Making It Personal:
It's not easy!

Supporting advocacy for older people in the personalisation process

Contents

1
Background to the Making it Personal project

What is OPAAL?

OPAAL is the Older People's Advocacy Alliance.

OPAAL is the only national UK membership based organisation supporting, promoting and developing the provision of independent advocacy services for older people. Our members have empathy with, and an understanding of the things affecting the lives of, older people.

OPAAL works with its members to speak up for advocacy with local and central government, funders and commissioners.

OPAAL informs its members of key issues and developments affecting them, responding to consultations and bringing organisations together.

OPAAL works to improve the quality of independent advocacy through benchmarking, quality standards, training, national projects and other advice and events.

What is advocacy?

Advocacy supports and enables people who have difficulty representing their interests, to exercise their rights, express their views, explore and make informed choices.

Independent Advocacy supports the person regardless of the demands and concerns of others. It challenges the causes and effects of injustice, oppression and abuse and upholds human rights. (OPAAL National Forum 2008)

Dunning (1995) captures the context in which most advocates try to practice. Advocacy is:

'a one-to-one partnership between a trained, independent advocate and an [older] person who needs support in order to secure or exercise their rights, choices and interests'.

Independent Living Association West Sussex

OPAAL had made contact with Independent Living Association West Sussex (ILAWS) in 2007. ILAWS had financed their own advocacy project to support take-up of individual budgets by older people during the lifetime of their regional pilot. OPAAL featured the responses of ILAWS to both the personalisation and safeguarding agendas in its newsletter of autumn 2007.

It was immediately evident that the quality of their case-work, developed as it had been from within the independent living movement, had broken new ground. Nicky Kentell, for ILAWS, and John Miles, for OPAAL, went on to collaborate on a workshop presentation at the Community Care conference in the summer of 2008, and these working arrangements were to form the basis of the Making it Personal bid later that year.

Funding

The Making it Personal (MIP) project was set up by OPAAL with funding from the Department of Health's Innovation, Excellence and Strategic Development Fund. The project started in October 2009 with the appointment of the project manager and concluded in September 2012.

2
Project aims

MIP was a programme for independent advocacy schemes to support their users' engagement with personal budgets and independent living. There was a focus on developing service protocols for wider dissemination. Key themes included: access for minority communities; demonstrating advocacy's role to care managers and commissioners; countering bureaucracy and unresponsive services, and enabling users to achieve meaningful solutions to their needs for care and independence.

The project aimed to show that

- independent advocates can ensure that care service users understand and receive their entitlements
- independent advocates can ensure that care service users get support from unresponsive services
- independent advocates can support care service users who find the power of choice hard to exercise
- independent advocates can support care service users to make difficult decisions in uncomfortable contexts about matters they had not anticipated
- independent advocates can counter the serious risks of unequal access to important new opportunities developing among disadvantaged and/or excluded care service users.

The project also sought to demonstrate the following benefits arising through the work of independent advocates:

- highlight the importance, and improve understanding and appreciation, of the working partnership between service user and advocate
- demonstrate how independent advocacy enables service-users to better express themselves, engage in making decisions, and achieve what they want
- demonstrate the relevance to the personalisation process of advocacy's capability to pursue redress and right injustice
- show how advocacy can achieve significant alterations in care-work practice and joint-working between providers.

Anticipated Beneficiaries of the Project

- Older people who need time and support to reflect on the best ways to meet their needs for care and practice independent living

- Service providers concerned to get skilled and sustained help for service-users in crisis or subject to rapidly changing circumstances.

- Independent advocates needing to develop their skills and to access new tools to support their user partners effectively.

- Care-managers and commissioners concerned to ensure the inclusion of poorly supported individuals and members of more excluded communities.

3
Project structure

Advocacy for Independence

OPAAL worked with ILA West Sussex to develop a toolkit for advocacy provision to assist older people to take advantage of the development of individual budgets and independent living. West Sussex was one of the individual budgets pilot sites so Advocacy for Independence's (AfI), ILAWS's advocacy service was well developed by the time construction of their toolkit began in early 2010. An independent report was commissioned on the work of AfI. This report entitled "It ain't what you do – it's the way that you do it!" was produced by Les Bright, an independent consultant, and looked at the difference advocacy made in the lives of service users overwhelmed by a confusing care system. In addition, Les's report highlighted the advantages to AfI of working with volunteer advocates. The intention was to have Nicky Kentell, AfI's service manager, involved throughout the life of the project as an advisor to the project manager but unfortunately at the end of March 2010 ILA West Sussex lost their Local Authority advocacy funding and could not commit to such a high level of participation.

The Project Group

The MIP national project manager, employed by OPAAL, was Marie McWilliams; she co-ordinated the recruitment of project group participants. OPAAL members and other advocacy networks were invited to express interest in taking part to develop their own service responses to the ILAWS toolkit model. 11 organisations applied to take part with 6 final project group members chosen.

The successful organisations were:

- *Independent Living Advocacy (ILA) based in Essex*
- South Yorkshire Centre for Independent Living (SYCIL)
- Advocacy for Older People (AOP) formerly Bedfordshire Advocacy Service for Older People
- Dorset Advocacy (DA)
- East Hampshire Advocacy Scheme (EHAS)
- Age UK Leicester, Shire & Rutland (AgeUK LS&R) formerly Age Concern LS&R

Independent Living Advocacy was involved in the project for a 12 month period, from June 2010 until May 2011, and then withdrew due to lack of capacity.

Project group members represented a diverse geographic spread across 5 regions of England with some typically rural (DA and EHAS) and others (SYCIL and AgeUK LS&R) mainly urban. There was some familiarity in engaging with the BME population and most of the participants had experience of working with volunteers.

Terminology did prove to be an issue throughout the life of the project with different Local Authorities and therefore different independent advocacy providers using different words but meaning the same thing.

Over the period June 2010 to March 2012 project group members worked to produce their individual toolkits in response to the ILAWS model. Quarterly meetings were held which brought the project group together to share experiences, challenges and to discuss progress. An early issue was the apparent lack of focus on personalisation in the ILAWS toolkit which seemed to the project group to be rather more focused on volunteering. ILAWS response to this challenge was that personalisation was intrinsic in their work and went without saying but project group members were keen to ensure a personalisation focus in their own responses. Project group members also drew up a series of case studies to illustrate their work with older people. They shared experiences of promoting advocacy with older people in five different English localities. More information about each of the participant organisations can be found in their individual toolkits on the MIP section of OPAAL's website.

Each toolkit contains the following chapters:

- An introduction to the organisation and to personalisation in their local area
- Recruitment & selection of staff and/or volunteers
- Induction processes and training of staff and/or volunteers
- Advocacy case studies
- Supervision, support and reflective practice within the organisation
- Professional relationships

The final toolkits produced by the project highlight both the differences within the older people's advocacy sector and the diverse client group that they represent. They will hopefully be useful to other advocacy organisations looking for alternative or additional ways of working or for ideas on how to support or adapt their current service provision.

For instance, East Hampshire Advocacy Scheme's toolkit details the steps they took to develop a stronger, referring relationship with their local care management teams; Dorset Advocacy's toolkit will be especially helpful to groups using volunteers to help bring about person-centred outcomes; AgeUK Leicester, Shire & Rutland's toolkit has extensive induction materials based around the personalisation process; Advocacy for Older People's toolkit has details of their development into a full partnership, working with POhWER and South Yorkshire Centre for Inclusive Living's toolkit has useful information about their Choosing Independence service which provides peer support for people accessing Personal Budgets.

Later in the project a 'Wiki' was set up which allowed the uploading of toolkit chapters without everyone emailing each other. This became the main method of collating the work. It provided a useful learning experience and was helpful in facilitating the ongoing assessment of progress. In addition it allowed instant access to the toolkit materials for steering group members to review progress and for the report and website designers commissioned by OPAAL.

As MIP progressed it was agreed by the project group that some support and guidance on challenging social care decisions made by local authorities would be helpful. As a result a training event was commissioned and run in March 2012 by public lawyer, Jean Gould. In addition a document designed to inform and support local commissioners who might want to commission advocacy services was developed. This was made available not only to project group members but also to OPAAL's wider membership and is available on the OPAAL website.

Meetings were also held in 2011 and 2012 with a small group of black and minority ethnic groups in London to explore their experiences of personalisation and this work is detailed later.

The Steering Group

The project manager oversaw the setting up of a project steering group. The steering group also met quarterly and was made up of expert professionals from both within and outwith the advocacy and older people's communities. The steering group advised on the general direction of the project and agreed plans and documentation including the final project report. They made specific strategic recommendations for the successful delivery of the project, supported the project manager, shared project learning and outcomes and ensured that information about the project was disseminated as broadly as possible.

Overall, the steering group proved a valuable resource. It provided space for an ongoing discussion of national research and policy documents. Steering group members were able to contextualise issues with which the project group were grappling, and help the project manager coordinate responses.

Details of steering group membership can be found in the Appendix.

4
Evidencing outcomes: the case studies

Each of the 5 project group members was asked to provide 3 case studies reflecting their experience of providing independent advocacy for older people in the personalisation process.

It became apparent from early on in the project that participating organisations might find it difficult to provide case studies relating solely to personalisation. There were a number of reasons for this identified by members of the project group: implementation of personalisation was patchy; the system for rolling out personalisation left little room for the input of an advocate for older people; where an advocacy service was already commissioned to provide a service around personalisation (in Doncaster for example) referrals from social care services simply didn't materialise.

The decision was made therefore, that where there was an apparent lack of local emphasis on personalisation, advocacy case studies showing how independent advocates work in a personalised way, must suffice to evidence how independent advocacy could make a difference in the lives of older people who might benefit from its provision. Over a third of the project's case studies have an explicit connection with direct payments and personal budgets. The rest show what a significant role advocacy can play in older people's lives and what would be lost if it were confined solely to work around personalisation. All 20 case studies produced as part of the project have been brought together in one document which is available on the OPAAL website. The project group case studies all come from an advocate's perspective with the writer asked to explain what advocates actually do. They were asked to both illustrate the principles of advocacy and the way advocates interpret these creatively and flexibly within an overall commitment to reflective practice. The case studies were then, with agreement, re-drafted by the project manager and edited by John Miles. The purpose in doing this was to give them a common feel in use of language and terminology and so make it easier for the reader to view each one as part of a bigger story.

Here we have used extracts from the case studies to show how advocates working on Making it Personal met some of its thematic objectives.

Independent advocates can ensure that care service users understand and receive their entitlements

After a review **Peter** (**case study 13**) who has multiple disabilities was told his NHS Continuing Care funding would be withdrawn:

Peter's verbal communication is severely restricted but a face to face meeting... allowed him time to clarify his wishes and agree what action to take. Peter was really keen to stay in his own home and did not want to go into residential care... He told the advocate that the... review had been carried out without prior notice. He felt that... the care manager and Continuing Health Care assessor had talked between themselves and not taken his views into account.

Peter and the advocate decided that the advocate should draft a letter of appeal. When Peter was happy with what it said it should be sent to the NHS. The advocate would then help with all correspondence and communication in relation to the issue, attend any future assessments alongside Peter, and contact his local councillors to make them aware of his situation.

The entitlement here is the right to appeal. The advocate works at Peter's pace to enable him to make a decision and pursue a course of action of which he would not otherwise be capable.

Anne (**case study 12**) is unsettled in residential care, and unhappy that her son (who has power of attorney) is now occupying her home without permission. Social workers alert the police who, seeing no evidence of criminality, take no action. The community mental health team has referred her to the advocate:

[she] stated her wish to make a new will and change her Power of Attorney. The advocate considered how she could support Anne and enable acknowledgement of her legal rights. She researched these... met the... staff who knew her, and, with Anne's permission, her solicitor. They discussed her position, including her right to an assessment... under the Mental Capacity Act. It was agreed to seek such an assessment before any legal documents were signed. It was established she had the capacity to make her own decisions, so Anne was given the time and opportunity to state her wishes for a new will... Anne also revoked the existing Enduring Power of Attorney and confirmed a new Power of Attorney.

Here the advocate supports Anne in exercising her entitlements under the Court of Protection rules and practice directives. This case illustrates a pragmatic approach to 'safeguarding' drawing on the confidence of the 'victim' to resolve her concerns for herself.

Independent advocates can ensure that care service users get support from unresponsive services

Carer **Mrs AS** (**case study 16**): The advocate visited again at the beginning of December 2011. Since the last home visit neither AS, nor the advocate, had received an update. An OT had undertaken an assessment. AS explained that she had been phoned to ask her husband for his permission to continue with his care plan. AS explained he was not able to give his consent and was asked to give it on his behalf which she refused as she felt uncomfortable about it. Just before Christmas her husband fell, and the carers relief service pressed for a response to the day centre referral as a matter of urgency due... They were told by email that another team was following up the November assessment.

The advocate phoned AS in early January 2012 and was told nothing had happened. AS said she might have to put her husband into a care home because she was finding it difficult to cope. The advocate contacted the allocated worker who had passed the case to an external agency on 8th December. He agreed to chase the matter up. The advocate pointed out that the original referral had been made to the re-enablement team on 22 September. She phoned the allocated worker again to be told an administrative error meant the external agency had only now received the referral. They would contact AS to arrange to visit and do the support plan. The advocate updated AS who asked for her to attend when the support plan was done.

Joan (**case study 6**) was 101. She had lived in a care home for six months. The local authority's Financial and Benefits team had done an assessment and deemed Joan a self-funder who should meet her own costs. However, Joan's fees had not been paid since she moved. The local authority Care Manager referred her to the advocacy service...

The advocate contacted the financial assessment team. They said they would not reassess her without a further referral from the Care Manager. They said that since there were no recent bank statements they could not carry out an accurate assessment anyway. The advocate thought they should have already gone back to the Care Manager and asked her to get Joan's mail re-directed from her previous address. The Care Manager seemed at a loss what to do next. Given the time and space, (Joan) did have capacity to make her own decisions and with the advocate she was able to explore what she wanted to do. The advocate could give her the time and help her understand what was going on. The advocate decided her best way to support Joan would be to suggest a course of action to ensure something got done. (With Joan's permission) she offered to draft a letter to all of Joan's banks and other relevant organisations giving them Joan's new address and asking them to amend their records. Once she knew they had done this, the Care Manager could then ask for the financial reassessment.

Independent advocates can support care service users who find the power of choice hard to exercise

This example (**case study 3**) indicates the difficulty for service users who are anxious, keen to protect each other, or a little rigid in their thinking. This couple have been trying for a long time, and in the face of firm opposition, trying to establish an unusual personal budget to allow a husband to care for his wife. The advocate finds a way of reframing the confrontation which enables adult services to concede while dissuading Mr A from withdrawing:

In the course of these negotiations **Mr and Mrs A** sometimes did not understand the rationale for the information requested by Adult Services: some requests they found intrusive and an invasion of privacy. But with the advocate's support they began to see why some information might be important, rather than designed to "catch them out". However, Mr A was repeatedly frustrated and the advocate could see how his attitude might have been mis-interpreted by Adult Services and could have exacerbated the situation. The advocate therefore began, while continuing her support for Mr and Mrs A, to work as peacemaker and intermediary. For example, Adult Services suggested that input from a speech therapist might improve communications with Mrs A. Mr A was against it. He was anxious not to subject his wife to needless exhausting tests, but in this he appeared obstructive to Adult Services. The advocate found evidence from an earlier speech therapy intervention which indicated this would be unlikely to work. The speech impairment was the result of brain damage during an operation. Earlier notes from the GP, Adult Services themselves, and the District Nurse, all supported this: the advocate was then able to resolve the issue amicably. It took 18 months of intensive work before a satisfactory outcome was reached.

Independent advocates can support care service users to make difficult decisions in uncomfortable contexts about matters they had not anticipated

Sally is 78, the disabled head of a household, where she is also caring for her husband (**case study 4**). They are falling into debt. Over several months the advocate and Sally discussed the range of services and options available so she could make informed choices. As a result Sally is considering applying for a grant to replace the boiler, has applied for help with optical costs, insured her dog, and received detailed information about the potential for support from Social Services including aids and adaptations for the home and meals on wheels. She has made use of Dial-a-Ride services.

The advocate linked Sally up with a number of organisations. Without this support Sally could have become increasingly overwhelmed. By listening to her, and offering her time, the advocate helped her to resolve things in her own mind. Sally said how much it helped to talk things through. She is now considering the possibility of 'downsizing', including preparing the house for sale, and learning the processes for sale and purchase.

Independent advocates can counter the serious risks of unequal access to important new opportunities developing among disadvantaged and/or excluded care service users

Two examples of work within black and minority ethnic communities are considered here. The first (**case study 15**) illustrates both the creative use of a personal budget and the importance of a proactive approach to information-sharing:

Mr and Mrs C were of Asian origin. They had lived in their local area for 30 years. At a local drop-in they had been told that, because Mrs C had Alzheimer's, they might qualify for a Personal Budget. The drop-in staff also referred them for specialist welfare benefits advice which resulted in successful claims for Disability Living Allowance for Mrs C, and for Pension Credit for them both. Finally, they referred the couple to the advocacy service...

The advocate set out to strengthen Mr and Mrs C's case for an approach to Adult Services – she was aware that the local authority had recently raised the level of assessed need they would support. She went on to discuss possible options for a Personal Budget if it was awarded them. She also provided Mr and Mrs C with information about two older people's groups within their own ethnic community which met locally, and might reduce their social isolation. They could make new friends, engage in stimulating activities and have a hot meal at low cost. She arranged for them to visit these groups.

The second case (**case study 17**), involving a Somali family, indicates the time involved in bridging the gap between private and public worlds and shows the need for determined, well-prepared, case-work to challenge institutionally racist practice. **HW** has had her 'sitting service' withdrawn on the grounds that her need was only 'moderate':

In the assessment, there are the following statements:

> 'HW is reliant on her daughter to assist her with performing her personal care, meal preparations, community, shopping, domestic and laundry tasks. Therefore, she would be at some risk without the care and support of her daughter.'

> 'she states that that she is familiar with and aware of her surroundings and does not take unnecessary risks. Her daughter confirmed this. She also has access to neighbours who speak her language. Therefore there appears to be no reason why she cannot be left alone for periods of time.'

> 'There is a history of falls.'

'However..... her daughter/carer has confirmed that her mother is never left on her own for a long period of time.'

[Her daughter] '...states that she would rather have her mother staying with her than being somewhere else. She stated that it is the responsibility of an African daughter to care for their elderly parent or parents. Therefore she feels that she is only fulfilling the obligation of caring for her mother.'

[Her daughter] '...is requesting for OT intervention to install a shower unit ....states that it will make life and caring for her mother a lot easier. Beside her concerns at bath times, she states that she is happy to continue to live and provide her mother with the level of care that she is currently providing.'

Working with a Somali colleague the advocate made several visits of an hour or more to HW and her daughter to discuss the assessment and explore the realities of their situation. At one point her daughter said to HW 'you may not need this, but I do'. The advocate agreed with HW and her daughter to challenge the decision and arranged for a new assessment on the basis that:

- HW's care needs had been wrongly assessed

- there had been no interpreter

- no carers assessment had been undertaken.

The advocate and a colleague attended the assessment and, as a result, the nine hours was restored, with some of it in the form of direct care as opposed to a sit in service. The advocate had also to chase up the OT assessment and subsequently arranged with social services to help HW complete self-directed care assessment. The advocate also encouraged HW to attend a weekly session for Somali elders at the local resource centre.

The project would highlight the importance, and improve understanding and appreciation, of the working partnership between service user and advocate

This notion is at the core of advocacy. **Peggy** (**case study 8**) who supports her disabled son finds her direct payments for respite stopped:

She contacted the advocacy service for support to try and resolve the matter. At their first meeting the advocate went through the details of the situation and looked at the paperwork that Peggy had about the Direct Payment. They agreed the advocate's first task would be to find out if there was enough evidence to support a complaint to the local authority. When this proved to be the case Peggy asked the advocate to draft the letter as she had not wanted it to go so far and felt very let down.

Peggy and the advocate worked together to turn the draft into something she was happy with. The advocate noted that Peggy grew in confidence during this process. Once the content was agreed and the complaint typed up Peggy was happy to sign and have it sent off. She anxiously awaited the local authority's response. A week later Peggy told the advocate she had received no acknowledgement and to ask what could be done next. With Peggy's permission the advocate contacted the complaints officer to find out the time-scales for handling complaints. Within a few days Peggy received a letter from the local authority offering to re-instate the Direct Payment.

The project would demonstrate how independent advocacy enables service-users to better express themselves, engage in making decisions, and achieve what they want

Betty is a disabled woman who volunteers on the SYCIL scheme to promote direct payments (**case study 2**). For her social life she relies on a personal assistant to support her in making some venues wheelchair-accessible. Following a self-assessment with a social worker which she likened to being sold double-glazing she faces the threat of reduced payments which will end her participation in a choir.

So she turned to the advocacy service for support to challenge the decision. The advocate agreed to act as her sounding board and offer moral support at future meetings. She also explained how Betty could complain, providing her with the details of local councillors. She read and commented on what Betty wrote in the complaint. She helped Betty identify and clarify her priorities for the Support Plan, and attended her meetings with the social workers. Betty was in control of this process but the advocate helped her have a louder voice and ensure she made herself heard. At a review of the Personal Budget, where she was able to answer some of the questions differently, Betty was allocated more money. This time round she had more ownership of the process: the Support Plan was written in a way she could understand which gave her the confidence to use the Personal Budget in a way that met her needs. Betty felt confident to attend the final meeting to sign off the Support Plan on her own.

In the second example here, (**case study 11**) a man of 89 finds himself in the wrong kind of care home, and largely outside the remit of adult services. Put on the Local Authority's adult services waiting list he would have to wait six or eight months for an assessment. Had he not been a 'self-funder' the advocate judged it would have taken a month for the assessment to take place.

The advocate noted that there was never any formal discharge planning meeting (in the hospital). A doctor talked to them about the possibilities, and listed homes that might be appropriate. **John** and the advocate sat together and looked at brochures to review what was available. John chose two that he wanted to visit. The advocate made the arrangements and accompanied him. He became very animated when visiting one home that had extensive gardens and no access restrictions. It also had a large conservatory where he felt "in the open". It was agreed John would move to this new care home as soon as possible. He settled in very well and continues to live there. The advocate was able to help him choose a solicitor and so John set up a Power of Attorney. He did not want to make a will but was happy to talk to the advocate about his family. He had a sister with a family but John had not spoken to her for a number of years. John gave the advocate permission to divulge this information to the solicitor for future reference and left it at that. The advocate noted she found this case

very difficult to close... A step-by-step approach was taken to ending the partnership with the advocate helping John to see that he could now manage on his own without her support.

The project would demonstrate the relevance to the personalisation process of advocacy's capability to pursue redress and right injustice

Mrs B, who lives with her husband, has multiple sclerosis (**case study 10**). A decision is made that only her personal care needs will be met and the social support side of her package will go. The advocate undertakes extensive casework on behalf of the couple but at the core of the work is this sustained, collaborative, intervention:

Working together, the advocate and the Community Legal Service got Legal Aid to contest the NHS decision. They explored with Adult Services the options available before the funding transfer to NHS Continuing Care was finalised. This process helped Mr and Mrs B better understand the two funding procedures. They were able to negotiate additional support to enable Mrs B to continue with her social activities. It took two years for the care package to be transferred to the NHS. In the interim the NHS paid Adult Services for the cost of the Direct Payments. This was because it is illegal for Adult Services to provide financial support for someone who is eligible for NHS Continuing Care funding.

The project would show how advocacy can achieve significant alterations in care-work practice and joint-working between providers

In this example (**case study 1**), **Mary**, who is 78, has alienated the ambulance service. Bizarrely, this has undermined her status as an extra-care housing tenant. After some careful negotiation:

The advocate attended care planning meetings with Mary and would remind her of what she wanted to say. At one point she cited the Mental Capacity Act with respect to Mary's freedom to make an unwise decision: Mary said she felt less intimidated with the advocate by her side. The social worker became concerned that the scheme manager might ask Mary to leave. The advocate pointed out that, with her being involved, this was unlikely. The social worker asked how the manager knew about the advocate's involvement. The advocate explained that her service had worked in the scheme before so the manager knew some of the advocates. With Mary's permission, she recounted the earlier conversation with the manager: as Mary's advocate she would always disclose such conversations. In this way she could underline the boundaries and responsibilities of the advocacy relationship. The advocate then called a care review meeting so that the agencies involved were aware what each other was doing and so that Mary could attend and contribute to the discussion. As a result more care was delivered and Mary was able to stay in her flat. There were no more unnecessary calls to the ambulance service and the situation was resolved.

5
Project beneficiaries

Older people who needed time and support to reflect on the best ways to meet their needs for care and practice independent living.

The case studies produced as part of the project clearly indicate the benefits of independent advocacy for the older people involved. Within the project group however, referrals of older people to independent advocacy services in relation to personalisation were slow to materialise; a finding not dissimilar to the national picture. During the MIP regional dissemination tour which took place in September 2012 in Newcastle, Birmingham, Bristol and Manchester, many independent advocacy organisations listed a lack of referrals to their services as the reason they have not been more involved in the personalisation process in their areas. Many local authorities have been slow to get personalised services off the ground and only relatively recently has self directed support been offered. There would appear to be scope for local authorities to more actively involve advocates to support the older people now going through the process of assessment for personal budgets. This is especially important at a time when the main driver in getting older people onto personal budgets appears to be in meeting targets rather than ensuring true choice and control for the individuals involved.

Service providers concerned to get skilled and sustained help for service-users in crisis or subject to rapidly changing circumstances.

One example contained in case study 16 notes: "the carers' relief service referred AS to the advocate. They were providing her with two three-hour breaks a week. In referring they explained that AS was extremely stressed. Her caring role left her exhausted and sometimes feeling overwhelmed. She had been trying to get her husband accepted into a day centre. She had told the carers relief staff she was finding it very difficult to cope. She had contacted Social Services and been given a number to call so she could complain. She said she did not want to do that. She wanted her husband to attend a day centre, so she could have a proper rest." Here the service provider was keen to ensure that AS was properly supported at a time of crisis."

The case studies indicated that whilst there were occasional referrals from service providers to advocacy services involved in the project this was quite rare. The projects involved felt that the 'system' of personalisation for older people and resource allocation were not open to being proactive to engage and involve advocates. Projects involved found that where individual practitioners had a deeper understanding of advocacy then advocacy was more highly valued and understood.

Independent advocates needing to develop their skills and to access new tools to support their user partners effectively.

Throughout the project independent advocates have developed their skills. The regular project meetings developed into a strong peer learning network and this was a powerful way of bringing together different views and experiences of diverse advocacy projects.

One advocate stated that:

"The benefit is getting the wider picture from the other areas working in the project. It makes me see that we are behind in working with personalisation, but then I can learn from others, take what I feel is needed for my area and work with it. We are a diverse lot and our organisation structures differ."

The project led to significant reviews and updating of existing policies and procedures relevant to advocacy practice in the area of personalisation.

The toolkits produced by the project group have been useful not only to those directly involved in their production but also to those who attended the regional dissemination tour in September 2012. Comments from those attending these events included:

"Very informative – I knew little about personalisation but now have good email/web links"

and

"it was interesting and I will try to utilise everything I have learned in my working practice"

In addition, the materials now available online are freely available to the wider advocacy community and have been publicised to OPAAL members and through the newsletters of other advocacy support organisations.

Care-managers and commissioners concerned to ensure the inclusion of poorly supported individuals and members of more excluded communities.

The independent advocacy provided by those involved in the Making it Personal project has been shown to be beneficial not only to the older people accessing it but also to the health and social care professionals involved. Some of the case studies mentioned previously explain this in detail and the example of East Hampshire Advocacy Scheme (EHAS) shows how independent advocacy can help care managers work more productively. EHAS wanted both to raise their own profile and that of personalisation. They arranged a meeting with the operational service managers for both care management teams in their area to explain how advocacy could support the transformation of social care. Eventually, despite changes of senior personnel, this paid off. The lead advocate was invited to one of the area care management team meetings. She offered to base herself for an hour a week in the care management office to advise on advocacy if required. The care managers began to ask questions about the potential of advocacy in some of their cases. The advocate could clarify her role and its boundaries. As referrals trickled in the care management staff became clearer about it and began to see benefits to their clients and to themselves. The advocate came to the same arrangement with the second area team and began spending an hour a week there too. Referrals for advocacy for older people have increased: 35 in the most recent 12 month period compared to 18 the year before.

Having run this "loss-leader" for two years, EHAS began negotiating for the local authority to commission independent advocacy for older people. Without this, the service could not meet a growing demand. Care managers now support advocacy within the personalisation process and have reacted strongly to any hint that the service might be withdrawn. One care manager stated: 'Now I have experienced... advocacy on tap it has helped me to understand it better. It would be difficult now if I did not have access to it and it was no longer there. The clarification of its role has been very valuable'.

The EHAS advocate found that working with the social work team made it easier to challenge decisions and produced a better understanding of advocacy – now the social workers see the service as an asset – able to fight the service users' corner.

The project evaluator found that there was limited and mixed experience of the uptake for personalisation specific advocacy services – one of the projects commented that many budgets for older people continue to be managed by the local authority and that this is often through the choice of the older person. However, looking at the 20 case studies produced by the project, 20% were referred by social care staff and of the advocacy organisations directly involved in the project 4 (AgeUK Leicester, Shire & Rutland, Advocacy for Older People, Dorset Advocacy and South Yorkshire Centre for Inclusive Living) were commissioned by their local authority to provide advocacy support and the fifth (EHAS) is negotiating this at present.

6

Involving black and minority ethnic partners in London

Only one of the five participating organisations served an area with a large black and minority ethnic (BME) population (the city of Leicester). Two others (Bedford, Doncaster) had moderate representations often concentrated in particular localities. Dorset and East Hampshire have very small BME populations. Representatives agreed during the first year of the project that they needed external advice. Conditions were no longer favourable to develop a black and minority ethnic arm of the national project group in London: resources were not sufficient. A small seminar group to consider the ethnic dimensions of older people's experience of advocacy and personalisation was set up using contacts made through John Miles. These discussions were a response to the need for "action research into effective outreach to BME communities" proposed by the Ethnic Minority Dementia Advocacy Project (EMDAP) in 2009.

A report from the first event held on July 27th 2011 was produced. Attendance was by invitation, with brief planning interviews carried out by John. Five organisations took part, two from east London and three from 'inner' north-west London. The seminar was designed, not to represent advocacy organisations as such, but to link working advocates and campaigners with a provider already involved with personalisation. Three culturally-specific organisations and two generic bodies were involved (a south Asian carer support worker was invited but could not attend). Older people served included those of Somali, west African, African-Caribbean and south Asian origin.

Chatham House rules applied and so the organisations were not identified in the report. Those represented were:

- a diversifying Asian day services organisation with experience of delivering advocacy (represented by their chief executive)
- a generic older people's service provider with an advocacy remit, including that of IMCA (represented by an advocacy manager)
- an older people's network covering three local authority wards (represented by their external adviser)
- a black self-help organisation run entirely on a voluntary basis (represented by their chair, referred to below as an 'activist')
  a large Somali support group (represented by their advice worker).

Participants were asked to address three themes:

- the experience black and minority ethnic service-users are having of personal budgets (and other aspects of independent living)

- how far these issues are a priority within black and minority ethnic communities and therefore for people case-working and advocating with them
- the experience advocates and service-users have of health and social-care providers and commissioners on these issues.

Contributions were not restricted to advocacy: participants were invited to focus generally on the experience of personalisation and independent living for older people. Discussions were wide-ranging and reflected a desire to articulate common ground as well as address the difficulties faced by the project group. Two case studies are included in the case study document produced as part of the project and available on the OPAAL website. A year later a follow-up meeting on June 22nd 2012 enabled participants to review and update their discussion.

Getting the message across

There were several themes from the seminar. Both the experience of racism and some cultural factors (where for example there is no term for 'dementia' or 'family carer') require concerted effort to mitigate their influence and counter their negative effect. Whilst advocacy is considered to be a potential asset in this work it was agreed it can be difficult to communicate this within some communities. A two-way process is called for whereby advocates make sustained efforts to engage minority communities while representatives of the latter come better to appreciate what advocacy has to offer. Community development work may be as important as service development in accomplishing these changes.

Misplaced family expectations

Personalisation chimes with some black and minority ethnic people's preferences when they accept there is a need for care outside the family. This may not always conform to the account of personalisation proposed through 'independent living' and it can open up some complex issues about people's standing within their families. Misuse of personalisation to exert control may endanger some BME older people who are in reality isolated within their own homes. One or two examples from east London were described of younger people seeking to displace older family members from their homes and making advocacy 'referrals' to try and accomplish this. Relations were so bad in one case that the advocates had to be withdrawn. Bad experiences of the administration of personalisation also caused significant anxiety for some BME older people. The meeting heard numerous examples of poor practice and some alarming approaches to commissioning and contracting services. In some cases the advocate had felt it necessary to make safeguarding referrals to challenge delays in assessment or case review – but these applied across all communities and were not exclusively BME experiences.

Changes one year on

Reconvening a year later, there had been significant changes for three of the groups. The 'day centre' had just received Lottery funding to develop a personalisation support service for south Asian older people in their borough. All its users now had a 'personal budget' although local authority funding rates were so low as to make it difficult to deliver the service for people with high support needs. In north-west London the Somali group reported an increased take-up of personal budgets within a growing culture of appointing personal assistants, while they were negotiating day support for half a dozen people with a local authority centre. Both organisations were concerned at the extent to which personalisation was invoked at the initiative of family members rather than by the disabled individual.

All the organisations felt more distant from the commissioning process as local authorities withdrew support from familiar partnership structures and information exchanges. The advocacy manager's organisation had lost the advocacy tender, leaving a worrying vacuum in her borough of origin. She was now working on user engagement across three boroughs. Overall, she had become less optimistic about personalisation, as service restructuring had undermined the local authority's accessibility and performance.

Recommendations for OPAAL and others from this work

Consideration was given to the difficulties faced by MIP project group members who wanted to open up their services and engage potential users across language barriers and cultural differences. First, it was thought that OPAAL itself was in a position to give issues relating to racism, culture and identity more prominence, and to make sure that concerns about exclusion from services are heard at a political level. Secondly, advocacy schemes could work more closely with community groups and voluntary associations. The Black disabled group had been able to link its members socially by meeting in each other's homes, and using small local meeting rooms. In these circumstances, the line between 'advocacy' and other support can become blurred. Ways of maintaining a reasonable distinction and enabling advocacy to be offered alongside other functions were explored in the meeting. Thirdly, advocates looking to achieve better inclusion would need to invest time and energy in building partnerships. Patience and persistence are critical: it can take years to build up an engagement with small community organisations.

7

What worked well and what not so well?

What worked well?

Bringing the organisations directly involved in the project together to learn from and support each other worked very well. They were able to use materials and ideas provided by each other to inform their own advocacy and organisational practice. They benefited from scrutinising their own service to enable them to explain it to someone else. This frequently led project group members to update their existing systems and procedures when producing their toolkit chapters. For instance, Age UK Leicester, Shire & Rutland re-assessed and changed their advocacy induction programme to link it to personalisation. In addition, seeing what others had produced made them think carefully about their own practice. While this might reaffirm what they already had in place it also prompted changes and improvements.

In addition to the initial toolkit produced by ILAWS, the toolkits produced by project group members represent a valuable resource for the advocacy community. They detail how each organisation goes about the business of independent advocacy and contain some fine examples of good practice which can be shared across the sector. The diversity of organisations involved in their production means that there is likely to be a toolkit suitable to be adapted by other advocacy organisations, be they large, small, rural, urban, etc.

Project group members were able to identify things which made their own toolkits different from the others and amongst these differences were the following: East Hampshire Advocacy Scheme's toolkit details the steps they took to develop a stronger working relationship with their local care management teams; Dorset Advocacy's toolkit will be especially helpful to groups using volunteers to help bring about person-centred outcomes; Advocacy for Older People's toolkit has details of their developing a partnership with POhWER; SYCIL's toolkit has useful information about their Choosing Independence service and the way it provides peer support for people accessing Personal Budgets; AgeUK Leicester, Shire & Rutland's toolkit explains how their BME forum is used to feed views into the local authority service delivery process. Details of the work that EHAS did with local care management teams was especially well received at project dissemination events (see below for more information on these events). The toolkits therefore represent an opportunity for providers of independent advocacy to examine their practice and to learn from the good practices of others. All of the toolkits are now accessible through the OPAAL website.

As part of the dissemination of project findings a regional dissemination tour took place and this was very well received. Events were widely publicised through various advocacy and older people's networks and were held in Newcastle, Birmingham, Bristol and Manchester.

Attendees of each of the regional events were asked directly what they would do as a result of the training they had received. As an example, these were the responses in Newcastle which included:

Await the MIP info on the website; check out other info on OPAAL website, e.g. info for commissioners, Dorset Advocacy engagement protocol; contact EHAS for more info on their project of an advocate going to SWD for 1 hour per week.

Research and be more aware of issues around personalisation in my role, ensuring it is being practiced by all professionals surrounding an individual's care and support.

Use knowledge to guide induction of new workers – has provided good resources to access.

Go onto MIP/OPAAL website to obtain questions for commissioners and use as a personalisation resource tool.

Check website with regards to commissioning; will look at toolkits and use them

It was important for MIP to take into account the views of the BME population. Project group members were not especially active in the provision of advocacy to the BME population so two listening events were held 12 months apart (see above for details) which served to reinforce the view that the BME population faces all of the same situations as the general population but that they also face additional issues not accounted for elsewhere in the findings of MIP. The holding of these events therefore added value to the project and to OPAAL's understanding of the issues faced.

The case studies which show advocates working directly with older people around personal budgets give a strong indication of how helpful to the older person advocacy can be in this process and gives power to the argument that commissioning of independent advocacy services in the personalisation process

should be wider than it currently is. The examples from ILAWS contained in the report "It ain't what you do – it's the way that you do it!" and re-produced in the "20 Case Studies" document explain how advocates, engaged in working with people to exercise choice and control in the personalisation process, have a positive impact in supporting the older person get the outcome they are seeking. This is reflected in places like Leicester where the advocate was actively engaged with personalisation. A couple, who are the subject of one of Age UK Leicester, Shire & Rutland's case studies, were filmed for the project and their views on the difference independent advocacy made for them can be seen on the OPAAL website.

Independent advocates have been keen for some time to improve public understanding of advocacy and show how its outcomes can increase health and wellbeing outcomes. The work of the Gateshead Advocacy Information Network (GAIN) has been valuable in this respect. Through GAIN's project lead, Angela Gallant, a member of MIP's steering group, the project group was introduced to the 'A Stronger Voice' project and various resources were made available. Following this work EHAS noted:

'We have had discussions with trustees and volunteer advocates to see if they felt the star would be useful to us. It was agreed that it would and we adapted it for our own use. It has been useful to see the progress of an individual and is proving to be useful for funding and personal goals alike. Volunteers say that it's good to see the progress when it sometimes feels there has not been any.'

By adding to the project group's, and later those who attended the dissemination events, understanding of the benefits of an outcomes focus, MIP has strengthened the sector's ability to explain what can be gained from independent advocacy's involvement.

The Wiki which was developed for MIP by the project manager worked very well and was helpful in a number of ways; it provided a central repository for materials produced by the project and was a point of reference for topical information posted by both the project manager and members of the steering group; it enabled steering group members to have easy access to the work of the project group so that they could ascertain progress; it provided a learning opportunity for all involved as there was little if any prior experience of using a Wiki; it enabled access to finalised project materials to both the MIP document designer and the OPAAL website designer thereby removing the need to send bulky materials by a number of separate emails.

...and what not so well?

ILA West Sussex lost its advocacy contract in March 2010, almost as soon as the project began making it impossible for its advocacy manager to remain part of the project in a support role. The loss of this expertise perhaps hindered those project group members who had little or no experience of local personalisation where it had not yet been fully developed and was a loss also to the project manager.

The withdrawal of Independent Living Advocacy, based in Essex, after only 12 months was a blow to the project. Of all geographic areas involved within the project group, Essex had the most developed working practices around self directed support. Independent advocacy provision was built in to the process for older people who needed it and ILA had the most experience of working with older people around personal budgets. Their withdrawal whilst regrettable was systematic of the difficulties that all members of the project group faced in sustaining project activity at a time of intense pressure on service delivery and on resources. ILA, represented by their Director, felt they no longer had the resources to spare for MIP project work and therefore took the difficult decision to pull out. At one point the project manager feared that this withdrawal might be the first of many but thankfully the other project group members were able to continue. Participation did prove problematic for everyone however and in particular Advocacy for Older People, represented by their Chief Executive and Dorset Advocacy, represented by their Development Manager, found it noticeably more difficult to attend every quarterly project group meeting as regularly as other project participants as there were sometimes issues of strategic importance requiring their attention, often at short notice, which had to take precedence.

MIP began at a time of financial uncertainty for Local Authorities, the main commissioners of independent advocacy services. The UK was already experiencing recession and following the change of Government in May 2010 and the ensuing comprehensive spending review Local Authorities saw their funding cut by 7.1% each year for the next four years, commencing in 2011. In addition the ring fencing of Local Authority social care budgets was removed. Many Local Authorities subsequently restricted eligibility criteria for social care services. For instance, in Leicestershire some 4,700 people stopped receiving services when moderate support needs were no longer eligible to be met and by the end of the project in September 2012 of the 5 participants remaining only SYCIL, based in Doncaster, still had a Local Authority meeting moderate needs.

For MIP participants the economic climate had an immediate impact. As Local Authorities tightened their belts they sought economies of scale and began to seek partnership or consortia bids for advocacy provision. Both Dorset Advocacy through its partnership work with Help and Care, and EHAS through the Hampshire Advocacy Regional Group (HARG) consortium, were already involved in this to some degree. Independent Living Advocacy in Essex, which pulled out of the project after 12 months, was already involved in what they themselves described as an "unsatisfactory" hub and spoke model of service delivery. In both Leicestershire and Bedfordshire there was a Local Authority drive to promote this way of working. AgeUK Leicester, Shire & Rutland came under a degree of Local Authority pressure to act as the lead partner in a local consortia

bid which they ultimately agreed to do. Unfortunately the resultant tender was awarded elsewhere and led to the loss of AgeUK L, S&R's very experienced advocate who did not want to TUPE over to the newly commissioned provider and who then left advocacy completely. In Bedfordshire AOP was too small an organisation to apply for the tender offered by the Local Authority. An attempt at a hub and spoke model floundered very soon after set up and left AOP with some difficult choices to make. Ultimately they developed a partnership agreement with POhWER, one of the larger advocacy providers in England, which enabled them to continue as an independent entity and to continue delivering advocacy for older people. All of this emphasis on organisational survival meant there was less managerial time or opportunity available to concentrate on developing links into what local personalisation process there was.

Each member of the project group was asked to provide 3 case studies, ideally to reflect their advocacy practice around personalisation. This proved to be very problematic since few referrals had any involvement with personal budgets or person-centred planning. Despite a willingness to deal with such issues the advocacy organisations involved rarely came into contact with older people seeking, or referred for, support in such matters. SYCIL for instance was contracted to provide advocacy support for what turned out to be a diminishing group of people. Figures for Doncaster show that in the year 2010-2011 there were 4,341 older people (over 65) receiving services and of those 174 were in receipt of a Direct Payment. The following year 2011-2012 there were only 3,224 older people receiving services and the number in receipt of a Direct Payment had reduced to 108 (a drop of over 25% and 37% respectively)

One project participant explained that her advocacy service has had to generate interest in advocacy in the personalisation process itself rather than rely on Local Authority referrals. "When referrals are made to the LA there can be long delays in any action in spite of the fact that they should be dealt with within 28 days."

In spite of a lack of opportunity to provide support in personalisation related cases, there was no shortage of older people accessing independent advocacy support.

There may be a number of reasons for this:

Older people could be missing out on real choice and control because target setting has reduced the impact and potential of personalisation. Local Authorities had a target of 30% of all service users to be in receipt of a personal budget by April 2011. There has been widespread concern across the project group about how many older people are even aware that they have been transferred to managed budgets. The figure achieved was actually 29.2%[1] up from 13% the previous year. In June 2011 Community Care magazine raised the following concern: "there has been criticism that council-managed budgets have left local authorities with too much control over the services that users purchase… "We are supposed to be putting the person at the centre of the care plan and doing more support planning with them. You would think that would lead to more innovative approaches but it seems… we are still fitting clients into existing services rather than developing new ones."[1] Indeed the Personal Budget Survey report noted: "Older people were more likely than other groups to not know how their personal budget was managed"[3];

There could be possible misunderstandings within some Local Authorities that older people are not suitable candidates for direct payments or even for personal budgets. This is in spite of some examples of excellent work in co-production with older people available to Local Authorities such as that produced by Helen Sanderson Associates and the National Development Team for Inclusion[4] which "*show how working in person-centred ways and adopting person-centred thinking skills and tools can make a real difference to older people's support and their lives*";

The project did not come across any referral requests for advocacy support for an older person with dementia to enable them to access personalised services. This would seem to be in line with the findings of the Dementia Choices project run by the Mental Health Foundation: "Throughout the project we found that there was a very low level of awareness and understanding of self-directed support among people living with dementia and their family carers. We also found that a wide variety of social care workers at a local level needed practical information about how self-directed support can work for people living with dementia."[5] Whilst MIP did not concentrate on individual specialisms within older people's advocacy such as supporting those with dementia, OPAAL does support work in this area on an ongoing basis. For instance, Jeff Lee has recently produced a "Quick-start guide to memory recording for people with dementia"[6] on behalf of OPAAL aimed at supporting the development of expertise.

MIP struggled to engage with commissioners of services in spite of having two commissioners involved with the steering group for a short time. One of these commissioners wrote to the Local Authority areas involved through the project group seeking clarification on the commissioning of advocacy services but he received limited response. It appeared to project group members in places such as Leicester and Doncaster that commissioners at the time were focusing on an overhaul of commissioning practices and were less interested in entering into dialogue with individual service providers. In East Hampshire there has been no recognised commissioner of older people's services for a number of years. Even though the project document "Information and Questions for Commissioners" was produced, engaging with commissioners remains an area of concern and for future development by OPAAL.

It is apparent that there continues to be uncertainty about what independent advocacy is and what it can do for older people. This uncertainty lies not only with some care managers and commissioners but also with older people themselves. If older people know and understand about independent advocacy they are more likely to request it. Since localism is a major driver of current government policy it is vital that older people know about independent advocacy so they can request it and feed it into their Local Authorities Joint Strategic Needs Assessment. OPAAL recognises that it must work harder to promote an understanding of advocacy at a national level and support local advocacy organisations to promote an understanding of advocacy locally.

There is evidence from MIP that even when some older people are provided with the support of an independent advocate they still find the process of accessing social care services too confusing and complicated. In one case study provided by SYCIL they record that in spite of advocacy support the service user, who

wanted to attend a local day centre, gave up: "even with the advocate's support, Margaret found the process bewildering and confusing. She got very anxious about it. The advocate knew that all Margaret wanted was to know when she could start going and what time the transport would pick her up. Faced, with such a lengthy process, Margaret decided that she would much rather pay to attend than go through the assessment. This was very unfortunate: since she was in receipt of means tested benefits she would have been able to attend free of charge. Here, the complex personalisation process obstructed her receiving her entitlement."

This would appear to be corroborated by Community Care Magazine's personalisation survey of social care professionals which states: "Just one-fifth of respondents said they had enough time with service users to effectively support self-assessment – despite the fact that only 1% of respondents felt the paperwork relating to assessments was suitable for users to complete without support."[7]

It might be helpful for Local Authorities if independent advocacy providers were to feedback the difficulties being faced by social care service users so that the Local Authority can take these difficulties into account when designing local processes.

There was concern expressed by members of the project group that some Local Authority care management teams are losing expertise through redundancy or restructuring and that as a result morale has been affected. In some areas advocates often support care managers as well as their service users to understand what personalisation is about. They can also end up helping their service users by carrying out functions that are actually Care Management responsibility to ensure that progress is made. In one case study the advocate had to explain to the Care Manager that a "Personal Budget should allow the couple to be creative in finding ways to meet their assessed needs" when they were told they could not use their personal budget to buy food from a takeaway. This decision was ultimately overturned. In another case study from East Hampshire the advocate noted that the Care Manager "admitted that time constraints would not allow her to deal with Joan in the way the advocate could. The advocate felt there had been so many changes within Adult Services that responsibilities had become confused. She, the advocate, was regularly being left to co-ordinate situations that were the responsibility of the Care Manager."

It is to be hoped that as personalised services become embedded across the country and Local Authorities find their financial situation stabilising that independent advocates will find these factors less of an issue and they will be able to get on with what they do best, advocating.

8
Making it Personal evaluation

The Making it Personal project was independently evaluated by Frameworks4Change.

Andy Bradley, the Founder and Chief Executive Director of Frameworks4Change led the evaluation. Andy evaluated the high profile national Mental Capacity Advocacy Project led by Age Concern England (now Age UK).

The evaluation report is, in the main, positive about MIP's achievements and acknowledges the difficulties that were faced.

Key points from the evaluation report

The MIP project has taken place at a time of major transformation of policy, politics and uncertainty regarding commissioning and resources for health and social care services and for advocacy.

Where advocacy organisations have sought to become more involved in the detail of supporting older people through the personalisation process a major implementation gap has been evident with strategies and statements from local authorities and their partners not apparently translating into older people being able to make real choices about the support they receive.

There is evidence both from case studies and comments received that at a local level MIP has generated improved understanding of and appreciation of the role of the advocate and the part the advocate plays in empowering the older person.

There is little evidence of a general impact on the capacity of advocacy to pursue redress and right injustice in the context of the personalisation process across the MIP project. Advocates in all of the organisations taking part have been well supported by the project, well informed and pro-active but found themselves working in situations where the implementation of personalisation has been patchy or in development so few older people were directly involved in personalisation with the input of an advocate.

A small number of personalisation cases did show where advocates have been very influential and significant gains for older people have been made.

- Advocacy did achieve significant alterations in care-work practice and joint-working between providers

- There were examples of social workers becoming more vigilant in the decision making process

- A project co-ordinator who spent direct contact time with social work teams, specifically 'selling the benefits' to social workers, found that the social workers developed a clearer understanding of what advocacy could achieve.

Other projects which were more well established in providing various forms of advocacy were unable to see significant alterations in care work practice.

There are powerful examples given in the case studies of older people receiving the time and space they needed to consider their own preferred course of action and to assert their view. Older people valued having an advocate listening in a non-judgemental way and an advocate 'fighting their corner' helped them to achieve outcomes that were important to them.

The project led to significant reviews and updating of existing policies and procedures relevant to advocacy practice in the area of personalisation.

There was limited and mixed experience of the uptake for personalisation. One of the projects found that many budgets for older people were managed by the local authority and that this is often through the choice of the older person. EHAS's advocate was proactive and spent time based in Care Manager's offices and this led to Care Managers actively referring and seeking the support of the advocacy service for their clients.

Learning from the Case Work

As part of reflecting on and sharing the learning regarding the project the five organisations collated and shared three case studies; of the 15 collected only four relate directly to the personalisation process – this is a disappointing finding.

However, whilst not directly related to the 'personalisation processes' other advocacy cases were significant in their benefit and impact for the older people concerned and included. For example:

- Clarification and empowerment around financial affairs and rights and entitlements and working with Care Managers to put affairs properly in order

- Being the only constant presence and building up trust and insight into the views and rights of a man who was bereaved and diagnosed with dementia at around the same time; ensuring the man's voice was central to decisions made resulting in him having a real say in a move to a care home of his choice.

- Support for a couple through a hospital admission and listening to both husband and wife to facilitate a plan which ultimately enabled the couple to live at home together with a package of care at home (averting a permanent move for the wife into a nursing home)

Appendix

Definitions

What is personalisation?

Personalisation is an approach to delivering services to people who need them, following the principles of *self-directed support*.

'Personalisation means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It requires a significant transformation of adult social care so that all systems, processes, staff and services are geared up to put people first.'[8](SCIE, 2007)

Personalisation involves a wide interpretation of independent living, covering access to housing, education, transport, work and leisure as well as health and social care. Two instruments of personalisation are *direct payments* and *personal budgets* which are the responsibility of local authorities, and are also being piloted within the NHS.

A direct payment[8]

'A direct payment is a means-tested cash payment made in the place of regular social service provision to an individual who has been assessed as needing support. Following a financial assessment, those eligible can choose to take a direct payment and arrange for their own support instead. The money included in a direct payment only applies to social services. A direct payment is one way of taking a personal budget.'

A personal budget[8]

In December 2007, *Putting people first*[9] proposed that all social care users should have access to a personal budget, with the intention that they can use it to exercise choice and control to meet their agreed social care outcomes. Key to the personal budget approach is giving clear, early understanding of the amount available to the individual, so that they can influence or control how it is spent, in a way which helps them best meet their needs. A personal budget should focus on providing for on-going support and care needs, and should normally be considered only after examination of relevant preventative and re-ablement options (ADASS, 2009a).

Steering Group membership

The steering group members were:

Jan Kendall, *Dementia Advocacy Network*

Katharine Orellana, *AgeUK*

Angela Gallant, *Gateshead Advocacy Information Network*

Kath Parson, *OPAAL*

The following also attended and contributed:

Nicky Kentell, *ILA West Sussex*

Jon Palmer, *formerly London Borough of Sutton*

Eryl Davies, *London Borough of Barnet*

Kay Steven, *OPAAL*

Steve Cowan, *Gateshead Advocacy Information Network*

Notes

[1] Social Care and Mental Health indicators from the National Indicator Set –NHS: The Information Centre 2010-2011
http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/NIS_201011/NIS_2010_11_Final.pdf

[2] http://www.communitycare.co.uk/Articles/01/06/2011/116904/Direct-payments-made-default-option-for-personal-budgets.htm

[3] Think Local Act Personal 2011: Personal Budgets, Taking Stock, Moving Forward

[4] National Development Team for Inclusion: A guide to co-production with older people (2009)
http://www.ndti.org.uk/uploads/files/Personalisation - dont_just_do_it_coproduce_it.pdf

[5] Dementia Choices: Developing self-directed support in social care for people with dementia. Mental Health Foundation
http://www.mentalhealth.org.uk/our-work/research/research-projects/dementia-choices/

[6] Quick-start guide to memory recording for people with dementia: Jeffrey Lee, 2012
http://www.opaal.org.uk/default.aspx?page=26992

[7] http://www.communitycare.co.uk/Articles/25/05/2011/116867/bureaucracy-is-damaging-personalisation-social-workers-say.htm

[8] Personalisation – a rough guide: Social Care Institute for Excellence, 2010
http://www.scie.org.uk/publications/guides/guide47/files/guide47.pdf

[9] Putting People First: A shared vision and commitment to the transformation of Adult Social Care: HM Government 2007
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf