

# Positive & Possible

Supporting young people with learning disabilities in their communities- nine case studies



Joint Improvement  
Partnership

This paper is part of a series of resources produced for the London JIP Transition Project . Written by Alicia Wood & Linnet Macintyre, Housing & Support Alliance

## Contents

Introduction .....	2
1. Amy Garvey House- accommodation for young adults in the Royal Borough of Kensington & Chelsea .....	2
2. Lucy's Personal Health Budget.....	5
3. Richard House Hospice- London Borough of Newham.....	8
4. Ealing Intensive Therapy and Short Breaks Service (ITSBS)- London Borough of Ealing .....	10
5. IBK Initiatives: Citizenship and Community Learning for Adults .....	13
6. My Life- Community Interest Company- Wigan .....	16
7. Bringing AB back to London- Islington Transition Team .....	18
8. Jake purchased his own home through shared ownership. He has a 2:1 24 hour support package which includes a community support volunteer. ....	21
9. Kelly & Pippa- friends who set up home together.....	27

## Introduction

It is easy (and understandable) to get caught up in a spiral of negative and narrow thinking about how we can enable young people with learning disabilities given the gloomy economic outlook. A fear is that we are forced to return to institutional type services because we simply do not have the money to be person centred.

We do know that despite difficult times that people and organisations in London and around the country are doing things that enhance the lives of young people with learning disabilities and are making good use of the resources we have. These case studies are examples of what can and is being achieved in and outside of London by thinking differently, working with young people and families and developing cost effective approaches to supporting young people with learning disabilities.

We will continue to add to these case studies over the coming months. Be inspired.

### 1. Amy Garvey House- accommodation for young adults in the Royal Borough of Kensington & Chelsea



Amy Garvey house is situated in the heart of Notting Hill, on a quiet street close to the bustling All Saints Road. It has excellent transport links and easy access to a vibrant diverse and urban community. The house was converted in May 2011 to 11 self-contained 'bedsits' all with their own bright front door, kitchen area, bed/sitting room and small shower room. There are communal laundry facilities on each floor. On the ground floor there is an office, communal kitchen/dining/sitting room. There is CCTV in communal areas, sleep in night staff on night duty and a full-time manager on site. The building is owned by the Notting Hill Housing Trust and managed by Look Ahead.

The house is currently full with 11 young people, 'customers' living there, all but one aged between 18 and 25. It is designed to be a safe place where young people can be supported to become more independent. Most of the customers would be

described as having additional needs falling within the autistic spectrum, but additionally there are customers with physical disabilities and mental health issues. It provides a very warm, welcoming and relaxed atmosphere in which the young people are actively encouraged to develop skills for living in a more independent way but in an appropriate adult orientated manner.

Each young person arrives with a 'moving-on' plan. This is further developed with the support of the house team, linking into the local community as well as supporting access to more targeted activities. It is a huge testament to the staff that no young person is accessing a traditional day service but are more likely to be involved in a combination of colleges like City Lit or Capel Manor with additional drama, music courses or gym membership. Some of the young people have been helped to find paid employment and all now have plans that reflect their individual interests and the way they want to live their lives.

The model of support is based on a core offer of 3.6 hours a week delivered by the staff team. This is then topped up with personal budgets so that the customers can employ their own Personal Support Assistants. Some of the customers have chosen to employ family members, and whilst others are free to choose and employ their own PSA, in reality this is often done with or by the manager of the house. Great care is taken to identify passionate, enthusiastic but caring people. Less emphasis is put on a background in care and more on being an adaptable person who is up for a challenge! A PSA is likely to be involved with shopping, cooking and travel training as well as providing emotional support and accompanying the customer to social events, clubs and pubs. The staff group and the customers are well matched in youth, enthusiasm and sensitivity. Although some customers will have an additional 6-10 hours a week other are supported by a PSA during all their waking hours. Sometimes the house manager will negotiate and liaise with the social work team to get additional support. In all cases this allows the customer to be treated as an individual with their complex plans reflecting their needs. The diversity in their plans closely reflects the diversity in their lives and aspirations.

The house support team led by the manager get involved in all aspects of their customers lives . If for example, the young person develops an additional health need they will be supported to make appointments, take medication and if necessary adapt to a healthier lifestyle. Equally they can be supported opening bank accounts, applying to colleges or networking to supported employment opportunities.

Families can continue to choose to be involved in all aspects of their sons and daughters lives when they move to Amy Garvey House from managing their Personal Budgets to helping recruit PSA's and liaising with house staff, or can concentrate on being a parent entrusting the administration and co-ordination to the capable staff.

The house has been opened for little more than a year and is looking forward to two of their customers leaving to move into a flat share together. This is a real measure of success as neither young person would have been able to take this step without the transitional placement at Amy Garvey House. Despite the staff's obvious sadness at losing the two customers they can take satisfaction that the two young people not only established a bond in the year, they have also developed the skills to live more independently in their year at the house.

Service users pay for the service through their Housing Benefit with weekly top ups of between £13 and £29. Individual Budgets vary from £70 per week to £810 per week for the most supported packages. The service is currently full but there is little capacity to support empty units should they arise as the overall budget is already stretched. There may be an opportunity for the borough to fund 1 unit as a short break option, which would provide a valuable local resource to families where the young person has chosen to stay at home longer.

Amy Garvey House is providing an indispensable transition house for young adults in the borough of Kensington and Chelsea. It is providing a useful resource to people who would like to live independently of their families and allowing them space and time to develop the necessary skills. The only alternative to this provision would be an out of borough placement which would be a much more radical transition and an unwanted distance from home. The cost differential would be massive given the most expensive package at Amy Garvey being in the region of £55000. Much of the work of the Amy Garvey House is embedded in a person centred approach and grounding the young person in their local community, something that will take them firmly into their adult life.

## 2. Lucy's Personal Health Budget



### **Background**

Lucy is a charming and happy young woman who loves to be out and about in local cafe's, enjoying music and walks in the sunshine. She keeps active by doing yoga, swimming and trampolining. She is profoundly disabled and has a rare genetic condition. She has a sensory impairment, communicates by body movement and has very severe and largely uncontrolled epilepsy. She requires emergency medication on an almost daily basis and has long periods in non convulsive status. She lives in her family home with her parents and is supported by lively and intelligent PA's both at night and during some parts of the day.

Lucy previously attended a residential school in Surrey where she was funded for a 50 week placement. Lucy only used the placement mid week and for school terms so received additional funding during school holidays and weekends. Due to her high level of need she also had additional funding for 1-1 support during her waking hours. Transport was funded on alternate weekends.

The placement, however, broke down completely after 4 terms, largely due to the distance from the family home. Lucy's health declined, probably as a result of her underlying health condition, exacerbated by the placement which although providing excellent medical backup could not provide the love, warmth, and personal daily input that her family could.

Lucy now attends her local special needs school. Her PA comes to her home before school, acts as her escort and driver and acts as her TA at school, helping to enhance the more limited curriculum with 1-1 input and knowledge backed up by both professional knowledge and training. If Lucy is too ill to attend school all day the PA will stay with her at home providing both Lucy and her family with physical and emotional support. Lucy's mother has been able to return to work confident that in

most circumstances the PA's will cope but with the knowledge that good back up plans are in place for emergencies. This part of Lucy's package is funded through education, using the allocation for a fulltime TA to be paid indirectly to the family who are then responsible for recruiting, training and managing the PA's. This budget had now been subsumed into Lucy's Personal Health Budget.

Lucy's Personal Health Budget allows her maximum flexibility, choice and control. Lucy and her family recruit and train her PA's employing a team of 8 part-time carers providing high quality support. The training has been very person centred and has included massage therapy, sensory skills and rebound therapy alongside more health based interventions, relating to epilepsy and safety.

The new package is largely supportive of Lucy's desire to live as normal a life as possible but her family have identified a number of issues for the future. There are no appropriate college places when school ends and no local "respite centres" where Lucy can remain in her community but start to live a more independent life. Equally there are no supported housing options. Lucy's family are deeply concerned that Lucy will become increasingly isolated and yet know that an out of borough option will most likely fail with possibly devastating consequences.

### **The cost**

Total Cost Of Current package approximately £160,000

The Costings of Traditional Model provided by Residential Placement

Total Annual Cost ( incl, 1-1 support) Approx £215,000

### **Residential Model**

On paper this would appear to be the most straightforward, one cheque, one contract and everything taken care of under one roof. The placement was fantastically well resourced but sadly lost track of the child and the family. There were disagreements every step of the way usually based on the schools "professional gift model" or medical model combined with over zealous/cautious risk assessments. An example of this was in Lucy's communication passport that the school identified themselves as Lucy's main place of residence and her family home as somewhere she might visit. Not only was this hugely insensitive and upsetting to the family but also factually incorrect. It seemed to illustrate the gap in understanding between the family and the school.

However, the school did have some outstanding features. It was well resourced and had onsite doctors, nurses and visiting clinical consultants. It also had fantastic physiotherapists, organised and abundant O.T's and SALT's and a well developed sensory curriculum.

Lucy, however, became over managed, her health deteriorated and she became depressed and withdrawn. She slowly became unwilling to eat or drink and Lucy returned home under palliative care.

### **Personal Health Budget**

Lucy is now supported by a Personal Health Budget. Her health needs are broadly managed by her mother and supported by a local adult neurologist WITH the team at the local hospice providing a more holistic backup.

Lucy's PA's fill in where there is a lack of therapy services and have been supported in this with additional training in communication, physiotherapy and sensory stimulation.

Lucy extends a more limited educational curriculum with sessions at Nordoff Robbins and her local swimming pool.

Lucy is now well integrated in her local community with regular trips to cafes, parks and music venues. She constantly "bumps" into people she know which helps keep her safe.

She tries out new things and now that she is 18 she is beginning to plan trips away.

### 3. Richard House Hospice- London Borough of Newham



Richard House Hospice is in the Borough of Newham. The primary purpose of the hospice is to “accompany families caring for children and young people with life limiting, life-threatening or complex healthcare conditions during the person’s life” They provide not only holistic care for the Young Person but also support the whole family. They recognise that advances in technology and care as well as breakthroughs in treatments have resulted in many of their young people living into adulthood.

Richard House now has a full-time transition service co-ordinator, Neal Williamson, dedicated to helping the young person and their families plan for the future. He works with 65 people aged between 18-25, from 11 different boroughs from Camden to Havering. Neal is a passionate believer in the power of the Person Centred approach and works with the Young People as a “lynchpin” during the transition years. At the moment his work is supported by Richard House but funded through the City Bridge Trust and the Shaw Trust.

Neal has also helped set up YAG, a group dedicated to Young People which meets up once a month at St Joseph’s hospice. This is now a meeting place and support group for Young People providing continuity and friendship at a time of significant change. The group is totally integrated and supported by a large number of volunteers from local colleges and universities. This allows friendships to develop across the board and as Neal pointed out can allow the more able to support those with higher needs letting them see, “that they were better off than they thought” and conversely adding to the self worth of those less able feeling that their friendship is really valued.

Neal has also instigated the use of a new ward at St Joseph’s hospice modified to support Young Adults. They are able to book themselves in and begin to move away from the children’s hospice model. Instead of being seen as a place of respite, they are often used for therapy services, for an MOT of their health condition or just as a much needed break from their ‘overly possessive families!’

Neal has also facilitated the pooling of personal health budgets and arranged holidays for groups of young adults going to Blackpool, Bognor or France.

Neal is now working alongside other adult hospices developing pathways for either acute admissions or holistic day services.

The key strength of the hospice lies not only in the long standing knowledge and relationship with the young people and their families prior to transition but their ability to support them until they are comfortable embedded in their new adult life, but also in their ability to draw together all the agencies, health, education and social services. Sadly, however, one of the difficulties identified is around housing. Neal talked shockingly of one young adult who could only access the bedroom in his family home and had to be picked up by the hospice for a bath or shower once a week.

Neal has been able to support people with a wide variety of health conditions, all complex, some to live more independently in their family home, others to move onto university ( in one particular case by using the family flat in Richard House to allow the person to gain the skills to live independently, to do the washing, shopping, cooking and ultimately to invite his mum around for a meal!) and has also supported some into independent living.

The strength of this approach lies in Neal's can-do approach but also in his warm and positive manner and the excellent rapport he has with the young people. He has taken many years to get to know them and is working to make sure that each young person has a person centred plan by 18 but ideally starting at a much younger age and in the future when they are first known to the hospice. This allows the transition planning to be done in a positive, pro-active and holistic way by someone who can put in place and guide people through the often complicated process of moving to adult health care. Neal has been known to accompany YP to their meetings with neurologists thus initiating and then facilitating the process through to the adult specialists.

This service is provided free to the users of Richard House hospice, as part of the transition service provided to young people using the hospice. It is supported by the hospice and through charitable grants. There is mounting awareness amongst hospices and palliative care consultants that there is a desperate need for resources to meet the needs for young adults with very complex health needs moving into the adult world. This is a step in the right direction but needs to be matched with additional 'respite provision' to replicate the role of the childrens hospice movement for young people with neuro disabilities. As one leading palliative care consultant noted that she has seen families closer to the brink when contemplating the adult world than even at the times of enormous pressure that comes with looking after a child with conditions requiring palliative care.

#### 4. Ealing Intensive Therapy and Short Breaks Service (ITSBS)- London Borough of Ealing



In 2009, the local authority in Ealing identified a large % of out of borough residential placements were being taken by boys aged 13-14 with Learning Disabilities and Challenging Behaviour. Not only was this recognised as an inefficient use of resources but also evidence that the borough was failing to provide alternative services locally. Thus in 2009, the Intensive Therapeutic and Short Break Service was funded with the aim of, 'preventing family breakdown and a move to residential care for a small number of young people with Learning disabilities and challenging behaviour.

Between 2009 to date, a total of 18 young people have been supported with only 1 moving out to a residential placement ( this was for a time limited period when family illness and housing issues were addressed). Starting slowly with just 1 case, the service now supports 6-8 new families annually, with young people being discharged to CAHMS to make way for new cases. Recently some cases have been re-referred and funding is being sought to develop an ongoing programme of support to build on and maintain progress after the initial period.

The scheme is run by a dedicated clinical psychologist, supported by a full-time band 5 assistant psychologist. This high level of professional expertise is critical to the success of the service not just in terms of quality but in order to lead and motivate multi-disciplinary teams.

Most of the young people referred are referred at a time of crisis, either theirs or their families. They are likely to be exhibiting behaviour that challenges, for example, physical aggression, pushing, biting, pulling hair, shouting and screaming, running away and towards danger, urinating or defecating in inappropriate places. Prior to the introduction of this service the only solution would have been a residential placement.

The success of the ISTBS service has been largely down to 4 key factors:

1. **Culture change.** Over the last 3 years the psychologists have worked hard with their colleagues to change the assumption that residential was the only solution to crisis. Prior to this scheme this was the default at panel. Although this attitude prevails at ground level amongst social workers and teachers, panel will now direct cases towards the ITSBS service. Families are less likely to ask for residential places knowing there is now an alternative.

2. **The development of The Short Breaks Programme.** At the beginning of each young person's assessment they will be offered a 3 week stay at Heller House, a local 12 bedroom council run house, which will give an opportunity for assessment, not only of the young person but the family as well. This provision is dated, and in need of modernisation and development, but currently provides a useful service. In addition to the 3 week placement each young person will be offered a 1 night placement weekly as additional respite. This service is now supplemented increasingly by the use of Direct Payments, and links have also been made with Somali carers. As the service is developed increasingly creative routes are being explored to support the individual needs of the young person and their family.

3. **Network Support** is an intrinsic and critical part of the service. This operates on a number of different levels. The Clinical Psychologists are responsible for bringing everyone who is important to the young person together, from parents, to support workers, teachers and social workers. They play a key role in motivating the individuals and building a team around the young person, ensuring that they are all pulling in the same direction. They meet fortnightly to begin with to build up a clear picture of the young person and their situation. They then initiate Network Training: This will be tailor-made around each individual case, and can involve up to 25 people every couple of months. They further support the staff at Heller House with emotional support, looking at issues around sole working and managing challenging behaviour. Not only does this give the staff an opportunity to share it also allows the clinical team to build up a more complete picture of the young person. Additionally the clinical psychologists offer generic training to all short breaks staff around issues such as child protection, sexuality and attachment theory. This allows the taskforce to develop and acquire new skills. The clinical psychologists are also involved in providing a key support role and are available by phone, text or email for immediate support and advice. The clinical psychologists have become adept at managing

boundaries and adapting practice to work with individuals, families or groups in the community, short breaks, family or clinical settings.

4. **Therapeutic Interventions.** The psychologists offer therapy not just to the young person but also to the families and siblings and work in a systemic way. For many of the families this will address complicated histories, involving many past and related issues, but also dealing with anger, loss, grief and trauma working towards and incorporating a better understanding of their child and their disability. The work with siblings is most likely to be time limited dealing with anxiety. Whole family issues are also likely to be addressed. One family member noted, 'I found some of the ideas helpful but most of all I felt comfortable talking to the psychologist and often felt I could offload some of my worries. I knew I could say anything and it was very easy to talk to the Psychologist'

The ITSBS works on a number of levels. Identifying and drawing up a number of consistent psychological formulations that allow for a better understanding of the young person and appropriate strategies for addressing them consistently. Ensuring continuity of approach by having a network approach to meeting and training. Providing a therapeutic approach to the whole family situation and developing a range of short breaks to meet the individual situation, starting off with a prolonged assessment period at Heller House. This ensures not only positive intervention for the young person but also over time builds a knowledge bank and growing expertise in the local community.

The costs of the clinical psychology service is approximately £70 000 with the short breaks component unlikely to exceed £25 000 per young person, with many packages significantly less. This £35 000 per case is significantly less than the average cost of £200 000 for a residential placement for this client group.

Going forward there are a number of challenges for this service. Until recently given the lifespan of the project the service has been confined to childrens' services. However work is now needed to develop a consistent approach through transition into adult services. Further commitment will be needed to ensure that the good practice, culture change and short break development is extended further and that appropriate local solutions are developed for this client group in adulthood. It would be a shame if this good practice were to stop at 18 and the young people were once again facing a transfer out of borough to residential services.

It is ,however, fair to say that much has already been achieved on a very limited budget and perhaps with greater resources this excellent practice could be developed further.

## 5. IBK Initiatives: Citizenship and Community Learning for Adults



IBK Initiatives is pioneering a new educational scheme to support young people leaving school where current provision is either unsuitable or unavailable. The prospective students all have complex learning difficulties and currently attend specialist colleges. Two groups of 6 students, aged 17-19, have been identified. The first group based in Sheffield will follow, 'Learning through Citizenship' and the other in Kirklees who will be taking a 'Citizenship and Community Learning for Adults' course. Traditionally these students would have been expected either to leave the borough for residential placements, stay at home or attend day centres with no further educational input.

This educational project follows on from earlier work in Sheffield around a 'personalised transition' which began in 2006. Through this each student already leaves school with an aspirational, 'innovative, holistic plan' addressing their whole life. The educational element sits as an additional dimension complementing and enhancing the already existing plan

In both Sheffield and Kirklees the course will be delivered by an assessor supported by a number of teaching assistants. In Sheffield this support will be based at a special needs college and in Kirklees this will sit within an innovative and independent day centre WAVES. The first half term has been devoted to curriculum development allowing the staff group to really get to know the students, their motivation and their interests, allowing for the development of highly individualised timetables. Both the assessors have backgrounds in further education and additionally have been selected for being passionate, enthusiastic, energetic and committed. These skills are recognised as being particularly important for the early implementation work not just with the students but also with their families, communities and with the Local Authority.

Whilst the students person-centred plans focus on their social and life goals, the education goals will follow on from their school learning plans and annual reviews ensuring that learning and education remain part of the students ambition. It is

recognised that for many students in this peer group that education is a life long component for successful inclusion and citizenship.

The majority of the teaching hours will be delivered peripatetically either in the community, at the students home, or at a pertinent venue for example at a leisure centre, during an activity, in the work place, park or cafe. Anywhere that has been identified that will enhance the learning experience. Additionally one day a week all the students will gather at their hub, this may be further developed to encourage more shared learning and more group work.

A large part of the education plans will be based around communication, intensive interaction, sensory curriculum and therapy but will be modified according to the interests and skills of the individual. There will be a strong emphasis on augmentative technology, with the use of IPADs not only for communication but also for monitoring progress. Multi-media will be used both to assist communication and to allow students to share their experiences with a wider community.

As the planning for this scheme has taken place at school, initial groups of students have been easily identified. As this work develops further it is hoped that more students can be included.

The funding has come through the LLDD Specialist Placement Budget, with both the YPLA and the LA involved. The budget allocation is through, 'additional learning support' which is available to students whose needs cannot be met through local FE colleges or Individual Service Providers. Although this funding cannot go direct to the student it can be directed through a designated learning provider. Critically the student does not have to attend a ready made course but rather the provider acts in an overseer role ensuring that a tailor made programme is in place but delivered in a range of settings.

It is critical that prior to the student leaving school a 'decent' section 139A has been completed. IBK Initiatives are currently drawing up an exemplar. The 139A needs to draw on the students learning needs, for example, their sensory curriculum, their learning style and have an outline of a plan to meet future learning needs. Furthermore, it must identify a local learning provider or a college, school or Independent Service Provider who will manage and release the budget appropriately.

The costings including the development of the service currently run at approximately £25000 per annum. This includes all salaries, management costs, admin and resources. There is no additional cost to the Local Authority as the entire cost is funded through the existing LLDD Specialist Placement Budget.

This sensible, pragmatic but unique approach to further education provides previously excluded students with a mechanism to engage in further education within their local community. Ultimately there will be an opportunity for this approach to be further developed to serve the students well beyond traditional FE and into life long learning. Relevant and pertinent expertise will be harnessed and developed and there should be no barriers to prevent individual students accessing sessions throughout their adult lives with the use of their individual budgets.

A number of smokescreens have been identified and overcome in the development of this programme. Firstly, that there was no existing funding pool. Secondly, that students with complex needs somehow did not need section 139A's. Thirdly, that progression could not be measure for this group of students. This is tied into the commonly held myth that funding for FE courses is "dependent on all young people having to show developmental progression. IBK Initiatives have surmounted these problems by individualising all learning plans and allowing for lateral rather than developmental progression.

IBK Initiatives have shown strong leadership and commitment in getting this project off the ground allowing equal access to education for a largely disenfranchised group of students. Using and pooling existing education budgets in a way that makes sense to the individual students, whilst ensuring professional oversight and guidance in all aspects of delivery. Although early days, with much opportunity for learning and development, this scheme has already much to recommend it.

## 6. My Life- Community Interest Company- Wigan



My Life ( [www.my-life.org.uk](http://www.my-life.org.uk)) is a Community Interest Company based in Wigan, Lancashire. Despite the families of Wigan being amongst the first in the country to have personal budgets there was little support when the children left, 'children's services' and transitioned to the adult world. Families asked the questions, 'Transition to what?' and "Support to do what?' Having experienced personalisation, independence and choice from a young age families were reluctant to use more traditional day centres and found "college courses just, 'weren't happening'. They recognised that there was a very real danger the young people could end up very isolated and alone.

Caroline Tomlinson, a dynamic, gregarious and well respected community leader gathered together a number of families, young people and PA's and after a number of consultations and informal meetings decided to launch My Life. A CIC whose objectives are to be inclusive, to help young people live meaningful lives and to be active contributors to their communities. It is also about building more inclusive and sustainable communities for the future, developing choice to the point where you can ask the question, 'Can there be too much choice?' Fundamentally seeking to extend communities, reducing isolation and giving people more of a sense of belonging.

The organisation currently has 60 members. The young people are asked to pay a monthly subscription of £5.00, but PA's, friends and family are free, encouraging integration and participation. My Life started by organising low key small events, booking village halls and running arts and crafts sessions. These allowed not only the young people but their PA's and friends to come together and share ideas but also to get to know one another in a low cost and low risk way. This staggered start has now developed into a full programme of activities including a 3 day Olympics, community walks, day-trips, Zumba sessions, cooking, themed evenings and karaoke nights. The sessions all incur a small charge of up to £5.00 and are bookable in advance. Concurrently, fund raising events were held with a sale of hanging baskets and a further sale of My Life bags. These provided not just ample funds but an opportunity for the young person to be more fully involved in their

community. 'After all,' Caroline notes, 'each transaction provides an excuse to connect with another person. Each time you talk to another there is an interaction.' Caroline refers to this as 'community ramps'. Further planning of products and events are scheduled in the Autumn programme to promote ownership of My Life to all members, and the community in which it sits.

Additionally, My Life, seeks to support and develop a whole raft of new social entrepreneurs, building a long lasting legacy of new opportunities serving a diverse community and it's interests. My Life has so far supported two young entrepreneurs, one in sports development and the other in holistic therapies. The social entrepreneurs are expected to be self starters with bundles of enthusiasm and initiative but are then mentored through the early stages of business development. More events and training are being held to develop this further.

The effects of this low cost project are already rippling out. My Life is extending through Lancs, St Helens, Blackburn and Wigan including many young people and their families. Although overseen by Caroline much of the impetus is coming from the young people and their PA's ensuring the programme reflects their wishes and interests. The benefits are being felt by both the young people and their PA's. It is recognised that being a PA can sometimes be a tough and singular profession, being part of My Life adds a further dimension to their role and brings the PA into a wider community too.

A new community with new sustainable opportunities is being built by the people who will benefit most in a way that matters most to them. This project has generated all it's own funding and will remain sustainable and low cost. The business, however, is being driven by the energy and passion of Caroline, an instinctive and natural leader, motivated to build a better future for her son Joe. In so doing she will help build a more inclusive community that will be better able to meet the needs of many others in the future.

## 7. Bringing AB back to London- Islington Transition Team



### **Background**

AB is a young man of Bangladeshi descent. Up until approx one year ago, he was residing at the family home and attending special school. The home situation was extremely difficult as his mother was diagnosed with a terminal illness and his father has mental health problems. Therefore his main carer was his sister. AB displays behaviours that are very challenging (hitting, spitting, breaking items of furniture, smearing) and the family decided to ask for support in terms of him becoming looked after. The Disabled Children's Team found a placement that provided accommodation and education within the one setting. This placement was in Shrewsbury.

When I had taken over as transition / statutory social worker for AB, he was still residing in Shrewsbury. However, during April of 2011 I was informed that due to financial constraints, the placement would be closing down in July of 2011. Another placement was offered, under the same company, in Hereford.

Discussions with the family indicated (as they had for some time) that they wanted him back closer to home. The travel was difficult for them and his mother, in particular, was not in a position to travel great distances. Equally I was concerned that the previous placement and the new proposed one were not only far and would impact on family contact but were also in isolated positions, thus not supporting AB to have community access and develop skills in that area.

### **ACTION – Transition**

In July 2011, a placement was identified for AB and he moved into a transition house (16-25yrs) in Stanmore.

The reasons why this was appropriate and why it is working for AB are:

- Joint work between the adult broker team and children's placement team. They have not worked together previously and have different ways of working and identifying apt placements. This was a learning curve for both.
- Joint Agency Panel (JAP) being flexible with regards to funding supported housing (which is what the placement is), which allowed him to stay up to the age of 25yrs.
- The education element being withdrawn from the placement search. My argument for this was with regards to AB being 16.5 years old and not benefitting from a traditional type of education. In my opinion, and that of his families, life education would have far greater positives for him (For example, being able to go a local shop and not pull food items down). Previous education (at his last placement) did not involve working with other young people and was 1-1 with a teacher.

## **Outcomes**

Since moving into his accommodation AB has:

- Lost over 2 stone in weight. His weight had impacted on his life / health and this is a huge benefit to him. He walks on a daily basis and has a new diet introduced. Food is very important to RK and he has probably had access to food as a way to calming his behaviours. However he is now eating fruit and other health foods.
- Access to all areas of his house. His previous placement had locks on the rooms / kitchen and on items of furniture in his room, such as the wardrobe. Although his new placement has locks on rooms, AB's access them with support. Therefore he uses the kitchen on a daily basis and participating in preparing snacks. AB now makes toast (with support) but is able to take items out of the fridge without it escalating into an incident (where he refuses to leave other peoples food). AB has access to furniture items in his bedroom.
- AB access his local community on a daily basis (walking, shopping, visiting re leisure centre). He lives in a diverse community and has access to many facilities / activities close to home.
- AB has started to visit the local mosque on a weekly basis, which wasn't available in his previous placement.
- The staff group at his placement are a diverse group, many of an Asian background. One of AB's key worker are of Muslim faith and this has been beneficial to AB in supporting him in this area.
- AB has accessed other local provisions such as the barbers, dentist and opticians. At his previous placement all these services were provided within the placement, therefore lacking in opportunity to access the community. Not only does this support AB to access the community but is also promoting the use of mainstream services for people with a disability.
- Increased family contact, roughly once every 3 weeks compared to 6 weekly before, in addition to this more family members are able to visit. Family are able to visit RK within 45 minutes by car.

- This is a transition house (16-25 years). AB will not need to move once he is 18 therefore decreasing the amount of moves so often experienced by looked after children.
- AB is living in a house, not a large complex / placement. The house sits on a residential street alongside other homes / houses that are not only for people with disabilities. The house and ethos / ways of supporting are similar to his experiences with his family. And whilst AB requires support to develop skills, he also requires this within a caring environment and this is provided in his new placement. Observations indicate that he has developed quality / caring relationships with staff and this has been commented upon by a leaving care worker from Islington who was impressed with the interactions between AB and staff.
- Effective use of my time in not having to use a whole day for a statutory visit in addition to savings to the council for travel.

## **COST**

	<b>Cost per week</b>	<b>Annual Cost</b>	<b>Annual Saving</b>
Placement 1	£4,149.46	£215,771.92	
Placement 2	£2,895.20	£150,550.40	<b>£65,221.52</b>

8. Jake purchased his own home through shared ownership. He has a 2:1 24 hour support package which includes a community support volunteer.



Jake's(not his real name) story illustrates how it is possible to make a person centred housing and support package work for someone with autism and complex needs and how it involves a great deal of commitment, time and creativity- and most importantly, an openness to charting new territory and learning. It also shows how even a person with the most complex needs can live independently.

## **Background**

Jake is 23 years old and has lived with his parents, brother and sister all of his life. Jake has autism and severe learning difficulties – he finds it difficult to communicate with people he does not know well and most people have difficulty understanding Jake. Jake is very close to his family and communicates with them using facial expressions, gestures and some sounds – sometimes his family also find it difficult to understand what Jake needs.

Jake has lived in the same house since he was born, going to a local school and now a local day centre and other local respite facilities. Although Jake has difficulties in forming relationships, he has known most of the people he sees on a daily basis for some years, many of whom he went to school with. There are and also a few staff working in the different units who have known Jake for some time and are able to understand his needs.

Jake also has epilepsy and began a few years ago to have such bad seizures, he needed 2 people with him constantly so that he did not harm himself during a seizure. This meant that his family were unable to continue caring for him at home and as a result he was hospitalised in order to monitor his seizures and find an effective treatment. This proved difficult and Jake continued to need such a high level of care, it was decided that he would not be able to return to the family home and alternative accommodation needed to be found.

## Getting a home

Jake had a social worker appointed to help him find accommodation. At this stage, a residential care home was being sought for Jake. This proved difficult as Jake required such a high level of care – the only possibility was a residential care home for people with challenging behaviour 100 miles away from where he currently lives – this was ruled out by his family who felt that it was important that Jake remain close to them. Jake remained in hospital for 18 months before his family sought expert help to secure housing.

The housing advisor worked with Jake's family and social worker to initially look at an ideal housing and care scenario for him.

The most important things that Jake needed in a home were;

- his own home – Jake had some behaviours that made it difficult for other people to live with him, especially people who also had learning difficulties and had not chosen to live with him
- a detached property – Jake liked to bang on the walls regularly which would become noisy for any attached neighbours
- located near his family home – his family were the only people Jake had in his life who he was truly close to, therefore it was important for him to be able to see them several times a week and maintain regular contacts such as his day service
- he would need a house that was large enough to accommodate 2 carers for 24 hours a day
- he needed a property that allowed him to be closely supervised but have the freedom to be wherever he wanted in privacy and safety
- he needed a garden – one of Jake's favourite pastimes is to wander around the garden

It was recognised that whilst this housing scenario may be ambitious and possibly difficult to achieve, Jake had such specific and complex needs that in order for his move to succeed, all of the above needed to happen.

As Jake had such specific needs and essentially, needed to live alone and have long term security, the two main housing possibilities for him were renting his home from the council or a housing association and buying his own home through Shared Ownership.

Firstly, Jake had to apply to the local housing register for a rented property and make applications to the housing associations that ran Shared Ownership schemes in the area.

Jake was accepted on to the local housing register but the housing department said that they could not allocate a 3 bedroom home to a single person – Jake also lives in

an area where there was a lack of public housing available so the reality was that he may have to wait for some time before a property that was not necessarily suitable for him would become available.

There were similar problems with Shared Ownership – some housing associations only deal with people who are in work or who have enough capital to purchase a share outright.

One local housing association was willing to help Jake buy a home through a Home Ownership for People with Long Term Disabilities (HOLD) scheme. This meant that Jake and his family in this case would look for a suitable property on the open market within a pre-agreed limit, the housing association would purchase, repair and adapt the property then sell a share on to Jake. They agreed to accept Jake on to this scheme if the local authority would provide a proportion of the grant for it.

It took several months and a great deal of negotiation to get the local authority to provide this grant. They did so on the basis that Jake was made 'statutorily homeless' and therefore they had to accept a responsibility to house him. It made more sense for them to pay for a proportion of a property under the HOLD scheme rather than allocate a rental property that they would need to fully fund.

Jake's family soon found a suitable 3 bedroom detached bungalow very close to where they lived. An architect was employed by the housing association to work with Jake's family to look at how best the house could be adapted to meet his needs. This included having stable doors and hatches in strategic places so that Jake could be supervised from any areas that carers may be but without being 'followed' around the house. The garden was also designed with this in mind and particular care was taken with design and planting to make sure it was safe enough for him to use alone.

The house required extensive renovation so it would take several months of work before it was ready for Jake to purchase and move in.

Another major problem surfaced at this stage, Jake did not have the legal capacity to understand the nature of the house purchase and taking out the mortgage required to purchase the property. After looking at several alternatives, it was decided that the best way around this would be to appoint a receiver through the Court of Protection to deal with these matters on Jake's behalf. What could have potentially been a long winded process was 'fast-tracked' through the system and the mortgage lender, solicitors and housing association were happy with the results.

## **Getting support**

Jake had very high support needs and required total support to eat, have personal care and for getting about generally. Because of his epilepsy and the nature of his

seizures, the hospital assessed that Jake needed 2 people around him at all times so that he did not harm himself during a seizure. A major problem with this was that Jake loves being on his own and does not like having company imposed on him and will be around people only on his own terms.

His family and advisor felt that they needed to put a great deal of thought into his environment and how it could be made easier to support Jake effectively and give him the space he needed. An architect helped them think through how the building could be used to the greatest benefit. Doors and windows were moved accordingly and the layout was such that Jake could walk freely around his house and garden without putting himself in any danger.

Social Services had been involved with Jake soon after he was admitted to hospital to help him find alternative accommodation – they knew that he would need a high cost placement from the outset so it was agreed in principle that they would need to spend a lot of money to support Jake. They were not prepared for the excessive cost of the quotes they received from providers to give Jake 2 carers for 24 hours a day. It was agreed that more thought would need to go into Jake's precise care needs in order to see where costs could be reduced so that the package could be more affordable.

It was agreed that whilst it was necessary for Jake to have two support staff with him at all times, it was not necessary for both of those people to be experienced paid staff. One local provider who had provided the most expensive but also the most robust quote and care package outline, were asked to quote again and include a Community Service Volunteer (CSV) in the quote. A CSV is usually a student or professional from another country who wants to gain experience of working with people who have learning difficulties. The CSV would live in and provide 40 hours of direct care per week for a minimum of 6 months, working under the supervision of both CSV, the organisation and the care provider. The cost was reduced significantly and the care package was agreed.

The care provider spent the coming months recruiting a manager and support staff alongside Jake's family. They also worked with CSV to draw up a profile of the ideal person to live in with Jake and provide his support. A suitable volunteer was identified but unfortunately, as he lived in another country, could not meet Jake and his family before committing to move in with Jake. This meant that Jake's family had several telephone interviews with the volunteer so they could be satisfied that it was worth trying out.

This complex support package had to be timed to co-ordinate with his discharge from hospital, and allow several weeks before hand to enable the staff to get to know Jake – this also had to co-incide with the completion of works and purchase of the house. This was not possible in the end and the house remained finished and empty

for a few months before Jake could purchase and move in with the volunteer and support providers.

## **Finance**

The financing of Jake's housing and support package is complex and can be broken down into the following areas:

### **Capital**

Jake's home was originally purchased for £255,000 and after adaptation and repair was valued at £272,000. The local authority provided a housing grant of £55,000 and the housing association took a loan out which would be recouped through rental income. Jake purchased 40% of the property which was worth £102,000

### **Mortgage**

People who receive Income Support and need to purchase a property 'more suited to the needs of a disabled person' (regs) can have the interest paid on a mortgage (SMI) up to £200,000. A mortgage lender was found and they were happy to give Jake an interest only mortgage for 100% of his purchase price.

Unfortunately, in Jake's case, he had been a hospital inpatient long enough to lose his income support entitlement. Part of the criteria to entitlement of ISMI is to have been in receipt of Income support for 39 weeks. As Jake could not claim Income Support until he was discharged from hospital and he could not be discharged from hospital until he purchased his home, the only way to get around this was to find the money to pay for the interest on the mortgage for 39 weeks.

Jake's family agreed to do this and the amount needed was approximately £2,000. Jake's mortgage interest was then paid by the DWP after 39 weeks.

### **Rent**

Jake pays rent to the housing association on 60% of his property. This is subsidised by the local authority grant and is therefore very low and is fully covered by housing benefit.

### **Support Costs**

Jake's support package cost totals approximately £2,500 per week. This includes £140 per week that is paid for the CSV and costs incurred for staff expenses such as food and outings. This initial high cost was agreed on the basis that his support package be reviewed every 6 months and risk assessments taken to gradually reduce the level of support.

Of this amount, £450 per week is funded through the Supporting People Grant for housing related support and the remaining £2050 per week is funded by Health and Social Services.

## **Setting up costs**

The solicitors costs when purchasing the property were approximately £1500 – Jake's family paid these costs.

Jake received a Community Care Grant of £1,700 to purchase furnishings. He also received donations of furniture from his family and friends.

Jake's family also chose to decorate the house as it meant that it allowed the housing association to spend more on adaptations.

## **Living Costs**

Jake is in receipt of Income Support with the maximum premiums, Council Tax Benefit, Incapacity Benefit and Disability Living Allowance at the high rates. He buys his own food and clothing, pays his gas, electricity and telephone bills and his expenses when he goes out.

## **Conclusion**

There have been many 'teething' problems with the support package but because Jake's family have been so involved with his support, these have been identified and resolved as they happen. Jake and his family became very close to his first 'volunteer' and then he had to leave and another one found.

Jake started sleeping through the night more often and stopped having regular seizures after he moved into his home. He knows where his family live and is able to communicate when he wants to go and visit them to his support staff, and he leads the way. He has stayed in the day service he knows and has kept his GP who has known him since he was a child. Jake knows that it is his home.

## 9. Kelly & Pippa- friends who set up home together



Kelly & Pippa (not their real names) are two young Londoners in their late- twenties who have been friends since they were young children when they attended a school holiday club organised by a local Downs Syndrome Association.

When they became young adults they took different directions in their lives ; Pippa went off to a residential college for 3 years and Kelly stayed at home with her family and went to college and got a part time job.

When Pippa was in her last year of college, sadly her mother died and she was unable to return to her family home. When asked where she wanted to live when she left college, she said she wanted to live with her friend Kelly. Kelly also wanted to live with Pippa and was ready to be more independent from her family. There were lots of complicated factors in making this happen for Pippa and Kelly;

- They lived in different neighbouring boroughs so negotiating with two different councils for care and support was complicated
- It involved setting up a bespoke housing and support arrangement and both councils and local providers had little experience of doing this at that time
- It was believed that this would be a high cost solution because it was two women living together who both needed support around the clock

Because of the problems with making it happen, Pippa was offered a place in a small residential care home that cost £960 per week. Pippa was not happy with this so her family got together with Kelly's family so that they could come up with an alternative solution where they rented a property from a private landlord and put together support that worked for both Kelly and Pippa and cost less than the residential care that was being offered.

### **The solution**

Kelly & Pippa rent a 3 bedroom house from a private landlord. The location of the house was very important because it needed to be near Kelly's family so that they could offer support and back up and it needed to be near particular bus routes that enable Kelly to get to college and work more independently and so that Pippa could learn how to get the bus to a supported employment service that she planned to go

to. The nearest bus also needed to be near a pedestrian crossing so that it felt safe to cross over the road to the bus stop. The ideal location was down to 2-3 blocks and because this needed to happen quickly, it was decided that renting privately was the best option.

When looking at Kelly and Pippa's support needs they had to think hard about the support that actually needed. Pippa had a care assessment that said she needed 24 hour care because she had never been on her own and despite 3 years of learning independent living skills at a residential college, it was not felt that she had sufficient skills to deal with some situations without someone supporting her. Kelly had learned many skills at home and in her part time job and was keen to do things for herself as much as possible but she needed skilled help to learn to do things for herself.

When they broke down what it was they actually needed it was the following;

- Support that did not make them more dependent but gave them the skills to be less dependent- they needed to learn how to cook and manage the house, how to get out and about, how to shop and get money out of the bank. This meant having more support to begin with and less as they became more able to do things for themselves
- They needed this help in the late afternoons and on weekends as they were out 5 days a week.
- They needed some support 'just in case' at night but they did not need active support
- They needed an emergency back up just in case either of them were ill and needed help on a weekday.

A London based service provider was found who provided specific and tailored support to learn skills and reduce the amount of support over time. They began by providing 48 hours of support every week to Kelly and Pippa working 4-10pm weekdays and 9 hours each day on the weekend. To have a safety net at night, they found a support tenant who lived rent free in return for some support which included cooking some meals together, cleaning together and helping to get ready to go out in the morning and get the bus. The support tenant was recruited by the families but managed by the provider. Kelly's family lived around the corner and agreed to provide back up support if there were any problems. They also allowed 4 weeks of extra support for when the support tenant was on holiday. This meant that Kelly and Pippa had round the clock support but it was provided in a different way to the typical staffed service. This reduced to 40 hours per week as they learned new skills.

### **The cost**

For support for the first 12 months, the cost was £1104 per week (£594 each)

This reduced and has stabilised at approximately £920 per week (£460 each)

Rent for the 3 bedrooms is paid by Housing Benefit

The support tenant is voluntary and the support organisation include costs for management and recruitment in the package.

A small residential care home at that time would have cost £960 per week

## **Conclusion**

Kelly and Pippa are leading similar lives to other twenty something Londoners, living with friends, going shopping, having an active social life and learning how to use the washing machine and progress beyond microwave meals and baked beans on toast. They and their support tenant have friends over to stay on the weekend with regular parties as well as going out and about. They have made friends with people who don't have learning disabilities because their circle of friends has widened.

They live close to their families who keep an eye out for them and this alongside the skills they have learned and the number of people involved in their lives has kept them safe. Their families have been able to 'let go' because they see that Kelly and Pippa are learning, growing and happy and have close and regular contact.

Their support tenants have benefitted from having rent free accommodation while they study in London and they have been able to recruit great support tenants from the nearby college.

This ordinary lifestyle simply would not happen in a residential care or supported housing setup. A simple thing like choosing to live with a friend can be so difficult if you need support yet in this case has been relatively simple to make happen and has cost less than a residential care option.

At the transition to adulthood of all young people, including those with learning disabilities, this is a crucial time in developing independent living skills and in over supporting young people at this time, they can be set up for a life of dependency on care. There needs to be just enough support. Kelly and Pippa will always need a fair bit of support but because of the skilled support they have to really learn how to do things for themselves, they have developed and grown beyond the expectations that were had of them.

In this case, Kelly and Pippa were fortunate because the commissioner could access Supporting People funding at that time that was not tied to a service so that meant there were no battles over funding or the fact that they were from different local authorities. Commissioning really needs to incorporate ways that we can 'invest to save' by putting in possibly higher cost, highly skilled support to really enable independence, something that a 3 year placement in an expensive residential college was not able to achieve.

The provider in this case was focussed on really enabling independence (all providers say they do this in brochures...) but this provider was prepared to train staff to enable people to be independent, pay them a bit more for their skills and work to reduce the number of hours they provide on the basis that them doing less was a good outcome. Commissioners and providers need to find sustainable ways to work together to achieve this.

Most importantly in Kelly and Pippa's story is that their families and professionals listened to what they said they wanted and despite it being something unusual for young people with learning disabilities, they explored it and found a solution that worked. This is what real personalisation is about.

