

# A life transformed – Kathy’s story



Between 2010 and 2014 Choice Support and Southwark Adult Services reconfigured learning disabilities services by breaking up a long-standing block contract worth £6.5 million. Changes included deregistering 18 care homes, replacing them with supported living services and creating 83 Individual Service Funds (ISFs). By focusing on providing support to individuals Choice Support transformed their services making them much more effective. Independent research verified that this work not only led to better quality, more personalised services, but also reduced costs by £1.79 million (29.75 per cent). **Juli Carson** and **Sian Hoolahan** explain how it worked for Kathy.

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been living in conditions which were widely reported as being harsh and difficult with up to 40 people in each ward.

She was ‘resettled’ in a group registered care home for four people in 1988. Her problems began immediately as she had to live with three other people who were all incompatible. Kathy responded negatively which reinforced a growing reputation that she was challenging. Staff became afraid to support her and the neighbours complained about noise and property damage.

Kathy’s behaviour ranged from hair pulling, grabbing and pulling down her staff until they were on the floor, tearing clothing, pinching, throwing objects, screaming and attacking children. She could also threaten staff with knives and self-harm with sharp objects. None of the female staff were able to support her at this point. She only responded to males which influenced her behaviour; for example, she dressed in a masculine way and wouldn’t wear a bra.

Kathy’s behaviour had an impact on every area of her life. She could challenge when out in the community – shopping trips were high risk as were visits to the bank or to general leisure facilities. She was terrified of

**Kathy, a 53-year old lady with a moderate to severe learning disability and autism, is just one of the people whose life was transformed by Choice Support’s initiative. She had been living in a registered care home in Southwark and now lives in her own supported living flat.**

### **Kathy’s early years**

Kathy was born with no complications but at around three years of age started to present behaviours that challenge. As she grew older she would physically attack her brother and sister. Kathy was diagnosed with autism and had very limited speech but her siblings found it difficult to forgive her and became estranged.

In 1974 Kathy was admitted to Darenth Park hospital when she was aged 13. Autism was not understood as a condition at that time and she was described as being mentally subnormal and maladjusted. Unfortunately, Kathy’s mother had mental health problems and found it difficult to be consistent and keep to any planned visits or arrangements. She found Kathy’s autism difficult to accept and understand. Interactions with her mother were always encouraged but had to be carefully managed so that Kathy wouldn’t become too distressed if plans changed or her mother refused to see her at the last minute.

### **Adult years**

By the time Darenth Park hospital closed in the late 1980s Kathy had

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medical practitioners which meant visits to the GP were not possible.

After Kathy attacked a neighbour's child she was moved to a single person registered service on a campus site. Here, the risks around Kathy's support intensified and her service remained 'on the edge' for many years. Only a few males could or were willing to support her. Those who could were intensely loyal to her and kept the service going by working many hours and additional back-to-back shifts.

## Positive change

A positive change began in 2008 when Mary, a female support worker who worked in another service on the campus site, asked if she could try and support Kathy. The first shift went as expected with Mary being attacked but she didn't give up.

This coincided with a new female area manager, Juli, taking over the service in 2009. The personalisation agenda was a new concept at this time and both Mary and Juli firmly believed in putting Kathy at the centre of her support and involving her in every decision.

Juli wanted to build trust and create an equal positive relationship with Kathy. Every week she would visit Kathy and ask if she could talk to her. "Talk no" was always Kathy's response. Mary also persevered and gradually built up trust with Kathy. She was able to get a positive response from her and incidents became less frequent.

## De-escalate anxiety

Mary became the manager of Kathy's service and after about six months she finally said, "talk yes" and Juli was able to come in and have a cup of tea. Kathy instigated a process where she would talk and Juli would write down a record of what she said. At the end both would sign this record. This seemed to de-escalate Kathy's anxiety as it gave her the opportunity to get concerns off her chest.

## Turning point

A turning point was when Kathy was involved in recruiting and interviewing a new staff team. All the male staff

members were replaced by females she had chosen. It wasn't completely 'plain sailing' with some new staff unable to handle the challenges that Kathy still presented but there was progress. The core staff team understood autism, the need to limit change and maintain a routine. They also understood personalisation, the need to base everything around Kathy and what she wanted.

During this time Choice Support had been working closely with the London Borough of Southwark to divide up the Southwark block contract into Individual Service Funds (ISFs). This was ground-breaking work which had never been attempted before. Kathy's service was one of the first to be piloted. Under the block contract her service cost £122,000 per year to run. It was calculated that Kathy needed 14 hours support per day and sleep-in night support which meant her ISF at £98,000 was one of the highest. Each hour of her day was discussed with Kathy and her Circle of Support to see what she wanted to do.

It was discovered at this time that Kathy had problems with sequencing and transition from one activity to the next. This seemed to be the main cause of her anxiety which in turn led to behaviours. To address this two activity boards were created, one for the morning and one for the afternoon. The planned activities were put on the board in picture form in the sequence they would occur. Her supporters knew they had to adhere to the sequences put on the board. This innovation significantly reduced Kathy's anxiety. In addition, Juli would still meet with Kathy every Friday and write up her concerns and frustrations, de-escalating any remaining anxiety.

## Calmer

Around 2011 the staff team were able to re-introduce Kathy to her family. The new calmer Kathy won them over and they started to visit regularly, becoming part of her Circle of Support. Kathy's mother recently passed away but before she did Kathy was able to reunite and rekindle their relationship and it became the most positive it had ever been.

Kathy was supported with de-sensitisation around medical practitioners and for the first time she was able to attend the GP surgery and the dentist. She got a small job delivering newspapers. She needed to be supported to do this but it was a great way for her to be out in the community meeting her neighbours.

Kathy's ISF created a saving for Southwark Council of £24,000 per annum.

## Today

There were plans to re-develop the campus site where Kathy was living so she needed to move. She was calmer than she had ever been so when a beautiful flat with a large garden became available it was felt that she would be able to cope with such a huge change. The staff team wanted to move with her. The new service was set up as supported living so Kathy now had rights with her tenancy agreement and access to several benefit entitlements. This gave her a significantly increased income and the opportunity to go on holiday.

The move was successful but afterwards Kathy was unfortunately diagnosed with rheumatoid arthritis which impaired her mobility. However, she has been able to undergo invasive medical procedures which she wouldn't previously have agreed to.

The last time Kathy had an incident where she challenged was 17 July 2011. Since then she has lived happily in her own flat. She gets out regularly, has a job, visits friends and pursues interests. She enjoys picking fruit from her garden in the summer and gets on well with her neighbours.

Kathy is no longer living on the fringes of her community. Her story demonstrates how, when someone is able to make their own decisions, their lives can be transformed.

*Juli Carson is Positive Behaviour Support Development Manager and Sian Hoolahan is Communication Manager for Choice Support. ●*