

**A
Stronger
Voice**

The role and value of advocacy in personalisation

Highlights from the literature
August 2011

GAIN



Gateshead Advocacy
Information Network

Contents

Introduction	3
Key topics in the literature	3
The role of independent advocacy in personalisation and self-directed support	3
Implications for advocacy projects	9
Advocacy and brokerage	10
Paying for advocacy from personal budgets	12
Personalisation, advocacy and safeguarding	13
The changing role of the social worker (social worker as advocate)	13
Culture change and personalisation	14
Glossary of key terms	15

Introduction

The initial strand of the 'A Stronger Voice' project was concerned with exploring the role and value of independent advocacy in personalisation and self-directed support. GAIN, together with Gateshead independent advocacy projects, worked closely with Gateshead Council to develop processes and thinking which helped to define where advocacy sits in the cycle of self-directed support. This was informed by literature from a range of sources, including guidance from Department of Health, the Social Care Institute for Excellence and the Equality and Human Rights Commission amongst others, which is presented in this report.

This will be followed by a report documenting Gateshead advocacy projects' experiences of personalisation and self-directed support.

Key topics in the literature

- The role of independent advocacy in personalisation and self-directed support
- Implications for advocacy projects
- Advocacy and brokerage
- Paying for advocacy from personal budgets
- Personalisation, advocacy and safeguarding
- The changing role of the social worker (social worker as advocate)
- Culture change and personalisation

The role of independent advocacy in personalisation and self-directed support

Department of Health with Department for Children, Schools and Families 'Guidance on direct payments for community care, services for carers and children's services England 2009'

"Many people who receive direct payments also find it helpful to have access to advocacy support. This will include some older people, people with learning disabilities and people with mental health problems, for example. Advocacy may also be useful in providing support for people who lack mental capacity to consent to the making of direct payments.

A support service may also be well placed to act as an advocate for local recipients as a group when their council is considering changes to the scheme.

However, it may well be preferable to separate any support role from an advocacy role on behalf of individuals to avoid any conflict of interest. Extra time may be needed to set up the direct payments to ensure that the advocate fully understands the individual's wishes" (2009, p.18)

DH and DfES, 2009, 'Guidance on Direct Payments for Community Care, services for carers and Children's Services England 2009' [online]
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121131.pdf (accessed 31/05/11)

Local Government Improvement and Development Agency (formerly IDeA) 'Transforming adult social care: access to information, advice and advocacy'

"Recommendations: Articulate and reiterate the principle that transformation and personalisation are dependent upon good information, advice, advocacy, support planning and brokerage being available. These services need to encompass developments in both consumer and social inclusion and community models" (p.43)

IDeA, 2009, 'Transforming Adult Social Care: Access to Information, Advice and Advocacy' [online]
www.idea.gov.uk/idk/core/page.do?pagelD=9454439 (accessed 31/05/11)

Equality and Human Rights Commission 'From safety net to springboard: A new approach to care and support for all based on equality and human rights'

"Proposal 2.3.1 Everyone seeking care and support should be given access to accurate, accessible and tailored information and advice and where appropriate brokerage and advocacy, including in relation to human rights, nondiscrimination and equality" (p.24)

"Proposal 2.3.3 Local authorities should make provision, including working in partnership with other agencies or via a budget-holding lead professional to ensure that independent advocacy is made available to those who require it, in particular people with learning disabilities, mental health conditions, dementia or who are on the autistic spectrum" (p.24)

“Robust policies must also be available to avoid individuals and families finding themselves in vulnerable situations. High quality advocacy should be made available to assist people who may otherwise not benefit from personalisation in self-directed assessment and planning individual budgets.” (p.26)

“Independent advocacy has a central role to play in promoting people’s safety and security without compromising their personal autonomy through supporting decision-making and communication, removing the undue interference of others and in enabling individuals to recognise the strengths and weakness, opportunities and threats of different options available to them... Having the support to participate and engage in employment or the wider community can provide access to the social networks which make us all safer than we would otherwise be, and make it harder for criminals to target otherwise lonely and isolated individuals” (P.29-30)

EHRC (2009) ‘From Safety Net to Springboard’ [online]
www.equalityhumanrights.com/uploaded_files/safetynet_springboard.pdf
(accessed 31/05/11)

Joseph Rowntree Foundation ‘Response to the Law Commission Consultation on Adult Social Care’

“JRF welcomes the Commission’s proposal to place a duty on a local social services authority to provide information about services available in the local area. However, JRF research and consultation with service users has found that information alone is often inadequate, and there is a real need for information, advice and advocacy. Advocacy - including peer advocacy and collective advocacy through user-led organisations - is essential if both a) information and advice and b) personalised care and support are to be delivered, effective and meaningful to people using services and their families.” (Godfrey et al., 2004; Horton, 2009) (p.4)

JRF (2010) ‘Response to the Law Commission Consultation on Adult Social Care’ [Online] <http://www.jrf.org.uk/sites/files/jrf/consultation-law-commission-adult-care.pdf> (accessed 31/05/11)

Department of Health ‘Putting People First’

“A universal information, advice and advocacy service for people needing services and their carers irrespective of their eligibility for public funding. A ‘first shop stop’, which could be accessed by phone, letter, email, internet or at accessible community locations. Key strategic partners to be the Pensions Agency and relevant voluntary organisations. The LinkAge Plus pilots are providing strong evidence of the benefits for older people of this approach.

Personal advocates to be available in the absence of a carer or in circumstances where people require support to articulate their needs and/or utilise the personal budget.” (p.3)

DH (2007) ‘Putting People First: A Shared Vision and Commitment to the transformation of Adult Social Care’ [online]
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118 (accessed 31/05/11)

Department of Health ‘Raising our Sights: services for adults with profound intellectual and multiple disabilities’

“Recommendation 3. Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of adults with profound intellectual and multiple disabilities. They should include funding for continued advocacy in the package of self-directed services for adults with profound intellectual and multiple disabilities.” (p.17)

DH (2010) ‘Raising our Sights: Services for adults with profound intellectual and multiple disabilities’ [online]
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346 (accessed 31/05/11)

Equalities and Human Rights Commission, personalisation in the reform of social care: key messages

“Our overall view now is that there appears to be a postcode lottery of availability of advocacy, and that if this continues it will result in many people not being able to access and use self-directed care such as personal budgets.

We believe there is a strong case for guidance to be produced by the Department of Health or the envisaged NHS commissioning board on developing local advocacy frameworks that ensure that non-statutory advocacy provision, such as that to support people to use personal budgets, is commissioned. This would be in addition to statutory provision such as independent mental health and mental capacity advocacy. Department of Health-funded research by Advocacy Consortium UK exploring the desirability and feasibility of such a framework for advocacy has already demonstrated indicative support for this amongst a selection of advocacy providers” (p.9)

“The commission recognises that for most people good quality information, advice and signposting services will be adequate for them to access and utilise personal budgets. The commission strongly believes that independent advocacy needs to be available for those people, however, who are at greatest risk of not benefiting from self-directed care. These include people who have limited mental capacity and/or who face sudden vulnerable circumstances, such as onset of severe impairment.” (p.9)

EHRC (2011) ‘Personalisation in the reform of social care: key messages’ [online]

www.equalityhumanrights.com/uploaded_files/care_and_support/personalisation_in_the_reform_of_social_care_-_key_messages.pdf (accessed 31/05/11)

Sector-wide commitment ‘Think Local Act Personal’

It should be noted that Think Local Act Personal makes no direct reference to independent advocacy.

“Ensure all people have the information and advice needed to make care and support decisions which work for them, regardless of who is paying for that care. This includes help to make the best use of their own resources to support their independence and reduce their need for long-term care (p.2)”

“Councils and providers can take an active role in promoting individuals’ mental health as well as their physical well-being. This means ensuring that people with mental health and/or mental capacity issues are able to make informed choices and have as much opportunity for personalisation, dignity and respect as other citizens.” (p.5)

Sector-wide publication (2010) ‘Think Local Act Personal’ [online]

www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/THINK_LOCAL_ACT_PERSONAL_5_4_11.pdf (accessed 31/05/11)

Community care ‘Proven Practice: Self-advocacy for those with high support needs’ (summary of SCIE’s Adult Services 24: Personalisation and learning disabilities)

“Take-up of direct payments among people with high support needs is generally low. Advocacy support is needed in managing direct payments and individual budgets so that self-directed support can become a possibility without putting further strain on families and carers.” (p.1)

“To improve the services for people with learning disabilities and high support needs service providers should concentrate on... [an] evidence base for advocacy for people with high support needs should be created by researching the effectiveness of approaches, strengthening the focus on outcomes and commissioning research on gaps in the knowledge base... services should be developed in line with the evidence base founded on reliable evaluation and best practice.” (p.1)

“Utilise the adult social care workforce strategy (DH 2009): build personalisation into the education and development opportunities provided to local advocacy services and practitioners by identifying roles required to facilitate self-directed support, clarifying a framework through which advocacy development happens, raising the profile of the evidence base, and using collaborative development commissioning based on local needs and services.” (p.1)

Community Care (2 Oct 2009) ‘Proven Practice: Self-advocacy for those with high support needs’ [online]
www.communitycare.co.uk/Articles/2009/10/02/112762/proven-practice-self-advocacy-and-complex-needs.htm (accessed 01/06/11)

SCIE Adult Services report 40 ‘Keeping personal budgets personal; learning from the experiences of older people, people with mental health problems and their carers’

“However, if a PB (personal budget) holder wishes to challenge the amount offered (and several older PB holders who contributed to the study had done this successfully) they, or someone acting on their behalf, needs to understand the mechanics of the resource allocation system or budget-setting process. Staff and providers also highlighted the importance of PB holders being able to challenge their allocations and the need for independent support or advocacy to do this.” (p.37)

SCIE (2011) ‘Adult Services Report 40: Keeping personal budgets personal’ [online] www.scie.org.uk/publications/reports/report40/files/report40.pdf (accessed 01/06/11)

Department of Health ‘A Vision for Adult Social Care: Capable Communities and Active Citizens’

“Personalisation in social care is under way, but there is plenty of scope for progress. An Association of Directors of Adult Social Services (ADASS) survey in April 2010 said that 42 out of 152 councils (30 per cent) had made good progress towards personalisation.

Forty-two councils should... focus on improving the range, quality and accessibility of information, advice and advocacy available for all in their communities – regardless of how their care is paid for – to support their social care choices.” (p.19)

“To deliver the vision the workforce will need to respond to the challenges of the principles at its core when delivering care. They will be crucial to delivering personalisation.

People with more choice and control over their care and support will need more information and advice, and want to know how to access and fund services, including from new brokerage and advocacy roles. The provision of personal budgets for all eligible people will mean personal assistants (PAs), directly employed by people who use care and support services, working in new, creative and person-centred ways to play an increasingly important role in providing tailored support to meet individual needs.” (p.34)

DH (2010) ‘A Vision for Adult Social Care: Capable Communities and Active Citizens’ [online]

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508 (accessed 01/06/11)

Implications for advocacy projects

Social Care Institute for Excellence (SCIE) ‘At a glance 12 – Personalisation: implications for advocacy workers’

“Real choice and control depends on people having the right information to take decisions, and on getting support if it is needed. This is where advocacy comes into its own. For this reason the role of advocates will become more important as the transformation of social care gathers pace.” (SCIE, 2009, p1)

“Personalisation, including personal budgets, requires new ways of doing things. This may change the type of support that people ask their advocacy workers to provide. In particular there may be a greater need for support from advocates to enable people to consider how money is spent and support organised. Other people may wish to use a part of their personal budget to buy support from an advocate, additional to that which should be freely provided as part of a universal information and advice service. Advocates and their organisations may want to consider whether and how they change in view of the potential changing requests.” (SCIE, 2009, p.2)

“Advocates and their organisations may want to consider the full range of tasks needed to enable people to plan and arrange social care and support so that they can decide where their contribution is best made. Some might wish to consider the implications of, and opportunities for, developing specialist support brokerage roles.” (SCIE, 2009, p.3)

(SCIE, 2009, ‘At a glance 12: Personalisation briefing’ [online]
www.scie.org.uk/publications/ata glance/ata glance12.pdf (accessed 31/05/11))

Advocacy and brokerage

Counsel and care ‘independent advocacy’

“As a result of the personalisation of social care, the creation of personalisation advocates is beginning to emerge to support older people to identify care options and try to secure them to meet their care needs. This would be a different and distinct role from the care brokerage role that some social workers or care managers may have.” (p.26)

Counsel and Care (2010) ‘25: independent advocacy’ [online]
www.housingcare.org/downloads/kbase/2716.pdf (accessed 31/05/11)

‘Advocacy Action Learning Set Discussion Group’ facilitated by Durham Employers Care and Health Alliance (DECHA)

"The group stressed the distinction between advocacy and brokerage as being two different roles. Both of these roles have specific and different functions/responsibilities which can impact training needs and qualifications. Each role needs to be defined with its own skill mix and job roles. They also defined the amount of involvement each role would need with the client/service user.

- Advocacy – long-term involvement with client/service user
- Broker – short-term involvement with client/service user

The group discussed how brokerage is potentially open to financial abuse and that accreditation and training may reduce this from happening. Who should undertake brokerage? There is a natural link to advocacy but it should be independent, and not part of a care package. There have been approaches made to advocates to deliver brokerage, by both clients and carers and the advocacy role can become confused. The group felt that there is a real need for clarity here.” (p.5)

DECHA, (2009) 'Advocacy Action Learning Set Discussion' [online] www.decha.org.uk/doc_up/1_164_Advocacy-Briefing-Paper.pdf (accessed 31/05/11)

Department of Health, Putting People First 'Good Practice in Support Planning and Brokerage'

"When brokerage is seen as a range of tasks and activities, it is quite obvious that there is not a clear and succinct boundary. Indeed, there is significant overlap with advocacy, information and support.

Whilst it is important to understand this overlap, it is particularly important to understand the succinct role each one has to play, and in particular, that of brokerage. (p.9)

However, brokerage does not replace advocacy and there is still a clear need for distinct and thriving advocacy services at a local level. In nearly every brokerage situation we have seen there has been an element of advocacy within it. However, there is an important distinction between the role of an advocate and broker – most often a broker will be involved in the implementation of the outcome of the advocacy in some way, whilst the advocate may not." (p.18)

DH (2008) 'Good Practice in Support Planning and Brokerage' [online] www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/Good_Practice_in_Support_Planning_and_Brokerage.pdf (accessed 01/06/11)

Equality and Human Rights Commission 'From safety net to springboard: A new approach to care and support for all based on equality and human rights'

"For independent advocacy to be effective, its provision must be clearly separated from the provision of assessment, information, advice and brokerage." (p.26)

EHRC (2009) 'From Safety Net to Springboard' [online] www.equalityhumanrights.com/uploaded_files/safetynet_springboard.pdf (accessed 31/05/11)

ACUK 'Manifesto for Independent Advocacy Services'

- We believe...that government and local commissioners should recognise that independent advocacy and brokerage, whilst complimentary, are two distinct roles. This is the case even where both services are provided by the same organisation." (pp.12-13)

ACUK (2010) 'Manifesto for Independent Advocacy Services in England & Wales' [online]

<http://gain.org.uk/documents/ADVOCACYMANIFESTOWEB.pdf> (accessed 31/05/11)

Paying for advocacy from personal budgets

Baring Foundation 'Rights with Meaning'

"Also, paying for advocacy from individual budgets can be said to compromise the long held belief that advocacy must be free to the end service user. For individuals, this could mean a choice between purchasing a number of hours of important care support or the ability to be heard." (p.2)

"The Equalities and Human Rights Commission has recognised the danger that a shift towards personalised budgets without the support of freely available advocacy is likely to create a greater inequality of access to services." (p.19)

Smerdon, M. (2009) Baring Foundation 'Rights with Meaning: Background and Aims of the 2008 STVS Independent programme focusing on advice and advocacy organisations' [online]

www.baringfoundation.org.uk/RightswithMeaning.pdf (accessed 31/05/11)

ACUK 'Manifesto for Independent Advocacy Services'

- "We believe...that independent advocacy should be free at the point of use. It should not be a requirement that independent advocacy be paid for from an individual's personal budget." (p.12)

ACUK (2010) 'Manifesto for Independent Advocacy Services in England & Wales' [online]

<http://gain.org.uk/documents/ADVOCACYMANIFESTOWEB.pdf> (accessed 31/05/11)

Personalisation, advocacy and safeguarding

Equality and Human Rights Commission 'From safety net to springboard: A new approach to care and support for all based on equality and human rights'

“Independent advocacy has a central role in play in promoting people’s safety and security without compromising their personal autonomy through supporting decision-making and communication, removing the undue interference of others and in enabling individuals to recognise the strengths and weakness, opportunities and threats of different options available to them... Having the support to participate and engage in employment or the wider community can provide access to the social networks which make us all safer than we would otherwise be, and make it harder for criminals to target otherwise lonely and isolated individuals.” (p.29-30)

EHRC (2009) 'From Safety Net to Springboard' [online]
www.equalityhumanrights.com/uploaded_files/safetynet_springboard.pdf
(accessed 31/05/11)

The changing world of the social worker (social worker as advocate)

Social Care Institute for Excellence (SCIE) 'Guide 34 Practice Development: Collaborative Working in Social Care'

“There is now the potential for social workers to move away from gate keeping and resource management to advocacy and support tasks.”(SCIE, 2008, p.1 taken from A Rough Guide to Personalisation, 2008, p.16)

SCIE, (2008), 'Guide 34, Practice development: collaborative working in social care' [online]
www.scie.org.uk/publications/guides/guide34/background/policycontext.asp
(accessed 31/05/11)

Culture change and personalisation

North East Improvement and Efficiency Partnership (NEIEP) Lessons learned from personalisation pilots and readiness of local authorities across the North East

“Recommendation: Invest in organisations to provide independent information, advocacy and advice... Don't assume these organisations have the capacity to set up and provide a service without core funding and support from the council.” (p.27)

Respondent quotes about staff culture change:

“One young man received his allocation and decided, with his family, to use it to do things he wanted to do... there is so much professional control and we had issues on a daily basis... ‘How do you know it is not just what people's families want?’”

“All the people I spoke to had support plans that they did with their social worker. Social work teams said that they give people information about advocacy – but people I spoke to don't recall this. Most are happy that their plan was done with the social worker, maybe because it is new; ‘you were finding your way and we were happy to find it with you.’ Maybe later in the process people will question this more.” (p.54)

Respondent quotes about advocacy:

“I have referred **2** people to the advocacy service as they haven't spoken up about the help they need. They are both people who live alone and are saying ‘I'm OK I can manage’ when things are not working. The role of an advocate for some people is crucial. They should have that external view to question things that the person themselves might take as a given. This is obviously a particular issue if people don't have supportive others in their lives.” (p.59)

NEIEP, Nicoll, T (2008) ‘Lessons Learned from Personalisation Pilots and readiness of Local Authorities across the North East’ [online]
<http://www.northeastiep.gov.uk/adult/projects.htm> (accessed 03/06/11)

Glossary of key terms

Brokerage

The process through which people work out how best to achieve the goals set out in their support plan, the support they might need to make it happen and how to spend their personal budget. Individuals can broker their own support, or do so with the help of family, carer, friends, or an advocate. An individual could also access a brokerage service to help them to choose and access services.

Direct payment

The individual chooses to receive their personal budget in the form of payment into a bank account (a new account set up for this purpose) to purchase their own support to meet the outcomes set out in their support plan.

Independent advocacy

The process of standing alongside another, speaking on behalf of another and encouraging the person to speak up for themselves. Sometimes the advocate represents another's views and wishes as if they were their own.

Independent advocacy project

Independent advocacy projects are structurally, financially and psychologically separate from service providers and other services.

Independent Service Fund

Another option for managing a personal budget: the individual chooses a third party organisation to manage the personal budget; they retain the choice about how to meet the outcomes in their support plan.

Personalisation

The government agenda to give people choice and control - this could be about the care they receive, or about education, health, housing and other issues.

Personal budget

Traditionally an individual's social care services were provided and managed by the local authority. Everyone receiving care and support through the local authority is entitled to know the cost or value of that support. A personal budget is an upfront allocation of social care resources to a person who is eligible for support.

The personal budget can be taken as a direct payment; the local authority can manage the budget and commission services on the individual's behalf; a third party could manage the personal budget, this could be a friend or relative, or an Individual Service Fund provider; or a combination of the three.