views and negotiate on their behalf as needed
- are specifically trained to listen to and represent people's views and receive supervision to support them skilfully and independently
- usually have a wide brief to act on issues important to the person, whether about their life and support now or in the future, and across agencies.

## How is advocacy different to support from relatives?

- many relatives turn to advocacy services as they feel that neither the views of their relative, nor their own, are listened to and some will not know the options and possibilities available to them
- advocacy provides a different avenue for people to express their views - some people feel confident in speaking with their relatives about all issues, some do not
- many relatives may themselves find it difficult to understand and navigate services – advocates are trained to do this
- relatives can bring their own feelings, concerns and history to the debate about someone's care; these are enormous assets, but can also be well complemented by someone looking afresh.

\* FAQ information compiled using background material and references from the Social Care Institute for Excellence, Care Quality Commission, Action for Advocacy, Department of Health, the Law Commission and VoiceAbility.

21 Mental Capacity Act 2005: [legislation.gov.uk/ukpga/2005/9/contents](http://legislation.gov.uk/ukpga/2005/9/contents)

22 Mental Health Act 1983: [dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH\\_4002034](http://dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_4002034)

23 Health and Social Care Act 2012: [legislation.gov.uk/ukpga/2012/7/contents/enacted](http://legislation.gov.uk/ukpga/2012/7/contents/enacted)

# Personalisation and advocacy: VoiceAbility



*Advocacy supports the personalisation agenda, helping ensure support plans are tailored to the individual.*

It is over a year since Mary has been admitted to hospital or a mental health crisis centre. Before she began managing her own care, through a personal budget she secured with the support of her advocate, she seemed locked into the crisis-driven revolving door of mental health services.

Previously, Mary had spent an average of eight weeks a year in a crisis centre, at a weekly cost to the NHS of £1,300. In addition, she had also been attending a resource base for mental health patients.

In the past, Mary's psychologist referred her for crisis support following a risk assessment which judged that she would be at risk from harm. The psychologist knew that when Mary experiences an episode of acute anxiety or depression, something she has suffered from since she was in her 20s, she stops eating and caring for herself.

What Mary wanted was a support plan, which would allow her to overcome such episodes on her own terms, rather than relying on emergency crisis care. Thanks to support from her advocate at VoiceAbility, this is exactly what she was able to achieve.

A year ago, Mary needed support staff to accompany her whenever she spoke to people she didn't know. Now, after working with an advocate to develop her confidence, self-esteem and ability to speak up, she feels able to go to the shops and talk to assistants about different models of phones, prices and payment options, without the support of others. At the moment, Mary is looking forward to getting into paid employment, having developed the confidence to sign up with a volunteer bureau.

"I feel more in control of my life," says the 42-year-old from North London, "and I'm slowly becoming able to deal with my problems, without resorting to hospital admission. The general thrust of my support plan is to steer away from mental health professionals and services. My future lies in integrating myself in the community and I want to enable myself by using general community services, rather than mental health specific ones."

Mary adds, "I am so pleased with the work that I have done through managing my own care, and I am grateful for the support of my advocate in helping me to express my needs, to be heard and to access the information which enabled me to have, and manage, a personal budget."

Mary's story demonstrates how advocacy can turn someone's desire to move away from a reliance on emergency services into a reality. With advocacy support, Mary was able to adopt a more community based approach, which not only gave her more choice and control in her life; it also saved emergency NHS resources for others in difficult situations.

Mary's support from VoiceAbility began when she heard the charity had supported someone she knew in the mental health community to access a personal budget. Based on this recommendation, Mary, who cares for and lives with her elderly mother, contacted Michelle Murray, a senior advocate with VoiceAbility's London Advocacy for Independence service.

The initial meeting was short, in familiar surroundings of the hospital canteen and taken at a pace that Mary felt comfortable with, recalls Michelle. "Mary noticed I wasn't going to go over her head or fill in the form for her. I remember her saying 'you're not pushing me to get results'." Previously, Mary had felt under pressure, as her care coordinator had wanted the support plan assessment to be completed within four days. Michelle was able to negotiate a longer deadline, to allow Mary to feel more in control of the process.

Tailoring the support planning to Mary's needs, at a comfortable pace and using materials such as photographs

rather than lengthy pieces of writing, Michelle was able to engage Mary in directing her own support.

Mary explains: "I find form filling, processing information and making sense of things extremely scary and worrying and I get really obsessive and fearful. With Michelle's support, I've been able to get the things that will greatly help me in my recovery out of the mental health system. Without this support, I would have most definitely given up and therefore been in the same position and not moving forward as I have now been able, in many areas, to do. I only wish other people were able to receive the same support."

From the advocate's point of view, Michelle says "my role as an advocate is to provide information so people can make an informed choice; it is about supporting someone's voice to be heard." She adds "with Mary, it was also about creating a safe place to develop a process to allow her to access a personal budget."

Michelle stresses that the process wasn't easy; it took time and was at times stressful for Mary. But it has enabled her to work towards the kind of recovery she wanted, without relying solely on crisis-driven care. "Slowly, Mary is making friends in her local community, not just within the mental health community, which is exactly what she wanted."



## Key themes:

**Personalisation:** supporting people to make choices about how they are cared for and tailoring support plans to suit individuals.

**Co-production:** involving individuals in drawing up care plans, which makes recovery more sustainable.

**Cost saving:** supporting recovery and preventing crisis can lead to significant savings through a decreased reliance on acute services and a move towards self-directed and community based support.

# Partnership in advocacy: Certitude



*Partnership involves constructive relationships between advocates and care providers.*

Without much contact with her family and in hospital for six weeks, Jenny (not her real name) wanted the comfort of family, but lacked the capacity to organise people to come and see her.

Although staff from her Certitude care home in Ealing, west London, were already in a visiting rota, what Jenny really wanted was to see her parents or sister. Her advocate, Amanda, contacted Jenny's family and explained how important it was to Jenny, who was having treatment on her legs, that they visit her.

Jenny's family did visit the hospital last year and, although they have not maintained much contact since then, the difference their presence made to Jenny's well-being at the time was immense.

Albeit a simple example, it illustrates perfectly the role of the advocate speaking up on the individual's behalf, acting as a go-between and bridging the vital gaps between service user, care provider and family.

Jenny, 57-years-old, has a mild to moderate learning disability and is partially sighted. Her vulnerability is increased by her health issues that include diabetes, a heart condition,

and problems with her immune system that affects her skin's ability to heal itself. Her advocate Amanda, who she has been supported by on a weekly basis for two years, is provided by a voluntary sector organisation Advocacy Voice.

"Advocacy is speaking out for clients who cannot necessarily speak up for themselves," explains Jenny's house manager Tracy Penfold, "it's about supporting people to access services they may not even realise are out there."

There is a clear distinction between the role of staff and advocates; although Jenny receives person-centred support from Certitude, her carers are still employees. Tracy elaborates: "Amanda fulfills more of a friendship role, Jenny knows she has an advocate but she also sees her as a good friend, not a carer. Jenny has a great keyworker who she'll go out with and we often have events like parties, but from Jenny's point of view, we're all still staff and it's our duty to care for her, whereas Amanda is from the outside and that gives her a unique position."

For example, Jenny enjoys eating out but her diabetes means she has to be careful about her diet. She also knows she should keep fit, but dislikes exercise. Amanda might therefore take her out to lunch but encourage her to walk there and back. On a more basic level, Amanda also comes to all Jenny's six-monthly care reviews and helps ensure that

Certitude staff are fulfilling all the action plans that Jenny has agreed with them for the year.

Jenny's advocate enjoys a good relationship with the staff team but is also able to raise issues constructively. When Jenny wanted to paint her room pink and buy a new dressing table, staff explained that the changes might be expensive and take time. Amanda also explained to Jenny the importance of a timetable and budget to redecorate her room to her tastes.

"Advocates have the ability to enhance and support the role of paid staff," says Tracy. "An advocate is someone from outside who is able to have a more lateral take on things and question us in a constructive, positive way."

The advocacy Jenny receives, says Tracy, means she is helped to put forward her views. "There is power in questioning those you assume to have responsibility and authority. Just because someone has a disability, it doesn't mean they can't challenge or question us; often people with disabilities might feel unable to question those caring for them, and that isn't a healthy state of affairs."

certitude

## Key themes:

**Partnership:** constructive relationships between advocates and care providers enhance individuals' lives.

**Person-centred approaches:** advocates can speak up for the specific wishes of individuals and support them towards tailor-made care.

# Transition and family voices in advocacy: SeeAbility



*Advocacy can be used in transition, as young people move from child social services to adult social care.*

The advert for support staff was short and to the point. “You must like horse riding,” it stated, “and swimming”. Active individuals with a love for the outdoors and socialising required, was the message. Written by a group of young adults with disabilities moving into supported living provided by the charity SeeAbility in the Royal Borough of Kingston upon Thames, the job advert ensured that the young people could attract the kind of support staff they wanted.

SeeAbility supported the young people’s parents to take on the role of advocates with staff, so everything from the job specification for the house in Surbiton to staffing profiles to décor was drawn up with individuals’ wishes in mind. The parents were involved in interviewing staff and the young people were able to meet prospective candidates

“The parents are very much part of the service,” explains Steve Drew, SeeAbility’s former personalisation director, “they take part in all day to day arrangements and they view it very much as their son or daughter’s tenancy rather than us running it like a registered home where they need permission to enter. There is a sense of ownership from the family’s point of view and we are in their son or daughter’s home; that is important in terms of empowerment.”

The Surbiton service houses five young people who are all in their late teens to early 20s. The service, opened in November 2009, was a response to the fact that the local authority had a group of young people with profound and multiple learning disabilities and visual impairments who were coming to the end of their residential school placements.

The service was designed with the families. SeeAbility staff, who meet with the families once a month to talk through any issues, offer a combination of one to one and shared support. Because the service has been designed around the young people and their families have been involved from the start, communication over shared care is easy. At night, for example, the young people pool their personal budgets to purchase night cover.

Steve defines advocacy “with a small ‘a’”. By this he means that while some organisations provide formal advocates, what SeeAbility does is support advocacy in its widest sense where families act as advocates for those being supported.

Steve explains: “People with learning disabilities are vulnerable and need people to speak for them. Sometimes people cannot articulate their needs, but those closest to them become a proxy for them. The people who are most likely to advocate for those with disabilities are their families and, historically in social care, some organisations have treated families almost as part of the problem. I think that needs to be turned on its head. If you imagine a circle of support, who is closest to the individual beyond those who are paid to care for them? It’s the families.”

The service, says Steve, would be entirely different without the use of family-based advocacy. “Imagine it was you in this position of vulnerability and being in need of care? If you needed support you would want to be totally in charge of who was supporting you, how they supported you and where and when. That’s certainly what I would want and that is what people we support should have as standard. Once you get into that mindset, advocacy-based approaches make perfect sense.”



## Key themes:

**Transition:** services supporting young people transitioning from child social services to adult social services must have advocacy at their heart.

**Quality of care:** services can be designed to a high specification with individuals’ requirements in mind if advocates can speak up for users.

**Co-production:** advocacy built in from the start makes for high quality care.

**Parent advocates:** sometimes family members speaking up for individuals can bridge gaps between commissioners and care providers.

# Safeguarding and provider support in advocacy: **KeyRing**



*Advocates can support people to learn the skills to care for themselves and their families.*

Ask three-year-old Daisy and she will tell you she has the best parents in the world. She has a baby brother Tom, who was born in June, and she is a bright, happy and confident pre-schooler. While mother Karen, 32, takes a quick nap, Dave, 30, enjoys some playtime with Daisy; they seem like any other young family (Daisy, Tom, Karen and Dave are not their real names).

But had it not been for the advocacy role of support organisation KeyRing, Daisy would most likely have ended up in care and Karen and Dave would never have had the family they wanted so badly.

Both parents have mild to moderate learning difficulties. Dave has problems reading and writing and Karen, who has spina bifida, has suffered in the past from the sleep disorder narcolepsy.

Having met at a special needs residential college, both had been supported by family. However, since moving further away from home and into a flat in the south east of England, Karen and Dave were regularly contacting the duty desk at their local social services department over routine - rather than crisis - issues, such as bills, and often for simply some social contact.

Karen's pregnancy sparked the council to question the couple's parenting ability. Before Karen gave birth, social services said the baby would be on the at risk register, which raised the potential of the child being taken into care. Both Dave and Karen could be uncooperative and were initially unwilling to engage with agencies offering support around parenthood. The couple was referred to KeyRing.

KeyRing's model is based on a local network of 10 people - nine people with support needs and one good neighbour-style volunteer to help build connections and help with things like reading bills, writing forms and letters.

The first thing that the KeyRing team did, says Gaenor Watts, a supported living manager managing the organisation's support workers, was to encourage more community involvement. "Our first meeting was to talk about how important it is to know other people and build up a social network," says Gaenor. "It was also important to explain in accessible terms the impact of having a child, and how crucial it was that they both prepared for the new arrival." By coincidence, Gaenor was also expecting her first child at the same time, so Karen felt some affinity with her.

Sharing plain English, easy read books on birth, parenting and child development with the couple, Gaenor and her team ensured that all pre and post-natal professionals were aware of not overwhelming Karen and Dave with technical terms.

In the six months before the birth, Dave learned to drive, passed his test and bought a car. KeyRing support workers were in daily contact with the couple, helping them stay to date with benefit entitlements, securing them a social worker and introducing them to local SureStart and Home-Start services, as well as more specialist learning disability groups.

As well as moving into a larger property, securing a community

care grant and a SureStart grant to help with costs, KeyRing supported the couple to arrange for a delayed discharge after the birth, so that Karen could be supported to care for her new baby before returning home.

With social services, the KeyRing team and the couple drew up a plan to manage potential risks. To prevent any return of Karen's narcolepsy, for example, they decided a rest schedule and regular visits from SureStart volunteers to check both Karen and Dave were on board with managing risk.

Daisy was taken off the at risk register after her third birthday.

While the couple will always require some level of support, there is nothing to suggest that they cannot cope with the arrival of their second child, a boy. Three years ago the KeyRing team was at the hospital minutes after Daisy's birth to ensure Dave and Karen were supported as maternity staff changed shifts - this time they were there again, but only with flowers to wish the second-time-parents well.

The early intervention supported by KeyRing means that the couple only require access to generic early years services. Exact savings are difficult to quantify. However, it costs around £1,000 to complete a needs assessment and then on average of £489 per week for foster care. Calls to the duty desk, which the couple were making regularly, cost around £50 an hour. In comparison, being an associate member of KeyRing costs £60 per week.

Advocacy, says Gaenor, is about having your point heard. "The wishes of the individual are listened to and put first; as an advocate you don't take over or make the decisions, but you help to empower people," she adds. "Give someone the right support and you can minimize what might seem to some people as insurmountable risk."



## Key themes:

**Safeguarding and risk management:** ensuring that people are supported and given appropriate skills to care for each other and their family.

**Community-based support:** reinforcing advocacy with local networks can help sustain successful outcomes.

# Support planning and advocacy: **Wired**



*Advocacy can strengthen support plans, ensuring they are tailor made for individuals and carers needing help.*

By the time that 92-year-old Sara's case was referred to advocacy organisation Wired, the daughter who cared for her full-time was overwhelmed.

Sara, who is partially sighted and has mobility and hearing issues, was referred by the social services department of Wirral council, Merseyside, when her daughter Mira was due to go on holiday (Sara and Mira are not their real names). Mira, 60, was under a huge amount of stress as she also cared for her disabled husband. Sara usually went into respite care if Mira was away, but the personalisation agenda meant the respite request triggered the need for a support plan. A plan, said the council, would mean Sara could have a personal budget so her needs were met whilst Mira was away.

The problem was that both mother and daughter found personalisation and the support planning process confusing and complicated; the system was alien to them and they felt unable to engage with the council.

Sara and Mira's story illustrates how advocacy can strengthen support plans, boost carers' roles and encourage self-advocacy, which is when people speak up for themselves.

Wired advocate Karen Blair explains how she picked up the family's case: "As an advocate, my aim was to empower

Mira and for both her and her daughter to achieve their goals in terms of getting the right support. I was able to spend more time with them than statutory agencies could and have perhaps what they saw as more relaxed, informal conversations than the ones they might have had with someone from a social services agency."

The challenge was that Sara, who had previously had negative experience of carers, wanted nothing to do with the support planning process and only wanted to be looked after by Mira. Meanwhile Mira was under stress emotionally and financially after her life had been overtaken by her caring responsibilities – she had given up work to care for her mother.

So Karen first met with Sara who gave her consent that Mira could speak on her behalf. The advocate then gave Mira plain English information on the aims of personalisation and helped her to write a person-centred support plan that met both their needs. "She felt nothing had been explained to her clearly before," adds Karen. "But I'd taken along visual aids like an anonymous support plan and I broke it down, chatted her through it, and explained it was about working out her mother's needs and how best they could be met. She said she found being able to sit and chat informally and ask questions really helpful."

The process took about three months and among the successful outcomes was the fact Mira began to be paid a small wage as a personal assistant for the care she gave her mother. "This was ideal for both women as it was in keeping

with the mother's wishes for her daughter to care for her, it improved the family dynamics and also removed some of the financial difficulties caused by Mira giving up work," explains Karen.

The plan allowed for the personal budget to be spent on petrol for outings and magazines in large print. In addition, personalisation meant the family moved from being simply the recipients of care towards becoming purchasers with a choice, so they were able to find a care agency that could guarantee low turnover of staff and a more mature workforce, issues that were important to Sara.

"Without advocacy, it's doubtful that Sara and Mira would have had as much choice within the support plan as they did," says Karen. "We find with carers' advocacy that carers are so busy and have much more important things to do than chase social care staff, that's where advocates come in."

Recently, adds Karen, Mira – who is no longer supported by Wired - told her she remembers when she saw the "light at the end of the tunnel" while being supported by Wired. "She felt so worn down by her caring roles, there was nothing else in her life," says Karen, "but now she tells us she can't believe how much their lives have changed for the better and how much her relationship with her mum has improved."

The fact that Mira then went on – with minimal support – to secure a personal budget for her disabled husband is the ultimate proof of the success of advocacy for the family.



## Key themes:

**Support planning:** using advocacy to help people complete tailor made support plans.

**Generic advocacy:** organisations that provide general advocacy services can still tailor approaches to suit individual clients, including carers

**Self-advocacy:** advocacy builds the confidence of people to speak up for themselves.

# Conclusion

High quality independent advocacy can transform an individual's quality of life and help the person to stay safe, as the case studies in this report have highlighted.

The vision of effective person-centred services has been articulated with ever greater conviction and understanding from the NHS and Community Care Act in 1990 to the recent care and support white paper, *Caring for Our Future*, and we have learnt more about how to unlock the potential of individuals and communities to achieve this.

Yet this vision remains so far from reality for hundreds of thousands of people who use social care services and their carers. In an age where “top down” solutions are frowned upon and money is tight, we simply can no longer afford to ignore advocacy; a well tried and tested individual, community focused approach.

Advocacy is vital to helping people stay safe from abuse and indignity. It delivers on the ambition of social care users and policy makers alike; that people are empowered, well supported by quality services and able to contribute.

Beneath the woeful incidents of abuse in institutional settings lies a common failure; the opinions and concerns of people using care services are either overlooked or given inadequate attention. The DH interim review into Winterbourne View<sup>24</sup> published in June, stated, “the experience of people who have contributed... is that their voice is still too often not heard and that they are not sufficiently involved in decisions about their health and care”.

Well-designed and delivered advocacy has an essential part to play in preventing, identifying and addressing abuse. It does this by building people's confidence, awareness of their rights, and ability to exercise them. It provides an independent person to report concerns to and someone who will ensure that action is taken.

Advocacy has the potential to be one of the driving forces in achieving the aims of the care and support white paper. However without action from a number of major stakeholders this potential will be lost and we will leave ourselves without the means to close the huge gap which exists between policy ambition and people's lived experience.

With that in mind, there are some key priorities for different stakeholders.

## Priority actions for government:

- ensure more people are legally entitled to advocacy by extending the statutory right to advocacy if they are involved in safeguarding or where they require it in order to participate fully in planning their own care and support
- require local authorities to develop advocacy strategies
- clarify the need for and impact of advocacy in relation to safeguarding in guidance to commissioners, regulators and providers
- encourage a review of the existing City and Guilds independent advocacy qualifications to ensure that these better reflect a modern understanding of social care and safeguarding.

## Priority actions for inspectors:

- CQC must deepen its understanding of advocacy so it can monitor if quality advocacy is genuinely available to individuals during inspection
- include better training and guidance for inspectors on advocacy

- ensure the inclusion of experts by experience (people with personal experience of these services as service users or family carers) in all inspections.

## Priority actions for advocacy organisations:

- explore how to use data collaboratively to better campaign on issues like funding and standards
- ensure that advocates are well trained and well managed, especially in relation to safeguarding
- umbrella group Action for Advocacy's quality performance mark for advocacy (QPM) must be updated to fully engage with personalisation and test organisational competence in relation to more challenging safeguarding situations
- develop a relationship with forthcoming Healthwatch<sup>25</sup> which the government says will act as the local consumer champion for users of health and care services.

## Priority actions for social care providers:

- ensure that members of staff and managers are aware of what advocacy provision is required by law and what is available locally
- consider the benefits of commissioning independent advocacy directly as part of the service provider's offer of personalised, responsive safe support
- build partnerships with advocacy services to support user input into the design, delivery and development of services
- remove barriers to advocates having free access to all non-private areas and to all necessary information (with the consent of the individual or in their best interest when the person cannot give consent due to capacity issues).

## Priority actions for commissioners (local authorities and clinical commissioning groups):

- take a strategic approach to developing and investing in advocacy, so people in priority groups can access advocacy and advocacy is well focused between prevention, improving the experience of social care and safeguarding
- recognise the potential for Healthwatch and its limitations<sup>26</sup>.

This report highlights the critical role that advocacy has to play in the new social care landscape. It also clarifies what advocacy looks like, what sort of advocacy can be commissioned to improve people's lives and how providers and advocates can work in partnership. Independent advocacy must be made more easily available to a much greater proportion of the people who need it.

Advocacy isn't just another service. It is something that allows individuals to understand their options, have a voice and take their own decisions. It has the potential to help people move from the margins of their communities to being valued and active citizens. And that is what the best of today's social care practice strives to support people to achieve.

<sup>24</sup> DH interim report into Winterbourne View: [dh.gov.uk/health/2012/06/interimwinterbourne/](http://dh.gov.uk/health/2012/06/interimwinterbourne/)

<sup>25</sup> DH website on Healthwatch: [dh.gov.uk/health/tag/healthwatch](http://dh.gov.uk/health/tag/healthwatch)

<sup>26</sup> The recent white paper says of the local Healthwatch organisations to be launched in April 2013, they “will help to connect care home residents to their communities, by talking with them about their experiences and scrutinising how care homes are working.” But Healthwatch is not a panacea for those whose views and experiences are rarely heard and is not required to fund generic advocacy.

## Appendix A: Participating organisations and case studies



VoiceAbility provides award-winning advocacy, self-advocacy, support planning and brokerage services across the country. Our aim is to ensure that people using our services are fully involved in the care they receive and feel informed and empowered to speak up for what they want in their lives. We have a broad client base, working with people with physical disabilities, learning disabilities, autism and mental health conditions, as well as older people, carers and looked after children. [voiceability.org](http://voiceability.org)



Certitude supports over 1400 adults who have mental health needs and learning disabilities living in Greater London. Certitude was established in 2010 with the merger of Southside Partnership and Support for Living. Through the sharing of resources, ideas and expertise, Certitude has continued to provide person centred, specialist support to people with a diverse range of support needs. [certitude.org.uk](http://certitude.org.uk)



SeeAbility is charity that provides support, advice and information about eye health and eye care to people with visual impairment and other disabilities. We operate supported living, residential care, outreach, day opportunities and rehabilitation in the south of England and a national information and advisory service, including the Eye2 Eye campaign and Look Up website. Formally the Royal School for the Blind, SeeAbility has been supporting visually impaired people for over 200 years. [seeability.org](http://seeability.org)



KeyRing provides Supported Living Networks that are made up of a number of vulnerable adults and a volunteer. The Network style of support enables adults to live independently in their own homes, to be involved in their Network and to take a full part in their community. The resulting mixture of paid for and natural support is a powerful combination that mitigates risk and allows people to develop life skills. [keyring.org](http://keyring.org)



Wired is a provider of Independent statutory and generic advocacy services for people who are disadvantaged, particularly those who are disabled or who have caring responsibilities. Wired also provides a range of support services including advice services. The organisation's head office is in Wirral but services are currently delivered across North West England and Wales. Wired's mission is to support disadvantaged people to live independent, fulfilling lives. [wired.me.uk](http://wired.me.uk)

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## Appendix C: list of VODG members

Action on Hearing Loss

Advance UK

Affinity Trust

ARC

Avenues Trust Group

Bethphage

Brandon Trust

The British Home

The Camden Society

Camphill Village Trust

Canterbury Oast Trust

Certitude

Choice Support

Crossroads Care

Deafblind UK

Dimensions

The Disabilities Trust

Enham

Epilepsy Society

FitzRoy

The Guide Dogs for the Blind

Association

Guideposts Trust

Havencare

Heritage Care

Hft

KeyRing

Leonard Cheshire Disability

Livability

Macintyre

Martha Trust

mcch

Mencap

Multiple Sclerosis Society

The National Autistic Society

National Star Foundation

Norwood

Nottingham Community Housing

Association

Outlook Care

Outward

Papworth Trust

Pepenbury

Prospects

QEF

Radian Support

RCHL

Real Life Options

Robert Owen Communities

Royal London Society for the Blind

RNIB

Scope

SeeAbility

Self Unlimited

Sense

SignHealth

St. Anne's Community Services

St. Elizabeth's Centre

Sue Ryder

Thomas Pocklington Trust

Turning Point

United Response

Vitalise

VoiceAbility

Walsingham

The Westminster Society for people with learning disabilities

Wired

Young Epilepsy



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