

Moving out of ATUs: A best practice guide

Foreword

Welcome to Dimensions' contribution to the ongoing debate on how to support more people to leave ATUs.

We've included a very wide range of individual stories; we hope they will inspire people – families and professionals alike – to believe that in almost every case, better is possible.

The booklet also contains articles written by a range of different Dimensions experts, from the managers at the sharp end of supporting people out of ATUs to our CEO's view on funding challenges. Whether you are a policymaker, a commissioner, a medical professional or a family member we believe there will be content in here to make you think and maybe do things differently in future.

This publication doesn't engage in the equally important discussion about how to avoid people entering ATU in the first place. That is a topic for the future. For now, let's work together to support more people to get out. They deserve it.

Jackie Fletcher,
Group director of quality,
public affairs and policy (former)

Jordan Smith,
Advocacy lead



Content by theme

There are recurring themes in the success stories in this report. Although most people's stories reflect all (or most) of these themes, for ease of reference we have picked out stories that reflect each theme particularly strongly below.

A number of reflective articles are also included, spotlighting particular issues:

Reflective articles

- Making Transforming Care work – a view from the sharp end page 4
- Transforming Care performance data in the spotlight page 16
- The politics of funding – the conflicts of interest for those charged with transforming care page 24
- Get out: strategies for families page 32
- Winning at whack-a-mole page 39

Believing in the person

- John page 7
- Barbara page 14
- Alan page 22
- Steve page 26

Getting the right living environment and staff

- Edward page 8
- Barbara page 14
- Alan page 22
- William page 34
- Farouk page 36

Focusing on health

- Katy page 20
- Henry page 31

Communication

- John page 7
- Steve page 26
- Richard page 28
- Rachel page 30
- Farouk page 36
- Karen page 38

Never too late

- Maggie & Doreen page 12
- Jackie page 18

Cost savings

- John page 7
- Steve page 26
- Richard page 28

Making Transforming Care work

By multiple Dimensions frontline managers



Every target set for the transforming care agenda has been missed. Numbers of people in ATUs are declining slowly – but at nowhere near the rate required to achieve the goal of halving their numbers. Indeed, at current rates the three year goal could easily become a 15-20 year goal.

So why? It's certainly not for lack of goodwill, commitment or hard work on all sides. Dimensions certainly doesn't pretend to have all the answers. If all the answers existed, there wouldn't be a problem in the first place.

With that in mind, we thought it might be instructive to ask some of those at the sharpest end – the supported living managers who have to negotiate and plan to get individuals out of ATUs – for their tips on what works well, and some of the pitfalls. The resulting 'interview' comes from a medley of expert voices.

If you are involved in Transforming Care as a provider, a local authority, CCG, health professional or of course a family, there may be something here that can help you.

Q: We're talking about making transforming care work better. What are the five topic areas that we should be addressing?

A: Challenging expectations. Funding. Working with families. Involvement and access. Housing.

Q: Ok. Let's start with challenging expectations. Can you tell me a bit more about this?

A: Many of the people currently living in ATUs have been failed many times by services in the places they spend their days. A history of failure can label someone as unsuited to life outside of ATUs when in reality it is the system that has failed those people.

In my experience clinical staff in particular have little understanding of supported living and like to share "horror stories" about the individual, not convinced that the person will ever be able to live outside of that environment. This is a particular problem in the many ATUs that are running on high levels of agency staff that do not know the person well.

As with anything else in life, if you don't believe in what you're doing, you don't achieve success. It is critical that all those involved with an individual examine and tackle the systemic reasons for past failures, and begin plans for life back in their community with optimism and commitment. Otherwise failure becomes a self-fulfilling prophecy.

Q: Alright. Presumably funding is a key challenge here?

A: The central issue is a commissioner's ability to take a long view. Sometimes there won't be an instant saving, as people may come out of hospital with fairly high costs. However, with the right support, costs often then reduce quickly and significantly. This takes trust.

It is understandable that many funding authorities see things through the lens of cost and funding. But this approach will almost invariably cost more, and lead to worse outcomes, in the long run. Let me give you an example.

We have recently supported two men, let's call them Jim and John, out of an ATU and into a shared living environment. Having supported Jim and John for several months, and experienced their unexpected interpersonal dynamics, we now believe they need single person services. Unfortunately the process to secure funding for this is crisis-driven. No crisis, no funding. The system often demands a failure before it steps in to support appropriately. In the long run of course this is far more expensive as it will probably entail a return to ATU.

Jim is an autistic man who likes a calm, quiet environment where people treat him with respect. As he takes things literally he can't cope with a jokey environment; joking around undermines his confidence.

Housemate John is a natural, continuous joker. He's a real fun loving guy.

As a result of living in each other's space for a while, Jim is now spending more and more time in his room. He thinks people like him less. But joker John is also spending more time in his room. He is cancelling appointments, struggling to motivate himself. Both men are starting to sleep through the day and stay up at night, a sure sign of stress and a habit which puts their support plans at risk. Both men could undoubtedly thrive outside an ATU but, it turns out, not in each other's company. Despite every strategy we employ, shared living isn't achieving the desired outcomes at the moment and there is a real risk of a failed placement. Maybe next week. Maybe next month. Maybe a little longer. But unless something fundamental changes, it will happen.

“More and more local authorities are finding ways to take a long term view when it comes to Transforming Care rather than selecting the cheapest short term option.”

Single person living is not always the answer. Very often it is beneficial for well matched people to live together, and even with trial periods and the best possible preparation, it is not always possible to anticipate when people will not get along. But where a situation is breaking down, the ability to make changes quickly – and not embark upon a multi-year 'evidence gathering' phase – is clearly in everyone's interests.

The really good news is that nationally, we are beginning to see a shift in approach. More and more local authorities are finding ways to take a long term view when it comes to Transforming Care rather than selecting the cheapest short term option.

Q: That's a positive note. I guess families are key to achieving change?

A: Absolutely. Families can be a massive asset. A family determined to see their loved one out of hospital and backed up by advocates, legal support and a support network is hard for the system to resist.

However, some families can fear change – fear seeing a loved one moving out of a secure environment into supported living. Families who have been let down so many times in the past may find it hard to imagine any other kind of life for their loved one. Some families don't want the responsibility. Some don't see the potential for their loved one to lead a self-determined life. In our experience when people are shown real life examples of success and have the opportunity to meet with other families who have similar experiences it is possible to build strong working partnerships for change.

The solution to this is never a head-to-head argument. It is essential to build a strong, trusting relationship with the family – take the time to engage properly. Show them existing services. Introduce them to other parents who have been on the same journey. This gives a very high chance of success.

It is tough for families. Often, by the time I meet them, their relative has been assessed by a number of providers ahead of us. This means it can be difficult to win their trust due to the experience that they have already had and the barriers that they may have faced themselves.

Q: Tell me a bit about involvement and access?

A: In my experience, support breaks down when the provider has been brought in late. When housing, staff ratios and so on have already been decided.

The earlier a provider can be brought into the process, the better. Introduce a provider before a detailed plan for discharge has been made; that plan will be much stronger as a result. It is essential to properly understand an individual – it's the basic principle behind person centred planning and it remains as true now as it ever was. The provider can ensure close liaison between behaviour consultants, SALTs and OTs and other agencies as required. It can work with registered providers on an appropriate housing solution. And it can build direct relationships with the individual and their family.

On that note, some hospitals seem to find it difficult to allow potential providers in to meet, build relationships with, and shadow an individual. Lack of opportunities to meet up and spend time getting to know an individual can be a real problem – after all, would you want to leave your room in an ATU to be supported by a bunch of strangers?

And for many people, it takes a long time to build up trust. Lack of co-operation creates stress all round, hinders recruitment of matched staff and directly contributes to failed placements.

The problem applies to NHS hospitals, but can be worse with private hospitals. I wonder if what I perceive as an unwillingness to engage driven by an unwillingness to discharge as the person is a financial asset all the time they are in hospital care?

Q: Thank you. What about housing?

A: The right housing can obviously make or break a move into the community. In my experience, a lot depends on the individual housing provider. A good housing provider, like a good support provider, will want to be involved early on in the assessment process. The right housing will be built or adapted to minimise the changes of a person hurting themselves or damaging their surroundings. And where the housing solution is mandated from the outset (such as an unsuitable council property that happens to be available) a failed 'placement' is a more likely outcome than a settled home for life.

When a person's distress may lead to damage to property – it is also important to pre-agree a pot of money for repairs, and responsibility for repairs beyond that pot. A damaged house provides a negative day-to-day environment that makes a return to ATU more likely.



Learning to communicate: John



John's achievements

- The ability to communicate with those around him
- Living independently in the community
- Behaviours of distress all but disappeared
- Staffing needs down to from 3:1 to 1:1 when out and about
- Significant reductions to staffing needs at home
- Strong relationships with all those around him

John* is profoundly deaf and communicates using British Sign Language which he has significantly adapted with a unique “accent”. Before joining us, he had been locked up in an Assessment and Treatment Centre because of his ‘challenging behaviour’.

Where others may have seen a young man with a history of violence, we saw John’s unique situation as an opportunity to develop a positive behaviour support programme to both reduce his behaviours of distress and improve his quality of life.

His staff team, with help from Dimensions Behaviour Support Team, worked hard to learn how best to communicate with him. We learned that one of his first goals was to become more independent.

After time, they could identify precursor behaviours and respond to bring any episodes of behaviours of distress to a close quickly and safely before they escalated.

After just three months with us, John’s behaviour was transformed. He became much happier and more at ease and as a result, his support in the community was reduced from 3:1 to 2:1.

Similarly his in-house support reduced to 1:1, resulting in savings to his support package and much greater independence. And shortly after, his support was reduced to just 1:1 full-time.

Behaviours of distress were John’s way of communicating that he was unhappy.

Yet with the right support, he’s had no reported incidents of severe physical aggression since July 2012.

Initially, staff supported John with all areas of personal care but over the years he has learnt how to do these himself and become more independent.

Most importantly he has developed strong relationships with his staff team, enabling him to live the life that he chooses.

John’s story is just one example of how by giving the right support, substantial savings can be made and individual’s quality of life can be transformed.

*Not his real image used

Pointers to a good transition: A story for families of autistic young adults

By Edward's support team and family



Key steps to success:

- Staff team recruited in advance and got to know Edward by visiting him in his family home.
- Functional Behaviour Analysis helped staff understand roots of his behaviours of distress.
- Edward and his family had time to view his flat and local area before his move.

Introducing Edward

For 23-year old Edward, transition from children's to adult services was spontaneous rather than the result of a long term plan.

Edward was at a residential college for children with special needs through his teens, but returned to living with his parents after college. A social worker recognised that Dimensions could meet his needs. Eight months of intensive planning followed Edward's referral to us and ten months into his support – in his own flat – the choice and control Edward exerts over his life continue to grow.

Edward's sensory sensitivities are managed through ear defenders, sunglasses etc. But his autism manifests in many other ways. He uses echolalia – he 'borrows' speech – typically from films and books – in order to communicate.

He is very sociable and capable but displays a high degree of demand avoidance. He has moments of lucid conversation but only very brief attention spans. When he gets anxious, he asks about people from the distant past. And when he feels unable to express himself, he may break things in frustration. All in all, it takes great skill as well as patience to communicate effectively with Edward, to encourage him to unlock his abilities rather than resting on his disabilities.

What is Transition?

Sandra, Edward's Locality Manager

It is the move from children's to adult services, often from a family home or residential college into a home of their own. Ultimately it is about autistic people taking control over their own lives, about making choices that may be unwise, about living as independently as possible, living ordinary, messy lives in the same communities as everyone else.

It is a huge, stressful step. The associated anxiety can easily result in behaviours of distress and create a vicious circle. After all, most children don't have to do all their growing up overnight! So it's the responsibility of everybody – family, college, adult and young person's support teams, housing and support provider – to work together to make change gradual, not abrupt.

I don't think anyone is ever wholly ready or unready for transition. But like most autistic people we support, Edward has proven to be absolutely capable of gaining and enjoying increased independence. Transition is a journey of years, not a moment in time and I expect him to continue to gain life skills for years to come.

“Ultimately [Transition] is about autistic people taking control over their own lives....living ordinary, messy lives in the same communities as everyone else.”
Sandra, Locality Manager

How did you plan for Edward's Transition?

Eva, Andy & Edward (Edward's mum and dad)

We were put in touch with a few other families by Edward's social worker and the staff at Edward's old school. Principally, those whose children had been through transition a year or two previously.

They were knowledgeable in recommending providers and helping us understand the process and procedures involved – from power of attorney to needs assessments.

Although we attended transition fairs organised by Edward's college, for us these were less helpful. It was difficult for us to distinguish the differences between providers there. And there are so many subtly different models of support to be considered. We feel that college didn't really prepare Edward or us for his transition – that is something I'd like to see improvement for in the future.

With Ed's social worker's help we concluded that supported living was the optimum type of support for Ed. We had spoken to a few providers and visited a few places in the vicinity of our home (and some we knew by their reputation amongst other families).

What were your priorities for Edward through Transition?

Sandra

The priorities are getting the right home and support team. We secured transition funding from the local authority which was vital; it provided for behaviour support input – in the shape of a Functional Behaviour Analysis – to help us all understand the roots of his behaviours of distress, and to plan in light of this. It meant we could recruit his staff team well in advance and create a 'Getting To Know You' period with staff spending time with Edward in the family home, which we know substantially reduces the chance of service failure. It meant there was time for both Edward and his family to view his flat and the local area and put some thought into whether it is the right environment and location for him.

For Edward in particular, we also knew it would be important to create the right relationship with planning, buying, cooking and eating food. The last thing we wanted was to be locking food cupboards following Best Interests meetings. So a great deal of time has been spent in actively supporting Edward to build his independence and ability to make good choices around food.

At home, mum does all this. That's great, but it does mean that after holidays with his family, we need to work extra hard with Edward to help him regain the independence he now achieves in his own home.

Nigel, support worker

Edward's transition is about taking small steps towards a range of goals. Edward will say no, no, no to pretty much everything. His default position is to let others do things for him. But we question and seek to understand why he is saying no; is it control? Is it inertia? Is it fear? By gradually removing the reasons for the 'no' and taking tiny developmental steps we've been able to get Edward to shop and cook semi-independently, to enjoy water-based activities and much more; indeed, his day is filled with things that would have been considered unfeasible not so long ago. That is not to say he is always filled with enthusiasm for household chores – nor am I – this is all part of living an ordinary life!

Consistency is key. As a support team, we make sure our communication is really robust, so that colleagues coming on shift hold the same priorities and give the same messages as those finishing.

There's no cracks in our approach. Detailed handover communications, active WhatsApp groups, regular team meetings and a range of other approaches help us achieve consistency.

Andy

It's all about getting the right staff at the end of the day. Staff who are going to get on well with Edward and support as well as motivate him to try new things. As parents, we did get involved in some of the interviewing for new staff. That was helpful. It was easy to rule some out but of course we're also mindful that it is hard to recruit social care staff these days so we were careful not to be too picky. The worst outcome is not having enough staff. I'm happy to say that Ed has some fantastic staff – some of whom can get him to do and try things that we as his family cannot! We believe that staff with the right personality and initiative could be better suited for Ed than some with lots of experience and qualifications.

We also made sure that staff got to know Ed at home before he moved. That was important – to create gradual change. We also worked to fill Ed's schedule with different activities to keep him busy.

What would you say to parents whose child is entering their teens?

Sandra

I would say that by the time your child is 14 or 15 you should have contacted both your child's college and your local authority to get an idea of the adult support options in your local area and to start the planning process. Not all local authorities are proactive; we all know how stretched they are and it is a sad fact that the families who get the best support for their loved ones are usually those that assert themselves – constructively and collaboratively – the best. Listen to the adult social care professionals in your area, develop a vision for the adult support you eventually want for your child, and take the lead.

Nigel

I'd agree with that. I've seen people having very different transition experiences, but a common factor in good transitions is early involvement from a clear-minded family. Parents' priorities, preferences and approach to partnership working are some of the ingredients that can really make that difference.

For me personally, it is nice when a family asks the support team for advice and listens to our thoughts. That's the point where we've 'earned our stripes' – we've built a trusting, robust partnership. Just as in any relationship, it doesn't happen overnight and it takes work.

Andy

Talk and learn from other families who have had similar experience, visit lots of different services, get involved as much as you can in recruitment for the right staff and prepare an activity curriculum.

“It's all about getting the right staff at the end of the day. Staff who are going to get on well with Edward and support as well as motivate him to try new things.”
Andy

What research should I do into transition planning?

Sandra

Adult social care does not often get a good press – good news stories don't sell newspapers – but there are a lot of very high quality providers out there. Find out who is commissioned to provide support in your local area, and who else is around.

Find out what constitutes good support – if terms like active support, positive behaviour support, person-centred practice, quality checkers, just enough support and choice & control aren't yet part of your vocabulary, they should be.

Dimensions has a free guide to transition which you can download on our website.

Nigel

Learn to identify good support providers. For example, a good one will work in partnership with families. That means seeking and acting on family advice, but it also means questioning, challenging and just occasionally, having considered all the angles, acting in a person's best interests against a family's preference. If the relationship is right – if it can withstand disagreement, if both parties can learn from what has and has not worked and move on without recrimination – then the person at the centre of all this has a great shot at a fulfilled and independent life.

You can begin to get a feel for a provider through some research. For example, find out how easy it is to get involved in the recruitment and performance management of your loved one's support team.

Find out if the provider has a 'family charter' or similar document, whether it employs 'family consultants' to advocate for families and how it handles complaints.

Lastly, be aware that many colleges are part of adult care groups; whilst I am absolutely not saying that this arrangement is to create a pipeline of 'business,' if your child's college is in this position you should check that you are being offered real choices at every point.

What is in store for Edward?

Sandra

You'd be better asking him that! But in general I would say that we don't yet know if his flat is his forever home or a stepping stone to something else. He is so much more independent around food and we want to extend this independence to other aspects of daily life; travelling, cleaning, managing his own diary, etc.

Nigel

More self reliance, managing his life with less prompting and on his own terms. It is also a particular goal to build Edward's social network beyond family and paid staff; our first tiny step in this direction is to get him involved in activities of his choice alongside other people we support. The future is bright!

Andy

A happy and fulfilling life!



Maggie and Doreen: a lifelong journey to independent living



Maggie and Doreen's lives are chapters from our social history. As more and more authorities abandon independent living in favour of large scale care facilities for people with learning disabilities and autism, we hope Maggie and Doreen's story will help them think again.

The pair, who have learning disabilities and complex physical needs, first met when they were placed in a large asylum in Sheffield together in the 1930s.

They instantly hit it off, providing a friendly, reassuring face for each other through some tough times.

Their friendship survived the war, rickets, german measles and general malnourishment. They shared a bedroom with 13 other people. Maggie would often be pulled around in a cot.

There was little opportunity to leave the building and people with fewer physical disabilities would often help support others because staff numbers were so low.

This was Maggie and Doreen's life for over 40 years.

Separated in hospitals

As part of the national policy to close asylums in the 1980s, the pair were transferred to a hospital together.

However, they were put in different rooms and for a while were even on separate wards.

Shared bedrooms, clinical settings, little stimulation and few opportunities to leave the hospital meant that the experience was worse, rather than better, for the two ladies.

A step towards independence

Care in the Community followed, and with it a move to a 6-bedroomed residential home during the 1990s.

A private bedroom each, four other housemates and higher staffing levels really gave Maggie and Doreen the chance to take their first steps to more independent living.

It was certainly the first chance they were given to make their own choices and to join the local community.

Challenges were overcome. Maggie loved her privacy and initially refused to leave her own room. Doreen took time to get used to sleeping in the dark – the lights were never off at night in the institutions. Staff successfully supported both ladies through these and many other hurdles.

When we first met the friends

Dimensions first met the ladies when we took over their service from the incumbent provider.

We introduced innovative (for that time) ideas such as person-centred support planning and the pair began to really see a positive difference in their lives.

For the first time they were involved in the recruitment process, choosing staff to support them who matched their own interests and needs.

Martin Bowler, the Assistant Locality Manager for their service said: "Things became so different for them both, in such a positive way.

The person-centred approach meant that they gained control of how they were supported and their community involvement.

"We took the time to really get to know them both and see their very bubbly personalities.

In the past, they had been dismissed because they do not speak; nobody had taken the time to find alternative ways to communicate with them.

Getting to know them

We were able to learn all about their needs and wants – which included wanting their own house." Maggie loves anything 'posh' and has been supported to visit Claridges in London several times where she enjoys being called 'Madame Maggie'.

Her bedroom is filled with ornate furniture and pretty jewellery. She chooses to furnish her room with designer items and enjoys going to spas.

Doreen is an adventurous person. She loves to visit Blackpool, goes to the cinema and has been on several holidays including cruises and Disneyland Paris.

But what is so great to see is their true friendship and love for one another – they have been through thick and thin together and the banter between them is incredible.

Moving into their own home together

This year, their dream of moving into their own home finally came true. Martin said: "Walking into the new bungalow for the first time was so emotional. Doreen was jumping around in her wheelchair and Maggie had tears in her eyes.

"The move was so exciting. It was amazing to be able to support Maggie and Doreen to achieve their dream, and to work with them to decorate it to their tastes.

But it does feel a little bittersweet because for the majority of their lives they haven't had the opportunity to really enjoy life to the full."

Living in a smaller property together means they have more one to one time with their support staff allowing them to have much more freedom to choose their activities and immerse themselves in their community, which has led to a growth in both ladies' confidence levels.

Both have travelled on a tram for the first time and they go to the theatre and on days out to safari parks together.

Individually, Maggie has found a good local hairdresser and Doreen has been supported to complete the Race for Life.

The difference made by having their own home has been evident to their support team. The ladies are much happier, they're smiling more and they are full of laughter!

They know each other inside out, and as all friends do, have the odd argument.

Moving forwards

But what is truly inspiring is that after years of being left in institutions, where they were treated poorly and their opinions went unheard, they finally have the life they deserve.

Dimensions wants everyone we support to have the opportunity to decide where they live and with whom.

For Maggie and Doreen this has meant moving into a shared house, but for others it may mean living alone or moving back to be closer to their family home.

No-one – no-one – chooses to move into big care homes or back into institutions. Austerity may be provoking cost cutting measures in some parts of the country but if Maggie was your mum which chapter from her life would you demand?

Believing in Barbara: the story of how one woman has finally started living her life



Barbara needed the right staff

- Staff who would make the effort
- Staff who would not let setbacks get them down
- Staff who could create the vibe that Barbara would respond to
- Staff who are as full of beans as she can be
- Staff who can help Barbara discover her own potential, and never, ever make her feel she's let them down

This is the story of how Dimensions is turning around the life of one young lady who has autism and a learning disability.

After a string of failed placements, Dimensions has halved Barbara's staffing needs and costs – from 2:1 to 1:1 . She is now out, about and meeting all sorts of characters in her local area.

Barbara, now in her mid-20s, has not had an easy life

Difficulties in school meant that she did not learn the relationship skills that most of us take for granted. Barbara's first supported living placement broke down when she was physically abusive towards others and age 21 she ended up being sectioned into an ATU where she lived for two years.

Dimensions met her at a residential home in Gateshead

The thing that struck us most about Barbara, was that no-one had anything nice to say about her at all.

No-one around her seemed willing to build Barbara up, to find her strengths, to engage with her in the way she needs.

Due to her verbal and occasionally physical aggression, no-one even seemed prepared to encourage her to go outdoors; she may have been living in the community but she was most definitely not part of it. Often, Barbara lay in bed all day – she got up after 11am on three out of four days. Her staff seemed to have given up.

Given the right environment Barbara can be full of life, full of energy

When her support changed to Dimensions, and following our Functional Behaviour Assessment, our two top priorities were to get the right living environment, and the right staff around her.

Welbeck Road is a core-and-cluster house (five independent flats in the same complex). This gives it a nice community atmosphere, whilst also providing the independent living that is so important to Barbara.

She can spend time at home, and go round to any of the other four tenants to build friendships. As a group, they go to the dogs, have film nights and get together for all sorts of things. Barbara is even planning to go to a Little Mix gig this year.

Overall, 56 % of her waking time is now spent doing activities, compared to 14 % before Dimensions. And most days, she chooses to get up before 11am.

Getting the right staff for Barbara meant recruiting energetic, positive people

- Staff who would make the effort.
- Who would not let setbacks get them down.
- Who could create the vibe that Barbara would respond to.
- Who are as full of beans as she can be.

Who can help Barbara discover her own potential, and never, ever make her feel she's let them down.

One of the first things we did was to get a high-energy playlist together

A playlist that now gets Barbara out of bed and going in the mornings.

We have also devised an activity planner so that regardless of what time Barbara gets out of bed, there is a plan for something to do.

It was important for Barbara to take control of her life

She's very target driven. She monitors her own sleep, has decorated her own home, chooses and buys her own shopping and has recently joined Slimming World, while challenging herself with a new Fitbit. Indeed, since beginning her fitness programme, Barbara has reached her target each week.

She's going out every day and enjoys visiting her mum. And, she has already completed one college course with skills for people and is looking into enrolling onto another in the near future.

There's a long way to go. But Barbara's story shows just how important it is, for all of us, to be surrounded by people who believe in us.

Transforming Care performance data in the spotlight

By Chris Woodhead, Director of Housing and Business Development



As I write we're just a few months from the end of Transforming Care. Whilst information suggests that its aims will continue as the 'learning disability' focus in Sustainability and Transformation Partnerships, there isn't what I would call open, inclusive dialogue about what this future should be.

Nobody seems to be suggesting that the work is done and no-one I speak to has lost the appetite to better support this group of people. The main question for me is: if we are to hold true to the original aims of Transforming Care, what is the data telling us about sharpening our collective effort? The latest numbers pose questions that, through wider debate, could inform what happens next:

- Is there a specific problem with support for young adults that providers can help solve? The number of inpatient under 18's has more than doubled since 2015, from 110 to 250. That's now over 10 % of all patients.
- Has the programme overlooked the specific needs of autistic people? Pleasingly, the number of people admitted with a learning disability has fallen but the number with an autism-only diagnosis has risen from 12 % in 2015 to 22 % of total admissions.
- Why is there less use of people and process to stand up for individuals? Whilst 5 % of patients had no advocate in 2015, that figure is now 23 %. Where 1 % of people didn't have a care co-ordinator in 2015, it's now 8 %. In 2015, 77 % of care co-ordinator reviews happened in the preceding six months. It's now 54 % and falling.
- Why have Care and Treatment Reviews not successfully replaced care co-ordinator reviews? Overall, 46 % of patients have not had a CTR within the mandated past six months. Everyone should have one. Yes, 62 % of patients have a transfer date, up from 50 % in 2015 but I politely question the likelihood of success without a CTR.



- I worry about where people transfer to. Roughly the same proportion of people are moving to community living and residential care as in 2015 but 25 % now move to ‘other’ establishments (was 6 %). ‘Other’ must have once been a last resort classification –what forms of accommodation are now coded to it and are they ‘transformational’?
- 30 % of existing care plans record no need for inpatient care. That’s an improvement from 2015 but 695 people are still locked up unnecessarily. Less than a quarter are working towards discharge and the average stay has risen to over five years. Why is this when community placements appear to be working? (There’s no change to the proportion of readmissions or where people are admitted from).
- Well, ‘lack of suitable housing’ was cited as a factor in 39 % of cases, and ‘waiting for residential care’ in 34 % – yet at Dimensions, we have nearly 100 supported living vacancies. Whilst I must acknowledge the inherent difficulties in supporting someone out of ATU into shared supported living, I do wonder if the NHS could work with providers to set up a vacancy register and matching service for those looking for compatible housemates.
- Finally, new data shows that 22 % of people are placed more than 100km from home, including 60 under-18s. Is this improving or worsening? Why?

Such mixed data suggests that Transforming Care has needed to fight for its place in the NHS spotlight. It was one strand of a forward plan that featured other critical aims. Despite the welcome announcement of £20bn new NHS funding (money that will arrive wrapped in more targets and priority objectives), the fact that money is being injected into health and not social care amplifies my fear that, unless we act quickly and in concert, the aims of Transforming Care’s sequel will need to jockey for position with other goals once again.

I have asked questions without answers because a) I don’t have all the answers (who does?) and b) these questions should be debated more widely, utilising cross-sector expertise. Collectively, we must be able to offer solutions to make whatever follows Transforming Care a bigger success.

The second-longest serving ATU resident has just left – but where is she now?



The second-longest serving resident of a UK mental health hospital has just left recently.

For the past 22 years, 59-year old Jackie has been shut up – first, inside the notorious (and now closed) South Ockendon institution in South Mimms where she first developed behaviours of distress and later at Heath Close, an NHS facility in Billericay.

She has recently moved into her own home where she will live independently, supported to do so by staff from Dimensions. New team manager Debbie takes up Jackie's story:

My first encounter with Jackie was an elderly lady sitting alone at a table, staring vacantly at a blank green wall. Bored beyond belief with nowhere to go, nothing to do and no-one to talk to. This would turn out to be typical of her days inside the hospital.

Since getting into a wheelchair during a bout of gout 5 years ago, she has barely left it at all. Not to sit on a sofa. Not to try to walk again. Not to make a cup of tea. Indeed, for the past five years Jackie wasn't even been able to enter her own kitchen as her wheelchair wouldn't fit.

Hospital staff did almost everything for Jackie – they made her tea, brought her meals, ran errands to the shop. This approach may masquerade as caring but over the years, it completely eliminated Jackie's independence and confidence to do things for herself.

Jackie had become depersonalised – her day was nothing more than a set of tasks for hospital staff to do. The highlight of Jackie's week was a pat-a-dog session that only lasts a few minutes. She developed serious anxiety around change, which led to behaviours of distress ... and so the vicious circle continued.



“ Jackie’s story is a real social indictment. She entered South Ockendon simply because her parents needed a little more support. 22 years of institutional living later I am deeply proud to be one of the team responsible for helping her leave successfully. Debbie ”

Then came Winterbourne View, the creaking cogs of change, and pressure on CCGs and local authorities to get people out of institutional living. Following one failed attempt to support her in the community (which Jackie won’t talk about) she was introduced to Dimensions.

It has taken 12 months to build relationships and develop trust to the point where Jackie couldn’t wait to leave. When I asked what she wanted from her new life, she replied:

“I want to be able to make my own cup of tea. I want to choose when I go to bed. I want there to be no health and safety posters in my house. I want to be able to hold my own front door key. I want my mum to visit lots. And, in August, I really want a party for my 60th birthday.”

Jackie had her initial priorities for her new life, as did we here at Dimensions. In the future we want to support her to walk again. To re-learn to cook (she wants to start with Chinese Chicken... no pressure on her staff then)!

She wants to get involved in the life of the beautiful community centre next door and access her long-forgotten savings accounts. And ironically, for someone leaving hospital, she wants to improve her health by registering with her local GP and dentist.

For someone as institutionalised as Jackie, life in supported living could well be overwhelming. But we think she’ll thrive. She has the capacity to make her own decisions, to take control of her life. And the early signs are promising.

The first thing she did on seeing her new living room was choose to get out of her wheelchair to sit in the armchair. That was pretty much the first time she’d left her wheelchair in five years.

Jackie will now be supported to live a far richer life in the community at a fraction of the cost to the NHS of keeping her in hospital. And as for her 60th... well, together we’ll make it a night to remember.

Tackling over medication: Katy re-emerges



How far Katy has come

- Katy's medication was drastically reduced
- Katy started speaking and even joking with her staff team
- Katy started moving and walking
- Her behaviours of distress reduced

Katy* was diagnosed with epilepsy and a learning disability when she was 11 years old.

She was reported to have 'drop seizures' and required medication to manage these. She lived with family until she was 19, when she moved into residential care.

From here, she moved through several residential care homes over the course of 27 years until she was hospitalised due to a fall caused by malnutrition.

As a result, she was unable to return to her previous setting as it was in an upstairs room and she had become bedbound. She was assessed and discharged to a shared support service for people with complicated health needs and specially trained staff – this is where Katy's journey with Dimensions began.

On admission to the service, she arrived only with a pair of pyjamas. There was little history on where she had been before or what had led her to require the care of the high dependency unit.

On admission, she weighed only 5st 3lbs. She was bed bound and too weak to move herself, requiring a hoist, never leaving the house and spending most of her time in bed.

Katy made no effort to interact with her staff or the other people. She had some speech but it was slurred and it seemed to cause her fatigue even to try.

Due to her severe malnutrition, she was prescribed a cocktail of vitamin supplements to give her essential nutrients, amongst a variety of other medications for epilepsy, depression and mood stabilisers.

It was clear that Katy disliked taking her medication as she often refused it. Family members explained to staff that they would only call her in the afternoon because there was no point in calling earlier as she was "too drugged up."

Katy displayed many behaviours of distress – she would spend hours just screaming non-stop and would assault any staff that were within her reach. The staff team were getting burned out – if they were not dealing with an incident, they were writing it up.

Katy's support staff raised concerns about the amount of medication Katy was on at their team meetings and took action to start a review process. The team took the lead in requesting a reduction in medication and also a referral to the Intensive Outreach Service from the doctor.

The family were consulted and were very much on board with the plan. The first medication to be reduced was Tegretol, a drug ordinarily used for the management of epilepsy, but also used for the control of bi-polar disorder as well as a mood stabiliser.

Katy was on Tegretol as a mood stabiliser rather than to control her epilepsy. Initially the G.P. reduced the Tegretol from 500mg to 400mg. Staff were to monitor the reactions to this reduction by completing daily logs, seizure activity logs and ABC charts.

Katy was unaltered by the change. There were no differences noted in presentation or frequency, both in her seizure activity or the behaviour. At the next review the doctor agreed a more drastic reduction, halving the Tegretol from 400mg to 200mg. The monitoring was to continue and the review to take place after the first two weeks. In the first week of this greater reduction, staff recorded a slight increase in seizure activity. The Intensive Outreach Service were on call for advice with these incidents, although these seemed to stabilise to ordinary levels within the week. Once the first week had passed something started to change.

Katy changed!

She became more alert and didn't spend the entire day in and out of sleep. There was no behaviours of distress from Katy towards her staff team... in fact she started speaking and joking with them! It even became apparent that Katy actually had an Irish accent – something that had been completely missed due to her limited communication.

Katy started to eat her food, build up her strength and be able to get herself in and out of her wheelchair. Before long, she began walking again.

She continued to change over the following weeks and staff were able to build up a strong relationship, finding out her likes and dislikes.

As she trusted her staff, she started going out with them. She had a new chance to engage with her peers, going to community based groups and attending a day centre.

Katy now enjoys going to a music group and staff have discovered that she knows many lyrics to songs – her favourites including 'Yellow Submarine' by the Beatles and 'Mama Mia' by Abba.

She has more choice, independence, and has been given the opportunity to start living her life.

Indeed, her family were speechless with the difference they witnessed in a recent visit. More than anything, they want Katy's story to be told – they were elated with the progress that had been made via the dedication of the staff team and the reduction in psychotropic medications.

Katy now weighs 7st 7lbs and enjoys picking clothes, perfume and make up to wear for the day's activities ahead. Her life has improved dramatically and she has transformed as a person.

So what's next? Well, she has now been discharged from the Behavioural Support Team and the dietician.

And as I write, this week she is looking forward to sharing an ordinary house with a few people she has got to know and like. Katy will continue her medication reduction journey with Dimensions complete support.

Katy has her life back!

*Not her real image used.

Belief and ambition: Alan leaves ATU



Sharing a home with other people is a major trigger for Alan's behaviours of distress so, when Dimensions supported him to move out of an assessment and treatment unit (ATU) and into his own home, he stopped intimidating others and started enjoying his life.

Alan is in his fifties. He lives with lots of labels including autism, moderate learning disabilities, obsessive compulsive disorder and bi-polar disorder. Living with others caused anxiety and behaviours of distress, putting a strain on the support service and his housemates.

While living in residential care Alan found it very difficult to share his home with other people – his compulsions to make other people drinks and keep the building clean couldn't be fulfilled. He displayed his anxiety through behaviours of distress, affecting himself, his staff and his housemates. His support provider couldn't cope with his severe behaviours of distress so he was transferred to sheltered accommodation.

While in sheltered accommodation Alan's anxieties increased. Without regular support he tried to make contact with his neighbours, sometimes forcing his way into their home. His behaviour became destructive and he started trying to flood his home. After threatening his neighbours the police intervened. Alan was moved to an assessment and treatment unit.

The assessment and treatment unit was no home for Alan, his anxieties increased and behaviours became more difficult. We got to know Alan and involved one of our specialist behaviour support analysts, to assess what would give him the best possible chance of success.



We had been told that this was Alan's last chance to live in the community and that he may spend the rest of his life in a secure unit. With the backing of his psychologist and psychiatrist, and the treatment unit, the local authority agreed to Dimensions' proposal to move Alan into his own home.

Since our Behaviour Support Team stepped in, Alan has only had nine instances of behaviours of distress.

We started his support gradually – our behaviour support team initiated the process by carrying out a functional behaviour assessment and developing a personalised behaviour support plan.

Angie, Alan's support worker, was with him at the ATU before Dimensions took on his support. Angie has carried on supporting him and is still working with him now.

To help with the transition his new manager spent time with him at the ATU and they worked together to create a personalised advert for support staff. The team shortlisted candidates who spent some time with Alan before being appointed, so that he could choose who he wanted to work with him.

When the support team were in place we trained them in person-centred thinking, how to implement his support plan and the best options for minimising his challenging behaviour.

Alan soon moved out of the ATU and into his own home.

In the first three years of support from Dimensions Alan's behaviours of distress has reduced drastically – he's happy in his own home, keeps it clean and spends his leisure time at a local life skills group and at football matches.

The politics of funding – the conflicts of interest for those charged with transforming care

By Steve Scown, chief executive (former)



Rachel has had a difficult life. Profoundly deaf, and with very little sight, her mother was ill with Rubella whilst pregnant.

She was stuck in a health-run ATU, with costs paid for by health, under the responsibility of her local Sensory team. But her diagnosis has changed, from developmental delay to learning disability. This enabled her to access different funding and she was referred to Dimensions. Without any doubt in my mind this nimble footwork helped get Rachel out and she is really thriving with our support. Her story got me thinking again about the politics of funding, and how this can both positively and negatively impact on people's lives.

Rachel's life is certainly better now. But what about fictional John? John has a learning disability and lives with his parents, who support him. He's going through a rough time and his parents ask the local authority for help. What John and his family really need is flexible, responsive, local, expert support. But this support isn't there, his situation at home deteriorates and John is referred to an Assessment and Treatment Unit (ATU). Not because he has a health need that needs treatment but because the right support wasn't available in the community. A place at the ATU is. Now, John's support is funded in whole or in part by Health.

Or consider similarly fictional Peter. Peter has been living in an ATU for two years, but there's no longer any reason for him to stay locked up. He could be supported to live in the community – he's desperate to get out and have a life. Everyone who is important in Peter's life knows this and wants this to happen. In three more years, the Health dowry will kick in (why five years? Dimensions, along with others, has repeatedly proposed a reduction from five to two) and health funding will be added to Peter's funding pot. If Peter leaves the ATU now, his local authority will have to pick up the whole cost of his support, and his current provider will have an empty bed. Do you think that if the money to fund Peter's services was controlled by his family, or an organisation acting on his / their behalf, that he would be in a minute longer than necessary? We could always call that a personal budget...

Too cynical? Put yourself in the shoes of an under-funded social care commissioner faced with balancing impossible demands on budget and service provision. In the cases of both Peter and John, there's no chance of their funding being redirected to community based preventative support – it is necessarily committed to sustaining current services and packages. I believe that short term investment funding – sustaining existing whilst investing in preventative community-based services is required. We know community-based services are not only better in terms of quality of life and outcomes, they are cheaper as well.



My cynicism is backed up by the data. 72 % of inpatients have been in hospital for a year or more (Oct 18 data) – hardly "assessment and treatment."

Of new admissions to hospital in Oct 18, just 27 % had a pre-admission Care and Treatment Review (which would oblige a discharge plan to be put in place). Just 15 % of the rest received a post-admission CTR at time of data collection (A CTR should be completed within 10 days following admission).

Looking more broadly, at all inpatients, just 58 % had a CTR within the allotted six month timescale; fully 18 % had not had one in the preceding year. I would note that these figures are improvements on two years ago but there is some way to go.

The HSCIC data also reveals that 72 % of inpatients' care plans say they need inpatient care; 28 % do not. This figure is virtually unchanged over time - so why are the 28 % not getting out?

There's an acid test to evaluate efforts to transform care. It is this: Are commercial providers of ATUs investing, or exiting the market?

The answer, I'm afraid, is that the major private players are investing in their facilities. They see more demand and more opportunity, not less. And overseas investors see opportunity too.

In the politics of funding, there remain many incentives for providers and commissioners not to push to get people out. The danger is that if we don't really invest in developing community alternatives whilst also funding current bed stock, people will move from NHS beds to non-NHS beds in so-called 'rehabilitation' and secure units, a pattern we have seen in mental health.

My grandma used to say that if it looks like a duck, and quacks like a duck, it is a duck. Well this looks like, and sounds like, funding politics keeping people locked up.

Life really can get better: Steve's journey



Steve's achievements

- The ability to communicate with those around him
- Elimination of antipsychotic medication
- Moving out of an ATU
- Behaviour of distress all but disappeared
- Staffing needs halved
- Strong relationships with all those around him

Steve* is a man with learning disabilities, suspected autism and a fierce reputation.

Until 1997 Steve was locked up in a secure hospital's Challenging Behaviour Unit and was on copious doses of antipsychotic medication. Now he's free of medication and out of the secure hospital unit.

Steve doesn't speak, and gets physically aggressive or self harms when his communication – Objects Of Reference or simple Makaton – is misunderstood. He damages buildings, has limited access to the community and rarely sees his parents.

After Steve left hospital he moved into a Dimensions registered care service. His reputation preceded him and initially his behaviour and the support he received was none too different. Indeed, the local community once petitioned for him to be removed.

It took a behaviour assessment to turn things around. A new approach to communication was taken – an iPad with pictures and video. His service was also made more robust, meaning he could be left to get on with more household tasks. And his day was made far more predictable.

Those interventions made all the difference. As Steve's behaviour of distress reduced, staff felt confident and relaxed and he could do more and more for himself. A virtuous circle was created. Steve's favourite support staff is now a small Scottish lady. He can go to local shops, the pool and the pub.



Despite initial reluctance on the part of his doctor, he is now completely free of antipsychotic medication. Best of all, he has had his first family Christmas since childhood.

There remains a long way to go. Steve doesn't get on with his housemate, and so the team has been looking for supported living arrangements for him.

Once again, Steve's ferocious reputation was cause for concern amongst those agencies familiar only with his past but Dimensions has been able to provide the behavioural data required to make the move.

As part of this, his previous support – 280 hours per week plus sleep in staff just a few years ago – will soon be down below 150.

Steve's support manager Tony commented "We had to understand why Steve was getting upset, avoid taking it personally and avoid focusing on his behaviour.

We kept asking ourselves, "Why are you communicating in this way? What can I do to help you not feel the need to display this behaviour? Once the team had this mindset, meeting the needs of Steve was easy."

So few people believed Steve could change. His story should give belief to all those people currently locked in ATUs or having a hard time elsewhere, and their families. Life really can get better.

*name has been changed to protect privacy. Not his real image used.

Swapping restraint for Positive Behaviour Support



Richard's achievements

- Richard's support has been reduced from 3:1 to 1:1 full-time, leading to major savings for the local authority
- There is now one behaviour of distress every two months, down from one a week; Control and Restraint were removed from his support programme after a year
- Richard is more included in his community, happier and with a better quality of life.

Richard* is a young man who has a learning disability and violent behaviours of distress.

When he joined Dimensions he moved from a secure unit with a 3:1 staffing ratio, costing around £200k per year. He now needs just 1:1 staffing and understands how to stop behaviour of distress triggers.

When Dimensions took over his support one of Richard's goals was to become more independent.

The team initially decided to focus on communication, decision making, and getting out and about.

The team felt that making a difference in these areas would have the greatest overall impact on his quality of life.

“ Richard now initiates interaction, he'll come and sit in communal areas and chat to everyone.
Kirsty, Support Worker

”



Making a difference

Communication

Because Richard's physical aggression involved biting and hitting, staff focused on mitigating this risk. Unfortunately, this often led to a defensive team rather than a supportive team. They identified this as a problem and developed strategies to build a meaningful rapport with him.

Decision making

Richard's team understand that it is important to give him time and space so he can make his own decisions; they don't place demands on him and don't rush him. Richard now decides what time he wants to get out of bed, when he wants to eat and what he does.

Out and about

Most triggers for Richard's behaviours of distress occurred when he was out of his home. They developed a strategy to help him cope by encouraging him to say the word 'home' when he felt uncomfortable. Staff would immediately take him home.

This system took several months to establish but, following each incident, his support team would talk about it and suggest using 'home' as an avoidance method. Richard eventually tried saying 'home' to staff when he was uncomfortable and was clearly pleased when he was immediately taken home.

Richard has now made so much progress he is able to go on holiday. He loves the seaside and has been to Skegness and Scarborough.

*name has been changed to protect privacy.

Making her own rules: Rachel leaves hospital

Marian's daughter, Rachel, lived in a hospital for 15 years with 25 other people.

Rachel doesn't speak. She loves life, she is totally absorbed by the world around her but she doesn't like following rules.

In the hospital everything was regimented. Everyone got up at the same time. Everyone was washed at the same time and everyone went to the day centre at the same time.

Rachel hated being ordered around.

The most demanding people in the hospital received most of the attention and so Rachel only had one-to-one support when Marian saw her. Marian would come to visit several times a week and together they would 'escape' and leave the hospital to go on trips.

When they returned Rachel would be upset and not want her mum to leave. Rachel would shut herself away and only come out of her room when she was made to.

Eventually, after the Winterbourne View scandal, the hospital was closed down and Marian began researching living options for Rachel.

With help from Dimensions Marian found a bungalow for Rachel which she now owns. In the hospital environment Rachel had significant amounts of behaviours of distress but this has now all but disappeared.

“What I always wanted was for her to have a second family. She's got that now...
Marian, Rachel's mum”

Rachel is supported by permanent staff who she chose and who she has grown very close to.

She has an action packed diary full of the activities she enjoys from meals out to swimming and wheelchair cycling.

Now that Rachel can make her own choices and have them respected, she is much happier.

Rachel is enjoying life again and now I feel I can pop up, when she wants, for a cup of tea. For me, my life is so much less stressful. I don't have to keep fighting.
Marian, Rachel's mum

Her staff team have worked with speech and language therapists to develop a detailed communication passport so that they know what Rachel wants even though she can't speak.

When Rachel wants to eat she will stand by the kitchen table and when she wants to wash she will sit on the bath. This has made a huge difference as Rachel is much less frustrated by people not understanding what she wants.

The cost of choice and control

Giving people with learning disabilities choice and control, a home in the community and an active life is not more expensive.

In fact, supported living is less expensive than keeping people in hospitals. There is consensus – amongst families and professionals alike – that people with learning disabilities should not be living in hospital settings.

“Now, I know she's safe. I know if anything happens to me she'll be ok.
Marian, Rachel's mum”

Positive steps for Henry



Outcomes

- Developed assertiveness skills
- Explored his thoughts and feelings with new environments and settings
- Put together his self-risk management plan
- Support package reduced from £96k to £87k per annum and will continue to fall

Henry* is a very sociable and personable individual who enjoys spending his time volunteering at a charity shop, shopping and going swimming with his support. But his ability to understand his sexuality has been complicated due to his own past traumatic experiences. He has been supported by Dimensions forensic team since 2015.

Background

When Dimensions first met Henry, he was living at a Step Down placement where he had been since 2008.

He was cautioned for sexual assault in 2000 and placed on the sex offenders register as a schedule 1 offender. Further allegations were made of sexual assault in 2003 and he re-offended.

Henry was sentenced and given an interim section 38 hospital order under the 1983 Mental Health Act and was admitted to a private medium secure hospital. In 2005 this was converted to section 37 of the Mental Health Act 1983.

Henry has engaged in the Sex Offender Treatment Programme and therapeutic support in relation to his own abusive experiences as well as therapy to understand and express emotions.

Outcomes

Henry is being supported to manage his emotions alongside his perception of feeling bullied or judged. He's developed assertiveness skills to enable him to say no, recognise the reasons why this is appropriate and that it is valid to do so.

Henry has explored his thoughts and feelings with new environments and settings to enable him to increase the activities that he accesses. He's also worked hard to put together his self-risk management plan for unsupported time at the local shop.

Henry has engaged in sessions with his Clinical Practitioner to explore what caused anxiety in being unsupported and is now building confidence in himself. This has enabled him to want to continue to further his unsupported time in the New Year.

Reduction of support levels will occur in conjunction with Henry's ability to self-risk manage and further unsupported time in agreement with the wider Multidisciplinary team around him.

*name has been changed to protect privacy.

Get out: strategies for families

By Liz Wilson, family consultant (former)



If your son, daughter or sibling is stuck in an ATU, there may be something here for you. We asked Liz Wilson, Dimensions' family consultant, for a few tips, to give families the best chance of successfully getting their loved one out of an ATU. Liz told us:

Don't try to do it alone, join the networks of families who are doing this together

It's vital to meet and talk with people who have succeeded in getting their loved ones out of ATU's, and those who are still trying. Listen too, to people with learning disabilities and autism who are willing to share their personal experience. Everyone can learn from each other's successes and challenges. Any provider should be able to put you in touch with families who have been in your position. Twitter and Facebook are good social networks; you'll find many allies and sources of support there including journalists. But I would specifically recommend the Stronger Together network: <https://bringingustogether.org.uk/stronger-together/>

Never give up on the possibility of a good life in the community

However many times your loved one has been failed by the system, however much more damaged he or she is now compared to when they went in to the ATU, a successful return to ordinary community life is always possible with the right approach, the right provider, the right housing and the right support team. But if you don't believe, no one else will either.

Dare to think big, but be prepared for real change to take time

Make sure your plans and those made by others are detailed, achievable and realistic and include clear goals and timescales with named people to take responsibility for each action. There will be ups and downs, times when you feel things are going backwards, but if you have a clear plan you can tick off successes and go back and create a different approach when things are stuck.



“...a successful return to ordinary community life is always possible with the right approach, the right provider, the right housing and the right support team.”

Count every success, no matter how small

Write them down and read them back from time to time. It's a simple psychological trick. You'll feel more positive. That will give you more energy to keep going, and more balance when things are looking bleak. You must remember to take care of yourself and your family, wearing yourself out won't help in the long run. You will find a network of families who will cheer you on and be cheered by your successes too.

Approach everything with human rights and inclusion in mind

If you can describe how your proposals support the legal and human rights and inclusion of your loved one then your voice has more power than simple opinion. If, like most families, you aren't familiar with human rights law, then:

- Use all the available advocacy and legal support that you can find. Find allies in the system, good people are there who will work with you to achieve your goals. But don't expect help to be supplied to you. You have to go looking for it.

All that said, it's also true that families have been fighting for years, doing all of the above and getting nowhere. The system is powerful. That's why we must organise.

Finding great housing for people with highly complex needs



By involving our in-house Housing Brokerage Team, paying careful attention to detail, involving family members and making a careful business case, we have been able to transform a complex young man's life and build our reputation for solving difficult problems.

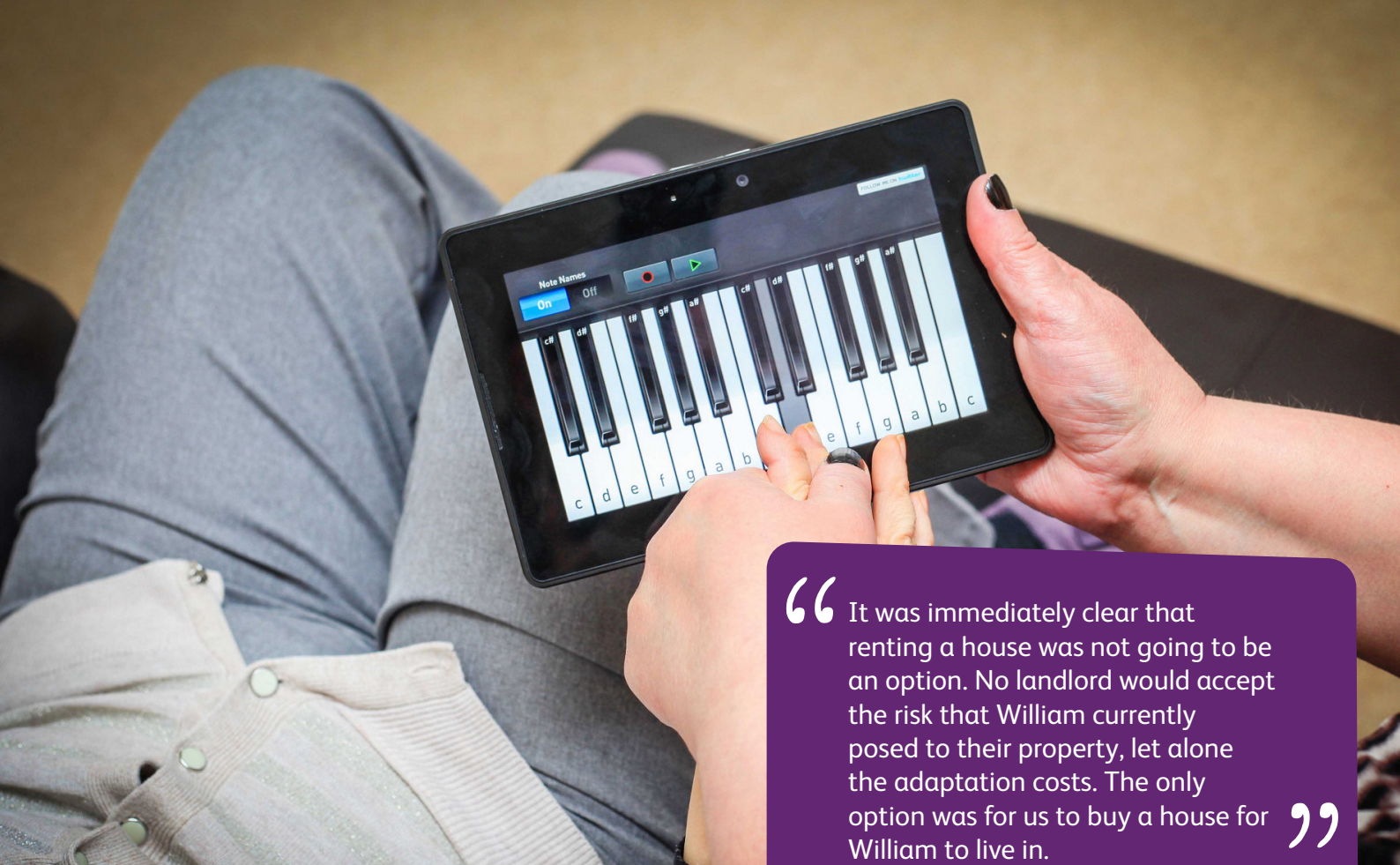
When Dimensions received a referral to support an extremely complex young man, who had been in and out of ATUs and with multiple placement breakdowns, we turned to our new Housing Brokerage team to find him a place to live.

William* was described as having severe challenging behaviour including a history of damaging property and physical abuse of others. He had been in many out-of-area placements. It was clear that living on his own in a modified home near his family was an essential start point for supporting William to begin to live an ordinary life, and move on from the past.

Beyond location, the list of requirements for the home was long. Every room would need two exits. Everything in the property would need to be safe or secured. And the house would need to be in a large, private plot of land due to the potential for William to make noise.

Dimensions housing broker Michael says, "Understandably given the failure of the 'system' to date, William's loving family were anxious about all aspects of support for their son."

Our Housing Brokerage team spent a few days with William's family, meeting the local estate agents together and exploring a wide range of property types. That time was invaluable; it gave us a real feel for William's needs beyond what we could read in black and white. It helped us understand why William's parents placed such great importance on seemingly small details. And for William's family, we hope it built a level of trust that Dimensions has William's best interests at heart – even when what we could offer fell short of what they wanted. Many conversations started with "I can't do that. But let me tell you what I can do..."



“ It was immediately clear that renting a house was not going to be an option. No landlord would accept the risk that William currently posed to their property, let alone the adaptation costs. The only option was for us to buy a house for William to live in. ”

William was funded by the CCG and Local Authority and, working together, we agreed that the NHS would pay for half the property purchase costs and the full adaptation cost of nearly £100k through a capital grant. Without this shared financial commitment, no support for William could possibly have got off the ground. Fortunately, the NHS was prepared to set these costs against the likely cost of continuing to support William in a variety of ATUs and through various crises. That made an important difference.

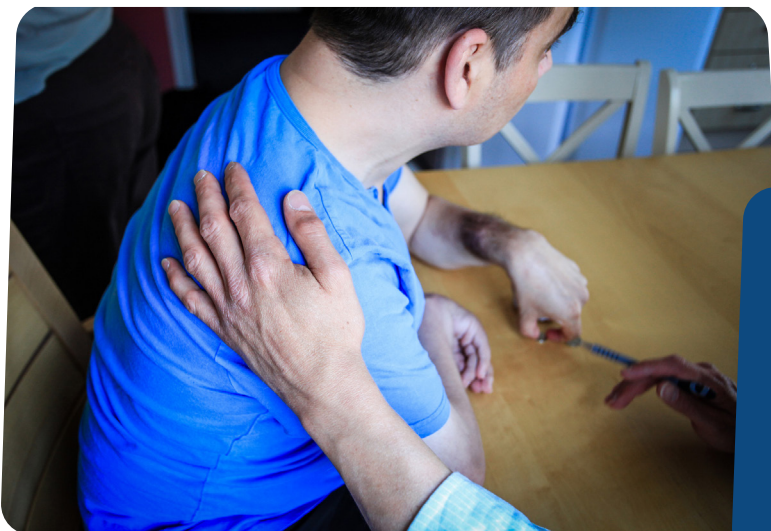
The next set of tricky negotiations surrounded housing benefit. Clearly William's rent would be high but, through building a strong, personal case for the local housing benefit team, we were able to agree a level of bespoke rent considerably in excess of local norms.

While many experts from Dimensions were involved in different aspects of all these negotiations, the Brokerage team provided the direction, the glue and the constant communication with all stakeholders to ensure that together, we were able to get the job done.

So much so in fact that the same Local Authority and CCG has already approached us again with Jayne* who has an extremely similar back story and needs. We look forward to finding a similar solution for Jayne and supporting both to live ordinary, fulfilling, safe lives in their local communities – where they both belong.

*name has been changed to protect privacy. Not his real image used.

An end to restraint for Farouk



How Dimensions is helping Farouk learn a new way of living and supporting him to take his first steps towards being able to take control of his life.

“Life in long stay hospital was not kind to Farouk*. On my initial visits, I would regularly witness five or more hospital staff flattening him into the ground using a variety of strong approaches to restraint. Farouk would fight back, which only made things worse. No one spoke his language and he would sleep three quarters of the day due to the sedatives he was being given. It was an attritional, trench warfare environment. There was no empathy, no dignity. It was awful, really.”

So says Angela*, the Dimensions manager entrusted with bringing a new team together to support Farouk out of this harsh environment and back into his local community. Angela continues,

“Dimensions does not use physical restraint. I was really apprehensive that Farouk’s brand new staff team, having seen what was taking place during ‘getting to know you’ meetings at the hospital, would quit before we even got him out. Could they believe that there was a better way for Farouk?”

Fortunately, they believed. It is very early days; we’re only five weeks into supporting Farouk but already his transformation, his ability to recover from his past life, has surpassed the most optimistic plans.

Farouk is learning a new way of living. He’s learning that instead of flattening him when he destroys property or has other moments of behaviours of distress, his staff will give him space. He’s learning that he can do things for himself and not rely on others; he’s helping load the washing machine, for example. He’s learning that he can exert control over routines. Overall he’s learning that those around him – his support team and our behaviour analysts – are there not to contain him but to help him take steps towards dignity and empowerment, towards being able to take control over his life.



Farouk's family are also learning this new approach to support – and they're teaching us, too. His mum is helping teach his support team to cook authentic national dishes – food he likes and is familiar with, far from hospital fare. And everyone is trying to learn Makaton, to help with communication.

Since leaving hospital, Farouk has also had a welcome change of psychiatrist. Alongside his support team, the new one is happy to explore a range of tactics to reduce his psychotropic medication, in particular those with severe sedative effects. And his new GP has been brought on board too, with appointments after hours or at home to ensure Farouk is comfortable.

Farouk loves taking long walks. In hospital, he was restricted to the grounds. Now, alongside staff, he's able to take walks around his local area. He's been able to go to Boots to pick up his medication. Such trips are planned carefully to avoid known triggers, and over time, PBS approaches will look to tackle these triggers in turn.

Angela adds, "Farouk's stay in hospital was prolonged by difficulty in finding accommodation that met his needs. But once a private landlord was found who would agree to the adaptations needed to support Farouk – including a sensory room and some safe space for his staff teams – it was social story time and all systems go.

At a time when there are so many terrible stories of 'life' in ATUs and other long stay hospitals being shared, we hope all long stay hospitals will look at Farouk's transformation and start believing in the possibilities for those they care for, too.

*name has been changed to protect privacy. Not his real image used.

Learning to communicate: Karen



How Dimensions helped Karen to be understood and reduce her behaviours of distress.

Almost two years ago we started supporting a lady called Karen*. Previously, she had been living in an ATU and showed behaviours of distress such as breaking windows and assaulting staff.

Karen is profoundly deaf and uses British Sign Language to communicate. Yet not a single member of staff in the ATU could use British Sign Language.

She felt alone, frustrated and totally misunderstood which led to her expressing her frustration through behaviours of distress. She would then be heavily medicated to deal with her behaviours. It was very much a vicious cycle.

Fast forward two years, and by using person-centred support and PBS techniques she now has a completely different life – entirely independent, able to cook, clean and go shopping for herself and even go on holiday for the first time ever without her family.

Karen's brother Michael now even works for us as a support worker!

*Not her real image used.

We are so proud of Karen and her support team. So we wanted to share this video which highlights just how far she has come over the past 12 months.

<https://www.youtube.com/watch?v=R-UNqNFqIYE>

Winning at whack-a-mole

By Alicia Wood, Head of public affairs (former)

Alicia Wood, Dimensions' Head of Public Affairs, offers a view on how policymakers can tackle institutional proliferation.

If you have never played whack-a-mole, may I recommend it to you. It's very therapeutic. You whack a rubber mole back into its hole with a hammer. Every time you whack one down, another one pops up. It's great fun. But now, let's replace moles with institutions.

Building the Right Support is very clear that in closing beds and ATUs, the model is not to reinvent more palatable institutions – and yet they are thriving. Who had heard of 'locked rehab,' for example, a couple of years ago? Not me. But it sounds a lot like an ATU in a different shirt. 'Stepdown facility' is another description that has more than a whiff of mole about it.

Looking at Transforming Care data, my colleague Chris writes elsewhere in this report:

Roughly the same proportion of people are moving to community living and residential care as in 2015 but 25 % now move to 'other' establishments (was 6 %). 'Other' must have once been a last resort classification – what forms of accommodation are now coded to it and are they 'transformational'?

Until someone at NHS digital tells me different, I'm going to believe these transfers are primarily to dressed-up institutions. Moles are popping up everywhere, and CQC isn't whacking them all.

One solution here is the monitoring and regulation of commissioning. Well-meaning commissioners that don't understand community support are responsible for commissioning these services. In addition we are seeing social care commissioners who are so stretched in terms of capacity and budgets that a knee jerk reaction has been to revert to the types of services that have been commissioned in the past.

It makes no sense that the organisations that have expertise and capacity, such as providers, self advocacy and carer groups and community partners are not around the table planning the right services from the outset.

I'd like to see alliance models and co-production where commissioners, clinical leads and social care providers come together around the needs of local people and families with a blank sheet of paper and bring together the best of what everyone has to offer in terms of knowledge and experience so we stop building services that are not in the best interests of the person at the centre.

Alongside this we need upfront ring-fenced funding around individuals so we can get around the virtually intractable 'who funds whom' situation. There will need to be commitment to double fund some services to move some people, particularly where NHSE has already contracted beds in hospitals for a fixed period.

We must simultaneously tackle the profit motive. It is not acceptable that US hedge funds are investing in this sector; pushing to increase occupancy and thus shareholder return. That conflict of interest alone demands improved regulation and oversight. We would like to see commissioning and procurement processes that favour providers with good ethical practice around employment and approaches to working with people and families.

Because all I can see right now, are fields of moles stretching to the horizon.



Proving life can get better

Dimensions provides evidence-based, outcomes-focused support including sector leading positive behaviour support for people with learning disabilities, autistic people and those with complex needs. We help the people we support to be actively involved in their communities.



Contact us to find out more:

www.dimensions-uk.org

0300 303 9001

enquiries@dimensions-uk.org

Find us on social media @DimensionsUK



Dimensions

2nd Floor, Building 1430, Arlington Business Park, Theale, Reading, RG7 4SA