TOGETHER WE CAN
Exploring asset-based approaches and complex needs service transformation
Victoria Boelman and Catherine Russell

“I need something which gives me that sense of purpose”
Research Participant
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This work would not have been possible without the generosity and willingness to contribute from many individuals and organisations.

The report is filled with the stories of people with complex needs who spent time with us over the course of the project. We are hugely grateful to them for their time and openness. The names of all those participating have been changed to protect their identities.

We are extremely thankful to the day centres and supported living services who allowed us to spend time with them, shared their experiences, and introduced us to the people they work with and for. Specifically, we would like to thank: the Ladywell Day Centre in Lewisham, Riverside Day Centre in Wiltshire, and the Look Ahead teams at Glenister Gardens, Harrow Road, Kean Street and Kent floating support.

Finally, we extend our thanks to all of the organisations who contributed to the work and shared their expertise with us. Thank you to: Brian Fisher MBE, Centre for Mental Health, Circles UK, Depression Alliance, Foundation for People with Learning Disabilities, Grapevine Coventry and Warwickshire, Mental Health Foundation, Mind, Newsome Timebank, Scope, Shared Lives Plus, South London and Maudsley NHS Foundation Trust, and Unlimited Potential.

This research is part of the Uplift programme, a partnership between the Young Foundation and Spice, funded by the Department of Health.
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.
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.

INTRODUCTION

The NHS, celebrating 65 years in 2013, is what makes people most proud to be British. 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, 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. To meet these needs, our health and social care systems must shift from being focused on acute care to the management of chronic conditions.

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.

Co-produced patient-centred care is seen as best practice for new service delivery models.

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.

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, 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.
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: 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.

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.

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, which recognises that although clinical symptoms of a mental health condition may never disappear, a ‘meaningful and satisfying life’ is attainable.

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 and mental health 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.

“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
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.

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

“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

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.

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. 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.

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.

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.

“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.

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.

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.

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. These include acting as a lead partner in the Lambeth Living Well Collaborative, 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 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.

“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

Figure 2. Spice Time Credits model
**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.

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.

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

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**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.

**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**

**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:

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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.

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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.
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.

**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.
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.

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 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.

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.

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.
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.

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.

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

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.

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.

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.
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.

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.

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.

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.

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.”

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**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.
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.
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)
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.

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.

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.

“The 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

“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

“Complementary currencies – Time Currencies – help us value things that the formal economy doesn’t value”

Philip Colligan, NESTA
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.
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.
REFERENCES

15. Slade, M (2009), *100 ways to support recovery: A guide for mental health professionals*. London: Rethink Mental Illness
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Sarah

Sarah is a 34 year old black woman living in supported accommodation in central London. She has lived there for almost two years and expects to be there for another year before moving on.

Sarah is welcoming, friendly and open. The strength of her personality shines through and her day is punctuated by visits to her room from other residents, and chatting to staff and residents around the building. Although noticeably less confident outside the home, it is clear she has also struck up friendly relationships with the staff at the local supermarket which she visits daily for “tobacco and tuck”.

She has had a difficult and troubled life from a young age. Sarah’s own mother suffered from mental health problems and so at a relatively young age they were fostered or adopted, but for some reason the placement failed. Sarah and her sister were then placed in a children’s home. She talks of her years in the children’s home as a happy time:

“It was great … I did Brownies and Guides … and after Church we always had a big roast lunch on a Sunday.”

The passage of time after childhood is blurry but it is evident that at some point shortly after leaving the children’s home, Sarah became homeless. In order to survive and afford a hostel or B&B for the night, she became a sex worker. During that period, Sarah gave birth to five children, all of whom were taken into care. It is something she clearly finds hard to talk or even think about. Although she has not had contact with any of them for many years she has a photo of one son, aged around 13, in her room. She says he would now be about 21. This photo is clearly one of her most important possessions.

It is unclear when she received her diagnosis of schizophrenia but talks of having been out of hospital for eight years. She describes her condition as “voices out my mouth” which she can’t control, but doesn’t have delusions or hear voices in her head. Initially she talked of her condition being very well controlled and not experiencing the voices like she used to. However, as Sarah became more tired, the voices became more frequent and obvious.

Whilst at home Sarah doesn’t seem to feel embarrassed by the voices. Outside en route to the supermarket the situation is very different and she worries about behaving oddly in public and what the consequences might be.

“It’s embarrassing … One time I was in Tesco and I just shouted out. I don’t drink but I had to pretend to the security guard ‘he, he, sorry. I’ve just had a bit too much drink’ and then I left.”

To control her condition Sarah takes eight pills a day. They used to make her drowsy so she now takes them all before bed. She now sleeps in until 11 or so most days, but does not attribute this to the pills. Sarah is very vigilant about her medication and “if I felt odd, I would go [to the doctor] straight away … the main thing is to be well”. Once a month she has a blood test and check-up on a Tuesday and then goes back on the Friday to collect her medication.
Although taking all the pills in the evening has made her less drowsy, Sarah finds extended periods of activity or engagement tiring. Somewhat overweight, she seems quite unfit and walking 10 minutes to the local supermarket is physically draining for her. The lack of fitness is almost certainly compounded by her chain smoking, predominantly roll-ups.

Sarah knows she is unfit but seems resigned to it, feeling she is unable to regain the fitness of her youth and writing off her ability to dance or enjoy most physical activities. As a result of her love of swimming, the staff at the home run a weekly trip to the local pool.

Sarah also appears to have a short attention span. She tends to focus exclusively on one thing at a time, be that eating, watching TV or making a cup of tea. She also appears to enjoy planning a structure around her day, deciding to “make a cup of tea in five minutes” or that “we’ll go to Sainsbury’s at three o’clock”, regularly checking the time.

Although Sarah spends much of her day in her room, this belies the true spirit of her days. She often chats with her friends amongst the other residents and particularly likes a good horror film. She also enjoys girly activities such as painting her nails and loves shoes, bags, clothes and make-up. Taking care of herself and personal hygiene are important to her. Her favourite shops are Boots and Superdrug and she sometimes goes to a big shopping centre in Wood Green or the markets in Camden. While she loves Boots and Superdrug and the products they sell, Sarah comments that she finds it quite difficult to shop there.

“There’s too much … I like it when I buy clothes and I can look at them and touch them.”

The array of different options appears to bewilder her and the shopping experience is not one of looking, comparing and lingering over different products. Deals and offers are also ignored, meaning the final basket of goods does not represent particularly good value. Generally though, Sarah feels she has enough money to live her life.

Other than the time she spends in her room, out shopping, or swimming, Sarah has a few outside interests. She sometimes joins in with arts activities, though she is not particularly passionate about it, but she loves going on theatre trips when she can.

At some point in the next year, Sarah is expecting to move to a small flat and is excited at the prospect. She intends to have the walls painted the same colour red as her current room and to buy some additional furniture. A dream is also to have a TV in the living room and another one in her bedroom – “A lot of people have a TV in their bedroom, don’t they?”

She is not worried about moving to a new place and having to be more independent and cook for herself as she was used to that in previous places that she lived. She also believes that her transient life means that she is well equipped to deal with regularly moving.

“I had best friends in Camden, a best friend in Kilburn and I’ve got a best friend here. I expect I’ll make new friends there … I like it. I’m used to it. It’s good to meet new people.”

Sarah talks of contact with only three people outside the home. The first and most important to her is her sister – “she’s the clever one” who works in electronics or as an electrician. She is clearly proud of her even though they don’t meet in person very often.

The second person Sarah sees more regularly is her boyfriend who she’s been with for several years. He visits every week on a Friday. However, she talks very little about him, has no photos of him and cannot recall how they met. The only other person Sarah mentions is the brother of someone she was friends with in a previous home. Even though she does not see her friend at the old home, the brother still comes to visit her sometimes.
Finally, although she does not mention it when asked, the staff also talk about Sarah’s role in the organisation working as an ‘expert by experience’ and helping with the interview and training process for new staff. This role fits perfectly with her confidence and openness in dealing with new people when on home turf.
DAVID

David is 39 years old and of Afro-Caribbean origin. Although born in the UK, he moved with his mother and sister at a young age to the Caribbean where he spent his childhood. He later moved to the US and completed High School before obtaining a Degree in Advanced Technology. He keeps his degree certificate and high school transcript safe and shows with pride a letter that all students received from George W. Bush upon graduation.

David is proud of his technological skills and can “fix anything – cars, bikes, planes … and programme computers too”. He has often helped out friends in the past who have been having problems with their cars and this is something he really enjoys.

Whilst living in the US, David had a little girl and he lived with her and her mother until she was about three years old. At this point, it appears that David’s mental health started to deteriorate. He describes how God told him that both the child and her mother had died and been replaced by “demons” and that he could no longer trust them. The loss of his daughter makes him very upset but he can recall times with her that made him very happy.

“I remember once when she had just two little teeth … she bit into my cheek so hard it really hurt but she just held on!”

At some point after this he returned to the Caribbean and was later unable to go back to America. The subsequent sequence of events is unclear but David regularly received messages from God and was given a “mission” which led him to the UK. It is not quite clear how or why, but he seems to equate this with “doing anything for my daughter”. Upon arrival in London he was homeless and spent six days on the streets before eventually he made it to Buckingham Palace and told the policemen there that he had been sent by God to speak to the Queen. This led to his hospitalisation and subsequent diagnosis of schizophrenia.

Upon discharge, David moved into a residential facility in central London. Although he does not like the fact that the medical team and support staff do not believe him and think he has schizophrenia, he says he is not bothered by it as he knows the diagnosis is rubbish. He now has a fortnightly blood test and takes his medication regularly. He is happy to take his medication as requested if it keeps him out of hospital, as he believes it has no effect.

Despite his unconventional beliefs, in most respects upon meeting David he appears to be an intelligent, friendly, outgoing and funny person. One of his main passions is health and fitness. When he was in hospital he took part in various sports events and Olympic sports days, regularly winning. Since being discharged, he has joined the local gym. He tries to go five days a week and spends an hour each time working out and using all the machines. He also talks about helping other guys in the gym if he can see them doing exercises incorrectly.

“I want to build my arm muscles up a bit and tone my chest … but I don’t want to get too big. That’s not a good look … like that guy over there. I think he needs to buy a bra!”

As a result of his interest in working out, it is being arranged for him to undertake a gym instructor’s coaching course. He is hoping to start it in the next week or so and it should take around five weeks to obtain the qualification. He is excited about the opportunity and hopes it will lead to work.
Other than going to the gym, David takes a keen interest in other sports, particularly basketball, American football and soccer. He has just purchased a basketball and hopes to go out to shoot some hoops with some of the staff at the centre. He also expressed some interest in being able to play full games on a casual basis but is reluctant to join a team as his focus is on his mission and gaining employment.

In the meantime, David has just secured a part-time job as an usher at one of the West End theatres. The opportunity arose after he took part in a theatre production organised between the residential centre and the theatre. After the show he was invited to interview and got the job. He will be working approximately two nights a week as a front of house usher checking tickets.

David is delighted to have the job. A big perk of the job is that he will be able to watch the shows on the nights he works and this is something he is really looking forward to. In preparation for the job, he has purchased a new uniform in Primark, which he thinks they will refund the cost of, and has been reading the information they sent in advance. He is also looking forward to meeting new people and earning some money for himself.

At the moment, he lives on just “a loan” of £30 a week. He thinks that there is some confusion and delay over both his benefits and freedom pass so he is hoping that eventually he will have more money, even though his needs are minimal.

“I don’t need much money. It’s the root of all evil. Just enough to get by.”

Other than this, David mainly fills his days going out and about or listening to music in his room. He is a particular fan of chilled reggae music and has a small CD player. At present he doesn’t have a TV in his room but he is hoping to save enough money to be able to get one soon. An early riser, he often wakes at around 6am for a cup of tea, before going back to bed until breakfast time and then listening to some reggae music.

Although he did some art in hospital and enjoys drawing, he does not want to join an art group. He says art “takes too long” but can’t explain why this is or why he lacks the time. Although he does not want to create art, in hospital he did develop a love of museums. They were taken on regular outings to London’s free museums and David is particularly passionate about the National Portrait Gallery.

“When I first saw some of the pictures in there my jaw dropped … when you look at some of them they look real …”

David has been to the National Portrait Gallery several times now, both before and since being discharged. Once he wanted to go to one of the special exhibitions but didn’t have £12 for the entrance fee. However, he got chatting to the person at the entrance and when he told her he was staying at the hospital, she checked in a book, asked him to sign something, and let him in free. He is really pleased that free entrance was available to him.

He has also been to many of the other museums such as the Wallace Collection and the Natural History Museum. He’d like to go to the “National Air Force museum” to see the World War aeroplanes but he is unsure where it is – he has just heard that there is such a museum. David is very interested in history generally and has borrowed historical books from the local library. However, the disconnect between the books and the reality in which he lives seems to be a struggle and he talks about not liking “the modern stuff” and lots of it being wrong or too focused on the bad stuff that happened in the past.
Bradley is currently in transition. He is preparing to move from 24-hour supported accommodation into a new place run by the charity, Mind, which provides a much lower level of support.

For Bradley this is a clear step in the right direction. His ultimate goal is to have his own place; to live independently and be able to work. However, moving from a familiar environment where he is happy and comfortable leaves Bradley feeling a mixture of anticipation and apprehension for the move.

He has been living at the residence in Harrow Road for the past two years. He was moved here following a short stay in prison. While inside he was diagnosed with a mental health condition and following his release, was housed here by the prison probation.

While he is at the residence, he will mostly stay in his room. He doesn’t mix much with the other residents, aside from the odd film night. Here a few residents will get together and watch a DVD in the evening, often action films. Once, a group from Harrow Road went to the cinema with his support worker, which he really enjoyed. Bradley is aware of Time Credits, and if he earned credits he would like to use them to go to the cinema.

He is, however, close to the staff, particularly his support worker Ben. Bradley has struggled with drinking in the past, and Ben is a real support who helps to “keep me in check with my drinking”. Once a week he also attends a support group at DWP for people with alcohol problems.

Bradley has a plain room with a single bed, and some simple cooking facilities. He has a television and an old computer. The computer was given to him by one of his brothers, but it is password protected and missing a mouse, meaning it goes unused. He would like to be able to use it. Recently he did a computer course, where he learnt email, and is now keen to do more.

Whilst in his room Bradley spends most of his time watching television which he enjoys. He follows most sport, and also cooking shows, especially the Hairy Bikers as they show food from all around Britain. There is currently no TV aerial in his new room, and he is clear that he will not move until this is sorted. Being able to watch television during the day is very important for Bradley.

Bradley tends to cook chicken at home, and every couple of weeks he will get the bus to Iceland to stock up on meat. Previously, he would have walked. However Bradley's heart has been giving him problems recently. He has had a few spells where he has blacked out. He's not sure what's causing this but it may be related to the medication he takes. He has been advised to not do any exercise which will raise his heart beat too far. This has also put an end to gym sessions which he and Ben, his support worker, used to attend.

Most afternoons he will spend a few hours visiting his niece who lives a short bus ride away. He enjoys spending time there, and she is the only family that Bradley has in London. Again he really values her support in helping to control how much he drinks. She will often cook for him, though she is a vegetarian so it is always vegetables! Sometimes he also sees her two daughters who are 13 and 18, though often they are at school.
Bradley’s mother lives in the United States. Bradley has visited previously but currently this is not an option. Whilst he was in prison someone stole his passport and three people tried to use his details fraudulently. His attempts to obtain a new passport have been rejected. In the meantime he relies on Skype at his niece’s house to talk to his mother.

Outside of London Bradley has a lot of family. He has many siblings, all of whom live in Milton Keynes. Bradley grew up in Paddington, but in the 1980s he moved to Milton Keynes with his family. Bradley wasn’t a fan of the area. He prefers the “hustle and bustle” of London, and comments that in Milton Keynes they don’t have proper pavements, and public transport is poor. His siblings visit when they can – often they will go to the West End to have a meal.

Bradley’s routine will likely stay very similar when he moves into his new accommodation. The key differences will be new staff, and a slightly shorter bus journey to visit his niece each day.

Previously Bradley worked as a truck driver, which he loved – “there’s no boss, you’re in charge”. He would like to work again, but is currently on incapacity benefit – “I’ve got a bad heart, I wouldn’t pass the medical.”

Failing this, he would like to become a support worker for people with mental health problems – “I know what it’s like to be in that situation”.

Bradley is a member of the ‘Experts by Experience’ programme for Look Ahead who run his accommodation. He will be able to continue his involvement in his new accommodation and this is very important to him. The group of experts is responsible for interviewing new staff members, and assessing the quality of different services within the organisation. The group is called on as and when they are needed. When interviewing, Bradley looks for staff who are “personable and outspoken”.

Bradley is obviously proud of his work with the group, and has recently been nominated for an award for his efforts. He is very much looking forward to the ceremony. He also believes that his involvement through the Experts by Experience programme may enable him to later qualify as a support worker.

Bradley’s immediate future is mapped out with his imminent move to a lower level accommodation. Despite some apprehension, he is hopeful that this will take him one step further towards his goal, to have his own place; be living independently and be able to work.
Andrew

Andrew is in his 60s and lives in a mental health residential home for men in North London. For much of the last decade Andrew has been flitting between hospital, homelessness – sometimes rough sleeping, sometimes in hostels – and prison. During one stay in prison, officers noticed he was acting strangely so took him to the prison hospital where he was diagnosed with bi-polar disorder. Alcohol has also played a big part in Andrew’s life, particularly when he was on the streets.

Andrew is passionate about music and regularly attends music therapy sessions – “the top point of the week”. He loves playing the keyboard, enjoying the freedom of improvising and the opportunity to interact with others through music. Andrew first started attending the music therapy sessions during a year-long stay in a psychiatric unit. He would love to play music much more. He is eagerly anticipating the arrival of the keyboard in his bedroom which will allow him another activity apart from watching television. He has heard of another music session which he may be able to attend but is a little vague on the details or how he will access this.

Andrew is supported by a volunteer. Melvin spends time travelling with Andrew to music therapy each week. “Well I thought if he knows Melvin is there waiting at 9 each Friday he would be much more likely to go and to be regular with it”. The plan has worked. Now each Friday the two will travel together, and Melvin will sit and wait for an hour during Andrew’s session before coming home together, often via a coffee shop.

Other than the music therapy sessions, Andrew finds his days tend to be quite regular and repetitive. Mostly he is at home, in his room, watching daytime television – “you know the same old shows, I like Fraser, but it all gets a bit boring”. He eats ready meals, normally a chicken curry from the Co-op. A good day for him is a sunny day, so that he can go and sit in the nearby park though even then he will often get bored quickly and come home again.

Recently Melvin organised a trip for Andrew and himself to go to the Tower of London. He paid for this using time credits earned for formal volunteering within the organisation that supports Andrew. Andrew talks a lot about this day – “I didn’t want to come home!”. Melvin reflects, smiling – “I wouldn’t have spent those Time Credits on anything else… He [Andrew] 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” he reflects. However, there is some confusion over his benefits and how Andrew can access his money. He worries about “lacking the means to do more”.

Andrew has now been at his current home for around two months. Staff comment that he has made brilliant progress so far. He doesn’t describe himself as happy there but is quite settled, and resigned to the fact – “It’s home so I’ve got to make the best of it”.

Within the home Andrew is assigned a support worker. The two do not always see eye-to-eye on what pressing priorities are. Andrew is keen to sort out his Oyster freedom pass which has been rejected, meaning he has to spend a lot on transport. He doesn’t feel his support worker prioritises this, commenting that, “she seems more worried about the state of my
room and personal hygiene”. However, generally he has a good relationship with the staff within the facility.

Andrew comments that he doesn’t have a huge amount of contact with other people who live at Harrow Road – “they seem like a good bunch but people do their own thing”. However, he has clearly established himself as the go-to person for a cup of tea or roll-up, with a relatively regular stream of people to his door. Andrew chuckles about this in a slightly resigned way, but there is an unmistakable hint of pride in his voice.

Some of the immediate people in Andrew’s life – particularly Melvin and staff at Harrow Road – are very important to Andrew. However, undoubtedly the most important people to him are his family. He has three siblings, two ex-wives and three children. He did not see very much of his eldest two children growing up, but was much more involved in the life of his youngest daughter.

He would love to see his family again, particularly his children. He tries to make contact through writing letters – “I write. That’s all I can do.” One of his ex-wives wrote to inform him a year or so ago that his daughter had written him a letter but the letter never reached Andrew. Aside from this he doesn’t hear back. He knows loosely what his children are doing, and that they’re okay, and he is quite resigned to this – “They’re doing their own thing, but I would love to see them again.”

A few years ago he went to visit his brother in Bournemouth where he grew up. “He’s more steady than me. He’s hard working, he doesn’t drink or smoke…” His brother told him “I’m a very busy man, you can’t just turn up unannounced”. Andrew ended up sleeping in a tent in his back garden and hasn’t seen him since.

Thinking to the future, once the weather improves Andrew and Melvin are planning more outings. Andrew reflects it’s important for him to have company for these trips – “It’s better to do things with someone”. Andrew plans to remain where he is for the foreseeable future – “there’s nothing else on the horizon”.
Nicola lives in a fisherman’s cottage a stone’s throw from the beach in Kent. Her cottage is cozy and decorated with family photos, amidst the hustle and bustle of a family home. Nicola lives here with her husband Hasan, 20 odd years her junior, who moved to the UK from Bangladesh a few years ago. Also Pickles, the much loved and smelly family dog.

Sofia, Poppy and Amy – Nicola’s children – are currently living with a foster family. This follows a recent breakdown where Nicola mixed various prescription drugs and alcohol before arriving to collect her daughters from school. The school phoned the police: Nicola was arrested, and her daughters taken into care. Unsurprisingly, she is devastated. “It’s been seven weeks, and it feels like forever. If it turns into seven months, I know it will feel like seven years.”

Her daughters are being cared for under a section-20 agreement. This stands as a voluntary agreement between Nicola and social services; technically she could ask for them back at any time. However, this is not the first time that she has had involvement with social services, and the local authority are now threatening to apply to take the girls into permanent care. “It’s one thing after another… It’s hard to shake off social services, you’ll always be the first suspect.” In light of this worry Nicola is adamant that she must be fully better before she has her children back.

Nicola suffers from bi-polar, and although undiagnosed for much of her adulthood, she can now recognise she had these symptoms since adolescence. When she was younger she used to use these traits to her advantage – excelling in sales in the city, competing in sailing to a national level. Alongside this achievement, and enjoyment of the euphoric times, however, sat a string of abusive relationships, and a problematic relationship with alcohol.

Since her crisis Nicola has been attending Alcoholics Anonymous (AA) several times a week. She now describes herself as a recovering alcoholic, and has been sober for five weeks. Nicola closely links her binges with tough moments in her past. For example the sudden death of her (adoptive) father, the death of her adoptive mother following a struggle with Alzheimer’s, and tracking down her birth mother to be informed she was the “devil’s spawn” and born following a rape. Nicola points out many people with young children have family to turn to at such times, to provide support or look after children. She was not this lucky.

Nicola is devastated by the loss of her children, and is fully focused on getting her daughters back. Coupled with her devastation are the pressing practicalities that need sorting, a key one being if and how her benefits will be affected. Money is tight.

Nicola has few close friends. She doesn’t trust them. Previous ‘friends’ have flagged concerns around her drinking to social services behind her back, and many people voiced disapproval around her marriage to Hasan, both ageism and racism, Nicola feels. Since recognising and purposefully tackling her problems head on, Nicola has found her social circles rapidly diminishing – “When I was eccentric, and a bit of a drinker I got invited to parties. I was fun, but as soon as I’m a recovering alcoholic with bi-polar no-one wants to know. But I prefer me this way.”

As a result, perhaps the peer support at Alcoholics Anonymous is invaluable to Nicola, and she is quickly building up rapport within this group.

Nicola feels this sense of judgment comes not only from friends, but too often those with a duty to support her. She perceives a big part of this is lack of understanding around mental
health problems – “With mental health, the minute you feel you’re being judged you want to fall back into the crack that you crawled out of”. She cites her current social worker in particular – “It’s not helpful, she’s aggressive … She has this idea that threatening is going to be productive”. The social worker also provides the face to the vast local authority, who Nicola has found highly bureaucratic and frustrating to deal with.

Partly as a result of her bi-polar, but mostly her current situation, Nicola has up days and down days. On the down days she will simply cry. Every morning though begins with a walk on the beach with Pickles, which is “a good flush out”. She is familiar with many of the other dog walkers, commenting – “it’s good, they don’t ask personal questions. It’s just how are you, and all about the dogs”.

She is trying hard to find the right balance of keeping herself busy, whilst leaving time for self reflection and recovery. She has an off-peak gym membership and will often visit during the day. The cottage is also very much a work in progress. Nicola loves to root through local junk shops and furniture emporiums to find hidden gems for their home. She’s in the process of redecorating the girls’ rooms as a surprise for when they return home. Nicola knows only too well from previous experience that if she doesn’t take time to recover fully after a break down she will likely relapse at some point in the future. She is acutely aware that she cannot afford any further encounters with social services if she wants to keep her daughters.

Having a sense of purpose is crucial for Nicola. She feels that the lack of this led to her most recent breakdown, partly as Hasan was out the country for some time in Bangladesh visiting sick relatives. For some, she comments – “having children is enough, that’s all people need, that gives them their sense of purpose. For me it’s not, I’m not content all day while they’re at school and out the house”.

In the long term Nicola envisages this sense of purpose will be met by employment, but she doesn’t feel ready for this in the short term. In the meanwhile she is very keen to put her personal experiences to good use and has recently signed up to a peer-support scheme within Look Ahead. “There’s no-one in a better place to help you than someone who knows what it’s like.” She is also interested in learning more about computers.

Getting her daughters back is the absolute priority for Nicola. A great worry for her is that the foster home her daughters are staying in is laughter-less. Another is that her children are being taken on lots of trips and days out – to see castles or to the zoo – which she simply cannot afford to do as the norm. These things are only treats, and she doesn’t want her daughters’ expectations to be altered.

If she had the money she would love to go sailing with her daughters. She used to sail regularly when she was younger. “I miss it desperately … It cleaned my mind. People would become dots on the horizon, the feeling was absolutely fantastic.” She wants her daughters to have these same opportunities she did growing up. Another is to be able to play the piano, as her adoptive mother used to be a piano teacher.

However, she cannot think too far ahead at the moment. When asked what she is most looking forward to doing when her daughters return, she simply answers: “I just want to small 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.”
JOHN

John is a 53 year old man who lives with his parents in a small village in Wiltshire. He has lived there for most of his life, after his family moved there from London when he was a small child. He has a good sense of humour, is cheeky and affectionate.

John has had learning disabilities from birth. He appears to have a relatively high level of comprehension but struggles to articulate what he wants to say and his verbal expression is limited. Throughout the day, John can be seen laughing with his friends, shaking his head in mock exasperation when one of them does something he finds silly, and responding to questions such as “How old are you?” with “21” and a twinkle in his eye.

Both his parents are now in their early 70s. His mother has osteoarthritis which often makes it very difficult for her to walk, but his father is relatively fit. The other most important resident in the household is the family dog, Dusty. John and Dusty are clearly close and have a relationship of mutual adoration. John does not usually take Dusty on the long walks that she needs, but he enjoys playing with her and stroking her.

John is very close to his family and in particular talks a lot about his sister, expressing a desire for them all to live together again. She is married and also has three children from her first marriage. John also talks often about his nieces and nephew, Charlotte, Abigail and James. Abigail also has learning difficulties and lives in a residential facility in Somerset where she is training to work in catering.

John’s parents are adamant that he should be able to do everything possible and encourage him to try to do new things and take on responsibilities. His mother says that she has felt this way from birth and was angry when the health visitor at the time suggested that John went into residential care and that the family “move on and have another child as soon as possible”. His mother contrasts the opportunities open to her granddaughter with those available to John when he was young, and is glad that things are very different now.

At the present time this wish to ensure he achieves as much as possible means that John has a number of “duties” at home. He “owns the Dyson … no-one else can touch it” and is also responsible for loading the dishwasher after evening meals and laying the table for breakfast. As he has to take a packed lunch every day when he goes to the day centre, he makes this himself. It typically comprises a sandwich – “he is very careful not to cut himself” – a cup-a-soup, some crisps, yoghurt and some fruit. In addition, he often helps out with other chores around the house and garden, and enjoys helping prepare dinner.

At home, John has his own room which overlooks the garden and is painted bright yellow with a cheerful orange and yellow border. The room contains many items related to his main passion in life – cars, and particularly racing cars. There are several large pictures on the wall reflecting this passion, including a large canvas of an F1 car. John never misses a Formula 1 race or the qualifying sessions and is “transfixed” by it. He knows the race results and likes to discuss it with friends and staff at the day centre he attends.

However, F1 is not his only passion and he loves all types of car. His room contains several hundred copies of car magazines. His room also has a large collection of model cars which he keeps on his window sills and in a drawer under his bed.
John’s interest in cars has clearly been fuelled by sharing the passion with his father. In the garage, his father has five vintage cars, including one that is 100 years old. He and John often go out in the cars and sometimes attend rallies together, with John sitting in the back.

During the week, John attends the nearest day centre. He is collected and returned home by minibus. He enjoys his time at the club and takes part in a range of activities including sports, zumba, tai chi, baking, sewing, crafts, music, rambling and a friendship group. The friendship group meets at the local liberal club and plays activities such as skittles or bingo, or simply spends time chatting and drinking tea or coffee.

One of his favourite activities, however, is the History Club. This is a small group of men who go on regular outings to places of interest. Ostensibly this is related to history but has recently included Cadbury World. They have visited lots of castles, London in the run up to the Olympics, and places in the countryside. It is led by one of the male staff members and the group seems to have lots of fun.

Whilst at club, John met his girlfriend, Pam, who is more able than him. They sit together during lunch and John’s parents say that they have met for dinner once or twice.

John also clearly has good relationships with the staff at the centre and is excited about the fact that two of the team are about to have a baby. John’s parents are positive about the experiences offered by the centre but lament the lack of opportunities for meaningful work.

“A long time ago they used to do some light manufacturing … He only earned a couple of pounds a week but he was very proud to come home with the money he earned … then health and safety, and the minimum wage came along and it all stopped. Some people thought it was slave labour but we didn’t … he enjoyed it.”

Later on, the day centre used to collect used aluminium, clean and press it into blocks. The blocks were sold and the funds used to raise money for their activities.

John has recently started earning Time Credits at the centre for cleaning up after baking. He seems to like the responsibility and earns the credits in five-minute blocks. He also voluntarily does the washing up at each session and puts away the equipment. His parents see the Time Credits scheme as a way of giving him at least some recognition for the work he does and think that is more important than whether or not he actually spends the credits.

On a Wednesday evening, John also attends a social club. He comes home after the day centre and then a taxi collects him later on to go to the club. It is more informal and less structured than the day centre, but many people John knows attend both. His parents are glad that there is transport available to take him to the club, particularly in the winter, as his father no longer likes to drive at night. John mostly spends other evenings and weekends at home with his family.

Last Christmas, John was given an ipad by his parents. He loves it and they hope it is also beneficial for his hand-eye coordination. John’s nephew and brother-in-law downloaded several apps for him and have made sure that he can’t accidentally accrue large bills by buying in-game credits. He can play the same game for extended periods of time.

Once a month, John goes to a local home for respite care. He typically goes there on a Tuesday night and then comes home again on a Friday night as usual. It gives both John and his parents a break and he likes spending time there. He doesn’t always stay with the same group but there are only four people there at any one time. He is often there with his friend Chris, who also attends the day centre.
CLAIRE

Claire is bubbly and talkative, often more intent on telling people about her morning’s activities than eating her lunch – to the dismay of her support workers. She has recently celebrated her 27th birthday and deftly manoeuvres herself around in her manual wheelchair. She is a big and bright personality, widely recognised as a great chatterbox.

Claire is a regular at the local day centre for adults with learning disabilities in Lewisham. Over the last few weeks she has been making a teapot in her pottery class and it is nearly finished. She attends three days a week and is very active within the centre. She takes part in User Forum Meetings, where users of the service come together to discuss how effectively it is running. She also helps to create the Newsletter, which is published to share news within the centre, and loves taking photographs. She also preparing her routine to Twist and Shout for Dare2Dream, the centre’s much anticipated annual show which takes place at a local theatre. Staff comment there has been a general shift within the centre to running activities which have an employment theme, or are associated with developing life skills.

Claire loves special events at the centre, such as a tea party for a friend who will no longer be able to attend as she is moving house. There is cake, presents and music. Lots of people are up and dancing. Claire is desperate to hear some Indian music, and dances away to the tunes. She shrieks with laughter as the staff spin her around in her wheelchair.

As with most of the day centre customers, Claire is picked up and dropped off each morning by the community bus. Claire is not confident travelling by taxi with her wheelchair, and so relies heavily on the bus.

Claire spends a lot of time preoccupied with the various drivers on her bus. Specifically, she spends a lot of time worrying that her favourite drivers are going to leave. During the day she makes various comments about the different drivers, worrying “I don’t want to drive him away”. At one point a support worker at the centre reassures her they haven’t heard news of anyone leaving. This delights Claire – “brilliant news!”

The staff at the centre comment that Claire often takes an instant liking or disliking to certain people. Once she has made this decision she rarely changes her mind. She is very strong willed, and has lashed out before at people she doesn’t like.

Jasmine, one of the support workers, is a clear favourite though. Jasmine laughs – “I’m not her support worker, but she always asks me to be!”

Claire lives at home with her mother a short drive from the centre. When she is at home she likes to watch TV. She especially likes Formula One, and is a big Lewis Hamilton fan. She also loves music and likes listening to the Script.

While at home she also receives support as part of her care package. Every Monday a befriender will visit for a couple of hours. They will often go out and about, and Claire’s mother will sometimes join them too. She also has some support from carers, which often goes towards Claire’s personal care. Claire comments that she often has lots of different carers and she doesn’t like this.
Claire’s mother is obviously protective of Claire, and worries about her getting over-tired. She comments that it is often when Claire is tired that she will become stressed, and lash out at people, or become overly anxious.

Once a year she will attend respite care, which she loves. It runs during the summer and there are various sports, activities and competition during the days.

Claire has lots and lots of ideas about things she would like to do in the future. She would like to do more outside of the centre, regularly suggesting a walk during the day. However, her desire for spontaneity is often met with a negative response due to health and safety or risk assessments. Claire finds this wearisome.

Claire’s impulsive nature shines through during the day. At different points she decides wholeheartedly that she wants to switch her days at the centre, she wants to start a sign language course, she wants to change day centres altogether, she wants to stop attending the User Forum Meetings, she wants to change her care package, she wants to go bowling, she wants to move house … The list continues.

Her support workers comment this is normal for Claire. She is inclined to change her mind a lot, and often at short notice – partly this is related to anxiety. This makes planning activities in advance with Claire quite difficult.

However, things that remain fairly consistent in terms of her ambitions are a desire to get out of the centre more – whether that is to do more in the local area, to take photographs or to simply have a walk. Another constant is swimming. Claire loves swimming. When she was younger she used to swim a lot with her school. However, her weight is now flagged up as a health and safety issue for getting into and out of the water. This means she is unable to go. This creates a vicious circle. Claire attends two exercise classes a week, and staff encourage her to push herself where she can. But there is no escaping that exercise is hard for Claire and what she is able to do physically and from within a wheelchair is very limited.

Claire tells me that this issue of how she can do more outside the centre was discussed at her recent social care review meeting. This is secondhand news to Claire, however, who decided on the day that she was not willing to miss her usual activities and refused to join the discussion. This meant the social care review took place with her mother and the social worker instead.

She is now looking forward to what can change as a result of the meeting.
Robert, or Junior as his mother calls him, is in his forties and lives with his mother and one of his younger sisters in Lewisham. Robert has complex learning disabilities which emerged when he was around nine months old.

His learning disabilities have a significant impact on his functioning – communication can be difficult, he tends to shuffle a lot, and he is prone to falling and seizures. His mother reflects – “he is very slow, and he needs a lot of prompting”. But his personality shines through strongly. He is a very affectionate, caring and sensitive man. He takes time to greet nearly every person that walks into a room he is in, and often introduces me to people also.

Robert lives at home with his mother and one of his sisters. Robert’s father left the family as he found Robert’s situation very hard to deal with. The absence of his father has left Celia very aware of the lack of men in her son’s life. So wherever possible she requests male support workers to help even out this balance. Robert knows his father has gone, sometimes he will get upset and cry about this. However he doesn’t seem to fully understand his father’s absence, at times suggests he has died.

Many of Celia’s family (siblings and other children) now live abroad – she grew up in South America, and several of the family have moved back to this part of the world. They regularly Skype, but rarely see one another.

Celia is, perhaps unsurprisingly, extremely protective of Robert. His doctor told her that Robert has the mental age of a three-year-old. She refers to this comment several times, telling me she must remember he is a child trapped inside an adult’s body. He does not travel unaccompanied – “he would just walk straight past the house”. Even at home, she walks up the stairs behind him to prevent him falling over.

This protectiveness often shows when new activities are suggested. Celia has many questions. How would he fit in? What would he be doing? Will it be warm enough (Robert’s seizures are often triggered by him being cold)? He might not tell you if he was feeling unwell, etc. This hesitation is especially true if there have been instances in the past where Robert has fallen. However, she does recognise “I have to let go at some point”.

Robert has regular meetings with his social worker to review his activities and support levels. Robert contributes to the conversation sporadically but much of his attention is focused on drawing intricate wobbly lines all over a sheet of paper. Occasionally however, he focuses intently and comments on the discussions, for example about computer training. At other times his conversation is less coherent. Practically, despite the best efforts of the social worker, much of the conversation happens between Robert’s mother and herself.

Robert now spends four days a week at a local day centre. An extra day is added during his social care review to incorporate a gardening project. Since moving down from North London a few years ago, Robert has attended two centres. The first did not work out, though it is unclear why and seems a bit of taboo subject.

Robert appears happy and settled at the centre, and his mother is happy that since attending Robert has not yet had a seizure. He is a very sociable member of the centre and takes great pride in his relationships with others. He greets people affectionately as they enter a room.
There is a woman at the centre who he calls his girlfriend, yet it is unclear if those affections are returned.

Robert will often vote with his feet. He tends to float between the assigned activities at the centre according to his mood. One afternoon is spent flower arranging. Many of the customers use real flowers for a small charge. However, Robert’s mother does not like real flowers in the house, and so Robert makes an arrangement with artificial flowers. He engages with the activity slowly but surely, carefully considering which flowers he would like to add. At times his support workers intervene, swopping around his flowers within the basket.

Robert arrives home and proudly passes over his flower arrangement to his mother. She swiftly passes the wicker basket back to him – to allow others at the centre to re-use the flowers. The house is immaculate, and Celia holds very high standards for her own and Robert’s appearance.

Robert is often quite tired when he arrives home but if it is a nice day they will sometimes wander across the road to visit the park. Celia is careful to not be out after dark though, as she worries for their safety. This fear partly stems from her own experience of being mugged. They rarely leave the house once it is dark.

A few days a week, carers will visit to help Robert wash. Celia comments that he is often very tired when he comes home and will sometimes have dozed off before they arrive. However, he will be up several times during the night to go the toilet. Celia finds this routine exhausting, but there is little she can do to change it. For a while she gave Robert less water but was then informed by the doctor Robert was not hydrated enough.

At the weekends Robert often watches television and enjoys listening to music. He enjoys watching sport on the television, and also things that make him laugh – Harry Hill’s TV burp is a firm favourite. Celia comments that “he knows the characters on Coronation Street better than me!”, but will often get quite upset if there is an argument on the show.

Celia will try to make sure they leave the house, though this is harder in the cold weather. They might go for fish and chips, or sometimes they will take a ride on the bus or train. They rarely travel at peak times however, as someone once shouted at her and Robert when they perceived he was staring at them. It was simply his natural expression. Celia talks fondly of friends in North London. She doesn’t seem to have the same network of friends in South London and seeing old friends is now much harder given the distance.

Robert finds it difficult to articulate what he would like to do in the future, and tends to talk enthusiastically about anything suggested to him.

His mother puts all of her energy into caring for him, and she has little capacity to do more than she already does. However, she recalls other activities from his old day centre he used to enjoy that he doesn’t get a chance to do anymore. Swimming, horses, and day trips to the beach are all things that Robert has really enjoyed in the past but no longer gets to do.

For Robert, it would be essential that these things happened through care providers, or the day centre as a structured group activity.
Tom is an incredibly energetic and sociable young man. Despite it sometimes being a little hard to understand his speech, he is easy going and happy to talk away to most people.

On paper, Tom has a complex diagnosis with a wide range of conditions affecting his functioning: Fragile X syndrome, autism, severe learning disabilities, Attention Deficit Disorder and hyperactivity, cerebral palsy and spastic diplegia. The reality of his life though finds him living his days to the full, for example as a member of the winning team during a lively game of Boccia at a local, dynamic hub for adults with learning disabilities in an outer London suburb.

Tom can be found with his mind half on the game, and half with the group of support workers who sit and chat at the edge while the others play. He shouts from one to the other, waiting for their attention to tell them “you smell!”, a comment which is often returned to him. From Tom, this is a true sign of affection and that he is relaxed and happy. Tom is supported by Julie, who has been spending time with Tom for the last eight months or so as an outreach support worker. Coincidentally his father is also with the group, as he is a support worker for another individual.

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 in the morning, which bus he will get to his activities etc.

At the age of 23, Tom has recently moved out of his family home where he lived with his father into supported accommodation.

He has now been living in his new flat for three weeks. It is a pristine and bright one-bedroomed flat. Tom is obviously very proud of it and it already feels like home. The window sill and surfaces are decorated with photos of his family, and a collection of welcome to your new home cards. On his fridge are detailed his busy routines – with activities planned through his outreach every weekday. He also likes to help with tasks such as vacuuming, washing, and helping with the cooking.

The flat is in a newly-built, supported accommodation complex specifically for people with learning disabilities. It is not yet full, and once full, there will be 12 customers living there. Tom is already a firm favourite. They hold a regular coffee morning in the lounge and Ben, Tom’s support worker, jokes that everyone wants to spend time with Tom!

Within the home individuals are assigned support workers. Ben helps Tom with various domestic tasks, including laundry, hoovering, cooking, helping him keep track of his money etc. The two have a good relationship (Tom regularly tells Ben he stinks) and Tom obviously sees Ben as a support figure, often deferring back to him for reassurance during our conversation.
Julie, who provides outreach support for Tom, has also been helping him through the transition. She has been very conscious to give Tom some consistency during the move. For the last few months they have been visiting the home for coffee mornings. Here, Julie would deliberately take a step back or remove herself from the situation, to allow Tom to develop relationships rather than deferring back to her.

This move signals a much greater level of independence for Tom. For close family this will inevitably mean some letting go. Tom’s support worker recalls a recent time when Tom became very keen to travel by bus. He would talk about this a lot, and so they made plans for Tom to get the bus. As outreach support they have a duty to support Tom to do what he wishes. His father, however, was very concerned, having had a very bad experience with Tom on public transport before. The trip went ahead. It was a real success, she laughs, “be absolutely loved it!”. She reflects it was an interesting revelation for Tom’s father that Tom, at times, could be a very different person depending on who he was around.

Whilst at home, Tom enjoys watching DVDs. He has a good collection, including several box sets of Friends, Monk and a few children’s compilation including firm favourite, The Hoobs. Tom eagerly loads up the DVD player with the Hoobs DVD and repeatedly watches the opening theme tune, before rewinding back to the beginning. This happens over and over again, Tom never lets it play for more than a few seconds before rewinding. After this he does the same with Friends, before switching back to the Hoobs again.

He also loves listening to music, particularly through his prized blue headphones. During conversations he will sometimes put the headphones on, without music playing and enjoys wearing them. He is excited about taking the bus tomorrow as it means he gets to listen to his iPod – Abba and Mamma Mia are his favourites.

Tom doesn’t go out on his own – “I think he is too inquisitive” comments Ben.

However, five days a week Tom receives outreach support through a private agency, which his Dad pays for. Incidentally, his dad is also a support worker, and so often the two see each other in the day during activities. Mostly Tom is very active. He attends multi-sports sessions a few times a week at various leisure centres, including keep fit, boccia and line dancing.

Sometimes the outreach workers will arrange a specific activity, for example clients will gather together and all go bowling. In the past they have been to the beach.

His weekends are generally spent with either his mother or his father.

For Tom, the current situation is very much the shaping of a new norm for him. The home has offered him a much greater level of independence, a chance to form new relationships, live away from home, and grow in his ability to look after himself.
Mary-Lynn is a 38-year old woman who lives in with her mother and older brother in a small town in Wiltshire. She is the youngest of seven children, with just one older sister and the rest brothers. Kevin is the middle child and in his mid-late 40s. Her father has passed away. Most of Mary-Lynn’s other siblings and their families live within a 30-mile radius and she sees the most local ones regularly. She is also particularly attached to twin nephews.

When Mary-Lynn was eight months old she had encephalitis. This resulted in brain damage which left her with a severe learning disability. While Mary-Lynn understands most day-to-day conversations and questions, her ability to understand more complex concepts is very limited. She has quite severe communication problems, with a very limited vocabulary – typically only the names for objects and not full sentences or grammatically constructed. She also pronounces most words in a unique way which mean that when someone new meets her, they are likely to need to have her key words explained/ ‘translated’ for them at the start.

In addition to her learning disability and communication problems, Mary-Lynn has problems with her balance and coordination which mean she often falls over. As a result she has lots of small cuts and bruises on her body, particularly on her hands and knees. Her family say that this usually happens when she is out and about with the day centre rather than in the home. Although they mostly do not appear to be severe or particularly painful, Mary-Lynn often points out the bruises to people and touches them a lot.

The urge to protect her means that her mother and brother are very careful about letting Mary-Lynn get into situations where she could potentially hurt herself at home. For example, Kevin always follows Mary-Lynn up the stairs to make sure she doesn’t trip or fall, and doesn’t let her stand alone at the landing window at the top of the stairs to wave goodbye to guests. This seems to have led to some tension in the family, with one of the other siblings suggesting that they are over-protective. However, Kevin says “I live with her and I know her best … and it’s not safe for her to stand there”.

Mary-Lynn clearly has her mother and brother at the centre of her universe and she will try to talk about them at every available opportunity. She also tends to repeat herself regularly – for example, “my brother Kevin lent me his camera” (indicated through a combination of key words and gesture). When seeing Mary-Lynn and her mother and brother together, it is immediately evident that the nature of the relationship is two-way and that she is as important to them as they are to her.

The inter-dependency of their relationship is highlighted by the feelings of her brother and mother about Mary-Lynn going to respite care once a month. Whilst they recognise that it is good for all of them to have a break, they comment:

“It’s so quiet without her here … you come in and don’t know what to do with yourself”.

Mary-Lynn attends a day centre five days a week where she participates in a range of activities including skittles, classical music, photo-art, communication, cooking, sewing, reading and sensory relaxation. She particularly loves classical music and her favourite artist is Andre Riu. At home she has many classical CDs which she likes listening to.
Mary-Lynn really enjoys the outings from the day centre and highlights have been a spa day, a trip to the pantomime, and an upcoming trip to the zoo. The zoo is particularly exciting as Mary-Lynn loves animals.

“She always comes home and tells us all about what she’s been doing … she’s very proud to bring home the things she’s made in sewing and everything, I think; she’s making a cushion for her cousin at the moment.”

Mary-Lynn also recently joined the new photo-art club at the day centre and she really enjoys it. The group recently went on a trip to a nearby animal farm centre which is specially designed to be accessible to people with learning disabilities. Mary-Lynn had a fantastic time and particularly enjoyed seeing the baby rabbits, donkeys, owl and pigs.

Owls are Mary-Lynn’s favourite animal and she is passionate about them. In her home she has a huge range of animal ornaments, toys, and cushions etc. For a while the family had rabbits and goldfish as pets, which she loved, but these have died and she no longer has any animals to help care for.

At home Mary-Lynn sits down when she first gets back from the centre and spends time flicking through a large binder of animal magazines and articles. She does this with a cup of tea and ‘Deal or No Deal’ on as well. Tea is her favourite drink and she drinks many cups a day! Her family are uncertain whether or not she can actually read but she enjoys sitting and looking through picture books and magazines like OK and Hello.

“She’s totally silent when she’s looking at the magazines and it has to be OK or Hello … I used to buy her ‘Pick me up’ but that wasn’t good enough!”

Outside of the day centre, Mary-Lynn does not attend any social clubs or organised activities. She spends most of her time at home or out and about with her family. They are not particularly well off and do not have a car so their ability to go far is constrained by transport options or they are reliant on a sibling taking them out in their car. Mary-Lynn likes to watch all the soaps and play board games with her family. Her room is also full of toys and various treasures. She has a large collection of soft toys, including many owls and some meerkats, as well as some dolls and crates full of beanies.

Mary-Lynn used to go horse-riding outside of the day centre and her family say that this was an activity she really loved. However, the funding was withdrawn so she is no longer able to go, although she would like to do so. Swimming (through the day centre) is another activity she is no longer able to enjoy as she is always waiting for cuts and bruises to heal, particularly one on her knee which is very persistent.

Mary-Lynn appears to have a very clear routine at home that starts when she wakes at 5am. At that time both her mother and brother also get up to settle her downstairs with a mug of tea and a nature DVD. She also has some responsibilities such as making her bed, helping do the washing up, and sometimes vacuuming. They are also in the process of redesigning the garden and are planning on making Mary-Lynn a small flower bed that she can tend. Mary-Lynn goes to bed around 9pm each night but apparently does not sleep until she has heard the neighbour come home at around 11-11.30pm.

Mary-Lynn is given £200 a month of her benefits money to spend as she pleases on things like DVDs, CDs, and trips etc. Her mother keeps the rest of the money to put towards her clothes and other expenses. Mary-Lynn does not have a good grasp of money and needs support to buy things such as coffee on days out. Kevin also comments that “she always wants coins, not paper money”, and would take the coins even if they were of less value than the notes!
Josie is a 26-year old woman who lives in supported accommodation in North West London. Josie was born with Downs Syndrome and grew up in London with her mother, step-father and sister. Her sister is just a couple of years younger than her.

Although she now lives close to her mother and grandmother, Josie lived in Somerset and Dorset for a while in her early 20s. She attended college there but the relationship turned abusive. The events were hugely stressful both for Josie and her family. Eventually she was able to return home to her family but unfortunately, at the end of last year, her mother had a breakdown and suffered a period of depression – “I found her and saved her”.

Her mother recovered but Josie has been living in the supported accommodation since March this year. Despite the difficulties she has faced, Josie is a highly motivated and determined individual who likes to fill her days with a range of activities – “I’m not going to let him affect me now … I want to make the most of it”.

In many respects, Josie is relatively able. She has basic to moderate numeracy and literacy skills and a good level of comprehension. Her verbal communication skills are also relatively good. However, she also has physical disabilities and uses a walker when she goes out and about, although she does not need it when in her flat.

Josie requires support with many everyday tasks such as showering, shopping, and cooking, as well as support with the daily administration of life – planning activities, filling forms, and budgeting. On Fridays and weekends, her core support hours are supplemented with longer periods when staff take her shopping, help with cleaning and also support her to participate in leisure activities. Josie likes living in her flat and the sociable environment – “I like it … I like the communal areas … I like my friends”.

Her flat opens onto the communal garden area and she has planted a few flowers in a small border and also has a rose plant in a tub. Whilst she enjoys her independence, Josie is a naturally messy girl and finds domestic chores a drag. She has a good sense of humour about it and laughs at herself.

“I hate washing up … I didn’t get a star yesterday because my room wasn’t clean enough. I wanted a star … [then tidying her room and finding clothes on the bed] … what am I like?! I slept with the clothes on my bed … no wonder it was hot and I had to keep moving the sheet!”

Josie also has support with cooking and her doctor has advised her to lose weight so she is now trying to eat more healthily. Once a week she sits down with her key worker to create a menu plan for the following week. The schedule is then pinned on her fridge. She and her key worker then shop together to buy all the food she needs.

Despite having moved out of home, she still sees her family often, and often talks with her mother on the phone. Josie is a very “girly” girl and particularly likes fashion. She has a large wardrobe of clothes and loves shopping in places like New Look and River Island. Her favourite colour is purple and as well as having clothes in the colour, she also has other touches of purple around: accessories and other items such as her bedding and hairdryer.
Her mobile is an important possession for her – “It’s a new one”. She particularly likes the media applications. “I take lots of photos … it’s my hobby … I know how to use YouTube and Facebook … you have to be careful … I’m friends with my family but people I don’t know, I block.”

For four days a week, Josie attends the local college to participate in Adult Learning classes. She loves attending college and has been going for two years. She takes a range of courses and is currently working on the college newspaper. She is developing her key skills as well as taking part in courses such as photography, arts and crafts. Josie believes that she can’t return next year but her key worker says it is simply a case of re-enrolling her on the classes she wishes to take. In addition, Josie attends social clubs two evenings a week.

With such a wide range of activities, transport is an issue. Josie’s key worker is trying to encourage her to use the bus more frequently but she is very nervous about taking the bus alone. When possible she uses Dial-A-Ride which offers free transport but is not particularly reliable. She therefore uses a lot of taxis to get to college but these are expensive and is another reason why staff are keen for her to use more public transport.

In her free time, Josie loves her soaps and also watches a lot of films, mainly comedies, Disney movies, rom-coms, and musicals. Most weeks she will go to the cinema on a Friday or Saturday with a member of staff. Another passion is swimming and Josie goes at least once a week, sometimes more during college holidays. This is good for her mobility and she has recently joined a special Saturday swimming club for people with disabilities.

Josie and her key worker have a fantastic relationship characterised by lots of giggles and chat. They work together and think about what activities Josie might like to do in her free time. A diary in the flat records all her appointments and upcoming events.

The other most significant person in Josie’s life is her boyfriend, Andrew. They met at an evening social club in 2010 and have been together ever since. He is partially sighted alongside his learning disability and is several years older than her. “He looks after me … we like to have a kiss and a cuddle.”

Apart from meeting at the social club every week, they do not get to spend much time together as Andrew does not attend the same college as her. However, during half-terms and holidays, they both attend the same programme of activities and enjoy the extra contact.

Josie is very much in love and they speak on the phone every day. She confesses that one day she’d like to marry Andrew but there is no rush – “We want to take it slowly”. Josie and Andrew have never been on a proper date due to the logistical challenges involved. Upon hearing this, her key worker offers to liaise with Andrew’s key worker to arrange a meal out at a local restaurant. Josie thinks this a great idea and wants to go “somewhere posh”. They finally settle on a local Indian restaurant as a good choice.

Josie has lots of hopes and aspirations for the future. She likes to be busy and is worried about not being able to return to college. It has recently been arranged for her to start a volunteering placement in the offices of the local disability association. She will be working there two hours a week. Josie is really looking forward to this and will be working in the reception area answering phones, photocopying and filing, etc.

Whilst Josie is looking forward to the new experience and responsibility of the volunteer work, she does not yet feel ready to take on paid employment. As with her relationship, she says “I want to take it slowly”. She does expect that in the future she will be able to get at least a part-time job, but is currently only focused on the volunteer placement.