Recovery

Choice, Control and Self Directed Support

Edited and co-ordinated by Chris Munt.

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Foreword

It is with great pleasure that I write this foreword to the third book in the Hertfordshire Partnership NHS Foundation Trust (HPFT) Recovery series. The series has generated much interest and new editions are always awaited with great anticipation.

I have long believed in the power of personal stories to inspire and inform and believe these new stories will continue to do so. I recently heard of someone who was really very unwell and who had lost hope of getting better and regaining meaning in his life. He was given the Recovery books and reading the experiences of others inspired him to dare to believe that there was hope for him too. Since then he has started to regain his life one step at a time and he really feels that he has begun his journey of Recovery.

It takes great courage and strength to share personal experiences publicly but this is why it is so important that we do, if we can. These stories inspire people who are receiving services and people supporting them whether they are professionals, family, loved ones or friends.

We take pride in being committed to providing high quality, Recovery orientated services throughout the organisation. Recovery orientation in services is necessary both to enable people to lead full and meaningful lives and also to ensure that scarce resources are spent most effectively and to the best effect.

Recovery is a journey, not a destination. It is about building a meaningful and satisfying life, as defined by people themselves, whether or not they experience ongoing or recurring symptoms. It does not define people by their illness and encourages people to retain or regain active control over their lives. Professionals might have a supporting role but not a controlling one.

At the heart of Recovery lie hope, self-determination and choice. Self-directed support has the potential to transform people's lives; affording real choices and support when and how they prefer it. Self-directed support not only enables people to choose how they want their support to be delivered, it also ensures that there is true partnership between professionals, people who use services and their families and loved ones. The stories in this book illustrate beautifully how this can work for people and I am particularly struck how many of the stories speak of the power of Direct Payments to find purpose and meaning in their lives.

My sincere thanks go to all contributors to the book for having the courage and strength to tell their personal stories and share their work. I believe this book will be inspirational to everyone who reads it. This is the first edition to include a staff contribution and I hope that this provides a helpful new perspective.

These are challenging times in the health and social care economy but they are also exciting times of opportunity, innovation and real change in how services are provided.

My thanks to Chris Munt for editing the book and for nurturing it into being; it is largely thanks to Chris that this book is in a series of three and looks set to grow further still.

Anne Markwick
Director of Recovery
September 2010

Introduction

This year the recovery booklet celebrates positive stories from individuals who have used a Direct Payment to meet their identified social care needs. By having more choice and control over how their needs are met, they have been able to use their Direct Payment to purchase a range of services which has enabled them to move on in their Recovery journey. Each person's experience of Recovery will be unique to the individual.

This booklet refers to ten stories on the theme of personalisation and Direct Payments. Eight of these stories are contributed directly by service users, one from a practioner and one from a carer.

Personalisation underpins the Recovery approach and has the potential to transform the way in which individuals have their social care needs met.

It is a process of active engagement with the individual which aims to create support plans which maximise potential and achieve personal goals. Family and social networks are often an important part of making personalised support plans work and help the individual to move on in their lives.

The stories in this booklet affirm that a Recovery focus is being brought to individual support planning which is enabling individuals to achieve their aspirations and move on in their lives.

By Wendy Szczesiak

Direct Payments have helped me gain confidence

I was approximately 20 years old when I had my breakdown over all sorts of issues such as debts, family issues and bottling things up; all of the normal everyday things. While dealing with this I was moved around from place to place, to different accommodation until a suitable place was found for my needs. Finally a flat was found for me in Cheshunt to help me become me again.

At this time I was quiet and isolated myself by spending most of my time in the flat and wouldn't leave the area as I would get panic attacks.

Then one day Anne came to our project and started talking about a charity called Together. As I said, I was not keen to leave my comfort zone, but thought I should give it a try and a member of staff came with me for support. I felt so relaxed there so I kept going and still go today.

A few days later I had an appointment to see my CPN (Community Psychiatric Nurse) she was the person who sorted out my care package and said I should go to a day centre. I thought if I wanted to sit in a room full of old people, talking about the war and playing cards I could do this in my own flat. Then I was told there was this new thing coming out for people with mental health called Direct Payments and I was asked if I would like to be the ambassador for Hertfordshire so I accepted.

First I had to open a separate account which was easy to do. I had no problems in the beginning and this is when the fun and games start. For the paper work you have to get everything spot on. As long as you are using it for your needs you don't have to worry.

I use Direct Payments for the gym, travelling and volunteering for Together. I have now gained a lot of confidence and can stand up for myself, and can speak in front of a large group. I'm also not as quiet or nervous anymore. I believe in Direct Payments because they empower the service user to make decisions on their treatment and wellbeing.

By Adam

The photographs in this booklet have been contributed by Gordon, a hertfordshire Service User. He tells me that his growing skill, knowledge and confidence have been enhanced by his Direct Payment.

My family and friends have noticed the difference

Before I knew about Direct Payments I didn't go out much as I didn't have the money to do so. I did voluntary work for The Citizens Advice Bureau a couple of times a week to get me out of the house. Then a service user in receipt of the payments came and gave a talk at our local self-help group and I made enquiries with my CMHT who were very helpful. The duty officer took my details, asked me what I wanted Direct Payments for and helped me complete the paperwork. I was kept informed how my application was progressing, and when I opened a new bank account the money was transferred.

The payments enable me to be able to exercise several times a week which has had a really positive effect on my wellbeing as well as keeping me fit. I've met new friends and as I'm new to the area this is a great benefit. I'm more outgoing as a result. My family and friends have noticed the difference in me and I am much happier.

I keep a receipt for anything I spend but the only paperwork I have to do is to send in a bank statement every three months to the Direct Payments department. I also keep a copy for my records.

Paying in advance gives me the incentive to do the exercise and even on a bad day, I feel better once the class has finished.

I would recommend anyone considering Direct Payments to apply; you have nothing to lose and so much to gain.

By Ruth

I have found new purpose

I have been ill for over ten years now and it was a gradual process to get well and strong. Once I had received confirmation of my Direct Payments I was so excited. I was going to university. Since starting, my life had dramatically changed. No longer am I wandering around the house looking for things to do or sleeping on my bed. I feel alive. My social life has opened up, I had no real friends before, but now I have 2 close friends and a class full of others. We ring each other, see each other outside of college and go on facebook. The funny thing is that I went to university only to find 2 friends who also have mental health issues. We didn't know that until we got to know each other and just talked.

The work was hard to get used to at first but now I get really involved in it, like last week we had to have a collection of rubbings of letters so I rang up a cathedral and asked if I could do it there, they said yes. It was amazing. In the first assessment I got 70% and came out top, it was such a great feeling.

I now have a purpose in life and hopefully this will lead me to have an independent life in the future.

By Susan

> **"I feel alive. My social life has opened up."**

My wellbeing gives meaning to my life

Roughly a year ago I started receiving Direct Payments after spending a number of years in a psychiatric hospital.

Straight away I started singing lessons with a lady in Welwyn. After several months I performed 2 songs at the Barn Theatre, Welwyn. The songs were 'Unchained Melody' by The Righteous Brothers and 'She Loves Me' by The Beatles, which went down well. My brother and his wife came to see me too, which was a bonus, but maybe not for them.

A few weeks later they had a 60's night at the same venue, where I sang 'All Shook Up' by Elvis. I wore an Elvis wig and dark sunglasses for effect and so I couldn't see the audience – quite scary as about 100 people were staring at me.

I have since then changed singing teachers to someone in St Albans, who I see once a week, as I felt I had gone as far as I could with my previous teacher.

I regularly sing 2-3 songs twice a month at a local pub. Last Friday I sung 'Run' by Snow Patrol, 'Back in the USSR' by The Beatles and 'Crazy Little Thing Called Love' by Queen. On other occasions I have sung 'Unchained Melody' by The Righteous Brothers, 'Don't Let the Sun Go down on me' by Elton John and many more hits.

Last year I decided to get fitter and Mind offered a sports package including; Boxercise on Mondays, Pilates on Wednesdays and weight training on Thursdays. All of these helped me to get a lot fitter and feeling better in myself, because if you feel well physically, you feel better mentally as well.

My money also helped to buy me a tracksuit and a pair of running shoes for the various sports.

I go to the gym once a week and I have a singing lesson once a week with my Direct Payment.

Now my life is not depressed and I am not going nowhere and I feel I have a purpose now in my life, my wellbeing gives meaning to my life and I am so grateful.

Yours sincerely

By RG

> **If you feel well physically, you feel better mentally as well.**

Direct Payments helped me to be more myself

I was introduced to Direct Payments through my CPN (Community Psychiatric Nurse). Before I received Direct Payments I hadn't had a holiday break. Last year myself and my two daughters went to Wales where we visited my brother who I hadn't seen for 13 years. I used my Direct Payments to enable me to meet up and spend time with my brother.

We reconnected through the Salvation Army. We had a long weekend in Wales. The Direct Payments paid for the hotel a meal and visits to the bowling ally and Pembroke castle and also the transport in Wales and to and from Wales. Unfortunately my brother passed away at Christmas last year but with the support of the assertive outreach team im am managing to come to terms with his absence. It makes it so much more important to me that we found each other again before he died.

My life before the Direct Payments was difficult and I needed something to get me out of the flat. Now I go to the gym twice or three times a week. I have therapy which is a back and neck massage which helps calm me and gives me time for myself. The Direct Payments have given me the freedom and time to be more myself and give me something to look forward to every week. It takes of the financial burden off me.

My two daughters have noticed the difference in my wellbeing and are aware of the support the trust have given me. With my recovery in progress I'm grateful for the support and for my CPN introducing Direct Payments to me. My advice to anyone applying for the payments, which was a task my CPNs helped me with, is make the most of it and if you have any difficulty in managing them to ask for help in managing the payments which I manage well by sending statements every three months.

By Bernadette

More motivated and independent

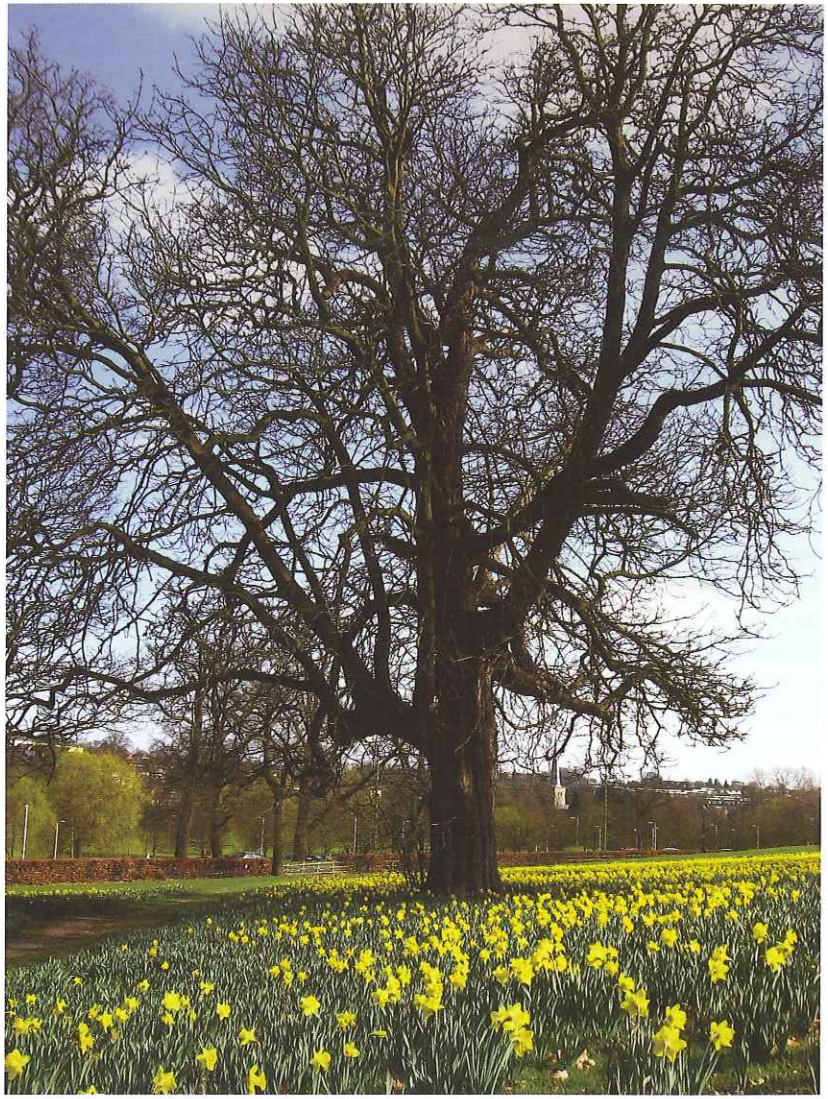
When my son was 19 and away at university he suffered his first experience of psychosis and was admitted to hospital for 6 weeks.

When he was discharged from hospital he was placed under the care of the Early Intervention Team who after several months suggested he could be awarded Direct Payments. In the first year he hardly left his room and trying to motivate him was difficult. Once he was regularly getting his Direct Payments he used the money to pay for bus and taxi fares. This encouraged him to go out and he began taking more care of his appearance and fitness. He began booking appointments for acupuncture, massages, going to the gym, playing golf and he started ice skating again and even managed to save up for some skates. He also went to music concerts and a couple of music festivals.

An additional benefit to my son of receiving Direct Payments is that having to keep all the receipts and list all his expense was good discipline and made him more aware of spending and budgeting.

I really appreciate my son receiving these payments. They have helped us as a family and enabled him to become more motivated and independent. Hopefully this will continue until he is able to return to studying or finds employment.

By Christine



I'm Fighting Back

It all started (My Bipolar-Disorder) when I was 33 years of age and my son was nearly a year old. Now I am 41 and he is eight years old. At first it was Psychosis, then deep, deep depression, anxiety and hypomania (feeling high). These resulted in two hospital admissions and lots of visits by CATT (Crisis Assessment Treatment Team) together with CPN (Community Psychiatric Nurse) imput.

The CATT team were particularly helpful when I required someone to assist and guide me to take my medication. My husband tried his best but some times he experienced difficulty in getting me to take my medication, especially during the acute psychotic episode which was very frustrating for him as he was desperate to help me get better.

Despite being reasonably well, I also encountered problems like isolation, lack of confidence and being overweight. During one of my visits to the CPN she suggested to me to learn to swim which could help me get out of the house and also make some friends, other than taking and picking my son from school and the weekly shopping, and hopefully help me lose some weight. But now the other problem was finding the money to pay for swimming lesions. My CPN suggested I apply for Direct Payment to see if I qualify. I did and after a thorough assessment, taking into account my income and expenditure, I succeeded and began some swimming lessons.

Not only did Direct Payment help me towards learning to swim, being able to get out of the house into a public place such a the swimming centre has helped me make new friends, enhanced my confidence and hopefully some weight loss to follow. Because I am now feeling much better in myself, things have also improved between me and my husband and generally those around me.

Because my confidence has improved, I applied for a job and now work as a Staff Nurse (18 Hours/week) in a nursing home. I have now stopped receiving Direct Payment because I work. I managed my Direct Payment by using it to pay for swimming and keeping receipts for verification.

My husband and both sides of the family have been very supportive, especially during acute depressive faces. My parents in-law came to help from time to time and my sister came from Ghana to stay for about 3 months to also help. I could not have come so far without their help. Although my son was only nearly a year old at the time of the acute phase of my illness, having him there has given me immense strength to keep going especially for his sake.

I am due to be discharged in August/September time back to my General Practitioner (GP) I did feel apprehensive at first when my CPN mentioned to me that I was going to be discharged from the mental health service team. But on reflection I can only see it to be a good thing and look forward to the future as I don't seem to need CPN and Psychiatrist imput for now.

By S.S.S.

Two days in the life of a carer

We're a family of five. In 2006 our three children were bumping through school coping with dyslexia or dyspraxia or both, and one with Asperger's Syndrome. My husband, was in his mid-50s. He has Lewy Body Disease (dementia + parkinsonism). He needs constant supervision to stay safe. He does not go to a day centre – there are none open to him, and never have been. Our social worker understands our needs, is proactive in meeting them and guides us through the provision maze with great skill. She organised Direct Payments for us to pay carers to look after him when I do other tasks, or go out of the house. Without them we would not have been able to function as a family. Our hope for the future is that my husband will continue to live at home. Direct Payments plus committed and smart professionals are the key enablers for this.

20th January 2006

Pretty average sort of night. I got him to bed at 10.30pm, then read through middle son's history coursework with him. He struggles to write or type so I'd spent the evening typing what he dictated, working in 10-minute bursts because he needs checking and settling regularly. Finished chores by about 12.30am, and tried to go to bed but he was half awake and needed turning and wanted a chat about Albania and Croatia – asked me to find some people of our own age to mumble mumble mumble… Settled by 1:00 am, so I dropped into deep sleep.

At 2.15am woken by my husband who was standing by the bed, talking. Poor chap was clearly trying not to wake me, so was calling the names of the children in turn instead, asking them to help because he was frozen. He was right – no idea how long he'd been out of bed. Settled into bed with a hot water bottle. He woke again at 4.20am, restless and talking. He needed help to turn onto his side. At 5.40am he woke me to say the lights weren't working and I needed to sort it out. He'd been to the bathroom and missed the loo. The trail led to the radiator and

through the floor by the pipe hole. Downstairs, urine was dripping through the light fitting just outside the kitchen. Mopped up, unscrewed ceiling rose, reset circuit breakers, went back to sleep. At 6.25am he was standing at the bottom of the bed flapping the duvet up and down. Shaved and dressed him, and started the day.

Usual sort of day – voluntary work with a Year 2 class on a mural with a jungle theme – the mayor was booked to unveil it and we needed to get it finished. He couldn't grasp the day's plan, insisted it was Sunday and said he didn't want to stay with the carer. Fair play. The days are getting pretty tricky for him. He can't follow newspapers, radio or television and spends much time shuffling the research papers from his PhD thesis, but not to any detectable pattern.

Arrived home at midday to find the carer stressed. My husband had kept going upstairs to find his watch, glasses and wallet – the three things he has a possessive/security obsession about, and he'd been refusing to stay downstairs. He can use the stairs OK, but sometimes freezes so it's not terribly safe.

Headed off to school later to pick up the two younger ones – eldest staying late to rehearse a play. Youngest child had a detention from a Food Tech teacher who seems light on skills – she once asked our profoundly disorganised dyslexic eldest son, who could never remember his ingredients, whether the problem was that his mother didn't care. About Food Tech? Possibly not. Children like ours certainly sort the strong teachers from the weak ones.

Usual sort of householdy sort of evening, with my husband needing regular attention or rescuing. He ate most of his dinner himself, and though he turned his plate over to see what was underneath he'd nearly finished so there wasn't a lot of mess. Eldest son came in late after the rehearsal, and my husband accused him of stealing his wallet and glasses, which made us all giggle and even he laughed when we turned it into a joke. He tired later and lost speech, so bathed him early and got him into bed by 9.30pm, leaving plenty of time for typing up quotes from 'To Kill a Mockingbird' for middle son. In bed not long after midnight.

4th February 2009

Great night – my husband was in bed by 9.00pm and slept right through to 5.30am. We gave up on night-time continence about a year ago, and it's made a big difference. Bit of a struggle getting him dressed and shaved. He's not cooperative and has a fiendishly strong grip. I've learnt to shave him with my left hand if he grabs my right. The gripping's a hazard though -- it can get pretty interesting if he grabs the banister from the stairlift...

This school year's been pretty tricky for getting out of the house without him. Direct Payments continue to be brilliant and flexible enough to meet our needs, but it's not really possible to leave my husband with a carer for extended periods because he's quite hard to manage – he's strong but not sensible. For instance he sometimes stands opening and shutting the front door, and occasionally lurches off out of it. It's hard to get him back and to stop him falling.

His main activity at the moment is book shuffling – taking books out of the bookcase and putting them on the floor, replacing them with things like shopping bags and picture frames, which he sometimes files in the bin. We do a lot of little trips out to break up the day...

My husbands speech is now limited and pretty much incomprehensible. He simply can't gather and process thoughts. Nor can he understand things like the boys going on school trips or having exams. He does a lot of clapping and tapping to get attention now, instead of calling.

His carer came in the afternoon so I could visit the physio – damaged shoulder caused by all the lifting. He helped me get him bathed and ready for bed before he left. He had dinner in his pyjamas and we managed a bit of quiet time together in among sorting the boys' dinner and posting them off to football practice.

He seemed exhausted so was in bed by 8.30pm, leaving me time for quiet reflection – a scary thought happily smothered by turning swiftly to face the ironing mountain…

By Fred

Direct payments have changed my life

I have had periods in and out of hospital over a period of four years. In 2006 I went to Turning Point where I had acupuncture and one-to-one counselling. I started working at Wot Nots charity shop and took a cooking class at college. After doing that for a year, I was offered a voluntary place as a teaching assistant in a cookery class helping others, and continued college with a healthy lifestyle course, including yoga. During that time I've built up a special relationship with my three daughters, and have had continuous support from my social workers.

I started Direct Payments on the advice of my social worker. This allowed me to have a holiday with my daughter, and now I also have a holiday with work once a year. I also go to the theatre, meals out, go karting etc and have hobbies such as card making and a sewing machine. I have enrolled and been accepted for a speacialised beauty course at level 2 at Oaklands College in September 2020, which has been paid for, plus equipment. Also I look forward to my holiday in September with Wot Nots to Minehead. Now that college has closed for the summer I work extra days at Wot Nots and have time out to enjoy lunch and outings with friends that I've made through work.

I hope very much to qualify at the beauty course and will also continue to work at Wot Nots, which has given me a purpose and structure to my life every day, allowing me time for my family, which when I was unwell took quite a strain. Its a continuing work in progress. Budgeting was also one of my weaknesses. With support I've been able to keep a healthier lifestyle. My home has improved and my friends have become firm ones. My confidence has grown and I've taken care not to become complacent. Hopefully the qualification will allow me to do some work in the field of beauty even if it's only part time.

Direct Payments have allowed me to do these things with the support of a very good NHS trust, social worker and an outreach support worker. Direct payments have changed things very much for me compared to what it was.

By Carol Fannon

> **“With support I've been able to keep a healthier lifestyle.”**

Overcome barriers to learning new skills

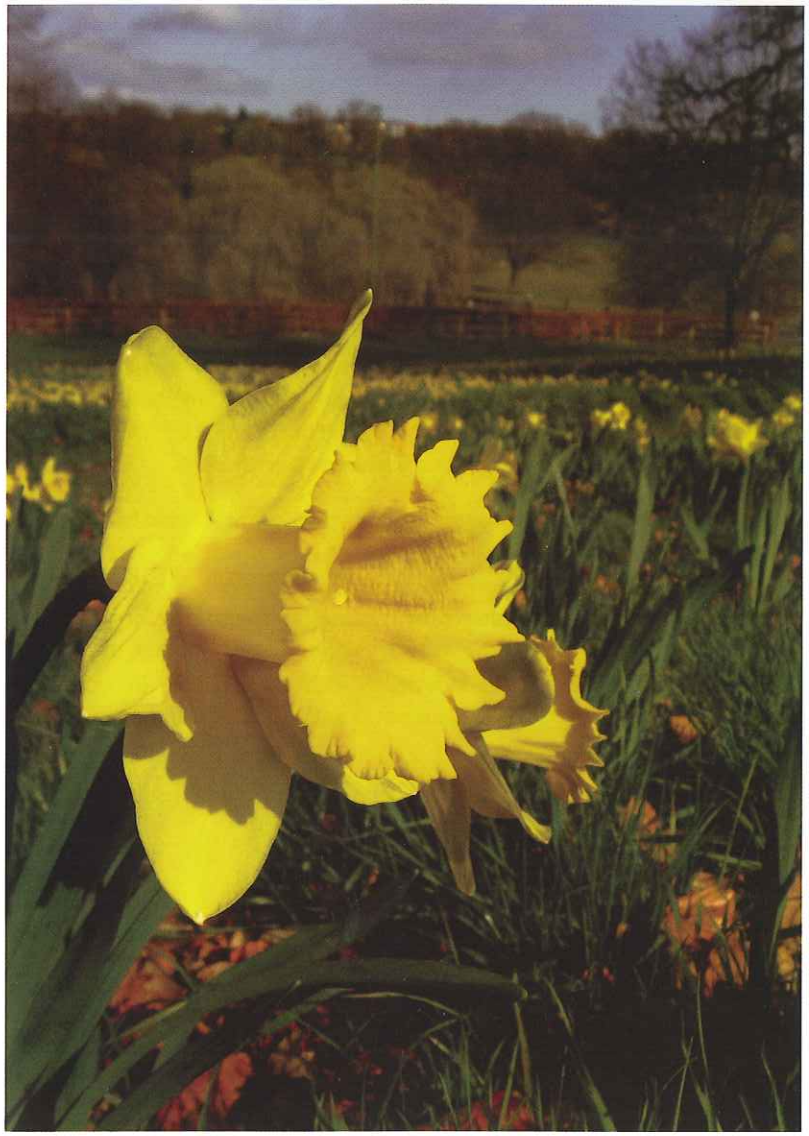
I currently work in a community mental health team, which was involved in the Personal Budgets pilot scheme. We have been delivering social care via Personal Budgets for nearly two years.

The process of setting up Personal Budgets has presented new challenges to professionals, but with new processes and paperwork being implemented it should become more straightforward.

Personal Budgets have enabled us to work in partnership with our service users to identify and access services and resources that are meaningful to their Recovery. They have enabled service users to overcome barriers to learning new skills or undertaking voluntary work. It has provided greater choice and control over care providers or support services. It has given service users new opportunities to access leisure activities and to develop their support network.

By Mandy

> **Individual budgets have enabled us to work in partnership.**



Afterword

If I was in need of any confirmation as to the merits of the personalisation agenda, which is radicalising the very nature of health and social care, my involvement in this project has secured that clarification. Self directed care, Direct Payments and Personal Budgets are key themes of the drive towards personalisation.

This publication looks to the experiences of those facilitating access to Direct Payments, and those receiving and managing them. It has been my privilege to have met many of the individuals who have contributed their experiences captured in this booklet, and I consider them to be pathfinders who find themselves in a very new and exciting landscape. Their individual testimony and shared experience tell of lives transformed, horizons broadened and identities enriched.

I feel sure that in a couple of decades from now, we will look back at how personalisation has transformed the way in which services are commissioned and delivered and conclude it being equally significant as the closure of long stay institutions which began wholesale reforms of mental health services back in the 1970's. My hope is that service users, carers and practitioners will be sufficiently inspired that they join this movement that celebrates uniqueness and maximises personal aspiration.

By Chris Munt