

A life after hospital

Kimberley Smith is 22 years old and rents a house with 2 flatmates in South London. She goes to college and studies Arts & Crafts, Maths and English as well as volunteering for a local charity.



was made of Kimberley then in her hospital notes; severe challenging behaviour, abusive, threatening...is in stark contrast to how people view her now.

A hospital is not the right place to live for most people with learning disabilities

Kimberley knows she had emotional and behavioural problems when growing up and given her life circumstances, these problems should be expected. What she also knows is that being placed in a hospital was not the right thing for her and made her behaviour worse. Seclusion, restraint and humiliation were regular occurrences in hospital for Kimberley. There is no doubt that the hospital environment made some of her behaviours escalate.

With the pressure of the government's Winterbourne View Joint Improvement Programme, Kimberley was given an opportunity to move on. Choice

Support, a national charity that supports people with learning disabilities in their communities, was asked to work with Kimberley to help her get a new home and the support she needed.

Real choice, control and good support is what helps people live ordinary lives

The first thing Choice Support did was ask Kimberley what she wanted, what her dreams were, what was important to her, and what made her happy. Simple. Kimberly suddenly became a human being with aspirations, skills and something to give society, rather than just a patient with a set of behaviours to be treated. Kimberley wanted to live with flatmates, go to college, get a job and all the normal things that most young people embarking on their life want. Choice Support planned with Kimberley to work towards achieving her dreams.

Kimberley's support team helped her work out what she needed to manage her behaviour and get what she wanted in life. They then got all the training and support they needed to support Kimberley well. She recently celebrated her first year in her new home and is settled, feeling better about herself and building relationships with family and friends.

Listening and acting on what people say makes all the difference

Hospital was not the right place for Kimberley, though it was justified because her behaviour became worse when she was not getting what she needed. This is a vicious cycle that many people with learning disabilities and/or autism detained in hospital face. What Kimberley and Choice Support have demonstrated is that if we simply listen to what people are saying, with their words or behaviours, and act on it, that people labelled with the most severe challenging behaviour can live an ordinary and fulfilled life in their communities.

Listen to an interview with Kimberley on BBC Radio 4 - www.bit.ly/bbc-r4-kimberley

Like many young women, Kimberley loves music, animals, shopping, girly magazines and make-up. People that know Kimberley well describe her as a positive, happy, bubbly person who has a good relationship with her flatmates and neighbours.

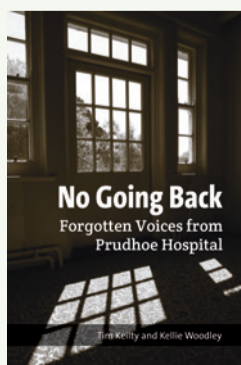
Life hasn't always been like this for Kimberley. Since she was 18 months old, she lived in various foster placements and care homes until she was 18 years old when she was sectioned under the Mental Health Act and hospitalised. The description that



The Keeping it Local project is funded by the Department of Health Innovation, Excellence and Strategic Development (IESD) fund.



Has your organisation signed up to the Driving Up Quality code? Help make services transparent and accountable: www.bit.ly/DUQ-code.



In **No Going Back** Keilty and Woodley document the experiences of people at Prudhoe Hospital, a 20th century institution that incarcerated people with learning difficulties. All H&SA members receive a free printed copy.



There is an Alternative. Read our report and more about our programme of support to develop community based housing and support.

Members Advice Service: Tel. 0300 2010 455

enquiries@housingandsupport.org.uk

Website: www.housingandsupport.org.uk

Keeping it Local



‘Keeping It Local’ was a 3 year national training and development programme, funded by the Department of Health that ended in March 2015. The purpose of Keeping it Local was to build knowledge in housing and support options. This is to help keep people with more complicated housing and support needs to stay in their communities, instead of going in to specialist services or hospitals away from their communities.

H&SA, alongside local partners, ran 24 x 3 day courses for 700 people all over the country. They invited self advocates, families, social care, health and housing professionals to attend and learn together. Each attendee was asked to share locally what they had learned on the course.

H&SA provided ongoing mentoring and support to course participants for the duration of the project, and collected feedback from the course participants about how they had shared their knowledge. H&SA has also been sharing the learning and knowledge in national forums that are concerned with getting local housing and support for people with challenging behaviour and complex needs.

We asked course participants whether what they had learned changed things locally. The responses indicate that whilst both greater knowledge and awareness has been achieved, there are local systems and issues stopping people from making the changes needed.

What Keeping it Local course participants said:

- 96% of respondents felt that after the courses they knew more about housing and support options for people with complex housing needs;
- 57% felt that after the courses, they had been able to plan more effectively with people with complex housing needs.

- After the courses, 50% had been able to help more people with complex housing needs to stay in their community or return to their community.
- After the courses, 61% stated that there had been developments in their area that have resulted in increased opportunities for people with complex housing needs to live in their community.

What Keeping it Local course participants say needs to happen locally to enable people with complex housing needs to live in their communities:

- 70% responded that *‘more housing needs to be available’*

- 85% responded that *‘better planning with people needs to be undertaken’*
- 85% responded that *‘more information about housing needs to be available’*
- 87% responded that *‘there needs to be better joint working between housing, health and social care’*

Subsequently we spent the last year of this programme addressing national groups and forums to try to unpick the problems local people have with moving the agenda on. In the final year of the project, H&SA ran 9 workshops for commissioners and housing providers with the Winterbourne View Joint Improvement Programme across the country. This was to get commissioners and housing providers to share what works and understand what stops things from working.

It was clear that across the country, people with challenging behaviour and complex housing needs are living in their own homes successfully but many are experiencing major barriers to achieving this.

These barriers include:

- Immediate pressures vs long term planning
- Budgetary pressures
- Lack of housing
- Accessing capital funding
- Risk sharing, learning, understanding

This newspaper shares what we learned in the Keeping it Local project and how organisations are dealing with these barriers.

Alicia Wood, Chief Executive, Housing & Support Alliance
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Where people live

People with learning disabilities want to have more control over their lives, live in their own homes, with people they choose to live with, within their own communities. We have known this for some time. We can see from recent statistics that local authority commissioners and providers have listened and are helping people with learning disabilities to do just that. Numbers of people in tenancies, home ownership and supported housing is up and the number of people being placed in residential care, nursing homes and acute facilities is down. Commissioners and providers have done this despite having ongoing pressures with budgets. So even though housing and social care can feel a bit gloomy at the moment, there are reasons to feel positive.

Number of adults with learning disabilities known to councils	2009/10	2013/14	+/-	Overall %
	136,350	142,240	4.41%	100

Where People with Learning Disabilities Live*

*from local authority returns to the Health and Social Care Information Centre based on adults aged 18+ known to councils

Settled housing with family/friends (inc flat share)	41,590	52,100	26.83%	36.63%
Registered care home	24,830	25,740	3.71%	18.10%
Supported accommodation (including group homes)	17,655	24,515	38.86%	17.23%
Tenant (council, housing association etc)	13,460	16,730	24.29%	11.76%
Tenant (private landlord)	3,710	4,835	30.32%	3.4%
Owner occupier/shared ownership	2,755	3,760	36.48%	2.64%
Shared Lives	2,695	3,560	32.10%	2.5%
Acute/long-stay residential facility/hospital (Commissioned by LA)	1,295	1,040	-19.69%	0.73%
Acute/long-stay residential facility/hospital (inc. NHS commissioned) LD Census Sep 2013		3250		2.28%
Registered nursing home	1,830	2,060	12.57%	1.45%
Sheltered housing	640	890	39.06%	0.63%
Other temporary accommodation	705	805	14.8%	0.57%
With family/friends as 'short term guest'	810	745	-8.02%	0.52%
Rough sleeping/shelters/refuges	120	100	-16.67%	0.07%
LA-placed temporary accomm (B&Bs etc)	195	210	7.69%	0.15%
Prison/other detention/probation hostel etc	65	75	15.38%	0.05%
Mobile accomm for Gypsy/Roma and Travellers	20	25	25%	0.02%

The Care Act and Housing

The Care Act is something else to be positive about. It is a major development in helping people with learning disabilities get the housing they need.

A new duty to prevent people going in to care and an explicit acknowledgement that the suitability of living accommodation is a key to well-being and independent living is welcomed. Housing must also now be part of the care assessment process and advice on housing options must be provided along with care advice.

Integration is central to how public bodies will deliver the Care Act. Housing authorities must co-operate with health, social care and criminal justice systems and we are likely to see more rigour from Health and Well-being boards and Joint Strategic Needs Assessments in the inclusion of housing for people who require health and social care.

This is all good, but in the context of stretched social care budgets and a new eligibility framework that will make people with lower support needs eligible for social and health care, there will be tensions for commissioners. Balancing budgets, local priorities and the requirements of the Care Act will be tricky.

Now is the time for commissioners to be collaborating with housing and care providers to find new ways to deliver services and make scarce resources go further. We are seeing exciting examples of Good Neighbour schemes, Timebanks, Support Tenants, Community Networks, and Assistive Technology that both improve people's lives and are cost effective. Now is the time to be talking to each other.

Community Based Services



Can people with learning disabilities and challenging behaviour live successfully in their own communities?

What is meant by community based services?

Community based services are housing, health, care and support services that aim to support people in their own homes or to remain in their own communities. Community based services have been developed as a response to local need and therefore align with local commissioning needs and the needs of local people with learning disabilities and challenging behaviour and their families. People with learning disabilities and challenging behaviour can and do live successfully in their communities with the right housing and support. Many organisations are helping people with learning disabilities and challenging behaviour buy and rent their own homes. Commissioners are delivering local health and social care support to enable people to live successfully in their homes.

Getting housing right for people with learning disabilities and challenging behaviour

People with learning disabilities and challenging behaviour currently placed in ATUs have very little control over where they live, who they live with, how they are supported, and their environment. These factors have a major impact on the individual's well-being and behaviour, yet are often not considered when enabling people to move on and is likely to be why so many 'placements' result in failure for the individual.

The right housing and environment

The right housing and environment is the foundation for getting everything else right in a person's life. People with challenging behaviour need more control over these aspects

of their life than most people if they are to be successful in managing their behaviour. Where people live, the location, the community and the built environment need to be understood from the individual perspective at the outset of planning.

Who you live with

Who people live with (if anyone) also has a major impact on wellbeing and behaviour and needs to be an early consideration when planning. 'Placing' people in voids in existing community based services is not acceptable practice unless it is an active choice and the result of a person centred approach to planning. Where a person actively chooses to live with others, careful planning and consideration of compatibility, and risk and sustainability needs to take place. It is not acceptable for housemates to be subjected to a risk of physical and psychological harm because of another housemate's behaviour, or for there to be a financial imperative to move new, unsuitable housemates in when original housemates move on.

Moving on from ATUs

People moving on from ATUs should have security of tenure in their home, especially when a bespoke housing solution is required. Housing arrangements that are tied in with care arrangements need to be flexible enough that the individual can remain in their home should their care needs change or they need to change care provider.

Principles for planning housing

- The right community, location and built environment need to be at the centre of planning a move on.
- People with learning disabilities and challenging behaviour should have housing arrangements that give them control over where they live, who they live with, and how they are supported if they are to maximise success in managing their behaviour.
- People with learning disabilities and challenging behaviour should not be placed in voids in existing services or group living arrangements if it is not an active choice, and based on a person centred approach to planning.
- It should not be assumed that people with learning disabilities and challenging behaviour should live with others unless it is an active choice and a result of a person centred approach to planning.
- People with learning disabilities and challenging behaviour should have security of tenure in their home.
- People with learning disabilities and challenging behaviour should be able to remain in their home if, and when, their care arrangements need to change so care arrangements should not be a condition of tenure.

People with learning disabilities and challenging behaviour live successfully in their own homes

The following routes to housing are being provided by Advance Housing, Best Housing Association, Cameron Trust, Dimensions, Golden Lane Housing, Hildale Housing Association, Keyring, mcch, United Response, My Safe Home and working successfully:



● Social Housing via the Housing Register

This is accommodation provided by councils and housing associations (RPs) which is let to people in the greatest housing need. Most local authorities operate a 'Choice Based Lettings' system which prioritises those in greatest housing need, usually using a banding or points system.

Sometimes specialist housing such as wheelchair accessible properties, sheltered housing, extra care or supported living properties are let in this way. Sometimes separate letting criteria are used. Applications for housing need to be made to local borough or district councils. People with learning disabilities are encouraged to register with their local authority for housing as soon as they are in need, as the information on housing register is used to inform local housing strategies as well as to consider people for vacant properties.

● Privately financed properties

Most housing providers have purchased properties using their own funding or borrowing. Sometimes this will supplement other funding such as Department of Health grant. The providers will then let those people with learning disabilities

using their own discretion, criteria, or in accordance with any funding terms or nominations agreements they may have with local authority housing or social services departments or CCGs.

This type of housing could take many forms, from individual single person flats and bungalows to shared houses through to specifically designed schemes.

● Private rented properties

Many providers have experience of working with private landlords. Properties are readily available and usually available immediately. There were many barriers voiced at the working groups and, like other housing options, private rented accommodation will not suit everyone, but it is an option that should be considered.

● Privately leased properties (PSL scheme)

Some housing providers act as intermediaries by leasing properties from the private landlord and then sub letting to people with learning disabilities who become tenants.

This 'private sector leasing' arrangement provides more comfort for the individual, the staff supporting them and

the landlord, but is often not financially possible, especially if rents are high and management fees need to be added

● Shared ownership

Shared ownership is a "part buy and part rent" scheme which allows someone to buy a share in a property – usually between 25% and 75%, using savings or a SMI mortgage, or both, and pay rent for the share retained by the housing association.

Some people with disabilities in receipt of a "qualifying benefit" may be eligible to obtain Support for Mortgage Interest (SMI) payments, which are additional welfare benefit payments from the DWP which help towards mortgage payments if someone borrows up to £100,000 in order to move to somewhere more suited to their disability. The leading mortgage arranger in the sector, My Safe Home, presented information about this.

Some housing associations will build or refurbish properties for sale on a shared ownership basis and others will use the HOLD (Home Ownership for People with Long Term Disabilities) programme, which allows someone to buy a property on the open market – within certain parameters.

Funding for HOLD is currently available and housing associations can bid for funds using the Continuous Market

Engagement process.

Some Housing Associations will assist with repairs. Some will only sell properties being built or converted by them; others will allow the person to choose a home on the open market, up to certain price limits. Inclusion in any scheme will depend on properties or capital funding being available.

● Community Network / KeyRing

A community network comprises a number of members (usually 6-10 people with learning disabilities) living in their own homes in close proximity to one another.

The properties could be rented from any type of landlord or owned by the individuals. Each member is supported for a few hours a week by a volunteer, who also lives locally, and by any additional support staff they need.

Members are encouraged to share their skills and talents with each other and with their community. KeyRing is a national organisation providing this type of support so these networks are often called KeyRing networks.

● More information

Further information about these and other housing options are available on the Housing & Support Alliance's website www.housingandsupport.org.uk

Capital Grant arrangements – Proposed new framework for capital release of NHS properties with Legal Charges.

From April 2015 legal charges on NHS England owned learning disability properties were transferred from the Department of Health to NHS England, enabling them to take decisions in relation to the proposed ‘recycling’ of existing grants into new schemes, to the benefit of this client group, and then work with CCGs, local authorities, housing providers and others to manage the necessary transactions, allowing new property investments.

NHS England, Local Authorities, social care providers and NHS Commissioners are currently working together on the business cases for currently identified sites and assets.

The Housing & Support Alliance has campaigned for changes to the way in which NHS grant funded properties are dealt with for some time and will continue to work with NHS

England and the Transforming Care Programme to address how such ‘recycling’ can most effectively be achieved. The hope is that a new framework will be formally made available later in the year, including a standardised approach to business case development, assurance approval, and a suite of legal and transactional documentation to be applied to all future projects.

For present purposes, individual proposals to ‘recycle’ properties previously granted by the NHS to local authorities and housing providers (most commonly to provide supported living arrangements), should be set out in a business case agreed by the relevant local authority and CCG. This should be submitted to the geographically relevant NHS England Regional Team.

The internal NHS England process will then be to consider the case on its merits against their investment priorities, to liaise with the stakeholders and the relevant housing provider, and to agree the key commercial and financial dimensions

of the business case. This will include the appropriate legal and commercial provisions that will enable the scheme to proceed once it is approved.

Aside from making the strategic case for NHS England capital investment in the proposed scheme, it will be very important to ensure that the commercial and financial arrangements proposed are acceptable in terms of enabling NHS England to ensure that it appropriately protects the NHS investment into the future in line with the relevant DH directions that empower them to make those grants.

Approval authority will lie with NHS England’s Chief Financial Officer.

Social Investment in Community Living



H&SA has been working for several years to increase investment in housing for people with learning disabilities. We know that access to capital has been one of the big issues for commissioners and providers. We also know that some housing investment models are unsustainable because of the high returns required, and that investment has usually been made into institutional models of care. So not all investment models work for people with learning disabilities.

In the *Winterbourne View - Time for Change* report for NHS England, a social investment model was proposed that could

enable commissioners and providers to get significant numbers of people out of hospital and into their own

homes in communities, and to stop people going in to hospital unnecessarily.

We are keen to support commissioners and housing providers to come together in commissioning areas or regions to put an infrastructure in place to make this happen.

We have recently been in discussions with a number of very large social investment capital funds eager to invest in building, buying or developing accommodation for disabled people who need local authority or health funded care and support.

They each offer a range of options and have their own basic investment model. Common to all, however, is the aim of funding high quality housing, on good terms, and in a spirit of partnership and flexibility.

H&SA worked with colleagues in the Winterbourne View JIP to develop a model to bring social

investors together with housing providers and commissioners to deliver a range of housing options to meet the needs of people with learning disabilities and in particular, those who need to be discharged from hospitals.

We are also proposing to bring together investors, housing providers and commissioners to develop some practical shared resources to include:

- Fit for purpose Contracting and Procurement frameworks
- Flexible model design based on negotiation
- Fit for purpose management and service level agreements
- Risk management approach to voids
- Pooled brokerage resources.

If you are interested in any of these developments, please contact steve.harris@housingandsupport.org.uk

Planning housing with people - is housing brokerage the answer?

Getting the right housing for people is central to enabling them to live successfully in the community. Through the national and regional working groups we heard that housing expertise was lacking in most areas:

- The housing needs of individuals are not known because many professionals are used to placing people in existing services and think only about 'placements'.
- Housing, brokerage and advocacy roles are not being utilised.
- Creating bespoke solutions around individuals' needs is not what people are used to doing in a joined up way with health, social care and housing.

When people want a housing solution that is outside of the regular service on offer, it often falls to social workers to arrange. Rarely do social workers have the housing expertise and time

required to create a bespoke housing solution to meet individual needs. This is where the blockage usually occurs. Frontline staff without the knowledge to help people with learning disabilities and families think about what they want and what works for them in the first place, reverting to placements in services that do not work. Some commissioners and providers are solving these problems by recruiting housing experts that can work with individuals, families and profession-

als to broker the right housing solution. H&SA are starting to see providers such as Dimensions, United Response and Choice Support exploring different forms of Housing Brokerage. Commissioners like Essex County Council are beginning to address these issues by piloting a brokerage service or recruiting housing specialists in their community teams. Whichever way it is done, we know that having housing expertise and a vision for what is possible when planning is crucial to getting the outcomes right.

If you want to talk through setting up a housing brokerage service, contact alicia.wood@housingandsupport.org.uk

CASE STUDY / Essex County Council (ECC) and Dimensions Housing Brokerage Service

When ECC set out to pilot a Housing Brokerage service in 2011 it was to address significant issues in the county in identifying and securing suitable properties for people with disabilities – the county has a deficit of social rented housing along with a very competitive private rental market.

It was felt that the best approach to supporting people with disabilities to find suitable housing would be through using specialist brokers (rather than social workers) who understood how local authority housing worked and who could also develop relationships with estate agents and private landlords.

The new approach paid off in terms of both financial and social outcomes and the mental health and substance misuse teams have now decided to pilot similar services. By asking Dimensions to take on all three from this April, the expanded Essex Housing Brokerage Service will support many more

vulnerable people to build their independence and live in their own home.

The service acts as an intermediary, offering a named individual who supports individuals, landlords, social workers and commissioners through the entire process. Dimensions' housing brokers identify requirements, find suitable properties and bring all parties together offering expert guidance and reassurance at every stage including ongoing support.

The Housing Brokerage will also deliver a Tenancy Sustainment Service and its main aim is to support people (identified through the Housing Brokerage

Prioritisation and eligibility criteria.) to live more independently and maintain their accommodation. The service will work to identify and secure suitable properties that will enable people to live independently with support that may prevent homelessness, moving on from supported housing or residential care, re-offending and other problems from spiralling out of control or recurring by providing information and practical help to gain the confidence they need to cope.

Dimensions will provide the tenancy sustainment service across the private and social rented sector and it may be that in the future Dimensions will also be the landlord for some of the accommodation within the service. The support workers will be in a position to ensure that any tenancy issues are

raised regardless of who is the landlord.

"Part of the problem is that whilst the County Council has the duty of care, it is the twelve Borough Councils in Essex that have the duty of housing," explains Sanna Westwood, the former commissioner who launched the pilot, *"and although the young couples housing was costing a fortune, from the borough council's perspective they were suitably housed (and off their books.) By introducing nonstandard housing options our housing brokers are basically the oil that makes the system work more efficiently."*

In its first year alone, the service paid for itself fully seven times over – remarkably, that's before considering ongoing lifetime cost savings. You could potentially apply our model to any vulnerable group and expect to see improved social and financial outcomes.

Join us...



H&SA can help with:

- Developing good supported living
- Reshaping services
- Improving quality using REACH
- Developing housing options
- Mental Capacity, DOLS, Community Care and Housing Law
- Welfare Benefits.

H&SA operates an independent advice service for it's members.

Join H&SA and help people with learning disabilities get housing and support that gives them control over their lives.

H&SA is a national membership organisation and charity that promotes good housing and support for people with learning disabilities. We support commissioners and housing and support providers to develop housing and support options that give people with learning disabilities control over their lives.

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