





making it real

how to do personalised care and support

"As a disabled person I want to lead an ordinary life and do not want to be defined or limited by my care and health needs. Making it Real does what is says on the tin and describes what good personalised care and support looks like. It should be taken up widely."

Clenton Farquharson MBE, Chair of Think Local Act Personal Programme Board

"Our world is increasingly one in which complexity is the norm and where people's needs are complex. Only when we provide care and support in combination with our colleagues in health and housing, that sees people in the round, can we better reflect this and ensure that personalisation becomes everyone's experience. Making it Real is an indispensable resource that can help achieve this and shows us what good looks like."

Glen Garrod, President of the Association of Directors of Adult Social Services (ADASS)

"Housing is essential to health and wellbeing. Without a suitable, secure, accessible home, in the right location, it is very difficult (or impossible) for a person to live an independent, active life, arrange personalised care and support, or achieve their potential. That is why the Housing LIN supports Making it Real, and would advocate the importance of Making it Real in housing."

Jeremy Porteus, Managing Director, Housing LIN "We are delighted that the updated Making it Real now includes a focus on health. I would urge all organisations serious about delivering personalised healthcare to make use of this fantastic resource."

Nigel Mathers, Co-Chair Coalition for Collaborative Care

"The NHS is on a journey to make personalised care business as usual across the health and care system. This will require a different relationship between people and professionals, with a shift in power and decision-making that enables people to have a voice and be connected to each other and their communities. Making it Real exemplifies this vision and is a practical tool that will help to achieve it."

James Sanderson, Director of Personalised Care, NHS England

"Skills for Care welcomes the publication of this easy to use Making it Real guide that will help services incorporate the principles of personalisation, and support a well-led, skilled and valued workforce so our fellow citizens have a life not just a service."

Sharon Allen, Chief Executive Officer, Skills for Care

"The development of Quality Matters, the sector-wide commitment to quality in adult social care, was founded on the principle that the voice of people using services, their carers and families should be heard and inform everyone's understanding of what good quality care and support looks like. The new version of Making it Real gives clarity and power to that voice and will really help to make a difference."

Andrea Sutcliffe CBE, Chief Inspector of Adult Social Care, Care Quality Commission

HOW TO DO PERSONALISED CARE AND SUPPORT

INTRODUCTION

Personalisation is rooted in the belief that people want to have a life not a service. Making it Real is a framework and a set of statements that describe what good, citizen-focused, personalised care and support look like from the point of view of people themselves.

The statements can be used to inspire and motivate organisations to keep getting better at what they do. They apply to a broad range of organisations, including those in health, social care, housing and the voluntary and community social enterprise sector as well as user-led organisations.

The framework is based on the following principles and values of personalisation and community-based support:

- People are citizens first and foremost.
- A sense of belonging, positive relationships and contributing to community life are important to people's health and wellbeing.
- Conversations with people are based on what matters most to them. Support is built up around people's strengths, their own networks of support, and resources (assets) that can be mobilised from the local community.
- People are at the centre. Support is available to enable people to have as much choice and control over their care and support as they wish.

- Co-production is key. People are involved as equal partners in designing their own care and support.
- People are treated equally and fairly and the diversity of individuals and their communities should be recognised and viewed as a strength.
- Feedback from people on their experience and outcomes is routinely sought and used to bring about improvement.

"Making it Real is not just another thing for organisations to do. It is a vision, inspiration and a guide that, if used in the way intended, will help people to lead their lives to the fullest."

Sally Percival, National Co-Production Advisory Group Making it Real has been co-produced with people who have experience of accessing health, social care and housing services and by Think Local Act Personal (TLAP) and the Coalition for Collaborative Care (C4CC). People with lived experience have been involved throughout, together with a large number of organisations. A working group, whose members are shown at the end of the document, has overseen the work.

WHO'S IT FOR?

Making it Real is relevant to people with care, treatment and support needs, including people of all ages with long-term conditions. It also applies to families, carers and young people moving into adulthood (in service terms often referred to as transitions, to cover the process of moving from children's to adult social care). It doesn't cover school education.

There are no named or specific conditions or labelled groups as these principles should apply to everyone. Throughout the document the terms personalisation and person-centred care are used interchangeably. Both are approaches that put the person at the centre.

The framework is applicable in a wide range of settings, including:

- home and community-based support (including NHS primary care)
- housing (including sheltered housing)
- residential care (including nursing homes)
- hospitals
- hospices
- other public services such as arts, culture, leisure and adult education.

There are specific audiences for the framework:

- people with care, health treatment and social support needs
- commissioners and providers across health, social care and housing
- local organisations, the voluntary and community social enterprise sector, selfadvocacy and co-production groups
- staff working in health, social care and housing at all levels (including professionally qualified) and people who work or volunteer in community-based organisations
- local partnerships across health, social care and housing
- local services such as leisure, culture and businesses
- national and regional organisations that do not directly provide services but play a role in regulation, improvement, training, qualifications and standards.

WHY SHOULD I USE IT?

The fundamental purpose of Making it Real is to support change and improvement by setting out what good personalised and community-centred care and support looks like. The guide will help you embed personalised support so that it becomes mainstream: the way we do things around here.

HOW IS MAKING IT REAL STRUCTURED?

Making it Real is built around six themes to reflect the most important elements of personalised care and support. Each theme has a number of I statements that describe what good looks like from an individual perspective. These are followed by We statements that express what organisations should be doing to make sure people's actual experience of care and support lives up to the I statements.

WHAT'S IN IT FOR PEOPLE?

- Making it Real can help individuals and groups to think about what's happening locally and to check how well their aspirations are being met and what needs to change.
- People can use the statements as a basis for a really good conversation with local services that focuses on making things better.
- It will also support co-production between people, commissioners and providers.

WHAT'S IN IT FOR ORGANISATIONS?

- Making it Real can help organisations that genuinely want to get better at personalisation to look at their current practice against the statements, identify areas for change, and develop plans for action.
- It can help organisations achieve a more positive and productive relationship with people who use services.
- It can help organisations to meet their legal duties and contribute to raising standards.
- For organisations that do not directly provide services, it can guide them in how to support the spread of personalised care and support.

Not all of the statements will be equally relevant to all people and organisations, and there will be some variation in how organisations use them within the overall approach.

Organisations and their staff have certain legal requirements which they must meet, for example around safeguarding. Making it Real provides a framework within which legal duties and responsibilities can be fulfilled through working in a person-centred way. Best Interest requirements should ensure that the principles set out in this framework apply where practicable and possible to people where reduced capacity has been established, or where there are legal restrictions or limited choices.

"We really like the I statements, they are specific and what everyone will relate to. The We statements are a good checklist as to whether we are meeting those priorities."

Hazel Brook, Wakefield Council

"We particularly welcome the We statements; these bring context to organisations and tangible examples of best practice."

Bethan McKenzie-Kerr, Action on Hearing Loss

HOW DOES MAKING IT REAL FIT IN WITH THE WIDER PICTURE?

First launched in 2012, Making it Real has been updated to take account of the Care Act 2014, with its emphasis on wellbeing, and growing importance of personalisation within health.

The framework also links with other areas that have a shared aim of developing personalised care and support.
These include:

 NHS England's 'comprehensive model for personalised care'¹, which aims to ensure that every person with a long-term condition has access to a care and support planning process in primary care. Also that the 5% of people with the most complex needs have access to integrated care and support planning through a multidisciplinary team, including access to a joint health and social care budget where appropriate.

- Developments to improve quality: the NHS Shared Commitment to Quality² and Quality Matters for social care.³ Making it Real is also consistent with the Care Quality Commission's objectives that health and care is person-centred, safe, effective, caring and responsive, and that services are well led and resources are used sustainably.
- National Institute for Health and Care Excellence (NICE) quality standards and guidance.
- Improving commissioning through the Integrated Commissioning for Better Outcomes framework developed by the Local Government Association.⁴
- Person-centred framework developed by Health Education England in partnership with Skills for Health and Skills for Care.
- C4CC's 'three Cs' their mission to change the health system, to ensure that co-production, community development and better conversations through care and support planning become part of business as usual in supporting people with long-term conditions.
- TLAP's wider work to promote and support the development of personalised and community-based approaches to care and support.

WHY IS CO-PRODUCTION ESSENTIAL TO MAKING IT REAL?

Making it Real is not a step-by-step toolkit or a rigid performance management framework. Organisations will need to decide for themselves how to make best use of it. The crucial element is that any work in support of Making it Real must be co-produced by people with lived experience and reflect the principles and values of co-production. By this we mean that people are involved as equal partners in designing their support and achieving outcomes agreed through a personalised care and support plan.

Co-production also recognises that people (and their families) have knowledge and experience that should be used to support improved planning and decision-making at the strategic level.

Information about the support available from TLAP's National Co-production Advisory Group (NCAG) to help organisations take up and use Making it Real is on the TLAP website.⁶

¹Universal, Personalised Care: 10 year delivery ambitions for England, NHS England, forthcoming.

²NHS Shared Commitment to Quality, NHS England, 2016

³Adult Social Care, Quality Matters, Care Quality Commission, 2017

⁴Integrated Commissioning for Better Outcomes: A commissioning framework, Local Government Association

⁵Person-Centred Care Framework, Health Education England, 2017

6www.thinklocalactpersonal.org.uk

LIVING THE LIFE I WANT, KEEPING SAFE AND WELL

WELLBEING AND INDEPENDENCE



Caroline Waugh, National Co-production Advisory Group

I STATEMENTS

- I can live the life I want and do the things that are important to me as independently as possible.
- I am treated with respect and dignity.
- I feel safe and am supported to understand and manage any risks.
- I am supported to manage my health in a way that makes sense to me.
- I have people in my life who care about me family, friends and people in my community.
- I am valued for the contribution that I make to my community.
- I have a place I can call home, not just a 'bed' or somewhere that provides me with care.
- I live in a home which is accessible and designed so that I can be as independent as possible.



- We have conversations with people to discover what they want from life and the care, support and housing that will enable this, without restricting solutions to formal services and conventional treatments.
- · We work with people to make sure that their personal plans promote wellbeing and enable them to be as independent as possible.
- We work with people to manage risks by thinking creatively about options for safe solutions that enable people to do things that matter to them.
- We know it can be helpful for people to share experiences so we encourage specialised support, peer support, self-help and self-advocacy groups.
- We welcome ideas about using personal budgets flexibly and creatively.

- We look for ways to involve people in their communities where they feel included and valued for their contribution.
- We make sure people feel safe and comfortable in their own home, which is accessible, with appropriate aids, adaptations, technology and medical equipment.
- We know that the place where people live, the people they live with, and the support they get, are important to their wellbeing and often interlinked. We have conversations with people to make sure we get all aspects right for them as individuals.

INFORMATION AND ADVICE

I STATEMENTS

- I can get information and advice that helps me think about and plan my life.
- I can get information and advice about my health and how I can be as well as possible – physically, mentally and emotionally.
- I can get information and advice that is accurate, up to date and provided in a way that I can understand.
- I know about the activities, social groups, leisure and learning opportunities in my community, as well as health and care services.
- I know what my rights are and can get information and advice on all the options for my health, care and housing.
- I know how to access my health and care records and decide which personal information can be shared with other people, including my family, care staff, school or college.

"Making it Real is about learning from listening and sharing what works. It is about having meaningful conversations and meaningful relationships."

Kathy Roberts, Association of Mental Health Providers



- We provide free information and advice to everyone, including people who arrange or fund their own support and care.
- We provide accurate and up-to-date information in formats that we tailor to individual needs, face to face if necessary.
- We talk to people to find out how much information they want and follow up to find out if they want more detail.
- We provide information and advice about health, social care and housing which is tailored to a person's situation without limiting their options and choices.
- We provide information and advice that reflects relevant law and/or clinical guidance.
- We provide information to make sure people know how to navigate the local health, care and housing system, including how to get more information or advice if needed.
- We make sure people know their legal rights and responsibilities.

- We tell people about person-centred approaches to planning and managing their support and make sure that they have the information, advice and support to think through what will work best for them.
- We provide information about what's happening in our local community and how people can get involved.
- We always include a contact name, telephone number and email address when giving advice or information electronically.
- We make sure we share information about what we do and how people can access our service with other relevant organisations so we can all work more effectively.
- We tell people about their rights to see their health and social care records and to ask for any mistakes to be put right.
- We get permission before sharing personal information.

KEEPING FAMILY, FRIENDS AND CONNECTIONS

ACTIVE AND SUPPORTIVE COMMUNITIES

"For all of us working to help personalised care and support to take root and thrive, a large part of our task must be to get alongside and to nurture the sorts of vibrant, diverse, supportive and inclusive communities that will enable all of us, including people with care and support needs, to be active, valued and empowered citizens."

Duncan Tree, Volunteering Matters

I STATEMENTS

- I have people who support me, such as family, friends and people in my community.
- I can meet people who share my interests and have the opportunity to join and participate in a range of groups.
- I feel welcome and safe in my local community and can join in community life and activities that are important to me.
- I have opportunities to learn, volunteer and work and can do things that match my interests, skills and abilities.
- I can keep in touch and meet up with people who are important to me, including family, friends and people who share my interests, identity and culture.
- I have a co-produced personal plan that sets out how I can be as active and involved in my community as possible.



- We make sure that people can keep in touch and meet up with their family, friends and people in the community who are important to them.
- We make sure that people have opportunities to make new friends and build relationships with other people who share their interests, culture and identity.
- We work in partnership with others to make our local area welcoming, supportive and inclusive for everyone.
- We work in partnership with others to create opportunities for people to work, both paid and voluntary, and to learn.
- We have a clear picture of all the community groups and resources in our area and use this when supporting people and planning services.

- We invest in community groups, supporting them with resources – not necessarily through funding – but with things like a place to meet or by sharing learning, knowledge or skills.
- We make sure that personalised care and support plans are co-produced and set out how people can be as active and involved in their community as possible, doing things that are important to them.

MY SUPPORT, MY OWN WA

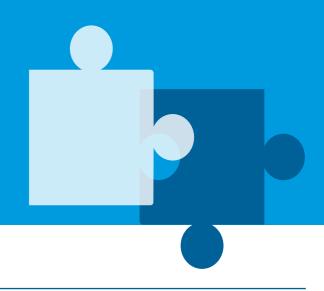
FLEXIBLE AND INTEGRATED CARE AND SUPPORT

"As someone who uses both health and social care, I want the best life I can have in the way that I want it. That's what Making it Real means to me, it's about people being supported to have choice and control."

Anna Severwright, Coalition for **Collaborative Care**

I STATEMENTS

- I have care and support that enables me to live as I want to, seeing me as a unique person with skills, strengths and personal goals.
- I am in control of planning my care and support. If I need help with this, people who know and care about me are involved.
- I know how much money is available to meet my care and support needs. I can decide how it's used – whether it's my own money, a health or social care personal budget, or a budget managed on my behalf.
- I have care and support that is coordinated and everyone works well together and with me.
- I can choose who supports me, and how, when and where my care and support is provided.
- I can get skilled advice and support to understand how my care and support budgets work and enable me to make the best use of the money available.
- I can get skilled advice and support to recruit and manage my personal assistants, whether I employ them or an organisation does.



- We work in partnership with others to make sure that all our services work seamlessly together from the perspective of the person accessing services.
- We work with others to agree a single, integrated personal plan and provide a named coordinator for people accessing more than one service.
- We talk with people to find out what matters most to them, their strengths and what they want to achieve and build these into their personalised care and support plans.
- We work with people as equal partners and combine our respective knowledge and experience to support joint decision-making.
- We tell people about their rights to advocacy and representation and make sure these services are available.
- We want people to be as involved as possible in writing their personalised care and support plans and provide help from people who understand the importance of personcentred planning.

- We make sure that people can rely on and build relationships with the people who work with them and get consistent support at times that make sense for them.
- We work flexibly to meet people's fluctuating requirements for care and support, enabling the flexible use of personal budgets over time and with minimal restrictions.
- We review people's personalised care and support plans with them regularly, focusing on whether they are doing the things they identified as important to them.
- We make sure that our organisational policies and procedures reflect the duties and spirit of the law and do not inadvertently restrict people's choice and control.



WHEN THINGS NEED TO CHANGE



I STATEMENTS

- I am supported to plan ahead for important changes in life that I can anticipate.
- When I move between services, settings or areas, there is a plan for what happens next and who will do what, and all the practical arrangements are in place before change happens.
- If I move from my home to another place, the people who are important to me are respected, listened to, supported and involved in decisions.
- If my medication has to change, I know why and am involved in the decision.
- I can plan ahead and stay in control in emergencies. I know who to contact and how to contact them and people follow my advance wishes and decisions as much as possible.
- I know what to do and who I can contact when I realise that things might be at risk of going wrong or my health condition may be worsening.

WE STATEMENTS

- We support people to plan for important life changes, so they can have enough time to make informed decisions about their future.
- We make sure that staff working in short-term settings or situations understand people's care, treatment and support requirements and work in a person-centred way.
- We talk to people during and after significant changes to find out if their requirements for care, support and housing have changed and to review their aspirations.
- We talk through changes in treatment or medication with people so they understand the changes and possible implications or side effects, seeing people holistically in the context of their life.
- We work with people to write a plan for emergencies and make sure that everyone involved in supporting the person knows what to do and who to contact in a health or social care emergency. We make sure that any people or animals that depend on the person are looked after and supported properly.
- We make sure that people, and those closest to them, know what to do and who to contact if their health condition, support arrangements or housing conditions are deteriorating and a crisis could develop. We respond guickly to anyone raising concerns.

"This will be a fabulous hospital discharge tool."

Chrissie Geeson, Suffolk County Council

THE PEOPLE WHO SUPPORT ME



WORKFORCE

I STATEMENTS

- I am supported by people who see me as a unique person with strengths, abilities and aspirations.
- I am supported by people who listen carefully so they know what matters to me and how to support me to live the life I want.
- I am supported to make decisions by people who see things from my point of view, with concern for what matters to me, my wellbeing and health.
- I have considerate support delivered by competent people.

"The I and We format is really helpful, as it will help front line staff translate principles into practice in a very tangible way."

Jane Lawson, Local **Government Association**

WE STATEMENTS

- We don't make assumptions about what people can or cannot do and don't limit or restrict people's options.
- We see people as individuals with unique strengths, abilities, aspirations and requirements and value people's unique backgrounds and cultures.
- We know how to have conversations with people that explore what matters most to them – how they can achieve their goals, where and how they live, and how they can manage their health, keep safe and be part of the local community.
- We have a 'can do' approach which focuses on what matters to people and we think and act creatively to make things happen for them.
- We keep up to date with local activities, events, groups and learning opportunities and share this knowledge so that people have the chance to be part of the local community.

MAKING A COMMITMENT

Our ambition is that Making it Real acts as an encouragement and resource to help embed personalised and community-centred support.

We want as many organisations and individuals as possible to publicly declare their commitment to Making it Real. The approach to making this commitment is flexible, so that organisations can choose what they want to focus on and work at their own pace.

INGREDIENTS FOR SUCCESS

When organisations commit, they must share their experiences for others to learn from, and be accountable for their commitments. These are the two most important ingredients for success, according to people who took part in the consultation.

THREE STEPS FOR GETTING INVOLVED

- 1 Develop and publicise your priorities via the TLAP website. Your plans for how you are improving good personalised care and support must be developed through co-production.
- **2** Share your experience, first making sure that what you say has been agreed and verified through co-production with people who access services.
- **3** Review progress and be open to feedback.

Details on how to register and get involved can be found on TLAP's website. The online resource includes stories from people and organisations who are using Making it Real to make a difference in people's lives. There you can be inspired by examples of good practice and share your own stories to encourage others. The website also contains information on the support available from the National Co-Production Advisory Group (NCAG).

In the spirit of this document we hope you will find your own way of using it and share your experience with us.

"I like to think of NCAG as our 'critical friends' – they told us the truth, held a mirror up to us and gave us support so that we can be better and make more of a difference to the people we support."

Graham Farrington-Horsfall, Lifeways

"I urge anyone who cares about people to embrace Making it Real. There's something in it for everyone."

Kate Sibthorp, National Co-Production Advisory Group

"Makes perfect sense."

Dr David Paynton, Royal College of General Practitioners

"Making It Real is about helping everyone to have ordinary lives."

Dame Philippa Russell, Carers UK

"CQC has been privileged to be involved in Making it Real. It is an incredibly useful way to support people in understanding what good and outstanding personcentred care looks like and what they should expect from providers."

David James, Care Quality Commission

THINK LOCAL ACT PERSONAL

Think Local Act Personal (TLAP) is a sector-wide partnership working to promote personalisation across social care, heath and housing by sharing learning and supporting innovation through networks, events and resources.

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COALITION FOR COLLABORATIVE CARE

The Coalition for Collaborative Care (C4CC) is a partnership of more than 50 national organisations working together to drive major change and achieve a better deal for people with long-term health conditions and their carers.

coalitionforcollaborativecare.org.uk

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TLAP and C4CC are sponsored by the Department of Health and Social Care and NHS England

ORGANISATIONS REPRESENTED ON THE MAKING IT REAL WORKING GROUP

- Alzheimer's Society
- Association of Directors of Adult Social Services (ADASS)
- Care Quality Commission (CQC)
- Carers UK
- Coalition for Collaborative Care (C4CC)
- In Control
- National Institute for Health and Care Excellence (NICE)

- National Voices
- NHS England
- Skills for Care
- United Kingdom Home Care Association (UKHCA)
- Think Local Act Personal (TLAP)
- TLAP's National Co-Production Advisory Group (NCAG)
- Volunteering Matters

A larger number of organisations were also involved through two summit meetings in 2017.

Our thanks and appreciation goes to everyone who has contributed to this project.

