



MAKING IT REAL:

personalisation in social
care, a case study report

June 2014

 think local
act personal

Voluntary
Organisations
Disability Group

VODG

The Voluntary Organisations Disability Group (VODG)

The VODG is the national umbrella body representing more than 80 leading voluntary sector and not-for-profit social care provider organisations.

VODG members work with around a million disabled people throughout the UK providing services that promote independence; choice and control, share common values, employ more than 75,000 staff and have a combined annual turnover in excess of £2.5 billion.

Our aim is to ensure that members, in partnership with commissioners, can provide progressive high quality and sustainable services that reflect Think Local Act Personal principles (see below), uphold the rights and meet the needs of disabled people.

We aim to influence the sector through a combined and expert voice that is authoritative, based on the applied experience of members. We build effective partnerships with central and local government and other key agencies and offer a means by which voluntary service providers can be consulted in a coherent way and provide information through regular news and policy briefings. The VODG promotes, conducts and engages in research to the benefit of its members and disabled people and offers exceptional networking opportunities and peer group support.

Find out more on our website www.vodg.org.uk or follow us on Twitter @VODGHQ, email info@vodg.org.uk or telephone 02032 420 387



Think Local, Act Personal (TLAP)

TLAP is a national, cross sector partnership spanning central and local government, health and social care, the independent and commercial sectors and people with care and support needs, carers and family members. The partnership

is focused on driving forward work with personalisation and community-based care and support through the commitment of partner organisations and the delivery of a co-produced national work programme.

TLAP's unique strength is bringing together the whole sector to galvanise effort towards the shared endeavour of transforming our care and support system so that it puts people at the centre. To do this, TLAP works closely with the National Co-production Advisory Group - a network of about 50 people with lived experiences of care and support who ensure that the TLAP programme is grounded in the things people say are important.

Making it Real is a central initiative of the TLAP programme, setting out markers of progress with personalisation for the whole sector and involving a process of coproduction and action planning that organisations take forward locally. At time of writing, almost 700 organisations are signed up to Making it Real, including more than half the councils in England and many VODG members.

Find out more on our website www.thinklocalactpersonal.org.uk or follow us on Twitter @TLAP1 email thinklocalactpersonal@scie.org.uk or call 020 7535 0900

Contents

- 4 Introduction: why Making it Real matters
- 8 Action on Hearing Loss is Making it Real with its workforce
- 12 Dimensions is Making it Real with risk enablement: feeling in control and safe
- 16 Dudley borough council is Making it Real with active and supportive communities
- 20 Sue Ryder is Making it Real with flexible integrated care and support: my support, my own way
- 24 Carers Trust is Making it Real with information and advice
- 28 The Wilf Ward Family Trust is Making it Real with personal budgets and self-funding
- 32 Conclusion: Making it Real - transforming personalisation into reality
- 34 List of organisations featured in this report

About this report:

The aim of this report is to highlight the usefulness of the Making it Real framework in delivering high quality personalised services, especially for people with lifelong disabilities. Innovation in social care is frequently led by providers working with disabled people, their families and carers and the examples in the report which illustrate collaboration and inclusion are great stories, worth telling.

The VODG is grateful to Steve Scown, chief executive of Dimensions and VODG trustee, for suggesting the report and overseeing its production, along with the valuable advice given by Sam Bennett, chief executive of TLAP. We are also grateful to Clenton Farquharson, TLAP co-chair and member of the National Co-production Advisory Group, who helpfully commented on the draft report.

VODG is a Department of Health voluntary sector strategic partner and we are grateful to our joint partners, The National Care Forum (NCF) and Sue Ryder for their support and advice throughout.



Why 'MAKING IT REAL' matters

Introduction from Sam Bennett, programme director, Think Local, Act Personal, and Steve Scown, chief executive, Dimensions, trustee VODG

"If you can't see the person for the paper work," as Sue Ryder's Angela Killip reflects on page 20 of this report, "there's something wrong".

Angela is referring to how the charity supports Luke, a 45-year-old with brain injury who has no speech and can only move two fingers of one hand. Despite his complex needs, the Sue Ryder team at the charity's neurological centre in the north of England strive to follow Luke's preferences. "We know how he likes his bed made, what he prefers to watch – he loves football but hates golf and soap operas," says Angela. "It's all about capturing aspects of Luke's personality and incorporating it into his care."

Angela's words underline why we have published this piece of work. Her comments refer to not only the inadequacies of traditional approaches to caregiving - where the individual is a passive recipient of support, rather than an active participant or decision-maker - but highlight how the Making it Real¹ framework, which this report illustrates, can make a difference to people's lives.

Making it Real enables social care professionals - providers, commissioners, policy experts and central and local government - to mark progress towards personalised, community-based support. It also allows people being supported and their families to judge how far an organisation puts them at the centre of the care.

Making it Real is part of Think Local, Act Personal (TLAP)², the sector wide voluntary movement to transform adult social care through personalisation³ and community-based support. The Making it Real markers of progress outline the distinct, practical steps to make personalisation a reality (see left, What is Making it Real?).

What is MAKING IT REAL?

Think Local Act Personal (TLAP) launched Making it Real: Marking progress towards personalised, community-based support in May 2012.

Making it Real was developed and co-produced with members of TLAP's national co-production advisory group, which includes people with experience of using services and carers.

The framework is divided into six themes - it is not a performance management tool, but a way of measuring progress towards personalisation. It changes the way organisations measure success in personalisation.

The themes are:

- Information and advice: having the information I need, when I need it
- Active and supportive communities: keeping friends, family and place
- Flexible and integrated support: my support, my own way
- Workforce: my support staff
- Risk enablement: feeling in control and safe
- Personal Budgets and self funding: my money.

Each theme is supported by accessible, practical, aspirational statements from the perspective of the individual - "I statements" (which are included in the individual case studies in this report). The statements describe what people might say if personalisation was working well for them and help indicate how far an organisation is making good progress towards personalisation. They express what people want to see and experience; what they would expect to find if personalisation is really working well.

The aim of this report

This report supports and illustrates Making it Real by sharing stories about people with lifelong disabilities. The stories reveals that the framework is accessible, the aims are achievable and can lead to positive outcomes. They describe what organisations signed up to Making it Real have done as a result of adopting the approach and what benefits they have gained.

Our report also shows how the framework can be successful in a variety of care settings, for a range of individuals with varying care needs and among organisations of different sizes and types. This report's conclusion (see page 32) describes some of the challenges that could undermine the framework and what a range of stakeholders might do to solve potential problems.

Why is MAKING IT REAL important - what makes it different to other approaches?

Why is Making it Real important? In essence, it is about enabling people with lifelong disabilities to live the kind of "ordinary life" that others usually take for granted. It ensures that support for vulnerable people extends beyond simply meeting their personal care needs, and more truly reflects their personal preferences, aspirations and choices.

The Making it Real approach is unique thanks to the inclusion of "I statements" (see left, What is Making it Real? and the case studies in the rest of this report). In addition, the framework has been co-produced by people with experience of services - families, carers or individuals themselves - and encourages the social care sector to not only drive change, but to publicly share the progress being made.

Using this approach means councils, organisations and all partners can look at their current practice, identify areas for change and develop plans for action. Making it Real can be used by any organisation involved in providing care and support including councils, providers of home based support and those providing residential and nursing care.

It can also be used by people who use services and carers to check out how well their aspirations are being met.

How is MAKING IT REAL relevant to other aspects of health and social care?

While Making it Real has an obvious place with the social care transformation agenda - as a backbone to personalisation - it also fits with other aspects of social policy. A raft of policy recommendations and changes, (for example, the new "consumer's champion" Healthwatch⁴ or the recent Francis report⁵), stress the need to place the patient or individual at the heart of care.

In addition, with the public and third sector in the midst of unprecedented spending cuts, it is more important than ever for organisations to illustrate their impact⁶ to funders. Making it Real is a practical way to measure positive outcomes and can be regarded as an additional litmus test when it comes to organisational effectiveness.

1 www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/

2 www.thinklocalactpersonal.org.uk

3 webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm

4 www.healthwatch.co.uk

5 www.midstaffpublicinquiry.com

6 www.ncvo-vol.org.uk/strategy-impact/assessing-impact/assessing-impact



What the stories in this report show

The six stories in this report show how organisations can use Making it Real to radically improve the quality of life and standards of care for the people they support:

- Dudley borough council is Making it Real with active and supportive communities: Dudley's story shows how commissioners aspire to change their approach, so contracted services really reflect the wishes of residents
- Sue Ryder is Making it Real with flexible integrated care and support: Sue Ryder's case reveals how choice and control can be offered to someone with complex needs
- Action on Hearing Loss is Making it Real with its workforce: Action on Hearing Loss allows people to influence and be involved in the recruitment, employment and management of staff
- Dimensions is Making it Real with risk enablement: Dimensions explains how it uses the strategies to strengthen its risk enablement work
- Carers Trust is Making it Real with information and advice: the Carers Trust story describes how families, as well as the individuals in receipt of care, can benefit from personalised support
- Wilf Ward Family Trust is Making it Real with personal budgets and self-funding: Wilf Ward Family Trust supports people with personal budgets in an innovative way so they can learn independence skills.

Making it Real, as Justin Haywood from Dudley council says on page 16, is about "organisations working differently and effectively to give people a better say in how they live their lives". The approach, as you will read over the next few pages, concerns people - not processes.

Making it Real can help create consistency between organisations providing community-based, personalised support and has the potential to help resolve inconsistencies in the quality and standard of care. Making it Real acts as an anchor for personalisation in social care; adopting it makes it easier to turn the theory of personalisation into a reality.

What are the practical steps towards MAKING IT REAL?

- register your organisation and the name of your Making it Real lead on TLAP's website (www.thinklocalactpersonal.org.uk)
- make a board level declaration (co-produced with people who use services and carers) confirming your organisation supports Making it Real
- identify where your organisation is in relation to the Making it Real "I statements" (see the case studies on the following pages for "I statements")
- identify gaps and challenges you need to address to support the outcomes identified in the framework
- develop an action plan confirming what actions your organisation has agreed to take - share this through your website, other local websites and networks or on the TLAP website
- identify three priority areas in your action plan, share them on the TLAP website and display the Making it Real kitemark (available on the TLAP website) on the websites you are using
- after six months, publish a report on your website to confirm progress made against your action plan; identify how you will achieve outstanding outcomes and upload an update made against your priorities
- publish a summary of a successful initiative on your website, so others can learn from your experience
- repeat these steps every six months, ensuring co-production is demonstrated throughout.

Information taken from the TLAP website www.thinklocalactpersonal.org.uk



Action on Hearing Loss is **MAKING IT REAL** with its workforce



When John interviews prospective care workers on behalf of Action for Hearing Loss, he looks forward to finding out more about their lives. Qualifications and experience are important, but John is more interested in candidates' hobbies. As part of an interview panel quizzing prospective staff at the Brondesbury Road housing scheme in north London, John's fellow interviewers focus on the CVs, leaving John to gauge how the applicant might get on with the people they will be supporting.

John, however, is not an employee of Action on Hearing Loss - he is one of the six people living at Brondesbury Road and supported by the social care charity. The organisation's adoption of Making it Real means that everyone living in the Queens Park housing scheme - deaf men aged 42 to 73 whose additional needs include mental health issues or learning disabilities - are involved in recruitment. Using the Making it Real framework, the charity has developed an accessible recruitment process which fully involves the individuals supported at Brondesbury in the hiring of new staff.

One recent successful outcome was the recruitment of a new senior support worker who is also deaf. service manager Pam Newman explains: "The new member of staff has that lived experience and is able to advocate on behalf of the person being supported better than those of us without a hearing impairment. I don't think we would have found her had it not been for our new approach with Making it Real."

"I like meeting people at interview and asking them about themselves," adds John, whose character wish list for new members of staff includes someone who is tidy, neat, friendly and happy. As well as interview questions specifically drafted to reflect what the people being supported want to know, interviewees might be questioned directly by them using photographs, sign language or written text questions.

Action on Hearing Loss, which supports about 400 people and runs 52 care and support services, decided to use Making it Real to reinforce its commitment to personalisation.



The work began in early 2012, with the recognition that the people using services did not usually have the final say on who was employed to work in their home. Using Making it Real for recruitment, says Pam, meant the charity could extend its person-centred work to its employment practices. She explains: "It's important to have choice because it's your home, and it's right to have a proper say in who comes in and helps you. It has to be user led - so it's about the person, rather than being management-led."

The Making it Real theme of workforce: my support staff, includes the aim of supporting people to influence and be involved in the recruitment, employment and management of staff. Providers should aim to achieve several outcomes that, from the perspective of the individual, include:

- "I have good information and advice on the range of options for choosing my support staff"
- "I have considerate support delivered by competent people"
- "I have access to a pool of people, advice on how to employ them and the opportunity to get advice from my peers"
- "I am supported by people who help me to make links in my local community"

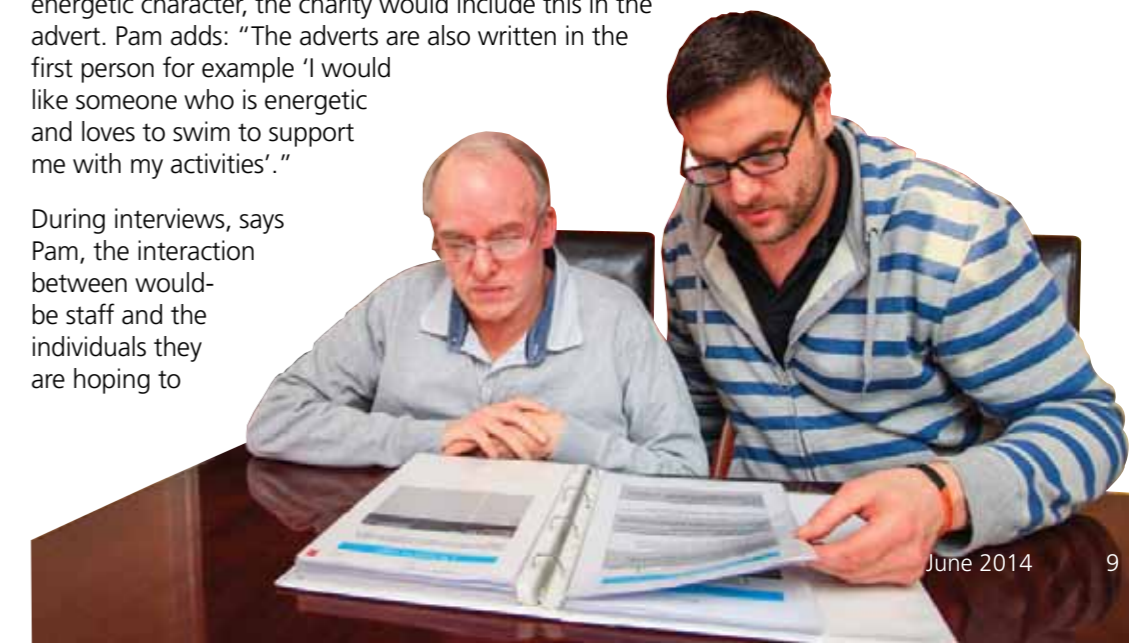
With these aspirations in mind, the charity's first step was to note that existing job descriptions and personal specifications were usually generic and that individuals themselves could provide valuable information on the care they would like to receive.

Next, the human resources team used a specialist recruitment agency to consult with the people at Brondesbury about how advertisements could be adapted to be more personal. John talked about his life, for example, describing things he enjoys and what he thinks makes a good support worker. This information was used to create a template for a personalised job advert and staff used a "matching tool" with each person being supported to see the sort of skills and attributes that new employees might offer to fit with individuals' wishes and interests.

Managers seek feedback from the people using the service before any position is advertised and the accessible recruitment process includes a questionnaire in a range of formats, so people can be more involved in the hiring of staff. The use of one-page personal profiles neatly captures the desires of each individual and is used to whittle down shortlisted candidates. The profiles state what people like and admire about themselves, what is important to them and how best to support them. This helps when Action on Hearing Loss looks at a job candidate's interests, skills and knowledge, allowing it to recruit the best person and make an appropriate match. Job specs and descriptions are changed each time a vacancy arises so people's current needs are met.

An example of a more person-centred job ad might include the fact that, if someone in the service has a desire to go swimming regularly and is also an energetic character, the charity would include this in the advert. Pam adds: "The adverts are also written in the first person for example 'I would like someone who is energetic and loves to swim to support me with my activities'."

During interviews, says Pam, the interaction between would-be staff and the individuals they are hoping to



support is a useful indication of how well they might get on. She adds: "The kinds of questions people want to ask include 'how will you help me keep my home safe', some can ask that directly, or use sign language, or we find a pictorial format to communicate the question. But the most important part of the interview is probably the interaction between the person and the interviewee, plus the feedback we get from them afterwards."

Among the challenges of involving people in recruitment, says Pam, is that some people might be anxious about change: "Aversion to change can be a problem, so we have spent a lot of time explaining the benefits of being able to choose support staff - explaining that while they will be professionals - not friends - they could have a shared interest." Action on Hearing Loss also looks at regular recruitment issues such as relevant experience, care industry qualifications, security checks and references. New support staff do not have to have a care and support background but must be able to demonstrate through their application, interview and interactions that they meet all of the requirements of the job.

The positive comments made to staff at Brondesbury Road about the new approach to recruitment proves its success. One person recently told Pam, "we really enjoy being part of the recruitment process as we can have people we really want working here." Involving people in the process of hiring staff breaks down barriers between employees and the people they support. As Pam explains: "A more personalised approach to recruitment can make a huge impact on a service - people feel more involved in their care and support and it helps to build their confidence and choice."

How to MAKE IT REAL for workforce issues:

- people who receive direct payments, self-funders and carers are supported in the recruitment, employment and management of personal assistants and other personal staff including advice about legal issues. People using council managed personal budgets have maximum possible influence over choice of support staff
- there is development of different kinds of workforce and ways of working, including new roles for workers who work across health and social care
- staff have the values, attitude, motivation, confidence, training, supervision and tools required to facilitate the outcomes that people who use services and carers want for themselves
- the workforce is supported, respected and valued
- there are easy and accessible processes to enhance security and safety in the employment of staff
- the formal and informal workforce is increasingly focused on and able to help people build and sustain community connections.

Extract from Making it Real, making progress towards personalised, community based support Think Local, Act Personal, 2012

Action on Hearing Loss key messages for MAKING IT REAL for workforce - my support staff:

- stay determined and focused - keep going even if it might seem as if your end goal is miles away
- keep a practical and resilient attitude - you are changing the whole dynamic of a service after all - recognise that you might not yet have achieved your aim, but it is as good as it can be right now
- involve as many people who use the service as possible, the harder you try, the more likely it will be that they will get involved.
- start small, talk about recruitment in community meetings with people who use the service, get feedback about the kind of staff people would want, ask how people would like to be involved giving examples
- use personalisation tools (such as TLAP's "Paths to personalisation") to engage people. Make sure you prepare people as much as possible using, for example, role play
- give rewards such as accessible thank you letters to the people who do get involved
- do not reinvent the wheel - see what existing materials there are to help you, the one page profiles, for example, can be used in a recruitment context
- change will happen and the more you do it the easier it gets. The benefits are huge, a happier work force people who love their jobs and staff who are well matched to the people you support. The people we support having a happier and more productive lifestyle.

For more information see: www.actiononhearingloss.org.uk



Dimensions is **MAKING IT REAL** with risk enablement: feeling in control and safe



Take away his support provider's commitment to the Making it Real drive, and 23-year-old Chris could easily be back in the secure, institutional care that he was in two years ago.

Without the Making it Real approach to managing risk, Chris would most likely still be displaying the kind of challenging behaviour that required round-the-clock care from three members of staff and multiple daily physical interventions. There would be little hope of change in the behaviour that led to the breakdown of his supported living tenancy, estrangement from his family and a nine-month stay in an assessment and treatment centre.

Yet today Chris, from West Yorkshire, is back in supported living accommodation, in a bungalow he shares with another man of a similar age. He is not physically aggressive, he sees his grandmother regularly and feels more included in his community. Based on 16 hours a day, his initial package of support was expensive but within three months, support in the community was reduced to 2:1 and in-house reduced to 1:1. Soon after, his support was reduced to 1:1 full-time. In the last year he has been on holiday to an activity centre, gone swimming, visited the theatre and enjoyed the odd pint in his local pub.

Apart from the quality of life improvement, from a local authority perspective, since care provider Dimensions took over his support two years ago, it has led to more than £130,000 savings a year.

Ask Chris what he likes about the changes in his life, and he will tell you he is keen on the fact that he only has one staff member at a time: "I like that I can pick my staff and only have staff I have chosen. I'm happy living here and I like my bedroom, it was a good thing to move here."

The improved outcomes - the fact Chris is happier, safe and poses no risk to himself or anyone else living in the community - reflects Dimensions' adoption of Making it Real, which complements the person-centred philosophy the organisation has established in recent years. Dimensions has used positive behaviour support strategies to reinforce its risk enablement work with Chris under Making it Real.

According to Making it Real, the notion of "feeling in control and safe" should involve several aims from the perspective of the individual. The checklist of desired outcomes includes specific statements:

- "I can plan ahead and keep control in a crisis"
- "I feel safe, I can live the life I want and I am supported to manage any risks"
- "I feel that my community is a safe place to live and local people look out for me and each other"
- "I have systems in place so that I can get help at an early stage to avoid a crisis"

Chris has achieved these outcomes. His story demonstrates how his support provider's approach has helped overcome his challenging behaviour, improved his wellbeing and led to savings for the local authority. The approach taken by Dimensions, which supports 3,000 people in England and Wales, is significant as the government wants to move people (individuals whose behaviour may be described as challenging) into more appropriate care.



Dimension's Making it Real action plan, drafted last year, includes a priority for service users to be in control of planning their own care and support and having opportunities to do activities that match their interests. These priorities link into its risk enablement work. One of the ways the priorities are achieved is through person-centred support plans (reflecting what people want to do, and who they want to be supported by when doing it) and by having a central contact within the organisation who oversees Making it Real progress.

That responsibility rests with Jackie Fletcher, executive director of quality and compliance. Jackie explains: "Having a choice and feeling in control of your support and what you do has a knock on impact on safeguarding. Chris has a say in his staff - we use one-page profiles to match staff to people they support - the more choice he has, the more decisions he feels he can make, the safer he feels, and the safer he feels, the more positive his behaviour is."

Jackie adds that it is important to have better ways to deal with the frustration or learnt behaviours often associated with not having the fundamental rights of choice and control. This sometimes requires additional help in the form of positive behaviour support, as in Chris's case, and the Making it Real framework reinforces that approach.

Nick Barratt, Dimension's lead consultant behaviour analyst, explains how Making it Real encourages positive behaviour support work: "The non-aversive approach emphasises understanding the reason behind the behaviour and reducing it through strategies that focus on skills teaching, lifestyle change and change in way the person is supported."

Nick and his 12-strong team of specialists disseminate positive behaviour support techniques to staff, model strategies and provide coaching. An important first step in the strategy, says Nick, is understanding the purpose or "function" of challenging behaviour: "A functional behaviour assessment is a procedure for gathering information on all the factors that contribute to a person's challenging behaviour. It allows us to generate a hypothesis about the purpose their behaviour serves."

"You have triggers and outcomes that set the context for the challenging behaviour, like someone going into supermarket, it gets busy, they're overwhelmed and need to leave. Once you figure out the context and understand the function, you teach the person a different way to get the outcome they desire. So, in the busy supermarket, maybe the person holds up a card with an exit sign on it, so the carer knows the environment is unpleasant and the person wants to leave. That is skills teaching component of positive behaviour support."

A major aspect of the support style involves reinforcing appropriate behaviour - for example, learning that if an individual says "no", this is an acceptable alternative to lashing out. It is a risk-reduction "no-pressure, patient approach", as Nick says.

In Chris' case, staff focus on reducing challenging behaviour and increasing his quality of life in line with the Making it Real statements. Strategies include offering Chris more control over his daily activities and training staff to recognise precursor behaviours and respond accordingly so any episode of challenging behaviour can be put to a close quickly and safely.

Involvement and choice when it comes to staff is also integral to the support. Chris, who Dimensions met after it successfully bid for a supported living service, has helped to recruit his own staff, introductions took time and worked at Chris' own pace (see the Action on Hearing Loss case study on workforce issues on page 8).

Chris has made strong connections with members of his staff team (a staff team he chose); there has been an increase in his assertiveness skills, he is very good at talking to the staff team about how he wants to be supported and by whom. If he gets upset, his initial response is to talk with staff about it, which is testament to the extent to which he trusts his team.

Chris has regular meetings with the service manager and also makes changes to his own behaviour support strategy. Recently, for example, he told staff how he wants to be supported if he gets anxious in the community - he will say "home", to which they must respond by bringing him home.

"Often behaviour that is deemed as challenging is a perfectly reasonable response to an unreasonable living situation - being forced to do things you don't want to do and feeling you have no say in what happens to you," says Nick. "Everybody has rights as citizens to a good quality of life and it's all about making sure that people with learning disabilities and autism who display challenging behaviour have the same opportunities as everyone else."

Dimensions' key messages for MAKING IT REAL for risk enablement - feeling safe and in control:

- use a one page profile and staff-service user matching tool to focus on someone's choices, interests and abilities
- invest time to really get to know someone and involve family and friends in an individual's support planning and person centred reviews
- maximize choice, control and decision making by involving the person in every aspect of their support, from recruitment through to staff appraisals
- positive behaviour support strategies and person centered thinking approaches should be fundamental elements of good support and learning and development opportunities available to staff.

For more information: www.dimensions-uk.org

How to MAKE IT REAL for risk enablement:

- people who use services and carers are supported to weigh up risks and benefits, including planning for any problems
- management of risk is proportionate to individual circumstances. Safeguarding approaches are also proportionate and co-ordinated so everyone understands their role
- where people want and need support, they are supported to manage their personal budget (or as appropriate their own money for purchasing care and support), and to maximise their opportunities and manage risk in a positive way
- good information and advice, including easy ways of reporting concerns, are widely available, supported by public awareness-raising and accessible literature
- people who use services and carers are informed at the outset about what they should expect from services and how to raise any concerns if necessary.

Extract from *Making it Real, making progress towards personalised, community based support Think Local, Act Personal, 2012*



Dudley borough council is **MAKING IT REAL** with active and supportive communities



Travel buddies for vulnerable people, disabled mystery shoppers on public transport, safe havens on high streets if people get lost on a day out and the pooling of personal budgets to offer more choice for people travelling around their local area.

These are among the possibilities being discussed in Dudley since the borough council adopted the Making it Real initiative last year. Its work shows how commissioners can adapt their approach to ensure the services they contract are in line with the wishes of the residents they support.

“Making it Real has given us the opportunity to bring stakeholders to the table,” says Justin Haywood, policy analyst for communities and resources. “Normally it takes a pot of money or a funding bid to do that, so the fact we are getting people from different perspectives - providers, families, users of community transport - to talk about the future, speaks volumes. There is no big pot of money, Making it Real is about organisations working differently and effectively to give people a better say in how they live their lives.”

Travel and transportation is one of the areas that the local authority is focusing its Making it Real work on. Access to effective affordable reliable and appropriate travel and a personalised approach to transport for disabled people is vital, according to Justin; if people can choose how and when to get about, they are more likely to get or remain involved in their local community.

“Travel and transportation form a golden thread throughout almost all the support work that Dudley council is doing with vulnerable people,” says Justin. He adds: “Unless you have an effective travel and transport system, all of the other stuff - people engaging in their local areas, having choice and control - cannot happen. Take personal budgets, if people want to spend their money in ways they really want, and truly be part of the community, they need to be able to get to events or activities at a time and manner of their choosing.”

Angela Pitchford, Dudley’s service manager for transport, elaborates: “Making it Real is about meeting and listening to individual needs, it’s moving away from the traditional concept of people being ‘bussed in and out’ of the local area, and towards recognising that there’s a lot more potential for people and their travel. We’re getting away from traditional expectations of door to door transport and trying to develop travel options to meet individual personalised wants and needs.”

As for the specific theme of “active and supportive communities - keeping friends, family and place”, says Angela, this means “helping people to help themselves and to remain part of community life...it’s about anything relating to promoting independence”.

The council describes the work so far as “aspirational”, stressing that it is groundwork building on the council’s Making it Real action plan. The action plan sets out a commitment to work with transport and travel services to promote accessibility and access. It also states that Dudley will place people who use services at the centre of its approach and raise the profile and public awareness of council services that promote independence.

In terms of outcomes so far, Dudley has invited users of social care services to events where they can talk directly to council officers, voluntary sector organisations and private companies - like bus firms - about how services can be more personalised.

The council has also established a transport steering group, the aim of which was to design and then act on feedback from the consultation and engagement event. The council is speaking to a number of disability groups including user led organisations like Disability In Action and Dudley Voices for Choice and Dudley Centre for Integrated Living. It is also involving third sector providers like Age Concern and travel group Centro.

Another plan involves developing, alongside library staff, the potential for the Dudley Community Information Directory to introduce customer ratings for travel providers listed in the directory. The Dudley Making it Real campaign also has its own YouTube channel, an attempt to make the approach more accessible and raise its profile. “We’re trying to be far more interactive and engaging with the local community,” says Justin. “We also have a specific website for Making it Real, separate to that of the council, because this isn’t just about the local authority but about a partnership project with the community and service providers.”

However, local government has a long history of consultation, so what makes Dudley’s current approach so different? Justin explains: “Critics would say councils have consulted and engaged people to boredom for years, and many events are simply token consultations. But this is direct and meaningful involvement, we are collaborating not just with the users of our services but their families and our local strategic partners such as the clinical commissioning groups and health and wellbeing board as well as local delivery partners such as transport companies and taxi services.”

Justin adds: “What sets our current engagement and involvement work apart from what’s gone before is the clear commitment to ‘You said - we did’ - local people being able to hold the council and other partners to account. It’s also about being honest - we won’t be able to do everything everyone asks of us. Where we can’t, we need to be open and honest as to the reasons why not, and then work with people to find alternative solutions.”

Dudley is working towards a number of targets set out by the Making it Real programme:

- “I have access to a range of support that helps me to live the life I want and remain a contributing member of my community.”
- “I have a network of people who support me - carers, family, friends, community and if needed paid support staff.”
- “I have opportunities to train, study, work or engage in activities that match my interests, skills, abilities.”
- “I feel welcomed and included in my local community.”
- “I feel valued for the contribution that I can make to my community.”



The consultation events so far have resulted in disabled people suggesting various ways to make travel and transport work better for them. There is, for example, the idea of the council and its providers offering more flexible travel so people can get about more easily - and choose to do so at the last minute - rather than book community transport in advance. The existing system largely involves minibuses on daily rounds, picking up at 9am and dropping off round 5pm.

Others want the current concessionary travel passes for disabled people to be changed because the existing system prevents them from travelling before 9.30am, for example, and they want to travel outside the allocated "core hours". One suggestion coming forward from users of services was the potential to top up their concessionary travel passes to unrestricted passes; and to explore the possibilities for adopting an electronic "Oyster style" travel card system, as used on London public transport, for easier use.

Another issue the council is exploring as a result of the consultation events, says Justin, is that the council and its various third sector partners have a fleet of minibuses that work solidly up until 9.30am and then again from 3-4pm, but tend to sit idle between those times. He explains: "So we're looking to encourage providers to work together to realise those assets that are sitting idle all day." One option could be a provider taking on the role of coordinating available travel services across the borough so transport can be offered in a more creative way and on demand.

Other local people with disabilities have asked about more and easily accessible travel training and those who want to build up their confidence on public transport have also raised the concept of "travel buddies". There has also been useful feedback at sessions where wheelchair users have offered simple tips to transport providers such as bus drivers not pulling away too quickly. It might seem like a simple point, but as disabled passengers have explained at the meetings so far, small solutions can make a big difference to someone's journey.

How to MAKE IT REAL for active and supportive communities - keeping families friends and place:

- people are supported to access a range of networks, relationships and activities to maximise independence, health and well-being and community connections (including public health)
- there is investment in community activity and community based care and support that involves and is contributed to by people who use services, their families and carers
- effective programmes are available that maximise people's health and well-being and enable them to recover and stay well
- longer-term community support and not just immediate crisis is considered and planned for
- a shift in resources towards supportive community activity is apparent
- systems and organisational culture support both people and carers to achieve and sustain employment if they are able to work.

Extract from Making it Real, making progress towards personalised, community based support Think Local, Act Personal, 2012

Dudley's key messages for MAKING IT REAL for active and supportive communities - keeping families friends and place

- involve local people so their input is not just tokenistic - aim to come up with workable solutions, don't just run a 'listening exercise'
- commit to a "You said - we did" approach to encourage local people to hold providers, including yourself, to account
- feedback to people as to what difference their involvement has made - however small - if you don't people will not see the point in getting involved in the future
- get the right people in the room, so not just your staff but service users, their families and local service providers
- think widely in terms of who to include - for example hospital transport is a big player in terms of transporting people to clinics and hospital appointments, health colleagues need to be part of the equation.

For more information: <http://www.dudley.gov.uk/resident/care-health/adult-health-social-care/do-you-want-to-get-involved/making-it-real-in-dudley/>



Sue Ryder is **MAKING IT REAL** with flexible integrated care and support: my support, my own way

Sue Ryder

Luke's family told Sue Ryder they have always been able to see the good care provided to their son, who has a brain injury. But since the charity changed its approach to reflect Making it Real, they said now they can see their son in the records - not just how Sue Ryder cares for him. They now see their son's personality and character reflected in his care and support plan.

Luke's care has become more personalised over the last year through Sue Ryder's adoption of Making it Real in its neurological care centres. The drive involves developing individual person centred support and wellbeing plans for people with highly complex needs. "If you can't see the person for the paper work," says Sue Ryder's Angela Killip, "there's something wrong".

Angela, the charity's quality manager and user involvement lead, describes the difference that Making it Real has made: "Before, much of the information that made a difference to Luke such as his likes and dislikes and aspects of his character was held in staff members' minds. Now it is embedded into his daily care."

Luke, 45, who lives in a centre in the north of England, sustained a brain injury after a road traffic accident in the 1990s. He has no speech and can only move two fingers of one hand. Yet, as Angela stresses, by working with his family on a support plan ("they took it home, scribbled all over it, wrote down his likes and dislikes") the charity is striving to follow his preferences. "We know how he likes his bed made, what he prefers to watch - he loves football but hates golf and soap operas. We know this from his family. If he doesn't like something, he grinds his teeth - while certain members of staff might have known this, it might not necessarily have been written down. It's all about capturing aspects of Luke's personality and incorporating it into his care."

Although there was nothing amiss with Sue Ryder's standards of care, the charity knew that its plans were, as Angela says, "too task-orientated and not enough about people". Support plans were a mix of information about the individual with clinical, health or care-related details around their daily living needs. The charity developed the new approach after thorough consultation with individuals in its neurological centres, their families, clinicians, and anyone else involved in their care.

Feedback from families and individuals, for example, led to changes in one section of the plans, which had been called "my life history".

Angela explains: "The my life history tool is meant to reflect aspects of someone's past to the present day - to help us know more about their lives - and their current needs. So the page begins with 'born' and further down states 'now'. People told us that the way it was presented made them think 'does that mean I'm going to die now or my life is over?' so we changed the tool and called it 'all about me'. This allowed the individual to tell us what they wanted us to know and gave them the opportunity to start with the here and now; a new road on their life's journey."

Sue Ryder divided information up into two sections - one showing the support plan, the other the health and wellbeing plan, so personal likes and dislikes could easily be referenced without having to sift through reams of medical detail. Angela says that the charity incorporated a simple question - "what makes an ordinary day a good day?" - into care plans after conversations with individuals and their families. This invites people to explain what really makes a difference - and this could be as basic as having cup of tea in bed or having a chapter of good book read to them.

The plans, which are reviewed immediately a change in need is identified or at least every six months, identify people's aspirations for the future of their care, as well as their clinical needs and are directly in line with aspects of Making it Real. From the individual's perspective, these goals are:

“

- "I am in control of planning my care and support."
- "I have care and support that is directed by me and responsive to my needs."
- "My support is coordinated, co-operative and works well together and I know who to contact to get things changed."
- "I have a clear line of communication, action and follow up."

The adoption of Making it Real, says Angela, has focused staffs' minds on the choices of the individual they care for. This can be as uncomplicated as choosing to Skype a relative at a certain time or preferring a bath to a shower and relates to the Making it Real integrated care marker of enabling people who use services to exercise choice over how they are supported (see box, How to Make it Real for flexible care and support). A challenge here is to manage expectation, for example, someone might not want a hoist to be used for support, but its use may be necessary. Here, says Angela, dialogue and negotiation with families and people supported is key.

The charity's hospital passport scheme, another part of the personalisation-led changes and part of the support plan, is in line with the Making it Real aim of streamlining processes to keep access to support "simple, rapid and proportionate to risk". It also picks up the Making it Real approach to joined up support, so people and carers do not experience delays in accessing support and there are minimal disruptions when making changes (see box on key messages, page 23).

The passport ensures that if the individual is admitted to hospital, admission staff have all the information they need to manage someone's care according to their needs and preferences. Angela explains: "This is essentially a quick emergency transfer form that gives basic information about how to keep someone safe, their preferences - how they likes to be washed or dressed, for example - and other issues which only people who know them well might know, for example if someone moves their leg a certain way or grinds their teeth, it can mean something,"



How to MAKE IT REAL for flexible care and support:

- people who use services and carers are able to exercise the maximum possible choice over how they are supported and are able to direct the support delivered
- support is genuinely available across a range of settings - starting with a person's own home or, where people choose, shared living arrangements or residential care
- processes are streamlined so that access to support is simple, rapid and proportionate to risk. Assessments are kept to a minimum, are portable, where possible, and do not cause difficulty or distress
- people who access support and their carers, know what they are entitled to and who is responsible for doing what
- collaborative relationships are in place at all levels so that organisations work together to deliver high quality support
- support is 'joined-up', so that people and carers do not experience delays in accessing support or fall between the gaps, and there are minimal disruptions when making changes
- transition from childhood to adulthood support services are pre-planned and well managed, so that support is centred on the individual, rather than services and organisational boundaries
- commissioners and providers of services enable people who access support to build their personal, social and support networks.

Extract from Making it Real, making progress towards personalised, community based support Think Local, Act Personal, 2012



The Making it Real drive, says Angela, has led to a major culture change: "We're saying the user of the service knows what's best in terms of how they're supported. Making it Real helps you focus on the person, it's about taking a step back and recognising - as obvious as it sounds - that when it comes to an individual's choice in care, they're the expert, not the professional providing the support."

Sue Ryder's key messages for MAKING IT REAL with flexible integrated care and support - my support, my own way:

- be open to feedback from staff, families and people you support
- specific "I statements" (see case study) help start off conversations with users of services and families
- listen to your service users and act on their advice - this is why the wording in our support plans was changed " my life history" became "all about me"
- get key people from frontline staff on board who are as keen as you - you are always going to get resistance to new ways of working, so find champions for change
- support staff through the process - for example, six monthly reviews once the new approach has launched, be on the end of the phone, offer video conferencing
- be realistic about time frames (our organisational change took a year) - it is massive cultural change, so give it time.

For more information see <http://www.sueryder.org>



Carers Trust is **MAKING IT REAL** with information and advice



“Fearsome” is the word used by one carer to describe the confusing amount of paperwork involved as she waited for her direct payment claim to be processed. The bureaucracy was bad enough, the woman told Carers Trust, but what made the experience worse was the scant information on the direct payment system and the lack of advice about how the claim was progressing.

Being overwhelmed by information or unsettled by the lack of it are, says Moira Fraser, Carers Trust director of policy, common challenges for carers seeking support: “Often, carers initially access support when they are crisis - things have come to crunch point - it’s too much when people throw information at you, you can’t pick out the important bits of detail and all you want is someone to go over relevant information face-to-face, for reassurance and support.”

The traditional service-led approach to social care - as opposed to the personalised approach - has meant that carers have not always received the right help or even been on the radar of care professionals.

Making it Real has the power to change that, says Carers Trust, which is signed up to Making it Real. “Making it Real is about ensuring that support is personalised not just towards individuals, but towards their families,” explains Moira, “it means we have a way of making sure the support offered is as meaningful to carers as it is to the person they care for.”

“Often, understandably, organisations focus on supporting the person with care needs, and carers are often seen as adjunct, as a provider of care rather than as an individual in their own right. But it’s unacceptable that both people with care needs and carers have to accept one-size-fits-all services that take no account of how they wish to live their lives. You should be able to choose the kind of care you want, when you want it, and provided by the right person.”

As for the specific information and advice goals involved in Making it Real, Moira says, these are particularly apt for carers:

- “I have the information and support I need in order to remain as independent as possible”
- “I have access to easy-to-understand information about care and support which is consistent, accurate, accessible and up to date”
- “I can speak to people who know something about care and support and can make things happen”
- “I have help to make informed choices if I need and want it”
- “I know where to get information about what is going on in my community”

A responsive, personalised approach to advice and information is vital if carers are to truly benefit from the Making it Real drive, adds Moira. “What carers say time and time again is ‘give me choice in how I receive information’ and the importance of that information being offered face-to-face is critical.” The aim is for all advice and information to be inclusive of all carers - including disabled carers, young or older carers, or those from ethnic minority groups.

To ensure that the carers’ perspective was fully embedded in Making it Real, the Carers Trust worked with Think Local Act Personal, the national partnership responsible for Making it Real, the Association of Directors of Adult Social Services and local carers organisations to produce a guide, Making it Real for Carers. Moira explains: “We felt that while Making it Real speaks to everyone, carers issues didn’t come out clearly enough; the aim was to complement Making it Real to ensure carers in their own right are in focus. All organisations - not simply carers groups - should be able to

Make it Real for carers. Making it Real for Carers has been co-produced with carers through workshops held in Lewisham, Durham and East Sussex. It explores how each Making it Real theme might look in practice. The document echoes Making it Real’s aims for information and advice, stressing that carers want “clear, consistent, coordinated information that is easy to access, and information giving to be a two-way process, where their voice is heard”. Making it Real for Carers also underlines the need for face-to-face support, “the right information at the right time”. The document includes the assertion that “if I am going to be in control as a carer, I need information about the choices available to me”.

There is also a practical checklist of items to ensure that information and advice is delivered in line with the Making it Real, this includes ensuring:

- information is easily available and easy to understand
- face-to-face contact to sort out problems
- carers are offered emotional support and someone to share concerns with (talking to another carer is helpful here)
- council and NHS staff who know the system 100 per cent
- regular reviews take a whole family approach, helping carers to consider their needs
- there is an information directory, catalogue of services and support and a list of helpful contacts
- confidentiality is not used as a barrier to communication with carers.

One example of good practice, as the document suggests, is for organisations to provide accessible online information - backed up by face-to-face contact. Durham county council’s online information guide, for example, is a database listing a range of services and providers. It includes a section specifically for carers, with details including emergency support and carers’ breaks. The information is also available in public areas such as post offices, leisure centres and cafes.

Carers Lewisham, a Carers Trust network partner, provides services for carers aged five upwards in Lewisham. It was among the groups that contributed to Making it Real for Carers. Diana Jones, Carers Lewisham chief executive, emphasises the role of personal contact for carers: “Although it’s important to have information in written form, the most important form is being able to provide direct help face-to-face or on the phone. When people first come to us, we often find they don’t where to turn to, how to cope and they feel their lives are lost. Having someone to talk to makes all the difference.”

Take Zena, says Diana. The lone parent of two boys with special needs was struggling to cope with the demands of work and her responsibilities as a carer and her employer was not “carer aware”, as Diana says. By the time she found her way to Carers Lewisham, she was on the verge of a breakdown.



"We just listened to start with," says Diana, "hearing what Zena was struggling with, then helping devise coping strategies and signposting her to services like counselling. We introduced her to support networks – group meetings and one to ones." As a result, Zena secured extra support for her sons in school that has allowed them to stay in mainstream education. She also got help with applying for grants and benefits and is thinking about going into further education. Diana adds: "If Zena hadn't had a tailor-made approach, with information as she needed it, given in a way that suited her best, she would probably have had a breakdown and the outcomes for her children would have been very different."

As Zena's story shows, a better focus on the specific needs of carers has an impact both on the carer themselves and the person they care for. "The most important thing is to get services to listen to carers properly," stresses Diana. "It sounds like such a small thing, but so many carers tell us 'you're the first people who really listened to me'. You have to remember that information alone isn't enough – you need to listen, value carers' concerns and support them to improve their situation."

How to MAKE IT REAL for information and advice - having the information I need when I need it:

- trusted information sources, are established and maintained that are accurate, free at the point of delivery, and linked to local and community information sources
- skilled and culturally sensitive advisory services are available to help people access support, and to think through support to think through their options and secure solutions
- a range of information sources are made available to meet individual communication needs, including the use of interactive technology which encourage an active dialogue and empower individuals to make their own choices
- local advice and support includes user led organisations, disabled people's and carers' organisations, self advocacy and peer support
- local, consistent information and support that relates to legislation around recruitment, employment and management of personal assistants and other personal staff is available.

Extract from Making it Real, making progress towards personalised, community based support Think Local, Act Personal, 2012

Carers Trust key messages for MAKING IT REAL for information and Advice - having the information I need when I need it:

- talk to carers specifically about what their information and advice needs are
- ensure your action plan is easy to understand so that a member of the public can understand it
- state clearly how carers have been involved in producing the plan and identify how they will be involved in reviewing progress
- try not to use any jargon or acronyms - these are confusing
- keep linking the actions back to the Making it Real for carers statements.



The Wilf Ward Family Trust is **MAKING IT REAL** with personal budgets and self-funding



Becky (not her real name) had never been on a mini break - let alone enjoyed a holiday with her boyfriend. Yet thanks to the Making it Real approach, the 35-year-old from Leeds not only enjoyed a “test run” supported break in the UK, but it was so successful that she went on to enjoy two weeks in Portugal with her partner.

The links to personal budgets comes from her choosing how to use her budget in an innovative way to access the support to learn these independence skills - the outcomes for her have been increased confidence, budgeting, travelling skills and much more independence to take control of spending her money.

The impact of her week away, says John Dossey, area operations manager of the Wilf Ward Family Trust for Leeds and Wakefield, which supports Becky, has been “massive”. John adds: “The positive impact on Becky’s life has been huge; she became a lot more confident – even after the trial break. She was telling us she wanted to go abroad, whereas before she wouldn’t have had the confidence to do that. Becky had choice and control in what she wanted to do; we used her personal budget in a way that supported her wishes.”

Becky says: “With support from Wilf Ward workers I have been able to live as independently as possible and access really wonderful holidays like going on an airplane to Portugal with my boyfriend and support worker which I didn’t think would ever be possible to do. I can’t wait till next year so I can decide which fabulous holiday to go on with support from my workers”

Had Becky, who has a moderate learning disability, not been supported in the person-centered way advocated by Making it Real, the outcome may have been very different. As John says: “She would have had some basic community-based support, a much more stagnant approach, as opposed to one where she was empowered to have choice, control and confidence to do things she really wants to do.”

Becky lives with her brother in a flat in Leeds. The Wilf Ward Family Trust supports her with, amongst other things, budgeting and life skills. When she and her boyfriend, who also has a learning disability, decided they wanted to go away together, staff helped her to explore the options.

John explains: “Becky had a certain amount of money and support hours available so we had to work with her to see how best we could support her to meet her aims. We have a flat we use as a short break service not far from where Becky lives, so we worked out what support she’d need to stay there a few days, how much money she had in her personal budget and how we could make it stretch to purchase transport and support hours.”

The four-day break was such a success that Becky began planning a trip to Portugal. This was an important step because Becky’s kitchen was being renovated and ordinarily, she would have just stayed in a bed and breakfast near her flat. Instead, Becky was able to plan and go on a two-week holiday to Portugal for the first time with her boyfriend and come back to a nice new kitchen.

John says the careful and transparent planning was vital. As well as the obvious safeguarding risk of an individual travelling abroad, there is the possible perception that care staff could benefit from a free holiday if the person they are supporting wants to go away. John adds: “You have to clearly show that an individual was fully involved and has made their own choice about where to go and how to be supported – that it’s not the person who’s supported simply paying for someone to go on holiday.”



Becky’s case followed the “I statements” that lie at the heart of Making it Real - she decided the support she wanted and how and where to receive it. She was also aware of how much money she had and had support to ensure that she could act on her wishes, using her money. The “I statements” for personal budgets and self-funding: my money are:



- “I can decide the kind of support I need and when, where and how to receive it”
- “I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it is my own money, direct payment, or a council managed personal budget)”
- “ I can get access to the money quickly without having to go through over-complicated procedures”
- “I am able to get skilled advice to plan my care and support, and also be given help to understand costs and make best use of the money involved where I want and need this”

John adds of the Making it Real way of working: “It’s a more focused approach to providing care and support. ‘I statements’ are vital because they ensure that organisations put their name publically to a method of support - organisations are more accountable. The statements make it easy to translate the work we do to the individual and ensure it is focused on what they expect.

“If you follow the ‘I statements’ you’re Making it Real for people - and it links it to all the other work around personalisation. Making it Real just puts a really good framework on the personalisation approach, it puts people in the centre of what we do and encourages their money to be spent in the way that they want it spent.”

John elaborates on the effect on Becky of achieving her dream of a holiday and being more in control of how she spends her money: “She comes in to our offices and is supported to use the computer, she is more confident in her interactions with our staff and instead of us explaining things to her, she asks questions more directly. She understands more the concepts of cost and savings.”

The experience, adds John, has been such a positive one, that Becky is excitedly planning her next trip.

How to make it real for personal budgets and self-funding:

- everyone eligible for on-going council funded support receives this as a personal budget. Direct payments are the main way of taking a personal budget and good quality information and advice is available to provide genuine and maximum choice and control
- council managed personal budgets offer genuine opportunities for real self-direction
- people who use social care (whether people who use services or carers) are able to direct the available resource. Processes and restrictions on use of budget are minimal
- there is a market of diverse and culturally appropriate support and services that people who use services and carers can access. People have maximum choice and control over a range of good value, safe and high quality supports
- people who use services and carers are given information about options for the management of their personal budgets, including support through a trust, voluntary or other organisation
- self-funders receive the information and advice that they need and are supported to have maximum choice and control
- councils understand how people are spending their money on care and support, track the outcomes achieved with people using social care and carers, and use this information to improve delivery.

Extract from Making it Real, making progress towards personalised, community based support Think Local, Act Personal, 2012



The Wilf Ward Family Trust key messages for Making it Real for personal budgets and self-funding:

- you should have a good relationship with the important people that support the service user to make decisions
- you should have a good relationship with the service users, care manager and other professionals this will make the best interest process more efficient
- you should keep a document trail to show how the person made that decision, it can be as simple as brochures - this will also help with future decisions
- when you deal with a personal budget, keep records on what has been done and why - people may change their minds about decisions and keeping a clear written record ensures transparency
- you should ensure there is ample time to plan which takes into account how the individual you are supporting communicates best interest - you may need to negotiate with the person to use some of their personal budget for staff time for a planning session
- Information is key, people need to understand their support plans, they need to know how much money is in the plan and how it is budgeted
- You should look at how the Making it Real approach fits into other areas of work or approaches - it is part of the personalization agenda, so tie them together so you have a cohesive approach.

For more information: www.wilfward.org.uk

Conclusion

MAKING IT REAL – transforming personalisation into reality

Personalisation is key to the modernisation of adult social care, but there is no single agreed path to success in implementing the agenda. Because much is open to interpretation, we risk huge inconsistencies in the delivery of personalised care.

Making it Real, however, is the cohesive, practical tool with which we can transform aspiration about person-centred support into action. It offers achievable markers of progress towards high-quality, tailor-made care.

This report highlights how Making it Real enables very diverse organisations to enhance the lives of people with a range of lifelong disabilities and care needs, from older people to adults and carers. The framework can be applied in a range of settings by care providers and by the people they support, by unpaid carers, by commissioners or by care professionals.

Making it Real enables organisations and individuals to reassess existing support, to earmark improvements and to develop new and publically accountable ways of working that transform the lives of vulnerable people.

Barriers to Making it Real

This is a voluntary movement for change; there is no obligation to embrace it, so we must be prepared to encounter - and break down - any barriers that may undermine the new approach:

Cost, for example, might be a concern - but the framework, as this report proves, does not need extra funding. Making it Real is, in fact, about efficiency. It encourages providers and commissioners of social care working with disabled people to consider how best to use money, and helps create a sustainable, long-term vision of care and support.

Reluctance from staff to sign up to “yet another initiative” might also prevent its wider adoption. Yet it is important to clarify how the tools are a world-away from the top-down, bureaucratic burden that might tempt some employees to be skeptical; Making it Real is co-produced and co-created with the individual.

Fear of cultural change can undermine Making it Real. Staff might be skeptical as to how the framework fits with the aims of their organisation and have concerns about additional tasks or responsibilities if their employer adopts Making it Real. To combat this, organisations should articulate the practical benefits, as described in this report, and explain how the solution-focused approach supports wider changes in health and social care (see Intro page 5). It is possible to connect the merits and aims of Making it Real to providers’ organisational remit or *raison d’être*.

Consultation fatigue might also put off individuals who are wary of being told, yet again, that they are “being listened to”. The key difference with Making it Real, as illustrated by Dudley’s story on page 16 or Carers Trust’s work on page 24, is that the approach involves not just listening, but actively hearing and then acting upon concerns. Making it Real transforms people into collaborative partners in their care and results in concrete actions. It is not a consultation exercise.

Action for stakeholders

Central and local government, providers, families, carers and individuals all have a role to play in promoting and carrying out the aims of Making it Real. The Association of Directors of Adult Social Services has, for example, already endorsed the framework but more organisations and sector-wide bodies should lead by example, sign up to the new approach and spread the word of good practice:

- **providers’** boards should consider adopting the framework and require regular progress reports from senior managers on how it is being used across their organisations
- **providers** can also encourage their peers to adopt the change
- **councils** can employ the programme when deciding what services and support individuals really want; they should consider how the framework might assist them in engaging with local citizens and in shaping local communities and explore Making it Real framework in thinking about market diversity and in producing market position statements
- **Clinical Commissioning Groups** (CCG’s) should consider using the framework as an assessment tool to support integrated care and co-production
- **user-led organisations** can use Making it Real to influence bodies such as Health and Wellbeing Boards and Health Watch
- **individuals** and **families** or **carers** can encourage their care and support provider to join the movement, reassured by the knowledge that they can check up on and scrutinize its progress.

A focus on the person

Making it Real is neither a national policy initiative nor an intangible vision for the future. It offers a practical, transparent framework for change, can be developed locally, adapted to reflect specific needs of people and places and is created in collaboration with families, carers and individuals themselves. It offers the sector an opportunity to make itself accountable to the very people it supports.

“The user of the service knows what’s best in terms of how they’re supported,” as Angela Killip of Sue Ryder so neatly puts it (see page 20). “Making it Real helps you focus on the person, it’s about taking a step back and recognising – as obvious as it sounds – that when it comes to an individual’s choice in care, they’re the expert, not the professional providing the support.”

List of organisations featured in this report



Action on Hearing Loss

Action on Hearing Loss is the charity working for a world where hearing loss doesn't limit or label people, where tinnitus is silenced and where people value and look after their hearing.

www.actiononhearingloss.org.uk



Dimensions

Dimensions provides personalised support to over 3,000 people with learning disabilities and autism. The not-for-profit organisation works with disabled people and their families in England and Wales offering a range of person centred services for children and adults, including those with complex needs or challenging behaviour.

www.dimensions-uk.org



Dudley metropolitan borough council

Transformation of adult social care is delivered through Making it Real in Dudley. The council works in partnership with the CCG and providers across all sectors, providing preventive services as well as ongoing care and support. This work encourages greater involvement from people who use services and their families and carers to improve care and support services.

www.makingitrealindudley.org



Sue Ryder

Sue Ryder provides incredible care for 16,000 people with life-changing illness each year in the UK, and much-needed emotional support for over 2,000 family members. It does this in its hospices, neurological care centres, in the community and in people's homes.

www.sueryder.org



Carers

Carers Trust was formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in April 2012. The charity works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. With its partners, Carers Trust aims to ensure that information, advice and practical support are available to all carers across the UK.

www.carers.org



Wilf Ward Family Trust

The Wilf Ward Family Trust was founded in November 1986 to give relief to carers through the provision of residential respite units and day facilities. Work began when founding Trustees Wilf and Phyllis Ward established Isabella Court in Pickering as a short break service for people with disabilities. The trust offers a range of services to children and young people with disabilities, adults with disabilities and older people.

www.wilfward.org.uk

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- Membership of the National Care Forum (NCF) reflects the wide diversity of care and support services provided by the not-for-profit sector. The NCF aims to improve the effectiveness of its members through the provision of information, policy analysis, knowledge exchange and representation to develop and deliver care services.



- Sue Ryder has over 3,000 staff and 9,000 volunteers based across the UK who are passionate about giving people incredible care in the way they want. By starting with the person as an individual with their strengths, characteristics, preferences and aspirations, they enable people to make choices about how and when they're supported to live their lives.



- The Voluntary Organisations Disability Group (VODG) is the national umbrella group for voluntary sector providers of social care services supporting adults with lifelong disabilities. The VODG's aim is to ensure that people with disabilities are supported in ways that they themselves define.