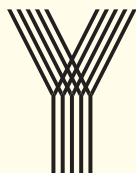# TOGETHER WE CAN

Exploring asset-based approaches and complex needs service transformation

Victoria Boelman and Catherine Russell
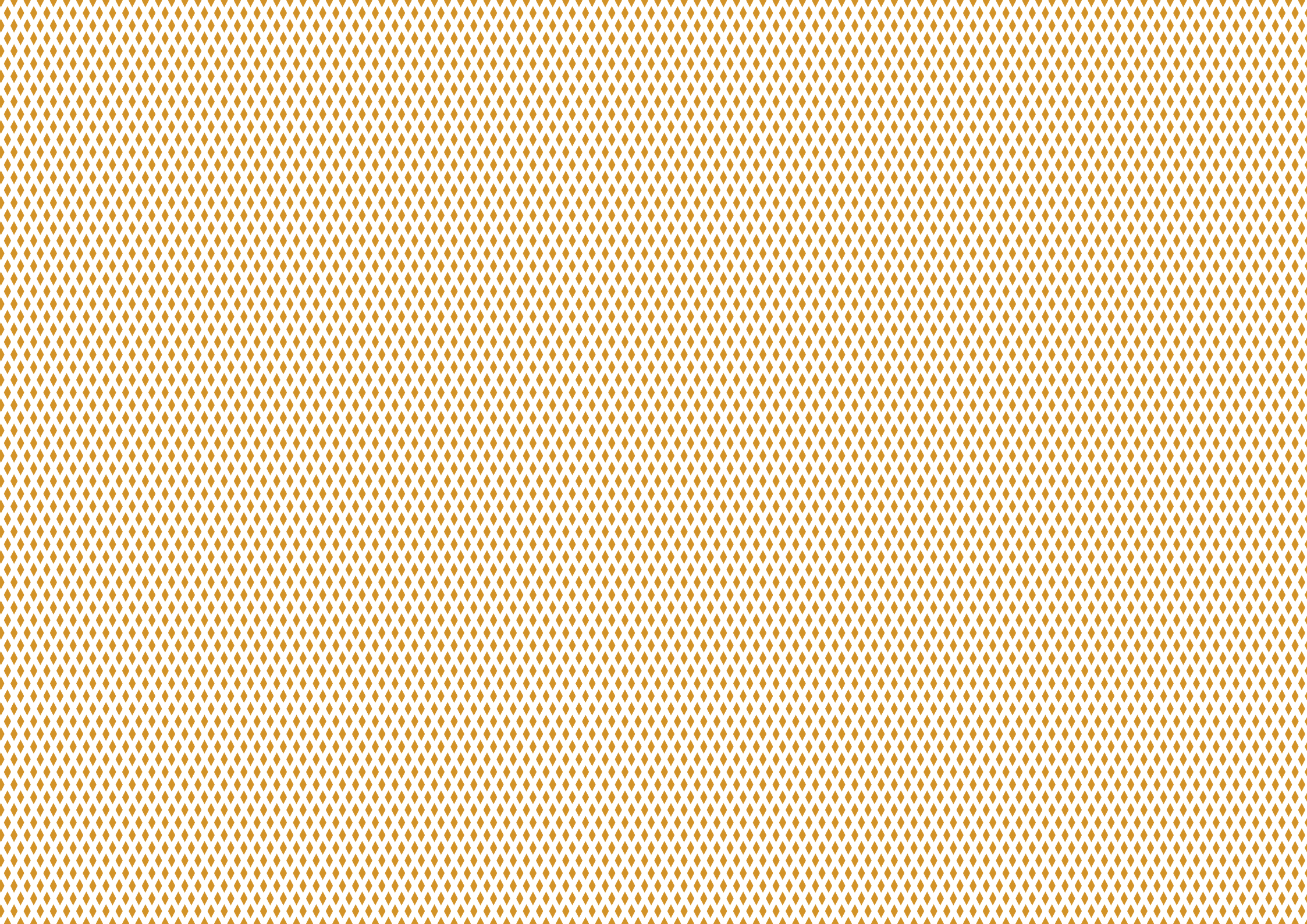
THE YOUNG FOUNDATION
THINKING
ACTION
CHANGE

SP!CE

"I need something which gives me that sense of purpose"
Research Participant

CONTENTS

ACKNOWLEDGEMENTS

FOREWORD FROM SPICE

Becky Booth
Chief Executive, Spice

Spice works with partners in health and social care and wider communities, using Time Credits as a tool to achieve co-production. Our model is simple: people receive Time Credits as a thank you for contributing time to their community or service. They can then 'spend' Time Credits to access events, training and leisure services, or to thank others in turn.

This report has grown out of our work with commissioners, support staff and service users across England as part of a Department of Health-funded programme to showcase Time Credits with local authority partners. Time Credits have shown great success when engaging people who are less likely to get involved in their service or community. However, our work in services that support people with complex needs came up against particular challenges. Time and time again we noted the potential for Time Credits in complex needs services, but equally we were aware of the very complex and diverse nature and structure of these services. Spice believes that everyone has something valuable to give, but the traditional service model in complex needs has tended towards a passive delivery model. What is the potential for asset-based approaches to enable people with complex needs to make an active contribution? This is what we set out to explore in this research – to understand people's lives, but also to look at the structural nature of service provision and to begin to map out a wider theory of change centred on individual choices and ambitions.

This report is inspired by and shaped around the lives of people with complex needs, and at its heart are the stories and experiences of eleven people. The profound insights and experiences that they share shine a light on the often hidden potential in this area of social care. This report puts a human face on complex needs services, reinforcing our similarities and humanising the challenges.

We chose ethnography over other research methods as it places individual service users' experiences and day-to-day lives at the heart of the research process. The research team spent time shadowing support staff and families as well as service users themselves to gain a nuanced understanding of services, the lives of individuals, and the interactions between services, home life and the wider world – whether that is in rural Wiltshire or inner London. They also interviewed key sector figures to gain further insights and recommendations.

What comes through again and again is how good many services are, but also how much more could be done as a sector and as communities to involve and include marginalised people. When services are designed with users and around their skills, assets and interests, they deliver enhanced outcomes – that much we know. The next challenge is to think about how we can do this at scale and how commissioners and communities can play key roles. It also raises some interesting and potentially exciting questions about what a service could or should be, who should deliver it and where.

At Spice we will be developing this work further over the coming years with partners and communities, and are excited about working with leaders, commissioners, users and staff across the sector to shape services that are flexible, enabling and connected to the wider community.

Finally we would like to extend a huge thank you to the research team, the individuals who participated, their families, service providers and the local authorities who participated in this research.

Becky

EXECUTIVE SUMMARY

A PRIORITY AREA FOR RESEARCH

Spice's work is based on the firm belief that everyone has something valuable to offer their community. Time Credits are used as a tool to engage people from across all walks of life and achieve co-production of services.

Spice already works in a wide range of community settings, including health and social care, but recognised that we need to work better in services that support people with complex needs.

This research grew out of a desire to address that challenge and understand the potential for asset based approaches to enable people with complex needs to make an active contribution to the services they use and the communities in which they live.

The research adopted an ethnographic approach, grounded in gaining a rich understanding of the lives of people with complex needs. Ethnography prioritises the experiences of individuals, hearing their stories and seeing the world in which they live. We shared in the daily lives of people, joining activities, visiting homes and services and meeting friends and family. We also spoke at length to the frontline staff delivering services and experts in asset-based approaches from across public, private and third sector organisations. A literature review placed our findings in the context of existing policy and latest developments in the field.

KEY FINDINGS

Our immersive and open approach helped us to identify a number of factors which shape the lives of people with complex needs. The core of this report addresses each of these themes in turn, reflecting first on the implications of these for services, and then exploring the potential for asset-based approaches to help transform lives and services.

Each person we met inspired us and taught us with their openness, passion and willingness to share. No person is defined by their diagnosis. However, the ability of individuals to follow their dreams is hugely dependent on the way in which their lives are structured.

Where and who someone lives with as well as the services they receive exerts a great influence on the amount of choice and support people have. It is no surprise that formal care settings – be they residential or day centres – typically run to firm timetables but we also found that home lives can be highly structured as well.

Inevitably, responses to the routines and structures in life vary significantly: While Tom craved routine and happily shared it with us, for others we met it is "boring" and "restrictive". A supportive key worker or family member are often instrumental in being able to break routines.

Like everyone, lives are also shaped by the practical logistics of life – how much money is available and how easy it is to get to where you want to be. For those with physical and learning disabilities, these challenges are particularly acute.

Opportunities to contribute and help others are often proactively sought out – from small gestures to more substantial activities – giving people an important sense of feeling a valued member of their community.

Indeed, for many of those we spent time with, participating in this research was an important way for them to make a difference – by giving voice to their "community" and standing up for their right to be heard. The honesty with which they shared their lives is testament to that, along with the many small but significant gestures, from "I've tidied up especially for you" to inviting us to dinner.

IMPLICATIONS FOR ASSET-BASED WORKING WITH PEOPLE WITH COMPLEX NEEDS

The literature review and our discussions with experts demonstrated that from a policy-perspective, the stage is clearly set for the adoption of asset-based approaches in health and social care, including explicit support for Time Credits and time-banking as a means of achieving this agenda.*

Our ethnographic research clearly shows that there is a gap between aspiration and reality, with a degree of uncertainty from many commissioners and service providers alike as to how these approaches can work with people who have complex needs.

Yet we also saw that people with complex needs are keen to have greater control over their lives and influence on the services they use. Many are also seeking out opportunities to make a meaningful contribution, and would welcome the chance to do more.

From the time we spent with people, it is evident that asset-based approaches could significantly transform lives.

We saw potential for people to be recognised for playing a greater role in supporting each other, being fully involved in co-designing service provision, and having control over their own schedule and the activities which fill it. For some there is enthusiasm to take on substantial responsibility and earn money, either for themselves or the benefit of a group.

We recognise, however, that this is not a simple shift for individuals and services. Implementing asset-based approaches requires time, sustained support from commissioners and service providers, and new ways of working and support for staff. Perhaps most importantly it also requires flexibility and creativity – a willingness to experiment with tools such as Time Credits, to share lessons and successes, and to use individual and organisational assets in new ways.

We conclude our report by setting out three important calls to action. We direct these equally to policy makers and influencers, commissioners and services. For it is only by working together in collaborative and integrated ways with people that true change will be achieved. We hope that the stories in this report will inspire you to take up those calls and rise to the challenge.

*HM Government (2012) *Caring for our future: care and support,* London: HM Government

INTRODUCTION

The NHS, celebrating 65 years in 2013, is what makes people most proud to be British.[1] Given a starring role in the 2012 Olympic opening ceremony, there is an expectation that we will continue to have a world-class health and social care service well into the 21st century and beyond. Yet to achieve that vision, the services of the future need to be radically different to what has gone before.

Our health needs as a nation are changing. Improvements in healthcare mean we are now living longer than ever,[2] yet these advances also bring new challenges. In particular, more people are living with long-term illnesses and increasing numbers of people have complex needs arising from severe and enduring problems or multiple diagnoses and support requirements.[3] To meet these needs, our health and social care systems must shift from being focused on acute care to the management of chronic conditions.[4]

At the same time, we are living in a society which places greater value on individual empowerment, blurring the traditional divide between professional 'experts' and passive service users. Patients are now recognised as experts in their own lives and conditions, with a valuable contribution to make in determining their support needs.[5] Co-produced patient-centred care is seen as best practice for new service delivery models.[6]

The traditional domains of care are also changing, with a move in policy to reduce the role of institutions such as hospitals and care homes. A progressive shift to community-based care will transform the lives of current and future generations.[7]

All this is taking place against a backdrop of austerity and cuts to services. The scale of the cuts, along with the changing landscape of health and social care, means that a radical rethink is required around service design and delivery. Many innovative solutions to empower service users are gaining traction. Some of the most common are the introduction of self-management programmes for long-term conditions, shared decision-making about care, expert patient programmes,[8] peer support programmes and time banking.

Commissioners and providers have a crucial role to play in promoting and funding the integration of asset-based approaches into service models so that they become the default way of working.

Yet when it comes to complex needs, our research showed that many commissioners and professionals are unsure about the ability of service users to contribute to shaping the services they use, or to wider society.

Our review of time banking and asset-based approaches across the UK showed that for the most part these innovations have been tried and tested among people with low to moderate needs or in mixed communities. In contrast, relatively few organisations have pioneered asset-based approaches or co-production of services with people who have the most complex needs.

It is this evident gap between policy and practice that we set out to explore. We wanted to understand the potential for asset-based approaches to enhance both the lives of people with complex needs and the services that support them.

As a result of this research, we believe co-production of services with people with complex needs is achievable and Time Credits in particular can be an effective tool to help bring about this change. Undoubtedly, though, there are many issues to consider. We set these out here but highlight most of all that by working with the unique skills and passions of each individual, there is huge potential to transform and enrich both lives and services.

This report aims to shine a light on the everyday lives of people with complex needs – the highs, the lows and the daily routines.

By doing so, we hope to highlight the potential for asset-based approaches to help transform lives and services, identifying both opportunities and the challenges along the way.

CONTEXT TO THE RESEARCH

There is no clear and simple definition of complex needs but the term is frequently used to indicate a high level of support need. Two core components are often considered to capture the essence of complex needs:[9] *Depth* – profound, severe and enduring problems; *Breadth* – multiple needs which are often inter-connected.

In this report we have chosen to focus on primary diagnoses of severe and enduring mental health problems, and moderate to severe learning disabilities. An initial scan of the literature revealed that these groups are relatively under-researched and represent a wide spectrum of needs, including those with physical, intellectual and sensory impairments.
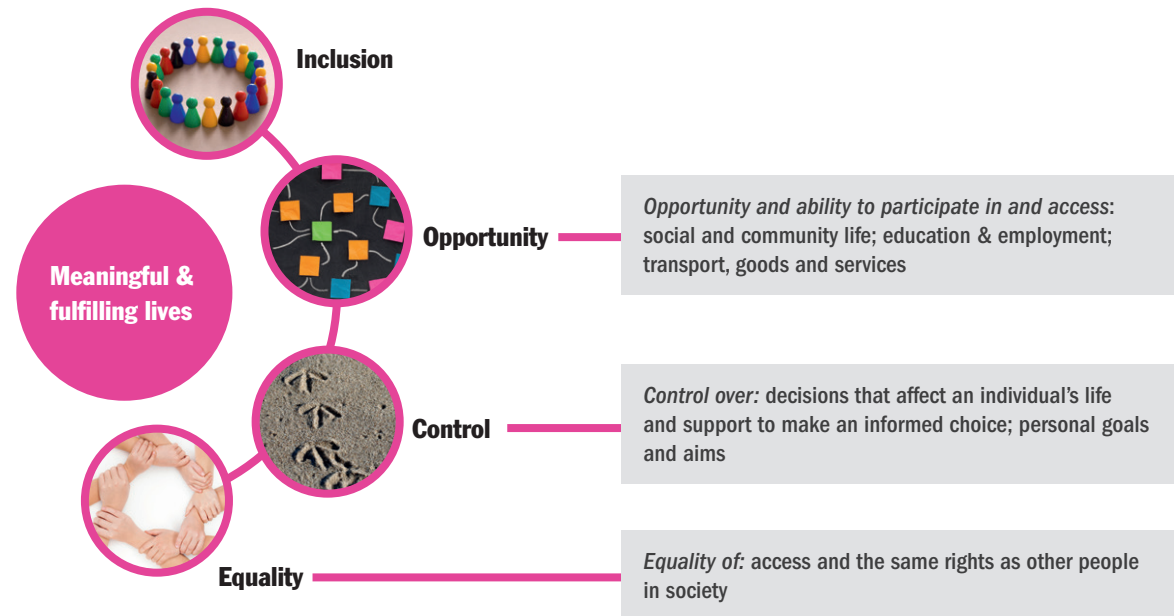
National policy around complex needs is increasingly orientated towards a holistic perspective on wellbeing and ensuring that health and social care services enable everyone to live a full and meaningful life.[10]

Individuals with learning disabilities and those with mental health problems each face unique challenges. However there are many similarities in terms of the underlying principles and expectations of best practice for care and support of those with complex needs across both groups.

> "Ensuring older people, people with chronic conditions, disabled people and people with mental health problems have the best possible quality of life and the equality of independent living is fundamental to a socially just society"
>
> **Department of Health**

Figure 1. Guiding principles for services and care

Opportunity and ability to participate in and access: social and community life; education & employment; transport, goods and services

Control over: decisions that affect an individual's life and support to make an informed choice; personal goals and aims

Equality of: access and the same rights as other people in society

Specific strategies for people with learning disabilities and those with mental health problems place individual needs at the heart of policy and service development. These include Valuing People, the 2001 white paper which set out a vision for people with learning disabilities, and No Health Without Mental Health,[11] which recognises that although clinical symptoms of a mental health condition may never disappear, a 'meaningful and satisfying life' is attainable.[12]

Leading experts and third sector support and advocacy organisations – including Scope, Foundation for People with Learning Disabilities, the Mental Health Foundation, Mind, Rethink Mental Illness and the Centre for Mental Health – also prioritise the needs of the individual in guides to best practice and outcomes for the people they represent.

Across the fields of both learning disabilities[13] and mental health[14,15,16] there is a clear focus on four core areas, as set out in Figure 1. These are social inclusion, opportunities and independence, personal control, and equality.

In the wider health and social care context, a number of solutions and approaches have been adopted to try to embed these principles into practice.

In particular, there is a shift of focus from deficits and needs to assets and capabilities. This means recognising what people can do, and building on this to help enable them to have a good quality of life.

Much of this is embodied in the concept of person-centred planning, and the personalisation of the care agenda also reflects many of these principles, for example through direct payments and personal budgets.

Yet although some progress has undoubtedly been made, there remain concerns that this shift in focus has been slower to reach those with more critical needs. For example, individuals who have a severe learning disability have been identified as failing to benefit as much from the strategies arising from Valuing People, compared to those with less complex needs.[17]

Others we spoke to, including those working on the frontline of disability services, identify a clear disparity between the rhetoric and the reality:

> "For people with quite high support needs the challenge is to change the way people see you. They see you in terms of your deficits, your support needs, they're frightened, put off"
> **Grapevine, a Learning Disability Community Project in Coventry**

ASSET-BASED APPROACHES

Assets are the skills, resources, knowledge or capacity that exist in individuals or communities, and these can be used to enhance or sustain health and wellbeing. Asset-based approaches place value in these strengths, promoting connectedness, reciprocity and social capital and the ability of people themselves to contribute.

In contrast, the more familiar 'deficit' approach focuses on the problems, needs and deficiencies. It designs services to fill the gaps and fix the problems and can lead to disempowerment and dependency.[18]

A FOCUS ON CO-PRODUCTION

One of the most widespread asset-based approaches is co-production. According to the Co-production Network it is about:

> "Delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours"

Asset-based approaches and co-production of services are widely considered to be best practice in health and social care.[19] In the white paper 'Caring For Our Future: Reforming care and support', the Government recognises their value as a way of strengthening support within communities and encouraging networks of support, with the overall aim of improving health and wellbeing.

It sets out the expectation that commissioners will build these principles into their Joint Strategic Needs Assessments and Joint Health And Wellbeing Strategies.

The white paper also explicitly acknowledges the value of approaches – such as peer support networks, projects building inter-generational relations, and time banking – in building supportive networks, trust and improving connections in local communities. A sense of reciprocity and being equally valued are further benefits.[20]

There is a growing body of evidence exploring the relationship between health and wellbeing and volunteering, with most studies indicating a positive relationship, including higher levels of self-esteem and self-efficacy, and reductions in depression.[21,22,23]

> "People have enormous amounts to give to their communities in enthusiasm, ideas, experience, time, skills, talents and leadership. We want to make it easier and more attractive for everyone, regardless of age or ability, to contribute to their communities and provide a helping hand to those who need it"
> **Caring For Our Future**

> "I think that commissioners are frightened of the public's involvement. We're stuck in a groove and it's very difficult […] There is perhaps a fear that if you take the genie out of the bottle, you won't be able to get it back in again […] you let people into the decision making process, messing about with money and direction of travel. Once people get a taste for a new way of working, you won't be able to say 'well we won't do that again'"
> **GP; Patient and Public Involvement Lead**

Co-production, however, is much more than simply volunteering. Its principles of equality and reciprocity, with traditional service users and providers working together as peers, have the potential to truly transform services and the way in which they are delivered.

Research is beginning to show that shifting to co-produced services brings in more human resources, reduces strain on services and prevents problems in the longer term, leading to cost savings.[24]

However, 'co-production' is not without its critics. Most people welcome the concept of co-production, but some are concerned over the frequent misappropriation of the term as it has become commonplace jargon.[25]

There can also be a stark tension between stated ambition at a strategic level and the reality in terms of commissioning and developing services. Many services are inherently risk averse and in the face of constrained budgets can be unwilling to trial approaches without a proven track record.

This challenge is one that many service providers attempting to introduce asset-based ways of working recognise all too well, particularly for those with the most complex needs.

"Commissioning attitudes are changing [...] but we always get asked, 'what about the really vulnerable people?' Like they can't quite believe that everyone has something to offer, or they can't dare to put public money behind it in such a way"

Circles Network

However, some commissioners and service providers have embraced asset-based approaches. There is clear evidence from our interviews that with a strategic approach, persistence and a willingness to innovate and experiment, co-production in complex needs settings is achievable and delivers benefits for all parties.

South London and Maudsley NHS Foundation Trust (SLAM) is an excellent example of an NHS trust which places a high strategic priority on asset-based approaches.

In practice, this has involved committing to a number of innovative projects.[26] These include acting as a lead partner in the Lambeth Living Well Collaborative,[27] a consortia of service users and providers, and looking to transform mental healthcare in the borough into a genuinely co-produced and co-delivered service.

Other projects include the establishment of a peer-led Recovery College, setting up time banks, and training clinicians in asset-based approaches to clinical decision-making.

TIME BANKING

Time banking is one mechanism that was developed by Edgar Cahn[28] specifically to unlock the hidden assets of individuals who had hitherto been seen simply as service users.

Spice Time Credits grew out of time banking approaches and work through organisations to encourage participation in communities and services. People 'earn' a Time Credit for each hour they give, and can 'spend' them on a wide range of leisure and other opportunities.

Earning and spending Time Credits gets more people involved, builds social networks and makes a positive contribution towards people's quality of life. Crucially, Time Credits can also act as a mechanism to achieve large-scale participation in the co-production of services. Spice's health and social care work, funded by the Department of Health, is exploring how Time Credits can support the shift towards co-production in a wide range of health and care services, including some that support people with complex needs.

Figure 2. Spice Time Credits model

EARN

Give 1 hour of time to help your community

Get 1 Time Credit worth 1 hour

SPEND

on an activity at the place where the credit was earned

on other local activities and opportunities

as a gift or thank you to someone else

somewhere else in our UK network

RESEARCH OBJECTIVES

Our starting point was the premise that in the future, expert commissioning must place a high strategic priority on asset-based approaches in order to deliver high quality, co-produced services which empower those with complex needs to live life to the full and receive excellent standards of care.

The policy environment to support the implementation of asset-based approaches is clearly in place. Making sure health and social care services work together is also a high priority for government.[29]

However, that is not to ignore the challenges and we recognised from the outset that the sheer number of contacts an individual with complex needs is likely to have with different organisations compounds the complexity. The multiple agencies from statutory, voluntary and private sectors who may be involved in the care and support of one individual are shown in Figure 3.

Our review of the literature and discussions with experts uncovered relatively little evidence that policy is translating into widespread practice or real impact on the daily lives of people with complex needs.

There is a danger that setting out these ambitions will raise expectations but failure to deliver in practice will then result in people feeling disempowered and disengaged.

It is this gap between aspiration and current provision that we wished to explore further, with a view to understanding if and how asset-based approaches can be used to improve the lives of people with complex needs and the services they use.

Figure 3. Multi-agency environment for people with complex needs
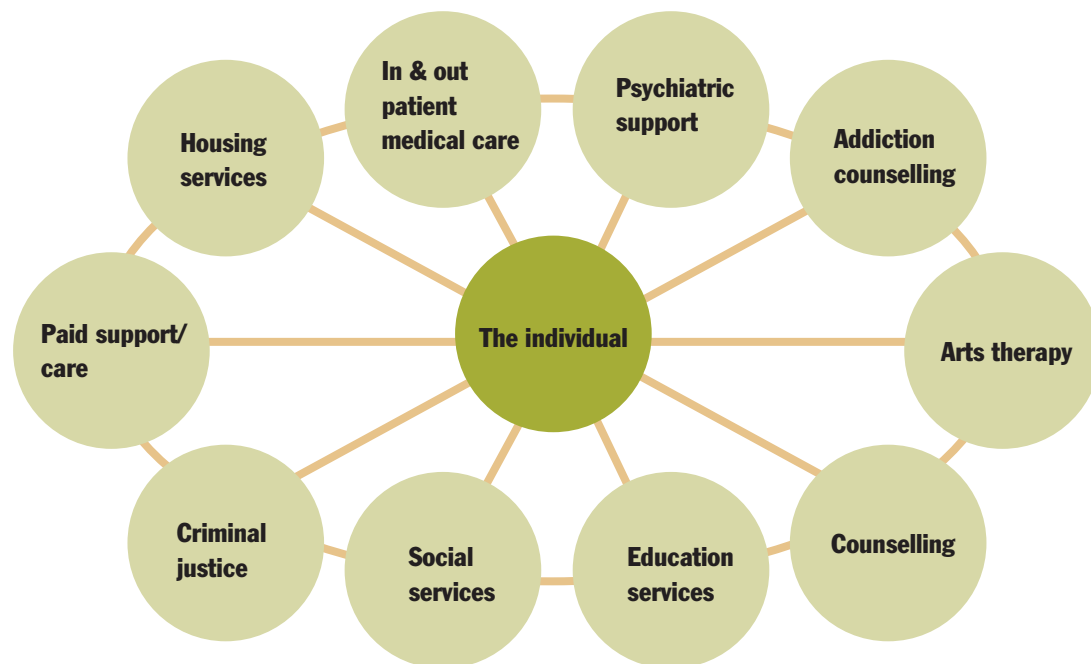
METHODOLOGY

The aim of this research was to explore the potential for asset-based approaches to enhance both the lives of people with complex needs and the services they are supported by.

We achieved this by gaining an in-depth understanding of peoples' lives and experiences at home, in services and in the wider community. The richness of this information was then analysed in the context of current policy, practice and evidence.

Between March and June 2013 we explored the lives of people with multiple and complex needs. Our research took place across Wiltshire, Kent and several London boroughs, and included:

- 11 ethnographic 'day in the life' visits – five with people with severe and enduring mental health problems, and six with people with moderate learning disabilities
- 13 in-depth interviews with experts from third and public sector organisations
- Informal discussions with staff from six day centres and residential facilities which we visited as part of the study
- A review of the literature relating to asset-based approaches and time banking with people with complex needs

In line with the ethos of enabling individuals to shape and share their stories as they see fit, we adopted an ethnographic approach to this research. Our priority was to understand the lives of people with complex needs from their perspective, with no pre-defined agenda or fixed hypothesis. What shapes and defines their choices? Who matters? What makes a good day and what makes a bad day? By understanding the bumps in the road, the bright spots along the way, and the hopes and aspirations for the future, it is possible to identify the opportunities and challenges that lie ahead.

Ethnography is a research approach which allows us to observe and participate in people's lives as well as talking to them. The ethnographer interacts not just with the individual

but also those around them in daily life – family, friends, acquaintances and staff. We believe that the best insight is gained by putting the people we wish to understand at the heart of our research, and being open to the unexpected.

Ethnography is a non-prescriptive method which allows us to adapt our approach to each individual. This is particularly important for those with complex needs and enabled us to use a range of techniques to facilitate participation.

The rich ethnographic stories we have collected form an important source of evidence. In our analysis, we combined this with the understanding gained from the literature review and speaking with service providers, commissioners and other experts. Together they provide a compelling insight into the lives of people with complex needs and the transformational potential of asset-based approaches.

HOW TO READ THIS REPORT

Spending time with someone and sharing in the day-to-day routine of their lives allows us to meet the people, visit the places, and see the activities and objects that matter, through the eyes of each individual. It also highlights the structures which make things possible, as well as those which are barriers to opportunities and integration.

A brief overview of the people we spoke to is overleaf. Fuller versions of their stories are in the appendix to this report, available online.

Through our research we identified eight main factors which shape the lives of people with complex needs. These themes are overarching and affect the lives of everyone albeit in differing ways and to a greater or lesser extent. The core of this report draws out the rich complexity of these factors, illustrated with examples from the people we met.

At the end of each section we have included a 'key points' box:

This is a summary of the main points that are important to hold in mind when reading the remainder of the report and thinking about how asset-based approaches can work with people with complex needs.

The report concludes by considering the potential for asset-based approaches, and Time Credits in particular, for increasing co-production of services. We highlight areas of opportunity and challenges to implementation for those with complex needs, and finish with a call to action for key players in the sector.

Figure 4. Example of a 'my life' map created by one of the participants with severe learning and communication difficulties

Figure 5. Overview of factors shaping the lives of people with complex needs

Social networks

Routine and choice

Getting out and about

Relationships

Individuality

A sense of purpose and worth

Place

Passions & experiences

Money

THE LIVES OF PEOPLE WITH COMPLEX NEEDS

These are the 11 people who shared a day in their life.

Full summaries of their stories can be found in the appendix to this report.

Available at www.youngfoundation.org and www.justaddspice.org

SARAH

Sarah is in her mid-30s and lives in a residential facility in central London. She has schizophrenia.Her priority is to stay well and move into a more independent home. She is very friendly and loves 'girly' things.

DAVID

David lives in a centre for people with mental health problems in London. He has schizophrenia but rejects the diagnosis. He has no family or friends in the UK. He loves sport and keeping fit and hopes to train as a gym instructor.

ANDREW

Andrew is settled in his current home in London but would love to get out and about to do more. He has bipolar disorder and loves the music therapy sessions he attends. He is close to his family and loves opportunities to do new things.

NICOLA

Nicola lives in Kent. She is married with two young children but her girls are currently in care. She has bipolar disorder and is a recovering alcoholic. She hopes to regain custody of her children and share some of her hobbies and passions with them.

BRADLEY

Bradley lives in accommodation for men with mental health problems. He has schizophrenia. He likes to stay in touch with his family and visits his nearby niece regularly. He would love to return to work but has recently experienced heart problems.

JOSIE

Josie has recently moved into a flat where she lives more independently but with support. She attends college, loves swimming and enjoys being active. One day she hopes to gain employment and is starting a work experience placement.

JOHN

John lives at home with his parents in a small rural village. He has a moderate learning disability.

He is passionate about cars and F1 racing and loves to spend time helping his Dad repair vintage vehicles.

TOM

Tom has recently moved into a supported living flat. Due to his complex range of conditions he receives a lot of individual support. He loves music and sport and his routine is very important to him.

MARY-LYNN

Mary-Lynn lives with her mother and brother in a small rural town. She has complex learning disabilities. She loves animals and enjoys a wide range of activities at the day centre she attends. She makes friends wherever she goes.

ROBERT

Robert lives with his mother in London and has severe learning difficulties requiring a high level of support. He enjoys a wide range of activities, often through a day centre, but will change group depending on his mood.

CLAIRE

Claire is in her 20s and lives at home with her mum. She has physical and learning disabilities but is very outgoing. She is very impulsive and changes her mind often, but has ambitions to spend much more time out and about doing new things.

'TREAT ME AS AN INDIVIDUAL'

A diagnosis is not what unites people. Everyone we met has their own likes and dislikes, skills, abilities and limitations.

For example, David and Andrew have very different diagnoses (schizophrenia and bipolar) but both want to be active and doing things; Sarah, however, also has schizophrenia but is happy to spend the majority of her days in her room.

The differing nature of learning disabilities and mental health problems also impacts on an individual's ability to engage with the opportunities on offer. Crucially, the majority of people with learning disabilities have relatively constant conditions, which in turn leads to relatively stable lives.

The landscape of service provision for those with learning disabilities is changing however, with a progressive shift away from day centres and towards community integration and independent living.[30]

Despite this, people are generally able to make commitments in the expectation that they will be able to participate for the foreseeable future. That said, some of those with the most profound disabilities lack the cognitive understanding of commitment and will only engage with an activity as and when they feel like it.

In contrast, individuals with severe and enduring mental health problems may often experience fluctuations in their wellbeing, and some will have regular crises or be readmitted to hospital. Medication to control conditions may result in drowsiness, reduced alertness or have other side-effects such as an impact on physical health.

Many mental health services also now have a policy of trying to progressively move people on from residential facilities after two years, each time into a more independent style of living. As a consequence of these changes, the ability of an individual to make specific commitments can be more

Nicola is currently in the middle of a mental health crisis. Her three daughters have been taken into care and she is determined to recover so they can return. Despite this, her condition and situation means that some days she can do little more than lie in bed and cry.

Liam attends the same day centre as John and Mary-Lynn and has profound and multiple learning disabilities. At the day centre he attends, his participation in activities depends on his mood of the moment. At times he enjoys getting involved and is keen to help, for example tidying up after art class. At other times, he simply refuses to engage with anything at all.

limited. What is easy one day may be impossible the next. Mood disorders themselves may also affect inclination to participate.

As would be expected, age is also a great shaper of wants, needs and preferences but in the context of complex needs, it also plays a more influential role. The radical changes in health and social care over the last 40 years mean that younger people with complex needs today are likely to end up in a very different place to an older person today with the same diagnosis. This is particularly true for people with learning disabilities who are now encouraged to lead far more independent lives than was typically the case previously.

Nonetheless, while some of the themes and issues uncovered may manifest themselves differently between people who have mental health problems and those who have a learning disability, or between younger and older individuals, there is also a significant amount of overlap in the challenges faced.
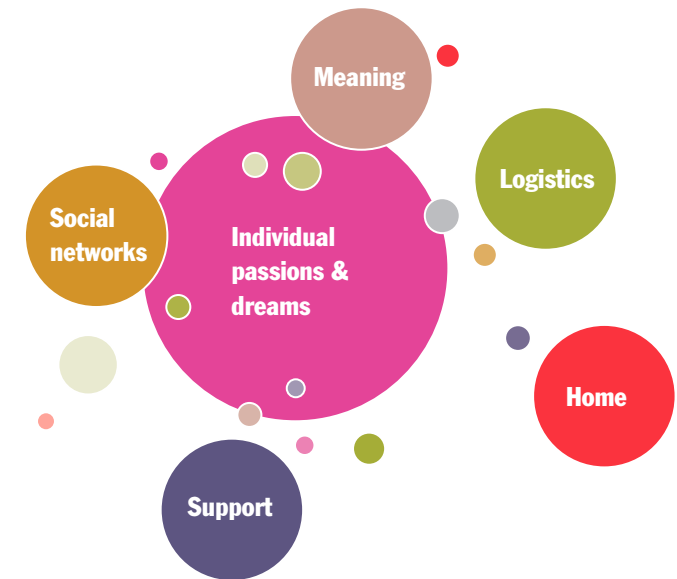
KEY POINTS

- People with complex needs are unique individuals. Diagnosis is not what defines people – two individuals with the same condition may have very different needs, preferences and aspirations.
- Age plays an important role in experiences of care and determining personal priorities.
- The fluctuating nature of mental health problems contrasts strongly with the relative stability of a learning disability. People may have times when they are more stable and able to commit to activities, while at other points they may simply be too unwell.

PASSIONS AND EXPERIENCES

Everyone we met is passionate about something – be it makeup and clothes, animals, cars, music or sports. Often passions and interests have been life-long and enduring. Those with mental health problems in particular tended to recall things they enjoyed in their youth or have retained an interest or hobby from a happier time in their lives.

One of the most common interests relates to sport, often seen as providing an escape from every day life. For example, Claire loves swimming as it is one of the few times she is able to get out of her wheelchair, while Sarah recalls being an excellent swimmer in her youth. Swimming is a popular activity with many of the people we met.

Music is also a popular passion. Andrew used to busk when he was homeless and now regularly attends music therapy sessions. These are the "top point" of his week, giving him the chance to interact with people through music. Tom, on the other hand, is rarely seen without his headphones and MP3 player, often singing along to Abba or Michael Jackson. Many of those we met like to get together, listen to some music and maybe sing and dance.

> "I miss it desperately [...] It cleaned my mind. People would become dots on the horizon; the feeling was absolutely fantastic"

Other passions are as unique and varied as might be expected: everyone has favourite TV programmes and enjoys many small pleasures of life, whether that be simply going out into a garden, painting fingernails with a friend, having a cup of tea, or visiting family.

Some people are able to regularly do the things they are most passionate about, and they form part of their routine. For others there are obstacles. Often this relates to the need for support; many individuals are fully reliant on the capacity of parents or carers to take them to various activities.

Predictably, cost is commonly cited as a barrier to people being able to do the things they are most passionate about. Nicola used to love sailing and in her youth competed at a national level. If she had the money she would love to join a local sailing club and teach her children to sail.

Similarly, Mary-Lynn was an avid horse rider until funding for the activity was cut. For others, supportive families can easily afford to fund hobbies.

While passions are unique, opportunities to go to new places or have new experiences are seized upon by almost everyone we met. Day trips to places of interest stand out as high points in the routine of life, particularly when trips ostensibly have a purpose, such as history, photography or art appreciation. Theatre visits, Christmas pantomimes, comedy nights and the cinema are all enthusiastically received too.

Trips are an opportunity to spend time with people with similar interests and such connectivity is important. An excellent example of this is the history group at a day centre in Wiltshire which takes a group of men with learning disabilities on regular outings to places of interest. The first time we met, John was still proudly wearing a key chain that he'd bought on a recent trip to Cadbury World. Often the most popular trips are those which take people into the community, including trips to the pub or coffee shops or more active outings like gardening projects.

For those with mental health problems, trips out represent a chance to forget about their problems for a while and immerse themselves in something different. David, for example, was previously taken on outings to London museums when he was in a psychiatric hospital and has since gone to visit some of his favourites independently. He would love to go to other museums that he has heard about but is not sure where they are or how to organise it.

Transport problems, financial constraints (individual or organisational), support needs and the routine commitments of daily life mean that these events are not 'every day' or taken for granted, and so have increased value for individuals.

Andrew recently went on a trip to The Tower of London with a peer support worker, Melvin, who spent his own Time Credits to take him. For Andrew, it was a high point of recent times: "I didn't want to come home!" Melvin reflects: "He forgot about his mental health or any problems that day. He just kept saying 'lets go here… then here… then here!' Andrew is keen to do more, "anything to get me out the house".

John is passionate about cars – his family owns several vintage cars and he loves to go for drives or attend rallies with his dad. He also collects model cars from all eras, particularly super-cars, and has subscriptions to car magazines. David is an avid Formula-1 fan and never misses a race!

KEY POINTS

- People have a wide range of hobbies and are passionate about diverse and unique things.
- Trips and outings to places of interest, the cinema or theatre, or even to pubs and coffee shops are all popular. They break the routine of every day life and provide access to new experiences. They also promote greater inclusion in society.
- Transport problems, financial constraints and high support needs are all barriers to participating in hobbies and activities.
- Supporting people to have experiences which promote social inclusion is essential and can have a significant impact on wellbeing.

PLACE

Where an individual lives and spends their time is important in determining the opportunities available to them and the people they are able to interact with.

- **Home** – residential supported accommodation offers a very different experience to living with family or independently in the community
- **Daytime activities** – day centres, colleges and structured, timetabled activity are a feature of most people's lives to a greater or lesser extent. In addition, some receive support to spend their free-time as they would like, while others have more free time to fill independently.
- **Evening and weekend activities** – There is huge variation in the extent to which individuals are willing and wish to access formal opportunities as well as informal spontaneous activities during evenings and weekends.

The people we met who live in residential supported accommodation, for both mental health and learning disabilities, have a dedicated key-worker and formal support or recovery plan, tailored to their needs. These members of staff have formal obligations to help the individual work towards their goals and achieve their aspirations. However, such environments are busy and personal support may not always be available at the right time or as often as needed.

The facilities in residential settings can also vary widely in terms of the existence or absence of communal and outdoor space. The same is true of day centres. While some have modern kitchens, music rooms or IT facilities, others have little more than a couple of sofas and TV in a small room. Some have dedicated space while others must share a multi-use room or site. Clearly all this affects the feasibility of offering certain activities and can constrain interaction between users themselves, or users and staff.

At one mental health supported residential facility the reception area is an important meeting point. Although run-down with just a couple of sofas, it provides a place for the residents to meet and interact with staff and visitors throughout the day. Each time we visit, people are passing through, debating football scores, reading the paper or hoping to just have a chat with new people like us! The area is so popular that there are plans to refurbish it.

However, another benefit of residential facilities and day centres is that they often have access to important resources like accessible transport and can organise group trips to places of interest.

By contrast, those we met living in the community – either alone or with family – can have a very different experience. A positive benefit is that they often have greater involvement in the wider community through family and friends. However, this can be tempered by less formal or intensive support from health and social care services. Their care and the opportunities they have access to are often more dependent on the attitudes, abilities and perspectives of their main carer. Logistical problems such as a lack of access to transport or support at necessary times can mean that a person ends up more isolated and has fewer chances to socialise outside of their immediate environment.

Working within the framework provided by these settings is crucial. Home is a place of safety and security, no matter where it may be. For some it is the place they have lived since childhood while for others it may be the first place of refuge after a period of homelessness or hospitalisation.

These different environments and the people who provide care within their walls are the gateway to reaching and engaging those with complex needs.

KEY POINTS

- Where someone lives and spends their days has an important influence on the facilities and opportunities available
- Those living in or attending specialist support centres are more likely to have access to facilities such as accessible transport
- Service providers should explore opportunities to collaborate in order to improve outcomes for individuals and groups

ROUTINE AND CHOICE

The lives of people with complex needs are often characterised by routine. For some it is an imposition which they resent, while others are ambivalent or take some comfort from it. For some it is driven by their high support needs.

Routine, however, does not mean that every moment of the day is filled. While some people schedule an array of activities, others face substantial stretches of empty time interspersed with the routine of meals, television programmes and the chores of daily life.

Tom and Claire for example both live in supported accommodation and have set meal times. They have choice over what to eat, but not when. Others like Sarah and David are simply provided with canteen meals at a set time. This imposes rigid structure on the day and fixes activities which for most other people are flexible and can be adjusted at will to suit changing circumstances.

For some, particularly those with mental health problems, this is an undesirable situation and compels them to be in the home at a certain time, limiting what can be done in the gaps between meals. Routine can be restrictive and increase a sense of institutionalisation and a lack of control.

For those with learning disabilities, attendance at a day centre, outreach activities or college often dictates the structure of the week. Attendance is regular and predictable and activities during the day are carefully timetabled. Although special events and trips are built in to the schedule, once activities have been chosen, it is difficult to change more than once or twice a year.

While such a timetabled approach – be it at a day centre or in a residential home – is necessarily routine and restrictive, it can also serve as a way of presenting choice in a manageable way.

By offering a range of activities for each session, attendees can choose how they would like to spend their time, without needing to identify or create opportunities themselves. This can be an important way of empowering people to have influence over their lives and the services they use, particularly when too much choice is overwhelming or cognitive abilities limit a person's potential to generate and evaluate their own options from scratch.

Evening social clubs often mark another fixed event in the week. For some with high support needs, even 'free time' outside of the day centre or college runs to a schedule, dictated by the allocation of support workers.

Recurring appointments also reinforce routines, particularly for those with mental health problems. All those we met need to have regular medical appointments to check on their medication and usually have a host of other meetings with social workers, psychiatric services, welfare services and in some cases the criminal justice system.

This sense of structure is important to some. It gives them a sense of control over their days and reduces anxiety. It can be a way of passing time – looking forward to lunch, a trip to the shop, or a favourite soap opera. This can be the case for some whose diagnosis means they crave order, but can also provide a sense of stability for those who have lived through disrupted and difficult periods.

Regardless of how comfortable people are with the routine of their life, everyone remembers the times when something different has happened – day trips, theatre visits or opportunities to try a new experience. Our visits were clearly a huge novelty and attracted interest and attention. When we joined in a Zumba class at one centre, lots of people were keen to dance with us and show off their moves.

Routine is very important to **Tom**. He has an excellent memory for the details of his week's schedule. Much of his conversation centres around this, often talking very fast and repetitively: which outreach worker he will spend time with tomorrow, what time they will arrive, what time he will go shopping, and so otn. He helps plan his schedule with his outreach workers who give him choices about how to spend his free time.

KEY POINTS
- The lives of people with complex needs are often characterised by routine.
- Routine can be imposed by the timetables of a residential facility (for example, meals), scheduling of activities at a day centre, regular health and social care appointments, or the availability of support staff.
- Some welcome the routine as they like or need structure to their days, but for others it is more of an imposition.
- Breaks in the routine stand-out and opportunities to try something new are almost always welcomed, assuming appropriate support is available.
- In working towards co-production of services, providers must evaluate the extent to which new processes and opportunities should be designed to work within existing routines and structures versus seeking to break the status quo.

MONEY

As for most people, money is an important part of life which affects everything from the essentials like food and clothing to the ability to socialise and spend money on the things that matter to them. All those we met receive benefits and many of those with learning disabilities are also supported by families.

The majority feel that they have sufficient income to do the things they would like on a daily basis. Several comment they are able to comfortably afford their everyday outgoings on food, accommodation, transport, other items such as tobacco and participating in organised trips or activities. Several factors help control outgoings:

- Fixed or limited outgoings on accommodation and food
- Free or subsidised transport – for example, a disability Freedom Pass in London, council run transport to and from day centres, or services like Dial-A-Ride
- Discounted rates at many museums, leisure facilities or other places of interest (although sometimes a lack of awareness of free or subsidised activities is also an issue)
- A wide range of activities on offer through day centres and social clubs at no or very reduced cost. Refreshments in these settings are also not charged at commercial rates.

That said, most do not seem to have much money to spare. Many of those with mental health problems talk about needing to save up to buy items of furniture or a television, and most purchase quite basic food and at least some of their clothes in charity shops.

For a few, money is a real concern. Often there is some confusion over the benefits system and they struggle to articulate exactly what the problem is or how they anticipate it will be resolved. Andrew describes delays in receiving his Freedom Pass and problems with his benefits such that he "lacks the means" to do the things he would like. To

Sarah feels she has an adequate income for her needs. "Tobacco and tuck" are high priorities for her and she buys most of her clothes in charity shops. She finds shopping can be bewildering and is worried about how people see her. This means she tends to rush and panic when choosing, so misses out on deals and offers which would save her considerable money.

his frustration, he feels that his support worker is more concerned about his personal hygiene and the state of his bedroom than resolving his financial problems. Nicola also worries that she does not have enough money to raise her children in the way she would like. She cannot afford piano or sailing lessons which would give them chances to bond.

Many people with complex needs, but particularly those with learning difficulties, have problems budgeting and handling money. At the more severe end of the learning difficulties spectrum there is a more general lack of awareness about money and its value is not truly understood. Mary-Lynn's brother comments, for example, that she "always wants coins, not paper money", even if the coins are worth less.

For those with mental health problems, the challenge is different. For some the stress associated with decision-making and purchasing can lead to poor choices. Nicola is able to recount many poor purchasing decisions made during 'manic' periods of her bi-polar where she was incredibly impulsive. Others simply appear to be out of the habit of planning for the future.

As a result, most people with learning disabilities tend to receive substantial support with budgeting from their support

Josie is currently focusing on improving her money management skills with her key worker. In the past she has taken a week's worth of cash to college and so is learning to budget daily.

workers and carers. While this is obviously important to ensure that vulnerable individuals are not taken advantage of or don't run short of money for essentials, there is a risk of taking away the individual's autonomy entirely.

KEY POINTS

- The majority feel they have sufficient income for their needs, although many have limited outgoings and take steps to save money
- However for some, money is a real concern and places significant constraints on their lifestyle
- Many people with complex needs – particularly but not exclusively those with learning disabilities – have problems handling money. These can range from not grasping the value of money at all, to problems with planning and budgeting. Others make poor financial choices because of stress.
- Many need support with other administrative areas of life such as dealing with banks, and arranging travel passes for example.

GETTING OUT AND ABOUT

One of the biggest potential barriers to accessing opportunities is the simple ability to reach the destination. Transport is inevitably a major challenge.

This is particularly acute for those with learning disabilities, as many have both physical and mental impairment. None of those we spent time with travel alone except on pre-arranged transport to a known destination such as a day centre or college. There are concerns about the safety of individuals if out and about without support, even for those at the less severe end of the spectrum, particularly in light of communication problems and difficulties handling money. Robert's mother commented: "He would just walk straight past the house." Physical difficulties also mean many need adapted transport. When independent travel is not possible, it places great constraints on an individual's freedom. Spontaneous trips are rarely possible for those reliant on professional care, with even simple excursions to the shop usually scheduled in as part of a routine. There may also simply be insufficient staff to accommodate the needs and wishes of everyone. Relying on family for support also has limitations. Older parents and carers may find it physically too exhausting and all families have other demands upon their time. Some trips are also dependent on the family having a car, which may not be the case.

Of course, most of those with mental health problems are able to go out and about independently. Generally, if somewhere is too far to walk, buses are the preferred option. However, with this group, barriers to transport are often more down to personal anxiety or a lack of confidence about getting out and about.

David only has very limited money so rarely uses any form of transport. Keeping fit and getting to know the area are also important to him so he walks everywhere but this limits the range of places he can go.

In rural communities, however, public transport is limited. As a result, some people end up using taxis which is a further drain on finances. Even in London where there are specialist services such as Dial-A-Ride, this is not considered particularly reliable.

Many of the people we spoke to, both with mental health problems and learning disabilities, expressed a nervousness and dislike of public transport. They are concerned about coping in unfamiliar settings or being stared at by members of the public. Some families and carers also commented that they do not like the way they feel judged or observed by the public sometimes. Here, one bad experience can shake the confidence of parents to travel with their children publicly. Robert's mother will no longer travel at busy times with him after a stranger confronted them, angry about the way Robert was staring at him.

Claire travels almost everywhere in a community transport bus, including going to and from the day centre. She becomes very preoccupied with the drivers and worries that her favourites will leave. She is not confident travelling by taxi with her wheelchair and prefers the bus.

KEY POINTS
- Transport is a major barrier to participating in activities.
- Many of those with learning disabilities are unable to travel independently and specially adapted or pre-arranged transport is also preferred.
- Those with mental health problems are more able to travel but tend to be restricted to public transport and may experience anxiety.
- In rural communities, transport is a particular problem.

RELATIONSHIPS AND SOCIAL NETWORKS

Individuals usually have a large number of people who are involved in their care and with whom they engage on a more or less regular basis.

Despite that, many people with complex needs have limited social networks. Even in mid-summer, Sarah still has the three Christmas cards she received up in her room, yet can't even remember who one was from.

People tend to lack the connections which help other people make new friends and networks. For example, the common interactions which arise from paid employment or having children simply don't happen for many. Also few are members of community sports clubs or attend evening classes, for example. Those in residential accommodation don't even have neighbours who fall outside their immediate social group.

Parents, carers, volunteers and service and support staff all have a huge influence over the lives of individuals with complex needs. While there is no doubting that everyone we met wants 'the best' for the person they care for, there is inevitably no one definition of what 'the best' may be.

Sometimes these differing priorities can create tension. For example, Andrew's support worker is very concerned about his levels of personal hygiene, whereas Andrew is more anxious to sort out problems he is having with his freedom pass. In Mary-Lynn's family, the tensions are internal, with her siblings disagreeing about how much she is capable of doing for herself.

In different ways, however, almost everyone involved in the care of someone with complex needs is subject to significant pressure. In statutory services, funding cuts, staff turnover and 'red tape' are challenges which often leave little time or energy for creative and visionary thinking. Families too can struggle in terms of time, energy and money, and lack of expertise or experience in navigating the system or identifying opportunities.

Figure 6. Main people involved in the lives of individuals with complex needs
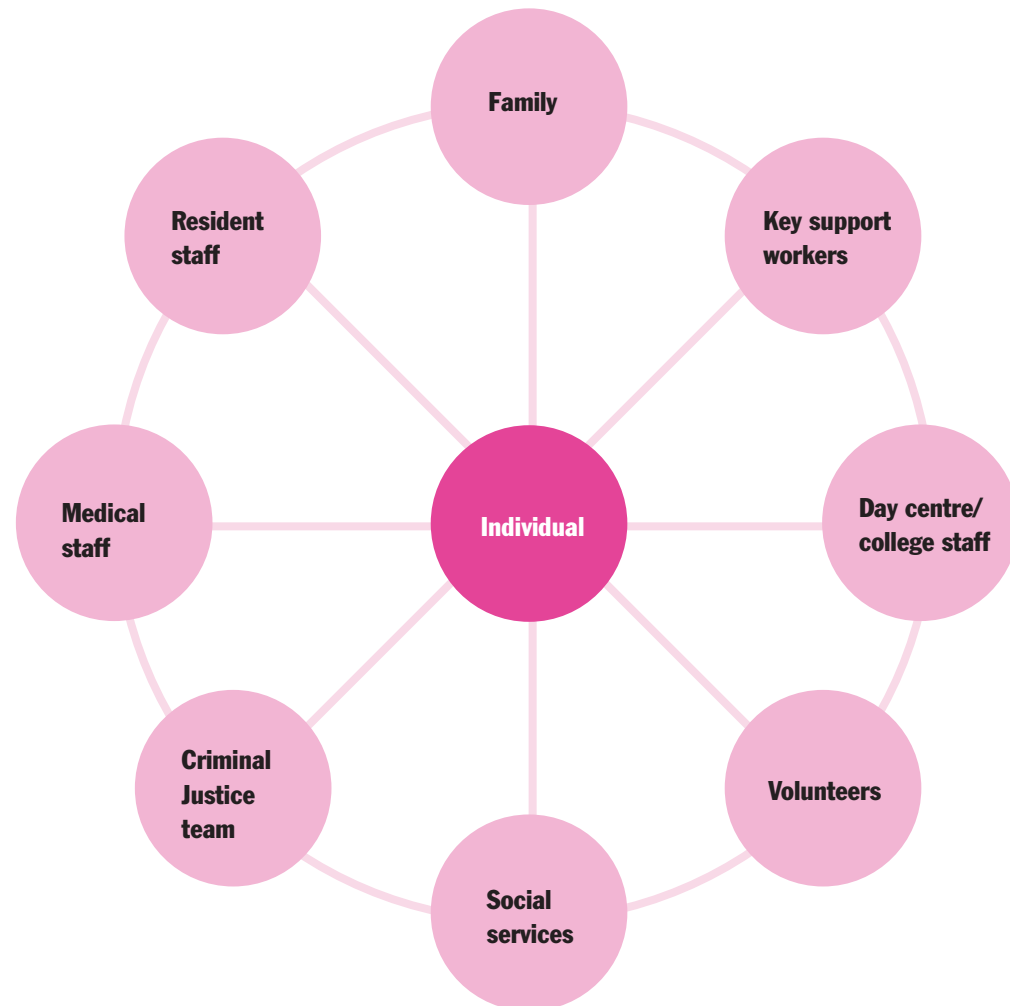
1. FAMILIES

The people we met with mental health problems are much less likely to have much, if any, contact with family. Several have lost contact with ex-partners, children, parents and siblings. However, where people do have family, it is usually a relationship they would love to strengthen.

Andrew, for example, regularly writes to his ex-wife and children in the hope that one day they will respond.

Even when all contact has been lost, children in particular are often sorely missed. Sarah has no hope of seeing her children but an old photo of one son takes pride of place in her room.

Those with learning disabilities by contrast are often still living with family or are in close and regular contact. Families are keen to support the person they love to lead a happy and fulfilling life but interpretations of what that means on a practical level vary substantially. Age, socio-economic position and prior experiences of health and social care services all seem to shape the views of those caring for someone with a learning disability. Although well-meaning, families can sometimes be over-protective of their loved ones and this can lead to a limiting of opportunities and experiences. Families worry about how a person will cope emotionally, whether they will be physically safe and often recall one or two negative incidents or accidents in the past which make them nervous about 'taking risks' again.

Nicola's children are currently in foster care and she has supervised access. She is desperate to regain custody of them: "I just want to smell them, to hold them, to have Amy on my lap. They're being washed with different bubble bath, and dressed in different clothes […] they don't look or smell like my girls". Her second husband is also out of the country at the moment which makes it even harder to cope.

In some cases there is clearly a level of co-dependency in which the family simply cannot envisage a life which does not revolve around the care of that person. In some homes we visited the mutual love and devotion was palpable but sadly too was the lack of aspiration.

In contrast, some other parents are determined that their children should not be held back in any way and actively encourage and promote their independence and right to experience new and meaningful activities. The age of parents also plays an influential role with many who are now well past the age of retirement feeling that they are physically struggling to cope with the demands of caring.

While no parent we spoke to expressed any resentment, the pressure placed on them in caring for a disabled child was obvious, especially if they now have their own health problems to contend with.

Wider families too are often close. Many of the people we spent time with are proud aunts and uncles or very close to brothers and sisters who also form part of the extended support network.

Bradley spends a few hours most afternoons with his niece who lives nearby. His mother lives in the US and he relies on Skype at his niece's to speak with her.

Tom's parents are fully behind him trying to live a more independent life in supported accommodation. His father works with adults with learning disabilities so understands the importance of helping individuals to achieve their goals. That said, he has acknowledged that as a father he will still over-worry. He learned a valuable lesson in this when Tom wanted to go on public transport, something he has always found difficult. He tried to warn the key worker, but her duty to support Tom took priority and the trip was a success!

Robert's mother is extremely protective of her son. She feels that she must constantly remember what the doctor told her: "He is a three-year-old in an adult's body". She is very wary of him getting lost or falling and at home follows him up the stairs just in case. Her nervousness extends to him trying new activities and she worries about how he would fit in or cope. As an older lady, she is now finding caring exhausting and cannot envisage doing more activities with Robert. He also has some home support but rarely goes out in evenings as his mother is too afraid since being mugged. He would like to go swimming but his mother is unable to take him.

2. SUPPORT STAFF AND CARERS

In the absence of family, individuals often form especially close bonds with support workers and volunteers who support them. Individuals are often quick to cite these relationships as some of the most important in their life – sometimes adopting the role of support, family, friend and mentor all in one.

During our visits we witnessed many testaments to this, from Tom bestowing his key worker with his favourite compliment "you smell", to banter with others about sports, and girly chats on the bed about boyfriends.

Key workers can become friends, and members of staff provide a proxy for the daily chat that others might experience in the workplace.

The nature of a severe and enduring mental health problem also tends to involve close supervision of medication and often psychiatric or therapeutic support. Many of those we met had led difficult and troubled lives resulting in regular contact with social services or the criminal justice system. Along with key workers and residential facility staff where relevant, all these professionals have huge influence over the opportunities available to a person and their progress towards achieving personal goals.

In both learning disability and mental health settings, the role of paid staff dictates the way in which they relate to and interact with those in their care. Key workers or outreach staff have more one-to-one time and a specific remit to create a personal plan for the individual. Other members of staff are often operating to a timetable of activities with several participants, limiting the extent to which things can be tailored.

Health and safety concerns can heavily influence decision-making as well. For those attending day centres, the structured nature of activities means that staff play an important role in creating and facilitating access to new opportunities.

Yet regardless of role, centre staff in both day and residential settings are often highly valued, and individuals will have a close relationship with them. Support workers can be among those who know most about someone, their likes and dislikes, their past and their hopes for the future.

In addition to paid support, some individuals receive support from trained peer support workers and 'experts by experience'. These relationships flourish on the basis of their more equal footing and the implicit understanding of shared experiences.

They are less formal in nature and provide a less threatening route in to new activities and building confidence.

Josie and her key worker have a close relationship. They enjoy planning new activities and ways for Josie to reach her goals. These include everything from spending more time with her boyfriend, to getting better at handling money, and building up confidence by volunteering.

Nicola has a close relationship with her community psychiatric nurse. She trusts her nurse and feels that she "celebrates people's right to be different". She contrasts her attitude with that of her social worker who she feels to be judgemental and not understanding of mental health.

3. FRIENDSHIPS AND PERSONAL RELATIONSHIPS

Social networks are often the same as support networks. For many their primary social circle is also the same across several settings. They may live in supported accommodation with people who are simultaneously their neighbours, the people they eat with and watch TV with, and the people they go on trips and outings with. Sometimes those same people will also attend the same day centre or college course. Many of those we met with mental health problems have lived quite transient and chaotic lifestyles – struggles with alcohol or substance misuse were commonplace. Most have moved from centre to centre and may have been homeless for a while. There is almost an expectation that friends will be lost when one or the other of them moves on.

Often those we met told us that they don't have much in common with most of the people they are living with, except for a shared diagnosis. As mental health services are dominated by men, this problem can be particularly acute for women. Women are in the minority where Sarah lives and although they are on a separate corridor, she dislikes the poor personal hygiene of many of the men who live there too.

In some instances we also found concerns over inappropriate behaviour, with staff purposefully not encouraging residents to mix – with a view that these relationships can often be unhealthy and not beneficial for residents' recovery.

Individuals may also be anxious about coping in the 'outside' world and have a fear of being stigmatised as a result of their condition. It can be easier to stay in the security of an environment where there is no judgement and less possibility of rejection.

As individuals with learning disabilities are much more likely to have strong family networks, this often leads on one level to greater integration into wider society as they go out to family events, to the shops and so on. However, their wider social networks are also still very limited. Typically it is largely constrained to other people they meet with disabilities at day centres or in a residential service.

They also tend to meet with the same people at day centres and then again at evening social clubs. This is particularly pronounced in rural areas where the catchment area for services can be relatively large and there is limited choice.

All those we met lack the independence and skills to meet with friends outside the organised routine of daily life or family environment. Particular barriers are transport, money management skills and self-confidence. For those at the more severe end of the spectrum it is simply not feasible to travel unsupported. As a result, even use of community facilities is often only in 'special' sessions, such as disability swimming or gym time. Segregated sessions can also be instigated by the service provider, such as a leisure centre, rather than at the specific request of the user group. Clearly this further limits social integration and inclusion.

That said, many of those we met made friends easily and some form attachments very quickly. Mary-Lynn treats everyone as "*my friend*" and loves to receive one-on-one attention from those around her. She is rather indiscriminate in her affections, however, and this leaves her vulnerable and easily led.

Some also talk about their romantic relationships. These vary from intense love and a desire to marry in the future, to relationships forged from a friendship with little contact outside the environment of day centres and social clubs.

As with everyone, some people are more gregarious than others, and younger people at the less severe end of the spectrum are typically more outgoing and socially active than those who face the most complex problems.

Sarah has lost touch with her five children who were taken into care, but is in touch with her younger sister, of whom she is very proud. She is used to a transient life, commenting: "I had best friends before, I've got a best friend here and I expect I'll make new friends there. I'm used to it. It's good to meet new people."

**KEY POINTS:
RELATIONSHIPS AND SOCIAL NETWORKS**

- An individual may have a large number of different people – including family, paid staff and volunteers – involved with their care.
- Different people involved in the care of an individual may have different views on what is 'best' for that person. This can lead to tension either between different carers or between the individual and their carer.
- Although well-meaning, some families can be over-protective of their loved one. Older parents can also find caring very demanding.
- Key workers and other support staff can often be close and seen as friends by individuals with complex needs.
- The differing nature of paid support roles means that some staff, such as key workers, inevitably have more time and motivation to help individuals achieve personal goals.
- When putting in place asset-based approaches, providers should seek input and collaboration from families, carers and key workers as well as senior staff.
- However, all those involved with the care of a person with complex needs tend to be under pressure and may need help to envision new systems and put them into place.

A SENSE OF PURPOSE AND WORTH

Lives are shaped by where we live and our social networks, by the things we love to do and those we don't, and by the structures within which our time is managed. Everyone we met had a strong personal identity, determined to be seen as more than their diagnosis. Fundamental to this also appeared to be the desire to live a meaningful life and make a meaningful contribution, be it to their family, a friend, the community they live or socialise in, or society as a whole.

The sense of contributing something is important and it manifests itself in many ways, from the small and almost unspoken, to a more explicit desire to make a difference. For example, Sarah is the 'go-to' person for the women where she lives, making tea and providing a friendly environment for a chat or to watch TV. Knocks at the door are frequent. Andrew fulfills the same role for many of the men.

Many others contribute in small ways to the activities they take part in and services they use – from cleaning up after cooking or games, to fetching the newspapers for a discussion group, to keeping score at a skittles match. Several of those with learning difficulties are also proud to have responsibilities in the home and to make a contribution to family life.

Some of those we met also take part in activities through day centres which allow people to make meaningful contributions. Claire, for example, contributes to an internal magazine within the day centre, updating members and carers of news and activities planned. Robert on the other hand takes part in a gardening project to grow salad for a local older people's lunch. Feeling that they are contributing to something that has wider impact helps to foster a sense of pride for individuals.

Bradley is a peer support worker and an 'expert by experience': "I know what it's like to be in that situation." He is proud that he has recently been nominated for an award for his work and hopes one day to qualify as a support worker.

A few of those with mental health problems are contributing through a more formal volunteering structure, as 'experts by experience' or 'peer mentoring'.

Reciprocity is inherent in many of these contributions. It helps build friendships and develop skills but can also have less tangible benefits. By making a meaningful contribution, it helps people to feel less like passive recipients of services and increases a sense of belonging. It fosters a sense of self-worth and people can take pride in giving as well as receiving.

For those who volunteer more formally, it is a way of giving back to a system which has supported them and can normalise relationships with staff, marking the start of a transition from service user to part of the support network. In addition they can serve as important stepping stones in the transition for some into paid employment or recovery. In the context of mental health, making an obvious difference can help reduce feelings of shame and embarrassment, by showing wider society that they have a valuable contribution to make.

John earns Time Credits at his day centre for sweeping up after baking class. However, he also takes it upon himself to wash and dry up too, without formal credit. At home he "owns the Dyson" and helps by vacuuming, loading the dishwasher after meals and preparing his own packed lunches. He would welcome the chance to contribute in more meaningful ways.

At a previous day centre he was involved with a scheme to raise money through recycling scrap metal – he loved the role and responsibility.

His parents welcome this type of experience for him.

KEY POINTS:
A SENSE OF PURPOSE AND WORTH
- People with complex needs are keen to make a meaningful contribution to their communities.
- Ways of contributing are varied, reflecting the unique skills and abilities of each individual.
- The reciprocal nature of many contributions is important – it increases self-worth, promotes a sense of belonging and normalises relationships with staff.
- Formalised opportunities can mark the start of the transition to co-produced services.

CALLS
TO ACTION

MIND THE GAP: ASPIRATION AND REALITY

The time we shared with people, the visits to services, our conversations with experts and review of the evidence all paint a consistent picture. It is clear that there is still a long way to go before we can truly say that the guiding principles for care and support which we outlined at the start of this report are being delivered in complex needs services.

There is no doubt that services are run by dedicated and committed teams, or that families and carers are fighting for what they feel is best, and that commissioners are trying to make difficult decisions in tough economic times.

Yet it is also clear that in the current climate, services are ripe for redesign to make them more fit for purpose, inclusive and efficient. Existing policy explicitly promotes and advocates asset-based approaches and new ways of working to deliver innovative, high-quality services that meet those goals.

Social inclusion, opportunity and control are core principles that underpin best practice in health and social care. They are also at the heart of asset-based approaches and the benefits they seek to deliver. Yet for everyone we met, there is huge potential to make improvements in these areas:

- Social inclusion is particularly constrained by institutional living arrangements, and day services which operate separately from other community groups. The opportunity to meet other people is limited.
- Stigma is also a significant barrier to social inclusion, as reflected by those we met both with mental health problems and learning disabilities who have experienced discrimination or been treated differently when out in their communities. Yet greater levels of social contact have been shown to reduce stigma and discrimination.[31]

- Practical problems like financial limitations, transport problems or the inability or unwillingness of a carer to facilitate outings or access new experiences compounds social isolation and limits opportunity to pursue personal goals.
- For a variety of reasons people often live to a strict routine. Regardless of whether the individual values or resents this, routine fundamentally shapes awareness of opportunities and the ability to take advantage of them in all spheres of life.

These overarching influences that shape people's lives – the practical logistics, family and support networks, and routine – all mean that those we spoke with typically feel they have little control over their lives.

Our conversations with experts, front line staff and observations of services also underlined that many professionals and commissioners are either not used to thinking about ways in which they can work with users to co-design and co-produce services and individual plans, and struggle to envisage it, or simply feel they do not have the skills, tools and resources to change their ways of working.

Together, social inclusion, opportunity and control are essential to leading a **meaningful and fulfilling life**. Given the limitations faced by everyone we met, it seems difficult to say that they experience **equality** with other people in society.

The frustrations of limited control over decisions relating to personal goals, the limited opportunities to pursue new experiences or follow passions and influence the routines and structures that dictate daily life are evident. Breaks from the norm are almost always seized upon, and many of those we met are keen and curious to meet new people and make new friends. Almost everyone wanted to feel that their life had purpose and that they can contribute to their community, be it through small gestures, spontaneous actions or planned activities.

Identifying, and for some articulating, the way in which they can contribute and the extent to which that is valued by the community can require significant support and a personalised approach. The rewards can be huge, however, as demonstrated by the pride and satisfaction of the people we met who are being supported to do so – the 'experts by experience', those with responsibilities for group activities, or those earning Time Credits.

THE GAP MUST BE CLOSED

Our research shows that the stage is set from a policy perspective to support the adoption of asset-based approaches. Many public and voluntary sector organisations explicitly support the growth and development of time banking and other approaches that help people use their time and skills.

Connecting with people through shared interests provides an opportunity for people with complex needs to be recognised as individuals rather than be defined by their diagnoses. Experts we spoke to stressed the ways that asset-based approaches can unlock opportunities, enable people to fulfil personal goals and increase social inclusion. The evidence available indicates that despite the challenges, asset-based approaches can be successful and have a huge impact on the lives of people with complex needs. This includes time banking approaches, of primary interest to our research.

Although the use of these approaches with this population is still in its infancy, there exists an increasing number of organisations that aim to help people with complex needs by connecting them to other people in the community. These include Grapevine Coventry and Warwickshire, KeyRing, and Circles UK.

Grapevine Coventry and Warwickshire is a learning disability project that supports people to make a contribution to their localities. They told us the story of a woman with high support needs who had just moved out of home. She had no speech, but she liked pantomimes, so they connected her to a weekly circus skills workshop.

"They didn't have any special training, they were just the right kinds of people. They would rub the balls on her face, and play with her wheelchair […] Every time they dropped something she would giggle […] She provided encouragement and humour to people practising […] For her it was being welcome and accepted. She enjoyed it, and people liked having her there."

It is easy to envisage how the lives of the people we met during this research could be enriched by similar opportunities linked to their personal passions and local communities.

OVERCOMING THE CHALLENGES

Of course, although hugely important, the task is not simple and there are many challenges along the road. We do not suggest either that services can be transformed overnight, or that models of co-production and asset-based ways of working can be embedded without considerable time, effort and patience.
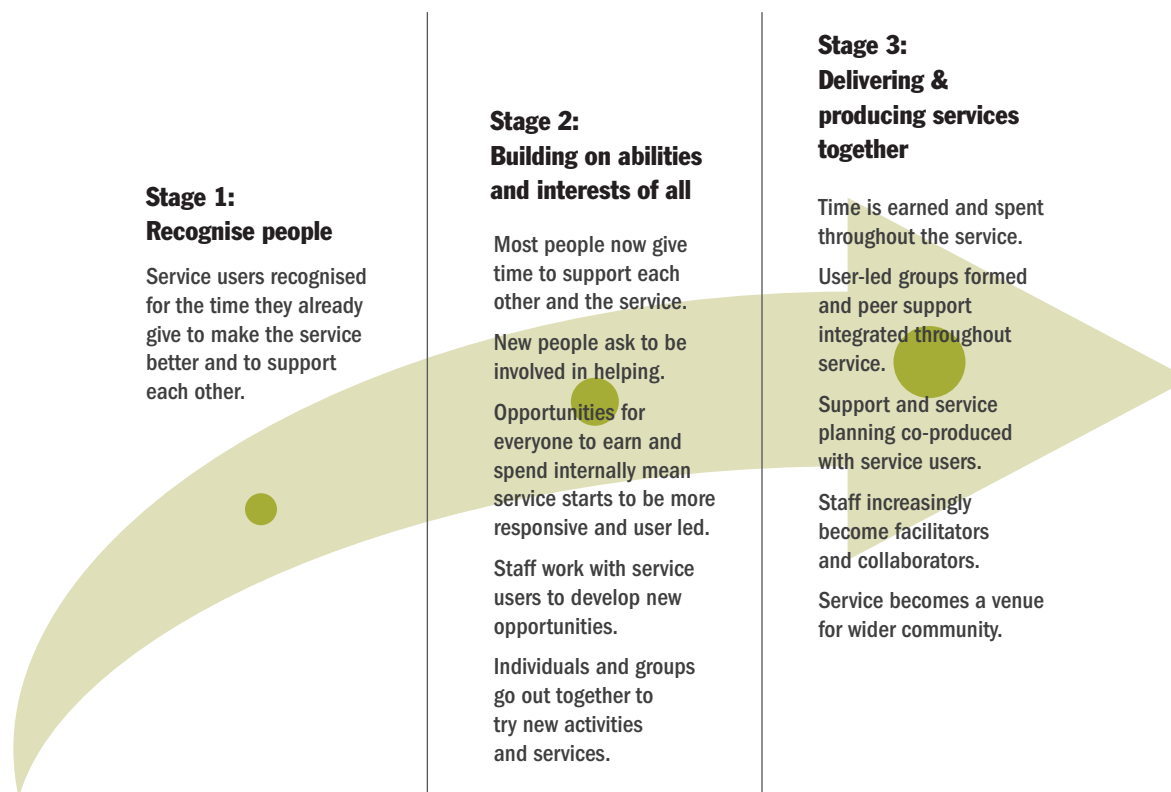
Through our review of the literature and interviews with experts, we identified a number of common challenges and potential ways of overcoming them.

It takes time

Many of those who have started to use asset-based approaches caution that when working with people who have complex needs, it will take considerable time to become established.

Allied to this is the need to have sufficient funding and resources in place to allow for a supported, progressive implementation. A lack of funding beyond an initial one to two year period or tied to specific milestones has been a challenge for several of the organisations we spoke to. "It was unrealistic to expect us to recruit two hundred participants within a year."

Figure 7. An example of the stages in a journey to co-produced services (Spice, 2013)

Stage 1:
Recognise people

Service users recognised for the time they already give to make the service better and to support each other.

Stage 2:
Building on abilities and interests of all

Most people now give time to support each other and the service.

New people ask to be involved in helping.

Opportunities for everyone to earn and spend internally mean service starts to be more responsive and user led.

Staff work with service users to develop new opportunities.

Individuals and groups go out together to try new activities and services.

Stage 3:
Delivering & producing services together

Time is earned and spent throughout the service.

User-led groups formed and peer support integrated throughout service.

Support and service planning co-produced with service users.

Staff increasingly become facilitators and collaborators.

Service becomes a venue for wider community.

Asset-based approaches should be an integral part of the way in which an organisation works and is funded. Commissioners and service providers must recognise that moving to a co-produced service model is a process of gradual evolution. Figure 7 illustrates an example of the stages of a journey to co-produced services using a time credit system as the mechanism.

This must be reinforced to commissioners to help them better understand the nature and merits of asset-based approaches, and how they might commission them, in order to overcome the reticence identified earlier in this report.

Flexibility and creativity breed success

Strict targets or visions for how the approaches might work can be unhelpful not only in terms of funding arrangements but also run counter to their spirit of co-production and user involvement.

Part of the reason that many asset-based approaches take time to become embedded and established is because they involve new ways of working and interacting for both service providers and users. A level of understanding, trust and confidence is required. Even some of the most successful time bank managers we spoke to had spent several years carefully building up numbers and engagement. Working with an existing user group can help to smooth the journey as a greater level of trust already exists.

People also need to have the trust and confidence that moving to new ways of engaging, in which they have greater control over their own care, is not temporary and will lead to longer-term improvements in their lives. The shift from passive recipient of services to active co-production can only ever be gradual.

Use organisational as well as individual assets

Implementation should ideally be facilitated and supported by organisations with skill and expertise in asset-based approaches. Organisations should also consider mapping their own assets and how they can support implementation and development – from facilities and staff to external relationships and local amenities.

Although limited in number, the organisations that are using asset-based approaches with people with complex needs are more than willing to share their learning and best practice. Failure should not be hidden away, but as with some of the examples included in this report, opportunities should be taken to measure impact and identify the success factors. There is a need to experiment, pilot and evaluate different routes with willing 'champions'.

"It's important that it's not target-driven. People with more complex needs may need lots of time to get used to things. All of it takes skilful support and it takes time, so any funding system that doesn't give you that is unhelpful and it's a barrier"
Grapevine Coventry and Warwickshire, a Learning Disability Community Project

SPICE TIME CREDITS – WORKING ACROSS THE SYSTEM

Spice Time Credits are designed to work across the whole system, integrating with service delivery to support and enhance outcomes for individuals, services and communities. In health and social care this means empowering people receiving services as genuine co-producers.

Time Credits programmes work well when they are integrated into services and co-designed with service users, their families and carers, local people and public services, working toward shared outcomes. This is a culture shift from how services have traditionally been designed and delivered, and Time Credits can be a powerful way of starting that conversation.

Time Credits support the principles of good personalised care and support, as well as many of the themes this research has identified as important to people with complex needs. They are a simple but powerful tool to build confidence and reveal the often hidden interests, skills and voices of people in the care system and across communities. They can open up new opportunities, reducing inequalities and financial barriers, and building connections between people as they take part in earning and spending together, in services, families and crucially also across the community.

Time Credits also recognise and value the experience and expertise that people have of their own conditions and lives. This is particularly effective in peer support settings, helping widen people's self-perception from someone who receives support to also being an active contributor to the health and wellbeing of others. Spice has also seen that Time Credits can have a positive effect where professionals and service users come together, enabling an environment of mutual respect and a level playing field between everyone involved.

> "Time Credits are a really good way to challenge the difficulty of engaging with customers [...] They also make customers feel worthwhile and makes them realise what they do is really important"
>
> **Support worker, Look Ahead Care and Support**

It is vital to take a long-term view to enable programmes to achieve transformational outcomes across sectors and communities. Spice's council partners view Time Credits as a powerful tool to empower local communities and organisations to take ownership of local issues in collaboration with the council as part of a long-term view of service delivery. "We decided to scale up the Time Credits programme within Chorley because we saw the success we currently had in the health and social care setting. We're encouraging members and the senior management team to engage in Time Credits on the basis that it's the solution – one of the solutions – to service delivery going forward." Simon Clark, Chorley Council

However, alongside the opportunities offered by Time Credits are some challenges to be overcome when it comes to working with complex needs services and the commissioning system. Working with people with complex needs demands flexibility and a personal approach in everything, from details like how much a Time Credit is worth and how they can be earned, to the underpinnings of the model. For example, Spice Time Credits have traditionally been valued and structured around whole hours, whereas in a complex needs setting, breaking this down is being explored to better suit individual abilities. A key element of this will be supporting the workforce and nurturing creativity and flexibility to enable new approaches to emerge to meet the demand for a more personalised and integrated system.

To enable this there is a need for much greater recognition of the time needed from paid staff to implement and integrate Time Credits into existing systems within services for people with complex needs. This should be supplemented by strategic support from commissioners and managers creating a strong vision for improvement. The support needed to help people spend Time Credits is also much more intensive than in less complex health and social care, and needs integration with existing structures and outcome frameworks.

> "Complementary currencies – Time Currencies – help us value things that the formal economy doesn't value"
>
> **Philip Colligan, NESTA**

As well as looking to unlock the assets of participants, organisations participating in Time Credit systems must consider their own assets and how they are used. Openness to new collaborations and partnerships is vital, such as pooling resources across services or linking with local communities in new ways. Taking integration this step further into the wider community – through opening up to local volunteers or building new working relationships with other organisations – can be a challenge in risk-averse services, but Time Credits offer a framework that supports this. For example, the Stroke Association in Wiltshire is exploring links with The Nature of It, a local environmental group, through the local Time Credits network to develop new activities that are accessible for stroke survivors. Different asset-based approaches can also be combined to provide meaningful opportunities – for example, participatory budgeting for a service refurbishment or a summer trip, with input recognised through Time Credits.

Time Credits have achieved some notable successes in complex needs services but there is a need for investment in further exploration and development to overcome some of the practical and structural challenges that are still being faced, and to achieve a true move to asset-based approaches and co-production.

> "Time Credits have given us quality family time together which was not possible before earning Time Credits, as we just could not afford to do the things we can now"
>
> **Time Credits member**

> "I feel that time credits have taken me places that I haven't seen before [...] It has helped me to gain confidence in myself and improve the way I now live my life"
>
> **Time Credits member**

CALLS TO ACTION

CALL 1

The sector must capture and share learning better from both successes and failures, to enable replication and long-term success

CALL 2

Commissioning and delivery models should prioritise outcomes and enable innovation

CALL 3

Collaboration and partnership working must be embraced to achieve transformation

MAKING IT HAPPEN

CALL 1

- Policymakers and influencers must continue to share learning to enable commissioners and services to understand the long-term commitment and inputs required to achieve transformational change. This should include not only successes but also challenges and learning from projects which have been less impactful or unsustainable. They must make a compelling case for change and bring the voice of people to the fore.

- Commissioners who pioneer innovative ways of working must share their knowledge and learning across the sector, capturing what is working, impact on resources and what is not working in order to drive change and identify best practice. They must support and promote the evaluation of services and the gathering of evidence on impact and outcomes.

- Services and providers who are utilising asset-based approaches and seeking to achieve co-production in services must gather evidence of impact, outcomes and success factors, and build knowledge and expertise among their workforce to drive new ways of working. They should also showcase successes and champion these approaches across the sector.
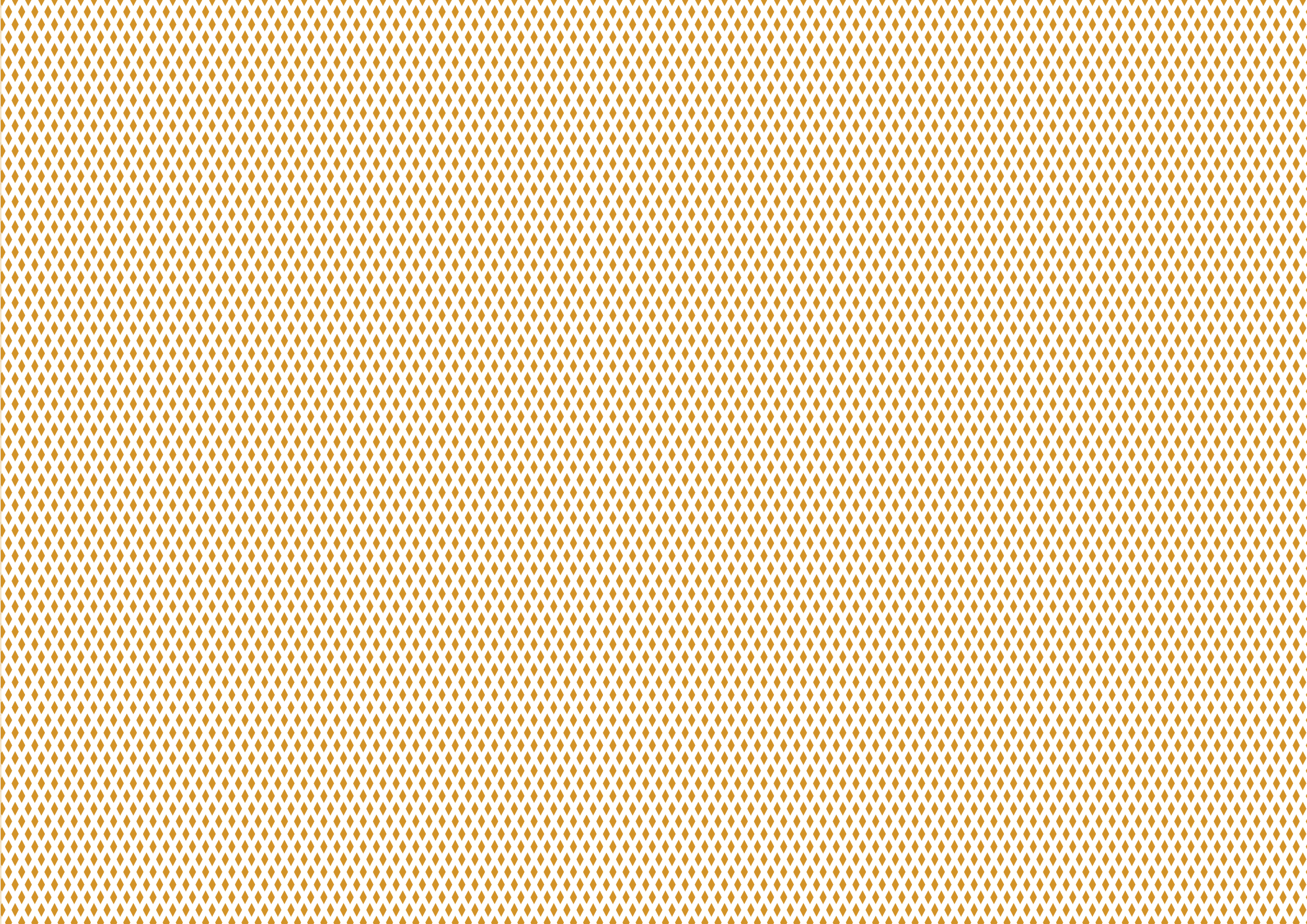
CALL 2

- Commissioning practices must encourage and reward service providers who are taking innovative or asset-based approaches to achieving the co-production of services, and allow risk-taking, flexibility and creativity by providing long-term funding and focusing on outcomes and impact rather than output targets alone.

- Services must commit to integrating asset-based approaches and co-production into delivery of services, and support their workforce to use their skills and experiences to develop and drive innovation. Asset-based approaches should be written into the core funding and evaluation of service providers in line with existing agendas around personalisation and integration.

- Policymakers and influencers must support commissioners to commission this type of creative work more widely, and to take risks in developing approaches and adopting innovations. Funding and resources must be made available to commissioners to facilitate integrated and wide-scale commissioning.
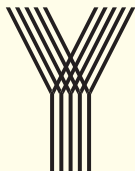
CALL 3

- Services must explore new delivery relationships and partnerships, including linking with the wider community and voluntary sectors that go beyond traditional health and social care. The untapped potential for community groups, traditional service providers and larger bodies to innovate together and pool budgets and resources to enable integration across health and care, and beyond that to the wider community, must be explored more fully.

- Commissioners should encourage and support collaborative approaches and partnerships between agencies and bodies with a vested interest such as CCGs, community groups, grant funders and user groups through the commissioning process.

- Policymakers and influencers should promote the role of communities in health and care in service transformation, embracing people-powered initiatives in policy and practice.

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