

Helping People Thrive

Stories and Lessons in Transforming Care



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Helping People Thrive

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Helping People Thrive

STORIES AND LESSONS IN
TRANSFORMING CARE



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Foreword



This is the first of 2 planned practical guides to how to transform the lives of people who have been detained in hospital far beyond any reasonably needed time period for clinical assessment and treatment. The stories in this first publication were inspired by a workshop on good practice which the Department of Health and Social Care supported me to convene earlier this year.

I am grateful to the attendees who generously gave their time and especially the storytellers; the skilled facilitators and group leaders and Alicia Wood who has brought the stories so clearly to life to share with you, the reader. Our second guide will look at the barriers and solutions we have identified in the reports from the Independently chaired CETR's that the Secretary of State asked me to oversee.

I sincerely hope that these stories will help to raise the aspirations of everyone involved including the person themselves, their family members, advocates, social workers, clinicians, commissioners, home and support providers, hospital managers, policy makers and regulators. The stories show how it is possible to create a new and satisfying life in which even the most traumatised person can regain a sense of well-being and belonging.

Some themes have emerged from the stories of these 5 people's lives; lives that have changed so positively, and which now much more clearly match the aspirations in Building the Right Support. We have tried to identify the essential ingredients required to achieve a real and sustainable transformation in the way in which services meet the needs of people with

learning disabilities and/or autistic people who have been, or are at risk of being admitted to an assessment and treatment unit: An aspirational and passionate advocate who believes in this individual's right to an ordinary life with the right support; An accountable named leader who takes responsibility for problem solving and delivery; A multiagency partnership jointly committed to an agreed and funded plan which is realistic about timescale, honest about risks and establishes shared responsibility for addressing these. A plan and individualised specification for home environment, occupation and support, including ongoing clinical support in the community, which has been developed and agreed with the individual and their family.

Everyone was committed to the same clearly understood goal, to help each person start a new life 'back home'. Clearly, we also need national policies, initiatives, and practical support locally that will make it more possible for other people to benefit from the lessons learnt from Susan, Andrew, Rodney, Mary and Mr. Wonderful's stories. The aspirations set out in Building the Right Support require a long term commitment to strengthening local, person-centred approaches and capacities.

Professor Sheila the Baroness Hollins, *Chairperson of the Oversight Panel for the Independent Care (Education) and Treatment Review process*



Introduction

Story telling is one the most powerful forms of communication. Stories help us to understand concepts we find difficult to understand and they help us to make sense of a complicated world. Stories inspire us and spark our imaginations. Stories make us think and they make us feel.

The horrific story of the abuse of people with learning disabilities in the Winterbourne View hospital back in 2011 that we witnessed by secret filming on BBC's Panorama shocked many of us profoundly. That terrible story inspired a whole range of organisations to work to change what they do and to stop abuse and stop people with learning disabilities and autistic people going in to hospitals. There is much work happening around the country under the Building the Right Support programme which was launched in 2015.

Despite all the work happening to transform care, there are a steady stream of stories of failing services, abuse and people with learning disabilities and autistic people still going in to hospitals when they should have better support in their communities. These stories are told in newspapers, radio and television by journalists. They are told in books, blogs and social media by individuals and families who have experienced abuse, poor care and wrongful detention. Some stories are of people who have died in hospitals. They are powerful and disturbing stories and are necessary to hear.

However just hearing stories is not enough and we need to be able to respond and take action to stop what is happening that is wrong and do more of what is right.

In order to find the knowledge and motivation to change things for people in these situations, we also need to hear the stories of the many who have left hospitals and are living good lives in their communities. We need to hear the stories of how they managed to get what they needed when others don't. We need to know what is happening that is different in places where the NHS, Councils, housing and care providers and families are helping people to thrive.

We invited story tellers who had been involved in helping people to come out of hospital and live good lives in their communities to meet and tell their stories in a one day event. We also talked to people after the event who couldn't make it on the day, and listened to their stories too. These stories give us hope that a good future is not only possible but achievable. They give us a sense that we can really change things if we learn from what people get right. We hope they do the same for you.

We need to know what is happening that is different in places where the NHS, Councils, housing and care providers and families are helping people to thrive.

Stories and Lessons

These are stories about people with learning disabilities and autistic people who are thriving, living in their own homes, in their own communities. People who were in Assessment and Treatment Units (ATU's) for years, often segregated from others. Some of the people whose stories we've told were thought not able to live in their communities. Some had spent too many years in the 'too complicated box' and left in hospitals where they shouldn't have been. Most were traumatised by their experiences.

These stories are of hope. They are mainly stories of where Building the Right Support has worked and good commissioning systems, clinicians, care organisations, self-advocates and families have made good things happen. All of the names of people in these stories have been changed and some details changed to avoid identification.



Key Ingredients: Mr Wonderful

A passionate commissioner driving it who used procurement laws in a better way to meet local needs

Thorough clinical formulation leading to an effective therapeutic plan

Skilled/Experienced care provider with well trained staff

Individual Service Fund and flexibility with £

£60k transition and crisis fund for 12 months

NHSE Capital Fund for housing

Shared risk between all involved

Pro-active plan to avoid re-admission

They call him Mr Wonderful

Introducing Mr Wonderful....

“I’m going to call him Mr Wonderful because that is exactly what he is, wonderful”. This is the CEO of a care provider talking about a man that her organisation supports. This introduction tells us so much already about the nature of relationships and attitudes needed to make things work- she clearly genuinely cares for Mr Wonderful. For the purposes of this story, we’ll call this care provider Going the Extra Mile, GTEM for short.

Mr Wonderful lived in a hospital for 20 years. When he lived with his family, he was often angry and hurt himself regularly. His parents couldn’t cope and didn’t feel they could have him at home any more. He was admitted to hospital for treatment but instead of getting better, his behaviour got worse.

In the hospital, Mr Wonderful spent a lot of time being secluded in a room with a hatch, where he was given food and on constant watch by staff. In the last two years of being in hospital he tried to kill himself so often that ambulances were called 161 times. He tried to run away from hospital many times.

His parents were angry about what had happened to their son and didn’t trust services or professionals. Professionals found it hard to work with them and they had a reputation for being ‘difficult’. A story that will be familiar to many families and professionals in situations where services have not met needs over a long period of time.

Now, Mr Wonderful lives in his own home and has been there for over a year at the time of writing. He is supported by GTEM, a small specialist support provider, owns his own home through shared ownership. NHS England provided some of the money for his house through the Transforming Care capital fund.

For the first time in his life, Mr Wonderful was asked what he wanted and what was important to him, and his home and support were built around this. He has his own team of support. He has an Individual Service Fund (ISF) to pay for it, which means the council and/or the NHS commissioner (meaning the person whose job it is to arrange and pay for care) give the money directly to the care provider but the person being cared for and family still control how it is spent. Life has gotten much better for Mr Wonderful and just to give you an idea of how much things have changed for him, he has been on holiday, and to the pub by himself- something he could have only dreamt of a year ago.

Meet Mr Wonderful's care provider....

This isn't of course the full story. Much work has gone on to get Mr Wonderful here so let's explain a bit more about that. First of all GTEM has had lots of experience supporting people who other care providers struggled to support. They have helped countless people move on from hospital and live successfully in their communities.

GTEM only supports people coming out of hospital in their own homes as they know that shared living does not work for most people where previous services have failed them. Of course living with others can be a consideration later on but GTEM will not set people up to fail. They focus on helping the people they support to make friends and form relationships with others outside their homes.



A shared vision

The most important criteria for success is starting with a clear shared vision and understanding between everyone involved about what needs to be achieved. This always includes

in depth, person centred approaches to planning with the person and their family, understanding what the persons' experience has been until now, what they want for their lives and what makes them tick.

Flexible funding and a safety net

GTEM insists on funding for a transition phase so that they all have a safety net to work with- this means having double funding in place between the hospital and new support and having some extra, flexible funding to help the person settle in, minimise risk and deal with crises. For Mr Wonderful, this was £60k for crisis and the 6 month transition from hospital to home. They also insist that the commissioner pays money on time and upfront. Mr Wonderful has a totally transparent budget, startup costs and cash flow so everyone knows where they stand with money. GTEM makes a commitment to the commissioner to give money back when it's not needed. An example of how this flexible funding is spent is that they rent a flat around the corner from Mr Wonderful's house so back up staff can stay there and rotate and support each other more easily.

Sharing the risk

GTEM will only work with health and social care commissioners who will share the risk. Working with all local professionals as equals, health, police, ambulance, fire service, Psychiatric Intensive Care Unit (PICU), community health services, as well as the council and Clinical Commissioning Group (CCG), and feel like one team. This is essential for building trust.

GTEM always works on the assumption that things will be difficult and will go wrong. Planning for the worst case as well as the likely scenarios is the only way to manage and minimise risk. GTEM makes a commitment to stick with the person through thick and thin, and in turn expects the commissioner to stick with

them as a care provider. Mr Wonderful has had a few short term admissions to the local PICU working in partnership with GTEM, it has been a well managed process.

Skilled and confident care staff

GTEM's CEO is a hands-on leader who believes in rigorous, face to face training for support staff. She uses a practice development approach where she rolls her sleeves up and gets involved with the support team whenever needed, modelling what good support looks like and leading by example. This usually means that she is totally involved in supporting the person and family at the start until the person, family and support team are confident and settled.

GTEM has a policy to not take too much on too quickly, and instead of growing rapidly, will help other providers become specialist in supporting people coming out of hospital, work alongside other local providers and share staff, training and crisis back up.

And finally, meet Dave the commissioner, who organises and pays for Mr Wonderful's care..

At this point let's introduce the commissioner, because he was the one who first believed that Mr Wonderful could move back to his community with the right support. Though I'm tempted to call him Wonderful Commissioner, which he is, we'll call him Dave instead. Dave is what's called a joint commissioner as he works for the council and the Clinical Commissioning Group to arrange and buy care.

Finding the right care providers

Dave had worked as a learning disability commissioner for some years before he took on the role of helping the people in his area come out of hospital. They'd tried the usual ways that commissioners choose and buy services



(procurement) and that hadn't worked and he was determined not to repeat mistakes.

He had to convince his legal, procurement and NHS colleagues that using traditional procurement methods had failed to deal with getting people out of hospital in the past so they had to do it a different way. His colleagues were sceptical but he decided to break the protocols that had been put in place locally and use procurement laws in a different and better way.

He chose to do what he calls a 'soft market testing' to find a small group of providers to help 11 people come out of hospitals. He had already identified GTEM and put a call out to interested care providers to come to a workshop and find out what would be involved to support the 11

people he needed to get out of hospital. He made clear that he only wanted bespoke support and housing for this group and not step down or transition services.

He enrolled GTEM to set out to other providers 'what good looks like' through a presentation about the reality of supporting people who have been in hospital for a long time, and asked providers that wanted to go to the next stage to sign up to this way of working. At this stage, some providers ruled themselves out and then he ruled out some others and ended up with 4 small providers as well as GTEM. These 5 providers work as a local network sharing resources, staff and training. GTEM trains and mentors them to take on the support of the 11 people needing to move back home. So far 7 of the 11 people have moved back home from ATU's and get bespoke support.

Making the money work

For Mr Wonderful, Dave had to invest in a 'crisis and de-escalation plan' to manage what they had to do if anything went wrong and keep Mr Wonderful in his home and community. This involved working with police, ambulance, fire brigade, PICU and Accident & Emergency to agree a joined up response should Mr Wonderful enter in to a crisis. He secured a £60k crisis / transition fund, some of which funded a retainer for a private ambulance when Mr Wonderful needed a safe way of returning to the hospital for a short time during the transition period. In the first year of living there, Mr Wonderful returned to the hospital once for a short time and that was mainly down to a misunderstanding by one of the agencies in the risk management plan.

Dave pays £350,000 (less than was spent on hospital care) a year for the entire package of support and estimates that this will reduce to £250k after 2 years. It is paid quarterly in advance with an agreement that GTEM will hand back what is not used.

In telling this story, Dave quoted a well known saying '*if you do what you've always done, you'll get what you've always gotten*'. He saw that the strategy to get people out of hospital in his area was about using the same methods they always had to provide similar services to what they always had, and this simply wasn't working. Essentially Dave is what might be called a 'disruptor' – he challenged every part of the system that was failing people in hospital, and found better ways for the system to work to help people live in their communities. Dave also knows how to manage risk, and that is not by taking away all risk, but by working together with everyone involved to work out a plan to minimise things going wrong and to have a safety net when they do.

Probably the most important part of how Dave works as a commissioner is that he focusses on human rights. He came across the CEO of GTEM and her story of how she had helped people live in their communities over many years. He saw that this was a different way of supporting people that evidenced if we treat people as individuals, really listen to them and use the framework of equality and human rights, that people respond positively. Mr Wonderful's arrangement is one of several examples of where this approach has worked in his area.

Clinicians who were sceptical about whether Mr Wonderful could be supported in the community are amazed and now on board with this way of working. Mr Wonderful, GTEM and Dave have changed how all sorts of people think, from Mr Wonderful's family, community services and commissioners and clinicians. Recently Dave left his job to work elsewhere and there have been some small glitches without the continuity of Dave's approach and knowledge, but their work has made sufficient inroads into the culture change needed to keep people out of hospital that GTEM is confident the glitches are being ironed out.

Local authorities need to ensure that the social care provider market can meet the needs of people who display behaviour that challenges. It is recommended that commissioners consider working with a smaller number of highly skilled providers that have staff who are trained and experienced in supporting people who display behaviour that challenges, including behaviours which may result in contact with the criminal justice system. Commissioners should ensure that within this group of providers, individuals are offered choice of support that meets their needs.

Building the Right Support, 2015



Key Ingredients: Susan

Project managed – working with experts

Person Centred Planning

Thorough clinical formulation leading to an effective therapeutic plan

8 month transition while Susan was in hospital

Care provider that understands her needs

Commissioners working together to solve problems

NHSE Capital funding for housing

A garden and a cat – Susan’s new life

Meet Susan...

Susan is a 40 year old woman living in her own flat with her beloved cat Tootsy. One of the people who helped Susan get her own home, Alice, tells the story about the last time she saw Susan. “I saw Susan a year or so ago, telling an audience at an event about her life and how she had turned it around. I had met her 7 years before in the Assessment and Treatment Unit (ATU) where she lived, the fifth hospital she had lived in over 10 years. I didn’t recognise her at first, she was so different. Her confident posture and composure, the animation in her face and the light in her eyes, talking about her love for her cat.”

When Alice first met Susan, Susan was unable to talk about her life and what she wanted for her future. Susan’s social worker had known her for 20 years and told Alice everything she knew about her. Susan had grown up in the care system, she is autistic and when her social worker met her she was abusing drugs and alcohol and caught up in a cycle of prostitution, self-harm and rough sleeping. She had a thick file of behavioural issues and interventions from professionals. She had had several placements in residential care and as her mental health deteriorated, in hospitals. Susan was sectioned under the Mental Health Act after a suicide attempt. Her continual self-harming meant that she was kept in seclusion in a bare room without ligature points and under constant supervision.

A partnership between 6 health and social care commissioners.

Alice worked for an independent consultancy that was brought in to manage a project between 6 councils and health trusts to commission specialist services between them. They had worked together previously to develop specialist respite services and had identified that they all had small numbers of people whom they had placed in hospital because they did not have the right local services needed to support them.

It was a challenge for each individual council to develop very bespoke and specialist services for just 2- 3 people but by working together they could arrange the housing and care people needed. A major issue for the councils was that they did not have a sufficiently skilled care

provider and they struggled to get housing as most were in high cost housing areas.

The 8 councils were clear from the start that the project needed to be about person centred housing and care, built around what individual people needed, instead of a 'specialist service' that was built for people to fit in to. They also knew that to make it work, they needed to take a strategic and 'top down' approach to arranging the housing and support needed because it would have taken too long to find the right housing and care for one person at a time.

One of the challenges they faced in supporting people who need intensive or specialist care in their own homes was that care workers usually end up working in isolation. This is sometimes resolved by employing two or more care workers supporting one person at a time, but this is not always what the person needs. So to make sure that care workers are well supported and connected, they decided to plan housing in close proximity.

They also needed to make sure that their new housing and care approach would be one that others could use to avoid hospital in the future, so there needed to be some flexibility built in to it so that it could grow if and when needed.

What the partnership did.

Each of the councils had 2-3 people who were living outside of the area in Assessment and Treatment Units (ATU's) and could be discharged. They carried out person centred plans with each of those people, their families and support staff and other professionals.

From the person centred plans, they developed individual housing specifications, support plans and clinical and therapeutic plans for each of the people, including Susan. They identified what was essential for the person and their well-being and what was desirable. They identified what was needed to make individual support packages sustainable in terms of staffing and location.

PERSON CENTRED PLANNING

Person centred planning provides a way of helping a person plan all aspects of their life, whilst making sure that they remain central to the plans that will affect them.

Person centred planning is not an assessment, though assessments of need can be built on person centred planning. There are several person centred planning tools that can help in different situations, to understand the person's past, to plan their future, to understand communication or to plan how to manage risk for example. The important points about person centred planning are that we really listen to what people want and/or what they are telling us with their actions or behaviour; we involve their families and people who know and love them; and we take a positive, creative problem solving approach so that we can help people to take more control of their lives.

www.bit.ly/hsa-person-centred-tools

To Susan, what was important was having her own home and she didn't want to live with other people. She wanted a garden and a cat. It was important for Susan to have an environment that was as safe as possible for her because of self-harm and suicide attempts. Susan needed round the clock support in the hospital to manage these risks but she didn't like to have carers with her all the time as she wanted time to herself. Susan would need a lot of therapeutic help when she came out of hospital, and her carers would also need some therapeutic input to know how to support her well.

All of the 16 people who'd had plans went through the same process as Susan. They looked at what was desirable and essential for each of the 16 people and used this information to set out three different ways that the housing, care and clinical support could be arranged that

would work for people and give them what was important to them. This was called a 'model service specification' and was used to look for the right housing and support for 16 people.

The project team worked with housing departments in the councils and estates departments in the NHS to search for and secure existing sites where the housing that was needed could be developed- they were former care services that had been run by councils. Two sites in different councils were offered and the health and social care commissioners secured £2.4m in capital from NHS England to develop them. Both were refurbishments of existing buildings converted into individual flats. Other individual housing was secured through various means such as shared ownership and a housing association leasing scheme.

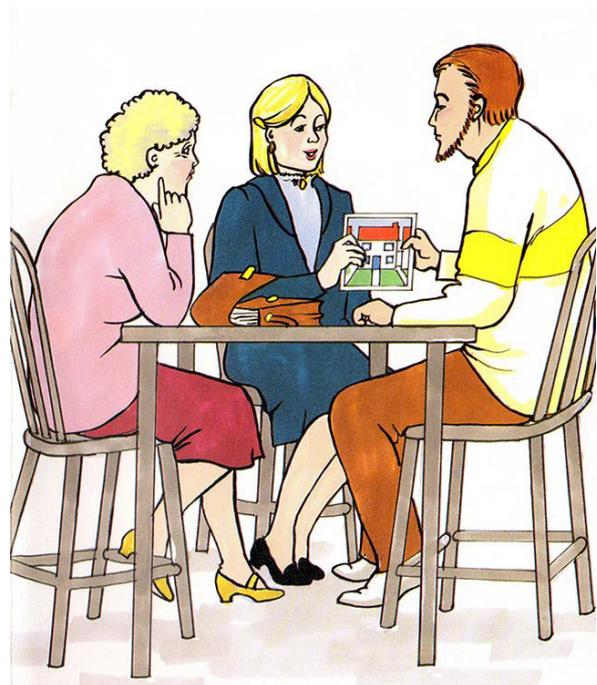
The outcome was that 2 small developments of flats were developed on 2 sites, as well as a number of bespoke individual arrangements close by to benefit from care and clinical support.

In order to find the support that was needed, the councils asked for mental health and learning disability care providers to work together so that they could each bring their expertise to support this group of people. The councils jointly funded extra clinical and psychology support.

The councils and Clinical Commissioning Groups (CCGs) have a formal agreement in place that deals with what would happen when a person moves on, e.g. in terms of re-letting the empty property, which council has first preference for the use of the property, and which council is responsible for funding care and clinical support.

Susan's transition from hospital to own home.

Susan was one of 16 people who was helped to move back to her area because of this project and get the support they each needed. She has a ground floor flat with a garden in one of the developments. Susan's support works because



she has a mix of one to one support and time by herself and an agreement to use assistive technology to monitor her stress remotely and keep her safe. Support staff can be with Susan in seconds if she needs extra support and this makes the arrangement sustainable and minimises risks.

As well as being autistic, Susan had long term and complex mental health issues and clinicians and other professionals were concerned about the risks that were posed by a move to her own home, despite knowing that hospital was not the right place for her. They wanted to ensure that the therapy that had worked for Susan could be continued when she moved to her own home. They also didn't want Susan to move so quickly that it would create too much anxiety and set her back.

The hospital clinicians worked together with Susan, her social worker, a specialist in autism and local clinician to prepare a treatment plan and review process for the transition and move. They agreed what was helping in the hospital and what was not working and discussed with the local clinician how this could be offered when Susan moved into her new home. Susan's current medication was working, as was the psychotherapy she had started. However, the



environment of the hospital and being around others in distress often led to Susan becoming distressed.

The autism specialist worked with Susan to identify her sensory and environmental needs. A garden and being able to go outdoors easily was essential, a quiet environment without loud noise was important, low lighting and feeling safe and in control over her environment.

Together they set out a treatment agreement and local clinicians and commissioners made a commitment that the therapeutic offer would continue after discharge. Clinicians agreed a staged approach where the local clinician would get to know Susan while she was in the hospital and the hospital clinician would continue to input into treatment after Susan moved from hospital. The psychiatrist and commissioners

agreed a date with Susan when she would be ready to start the transition but did not yet talk about a discharge date because they wanted to ensure that she was ready.

When the care provider had been identified, they got involved in the transition and started meeting Susan 3 times a week. All of the clinical team at this stage were meeting with Susan and the care provider weekly to review how the transition was going. Both the local hospital and the local clinicians were supporting the care provider to understand and work with Susan's autism and mental health issues.

Susan, the clinicians and the care team put together a crisis contingency plan for when she moved. They discussed what was likely to happen and what they would need to do to minimise harm and long term readmission to hospital. The biggest risks were self harm and attempted suicide. The triggers for this were mainly environmental and sensory; noise and lights that triggered distress and panic. The plan included measures to minimise triggers in the environment. It also included the use of assistive technology and Susan agreed to wear a monitor on her wrist so that her vital signs and stress levels could be monitored remotely and enable her to spend short amounts of time in her flat alone with staff available to support within 30 seconds should she need it. The plan also included an agreement that Susan could return to the hospital for short periods in the first few months should she need it.

This transition phase took 8 months before Susan was ready for discharge, this required double funding for some of that time and it was paid for from a joint health and social care budget. The clinicians at the hospital continued to support the local clinician and Susan's care team as part of the transition for the first three months after Susan moved. In that time she did not have to be readmitted to hospital.

Reflections on Susan and the project.

In large scale projects to move people out of hospital, we either see a top down approach where the commissioners build something and try and fit people in, or we see one person at a time getting help to move back to their communities. Neither approach would have worked for Susan. Susan had lived in hospital and other institutional care for many years and none of those had worked for her- she had such specific needs, the only way to make her discharge work was to build her home and support around her specific needs and to continue to provide the therapeutic expertise she had in her last hospital.

Helping one person at a time to move has its merits but it is harder to invest in long term local change and local capacity development this way. Getting individual housing solutions in some of the most expensive parts of the area would always have been slow and difficult. Supporting people with significant challenges requires better ways to ensure support staff are looked after and don't burn out- having concentrated services that are not congregate enables support staff to rotate more easily and draw on support more readily from team members. Susan's care needs were such that she needed the flexibility of a staff team to be on call but not always be in her home so this arrangement worked well for her.

Working across several councils and health trusts brings its own set of complications and cost in terms of creating a legal partnership and a practical way to work together. Despite the complexity, this approach has saved each of the individual commissioners much time, resource and money.

Susan now has her own cat and garden. This area now has expertise to draw upon to help avoid more people going in to hospitals unnecessarily. That has to be a good thing.



Key Ingredients: **Mary**

Advocacy

Having a specialist therapy organisation involved

Leadership from the commissioner to make it happen

The right care provider and environment

Calculated risk taking

Mary starts her new life

Meet Mary

This story is about Mary, who is 23 years old, is autistic and has a mild learning disability. She had an early history of extreme neglect and physical and sexual abuse. Mary was fostered at a young age and her long term foster family were not supported regarding her specific needs so the fostering broke down during her early teenage years. She moved between many different settings – residential schools, social care, was eventually sectioned and moved to several hospitals, brief attempts at discharge with 5 failures leading to re-admission.

Mary was reported to be violent, attacking members of the public, those in authority and other patients within hospital. She had extreme self-harming behaviours and had tried on several occasions to take her own life. These behaviours would be present on a daily basis, to the point that she was not trusted to be in possession of any items in case she used them to either hurt herself or others. It had got to a stage where she had been segregated in the special care unit and her room was empty except for a mattress.

From piecing together Mary's life history and meeting with the key people in her network of support, the therapy charity, Harmony, concluded from all that they had learned about Mary that it seemed highly likely that the prolonged experiences of neglect and abuse in her early life were at the root of her current situation. She has had many disrupted attachments and felt that she had no one in life who really cared about or loved her, it was felt that this has led to what they now see as very traumatised behaviour. This was the

first time that Mary had been considered through this perspective, everyone had been very focused on her distressing behaviour but had not put a context to it.

Harmony is a small national charity that is telling this story. It was set up in response to the recognition that people with learning disabilities were often the victims of sexual abuse.

Harmony has been developing, delivering and promoting the importance of working with a trauma informed approach for nearly 30 years and is now also specifically working with people who have been traumatised within the care system.

Harmony's model is relational which means that positive change occurs through building relationships. They recognise the importance of working with the 'system' around the person as well as working. This story focuses on the therapeutic transition process Harmony took with Mary to enable her to be discharged from the hospital, and the lessons learned.

Stage 1

Harmony's staff team began regular 1-1 visits with Mary on a weekly basis. These visits aimed to hold hope for her future, become a symbol of life beyond hospital, help the hospital to start thinking of her differently, enable Harmony to get to know what she will need from a future provider and build a different narrative around Mary. In addition, to search for a care provider that would be suitable for Mary in partnership with commissioners.

Early outcomes

Mary's extremely concerning behaviour began to reduce substantially but slowly. The hospital began to take small risks in supporting her. By the end of the third month of Harmony's input she began to leave her segregation room for short periods within the hospital grounds. Eventually she began to go on community leave and gradually mix in small ways with other residents. She became much less anxious and was able to interact with staff while out rather than being overwhelmed by anxiety.

One year on...

Staff support reduces (down from 5-1 to 3-1) Mary is trusted to spend much more time out of seclusion, has regular interactions with other residents (e.g. movie night every week for which she buys snacks). She is taking part in a wider range of activities - cooking, gym sessions, shopping.

She begins to travel on public transport (with support) Mary is now able to manage money in small ways with support from staff. She is trusted to walk the therapy dog independently, with staff simply following her and is allowed to have lunch with staff using ordinary crockery and cutlery. Indications that she is ready for a successful transition Self-harming has almost disappeared, suicide attempts (by swallowing)

do not take place more than once or twice a month (down from being almost daily occurrences). Anti-ligature clothing used to regularly be used, is now almost never used. Attacks on staff have considerably reduced and are more predictable, the doors of her room rarely get shut (lockdown) whereas this would happen all the time previously. Mary is now allowed to keep her belongings in her room pretty much all the time while previously she was not trusted to do so.

Finding the right provider

Early on the commissioners and Harmony agreed on a provider that both thought would provide Mary with what she needed. They seemed willing and open to working with all parties to develop a bespoke trauma informed approach to Mary's support. However after a few months it became clear that they were paying lip service to this and were still trying to fit her into their pre-existing and unsuitable model. Harmony became concerned that they would not be able to offer Mary what she needed.

Being prepared to think outside of the box

Harmony discussed this in depth with the commissioners detailing the evidence to back up this claim. All parties were clear that they could not let Mary have another failed discharge. Harmony spent some time researching and considering who could provide the kind of support Mary needed.

They approached a therapeutic community which had no previous experience of working with people with learning disabilities or autistic people but a lot of experience of trauma and people labelled as having personality disorder. Harmony worked with them to consider whether this was something they could do, they joined Harmony's team to do a relational assessment together and agreed to work with Mary.

Harmony has supported them to build a confident therapeutic relationship with her whilst she is still in hospital and will provide training and reflective practice to them during and after transition. Mary has built stronger internal resources Mary has greater self-confidence and ability to self-care (e.g. choosing her own clothes, haircut, having her nails polished). She is more able to have conversations around her abusive past, difficult behaviours, fears and anxieties and is more able to develop trusting relationships.

Mary's discharge

This is a critical time, there is plenty of anxiety all round. Mary knows a lot about her transition plans and feels comfortable with these. She has built relationships with key members of her new team and she will continue to work with her Harmony team.

The hospital are currently holding the most anxiety as we move from a medical model of containing risk to a relational model. All parties remain committed to the discharge and are in regular honest dialogue to resolve all concerns.

Some of the key elements of success

- Willingness of all parties to work together and have honest discussions
- Clear confident leadership from commissioning combined with an ability to hear and consider different perspectives
- An element of calculated risk taking
- Seeing the person as a human being in the context of their life history. Asking “what has happened to you”?
- Not pathologising the behaviour- which means seeing Mary's behaviour as a result of her trauma rather than a mental health diagnosis.

Family and belonging

One of the biggest concerns at the start of the work was Mary's isolation, the lack of any family or relationships outside of services. Harmony continued to reach out to her foster family and give this careful thought together. A year after the work began the family made their first visit in over two years. They are now feeling more hopeful that they can resume a relationship with her and have more understanding of her difficulties

How were funding issues managed so as to promote success and ensure sustainability?

In this scenario both Specialist NHS commissioning as well as local commissioners were involved. There was an agreement made that there would need to be some double funding in order to support the relationship building with the social care team. The success has been in keeping Mary and her long term needs at the centre of all decisions made. This has been a key function of Harmony when attending all of Mary's meetings.

What enabled or supported both commissioning and care provider systems to achieve success?

Harmony aims to enable a partnership between all of the complex systems involved to keep a focus on the long term needs of the individual in the centre of the process. They do this through a focus on developing positive relationships with and between all agencies, combined with developing an in depth knowledge of the person and their needs from a community perspective.



Key Ingredients: **Rodney**

Commissioner driving it through a provider framework

Individual Service Fund and flexibility with money

Crisis Fund £20k per year

Having specialist therapeutic support on leaving hospital

Having a care provider who believed in and listened to him

Working in partnership with Rodney's family

Bespoke housing arrangement

Rodney sits in the front seat

Introducing Rodney

Rodney has a learning disability, is now in his late twenties and lives in his own home. Before he got his own home, he lived in a mental health hospital and other residential care services from when he was a teenager. His parents couldn't cope with him at home because he had aggressive behaviour and often smashed up his home. Things were made even more difficult for Rodney because he is big and tall and people are scared of him.

Rodney started out in a children's mental health hospital. He had three staff with him in the hospital at all times because that was what they thought they needed to manage Rodney's behaviour. The hospital staff were so worried about Rodney harming others that he was often segregated from other children and spent long periods of time by himself.

When Rodney was in hospital, he had caused £3000 damage to a car that was used to take him out. He then had to have his own car with restraints fitted in to it – this was the only way they would let him leave the hospital. By the time Rodney was a young man, he had a big reputation.

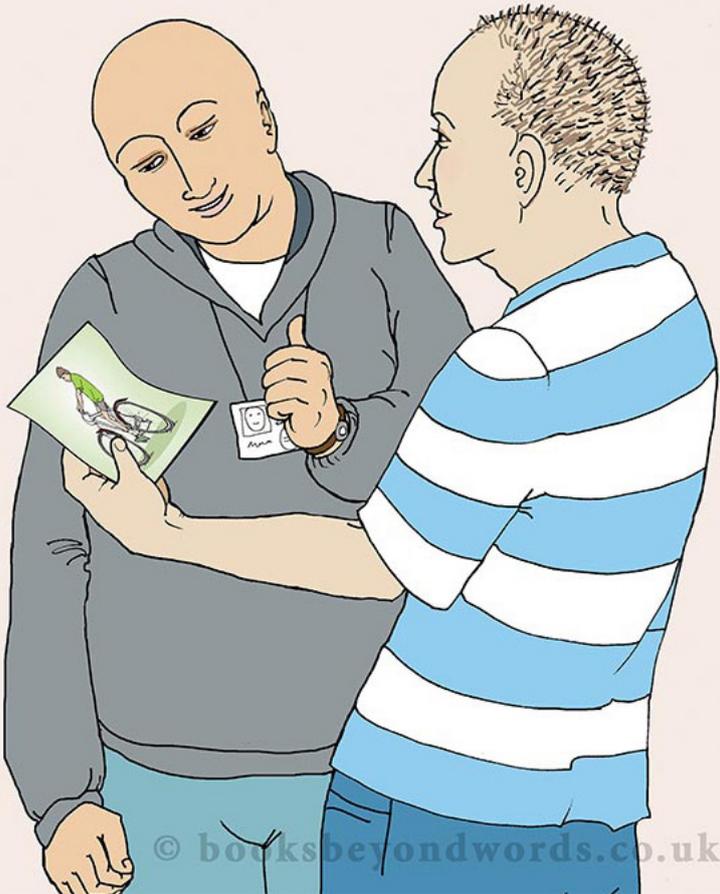
How Rodney's care worked..

Rodney's care provider is a medium size charity that works all over the country supporting people with learning disabilities- we'll call them Brown's Support. They already worked in the council area where Rodney came from and had a good relationship with the council. When Rodney

became an adult, the council asked Brown's if they could set some housing and care up around Rodney's needs.

Brown's say that they always start with person centred planning. This means asking Rodney what is important to him and getting him and his family involved in making decisions about his life. Rodney loves cars and has an encyclopedic knowledge of makes and models of old and new cars. Rodney had never been asked what he wants before and he found it hard to say. His family and Brown's had to make some good guesses based on what Rodney had shown them in the past. Though Rodney liked other people, he liked his own space more and personal space is important to him. He loves his family and needed to be close enough that they could see each other regularly. Rodney likes to be in control of who supports him, he really likes being with some care workers but not others. He also wants to control the medication he takes.

At the time of arranging Rodney's transition from hospital Brown's trained their care workers in positive behaviour support methods to support



Rodney. This meant in practice that they focused on doing things that Rodney loved doing rather than what he didn't like doing and worked out what made Rodney aggressive and changed the environment or the way they supported him to something that worked better for him. The manager that set up Rodney's housing and support, Paul, said that they just treated Rodney as the boss and did what he wanted, it was that simple really.

The council gave Brown's money through an Individual Service Fund (ISF) which means a pot of money that is only to be spent on Rodney's needs, giving him and his family as much control as possible over how it is spent. Rodney chooses

who supports him and Brown's only employ people that Rodney likes. The council also gave Brown's an extra £20,000 fund to be used flexibly if and when it is needed, just in case they needed more to support Rodney.

Rodney always has two carers with him. His ISF also paid for therapeutic input through a specialist therapy organisation that provide therapy to people with learning disabilities. They worked intensively with Rodney and his care team to help support with his trauma and distress. So that Rodney had more understanding of and control over the medication he is taking, he was supported to take his prescription to the local pharmacist every month to collect. The pharmacist talked Rodney through what his medication was for, how they helped him and the possible side effects. This helped Rodney understand how important it was to take it and not just stop abruptly. It also gave Rodney the confidence to talk directly to his GP about the medication and after 2 years he started to slowly reduce the dosage.

Rodney has an ordinary house in an ordinary street, half an hour drive from his family. He has the downstairs area all to himself and upstairs has been converted to a flat for care staff so they can be close by on call but give Rodney his own space.

After the first two years of living in his own home, Rodney did not need to be restrained and has never been restrained since. Brown's supported Rodney so well that he did not need as much support. His support cost one third less and they gave the money back to the council, Rodney's care cost reduced from £360, 000 to £270,000 a year.

Rodney owns a small car where he sits in the front and reads the map for the driver instead of being restrained in a special car. He is totally in control of what happens in his life and goes swimming, to the sports centre and cinema regularly.

Paul, who has now supported Rodney for more than 5 years talked about what he thinks the main

reasons were for success; he said that trust is the most important element in getting it right- when the person, family, care provider and health and social care all trust each other, magic happens. The usual ways that councils organise and pay for care (procurement) gets in the way and stops magic from happening. Competitive processes between care providers don't work. Paying for care on an hourly basis is a disincentive for care providers to reduce costs when they can. Paul is also quick to say that reducing the cost of care as a focus is a red herring, yes it happens with many people when they get the support they need, but it should not be a focus of an arrangement between those who pay for the support and the care provider because for some people, it simply won't work.

Paul also says that Rodney's success is down to him being properly listened to and understood, supporting him positively to do what he loves rather than continually trying to control him. He also attributes the success to the therapeutic support Rodney and the care team receive from the therapy charity. "All the effort has been on getting people out of ATU's but not stopping them going back in. We need to have honest relationships with everyone involved and most importantly we need to just accept there will be crises and have 'stickability' to get through them.

How Rodney's care was organised.

Karen works for the council and organises and pays for Rodney's care. She too talks about the trusting relationship she has with Brown's as a factor in Rodney's successful discharge from hospital "This level of honesty and transparency builds trust between care providers and us as commissioners". Brown's are part of a Regional 'framework'¹ where several care providers that share the same values work together to get people out of hospitals.

"Having 'equal' conversations between the care providers and commissioners and starting with a blank sheet from which to work together on is essential" says Karen. Together they work towards



what the people coming out of hospital want to achieve rather than negotiating hourly funding and tasks. For Rodney this has meant that the only focus is on what is best for Rodney so he has therapy funded as part of his care package, which would usually simply not happen in traditional ways of arranging and paying for care.

The council uses Individual Service Funds as the main way to fund people coming out of hospital. They also focus on developing housing that is bespoke and/or designed to a high standard and enables autonomy and independence as well as safety and comfort. For Rodney having a separate flat above his for care workers has meant that he can readily access support and his care workers have a safe and comfortable space from which to support Rodney. Without this, they would have failed Rodney and he would end up back in hospital.

Karen reflected on the fact that the successful work to support Rodney has led the council to create more flexibility with funding and give care providers a blank sheet of paper to start with, rather than a service specification. The council has trained social workers to support individual

service design and this process enables people and families to set out what they really want and what works for them. Now the council spends less time on the traditional procurement of care, they are investing more time on monitoring the quality of care they pay for instead.

Is it about attitudes?

Paul and his colleague Gary who both work for Brown's were interviewed for this story and both are senior in their organisation. What was very clear was their personal commitment to Rodney. They both know him well and clearly like him, they weren't talking about him as a client or service user but as Rodney, a human being,

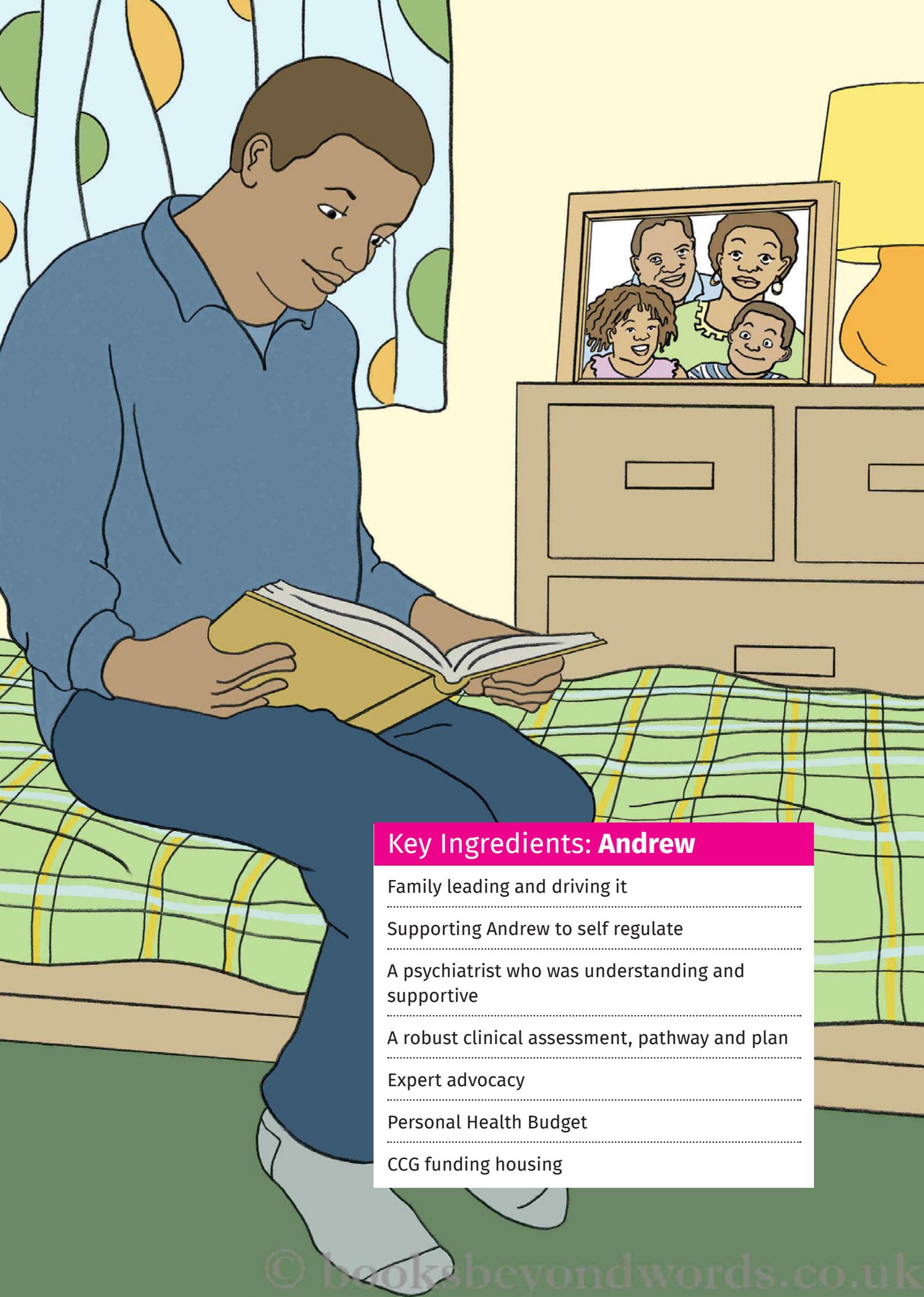
with smiles on their faces as they describe him. It's hard to pin down exactly why this happens – what makes staff from a care provider like or not like the people they support? Why do some care providers see people they care for as a unit of work to complete and others as relationships to nurture and support? Is it down to individual relationships, training and/or organisational culture? Whatever the answer is, it is part of what makes the 'magic' that Paul described earlier.

Notes

1. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/560268/Guidance_on_Frameworks_-_Oct_16.pdf

“It seems to me that a common thread for these stories is a commissioner working with a set of providers, leading to thoughtful commissioning that interprets and applies the rules sensibly and not in a rigid way. The flexible funding and double funding also seem critical to success.”

“If these stories can provide anything, it should be an illustration of just how ambitious commissioners need to be – just how far they need to set their sights – in order to achieve success for individuals under their care.”



Key Ingredients: Andrew

Family leading and driving it

Supporting Andrew to self regulate

A psychiatrist who was understanding and supportive

A robust clinical assessment, pathway and plan

Expert advocacy

Personal Health Budget

CCG funding housing

Pizza and Jacuzzi- Andrew does 'behaviour management' his way

Meet Andrew

Andrew is a 24 year old man who is an important part of his loving family - his mum, dad and brothers. Andrew loves trains, particularly Thomas the Tank Engine. He is also an outdoors person and loves to be out and about rather than sitting in at home. He is a whizz with dates and is interested in finding out when people are born so he can tell how old they are. Andrew loves water, and being immersed in water, and taking his clothes off is how he regulates himself when he needs to relax.

Andrew has severe learning disabilities and is diagnosed with autism.

When Andrew was a teenager, things started getting difficult for him and he showed this in a change of behaviour – he went from being happy and relaxed to getting easily frustrated, angry and sometimes aggressive. His family did not have any professional support and didn't know what to do to help him.

After advice from a social worker, Andrew went to two residential schools that both failed him. When he was 17 he didn't have a school to go to so he was given 10 hours of support a week at home but mostly his family stepped in and made sure that Andrew was doing things he liked and was learning.

When Andrew moved to the care of adult services he was offered a 28 day assessment in an Assessment and Treatment Unit (ATU).

His family were grateful as they thought that Andrew's needs were finally going to be looked at properly and they would be able to plan better for his future.

Andrew went into hospital, a healthy young man who needed some help to manage the emotional changes he was going through.

Five years and £2.5m later, Andrew left hospital on a cocktail of anti-psychotic drugs and poor physical health, traumatised and distressed.

The first two hospitals Andrew was in did not meet his needs and a safeguarding review found evidence of abuse. Andrew was segregated and restrained because the so called 'specialist' hospital did not understand his autism. The safeguarding review was a trigger for moving to a new hospital and then planning his long term situation.

How Assessment and Treatment should work

The last hospital that Andrew was sent to employed specialists in autism who finally understood him. They worked with him and his family to plan for the future and this was the first time that Andrew and his family actually got the help they needed. The new hospital were clear from before he was admitted about the purpose of his admission, which was to assess what Andrew needed to live in his community, the medication and therapy he needed, and work towards discharge from day one.

They worked with Andrew's family to get a detailed history from them and did a full clinical assessment in the first few days. As this was the first proper assessment of Andrew's needs, it was a comprehensive assessment that included developing an in depth understanding of Andrew's behaviour triggers. The family felt that the psychiatrist really listened to them.

The hospital also went out of their way to make sure that Andrew's family were fully involved in every aspect of his care and made sure they could easily keep in touch by regular phone calls and paying travel expenses for family visits.

Getting a house and care

Andrew's family sourced his house themselves with the help and advice of a charity who had been advocating for them throughout this process. They knew he needed space and to be close by to them so that they could help with his care. The family found a housing association that was willing to buy and adapt a home for Andrew with help from the Clinical Commissioning Group (CCG). The charity informed the housing association and CCG that there was capital funding available via NHS England so this was applied for. It wasn't a smooth process- there were delays because of grant decision making so the seller pulled out but before it was sold, they were able to go back and make a higher offer

and secured the property. The family had to act as expert and co-ordinator to get the housing in place otherwise it wouldn't have happened.

At the same time, Andrew had been allocated a Personal Health Budget (PHB) for his care and his parents had to recruit staff, train them and get them started in a transition process. The hospital again, were helpful and prepared a treatment plan that could support Andrew when he moved, they co-ordinated the local multi-disciplinary team (social worker, psychiatrist, learning disability nurse, behaviour specialist) as well as Andrew's family and new carers and they started weekly meetings to plan how to support Andrew well in his new home.

The CCG gave double funding so the process of transition could go at Andrew's pace.

Adam has his own home with support to do activities in the community. Andrew had a full care team including two of the staff from the hospital who he brought with him to care for him in his new home.

Self- regulation

Andrew has his own detached bungalow with a big garden, near his family and in a community he knows well. He has a Jacuzzi that he can use whenever he wants. He has a stable staff team that have been with him now for 2.5 years. He spends his days going out, plenty of activities like going to the beach, watching trains, using his swing in the garden. He has never needed to be restrained since he has had his own home.

Life is good for Andrew. He had additional therapy to help with the trauma he experienced and that has helped. That's not to say he doesn't have ups and downs, he does, but they are managed differently to how they were in school and hospital. After one incident where Andrew was upset and damaged his home, his dad and brother came and spent time with him watching DVDs, and eating his favourite food pizza, instead of calling the police. This enabled Andrew to calm down and self regulate- sending him

to hospital would have achieved completely the opposite.

Whilst Andrew's parents wouldn't have this any other way, at least for the time being, they have to totally manage Andrew's support. They do the jobs of a CEO, a manager, a trainer, a recruiter etc. without being paid. This is not sustainable in the long term even though Andrew's family are committed to do it for as long as they can. It impacts hugely on the quality of their lives.

What made the difference?

First and foremost this worked because Andrew's family drove it and they had independent expert advocacy and advice from a charity. This story shows that even without a commissioner driving, it can be achieved.

Secondly it worked because the last hospital Andrew was admitted to was good, they were experts and knew what they were doing. The family had time to think about what Andrew needed.



Andrew has the right housing and is not trying to manage within the wrong environment. He has a Personal Health Budget so his family could more easily make that happen, even though there is a question about how long it can be sustained for. Staff that support Andrew are paid well and have compassion and empathy. He had additional therapy to help with the trauma he experienced.

Andrew does activities he loves and has a full life- he is out everyday. He has access to water via the jacuzzi at home so he can get in whenever he wants to regulate himself. Some of Andrew's previous care providers tried to manage his behaviour with restraint and seclusion and they didn't understand how to listen to what Andrew really wanted. They saw Andrew's behaviour as the 'problem' instead of seeing their own methods of care as the problem in this situation.

All of this is underpinned by a person and family led approach – Andrew and his family have been listened to and given the power and money to act. Despite the great outcome, not all families can do this or should have to do this. This is an important question to unravel- how do we unleash the knowledge, commitment and energy of families without leaving it all to them?

Reflection

As part of Andrew's storytelling process, a psychiatrist who was part of the group reflects on Andrew's story:

“The principles of being ‘person centred’ and ‘family led’ are important, but are empty concepts if left unillustrated. The importance of drawing on some of the details in Mr A's story is in demonstrating the ambition and scope systems must have in formulating plans adequately for people in their care.

I hope that no commissioner in the country would be surprised to be told their plans should be person centred – and I'm sure they would all understand in principle that this means shaping their care package around the individual. But I

would be surprised if the fact that Andrew's CCG bought a house with a jacuzzi for him didn't raise some eyebrows. If care is a journey, then principles set the direction, whilst details guide the 'distance' – i.e. how far one should set one's sights. I imagine that in almost every case, commissioners' sights are not set far enough – perhaps they do not have adequate hope for people like Andrew, perhaps they lack ambition. Some of this is likely due to short-term financial reporting, causing

commissioners to balk at large initial outlays – but much is probably accounted for by unspoken value assumptions about people with learning disabilities and / or autistic people.

If these stories can provide anything, it should be an illustration of just how ambitious commissioners need to be – just how far they need to set their sights – in order to achieve success for individuals under their care.”



Final Words



Belonging in communities

As the details in these stories show, people belong in their communities. We see the common threads; Person Centred Planning and Approaches and really listening to what people want; commissioners working flexibly with providers; empowered, thoughtful commissioning which interprets and applies the rules sensibly and not in a rigid way; flexibility with funding and double funding so that people have the time and safety net to move on in the best way for them.

These transformations in people's lives have been achieved through the efforts of the individuals themselves and the way those around them have ensured:

A sustained focus on their experiences and aspirations

Therapeutic optimism - continuing to believe that a better life is possible

Trust and effective partnerships in what are typically complex service systems

The capacity to stick at this over the long term.

We all need to ensure that this quality of support is available to all those waiting for a better life.

The **BELONG MANIFESTO** summarises the 6 things we all need to live healthy and fulfilling lives. The stories tell us that not only do we need good housing, support and healthcare to thrive. People need a meaningful occupation and a community to belong to.

B

Being active and healthy

Andrew has his jacuzzi and regularly uses the swing in his garden; Susan enjoys the peace and quiet of her garden; Rodney goes swimming.

E

Enjoying our friends and family

Rodney loves his family who now live just 30 minutes away; Andrew's family are closely involved in his everyday life.

L

Love

Mary's family are back in touch and beginning to rebuild a relationship with her; Mr Wonderful is back living close by to his family.

O

Ordinary things like choosing where we live

All of the people in the stories were involved in choosing their own staff.

N

New things to make our lives more interesting

Andrew now goes to the pub on his own and has been on holiday; Rodney is passionate about cars, he now has his own car and staff take him out regularly; he also goes to the cinema regularly.

G

Giving something to someone else

Susan has her cat to look after; Andrew helps his brother do the gardening.

www.booksbeyondwords.co.uk/belong-manifesto

Everyone was committed to the same clearly understood goal, to help each person start a new life 'back home'. Clearly, we also need national policies, initiatives, and practical support locally that will make it more possible for other people to benefit from the lessons learnt from Susan, Andrew, Rodney, Mary and Mr. Wonderful's stories. The aspirations set out in Building the Right Support require a long term commitment to strengthening local, person-centred approaches and capacities.

